Investigating Elder Self-neglect:
Interviews with Adult Protective Service Workers

Dissertation

Presented in Partial Fulfillment of the Requirements for the Degree
Doctor of Social Work in the Graduate School of The Ohio State University

By
Walter Brian Bohl
Doctoral Program in Social Work

The Ohio State University
2010

Dissertation Committee:
Virginia Richardson, Advisor
Susan Saltzburg
Holly Dabelko-Schoeny
Abstract

Purpose: Elder self-neglect accounts for over half of all cases of abuse and neglect reported to Adult Protective Services (APS), with estimates of up to one million cases per year in the United States. The concept of self-neglect is socially constructed and varies between different communities, individuals, and experts. This study explored how APS investigators conceptualize, assess, and treat elder self-neglect. Methods: Sixteen APS workers from five central Ohio counties were interviewed regarding their views on investigating elder self-neglect. Results: Workers consistently described assessing mental capacity as a primary task. Their substantiation decisions were determined by health and environmental conditions. Their intervention decisions were determined by the clients’ decision-making abilities (competency) and by legal and ethical considerations regarding clients’ rights and self-determination. Workers described preferring case-by-case assessment rather than standardized assessment, in contrast to current recommendations found in the literature. They emphasized seeking peer consultation and supervision for challenging cases. Respondents were well educated, experienced (avg. experience was 13.9 years), and described having adequate access to meaningful peer consultation and supervision. Implications: Further research is needed regarding APS workers preferring case-by-case assessment. APS workers with less education, experience, or access to adequate consultation and supervision might prefer a standardized tool. To better understand the phenomenon of elder self-neglect, other groups such as clients, families, judges, policy-makers, and the general public need to be studied.
Acknowledgments

I would first like to thank the APS workers who shared their time and considerable experience. I would also like to thank the members of my candidacy examination and dissertation committees, Dr. Virginia Richardson, Dr. Bette Speziale, Dr. Shantha Balaswamy, Dr. Christine Price, Dr. Susan Saltzburg, and Dr. Holly Dabelko-Schoeny, for their time, encouragement, and assistance, particularly their assistance with helpful content recommendations on early drafts. Finally, I thank my parents, Dr. Ben Bohl and Claudette Bohl, and my friend and colleague Pamela Yow for their help and unwavering support.
Vita

1980.............................................................. Whetstone High School

1986.............................................................. B.A. English, The Ohio State University

1990.............................................................. MSW, The Ohio State University

1979-2006....................................................... Social Work Practitioner

2001 to present............................................... Graduate Teaching Associate and Instructor, College of Social Work, The Ohio State University

Field of Study

Major Field: Social Work

Specializations: Aging, Mental Health and Mental Retardation, Child and Family, Homelessness, Quality Assurance, Clinical Supervision
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CHAPTER ONE: INTRODUCTION

Statement of the Problem

The U.S. government, through federal and state mandates, becomes involved in assessing elder self-neglect when citizens report allegations of elder self-neglect to their local Adult Protective Services (APS). When investigating allegations of elder self-neglect, APS workers must balance the older adult’s right to freedom with the societal responsibility to ensure the older adult’s safety. Social workers face a particular ethical dilemma when working with older adults alleged to be self-neglecting. The National Association of Social Workers (NASW) Code of Ethics mandates that social workers have an ethical responsibility to respect and promote the right of clients to self-determination. The NASW Code of Ethics also states that social workers may limit clients’ right to self-determination when their actions pose an imminent risk to themselves or others (NASW Code of Ethics section 1.02, 2010).

Federal and state guidelines regarding assessing and treating elder self-neglect are deliberately broad to allow for inclusion of a wide range of problems. Thus, the responsibility of substantiating allegations of elder self-neglect and the degree to which treatment and service recommendations are enforced is left to Adult Protective Service workers in the field. Even when agencies provide written guidelines, each worker must interpret these guidelines through his or her own experience (Lauder, Scott, and Whyte, 2001). APS workers are often faced with the dilemma of wanting to link elders to needed services while at the same time needing to honor elders’ rights to decline intervention.
The ethical dilemma of balancing older adults’ freedom vs. safety will soon surface more frequently in the public domain due to the aging of the baby-boomer age cohort (those born between 1945 and 1960). This is the largest age cohort of people in the United States and they will begin turning 65 in 2010. The sheer numbers of people in this age cohort coupled with the U.S. demographic trends of increased life expectancy, decreased fertility rates, and increased mobility will create an increase in the number of persons experiencing self-neglect and an increase in the demand for formal and informal long-term care (Alexih, 2000).

Elder self-neglect is currently the most common referral allegation received by Adult Protective Service (APS) agencies in the United States (Iris, 2010; Fulmer, 2008; Dyer et al, 2008; Liebbrandt, 2008; Kutame, 2008; Teasler et al, 2006; Heisler and Bolton, 2006; Teasler, 2003; Roby and Sullivan, 2000). Researchers estimate that self-neglect referrals account for between approximately a third of all APS referrals (Teaster, et al, 2006 (27%); Teaster, 2003 (39%); Shiferaw, et al, 1994), to just over half of all referrals (Iris, 2010; Leibbrandt, 2008), to the majority of APS referrals (Kutame, 2008, Roby and Sullivan, 2000). Self-neglect is also the most prominent finding among cases reported to Adult Protective Services (Pickens, et al, 2007), accounting for up to 79% of substantiated APS cases (Duke, 1997).

Researchers for the National Committee for the Prevention of Elder Abuse and The National Adult Protective Services Association were commissioned by the National Center on Elder Abuse (NCEA) to conduct a 2004 national study of Adult Protective Services. They found that of 20 states responding, self-neglect was the most common category of investigated reports (27%) and the most common category of substantiated reports (37%) (Teaster, et al, 2006). This finding is consistent with previous national research. Researchers for The National Committee for the Prevention of Elder Abuse,
The National Association of Adult Protective Services Administrators, and The National Association of State Units on Aging were commissioned by the NCEA to conduct a 2000 national study of Adult Protective Services. They found that of 44 states responding, self-neglect was the most common category of investigated reports (39%) and of 40 states responding, self-neglect was the most common category of substantiated reports (41%) (Teaster, 2003). A 1990 study of Adult Protective Services conducted by The National Association of Adult Protective Services Administrators found that 79% of substantiated cases of adult abuse and neglect fell in the category of self-neglect (Duke, 1997).

In Ohio, APS agencies from 49 counties (56%) submitted self-neglect statistics for all four quarters for fiscal year 2005. Therefore, these statistics do not represent all of Ohio’s self-neglect cases. From July 1, 2004 through June 30, 2005, the county departments of job and family services received 14,103 reports of abuse, neglect, and exploitation for elders age 60 and over. Of these, 51 percent (7,183) were reports of self-neglect (Ohio Job & Family Services APS Fact Sheet for SFY 2005). Each state used their own criteria of defining elder self-neglect in all of the studies mentioned.

The National Center on Elder Abuse (NCEA) estimates that over one million cases of elder self-neglect occur in the United States each year (NCEA, 1999). The NCEA published the National Elder Abuse Incidence Study (NEAIS) in 1998. The NEAIS researchers estimated the 1996 national incidence (new cases) of elder abuse, neglect, and/or self-neglect by adding two numbers: 1) reports submitted to APS agencies and substantiated by those agencies, and 2) reports made by “sentinels” (specially trained individuals in a variety of community agencies having frequent contact with the elderly) and presumed to be substantiated. Since sentinel data are not officially reported to the APS agencies, they are not officially substantiated. The incidence estimates are statistically derived from a nationally representative sample drawn in 1996. According
to the NEAIS, the best national estimate is that in 1996 there were 101,087 new cases of persons aged 60 and over experiencing self-neglect in domestic settings (excluding institutions) (NEAIS, 1998).

NEAIS researchers estimated that for every one case of elder self-neglect reported to authorities, about five more go unreported (NCEA, 1998, 2005). In the 2004 national survey of Adult Protective Services (APS) conducted for the NCEA, researchers found that APS agencies received a total of 84,767 reports of self-neglect on persons aged 60+(based on responses from 21 states), investigated a total of 82,007 reports (based on 20 states), and substantiated 57% (46,794) of self-neglect reports (based on 20 states) (NCEA 2006). In the 2000 national survey of APS agencies conducted for the NCEA, researchers found that APS agencies investigated 118,447 reports of self-neglect (based on 44 states), and substantiated 42% of self-neglect reports (based on 40 states) (Teaster, 2003). If these numbers represent only 1/6 of all cases of self-neglect (as estimated by the NCEA), there would have been an occurrence rate of at least 280,764 cases (based on 20 states) in 2004 and at least 710,682 cases (based on 44 states) in 2000.

National data does not exist on how many APS self-neglect cases are repeat investigations, so we do not know how many newly reported cases are actually new cases of elder self-neglect. Incidence refers to the number of new cases in a specified time-period. Prevalence refers to the total number of people who are experiencing something in a specified time-period. No empirical data exists on the national prevalence of elder self-neglect in the U.S. However, based on the NCEA estimated national incidence rate of 101,087 new cases reported in 1996 and on reported incidence rates of 118,447 new cases (by 44 states) in 2000, and of 82,007 new cases (by 20 states) in 2004, the NCEA estimate of over a million cases of elder self-neglect in the U.S. each year seems credible.
Purpose and Relevance of the Study

The purpose of this study is to explore how government APS workers, particularly those who are social workers, conceptualize, assess and treat elder self-neglect. The target population of this study is Ohio Adult Protective Service workers who investigate allegations of elder self-neglect reported to APS. These APS investigators are charged with assessing the presence of self-neglect and with making service (treatment) recommendations. The APS workers make their assessment of self-neglect by either substantiating or not substantiating the allegations of self-neglect. In this study, both substantiated and unsubstantiated cases of elder self-neglect are discussed with APS workers to gain a better understanding of how they conceptualize and assess elder self-neglect.

APS treatment of elder self-neglect consists primarily of providing service referrals to address unmet needs. APS workers present their treatment recommendations to older adults as service recommendations and referrals. These services may be declined by competent adults. Workers may seek court orders for a competency hearing for involuntary services if they think an older adult who declines services is at imminent risk of harm. Of particular interest in this study is the exploration of themes and issues that arise when APS workers seek involuntary services for older adults or strongly recommend services for elders who decline services.

Treatment also includes the manner in which the workers approach the older adults they are investigating. The APS workers’ personal and clinical approach, including the workers’ bedside manner and their manner of presenting service recommendations, will influence older adults’ responses and compliance to service recommendations. APS workers must establish trust with older adults to increase the likelihood of the older adults disclosing pertinent information and to facilitate their willingness to consider
service recommendations. This study will explore how workers approach treatment, including their use of specific practice models.

The rationale for this study is to shed light on a public intervention for which there are few practical guidelines available to assist with the implementation of vague public policies. This is important because the ethical dilemma arises for practitioners, agencies, and lawmakers of how to best balance older adults’ rights to self-determination with the community’s responsibility to monitor their safety. Some Adult Protective Service agencies refer to this ethical dilemma in terms of “Freedom vs. Safety,” and research has shown that it is one of the most sensitive and difficult dilemmas for practitioners working with older adults (Leibbrandt, 2008; Duke, 1997).

“Cases of self-neglect present challenges for service providers because many seniors who need care, often refuse it. The question of whether these elderly represent victims of self-neglect who require intervention or simply individuals invoking their right to self-determination is an ethical dilemma and one that continues to plague practitioners and researchers alike.” (Leibbrandt, dissertation abstract p. xi, 2008)

The primary relevance of this study is a practical one. Exploring and discussing how APS workers assess and treat elder self-neglect could be useful to other practitioners in the field facing the ethical dilemma of balancing freedom and safety when working with self-neglecting elders. Additional practice, policy, and research relevance of discovering current governmental practices of assessing and treating elder self-neglect are discussed in the Implications section of this dissertation.

**Choice of a Qualitative Research Method**

Scholars recommend using a qualitative research approach for the following reasons:

- Little is known about the topic
- The topic of interest is a sensitive one
• The researcher wants to capture the “lived experience” of the subjects
• The researcher wishes to get inside the “black box” of programs and interventions (Padgett, 1998; Strauss and Corbin, 1998).

This study of APS worker’s experience of elder self-neglect meets these criteria. There exists little research about the assessment and treatment of elder self-neglect (Fulmer, 2008; Leibbrandt, 2008; Gunstone, 2003; Steketee, Frost and Kim, 2001; Lauder, 1999; Duke, 1997). This is a sensitive topic for research because it explores an ethical dilemma faced by APS workers who may be sensitive about how they choose to resolve this dilemma. This study seeks to capture the lived experience of APS workers in the field and explore their interventions with self-neglecting elders. A qualitative approach to research was used in this study because of the exploratory nature of the study, the sensitivity of the topic, and the research goal of understanding APS workers’ lived experiences, perspectives, definitions, and interventions for elder self-neglect. The qualitative research methods that were used in this study will be discussed in detail in the Methodology chapter of this dissertation.

**Definition of Terms**

Definitions of self-neglect vary widely (Gibbons, 2009; Fulmer, 2008; Kelly et al, 2008; Naik, et al, 2008; Pavlou and Lachs, 2008). For purposes of this study, the Ohio Revised Code definition of adult self-neglect was used. The Ohio Revised Code defines adult self-neglect as “The failure of an adult to provide for himself the goods or services necessary to avoid physical harm, mental anguish, or mental illness” (ORC 5101.60 K).

Definitions of when a person becomes an older adult also vary, with most definitions considering a person to be an older adult beginning between the ages of 60 and 65. For purposes of this study, elderly persons were defined according to Ohio Adult Protective Services guidelines as persons over the age of 60. Involuntary services will be
defined as services that are court-ordered for an older person against that person’s expressed wishes.

In Adult Protective Service agencies, the assessment of elder self-neglect results in a finding by the investigating APS worker that the allegations of self-neglect are either substantiated or not substantiated. In this study, assessment was defined as activities and considerations made by Adult Protective Service workers while investigating allegations of elder self-neglect. Treatment was defined as service recommendations, referrals and suggestions made by the Adult Protective Service worker.

**Research Questions**

In this study, the following research questions were considered:

- What themes and issues arise when Adult Protective Service (APS) workers investigate allegations of elder self-neglect?
- How do APS workers conceptualize elder self-neglect?
- How do workers approach older adults alleged to be self-neglecting?
- What themes and issues arise when workers assess elder self-neglect?
- What decisional factors emerge when workers discuss their decision about whether or not to substantiate allegations of elder self-neglect?
- What kinds of treatment and service recommendation themes and issues arise?
- What themes and issues arise in cases where older adults decline services?
- When are involuntary services sought?
- What services are needed by older adults found to be self-neglecting?
- What are the gaps in service delivery?
- What services do older adults accept and what services do they reject?
- How do workers distinguish between elder self-determination and self-neglect?
CHAPTER TWO: LITERATURE REVIEW

Many researchers of elder self-neglect have identified a lack of research literature on the subject (Fulmer, 2008; Leibbrandt, 2008; Dyer, et al, 2008; Heisler and Bolton, 2006; Gunstone, 2003; Steketee, Frost and Kim, 2001; Lauder, 1999; Duke, 1997). Reasons for this lack of research include the sensitivity of the subject, difficulty gaining access to records, and the inherent difficulty in quantifying elder self-neglect. Other challenges to research of self-neglect include diagnosis, recruitment and retention of participants, attrition, non-standardized research language, and obtaining informed consent from subjects (Fulmer, 2008). Additionally, attempting to determine elder self-neglect gives rise to a number of difficult conceptual, identification and intervention problems for health and social care workers (Kelly, et al, 2008; Lauder, Anderson, and Barclay, 2005). This literature review focused on four areas of interest identified in the research questions of this Adult Protective Service study: conceptualizing elder self-neglect, assessing elder self-neglect, treating elder self-neglect, and honoring self-determination in cases of elder self-neglect. A brief historical overview of U.S. federal and Ohio elder protection systems is presented first.

Overview of Federal and Ohio Elder Protection Systems

Kohn (2009) provides the following overview of the federal U.S. elder protection system. In 1953, the American Public Welfare Association (APWA) formally identified a need for protective services for physically or mentally challenged adults. In the next twenty years, federal legislation was passed to fund demonstration projects to provide
services to physically and mentally challenged adults. In 1974, Congress passed Title XX of the Social Security Act, which required all states to create adult protective services (APS). All fifty states have enacted legislation to address elder abuse and neglect. Most elder protection laws fall into one of three categories: 1) laws that create and govern state APS programs, 2) elder abuse reporting laws, or 3) statutes that specifically prohibit or specially penalize certain treatment of older adults. Together, these three types of laws create the U.S. elder protection system, which exists predominantly at the state level.

APS originally focused on self-care and dementia issues but evolved to focus on elder abuse, neglect, and exploitation. In the late 1970’s, there was a change in how elder abuse was perceived, with the focus changing from vulnerability to age. Characterizing elder abuse as an “age” issue encouraged policymakers to model APS on existing child protective services (Kohn, 2009). There is considerable variation among states’ elder protection laws and their definitions of reportable elder abuse and neglect. Some states include self-neglect as reportable elder neglect; others do not. Kohn (2009) notes a current legislative trend to enlarge the scope of existing mandatory reporting laws to require reporting of self-neglect.

Kolacz (1999) provides the following overview of the Ohio elder protection system. The Ohio Adult Protective Services (APS) Act was enacted in 1981. This act requires mandatory reporting of elder abuse, neglect, and exploitation by certain professionals, establishes investigation procedures for allegations of abuse, neglect, and exploitation of adults aged 60 years and over residing in an independent living arrangement, and authorizes the provision of protective services to prevent, correct, or discontinue the abuse, neglect, or exploitation. Each County Department of Human Services is responsible for carrying out these laws. Through Title XX of the Social
Security Act, the federal government provides block grants to ensure county services. Title XX funds are allocated according to state law.

While acknowledging concerns about community safety, The Ohio APS Act of 1981 specifically includes guiding principles that emphasize clients’ rights. These principles include freedom over safety, self-determination, participation in decision-making, least restrictive alternatives, primacy to the adult, confidentiality, benefit of doubt, do no harm, avoidance of blame, and maintenance of the family. Relevant to this study on elder self-neglect, the Ohio APS Act of 1981 does not specifically include the term self-neglect, but the definition of “neglect” identifies and even prioritizes the concept of self-neglect:

“‘Neglect’ means the failure of an adult to provide for self the goods or services necessary to avoid physical harm, mental anguish, or mental illness of the failure of a caretaker to provide such goods or services.” (Ohio Revised Code section 5101.60 K, “APS definitions”)
CONCEPTUALIZING ELDER SELF-NEGLECT

One of the primary research questions of this study was to discover how Adult Protective Service workers conceptualize elder self-neglect. Some scholars suggest that the concept of self-neglect is socially constructed: that self-neglect is not an objective phenomenon but rather the product of a series of social judgments (Lauder, Scott, and Whyte, 2001). Lauder (2009) suggests that self-neglect remains a useful concept but contains a far wider range of presentations than previously reported. Major problems exist in defining self-neglect because self-neglect can be redefined by changes in context, cultural and community norms, and the capacity to accept or refuse treatment; thus the definition of self-neglect varies from study to study and from community to community (McDermott, 2010; Skelton, et al, 2010; Ballard, 2010; Gibbons, 2009; Fulmer, 2008; Kelly et al, 2008; Naik, et al, 2008; Pavlou and Lachs, 2008; O’Brien, et al., 1999). Even when agencies provide written guidelines, each social worker must interpret these guidelines through his or her own experience (Lauder, Scott and Whyte, 2001). Thus, the conceptualization, definition, and assessment of self-neglect are greatly influenced by the personal experiences and biases of APS workers in the field.

In a national study comparing elder abuse and neglect statues from all 50 states and the District of Columbia, Roby and Sullivan (2000) raised concern about the lack of a definition for self-neglect. They found that although self-neglect constitutes the most widely prevalent category of referrals, only five states list it as a separate category and 28 states include self-neglect as part of the definition of neglect. They identify a consequence and possible reason for this omission as follows:

“The lack of a definition for self-neglect may be very serious, since without a statutory definition no governmental resources may be available to address the situation. One of the main rationales for this omission may be the concern for the adult’s right of self-determination and the requirement of least restrictive alternative. The balancing of safety and self-autonomy is a realistic and difficult
task; however, a carefully drafted statues could serve both ends” (Roby and Sullivan, 2000, p. 25).

Roby and Sullivan (2000) provide a New York Social Service Law as an example of a carefully drafted statutory definition of elder self-neglect:

“Self-neglect means an adult’s inability, due to physical and/or mental impairments, to perform tasks essential to caring for oneself, including but not limited to, providing essential food, clothing, shelter and medical care; obtaining goods and services necessary to maintain physical health, mental health, emotional well-being, and general safety, or managing financial affairs” (New York Social Service Law 473 (6)(f))

The National Center on Elder Abuse provides the following definition of elder self-neglect:

“Self-neglect is characterized as the behavior of an elderly person that threatens his/her own health or safety. Self-neglect generally manifests itself in an older person as a refusal or failure to provide himself/herself with adequate food, water, clothing, shelter, personal hygiene, medication (when indicated) and safety precautions.

The definition of self-neglect excludes a situation in which a mentally competent older person, who understands the consequences of his/her decision, makes a conscious and voluntary decision to engage in acts that threaten his/her health or safety as a matter of personal choice” (NCEA, 2005).

Researchers typically define self-neglect as some variation of the inability to provide for oneself the goods or services to meet basic needs (Dyer, et al, 2007). Pavlou and Lachs (2008) suggest that self-neglect is characterized by profound inattention to health and hygiene. Sherman (2008) defines self-neglect as a geriatric syndrome or condition that manifests itself by the refusal or failure of an older adult to provide himself with adequate food, water, clothing, personal hygiene, and medication. Leibbrandt (2008) defines self-neglect as the consequence of not providing oneself with appropriate food, medical care, clothing, shelter, or the goods and services necessary to maintain physical, mental, and emotional well-being and general safety. Day (2010) notes that self-neglect can present along a continuum of severity:
“Self-neglect can present along a continuum of severity ranging from failure to attend to self-care; leaving bills unattended, noncompliance with treatment regimes, not eating or drinking, service refusal with evidence of self-neglect; to dilapidated homes and environments, faulty electrics, hoarding of rubbish, squalor and hoarding of animals.” (Day, 2010, p. 73)

Gibbons (2009) attempted to characterize self-neglect by studying a purposive sample of 20 in early stages of self-neglect referred by a convenience sample of seven healthcare providers. She found that coping problems were present in each participant and recommends a framework for characterizing self-neglect which emphasizes the need to consider coping skills. Paveza, VandeWeerd, and Laumann (2008) recommend using a risk-vulnerability model as a theoretical framework for the study of elder self-neglect because this model can begin to define elements that may be addressed using preventative measures as opposed to solely addressing intervention.

Gibbons (2007) identifies that the self-neglect characteristics of personal and environmental decline, described by outsiders as poor hygiene, squalid living conditions, and non-adherence to health care regimens, occur in competent and incompetent self-neglecting older adults. She suggests that self-neglect is related to an individual’s ability and willingness to address complex health and social circumstances. Similarly, Lauder (2009) suggests that people who self-neglect often do not undertake those activities which are judged necessary to maintain a socially accepted standard of personal and household hygiene or to maintain their health status. Gibbons’ (2007) and Lauder’s (2009) characterizations of self-neglect raise the issue of how an outsider’s attitude about self-neglect may differ from the attitudes of the people who are considered to be self-neglecting. Kutame’s (2008) research sheds more light on this issue of insider vs. outsider interpretations of self-neglect. In her unpublished dissertation, Kutame (2008) sought to understand the lived-experience of persons considered to be self-neglecting elders by interviewing twelve older persons identified by others as self-neglectful. She
found anecdotal evidence that these people who were identified as self-neglecting elders did not interpret their own behaviors and actions as self-neglectful.

Culture and cohort also influence perceptions of elder self-neglect. Filippo et al (2007) studied convenience samples of 494 people representing four cohorts (senior citizens, silent generation [those born during the depression and WW II], baby boomers, and generation X) and four cultural groups (Asian American, African American, White, and Latino) to explore differences in the perception of elder self-neglect. They administered a 22-question, Likert-type survey of items they developed that asked the respondents to identify how likely they thought it would be that different types of behaviors that an elder might engage in would lead to self-neglect. They discovered that self-neglect is viewed differently by members of various cultures and cohorts and that cultural and cohort differences among professionals may affect their definitions of self-neglecting behavior.

Specific cultural and cohort differences in conceptualizing elder self-neglect observed by Filippo et al (2007) were that Asian Americans were significantly less likely than Whites to attribute behaviors or situations to self-neglect, and that cultural groups, but not age cohorts, perceived being subject to violent behaviors very likely to result in self-neglect. Although Whites and Latinos perceived decreased social interaction to most likely lead to self-neglect, Latinos were significantly less likely than Whites to perceive this as resulting in self-neglect. Having no health insurance and having an income less than U.S. $500 per month were significant variables in conceptualizing self-neglect to the cultural groups, with Whites significantly more likely than Asian Americans to consider having no health insurance and having an income less than $500 per month indicative of self-neglect.
Filippo et al (2007) found that regarding health behaviors and self-neglect, cultural groups studied (Asian American, African American, White, and Latino) perceived caloric intake of fewer than 1,000 calories per day to be associated with self-neglect, but Asian Americans were significantly less likely than Whites to make this association. Liberal use of medications was perceived as a significant behavior associated with self-neglect by cultural groups studied but not by cohort group (senior citizens, silent generation, baby boomers, and generation X), with Latinos and Asian Americans significantly less likely than Whites to associate this behavior with self-neglect. Cohort and cultural groups viewed consuming three to four alcoholic drinks at a social occasion as a behavior leading to self-neglect, but Whites and Asian Americans were less likely to perceive this behavior as resulting in self-neglect than were African Americans.

In the Filippo et al (2007) study, keeping physically, socially, and mentally active was viewed by all groups to be less likely to result in self-neglect, with Whites perceiving these activities to be significantly less likely to contribute to self-neglect than Asian Americans. All cohort (senior citizens, silent generation, baby boomers, and generation X), and cultural groups (Asian American, African American, White, and Latino) represented in the study considered part-time employment significantly less likely to result in self-neglect, but Whites perceived part-time employment significantly more positively than did Latinos or Asian Americans. Baby boomers perceived persons engaged in part-time work more favorably than did Senior Citizens. Consulting religious leaders and using herbs rather than seeking traditional medical care were seen as contributing to self-neglect by the Silent Generation and as significantly less associated with self-neglect by Generation X respondents. These cohort and cultural findings clearly illustrate that there is no universal definition of self-neglect.
Reed and Leonard (1989) conceptualized self-neglect by defining attributes, antecedents, and consequences of self-neglect. They defined the following attributes as necessary characteristics of the concept of self-neglect and identified that all must be present for a valid description of self-neglect:

1. The behavior has notable potential to be harmful or life-threatening.
2. There is no specific purpose expressed or clearly identifiable reason for engaging in the behavior.
3. The behavior is not intended to end one’s life immediately.
4. Effects of the behavior are cumulative and realized over time.
5. The behavior represents a repetitive pattern that pervades several dimensions of self-care needs.

According to Reed and Leonard (1989), antecedents represent the context within which the concept of self-neglect occurs. The antecedents are important for identifying the health-related factors that must all be present for self-neglect to occur.

1. A self-care regimen has been prescribed to alleviate or prevent problems associated with physical illness.
2. The person has knowledge of the prescribed self-care regimen.
3. The person has available the cognitive, psychomotor, and material resources necessary for participating in the health care regimen.

Consequences are defined as those events that result from occurrence of the concept of self-neglect. A salient feature of the consequences is the negative or destructive nature of the event. Possible consequences of self-neglect include:

- Exacerbation of the health problem
- Prescription of additional and possibly unnecessary diagnostic and treatment procedures
- Increased risk for iatrogenic effects [symptoms caused by physician treatment]
- Generation of additional health care costs
• Increased possibility of negative interpersonal experiences between the client and health care professionals

• Increased risk for experiencing pain, impaired function, and impaired sense of well-being

• Increased risk for premature death

Reed (1988) adapted Nelson and Farberow’s (1977, 1980, 1982) Indirect Self-Destructive Behavior Scale (ISDB) to develop a 17-item scale, the Self-Neglect in Health Behavior (SNHB) Scale. The SNHB Scale measures the degree of self-neglect via the health care regimen. Items in this scale address the areas of diet, fluids, prescription and non-prescription drugs, activity, hygiene, and interactions with healthcare providers and other caregivers. Identifying these critical areas helps us to conceptualize self-neglect, however this scale was developed in an unpublished research article and is not available for evaluation or use. Nelson and Farberow’s ISDB Scale and other available assessment tools related to self-neglect are reviewed in the “assessment” section of this literature review.

In summary, the most notable finding from this literature review on conceptualizing elder self-neglect is that a wide range of variation exists in defining and conceptualizing self-neglect among scholars, practitioners, cultural groups, age cohort groups, and older adults identified by others as self-neglecting.

**Theoretical Perspectives on Elder Self-Neglect**

Self-neglect is multi-faceted; it may be viewed as a physical problem, a psychological problem, a societal problem, an interaction between person and environment, or as the result of a combination of factors. Self-neglect may be viewed as a physical syndrome or as a psychological/behavioral manifestation of unsuccessful aging. The physical syndrome theories are the simplest, explaining self-neglect as
functional impairments (such as physical incapacities, mental disorders, or polypharmacy/addiction) that may create medical needs, physical needs, and unsafe environments.

Examples of physical syndrome conceptualizations of self-neglect include aged recluse, squalor syndrome, social breakdown of the elderly, severe self-neglect syndrome, and Diogenes syndrome (Reyes, 2001). Clark and colleagues created the term Diogenes syndrome in 1975, theorizing that it is a lifelong subclinical personality disorder, turned gradually into gross self-neglect and social retreat, possibly precipitated by a stressful event (Reyes, 2001). The strength of physical explanatory theories of self-neglect is in their parsimony...they are the easiest to understand. Weaknesses of physical explanations of self-neglect are that they do not explain all cases and that they do not adequately incorporate environmental influences.

Theoretical explanations of self-neglect that emphasize psychological root causes rather than physical ones are more complex. From these frameworks, self-neglect may be viewed as a physical, psychological, and behavioral manifestation of unsuccessful aging. The theory found most frequently in this literature review was exchange theory. Other theories frequently represented were the ecological perspective (including socioenvironmental and salutogenic theories), labeling theory, disengagement theory, attachment theory, activity theory, continuity theory, maintain/gain control theories, communication theories (including message production and symbolic interactionism) and socioemotional selectivity theory. Other theories were functionalism/conflict theories, human potential phases (including differentiation theory, mental health theory, and religion), self-concept theory, stratification theory, finite amount of adaptive energy, self-care theory and gains and losses. The next sections explore how elder self-neglect may be explained by popular current theories of aging.
**Biological Theories of Aging**

Biological theorists suggest that successful aging involves the avoidance of disability and disease and the maximization of one’s reproductive potential through nurturing children and grandchildren (Papalia, Camp, & Feldman, 2002). Biological theorists such as Hayflick (1981) might explain self-neglect as a physical syndrome resulting from disability, disease, and functional impairments (such as physical incapacities, mental disorders, or polypharmacy/addiction) that may create medical needs, physical needs, and unsafe environments.

**Psychological Theories of Aging**

Psychological theorists suggest that successful aging occurs when persons complete the normal psychological and social tasks of each period of life in an emotionally healthy way. For example, Erikson (1986) saw the critical tasks of middle and late adulthood as generativity and integration, while Jung (1960) and Levinson (1978) identified the need to balance the masculine and feminine sides of one’s nature and to turn from striving for worldly success to exploring one’s inner life (Papalia, Camp, and Feldman, 2002). Peck (1961) identified three psychological adjustments required for optimal aging: shifting from a work role to another role, transcending body and health preoccupation, and accepting the inevitability of death (Zastrow and Kirst-Ashman, 2007). From these differing theoretical perspectives, elder self-neglect may be viewed as resulting from an unsuccessful resolution of late-life psychosocial developmental tasks.

Crain (1992) noted that few theorists have concerned themselves with development during the adult years. He presented Jung (1875-1961) and Erikson (1902-1994) as notable exceptions. Both identify developmental tasks for old age. Jung
believed that old people try to understand the nature of life in the face of death (Jung, 1960d). In Jung’s view, the aged “continue to struggle with the questions of existence and wonder what it is that makes a life whole and gives it meaning—they search, in Erikson’s term, for integrity” (Crain, 1992, p. 296).

Erikson identified eight developmental stages, the last one occurring in old age and emphasizing an inner struggle between ego integrity versus despair (Erikson & Erikson, 1986). Erikson defines ego integrity as including “the sense that there is an order to one’s life and the acceptance of one’s one and only life cycle as something that had to be and that, by necessity, permitted of no substitutions” (Crain, 1992, p. 260). Erikson’s eighth developmental stage is particularly relevant to conceptualizing self-neglect among elders in that it suggests we consider their internal experience as well as their external appearance. Crain asserts that Erikson and Jung are pointing to an inner struggle that we are apt to miss when we look at older people.

“We are aware of their many physical and social difficulties, and we may deplore the fact that older people seem so “useless.” But such judgments are only partly valid. They are opinions formed by looking only at external behavior. We see that older people lack the zest and youthfulness that we so greatly prize, but we fail to consider the inner struggle. We fail to see that the quiet older person may be grappling in some way with the most important of all questions: Was my live, as I face death, a meaningful one? What makes a life meaningful?” (Crain, 1992, p. 261-262.)

**Rowe and Kahn’s Theory of Successful Aging**

Rowe and Kahn (1998) are currently the most frequently quoted authors used when defining successful aging in the social-psychology literature. Their book *Successful Aging*, based on the results of the 10-year MacArthur Foundation Study of Aging in America, is considered a landmark. Rowe and Kahn (1998) define successful aging as involving three interrelated components: “low risk of disease and disease-related disability: high mental and physical function: and active engagement with life” (p.38).
Furthermore, they suggest that these components are hierarchically ordered, with avoiding disease and disability making it “easier to maintain mental and physical function which in turn enables (but does not guarantee) active engagement with life” (Rowe & Kahn, 1998, p. 39).

Successful aging theorists such as Rowe and Kahn might explain elder self-neglect as a lack of engagement with life resulting from disease, disability, or low cognitive and physical functioning. Successful aging proponents tend to emphasize a biomedical approach to healthy aging, and thus they would likely emphasize a biomedical approach to explaining self-neglect. Disease and disability would be considered likely causes, and areas of health assessment would include nutrition, blood pressure, pulmonary rate, and levels of physical activity and social engagement.

**Productive Aging and Exchange Theory**

The conceptualization of productive aging has its roots in social exchange theory, which emphasizes the ability to exchange materials and goods as a foundational premise of successful aging. From a productive aging perspective, elder self-neglect may be seen as the inability of the elder to produce goods and services that will reduce his or her demands on goods and services produced by others.

Exchange theorists assume that social interactions are attempts to maximize material and nonmaterial rewards and to reduce material and nonmaterial costs (Bengtson and Dowd, 1981). Francis Turner (1992) proposes that exchange theory is based on the nature and structure of the social, psychological, economic, and legal interactions between the generations. Like productive aging theorists, exchange theory proponents argue that the problems of aging come about because the aged have little to exchange, leading to their increased dependence and need to comply with others (Dowd,
From a social exchange theory perspective, elder self-neglect may be viewed as resulting from the inability to produce goods and services to exchange.

Several factors may contribute to an older adult’s inability to produce goods and services. For example, an older person who is socially isolated and has little or no contact with others cannot easily participate in the exchange of goods and services. Illness or disability may also result in the inability to exchange goods and services.

An older adult’s economic history has significant influence on his or her ability to produce goods and services. If an older person has always been part of the underclass, defined by Schaefer (2004) as “the long-term poor who lack training and skills,” it is unlikely that he or she will be able to begin producing financially valued goods and services in old age. Employing a tenet of social exchange theory, productive aging theorists might thus view elder self-neglect as an older person’s withdrawal from the exchange of goods and services, possibly as an alternative to requesting needed goods and services for which he or she has nothing to exchange. Many cultures have religions, myths, and folklore that identify the wisdom and virtue of elder self-sufficiency.

Stoller (1985) explored patterns of exchange within the informal support networks of 753 noninstitutionalized elderly using data from personal interviews. She found empirical support for exchange theory, particularly the hypothesis that inability to reciprocate is more likely to adversely affect the morale of an older person than the actual need for assistance. She observed a negative relationship between family assistance and the extent of formal service use. This finding suggests that from an exchange theory perspective, self-neglect may result from the inability of an elder to use informal exchange to meet her needs, and that formal services (such as Adult Protective Services) may be required to meet basic needs.
Conversely, Kart and Longino (1987) interviewed 1346 elders regarding their social support networks and observed that the more support given or received, the lower was the elder’s life satisfaction. They found that exchange theory fails to explain the relationship between support systems and the well-being or life satisfaction of older persons.

VanWilligan (1989) compared social network inventories of 139 rural Kentucky elders with social networks of elders in other American communities. He observed that the social exchange of older persons increased until they reached their mid 70’s and then declined. He also found that the socioeconomic structure of a community in which a person ages has a larger effect on social involvement than does age, and age-related changes in social exchange within communities are small compared to variations in social exchange norms between communities. These findings suggest that environmental context is an important factor in assessing older adults’ well being.

Choi, Kim, and Asseff (2009) examined assessment and investigation data from reported APS cases in Texas to explore the association between self-neglect (and neglect) and individual economic resources. They also examined health care and social service programs for the poor. Choi, et al (2009) found that elder self-neglect and neglect is, in large part, attributable to the lack of resources to pay for essential goods and services and to inadequate healthcare and other formal support programs rather than individual risk factors. This finding supports an exchange theory explanation of elder self-neglect. Choi, et al (2009) recommend that inadequate public policy coverage needs to be considered as a significant cause of elder self-neglect and neglect.

**Role Theory and Activity Theory**

Role theory originated during the 1920’s and 1930’s by analogy to the theater, where the same actor might play very different parts in different plays, and different
actors could play the same part quite similarly (Turner, 2000). Early role theorists identified roles as components of culture (Linton, 1936). The basic premises of role theory are that people play a variety of social roles in their lifetimes, that these roles provide social identity and self-concept, and that society conveys age norms through socialization.

Role theory may explain elder self-neglect as resulting from an unsuccessful negotiation of role discontinuity. Turner’s (1992) concept of “uprootedness” from the traditional roles of the social world may be seen as an underlying cause of elder self-neglect.

“With the shift from a family system based on consanguine values to one held together by bonds of conjugality and sentiment, the obligations and influences of kinship have been minimized and the older generation has been places outside the children’s circle of privatized domesticity. As a result, the normative definitions of the roles of adults and older family members are not clearly delineated” (Turner, 1992).

Other tenets of role theory that may be used to develop an explanation of self-neglect are that people play social roles established by socialization, that there are ‘sick’ roles that provide people with social exemptions, and that some life events are non-normative. Role theorists identify a process of altercasting in which an actor attempts to entice of force others to play those roles that enable the focal person to play a preferred role (Turner, 2000). From this perspective, self-neglect may be viewed as a form of altercasting in which the self-neglecting elder may be seen as choosing to play the social role of “patient” or “eccentric.”

Alternately, self-neglect may be viewed as resulting from non-normative life events (such as an unexpected loss of health, income, or interpersonal support) or role discontinuity that the elder was unable to negotiate successfully. Finally, a community may ascribe the role of “sick person” or “self-neglector” to an elder even if the elder does not self-identify this role. Once a person has been typecast in such a role it may be
difficult to altercast into a more successful role because the community looks for and reinforces behaviors ascribed to the assigned role.

Another element of role theory that may be relevant to self-neglect is the importance of marriage roles. Role theorists emphasize that work and marriage roles provide a strong sense of identify (Turner, 2000). Research has shown that the majority of self-neglecting elders live alone (Abrams, et al, 2002; Steketee, Frost & Kim, 2001; Gruman, Stern, and Caro, 1997; Longres, 1995), and people living alone don’t have a current, active marriage role to help provide a sense of identity.

The basic premise of activity theory is that older people who are active will be more satisfied and better adjusted than those who are less active (Hooyman and Kiyak, 2001). Key premises of activity theory are that a person’s self-concept is validated through participation in roles characteristic of middle age, that society’s withdrawal from the elderly occurs against older people’s will, and that elders must deny the existence of old age by maintaining middle-age lifestyles as long as possible (Hooyman and Kiyak, 2001). According to activity theorists, successful aging involves keeping up as many of these activities as possible and finding substitutes for lost roles (Papalia, Camp, and Feldman, 2002). Activity theory may explain elder self-neglect as resulting from the inability to remain active and find substitutes for lost roles.

**Continuity Theory**

Atchley (1989, 1999) proposed a Continuity Theory of successful aging that suggests successful aging involves maintaining some continuity with our past in both internal and external structures of their lives. Continuity theory may explain elder self-neglect from multiple perspectives. One perspective is that self-neglect may result from an older person attempting to maintain the familiar environment, even if it is unsafe, rather than change the environment and lose continuity. This explanation of elder self-
neglect shares with communications and ecological perspectives the assumption of the importance of elder’s having a continuous and coherent life story. Another continuity theory perspective on elder self-neglect suggests that self-neglect may be used by an older person to maintain control of some element of her life, for example her food intake.

Bozinovski (2000) conducted interviews with 30 Adult Protective Service (APS) clients aged 60 and older who had been categorized as self-neglecters and with 20 APS caseworkers who worked with these clients. She observed two basic social psychological processes that explained much of the self-neglecting behavior exhibited by the older clients: preserving and protecting self and maintaining customary control, which she suggests combine to compose the overarching process of maintaining continuity.

**Communications Perspectives**

Communication theorists may explain elder self-neglect from multiple perspectives. Communications theorists Hummert and Nussbaum (2001) emphasize that the ability to communicate one’s needs is an essential link between health and aging. They propose that successful aging is directly linked to an older adult’s ability to produce messages that will lead to the desired optimization or more meaningful relationship. Communications theorists such as Hummert and Nussbaum who emphasize the importance of message production may explain elder self-neglect as resulting from an elder’s inability to communicate his or her needs.

Communications theorists who emphasize the social construction of reality may explain the concept of self-neglect as a “collaborative accomplishment” between the elder, his or her culture, and the particular professional group who is identifying the self-neglect (Gubrium, Holstein and Buckholdt, 1994). Hazan (1994) suggests that there is no process of aging (or self-neglect) in itself, but rather that the discourse of aging is born of interpersonal relationships within a given culture at a given time. Gerken and
Gerken (2002) suggest that the scientific literature of later-life decline is culturally constructed as well.

“Rather, that a given configuration constitutes “decline”—or indeed, is worth mentioning at all—derives from a particular domain of values (such as productivity and individualism), along with various assumptions, vocabularies, measuring instruments, and so on.” (Gerken and Gerken, 2002, p. 6)

Gerken and Gerken (2002) argue that the values of individuality and independence falsely assume that it is possible to get along without the cooperation and support of others. They suggest that the rejection of the view that we all are interdependent lends itself to a resistance to recognizing the needs of older people and to a reluctance of people to ask others for help. Gerken and Gerken (2002) further suggest that the emphasis on decline (including the concept of self-neglect) may reflect the needs of scientific, medical, and social service professions that depend on the view that aging is a problem to remain viable.

Ecological Perspective

Ecological perspective theorists Germain and Gitterman (1995) stress that people and environments are best understood in terms of their relationship to each other.

“Both person and environment can be fully understood only in terms of their relationship in which each continually influences the other in a particular context.” (Germain and Gitterman, 1995, p. 816)

They coined the phrase “person:environment” to represent this connectedness. Proponents of the ecological perspective suggest that an elderly person’s ability to cope with aging depends not on personal strength alone, but also upon the environment (Lee, 1989). According to Schiamberg and Gans (2000), the ecological perspective identifies that risk factors exist in all levels of an older person’s environment: interpersonal, psychological, familial, social network, community, institutional, societal and cultural, as
well as physical, ecological, and historical. From an ecological perspective, elder self-neglect may be seen as a poor fit between an older person and her environment.

“When there is a poor fit between a person’s environment and his or her needs, capacities, rights, and aspirations, personal development and functioning are apt to be impaired and the environment may be damaged. When there is a good fit, both person and environment flourish.” (Germain and Gitterman, 1996)

The ecological perspective does not offer specific causal explanations for a poor fit between person and environment. Proponents of an ecological perspective such as Germain, Gitterman, and Bloom rely on theories such as Freudian psychodynamic theory (conflicts stem from individuals’ subconscious unresolved conflict), attachment theory (conflicts stem from avoidant or resistant attachment styles), Marxism (conflicts stem from inequitable distribution of wealth), communications theory (conflicts stem from communication and message production barriers) or a biomedical approach (disease and/or disability) to provide underlying causal explanations for the conflict between a person and his environment. However, the ecological perspective concepts of habitat, niche, effectance, and coercive power (Germain & Gitterman, 1995, 1996; Germain & Bloom, 1999) may be useful in assessing, understanding and describing the fit of person:environment.

Effectance is the concept that all organisms are innately motivated to affect their environment in order to survive (Germain & Gitterman, 1995). Combining exchange theory tenets with the ecological perspective concept of effectance provides a framework to explain elder self-neglect as a means of making difficult but necessary financial choices to maintain survival or to maintain a familiar standard of living. For example, an older person may opt to go without necessary medication in order to maintain phone service, cable television, or pet food.

Habitat refers to places where an organism can be found (Germain and Gitterman, 1995). People’s habitats include their dwelling places and other physical
settings such as schools, workplaces, social agencies, etc. Germain and Gitterman (1995) suggest that human habitats evoke spatial and temporal behaviors, and that such behaviors serve to regulate social distance, intimacy, privacy, and other interpersonal processes. For example, the way an older person keeps her home may be reflective of the level of social distance she desires.

A niche as the position occupied by a species within a biotic community. For humans, niche refers to the status occupied by an individual of family in the social structure of a community (Germain and Gitterman, 1995). Older adults’ habitats and niches may be heavily influenced by coercive power in their social environment. Germain and Gitterman (1995) assert that the existence of oppressive niches is related to issues of power. From this perspective, elder self-neglect may be seen as a symptom of older adults living in oppressive habitats or niches that do not support their needs.

“In the United States alone, millions of children and adults are forced to occupy community niches that do not support human rights, needs, and aspirations—often because of color, ethnicity, gender, age, poverty, sexual orientation, or physical or mental states (Germain and Gitterman, 1995, p. 818).

Advocates of an ecological perspective identify the relevance of recognizing the influence of culture and ethnicity when assessing elder self-neglect (Germain and Bloom, 1999). What may be viewed as elder self-neglect in one community may not be viewed as elder self-neglect in another community. For example, communities differ on standards of home maintenance, lawn care and pet care.

**Labeling Theory**

Although not a theory of successful aging, labeling theory is an explanatory theory relevant to self-neglect. Labeling theorists suggest that deviance is not an inherent property of any specific behaviors or persons, but rather a matter of social definition. Like ecological perspective theorists, labeling theorists point out that
behaviors defined as “normal” in one context may be defined as “deviant” in another (Robbins, Chatterjee, & Canda, 2006). Unlike exchange theory and ecological perspectives which might emphasize lack of adequate resources as an underlying cause of elder self-neglect, labeling theory might emphasize societal labeling as an explanation for self-neglect.

From a labeling theory perspective, elder self-neglect may be viewed as a stigmatizing label provided by an elder’s community or society created for the purpose of social control. Labeling theorists argue that applying disease labels to behavior may serve to medicalize deviance and produce stigma (Wadley & Haley, 2001). Conversely, attribution theory suggests that the practice of labeling older people as deviant may evoke sympathetic responses (Wadley & Haley, 2001).

Wadley and Haley (2001) had 221 female undergraduates read vignettes describing an older parent exhibiting inappropriate behavior in a social situation with a diagnostic label provided (Alzheimer’s disease, major depression, or no label). They observed that the Alzheimer’s label, and to a lesser extent the major depression label, produced more sympathy toward the parent, less blame, and greater willingness to help, indicating that these labels may facilitate compassionate attitudes and enhanced caregiving toward older adults with socially accepted medical conditions.

Ward (1979) interviewed 323 noninstitutionalized elders and observed that age identification was related primarily to age-related deprivation, health, activity and employment status. He found that although personal age identification labels may not be stigmatizing, societal labeling does affect the well being of older people. Alternately, Baum (1984) found little evidence to support labeling theory. He conducted a literature review and found that younger perceptions of self are shown to be related primarily to
subjective feelings of physical, emotional, and social well being, rather than a rejection of the label and stigma attached to being old.

To explore the impact of labeling on older adults, Bear (1989) interviewed 85 elders who had moved into an adult residential care facility in Orange or Seminole County, Florida, within the previous 2 months. She also interviewed 75 of their closest significant others. The label she explored was “out of place in the home and in need of residential care.” Findings revealed that the informal network of the frail elderly was primarily responsible for the residential care entry; over two-thirds of the new residents were labeled as out of place in their own homes and referred to a care facility by an informal network member. Over 50 percent of the labeling and referrals were attributed to family members. Very few residents had labeled themselves out of place or identified a residential care facility as an appropriate place for them to live.

Discussion of Theoretical Perspectives on Elder Self-Neglect

Because there is empirical support for and against most theories of successful aging, professional values become an important guide when selecting which theories to use as frameworks for explaining elder self-neglect. The ecological perspective is used as a standard of comparison for other theories in this discussion because it is a foundational element of education and practice in the field of social work and because it offers one of the most comprehensive explanations of elder self-neglect. Based on their emphases and assumptions, exchange theory, role theory, communications perspectives, and Eriksonian theory explanations for elder self-neglect seem to have the best fit with the professional values of social work and the ecological perspective on elder self-neglect.

Two primary areas of contrast are found when comparing theoretical perspectives on elder self-neglect: 1) the contrast between physical and psychological
causes, and 2) the contrast between individual and societal causes. Most of the theories and conceptualizations of successful aging discussed here emphasize only one end of these causal spectrums. To provide a comprehensive explanation of elder self-neglect, effective explanatory theories must adequately address both of these causal spectrums, either by clearly identifying why one explanation is more plausible than the other or by acknowledging and describing the balance between them. Of the theories reviewed, the ecological perspective comes closest to addressing the physical, psychological, societal and individual causes of self-neglect through its recognition of the importance of both the person and their environment.

Biological explanations of self-neglect (such as disease, disability, cognitive and functional impairments, physical incapacities, and polypharmacy/addiction) have the poorest fit with the ecological perspective and the social work profession’s value of self-determination. Interestingly, many biological theorists are moving away from the “wear-and-tear” theory of aging. Today, most biological theorists do not believe that normal wear and tear is an adequate explanation for aging because a human being is capable of self-repair and can compensate for damage to the system (Papalia, Camp, & Feldman, 2002).

The psychological and psychosocial perspectives on self-neglect tend to fit better with the ecological perspective’s emphasis on person:environment and with social work’s professional values. For example, Erikson’s (1986) concept that failure at one developmental stage does not assure failure at later stages fits well with the social work profession’s emphasis on empowerment and strengths rather than deficit, disease, and dysfunction. Conversely, Jung’s (1960d) emphasis on turning inward and away from community as one ages does not fit particularly well with the ecological perspective and social work emphasis on the person:environment relationship.
The role theory emphasis on multiple roles individuals play in different environments fits well with the ecological perspective. Critics of role theory argue that it fails to consider the unique mental processes of people (Strean, 1979) and that it underestimates the important effects of culture, social class, and power (Richardson and Barusch, 2004). Another criticism of role theory is that it does not address biological health concerns or the importance of meeting basic physiological needs such as food, shelter, and clothing as prerequisites for successful aging and/or the avoidance of self-neglect.

Critics of activity theory point out that this theory assumes that people can maintain the same level of activity as they were used to in middle age and disregard the natural decline in energy, stamina, power, and strength with advancing years (Turner, 1992). Critics of activity theory also argue that it does not explain why some elders are passive and happy while others are highly active and unhappy (Hooyman and Kiyak, 2001), and that it places impractical expectations on elders who may be comfortable living their lives at a more relaxed pace than they did during their middle years (Richardson and Barusch, 2004). An additional criticism of activity theory is that like role theory, it does not address biological health concerns or the importance of meeting basic physiological needs such as food, shelter, and clothing as prerequisites for successful aging and/or the avoidance of self-neglect.

Critics of continuity theory argue that it tends to disregard the need for personal growth that always implies change (Turner, 1992). Another criticism of continuity theory is that like role theory and activity theory, continuity theory does not address biological health concerns or the importance of meeting basic physiological needs such as food, shelter, and clothing as prerequisites for successful aging and/or avoiding self-neglect.
The social exchange theory emphasis on the importance of having access to goods and services as a requirement for successful aging and avoiding self-neglect fits well with the ecological perspective and the social work value of commitment to assisting client systems in obtaining needed resources. Conversely, the productive aging emphasis on the value of production does not fit well with the social work value of the inherent dignity and worth of each person. Critics of productive aging argue that a valuation of productivity, particularly paid work, necessarily excludes many people from success, including the disabled, those working in informal economies, and populations disadvantaged by discrimination in the marketplace, and may further marginalize and exclude disadvantaged elders, particularly minority, women, and disabled persons (Estes & Mahakian, 2001).

Communications perspectives’ emphasis on the importance of hearing an individual’s narrative fits very well with the social work value of respect for the individual’s right to make independent decisions and to participate actively in the helping process, but their lack of attention to the environment does not fit well with the ecological perspective and social work emphasis on person:environment. Consistent with social work values, communications perspectives on elder self-neglect emphasize a strengths approach to treatment and propose that the identification of client strengths supports the client’s sense of control. Critics of exchange argue that they lack specificity and attention to socio-structural and political issues such as poverty, oppression, discrimination, or unmet physiological needs (Estes and Mahakian, 2001).

A major criticism of an ecological perspective on successful aging is the impossibility of most American’s achieving the ecological perspective’s markers of successful aging, positive couplehood and grandparenthood (Germain and Bloom, 1999). Taking into account U.S. census estimates that that approximately 50% of American
marriages end in divorce, that 5% of Americans never marry and that 20% of American adults do not have children, these ecological markers of successful aging are unavailable to most older Americans. Another critique of the ecological perspective is that it involves drawing an arbitrary boundary around the client system, deciding what is the system and what is the environment, and choosing a focal system of attention (Anderson, Carter, & Lowe, 1999). For example, some ecological perspective theorists may view persons living with a self-neglecting elder as part of the client system while others may view them as part of the environment.

In summary, the most common deficit of the theories of aging reviewed is their lack of attention to the underlying economic concerns of aging associated with elder self-neglect. All of these theories (with the exception of exchange theory) identify the need for meaningful relationships and activities as foundational elements of successful aging (Rowe and Kahn, 1998; Schultz, 2001). Some theories include physical health in their definitions of successful aging (Rowe and Kahn, 1998). Although the ecological perspective recognizes the influence an environment has on a person’s health and well being, only exchange theory identifies the necessity of having adequate resources to exchange for needed goods and services as an essential element of successful aging. The other theories assume economic stability, or at least that basic human needs are being met. This is usually not the case for older adults experiencing self-neglect.

**Demographic Characteristics Associated with Elder Self-Neglect**

National Center on Elder Abuse (NCEA) researchers identified that there was little available data on the characteristics of self-neglecting elders (Teaster, 2006). The NCEA published the National Elder Abuse Incidence Study (NEAIS) in 1998. NEAIS researchers analyzed national demographic data on the sex, age, race/ethnicity, self-care
ability, confusion, and depression of elders with substantiated incidents of self-neglect. They found that approximately two-thirds of the self-neglecting elders were female, which was somewhat higher than the 58 percent representation of females in the total elderly population. They found that the largest proportions of self-neglecting elders were in the oldest age category (80 and older). Elders aged 80 or older, who comprised 19 percent of the elder population, made up 45 percent of self-neglecting elders. This suggests that the older an elderly person gets, the more likely it is that she will be self-neglecting.

In the NEAIS study, approximately three quarters (77 percent) of the self-neglecting elders were white. Black self-neglecting elders comprised 21 percent and others comprised the remaining two percent. According to the United States 2000 Census data, blacks comprised 12 percent of the population in the U.S. The NEAIS research indicates that blacks are overrepresented in the area of elder self-neglect. This finding contrasts with Longres (1992) finding that black elderly were less likely to experience self-neglect.

NEAIS researchers found that an extremely high proportion of elders with substantiated self-neglect had some difficulty caring for themselves, with one third overall not being able to care for themselves. Only five percent were judged as able to care for themselves. These findings strongly support the conceptual definition of self-neglect as the inability to care for oneself, however the findings also indicate that self-care was not the only criterion workers used in identifying elder self-neglect.

In the NEAIS study, three quarters of substantiated self-neglecting elders were found to suffer from some degree of confusion. Approximately one quarter (24 percent) were not confused and appeared to be aware of their actions. Regarding depression, in 28 percent of the incidents of substantiated self-neglect the APS agency was not able to
determine whether depression was present or not. Over half (54 percent) of the self-neglecting elders were assessed to not be depressed, while 15 percent were judged as moderately depressed. Only three percent were considered severely depressed (NEAIS, 1998).

Other research findings regarding the association between cognitive impairment and/or depression with elder self-neglect have been mixed. Gruman, Stern, and Caro (1997) found that self-neglecting persons had higher levels of functional impairment and cognitive limitations compared with abused elders. Longres (1995) observed that mental illness and dementia were only moderately associated with becoming involved in an elder abuse and neglect service system. Steketee, Frost and Kim (2001) found that 76 percent of elderly hoarders had no problems with cognitive function and 67 percent had no deficits in memory. Burnett, et al (2006) studied 91 self-neglecting older adults and a matched control group and found no significant differences in cognitive abilities between the groups according to Mini-Mental State exam scores, however they found the self-neglect group had a significantly higher rate of depression compared to the matched control group.

Abrams, Lachs, and McAvay (2002) examined data from 2,812 community residents age 65 years and older in 1982. They observed that elderly people living in the community who experienced clinically significant depressive symptoms and/or cognitive impairment were more likely than others to experience self-neglect. They found other risk factors for self-neglect to be male gender, older age, income less than $5,000 per year, living alone, history of hip fracture, and history of stroke.

Tierney, et al (2007) found empirical support for the association between cognitive impairment and self-neglect in elders who lived alone. They examined the accuracy of 8 neuropsychological tests in the prediction of harm resulting from self-
neglect in cognitively impaired seniors who lived alone. The tests were administered to 130 people aged 65 or older who scored less than 131 on the Dementia Rating Scale. They found 3 tests measuring recognition memory, executive functioning, and conceptualization were independent risk factors for harm resulting from self-neglect for elders who lived alone.

Researchers have consistently observed a strong relationship between living alone and self-neglect. Longres (1995) found that 72 percent of self-neglecting elders were living alone in their own homes at the time of the incident. Gruman, Stern, and Caro (1997) observed that self-neglecting persons aged 50-97 were more often living alone and subject to social isolation. In their study on hoarding, Steketee, Frost and Kim (2001) found that 82 percent of hoarders lived alone, that over half of the elderly hoarders had never married, and that never-married hoarders had more severe hoarding. Their finding that half of the elderly hoarders had never married is particularly striking because only about 4 percent of elders in the U.S. have never married (Bureau of the Census, 2005). Abrams, et al (2002) also found living alone to be a risk factor for self-neglect. Burnett, et al (2006) studied 91 self-neglecting older adults identified by APS and observed that 52% of them lived alone, compared with 34% in a matched control group. Xin-Qi (2010) studied data from the Chicago Health and Aging Project (CHAP) conducted from 1993-2005 and found that lower levels of social networks and social engagement were associated with increased risk of being reported for self-neglect.

Paveza, et al (2008) conducted a literature review and discovered that cognitive ability, depression, basic living skills, comorbid conditions, alcohol use, personality, childhood trauma, psychological status, self-esteem, behavioral acculturation and coping style were internal vulnerabilities associated with elder self-neglect. Leibbrandt (2008)
conducted a cross-sectional survey of 106 community-dwelling persons aged 60 and over from seven low-income apartment buildings in Cuyahoga county. She found that male gender, no medication use, moderate to high medication misuse, problems with eyesight, and alcohol problems were significant predictors of self-neglect. Male gender was identified as the only statistically significant potential risk factor for substantial to severe self-neglect.

Leibbrandt (2008) recommends investigating substance use and abuse in association with self-neglect, especially in older males. Other researchers have also observed an association between substance abuse and elder self-neglect. Spensley (2008) conducted a chart review on 704 elder clients with confirmed cases of self-neglect from San Francisco APS in 2004 and found a positive relationship between substance/alcohol abuse and recidivism of self-neglect cases. Gibbons (2008) discovered that research has repeatedly validated the links between self-neglect in incompetent community-dwelling adults and functional and/or mental impairment resulting from cognitive decline, depression, or alcohol abuse.

Researchers have identified that more demographic data on self-neglecting elders needs to be collected. NCEA (2006) researchers published the following (selected) recommendations from the 2004 Survey of Adult Protective Services:

- Accurate and uniform data must be continuously collected at both state and national levels so that abuse trends can be tracked and studied. A concerted effort is necessary to create uniform definitions of, and measures for reporting abuse. As a baseline, all states need to be able to provide the information that this survey requested.

- States should collect detailed age and gender specific information on race and ethnicity of victims and alleged perpetrators. Little is known about the racial composition and ethnic background data of elder abuse victims.

- It is critical that states collect outcome data on the clients served. This information will be extremely helpful in determining efficacy of APS intervention.
ASSESSING ELDER SELF-NEGLECT

A major purpose of this study was to explore themes and issues that arise when APS workers assess elder self-neglect. As discussed earlier, researchers have observed that there is no standardized definition of elder self-neglect (Gibbons, 2009; Fulmer, 2008; Kelly et al, 2008; Naik, et al, 2008; Pavlou and Lachs, 2008; O’Brien, et al., 1999). Elder self-neglect is a multi-faceted concept requiring assessment of an elder’s mental, physical, environmental, and social conditions. There is much room for the interpretation of “adequacy” or “normalcy” in each of these areas (Lauder, 2009; Lauder et al, 2001).

The interpretive nature of assessing self-neglect presents difficult conceptual, identification and intervention problems for health and social care workers (Kelly, et al, 2008; Lauder, Anderson, and Barclay, 2005). On one end of the assessment continuum there are scholars and practitioners who emphasize the primacy of the elder’s decision-making capacity as the standard of determining self-neglect, while on the other end there are those who believe that a less than optimal physical or social environment in itself may constitute self-neglect. The National Center on Elder Abuse (NCEA) identifies that signs and symptoms of elder self-neglect include but are not limited to:

- Dehydration, malnutrition, untreated or improperly attended medical conditions, and poor personal hygiene;
- Hazardous or unsafe living conditions/arrangement (e.g., improper wiring, no indoor plumbing, no heat, no running water);
- Unsanitary or unclean living quarters (e.g., animal/insect infestation, no functioning toilet, fecal/urine smell);
- Inappropriate and/or inadequate clothing, lack of the necessary medical aids (e.g., eyeglasses, hearing aids, dentures); and
- Grossly inadequate housing or homelessness (NCEA, 2005).
Researchers have identified that no tool exists for characterizing elder self-neglect (Kelly, et al, 2008, 2006; Pickens-Pace, et al, 2007). However, progress is being made in developing new assessment tools and adapting existing tools to provide a standardized characterization of self-neglect. For example, Naik, et al (2008) and Pickens-Pace, et al (2007) have identified the Kohlman Evaluation of Living Skills (KELS) test as a resource for characterizing elder self-neglect. The KELS test provides an objective measure of a person’s capacity and performance with self-care behaviors and everyday life-supporting tasks (Pickens-Pace, et al, 2007).

Naik, et al (2008) sought to characterize self-neglect definitively as a geriatric syndrome by identifying an association with functional impairment. They performed cross-sectional evaluations using the Kohlman Evaluation of Living Skills (KELS) test and a modified Physical Performance Test, comparing 100 community-living older adults referred by APS for geriatric self-neglect with a matched group of 100 adults from a community geriatrics clinic. They found that self-neglect explained a significant proportion of the variance in KELS test scores, with participants in the self-neglect group having impaired KELS scores compared with the community control group.

Pickens-Pace, et al (2007) also compared the scores of the KELS between substantiated cases of self-neglect and matched community-dwelling elders by conducting a cross-sectional study correlating KELS with components of a comprehensive geriatric assessment. They provided comprehensive in-home assessments to 100 people aged 65 years and older, comparing 50 older adults recruited from APS as documented cases of self-neglect with a matched group of 50 control participants recruited from Harris County Hospital District outpatient clinics. Tests administered included a physical examination, the Mini-Mental State Exam (MMSE),
the Wolf-Klein clock test, the Geriatric Depression Scale, physical performance tests, and others.

Pickens-Pace, et al (2007) found that the self-neglectors were significantly more likely to fail the KELS than people that were not self-neglectors (50% vs. 30%). Additionally, when stratified by MMSE scores, self-neglectors with intact cognitive function remained significantly more likely to fail the KELS compared to matched, cognitively intact controls (45% vs. 17%). Pickens-Pace et al (2007) concluded that the KELS test can help clinicians identify elders at risk for self-neglect.

Pickens-Pace, et al (2007) observed that there is currently no gold-standard measure for identifying capacity with self-care behaviors among cases of elder self-neglect. Kelly, et al (2008) pointed out that self-neglecters often have no caregivers or surrogates to interview regarding the neglect and are often too cognitively impaired to provide valid self-reports. They developed the Self-neglect Severity Scale (SSS) to address this need. Kelly and other researchers from the Consortium for Research in Elder Self-neglect of Texas (CREST) collaborated with experts in the field of elder self-neglect to design the Self-neglect Severity Scale. The SSS is an assessment tool specifically designed to detect elder self-neglect in a home setting. Structured interviews were conducted with 25 APS workers in Houston to help conceptualize what such an instrument would look like. Three domains of self-neglect indicators were identified:

1) Personal hygiene—dirty hair and clothing, poor condition of nails and skin

2) Impaired function—decline in cognitive function and activities of daily living, as measure using one or more short-form tests

3) Environment neglect—visual evidence of subject’s inability to make necessary household repairs, clean the house and yard, and manage material goods acquired over the years.

An item pool of indicators was developed for the SSS and provided to an expert panel that agreed with the three domains and added additional items as indicators of
self-neglect. Then another work group consisting revised the item pool and assembled the items into an initial version of the SSS tool. The initial version consisted of 50 items, but removal of redundant items during the pilot study reduced the scale to 37 items.

The SSS was field tested in homes of people who had been reported to and substantiated by Texas APS as self-neglecting and compared with results of people recruited from a local geriatric clinic who were reported to APS but had no history of self-neglect. The CREST researchers found that at a group level, the SSS could distinguish elderly self-neglecters from community-dwellers who do not self-neglect, but that sensitivity and specificity fell below the conventionally acceptable range at an individual level, making the current version unreliable as an individual diagnostic tool (Kelly, et al, 2008). CREST researchers propose to improve the scale’s sensitivity and specificity ranges at the individual level and to reduce the number of items to create a more feasible and time-efficient scale.

As the developers of the SSS sought to standardize the assessment of self-neglect, Skelton, et al (2010) identified the need for a standardized capacity assessment and intervention model to determine if an older adult can make and execute decisions to live safely at home.

“Determining an older adult’s capacity to live safely and independently in the community presents a serious and complicated challenge to the health care system. Evaluating one’s ability to make and execute decisions regarding safe and independent living incorporates clinical assessments, bioethical considerations, and often legal declarations of capacity. Capacity assessment usually result in life changes for patients and their families, including a caregiver managing some everyday tasks, placement outside of the home, and even legal guardianship. The process of determining capacity and recommending intervention is often inefficient and highly variable in most cases. Physicians are rarely trained to conduct capacity assessment and assessment methods are heterogeneous.” (Skelton, et al, 2010, p. 300)
Skelton, et al (2010) used an interdisciplinary team of clinicians to develop the capacity assessment and intervention model (CAI) in the belief that conducting assessments and interventions in a standardized fashion is optimal.


This dissertation seeks to explore how APS workers assess elder self-neglect and the decisional factors that emerge when they decide whether or not to substantiate allegations of elder self-neglect. Research findings regarding assessment in the areas of mental health, physical health, and environment are reviewed here because these are critical areas considered by clinicians when assessing self-neglect and making decisions about substantiating allegations of elder self-neglect. Assessment tools available to APS workers in the field are discussed in each section. These tools are included because they appear often in the literature, they are brief and readily available, and most have been tested experimentally and have established adequate validity and reliability.

The interviews with APS workers who participated in this study revealed that there is no standardized use of assessment tools among APS workers and that workers who do use existing tools often abbreviate or adapt them. APS workers interviewed for this study mentioned the Mini Mental State Exam and the Clock-Drawing Test most frequently. Their usage and opinions of these assessment tools are discussed further in the results section.

**Assessing Decision-Making Capacity, Mental Health, and Competency**

Adult Protective Service workers must first assess elders’ decision-making capacity. In their primer for clinicians working with self-neglect, Pavlou and Lachs (2008) suggest that determination of decision-making capacity of patients is the first
ethical issue that should be considered in a case concerning self-neglect. MacDermott (2010) observed 125 hours of meetings and home assessments conducted by professionals associated with the “community options program” in Sydney, Australia and interviewed 18 professionals who worked with community-dwelling self-neglecting elders in Sydney. She found that professional judgments of self-neglect focus on risk and capacity, and that these perceptions influence when and how interventions occur. In the interviews with 16 APS workers conducted for my study, assessing decision-making ability emerged as the central thematic category, with sub-categories of assessing decisions about health and hygiene, housing, relationships, and finances.

Although research findings are mixed on the association between mental health problems and self-neglect, depressive symptoms and cognitive impairment have been found by some researchers to be significant predictors of self-neglect (Paveza, et al, 2008; Gibbons, 2008; Tierney, et al, 2007; Abrams, et al, 2002). Iris (2010) used concept mapping with 50 experts and practitioners who work with self-neglecting elders to create a conceptual model of elder self-neglect. She found through cluster analysis that clusters with the highest importance ratings were physical living conditions and mental health. Research findings regarding the association between self-neglect and the mental health concerns of cognitive impairment, depression, and substance abuse are discussed in depth in the “demographics” section of this literature review.

“Competency” is a legal term and is determined by judges acting on mental health assessments provided by APS workers, social workers, psychologists, and other professionals. In her seminal national study of involuntary protective services to APS clients, Duke (1997) discovered that the issue of competency moderated the relationship between elder self-neglect and the need for care. She stated:

“The dilemma for APS social workers in cases of involuntary intervention is not in providing as service the adult does not want but rather in determining
whether the adult is capable of choosing what he/she wants. An adult’s right to choose danger over safety is undisputed. However, an adult who is unable to understand the options available to him/her and their probable consequences, who cannot comprehend information that is relevant to the decision to be made, and who cannot understand how pertinent information applies to his/her circumstances is not able to formulate an informed decision.” (Duke, 1997, p. 52)

Duke (1997) observed that once the investigating social worker had identified a need for specific services and had determined that the adult lacked the capacity to consent to receiving those services, the authority to impose those services usually reverted to the court.

Objective screening tools available to assess older adults’ capacity to consent include the Mini-Mental State exam (MMS) and the Clock Drawing Test (CDT). The Geriatric Depression Scale (GDS) is an instrument available to assess depression in older adults. The Bill-Paying test is a tool available to assess an older adult’s financial capability. The Life Satisfaction Indexes (LSIA and LSIB) are tools that were developed to provide measures of life satisfaction. These assessment tools are reviewed here because they appear most often in the literature on assessing older adults’ decision-making and mental health and/or they are brief and readily available. The MMS, CDT, and GDS have been tested extensively and have all been shown to have high levels of validity and reliability. APS workers interviewed for this study most frequently mentioned the Mini-Mental State Exam and the Clock-Drawing Test. Their usage and opinions of these assessment tools is discussed in the results section of this study.

**The Mini-Mental State Exam**

The Mini-Mental State exam (MMS) is an assessment tool developed by Folstein, Folstein and McHugh in 1975 to separate patients with cognitive disturbance from those without such disturbance. It is a short, standardized form devised for the serial testing of the cognitive mental state in patients on a neurogeriatric ward, as well as for
evaluating the mental state of consecutive admissions to a private hospital. The MMS consists of eleven questions and requires only 5-10 minutes to administer. It is "mini" because it concentrates only on the cognitive aspects of mental functions, excluding questions about mood, abstract thought, mental experiences, and forms of thinking.

The authors provide the following description of the MMS:

"The MMS is divided into two sections, the first of which requires vocal responses only and covers orientation, memory, and attention: the maximum score is 21. The second part tests ability to name, follow verbal and written commands, write a sentence spontaneously, and copy a complex polygon similar to a Bender-Gestalt Figure; the maximum score is 9. Because of the reading and writing involved in Part II, patients with severely impaired vision may have some extra difficulty that can usually be eased by large writing and allowed for in the scoring. Maximum total score is 30. The test is not timed."

There are three versions of the MMS: the standard version, the extended version and an abbreviated version, all of which have been shown to be effective with elders. Folstein, et al (1975) and subsequent researchers established the validity and reliability of the MMS and concluded that it is a valid test of cognitive function, separating patients with cognitive disturbance from those without such disturbance (Barrie, 2002).

"Standardization of the test... indicated that the score of 20 or less was found essentially only in patients with dementia, delirium, schizophrenia or affective disorder and not in normal elderly people or in patients with a primary diagnosis of neurosis and personality disorder." (Folstein et al, 1975, p. 196)

The Mini-Mental State exam is now widely used by doctors, lawyers, judges, and social workers who are evaluating elders' competency. The MMS has many advantages. It makes cognitive disability more objectively measurable, it has demonstrated reliability and validity, it correlates well with other quantified assessments of cognitive function such as the Wechsler Adult Intelligence Scale (WAIS), and it only takes 5-10 minutes to administer.

The Mini-Mental State exam is particularly relevant to self-neglect because one of the primary questions raised by allegations of elder self-neglect is whether or not the
elder is legally mentally competent to make lifestyle choices (such as housing, nutrition, finances, and health). Competency is determined by the probate court, and probate court judges usually rely on assessments provided by Adult Protective Services (APS) or done by practitioners consulted by APS. Judges typically identify cognitive ability as a primary element of competency, and the mini-mental state is often used as a measure of cognitive ability in cases of alleged self-neglect.

Barrie (2002) conducted a literature review of findings on the reliability and validity of the MMS. She identified it as a “gold standard” for mental status screening, citing 7 studies that found it reliable for community-dwelling and institutionalized patients and 8 studies that found it a valid measure of cognitive impairment with good sensitivity and specificity. She also found much evidence for concurrent validity, citing 5 studies that found the MMS correlates well with the Blessed Information-Memory-Concentration Test and the Blessed Orientation-Memory-Concentration Test, 5 studies that found it correlates well with the Wechsler Adult Intelligence Scale, 1 study that found it correlates well with the Wechsler Memory Scale, 7 studies that found it correlates well with the Clock Drawing Test, and 5 studies that found it correlates well with the Blessed Dementia Rating Scale (Barrie, 2002). Razani, et al (2009) administered the MMS to 61 patients with varied forms of dementia and observed that the orientation and attention subscores of the MMS correlated most significantly with predicting everyday functional abilities of dementia patients and that orientation was the single, best independent predictor of daily functioning.

Barrie (2002) identified the main disadvantages of the MMS as revolving around problems with its reliability and validity for use with patients who have lower educational levels, are from non-white ethnic backgrounds, do not speak English, and are older. Further exploration of these criticisms reveals that educational level and age
are the primary variables contributing to lower scores. Crum et al (1993) administered the MMS to 18,056 subjects in five sites across the United States and found age and education to be the primary variables for lower scores. Murden et al (1992) observed no difference between blacks and whites with similar educational levels and of similar age. Espino (2001) and Lopez and Taussig (1991) studied MMS scores of English and Spanish speakers, and both studies found that after adjusting for age and education, language of interview was not significantly associated with lower scores, but that education level did affect the score.

Another critique of the MMS is that it is a culture-laden tool reflecting the values and circumstances of its authors. It was developed for use in a private New York psychiatric hospital in 1975, an environment where literacy was the norm. In other settings, the inability to follow written commands and write a simple sentence may not be universally viewed as symptoms of cognitive disturbance. As Dean et al (2009) discovered, cultural factors may influence test performance and present an increased risk of false positives for cognitive impairment. Respondents’ use of English as a second language could also influence test results. These concerns may be addressed by adjusting scoring, as MMS developers Folstein and Folstein (1975) recommend doing for people who have impaired vision.

The MMS has been found to be effective in assessing cognitive impairment in Korean, Brazilian, Arabic-American, African-American, and deaf American older adults when scores are adjusted for educational levels and other demographic variables such as age, gender, and linguistic factors (Han, et al, 2008; Dutra de Abreu, et al, 2008; Wrobel and Farrag, 2007; Brown, et al, 2003; Dean, et al, 2009). Han, et al (2008) administered the MMS to a cognitively normal sample of 977 Korean subjects aged 60-84 and discovered that Korean MMS scores were significantly associated with age, gender, and
level of education. They recommended comparing individual scores with normative data they developed on age, gender, and educational strata when using the Korean MMS.

Dutra de Abreu et al (2008) administered the MMS to 191 elderly Brazilian subjects and found that the MMS demonstrated diagnostic accuracy in the identification of patients with mild cognitive impairment. Wrobel and Farrag (2007) administered the MMS to 200 elderly Arab-Americans and observed that the utility of the MMS in identifying cognitive impairment varied across educational levels.

Brown, et al (2003) administered the Modified MMS (3MS) to 238 community-dwelling African-American older adults aged 60-84. They observed that age, gender, and education accounted for moderate amounts of variance in performance and recommended that clinicians compare individual scores with normative data they developed on age, gender, and education. Dean, et al (2009) administered the MMS to 117 deaf American senior citizens and observed that cultural and linguistic factors associated with the deaf population may influence test performance and clinical interpretation of test results, presenting an increased risk of falsely diagnosing cognitive impairment.

Richardson and Barusch (2004) suggested that when the MMS gives a more accurate impression of a person’s mental status when it is used in conjunction with less culturally biased tools it. The creators of the MMS cautioned practitioners that the MMS cannot carry alone the diagnostic responsibility.

“Accurate diagnosis, including appraisal of the significance of cognitive disabilities documented in the MMS, depends on evidence developed from the psychiatric history, the full mental status examination, the physical status and pertinent laboratory data.” (Folstein et al 1975, p. 195)
**The Geriatric Depression Scale**

Assessing depression is relevant when considering allegations of elder self-neglect because symptoms of depression (such as sleeplessness, decreased appetite, reduced motivation, and cognitive and concentration impairment) may influence an elder’s ability to provide self-care. Brink, Yesavage, Lum, Heersema, Adey, and Rose (1982) developed the geriatric depression scale (GDS) in 1982 for use by non-psychologists because elders are not likely to present themselves to a psychologist or psychiatrist and request relief for mental problems. Other professionals such as physicians, nurses, social workers, pastors, are most likely to make initial contact with elders seeking assistance with physical, financial or legal problems. The GDS is widely used by hospitals and mental health centers to assess elders’ mood and formulate diagnoses. It is a 30-question yes/no self-rating scale that is easy to answer and geared toward geriatrics. There is also a 15-question revised version now available (GDS-15).

To establish parsimony and validity, the authors (Brinks, et al, 1982) tested it with an ethnically, educationally, and socioeconomically mixed group of 46 aged subjects in the San Francisco Bay Area. Concurrent validity was established by having each subject complete 2 other depression scales, the Zung and Hamilton depression scales. All three scales were found to be able to distinguish between depressed aged and the control group, with the GDS slightly superior to the others. Bedard et al (1999) found the GDS to be reliable when they conducted a home-based test and retest (at two weeks) of the GDS and the Short Happiness and Research Protocol (another standardized measure of mood) with 20 elders diagnosed with Alzheimer’s Disease.

Barrie (2002) researched findings on the validity and reliability of the GDS and cited 11 studies that found the GDS in all three forms (30, 15, and 5 questions) demonstrates good reliability and validity. Agrell and Dehlin (1989) compared the GDS
with five other scales in 40 older stroke survivors and found the GDS had good validity and was one of the best-suited scales for depression screening in elders. Barrie (2002) identified several studies that found the GDS to have concurrent validity with the Zung Scale, the Beck Depression Inventory, the Center for Epidemiologic Studies Depression Scale, the Hamilton Rating Scale, and the Comprehensive Psychopathological Rating Scale-Depression.

The creators of the GDS (Brink, et al, 1982) identify a primary criticism of interpreting GDS results:

“A real problem for the practitioner using test data is to move from a number on an interval scale to a binary decision: whether to initiate or withhold treatment. Selecting a cutoff point results in a tradeoff between sensitivity (making sure that the really depressed patients score at or above the cutoff) and specificity (making sure that nondepressed patients score below the cutoff).” (Brink et al, 1982, p. 41-42)

They found that using a cutoff score of 8 would result in 80 percent specificity and 90 percent sensitivity.

Another criticism of the GDS is that it is a culturally laden tool reflecting the values, biases, and environment of its authors. To address this concern, culturally sensitive versions of the GDS have been developed in different languages, including Hebrew, Mexican, Korean, Portuguese, Chinese-American, and Japanese-American versions. Researchers have consistently found the 30 and 15 question versions of the GDS to be reliable and valid screening tools for depression among culturally diverse groups of older adults, including Brazilian (Castelo, et al, 2010), Korean (Kim, 2008), and Portuguese (Vargas, et al, 2007). Vargas, et al (2007) suggested that the GDS cut-off point for identifying depression might vary across cultures.

To assess the criterion validity and reliability of the GDS-15 across different gender, age, ethnicity, and different comorbidities in community living elderly and nursing home residents, Nyunt (2009) interviewed 4253 non-demented elderly (age 60
and over). A structured clinical interview was used to make a DSM-IV diagnosis of major depressive disorder. Nyunt observed that although some items in the GDS-15 appeared to be biased by gender, age and ethnicity, there were no clinically significant differences in test performance among different age, gender, ethnicity and comorbidities at cutoff of 4/5. He concluded the GDS-15 was a reliable and valid screening tool for major depressive disorder across different age, gender, ethnicity and chronic illness status in the community and social service setting.

An additional of the GDS is that it does not maintain its validity in demented populations. Researchers have found that the GDS either fails to identify depression or has diminished validity in identifying depression in persons with mild to moderate dementia (Korner, 2006; Gilley and Wilson, 1997; Montorio and Izal, 1996; Feher, Larrabee and Crook, 1992). Feher, et al (1992) recommended that the GDS should be used with caution in patients with Alzheimer’s disease.

“Less self-awareness of cognitive deficits was associated with fewer self-reported depressive symptoms; it appears that Alzheimer’s disease patients who disavow cognitive deficits also tend to disavow depressive symptoms, so the GDS should be used with caution in such cases.” (Feher, Larrabee and Crook, 1992)

Other researchers have found the GDS to be as effective in identifying depression in individuals with cognitive impairment as it is in those who are cognitively intact (Bedard, et al, 1999; Burke et al, 1992). Researchers have found the GDS to be valid and reliable in screening for minor depression in poststroke patients (Sivrioglu, 2009), and for screening for depression in Parkinson’s patients (Mondolo, et al, 2006).

**The Clock Drawing Test**

Workers interviewed for this study most frequently identified the Clock Drawing Test (CDT) as the most effective tool available to aid in assessing older adults’ cognitive abilities. The CDT was developed by Critchley in 1953. It was originally developed to
assess visuo-constructional abilities but more recently has been shown to test abstract conceptualization and numerical and verbal memory. Several methods exist for performing and scoring the CDT. One method is to give the patient a blank paper and a pen or pencil with the two-step instruction “First draw a clock with all the numbers on it. Second, put hands on the clock to make it read 2:45.” In this method instructions are repeated as often as necessary but no other directions are given. Another method is to give the patient a piece of paper with preprinted, 4-inch-diameter circle and instruct him or her to “Draw a clock.” The same three-word instruction is repeated in response to questions, but no other directions are given. A person passes the clock-drawing test if they are able to demonstrate the ability to draw a clock. There are several clock drawing interpretation scales available.

Barrie (2002) identified seven studies that found the Clock Drawing Test correlates well with the Mini-Mental State Exam. Researchers have consistently found the CDT to be an effective, valid, and reliable screening tool for detecting moderate to severe cognitive impairment in older adults but ineffective at detecting milder cognitive impairment, questionable dementia, or early-stage Alzheimer’s disease (Trenkle, 2007; Nishiwaki, et al, 2004; Seigerschmidt, et al, 2002).

Another critique of the Clock-Drawing Test is that educational and cohort biases may affect the accuracy of the CDT in assessing cognitive impairment. Younger cohorts who grow up learning to tell time by digital clocks might not have learned or mastered the skill of reading “sundial” type analog clocks, so their inability to draw an analog clock and manipulate time on it may not accurately reflect cognitive impairment. Chan, et al (2008) observed that individuals under 60 years of age showed similar performance on the CDT with a digital prompt (“make the clock read 12:45”) or an analog prompt (“...quarter to 1”), whereas individuals over 70 years of age showed improved
performance with an analog prompt. Chan, et al (2008) suggest that younger cohorts may require alteration in the nature of prompts for recoding during administration of the CDT.

**The Bill-paying Test**

Half of the APS workers interviewed for this study specifically identified assessing bill-paying as part of their process of assessing elder self-neglect. Sherman (2008), a primary care physician, developed a simple bill-paying test to assess older adults’ financial capability. Sherman administers the test by giving the older adult an envelope with one of his old electric bills, a blank check, and a new envelope, then tells the older adult to “pay the bill.” Older adults pass the bill-paying test if they complete the check correctly and put it and the bill stub in a properly addressed return envelope. The bill-paying test has not been tested for validity and reliability.

**The Life Satisfaction Indexes**

Life satisfaction is relevant to self-neglect in that people experiencing lower levels of life satisfaction may have less motivation to provide self-care. The Life Satisfaction Indexes (LSIA and LSIB) are mentioned here because the LSIA is a popular tool used extensively in both research and practice. A literature review reveals that the LSIA is one of the most widely used life satisfaction assessment tools. Havighurst and Neugarten (1961) developed the Life Satisfaction Indexes based on their Life Satisfaction Rating (LSR), a set of 5 scales developed for rating life satisfaction among the elderly. The LSIA is a written summated rating scale that a respondent completes independently: the LSIB is a face-to-face interview schedule that requires interpretation in scoring the respondent’s answers. These indexes were created for purposed of group comparison, not for formulating clinical assessments of an individual’s level of life satisfaction. Thus,
the LSIA and LSIB are not valid assessment tools for clinicians to use with individual clients. The author’s state:

“While considerable effort was expended in refining these instruments, the effort was only moderately successful. If used with caution, the indexes will perhaps be useful for certain group measurements of persons over 65.” (Havighurst and Neugarten, 1961)

**Assessing Physical Health and Self-Care Capacity**

All of the APS workers interviewed in this study mentioned assessing a person’s physical health and self-care capacity as part of their process of assessing elder self-neglect. The most recent national studies on elder self-neglect (NCEA 2004, 2000) did not gather data on the specific underlying reasons for reports of self-neglect, and there are no recent studies in the literature that have explored specific behaviors or conditions underlying allegations of elder self-neglect. However, in the seminal national study of involuntary services to APS clients in the United States, Duke (1997) discovered that medical treatment for a physical health problem was the most frequent service provided through legal intervention by APS agencies. Researchers have discovered that nurses most often identified hygiene deficits, impaired tissue integrity and malnutrition as indicators of self-neglect (Lauder, 1999; Adams and Johnson, 1998). Vinton (1992) found the primary reasons for report of self-neglect were medical needs, physical needs, or an unsafe environment.

Physical functioning and self-care capacity are important considerations when assessing elder self-neglect. Dong, et al (2009) found that higher self-neglect severity among older adults was associated with lower levels of physical function. In contrast, Naik, et al (2008) found that self-neglect was not associated with lower physical performance test scores. U.S. Census data from 2004 reveal that 38% of older adults experience impairment in activities of daily living. Recent studies have consistently

Assessment tools available to assess physical health and self-care capacities include the Physical Self-Maintenance Scale (PSMS), the Instrumental Activities of Daily Living Scale (IADL), the Kohlman Evaluation of Living Skills (KELS), and the Indirect Self-Destructive Behavior Scale (ISDB). These assessment tools are included for review here because they appear most often in the literature on assessing older adults’ self-care capacity and because they are brief and/or readily available.

The Physical Self-Maintenance Scale and Instrumental Activities of Daily Living Scale

The objective assessment of an elder’s self-care in areas such as eating, toileting, bathing, dressing, home maintenance, and financial management are critical when considering allegations of self-neglect. Lawton and Brody developed the physical self-maintenance scale (PSMS) and the instrumental activities of daily living scale (IADL) in 1969 as objective measurements of elders’ functional abilities to be used at the Philadelphia Geriatric Center, an institutional setting for elders. The PSMS is a six-item scale adapted from the Langley-Porter(1964) physical self-maintenance scale. It contains interviewer ratings of self-care ability in the areas of toileting, feeding, dressing, grooming, locomotion, and bathing. The IADL scale contains interviewer ratings of more complex behaviors. The IADL items form an eight-point scale for women (telephoning, shopping, food preparation, housekeeping, laundering, use of transportation, use of medicine, and financial behavior) and a five-point scale for men.
(food preparation, laundry, and housekeeping did not meet acceptable scaling limits for men). The IADL (and its adaptations) is the most commonly mentioned tool found in the literature on assessing older adults’ self-care ability.

Practitioners and administrators commonly use the PSMS and IADL scales for assessment, treatment planning, casework, and facility planning. Benefits of these scales include their brevity, objectivity and specificity. The authors point out that “anchoring evaluation to the specifics of actual function serves to minimize distortions and to reduce global, subjective, or value-laden judgments” (Lawton and Brody, 1969, p. 183). The scales focus on concrete behavior and are easy to understand, thus they can be used by practitioners from different fields and differing skill levels. They are helpful in matching individuals with particular services or facilities.

“When changing capacities lead to consideration of a change in living arrangement, the PSMS and IADL survey of function can be checked against social, professional or instrumental service which can be provided by family, friends, or community.” (Lawton and Brody, 1969, p. 184)

Periodic re-application of the scales estimates change over time and provides evaluation of the treatment outcomes.

The authors established concurrent validity with three other functional measures (Physical Classification, Mental Status Questionnaire, Behavior and Adjustment rating scales). More recently, Logsdon, Gibbons, Mccurry, and Teri (1999) established concurrent validity between the Physical and Instrumental Self Maintenance scales and another functional ability scale, the Quality of Life in Alzheimer’s Disease scale. The author’s used test-retest methods to establish reliability of the PSMS and IADL scales. The test-retest reliability of both scales was established more recently by Green, Mohs, Schmeidler, Aryan, and Davis (1993) when they completed both PSMS and IADL scales on 104 persons with probable Alzheimer’s disease upon admission to the study and at 6-month intervals.
A criticism of the Lawton-Brody scales is that although the self-care tasks assessed by the PSMS appear universal, those assessed by the IADL seems more culture bound, especially regarding the assignment of tasks by gender. The identification and acceptance of these items as “women’s tasks” perpetuates sexism and double standards for assessing competency in men and women. This concern can be addressed by adjusting adaptations of the Lawton IADL to include assessment of food preparation, laundering, and housekeeping skills for men. Other IADL scales are also available.

Another criticism of the Lawton scales is their lack of attention to acknowledging and including differing perspectives on clients’ functional limitations. The fact that the interviewer rather than the client rates these scales implies a degree of paternalism and social control by assuming that the interviewer and ancillary others (family, staff) are better able to evaluate the clients functioning than is the client. This concern has been addressed by the development of self-report versions of the IADL scale.

Researchers have examined the extent to which practitioner’s assessment of a person’s IADL ability agreed with that of the patient and have found mixed results. Hsieh (2006) found agreement between IADL summary scores and patient self-report. Wisniewski, et al (2009) observed that language was not a barrier to agreement between provider and patient assessment of patient IADL ability and suggested that other patient or provider characteristics may be a factor. Goverover, et al (2009) found that patients with Multiple Sclerosis (MS) showed lower levels of self-awareness of (practitioner rated) IADL functional status than did subjects without MS.

Another factor to consider when evaluating the accuracy of IADL assessments in frail older adults is the setting in which the adult is observed. Provencher, et al (2009) conducted a literature review to determine if differences existed between home—based IADL assessments and clinical IADL assessments in an unfamiliar environment. They
found little extant literature on the topic and suggested that frail elderly patients may show different abilities in unfamiliar settings.

IADL scale creator Lawton recognized that issues such as frames of reference for defining disability, social roles and cultural context, and self-reporting versus proxy reporting arise when measuring ADLs and IADLs (Kovar and Lawton, 1994). Lawton and Brody cautioned against using their scales as sole determinants of service planning.

“The authors hope that the application of the PSMS, the IADL, or any other scales, will aid, but not substitute for, evaluation and planning. They should be viewed in perspective as one component of the complex system of determinants which also includes the availability of resources, and the needs and wishes of individual older people and their families.” (Lawton and Brody, 1969, p. 186)

Researchers have consistently found cognitive dysfunction and geriatric depression to be associated with impairment in IADLs (Kiosses and Alexopoulos, 2005). The literature indicates that clients’ perspectives, mental health, and self-determination must be considered when completing these assessments and when service planning based on their results.

**The Kohlman Evaluation of Living Skills**

The Kohlman Evaluation of Living Skills (KELS) is the most widely mentioned and tested assessment tool found in recent literature on elder self-neglect. It was developed by Kohlman Thomson in 1978 to assess 17 basic living skills in five areas:

- **Self-care**
  1. Appearance
  2. Frequency of self-care activities (self-report)

- **Safety and health**
  1. Awareness of dangerous household situations (from photographs)
  2. Identification of appropriate action for sickness and accidents
  3. Knowledge of emergency numbers
  4. Knowledge of location of medical and dental facilities
• Money management
  1. Use of money in purchasing items
  2. Obtain and maintain source of income
  3. Budgeting of money for food
  4. Budgeting of monthly income
  5. Use of banking forms
  6. Payment of bills

• Transportation and telephone
  1. Mobility within community – Methods:
  2. Basic Knowledge of transit system
  3. Use of phone book and telephone

• Work and leisure
  1. Plans for future employment
  2. Leisure activity involvement

The KELS was originally designed to be used by occupational therapists evaluating the living skills of people with psychiatric diagnoses on an inpatient psychiatric unit for the purpose of developing intervention plans and to assist in discharge planning in a timely manner (Kohlman Thomson, 1999). Setup, administration, and scoring can be completed in 30 to 45 minutes. The KELS requires the following equipment: a bar of soap, a bill, local phone number cards, four pictures, the local telephone books and a telephone. All of the equipment and forms, except for the telephone supplies, fit in a three-ring binder so it is easily transportable (Kohlman Thomson, 1999).

Scoring is from 0 to 16, with higher scores indicating a need for assistance to live in a community setting. The administrator scores each section as “Independent” or “Needs Assistance,” with each section marked Needs Assistance, excluding Work and Leisure, counting as 1 point. Needs assistance scores under Work and Leisure are counted as ½ point. The scoring system was originally designed to place clients into three categories for the purpose of discharge planning to the home environment: (a)
independent with a score of 5 or less, (b) borderline skills with a score between 5 and 5.5, and (c) needs assistance with a score greater than 6 (Kohlman Thomson, 1992, 1999; Pickens-Pace et al, 2007).

In 1987, Kohlman Thomson completed an unpublished predictive validity study with 50 psychiatric inpatients who were discharged to live alone in the community and found unfavorable validity results (Kohlman Thompson, 1999). She attributed this to major problems in the research design after the data was collected. Several other research studies have helped establish the reliability and validity of the KELS (Kohlman Thompson, 1999).

Burnett, Dyer, and Naik (2009) conducted a cross-sectional study correlating KELS with components of a comprehensive geriatric assessment to evaluate the convergent validity of the KELS to screen older adults’ ability to live safely and independently. They conducted comprehensive in-home assessments of 200 people aged 65 years and older comparing 100 persons referred by Adult Protective services with 100 ambulatory patients matched on age, race, sex, and socioeconomic status. Tests administered included the Mini-Mental State Examination, the Geriatric Depression Scale, the modified Physical Performance Test, the Executive Cognitive Test, the executive clock-drawing test, and other physical functioning tests.

Burnett, et al (2009) found that KELS demonstrated convergent validity with a battery of cognitive, affective, executive, and functional measures often used to determine older adults’ ability to live safely and independently in the community. Among the entire group of subjects, older adults with abnormal KELS scores performed significantly worse on all tests except for the Knee Extensor Break Test. Among those referred by APS, the KELS correlated with all tests except the 8-foot walk test and the Geriatric Depression Scale. Burnett et al (2009) concluded that KELS may be a valid and
pragmatic way to screen for the capacity of older adults to live safely and independently in the community.

Kohlman Thompson (1999) identifies several limitations to the KELS. At times, a patient will give a partial answer and the evaluator must ask additional questions to obtain a complete answer. Therefore a patient might be scored higher or lower by different evaluators, although research has demonstrated high reliability scores. Another limitation of the KELS is that some items are knowledge-based versus performance-based. This was done to make the administration and scoring time practical and short. In some cases, the administrator may not have confidence that the patient will actually be able to perform the living skill, even if the knowledge is present. In those cases, additional performance-based assessment beyond the scope of the KELS may be needed. Kohlman Thompson (1999) points out that if the KELS is to be used in a multidisciplinary setting it is essential to educate other professionals about it’s assessment, interpretation, and use of the results. “Without education, misinterpretation of results can occur” (Kohlman Thompson, 1999, p. 237).

Another problem in administering the KELS is that some evaluators may think a person should score all items in the “independent” category to be considered normal. Kohlman Thompson (1999) asserts that the term “needs assistance” should not be viewed as being abnormal or negative.

“The KELS was not designed with the intent that a score of Independent should be scored in all areas in order to live independently in the community. The circumstances and daily living environment of the patient must be considered.” (Kohlman Thompson, 1999, p. 237)

She emphasizes that the KELS is not meant to be used in isolation as the sole determinant of a client’s living situation, but as a contributing factor in making discharge plans (Kohlman Thompson, 1999).
A criticism of using the KELS to diagnose self-neglect in older adults living in the community is that it does not address the issues of intentionality, knowledge, and material resources. As discussed previously, Reed and Leonard (1989) suggest that for self-neglect to occur, there must be no specific purpose expressed or clearly identifiable reason for engaging in the behavior (attribute) and the person must have available the cognitive, psychomotor, and material resources necessary for participating in a prescribed health care regimen (antecedent). A person could have low KELS scores without meeting these conceptual criteria for self-neglect. For example, there might be clearly identifiable reasons for a person being assessed as “needing assistance” in some areas of the KELS. These reasons may include a lack of material resources, a lack of information, or a self-report of lifestyle choice or personal cost-benefit analysis.

**The Indirect Self-Destructive Behavior Scale**

Assessing elder self-neglect includes assessing the degree of risk that older adults’ behaviors will cause them harm. This risk of harm may be unintentional or indirect. Nelson and Farberow (1977, 1980, 1982) developed the Indirect Self-Destructive Behavior Scale (ISBD) to assess indirect self-destructive behavior among chronically ill medical patients. To develop the ISBD Scale, they provided examples of noncompliant and self-injurious behaviors obtained from previous studies and added behaviors thought to represent forms of self-destructive behavior that could occur among institutionalized chronically ill patients. This preliminary list was then modified by feedback from members of the medical and nursing staff of the Intermediate Care Unit at the VA Wadsworth Medical Center in Los Angeles. A final list of fifty-six observable behaviors grouped into nine categories was included in the ISDB Scale (Nelson and Farberow, 1982). The nine categories are:

- Noncompliant Eating
• Noncompliant Drinking
• Noncompliant Smoking
• Abuse of Medication
• Conflict with Other Patients
• Conflict with Staff
• Abuse of Treatment Program or Hospital Policy
• Overt Self-Injury
• Behaviors other than those specified

Nelson and Farberow (1982) tested this study with a sample of 201 in-patient veterans drawn from VA intermediate care and VA nursing facilities in the Los Angeles area. The behavior observed most frequently was the abuse of the treatment program or hospital policy (71%). The other categories of observed behavior were conflict with medical staff (48%), self-injurious eating behaviors (44%), non-compliant smoking (37%), self-injurious drinking behaviors (30%), conflicts with other patients (25%), abuse of medication (21%), more overt forms of self-injury (12%) and non-compliant or self-injurious behaviors other than those included in the scale (12%).

Because this tool is intended to assess institutionalized patients and requires 24-hour assessment, it is not suitable for assessing self-neglect in community-based elders. Nelson and Farberow (1982) did, however, relate their findings to previous research findings on the institutionalized elderly which suggest that certain behaviors that appear uncooperative or belligerent to the staff may actually serve to counteract feelings of powerlessness and low self-esteem.

“At some perceived or unconscious level of psychodynamic choice, a patient may feel compelled to risk his health or welfare through ISDB in an effort to gain some sense of mastery over a relatively powerless life situation.” (Nelson and Farberow, 1982, p. 12)
APS workers interviewed for this study also mentioned this as an important consideration when assessing elder self-neglect.

**Assessing Environment**

As mentioned previously, Iris (2010) used concept mapping with 50 experts and practitioners who work with self-neglecting elders to create a conceptual model of elder self-neglect. She found through cluster analysis that clusters with the highest importance ratings were physical living conditions and mental health. Although an unsafe environment has been found to be a primary reason for the report of elder self-neglect (Vinton, 1992), little research has been done on assessing the environment of self-neglecting elders. Safety in the residential space, lack of adequate economic resources, and the extent of physical and social isolation are important environmental factors to consider when assessing elder self-neglect (Rathbone-McCuan, 1996). The National Center for Elder Abuse (2005) identifies the following environmental conditions as signs of elder self-neglect:

- Improper wiring
- No indoor plumbing
- No heat
- No running water
- Animal/insect infestation
- No functioning toilet
- Fecal/urine smell (NEAC 2005).

Hoardng and housing code violations are two additional ways that safety in the residential space may be measured. Hoarding is sometimes used an environmental indicator of elder self-neglect. Steketee, Frost and Kim (2001) studied 62 elderly
hoarders and found, consistent with other studies, elderly clients commonly hoarded paper, containers, clothing, food, books, and objects form other people’s trash. They found that the clutter was typically chaotic with no apparent organization. The clutter interfered with service delivery in 63 percent of the cases, and no services could be delivered in 5 percent of the cases.

“In these cases elderly hoarders refused entry or claimed that the provider was stealing or throwing away valuable possessions, or the provider refused to enter the residence because of deplorable living conditions. Nearly one-fifth of hoarding clients restricted agency services, especially cleaning services” (Stekete, Frost, and Kim, 2001, p. 180).

In the Steketee et al (2001) study, service providers indicated that 90 percent of the elderly hoarder’s homes were “dirty or filthy” and reported that in 32 percent of the homes they noticed “overpowering odors from rotten food and animal or human feces” (p. 180). They found clutter from hoarding to interfere with normal functioning in the areas of inhibition of movement, access to furniture, access to food preparation, and interference with hygiene. 80 percent of the elderly hoarders experienced substantial to severe inhibition of movement. Nearly 70 percent of elderly hoarders were unable to use their furniture. Clutter prevented food preparation in over half the cases, and interfered with the personal hygiene of the elder in 56 percent of the cases.

“In the view of service providers, the hoarding constituted a physical health threat for 81 percent of their elderly clients, and nearly half faced substantial (11 percent) or extreme (36 percent) threats to their well-being...Among clients considered at physical risk, the clutter constituted a fire hazard for 45 percent because of flammable materials and blocked exits. In 39 percent of cases, providers expressed strong concern about the risk of falling because of the clutter, particularly for the one-quarter of clients who had problems with ambulation...About one-third of clients faced unsanitary conditions in their homes in the form of infestations, feces, and rotten food. For some elderly people, medical conditions were attributed to hoarding behavior” (Stekete, Frost, and Kim, 2001, p. 181).

Live animal hoarding is another form of hoarding encountered by APS workers. Nathanson (2009) conceptualizes animal hoarding as a form of dysfunctional human-
animal relationships needing attention and remediation. She describes animal hoarding as a deviant behavior associated with severe conditions of comorbid animal and self-neglect. Nathanson (2009) suggests that APS workers will be able to evoke greater rapport and cooperation from animal hoarders by recognizing the complex dynamics of the relationship between animal hoarders and their pets. She proposes that interdisciplinary efforts are essential for optimal resolution of animal hoarding.

In some communities, housing code violations are used as an environmental indicator of self-neglect. The use of housing code violations as an indicator of elder self-neglect is a prime example of the subjective, contextual nature of assessing self-neglect from the environment. For example, community expectations of appropriate property maintenance in terms of home repair, yard care and pet care may differ dramatically between an affluent suburban community and an impoverished rural community.

Recognizing the importance of the environment, Rathbone-McCuan (1996) recommended the following core areas of assessment for self-neglect:

- Impairment levels
- Economic resource adequacy
- Safety in the residential space
- Availability of formal and informal resource networks
- Adequacy of the assistance provided by the networks
- The extent of physical and social isolation
- Depression
- Cognitive orientation
- Related biopsychosocial problems.
TREATING ELDER SELF-NEGLECT

Two major purpose of this study were to explore what kinds of treatment and service recommendation issues arise for APS workers and what services are needed by older adults experiencing self-neglect. Torke and Sachs (2008) observed that there is little empirical data available to guide medical practice in cases of elder self-neglect, particularly with self-neglecting patients who resist interventions. They identified establishing a safe living environment as the goal of treatment self-neglecting elders. Pavlou and Lachs (2008) observed that there are no specific interventions or intervention trials to date for elder self-neglect. They proposed the goal of intervention as being to reduce co-morbidity from neglected chronic illnesses, maximize functionality and improve quality of life. They developed a table for clinicians assessing and treating self-neglect that included the following treatment recommendations:

- Educate, negotiate, partner with patient
- Homecare services as needed (visiting nurses, regular podiatric care)
- Psychiatric evaluation if indicated
- Identify social network and obtain permission to contact friends/family
- Help establish support system (e.g. social groups, senior center, adult day care, church group, volunteer work)
- Obtain advanced directives
- Home safety evaluation for equipment if indicated
- Refer to social service agency that may offer volunteer services for shopping, transportation money management, etc.
- May need inpatient or outpatient rehabilitation
- May need cleaning services, exterminator services
- May need legal services (e.g. faced with threat of eviction)
- May need to involve law enforcement authorities
Empirical data on service utilization and evidence-based best practice recommendations for self-neglecting elders are scarce. The treatment for elder self-neglect has traditionally been to attempt the implementation of home-based services or seek institutional placement. Anetzberger and Balaswamy (1994) found that the most common services for self-neglect used by APS workers in Ohio are home-delivered meals, guardianship, and institutional placement. Reyes (2001) proposed daycare centers and community care rather than hospital admission or nursing home care as the main lines of management for self-neglecting elders. Choi and Mayer (2000) sampled 370 self-neglect APS cases and made to following five recommendations for service delivery:

- Case management
- Formal support systems such as homemaker and health aids
- Alcohol/drug screening
- Financial management such as representative payee
- Home maintenance

The need to develop service and social support networks as an integral part of treating elder self-neglect arises consistently in the literature. In a study of more than 500 geriatric self-neglect patients, Dyer, et al (2007) suggested that inadequate support services such as medical care and assistance with bathing, dressing, home cleaning, laundry, and obtaining food is what distinguishes older persons who self-neglect from those who do not. In a study of 91 self-neglect cases ages 65 and older identified by APS, Burnett, et al (2006) found strong evidence for an association between self-neglect and decreased social resources, particularly those related to informal social networks.

Determining the need for care for self-neglecting elders is a difficult, non-standardized process. Researchers have observed that frequently the determination of
the need for care for a self-neglecting elder arises due to a dramatic decline in function often precipitated by an acute medical illness (such as falls, weakness, hip fracture, pneumonia, or stroke) resulting in unavoidable contact with the health care system (Pavlou and Lachs, 2008; O’Brien et al, 1999). Karpinski (1997) brought up another dimension of the process of determining the “need for care” among self-neglecting elders by pointing out that elders have a constitutional right to make decisions about how they want to live:

“In our society, adults have the constitutional right to make their own decisions about how they want to live…The question arises as to whether the “bad” choice places the individual or others at imminent danger of harm or is simply a choice with which we disagree…Thus two additional concepts arise which are central to working with self-neglecting elders: the concepts of decision-making capacity and least restrictive alternative” (Karpinski, 1997, p. 139)

This question of balancing self-determination with the obligation to provide needed care will be discussed further in the final section of this literature review about honoring self-determination.

O’Brien et al (1999) identified that many adult protective agencies do not intervene if the elder is determined to have the capacity to manage his own affairs and refuses services or assistance, and that the literature provides little help in terms of model programs to manage self-neglect.

“In-patient behavioral modification in conjunction with the use of medication such as antidepressants to treat underlying problems such as depression has been demonstrated to show success in isolated cases (Ungvari and Hantz, 1990)...[however] Repeated attempts to get self abusers to participate in day-care hospitals have met with mixed results. These patients often resume hoarding after their homes have been cleaned or simply refuse assistance...” (O’Brien, et al, 1999, p. 13).

O’Brien’s (1999) observation that self-neglecting elders often resume hoarding after their homes have been cleaned was supported by Steketee, Frost, and Kim’s (2001) finding that of hoarding client receiving some type of change effort, only 15 percent sustained gains. Steketee Frost and Kim (2001) suggested that involuntary cleaning of
the home is not a solution to the problem of hoarding and that effective treatment is likely to require engaging the client in modification of faulty beliefs, assistance with organizing and decision making, and examination of emotional attachment and behaviors that promote hoarding (a.k.a. cognitive restructuring).

Similarly, Karpinski (1997) suggested that the process of change has greater success when an older adult is actively engaged. Pavlou and Lachs (2008) emphasized the importance of medical practitioners negotiating and partnering with self-neglecting elders when planning treatment. Mixson (1991) also argued that building an ongoing relationship with the self-neglecting elder can play an important part in gaining acquiescence to accepting the need for care. She pointed out the importance to elders of maintaining a sense of control over some part of their lives.

“Self-care activities may be the last area of functioning over which an impaired adult can exert control. In self-neglect cases this control may be the impaired adult merely saying “no” to offers of assistance” (Mixson, 1991, p. 37).

A multi-database literature review revealed three dominant practice considerations for working with self-neglecting elders.

- An ecological perspective will provide the most thorough assessment and most effective treatment planning.
- Building a relationship with the elder is critical.
- Exchange theory may be helpful in engaging self-neglecting elders who are resistant to services.

A more detailed discussion of theoretical approaches to treating elder self-neglect and of practice considerations and common interventions for treating elder self-neglect follows.

**Theoretical Approaches to Treating Elder Self-neglect**

The most frequently represented treatment approaches to elder self-neglect found in the literature were the medical model (including mental health, hygiene,
nutrition, medications, disease, and functional impairments) and an ecological perspective (including the effect of community and formal and informal support networks).

Advocates of task-centered approaches to treating elder self-neglect (e.g. a medical model, an ecosystems perspective, or cognitive/behavioral approaches) emphasize the development of interventions and desired outcomes to reduce the impact of specified problems. These interventions include treatments, problem-solving tasks, and the mobilization and/or adaptation of an elder’s environment (Epstein, 1988, 1992; Germain and Bloom, 1999). Critics and advocates of task-centered approaches agree that tasks are less effective with problems that are broad in scope, global, or loose in focus (Epstein, 1988, 1992).

Advocates of person-centered approaches to elder self-neglect (e.g. relationship-oriented and communications approaches) emphasize that if a practitioner provides empathy, unconditional regard, and congruence, positive change will occur (Rogers, 1961). Unlike task-centered approaches, person-centered approaches usually do not propose specific outcomes or interventions: goal formation is an outgrowth of a mutual agreement between client and practitioner (Green and Blundo, 1999). Critics of person-centered approaches argue that the emphasis on the self does not fully address the influences of the environment (Bozarth, 1997).

Advocates of resource-centered approaches to self-neglect (e.g. social exchange theory or gains/losses models) assume that all social interactions are attempts to maximize rewards (material and nonmaterial) and reduce costs (Bengston and Dowd, 1981). Practitioners of these approaches assume that reciprocation perpetuates relationships and they attempt to create a sense of fair social exchange with clients (Mixson, 1991; Amilla, 1999). Critics of resource-centered approaches argue that the
emphasis on “fair” social exchange does not take into account human altruism and an age-related increase in humanitarian and moral purposes (Cheal, 1988).

A review of task-centered, person-centered, and resource-centered practice approaches suggests that that task-centered approaches are the most applicable for assessing self neglecting elders, primarily because they provide the most consistent guidelines and standardized assessment tools for practitioners to use when measuring self-neglect. Standardized assessment tools help practitioners define and measure the value-laden concept of elder self-neglect in the least amount of time, which is often of the essence in cases of self-neglect.

A communications approach to care planning can help to moderate the loss of individuality intrinsic to a standardized assessment strategy. By hearing the elders’ voices, communications approaches best provide practitioners guidance in negotiating the ethical dilemma of freedom vs. safety. Finally, resources are relevant to the degree that they promote or interfere with treatment, and are optimally addressed directly, regularly, consistently, and face-to-face with the elder by practitioners, not a billing office. Each of these approaches to treating elder self-neglect is reviewed here.

**Medical Model**

In the traditional medical model, physiological concerns are identified as problems and handled through assessment, diagnosis, and treatment. Assessments provide the basis for diagnosis and for eligibility determination. Practitioners may then implement treatments associated with particular diagnoses or design care plans to access services. Psychosocial problems are addressed with the goal of lessening their severity to the point of zero. The practitioner is viewed as an expert who treats the clients’ pathologies and deficits (Greene and Blundo, 1999).
Practitioners using a medical model identify typical causes of self-neglect as dementia, mental disorders, depression, polypharmacy, physical incapacity, and alcoholism. (Lau, 1986; Blondell, 1999; O’Brien, 1999). Lauder (1999) conducted interviews with 41 district nurses in Scotland and found the two most common nursing diagnoses for self-neglecting patients living in the community are bathing/hygiene deficit and impaired tissue integrity. Adams and Johnson (1998) interviewed 28 nurses in the United Kingdom, focusing on the key characteristics that they ascribe to self-neglect.

“The most common characteristics of gross self-neglect, identified by a majority of the nurses, were poor personal hygiene and poor nutrition. Other characteristics identified by five or more respondents included shabby clothes, loneliness, long toe nails, poor healing/sores, and dirty or limited furniture in the home.” (Adams and Johnson, 1998, p. 547)

A major critique of the medical model is that the practitioner is expected to identify client deficits, putting the practitioner in a position of authority over the client rather than a position of collaboration with the client (Greene and Blundo, 1999). This creates an unbalanced power relationship and conflicts with the value of client self-determination by limiting the client’s role in problem identification and treatment planning. Misdiagnosis or inaccurate assessment may occur when a client defers problem identification to a practitioner.

Another critique of the medical model is that its focus on deficits promotes a sense of pathology rather than health. Service eligibility and reimbursement requirements may reinforce this deficit focus (Kivnick and Murray, 2001). For example, Medicaid and private insurance companies will typically cover the costs of organ repair and replacement, diabetes treatment, kidney dialysis, and tooth extraction, but not the costs of preventative care to avoid these conditions. These reimbursement policies limit the treatment options available to practitioners and promote a crisis intervention approach to treatment rather than an integrated lifelong approach to treatment.
Pathology-based eligibility and reimbursement policies apply to mental health treatment as well. Most medical insurances, public and private, require mental health practitioners to diagnose specific pathology in order to receive reimbursement. This pathology-based reimbursement protocol promotes a deficit-based assessment process.

Conventional gerontological assessments reflect a medical model treatment approach by collecting deficit-focused data such as pathologies, disabilities, losses, needs, and risks (Kivnick and Murray, 2001). For example, the Franklin County Adult Protective Services (APS) risk assessment tool requires practitioners to identify “environmental conditions that contribute to abuse, neglect, exploitation,” “physical conditions that contribute to abuse, neglect, exploitation,” and to “describe observed hostility between customer and alleged abuser” (Franklin County APS Risk Assessment 2003). Using the words “describe observed hostility” rather than “describe interaction” presupposes that hostility is present and negatively influences the practitioner’s assessment. Another problem with using mandated deficit-based assessments is that practitioners may learn to pay more attention to recording data than to understanding clients (Kivnick and Murray, 2001).

Critics of the medical model also argue that it does not address environmental influences. Noel and Ames (1990) identified this problem when they sent a questionnaire measuring knowledge and attitudes about aging to 1,408 dieticians in Michigan. They found that the dieticians generally failed to consider the full range of all possible environments interacting with older adults and usually focused on only one specific area. In particular, families were rarely mentioned in considerations of nutritional problems of older adults.
An alternative to a deficit-based treatment approach is a strengths-based treatment approach. A strengths-based approach suggests that identifying client strengths will help to balance identified weaknesses.

“If we could focus on client strengths and assets along with deficits and problems, we could then design interventions both to decrease the weight of problems and also to increase the weight of assets, thereby doubly effectively altering the overall balance in a positive direction.” (Kivnick and Murray, 2001, p. 28)

Adding a strengths approach to the medical model may improve desired outcomes by balancing the power relationship between the practitioner and the client and thus promoting client inclusion. Client inclusion may lead to improved client motivation to participate in treatment.

“When using a strengths approach, the implication is no longer made that there is some expert who provides services, informs the public, and develops policy goals. Rather the role of helper is to give voice to clients perspectives, to help negotiate definitions and goals that include these perspectives, and to continue the focus on client as collaborator” (Chapin and Cox, 2001, p. 173).

**Ecosystems Approach**

Proponents of an ecological perspective argue that an elderly person’s ability to cope depends not on personal strength alone, but also upon the environment (Lee, 1989). They suggest that risk factors exist in all levels of an elder’s environment: interpersonal, psychological, familial, social network, community, institutional, societal and cultural, as well as physical, ecological, and historical (Schiamberg and Gans, 2000). Advocates of an ecological perspective identify the relevance of recognizing the influence of culture and ethnicity when assessing elder self-neglect (Germain and Bloom, 1999). For example, what may be viewed as elder self-neglect in one community may not be viewed as elder self-neglect in another community. From an ecological perspective, elder self-neglect may be seen as a poor fit between the elder and his or her environment.
“When there is a poor fit between a person’s environment and his or her needs, capacities, rights, and aspirations, personal development and functioning are apt to be impaired and the environment may be damaged. When there is a good fit, both person and environment flourish.” (Germain and Gitterman, 1996)

Practitioners who use systems theory believe that people have roles and functions within multiple systems (Anderson, Carter, and Lowe, 1999). Bertalanffy, the originator of systems theory, defines a system as “a complex of components in mutual interaction” (1974, p. 1100). Practitioners examine the dynamics between elders and the systems within which they interact. Practitioners using systems theory view causality as interactive rather than linear, thus situations of elder self-neglect are viewed as multi-causal and optimal interventions are multi-faceted (Greene, 2008, 1999). Early systems theory practitioners assumed that family development was orderly and centered around the phases of the life cycle connected to child-bearing (Greene, 2008, 1999). Current revisionists of systems theory challenge the idea that family development is fixed and sequential (Laird, 1996; Van Voorhis & McClain, 1997).

The environmental perspective and systems theory are sometimes linked and referred to as an ecosystems approach. Germain and Bloom (1999) use the term “person:environment,” to signify a holistic system as the object of analysis, not persons or environments separate from one another. Current revisionists of a person:environment approach identify “contexts” for person:environment transactions as the society, culture, the community, and the physical environment (Germain and Bloom, 1999).

Critics of the ecosystems approach argue that it is vague and arbitrary (Wakefield, 1996a). A primary example of this arbitrariness is how the ecosystems approach relies on the practitioners’ perceptions of system definition (Gallant and Thyer, 1999). One specific example of this is the common use of housing categorizations as boundaries of immediate family systems. Living arrangements may vary between
families; not all family systems conform to traditional “immediate family” living arrangement norms. Some homes (such as those of divorced parents and extended family systems) have fluid boundaries.

Another example of the particularly arbitrary nature of practitioner perceptions in an ecosystem practice approach may be found in the assessment of environments and the ordering of which environments will receive treatment priority. Ecosystems assessment involves drawing an arbitrary boundary around the client system, deciding what is the system and what is the environment, and choosing a focal system of attention (Anderson, Carter, & Lowe, 1999). Funding is often tied to specific environmental outcomes (such as housing, employment, reduction of hospital days), which cause programs and workers to prioritize these environments, and which may lead to treatment goals being determined by the funding needs of providing agencies rather than the needs of individual clients.

Ecosystems biases are also found at the practitioner level. For example, two social workers from different agencies working with the same client, both using an ecosystems practice approach, may have very different assessments of the adequacy of a clients home environment. These examples illustrate how definitions of environments, their “normal” states, and the subjective assessment of the adequacy of each environment reflect worker, employer, and program funding source biases.

Additional criticisms of an ecosystems approach are that it does not address underlying causal processes of conflict and that it promotes normalization and social control. Wakefield (1996a) states:

“The [systems theory] perspective cannot help in identifying the nature of the problem in any particular case because it makes no substantive assertions about specific causal processes.” (1996a p. 14)
The ecosystems approach may recognize when there is not a good fit between the person and the environment, but does not, in itself, address etiology or explain why. Underlying causal explanations of a poor fit between person and environment are provided by other theories such as Freudian psychodynamic theory (conflicts stem from individuals’ subconscious unresolved conflict) or Marxism (conflicts stem from inequitable distribution of wealth).

Regarding normalization, Greene and Blundo (1999) argue that all explanatory theories prescribe an evaluative and intervention methodology that becomes habituated, routinized, and ultimately insensitive to the individual needs of particular clients. They suggest that because this process involves practitioner values and biases, normalization may be a direct and undesirable consequence. Normalization occurs when the assumption is made that there must be a normal or organized state of a system that the system attempts to maintain. The concept of a normative state lends itself to a “what ought to be” assessment of the system where disruptions or disorganization within the system are viewed as pathology. They propose that a systems model positions the worker as an expert who is making treatment judgments and determining to what degree dysfunction is taking place based on his or her belief in the “normative standards.” Once established, these classifications are hard to change.

“The systems model assumes to know the way in which a family functions by first being able to know what optimal functions of family systems looks like and, based on this knowledge, evaluate and assess the number, age, and composition of the generations.” (Greene and Blundo, 1999, p. 93.)

Revisionists of an ecosystems approach have developed the concept of “life course” to address these criticisms.

“The term [life course] refers to the unique pathways of development that each human being takes—from conception and birth through old age—in varied environments and to our infinitely varied life experiences.” (Germain and Gitterman, 1996)
Germain and Gitterman (1996) suggest using a “life course” conceptualization as an alternative to the traditional “life cycle” models of human development in which life stages are assumed to be fixed, sequential, predictable, and universal. The life course conception assumes an ecological view of nonuniform pathways of human development within diverse environments and cultures. Examples of influences on these pathways of development include race, ethnicity, gender, culture, socioeconomic status, religion, sexual orientation, physical/mental states, and environmental diversity (economic, political, social, and historical). Other distinguishing elements of the life course conception include the recognition of the effects of poverty or prejudicial discrimination on human development and functioning, newly emerging family forms and their special tasks and developmental issues, rapid shifts in societal and community values and norms, and the critical significance of global and local environments.

**Communication/Relationship Approaches**

Practitioners of communication and relationship-based models (such as a Rogerian person-centered approach, narrative therapy, social constructionism, Postmodernism, and growth in connection) for working with the elderly seek to attend to older people’s interpretations of their own experiences. Practitioners of person-centered approaches assume that the need for unconditional positive regard, being heard, and relationship development are universal (Rogers, 1961; Jordan, 1991), while practitioners of communications approaches challenge the assumption that any universal treatment theories represent true knowledge and challenge social workers to recognize their own biases (Greene and Blundo, 1999; Gallant and Thyer, 1999). Although there are philosophical differences between these approaches, they are grouped together here because they share an emphasis on hearing and reflecting the experiences of others. The central theme of these treatment models is the need to understand a particular
individual situated within his or her sociocultural, political, economic, and historical context through client-practitioner discourse.

According to Greene and Blundo (1999), a postmodern treatment approach to working with families of later years assumes that client-practitioner discourse is the only acceptable way to understand an individual situated within his or her sociocultural context. They recommend allowing for a particular client story rather than rely on universal truths or norms, and emphasize that understanding a particular client’s story rests in his or her local, culturally-specific (and personal) experience. Other postmodern assumptions include generating meaning within therapy through participants’ interaction and using a method on inquiry or curiosity rater than one of assessment generated by family roles (such as wife and mother) (Greene and Blundo, 1999).

Practitioners of a person-centered approach emphasize the intrinsic value of all humans, empathy, and the paramount importance of the practitioner-client relationship in fostering positive growth (Lewis, 1999). Carl Rogers, the founder of the person-centered approach, identified that each client brings the same need to achieve self-awareness to the therapeutic relationship (Greene, 2008, 1999).

“It seems to me that at bottom each person is asking: Who am I really? How can I get in touch with this real self, underlying all my surface behavior? How can I become myself?” (Rogers, 1959, p. 357)

Examples of characteristics of a person-centered helping relationship include being in some way which will be perceived by the other person as trustworthy, as dependable or consistent in some deep sense, being expressive enough as a person that what you are will be communicated unambiguously, experiencing positive attitudes toward the other person, acting with sufficient sensitivity in the relationship so that the practitioner’s behavior will not be perceived as a threat, and meeting the other individual
as a person who is in process of becoming rather than something already fixed (static),
diagnosed and classified (Rogers, 1958, 1961).

Practitioners using communication-based treatment approaches identify that
establishing trust and rapport is especially crucial with self-neglecting clients who are
resistant to help (Mixson, 1991). Methods for establishing trust include explaining
things simply, going slowly, “mirroring” and “matching” the client’s verbal and
nonverbal behavior, and using exchange theory principles (Mixson, 1991). Complex
corcepts such as the quality of one’s relationships with others may be best understood by
a practice approach that focuses on individuals’ interpretations of their life experiences
rather than by standardized assessment tools (Ryff and Essex, 1991). By reframing
healthy aging in older adults’ own terms, the treatment model that emerges encourages
support of the individuals desired goals and outcomes rather than only medical
approaches to deficits and challenges (Bryant, Corbett, and Kutner, 2001).

Critics of communications/relational practice models argue that they lack
specificity and attention to socio-structural and political issues. An example of this lack
of specificity is that communications approaches do not address practitioner identified
needs (Thomas, 1997) for specific guidelines in working with individuals who cannot be
engaged in dialogue or who may need involuntary intervention (such as self-neglecting
elders who refuse treatment, or clients who are court-ordered for drug treatment,
domestic violence counseling, or child neglect). An example of the lack of attention to
socio-structural and political issues is that systematic problems such as poverty,
oppression, discrimination, or unmet physiological needs may exert more influence on a
client’s world than interpersonal needs.

Another criticism of relationship-based models is that they raise ethical issues
regarding practitioner/client boundaries in empathy and mutuality (Jordan, 1991).
Critics argue that the helping relationship may not be an appropriate place for “values” influence or education. Examples of possible areas of practitioner value imposition that may arise from a mutual sharing of self are AA, Christianity, and wymyn’s political agendas. These topics illustrate possible problems with boundaries in helping relationships and raise the question of whether we can be truly mutual if we do not share our values.

**Exchange Theory Principles**

Advocates of exchange theory argue that problems of aging come about because the aged have little to exchange, leading to their increased dependence and need to comply with others (Dowd, 1979). Exchange theorists assume that when the power in a relationship is unbalanced, the less powerful partner attempts to balance it. Withdrawal, symbolizing a reduction in desire for the rewards offered by the other, is one way to balance the power relationship (Dowd, 1979). Self-neglect may also be viewed as a social response to an unbalanced power relationship. For example, self-neglect may an expression of defiance in the face of a lack of resources required to engage in socially acceptable exchange (McGee and Barker, 1982). Elders may do without needed goods and services (such as food, medication, home maintenance and repair) rather than requesting assistance for which they have nothing to exchange.

Self-neglecting behaviors can represent attempts by an elder to gain control of and ameliorate a negative life situation (Thibault, O’Brien, and Turner, 1999). For example, McGee and Barker (1982) reviewed findings on the social impact of the physical setting and interactions between institutionalized old people and staff members. They found that age-linked decline in power resources may find nonverbal expression in new patterns of deferential behavior on the part of elders (such as food, medication, and hygiene assistance refusal). Keyes (2002) explored the hypothesis that unequal
exchanges in support should predict higher negative and lower positive affects with age through data from the Midlife in the United States study (3,032 participants aged 25-74). He found that unequal exchanges predicted worse emotional well-being only among the oldest people in the study, those aged 55-74.

Stoller (1985) explored exchange patterns within the informal support networks of 753 noninstitutionalized elderly using data from personal interviews. She found the majority of were involved in some type of exchange of assistance within the informal network, although the proportion reporting no exchange increased as the relationship moved from children to other relatives to friends or neighbors. Reciprocation of assistance received was the norm. Her findings support the exchange theory hypothesis that inability to reciprocate is more likely to adversely affect the morale of the older person than the actual need for assistance. She found a negative relationship between the extent of formal service use and family assistance.

Stoller (1989) further examined the relationship between the use of formal and informal services by conducting personal interviews with a sample of 461 people aged 72 and over (mean age 78.1) and their informal helpers in northeastern New York in 1979, and reinterviewing 173 of these elder-caregiver dyads in 1986. She found that the use of formal services did not reduce either the amount or scope of informal assistance. Older people who received more formal services also tended to receive more informal assistance, primarily because of high levels of impairment. In contrast with her earlier findings, these results do not support the hypothesis that formal services reduce the amount of informal assistance given to frail elderly (Stoller, 1989). Much of the literature on the use of formal and informal services for elders focuses on the financial costs of services, clearly illustrating the necessity of having something to exchange (such

Some practitioners use exchange theory principles when working with self-neglecting elders. Mixson (1991) identifies three steps for using exchange theory principles with self-neglecting elders who are resistant to help: stating exactly what you want or need, asking about and then listening carefully to any problems your request elicits from the other person (active listening), and finding ways to help resolve these problems and/or satisfy any other needs the other person may have so as to gain that person’s cooperation (offering incentives).

Critics of exchange theory argue that it fails to adequately explain altruism (Cheal, 1988) or the fact that some self-neglecting elders have adequate material and non-material resources. There are also conflicting research findings about the relationship of social support and the well-being of older persons. Kart and Longino (1987) interviewed 1,346 retirees (mean age 76.6) regarding their social support networks and found that the amount of support received or given had little effect on feelings of obligation to others. However, they also found that the more support given or received, the lower was the respondents’ life satisfaction. They suggest that exchange theory fails to explain the relationship between support systems and the well-being of older people. Another criticism of using exchange theory principles in practice is that a practitioner may be promoting compliance rather than client self-determination by offering rewards for desired behavior.
Summary of Practice Recommendations for Self-Neglecting Elders

- Assess the other person’s risk of imminent harm to self or others, competency, self-maintenance, and home environment. (Torke and Sachs, 2008)

- Honestly explain your purpose and hear the others wishes, needs and values. (Greene and Blundo, 1999; Mixson, 1991)

- Engage the other person in treatment planning and seek compromise. (Pavlou and Lachs, 2008; Karpinski, 1997)

- When offering referrals and services, always explain costs and eligibility. Display consistency and dependability by specifying follow-up, including date and time. (adapted from Amilla, 1999; Mixson, 1991)

- Consider using a strengths approach rather than or in addition to a deficits approach. (Kivnick and Murray, 2001; Chapin and Cox, 2001)

- Maintain conscious awareness of the balance between person, tasks, and resources. Each element exerts significant influence on outcomes. (Rogers, 1961; Green and Blundo, 1999; Epstein, 1988, 1992; Germain and Bloom, 1999; Choi, Kim, and Asseff, 2009)

- Practitioner self-awareness includes a conscious recognition of one’s own values (particularly regarding freedom and safety) and wishes for the other person. (Lauder 2009; Robbins, Chatterjee, & Canda, 2006; Lauder, Scott, and Whyte, 2001; Wadley & Haley, 2001)

Interventions for Treating Elder Self-neglect

Practice considerations most frequently represented in the literature included the importance of establishing a relationship with the older adult, the importance of assessment (including assessing informal support systems, alcohol use and polypharmacy), the use of exchange theory principles, recognizing issues of control and the need to maintain a sense of coherence and continuity, gender, and loss of will to live. Less frequently represented practice considerations were the substantiation of self-neglect, involuntary intervention, guardianship, living alone, in-home services, counseling, pets, race, mobility, money management, unsafe environment, and daycare. A discussion of in-home services, court-appointed guardianship, and institutionalization
is included here because these were the formal interventions most frequently mentioned in the literature and by APS workers interviewed for this study.

**In-Home Services**

APS workers interviewed for this dissertation consistently identified linkage to in-home services as their primary approach to treating elder self-neglect. In-home services are an essential part of treatment for elder self-neglect because most self-neglecting elders live alone in their own homes. A review of over 5,000 referrals to the Wisconsin Elder Abuse Reporting System between 1988 and 1990 revealed that 72.2 percent of self-neglecting elders were living alone in their own homes at the time of the incident (Longres, 1995).

Formal in-home services include meals-on-wheels, homemaker services (meal preparation, light housekeeping), home health aide services (assistance with physical self-maintenance activities), visiting nurses and doctors, senior friends (peer counselors who accompany clients on community outings), case management, counseling, and daily money management services. Ideally these formal services are coordinated with each other and with existing informal services available to the elder, but this is often not the case.

Formal in-home services are usually provided by private agencies that charge a fee for service. The client is typically responsible for all or part of this fee, depending on income and eligibility. Financial negotiations may be an obstacle to the implementation of formal in-home services. While the poorest elders may be eligible for some free services, most elders must pay for most services. The fees charged to clients are usually based on a sliding-fee scale or an eligibility cut-off point determined by the service providers. These costs may be absorbed by the provider (such as Medicaid vendors who accept Medicaid and/or insurance payment as payment in full), but are typically billed
directly to the client. The bills are often difficult to understand with small print, confusing language, and no explanation of third party billing procedures and status. In-home service providers often bill clients for the entire cost of the service, not just the co-pay, until the service provider receives payment from the third party. Thus clients often receive large bills stating that they are responsible for the total cost until third party payment is received. Multiple bills for each service are not unusual.

The practitioners making in-home service referrals usually do not discuss service costs and eligibility with the clients, but rather refer them to the service providers for fee determination. The in-home staff that have the most face-to-face contact with the client (health aides, homemakers, etc.) are often unaware of their employers billing policies and also refer the client to the service-providing agency for financial concerns. This is a problem because self-neglecting elders may lack the skills and motivation necessary to contact service providers for bill clarification. In-home services may then be stopped due to nonpayment or clients may acquire major debts that they cannot or will not pay.

Another problem with in-home services is that many elders, especially those living alone, do not wish to have strangers in their homes. APS workers interviewed for this study consistently identified this as a barrier to accepting in-home services. In-home service providers cannot guarantee that the same employee will be available for each service date, and it is not unusual for appointments to be cancelled or for total strangers to be sent to clients’ homes. This can be uncomfortable, confusing, or frightening for clients, and they may decline services from strangers.

Successful utilization of in-home services requires a good fit between clients and in-home services. Workers can foster a good fit between clients and in-home services by paying careful attention to the financial and relationship elements of the services and by demonstrating the ability and willingness to discuss billing policies. A consistent and
dependable positive relationship with in-home staff is also critical for successful service utilization.

**Guardianship**

Guardianship is a court ordered relationship established by the probate court for persons who have been adjudicated incompetent. A guardian acts on behalf of another person for personal needs and/or for money management. There are two kinds of guardianship: guardianship of the estate and guardianship of the person, and someone may have one or both. Limited guardianships (such as a guardian ad litem for legal issues) and Conservatorships are also available. A Conservatorship is a voluntary court supervised relationship established by the probate court for clients who are physically infirm yet mentally competent. Pavlou and Lachs (2008) identified that patients lacking capacity who are endangering themselves or others will likely need some form of temporary or permanent guardianship. Connolly (2008) argued that although legal interventions such as guardianship may serve to protect vulnerable older people, it is critical to ensure that such interventions do not inappropriately infringe on the older person’s civil liberties or result in exploitation or worse.

There is lack of consensus about the usefulness of guardianship with self-neglecting elders. Interviews with Adult Protective Services (APS) caseworkers revealed that most APS workers say that obtaining public guardianship for abused elders is a valuable intervention tool (Jones, 1996). Alternatively, findings based on results from four projects in Illinois (a model project providing guardianship services to low-income older adults, an elder abuse demonstration project, a study of judicial decision-making on guardianship and the elderly, and a survey of guardianship petitions and adjudications) suggested that guardianship is not always the most effective means for meeting the needs of at-risk older adults (Iris, 1990). APS workers interviewed for this

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dissertation consistently expressed that they consider guardianship an undesirable last resort that does not improve the quality of older adults’ lives.

Researchers have found wide inconsistencies in guardianship application, evaluation, approval, and implementation processes. (Rosenberg, 2009; Moye, et al, 2007; Dudley, et al, 2003; Burruss, et al, 2000; Scogin and Perry, 1986). Rosenberg (2009) studied older adult guardianship cases in New York City and observed that the guardianship system tends to fall short of meeting its objectives. He found the main flaw of guardianship laws was concerning their implementation. Moye, et al (2007) reviewed 298 cases of older adult guardianship in Massachusetts, Pennsylvania, and Colorado and found that states with progressive statues that promote functional assessment had increased quality of clinical testimony and use of limited orders.

Dudley, et al (2003) examined 119 evaluations of capacity from two states and compared the thoroughness of the guardianship evaluations to state law. They discovered that the guardianship evaluations were frequently the only source of information on cognitive and psychiatric symptoms, functional abilities, and current treatments. Dudley et al (2003) found that overall the thoroughness of guardianship evaluations was substandard, although full guardianship was granted in over 75% of cases. Burruss et al (2000) compared 13 guardianship applications for elderly patients that were approved with 26 applications that did not reach the court. They surveyed next of kin and discovered that the process had a much better chance of success when the unit social worker made the guardianship recommendation and when family members were given more information about the process of obtaining guardianship.

Scogin and Perry (1986) proposed that standardized assessment of functional capacities should become routine in guardianship hearings for older adults and that practitioners called on to present testimony in such guardianship proceedings should be
trained in geriatrics and/or gerontology. They noted the lack of guidelines for functional assessments that enable reliable and valid determinations of competency and recommended that legal codes should be revised to define competence in explicit behavioral and functional terms. 20 years later, Bergeron (2006) asserted that elder protection laws do not provide clear directives regarding terms of competency and self-determination. To date there remain widely inconsistent approaches to guardianship among states, communities, judges and evaluators.

An additional consideration for social workers considering guardianship for self-neglecting elders is the contrast between the social work value of client self-determination and the restrictive, punitive nature of the judicial/penal system from which guardianship comes. Guardianship is one of the most restrictive interventions available and is usually irreversible, ending only with death. A guardian can restrict an elder ward’s movements or place the ward in an institution, limiting the elder’s self-determination and ability to access advocacy programs. The imposition of a guardianship makes it almost impossible for a ward to independently secure the services of an attorney (Iris, 1990).

Iris (1990) found guardianships effective in protecting frail elders from abusive caretakers or relatives, but in most of these cases the ward was placed in a nursing home. She also found that the court consistently imposed the greatest degree of intervention despite alternatives such as limited guardianships. There is also concern of guardianship abuses because some states (including Illinois) minimally monitor guardians of estate and do not monitor guardians of the person. In cases of self-neglect, some state’s laws do not authorize guardians to remove individuals from their homes against their will nor sign a ward into a psychiatric facility.
“In cases of self-neglect, statutory restrictions give guardianship a questionable utility since those services most needed, i.e., relocation and medical care, are not easily attainable even with a guardian.” (Iris, 1990, p. 68)

**Institutionalization**

Institutionalization is the most restrictive intervention available for elder self-neglect. The placement of an older adult in an institution such as a nursing home, skilled nursing care facility, or supervised living facility is usually permanent, ending only with death or relocation to another institution. Studies have found that many people state they would rather die than live in a nursing home (Torke and Sachs, 2008). Two core clinical issues arise when considering institutionalization: assessing a person’s capacity to make decisions about their living environment, and ethically negotiating the balance between their freedom and their safety. Institutionalization generally provides increased safety for older adults at the expense of their freedom.

Involuntary institutionalization can happen only when a guardianship is established by the probate court for persons who have been adjudicated incompetent. However, family members and practitioners may try to convince older adults to voluntarily relocate to an institution. Forced or coerced institutionalization conflicts with the social work value of client self-determination and with laws that protect the people’s rights to live in the least restrictive environment.

Institutionalization may be viewed as a necessary intervention to address safety concerns for elders assessed as unsafe to live independently in the community, but it may also be viewed as a form of social control resulting from societal labeling. Bear (1989) interviewed 85 elders who had moved into an adult residential care facility in Orange or Seminole County, Florida within the previous 2 months. She also interviewed 75 of their closest significant others. The label she explored was “out of place in the home and in need of residential care.” Findings showed that the informal
network of the frail elderly was primarily responsible for the residential care entry; over
two-thirds of the new residents were labeled as out of place in their own homes and
referred to a care facility by an informal network member. Over 50 percent of the
labeling and referrals were attributed to family members. Very few residents had labeled
themselves out of place or identified a residential care facility as an appropriate place for
them to live.

Torke and Sachs (2008) point out that even if an older adult appears to lack the
insight to make decisions about their living environment, it may not be in their best
interest to be institutionalized or place in any other highly restrictive environment. They
state:

“The point at which a patient—even one with mild to moderate
dementia—should be forced to move from independent living to a nursing home
setting is not always clear.” (Torke and Sachs, 2008, p. 1927)

APS workers interviewed for this dissertation consistently stated that they valued
keeping people in their own homes and out of institutions.
The NASW Code of Ethics mandates that social workers should make every effort to foster maximum self-determination on the part of clients. This raises the question of how to define and foster self-determination in cases of elder self-neglect. To explore this question, APS workers interviewed for this dissertation were asked “How do you distinguish between elders’ self-determination and self-neglect?” Balancing seniors’ legal right to refuse care with workers’ professional responsibility to provide or link to needed care is an ongoing and international ethical dilemma. Ballard (2010) describes this dilemma as faced by Irish public health nurses:

“Possession of a clear legal framework for the local area that addresses both the nurse’s professional responsibility and the client’s rights is needed. Because a high incidence of depression and dementia seen in self-neglecting adults has prompted calls for wider screening of the agreeable client, an understanding of the definition of competence and capacity in the national legal system for that client becomes critical. In Ireland, as in many other countries, refusal of care of screening is the right of any competent adult. However, issues of mandatory reporting, confidentiality, and trespass may differ from other areas. Nursing care delivered at the community level to a client exhibiting self-neglecting behavior involves a delicate balance of trust and support.” (Ballard, 2010, p. 181)

Like self-neglect, self-determination is a subjective concept. Simons and O’Brien (1999) proposed that self-determination depends upon one’s knowing oneself and being able to do for oneself and others. They believe that a client’s decisions can be accepted as informed, rational, and responsible if the following three prerequisites are met:

- The ability to understand the diagnoses, alternative treatments available, and their prognoses
- The ability to relate personal values, commitments, loyalties, and interests to the medical data given
- The ability to communicate one’s decision based upon awareness of alternatives available, personal desires, and their consequences.
Behroozi (1992) recommends the following practice principles for honoring client self-determination when working with resistant or involuntary clients:

- Start where the client is
- Do not consider the client unmotivated
- Clients should be understood in the context of their environment
- Available services should be clearly explained
- Client perceptions, including their decision to not seek help, should be respected.

When considering the ethical dilemma of honoring self-determination versus recommending involuntary intervention in cases of self-neglect, it is important to remember that an elder’s non-compliance with treatment and service recommendations does not, by itself, constitute self-neglect. The determination of decision-making capacity is required. Torke and Sachs (2008) questioned, however, if it is possible to give adequate justifications for living in squalor or ignoring one’s basic needs. They suggested that a failure to provide for one’s basic human needs might provide enough evidence that a person lacks capacity.

Regarding self-determination and elder self-neglect, Bergeron (2006) observed that in practice, older adults’ right-to-refuse intervention if they are deemed competent appears to override APS workers’ duty-to-protect. He argued that according to guidelines in the NASW Code of Ethics, self-determination is not the only guiding principle professionals should reference in practice when working with competent elders suffering from abuse and neglect who refuse services. He acknowledged that the NASW Code of Ethics does not tell social workers how to incorporate these guidelines except that each case must be decided by the social worker through critical and ethical decision-making. Bergeron (2006) asserted that the principle of self-determination and the notion of competency are overly simplified in the social work and elder abuse literature.
and may be misused by allowing abused older victims to choose to remain in often life-threatening situations. He states:

“Professionals entrusted with the duty-to-protect victims of elder abuse absolutely cannot use the principle of self-determination as the primary reason to leave elder victims in life-threatening situations, or to unconditionally accept victims’ refusal-for-services.” (Bergeron, 2006, p. 99)

Bergeron (2006) suggested that honoring client choice might not necessarily mean honoring the overt refusal for intervention. He implied that accepting a client’s refusal-for-services is akin to patient abandonment, which he viewed as a clear violation of a social worker’s professional Ethical Code. He recommended the idea of “negotiated consent” in which practitioners offer differing degrees of assistance to minimize the elder abuse or neglect. He concluded that laws about elder abuse and neglect need to be reexamined and revised:

“Laws that only allow for investigating and substantiating allegations of abuse, but then allow exclusive rights to the victims to remain in serious, life-threatening situations because of his or her ‘right to choose’ begs our immediate attention.” (Bergeron, 2006, p. 100)

To honor older adults’ self-determination, some Adult Protective Services (including Franklin County) have openly adopted the value of freedom over safety. Franklin County APS prominently identifies this value in the principles listed on its information sheet.

“Freedom over safety: The client has a right to choose to live at risk of harm, providing he/she is capable of making that choice, harms no one and commits no crime.” (Franklin County APS)

APS workers interviewed for this dissertation shared their personal feelings about highly valuing self-determination/client’s rights more than they shared feelings about any other topic discussed.
CHAPTER THREE: METHODOLOGY

Qualitative Methods

According to research scholars Denzin and Lincoln (2000), “...qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them” (p. 3). Such an approach fits well with this study’s goal of researching themes, issues, and conditions surrounding the substantiation of allegations of elder self-neglect. The threshold of what constitutes elder self-neglect is subjective, guided by the values and experience of each APS worker who must interpret broad standards established by agencies, states, and the U.S. federal government.

Grounded theory, developed by Glaser and Strauss (1967), is considered by many scholars to be one of the most influential approaches to qualitative research (Padgett, 1998, Denzin and Lincoln 2000). Grounded theory is theory that is derived from data. Strauss and Corbin (1998) explain grounded theory as follows:

“In this method, data collection, analysis, and eventual theory stand in close relationship to one another. A researcher does not begin a project with a preconceived theory in mind. Rather, the researcher begins with an area of study and allows the theory to emerge from the data. Theory derived from data is more likely to resemble the ‘reality’ than is theory derived by putting together a series of concepts based on experience or solely through speculation. Grounded theories, because they are drawn from data, are likely to offer insight, enhance understanding, and provide a meaningful guide to action” (p. 12).

For this study, a modified grounded theory approach was used to explore and describe how Adult Protective Service workers conceptualize, assess, and treat elder self-
neglect, and to articulate workers’ theories about “best practice” methods of assessment and treatment for self-neglect. Strauss and Corbin acknowledge that “theory-building is not the goal of every research project, nor should it be.” (p. 8). They approved of researchers modifying their research methods by selecting to use some of their procedures but not others.

“We present only one way of doing analysis, and it would be unrealistic to assume or even suggest that researcher will use every procedure described in this book.” (Strauss and Corbin, 1998, p. 8)

Strauss and Corbin (1998) recommend using specific tools during data analysis to increase a researcher’s sensitivity to potential biases they might have and to help the researcher overcome analytic blocks. They argue that it is impossible for a researcher to be free from bias, and they offer the special techniques of constant comparative analysis, open, axial, and selective data coding, and memoing to help researchers avoid imposing their biases during data collection, interpretation, and analysis. These techniques were used to increase neutrality and avoid unnecessary biases. They will be discussed in depth in the data analysis section.

**Data Collection**

The method of data collection for this study was interviews with Adult Protective Service (APS) caseworkers. Procedures for data collection by interviewing followed guidelines suggested by Padgett (1998), Charmaz (2000), and Loftland and Loftland (1995). Procedures included identifying the researcher’s stance, developing an interview guide, using probes, facesheets (for respondent demographic characteristics) and interviewer reaction sheets (for observations), building rapport, and developing questions for second interviews based on analysis of data collected in the first round of interviews. Data collection procedures were developed regarding the number of interviews and the protection of respondent’s confidentiality.
Padgett (1998) recommends clarifying the interviewer’s stance by situating it along a detachment-attachment continuum. “Part of the interviewer stance involves deciding how much to engage in repartee with one’s informants...A judicious amount of ‘joining’ with one’s informants facilitates disclosure and makes an interview more conversational and free flowing” (Padgett, 1998, p. 60). For this study, my stance as an interviewer is situated around the midpoint of an attachment-detachment continuum.

To build repartee I disclosed my recent employment as an investigator for Franklin County Children Services (FCCS) making unannounced home visits to investigate allegations of abuse and/or neglect, however I did not spend our limited interview time sharing specific anecdotes about my experience with abuse and neglect investigations.

Padgett recommends that an interview guide should contain an initial set of questions that focus on the researcher’s areas of interest. “The guide should provide enough detail to cover key domains, but should not become a straitjacket” (Padgett, 1998, p. 60). Each participating caseworker was interviewed twice for this study, and each interview lasted approximately one hour. The interview guide for the first round of interviews was revised after analysis of three of the initial interviews and consultation with my committee. Some questions from the first interview were condensed and others that were ancillary to the primary research goals were moved to the second interview for time management purposes. After analyzing the first round of interviews, three new questions designed to fill in gaps in knowledge were developed for the second round of interviews. The original and revised interview schedules for the first and second interviews are included at the end of this chapter.

Padgett cautions that interview questions should not be phrased to lead respondents toward a particular answer or emotional state, but when a respondent mentions something that evokes in them an emotional or strong reaction, the
interviewer might use probes to go deeper. “Some of the most valuable information in qualitative interviews emerges from spontaneous probes; it is here that the interviewer must remain alert and open minded...Recognizing a lead, the interviewer may say, “you mentioned ____ earlier; could you tell me more about that?” (Padgett, 1998, p. 60).

Loftland and Lofland (1995) and Padgett (1998) recommend appending facesheets and interviewer reaction sheets to the interview guide. The facesheet is a standardized document for recording the date, time, and location of the interview and the demographic characteristics (age, sex, race or ethnicity, etc.) of the informant. The interviewer reaction sheet is a place to log observations about the interviewee and about the setting. Padgett suggests that observational data are critical when conducting interviews.

“It is difficult to overstate the importance of observational data as a crucial adjunct to interview data. Even the most meticulous transcript of the interview leaves out vital information. Tone of voice, affective expressions (sighs, sobs, laughs), body language, and the ambience of the setting (noise, interruptions by others) all provide a feeling for the context that enriches and informs” (Padgett, 1998, p. 61).

The facesheet and interviewer reaction sheet are included at the end of this chapter.

Finally, Padgett’s (1998) recommendations for eliciting and enhancing rapport were used in this study. As mentioned earlier, to build rapport I shared that I was previously employed as a child abuse and neglect investigator at Franklin County Children Services (FCCS). Padgett’s suggestion to beginning and ending the interview with “feel-good” questions (such as “tell me about your typical day”) designed to “put informants at ease and remind them that a qualitative research interview is more like a conversation than an inquisition” (Padgett, 1998, p. 62) was also adapted and incorporated.

Many APS workers are social workers, and social workers are ethically obligated to promote client self-determination according to the NASW Code of Ethics and many
state licensing boards. The NASW Code of Ethics also states that social workers may limit clients’ right to self-determination when their actions pose an imminent risk to themselves or others (NASW Code of Ethics section 1.02). The ethical dilemma of weighing an elder’s right to self-determination versus the imminence of risk of harm is therefore a sensitive issue for social workers faced with deciding about the substantiation and treatment of elder self-neglect.

Disadvantages of using interviews to explore this sensitive issue include the risks of reactivity (the potentially distorting effects of the qualitative researcher’s presence in the field) and respondent bias (where the respondent provides politically correct answers or responses that she thinks the interviewer wants to hear) (Padgett, 1998). Methods used to address these threats to trustworthiness will be described later. Padgett (1998) suggests that advantages provided by interviewing such as control over what, how and when data are produced and the firm grounding of the data in the real world of respondents makes interviewing worth the risk of reactivity.

The goal of a qualitative study is not to maximize numbers but to become “saturated” with information about a specific topic. Saturation occurs when additional documents become redundant and reveal no new information. Strauss and Corbin define theoretical saturation as “the point in category development at which no new properties, dimensions, or relationships emerge during analysis” (1998, p. 143). In qualitative research, data collection and analysis are complete when categories are saturated (Strauss and Corbin, 1998; Padgett, 1998).

Strauss and Corbin (1998) suggest that interviews and observations should continue until theoretical saturation occurs and no new data are uncovered. They point out that constraints of time, energy, availability of participants, and other conditions sometimes impose limits on data collection. They caution researchers to keep in mind
that “if he or she stops gathering data before theoretical saturation, then the researcher’s theory might not be fully developed in terms of density and variation” (Strauss and Corbin, p. 292). To seek saturation, I returned to respondents for a second interview. Questions for the second interview were developed to further explore themes and categories that arose during the first round of interviews. Saturation was not reached in this study.

The basic unit of data being collected for this study was interviews with Adult Protective Service workers. Based on the research questions and the literature review, the following areas of interest were identified:

- Assessing elder self-neglect
- Treating elder self-neglect
- Involuntary services
- The role of kin in care planning for self-neglecting elders
- Balancing elder self-determination with collective responsibility
- Research agenda recommendations about elder self-neglect.

Data collection included but was not limited to these areas of interest. Additional themes and issues emerged during data collection and analysis.

**Site Selection**

The selection of a site logically proceeds from the study’s aims (Padgett, 1998). As the goal of this study was to discover themes and issues that arise when Adult Protective Service (APS) workers make assessment and treatment recommendation decisions, it logically followed that APS agencies would be ideal sites for such a study. To maximize diversity in respondents and cases, five APS sites were used for this study.

Typically, each county has an APS agency or an APS department within its Job and Family Service agency. (Sometimes APS programs serve more than one county,
while some counties include APS with other human services such as children services and homemaker services provided by non-specialized caseworkers.) For this study, six single-county APS programs from counties in central Ohio were invited to participate and five accepted. Adult Protective Services supervisors in the central Ohio counties of Franklin, Delaware, Licking, Madison, Fairfield, and Pickaway were approached. Delaware APS declined to participate. It is interesting to note that at that time, Delaware County was the only county in Central Ohio using a privately contracted agency to administer its Adult Protective Services. Adult protective services in the other five central Ohio counties were then and still are provided by county agencies. Provision of Delaware county Adult Protective Services has since been resumed by a county agency.

The rationale for the selection of these sites was to maximize diversity by including urban, suburban, small town, and rural communities. Most of these counties had one to three APS caseworkers, based on county population size and available funding. The exception was Franklin County, the most populated county approached to participate in this study (containing Columbus, the state capital). Franklin County APS had 15 caseworkers. All participating APS programs had single-site offices, so the APS caseworkers were located at one site in each county. All sites that wished to participate were included.

Respondent Selection and Case Selection

When conducting qualitative research, researchers typically seek samples that will offer depth and richness rather than representativeness or generalizability (Denzin and Lincoln, 2000; Padgett, 1998). Purposive sampling, the most typical sampling method used in qualitative research (Locke, et al. 2000; Padgett, 1998), was used for this study. In purposive sampling, subjects are selected based on their capacity to provide relevant information for this investigation. The intent of using purposive sampling for
this study was to include participants who can provide information on self-neglect. APS workers who worked with self-neglect cases were selected and the following four criteria were used to determine a participant’s appropriateness to engage in this study:

- Participants were currently employed by Adult Protective Services
- Participants’ job duties included direct contact with self-neglecting elders (or direct supervision or workers who have contact with self-neglecting elders)
- Participants were the lead investigator (or supervisor) having primary responsibility for assessing elder self-neglect (e.g. they were not case aides/assistants, interns, students, or employees in training)
- Participants conducted (or supervised) at least three (3) investigations of elder self-neglect within the past year.

The rationale for using these sampling criteria was to ensure that respondents had recent and varied experience with self-neglecting elders. Selecting workers from multiple sites maximized the diversity of the sample. Respondents were recruited by having the supervisors in each county offer a sign-up sheet for those interested. The sign-up sheet was written so that participation was clearly described as optional and not affecting employment. This recruitment process was approved by the OSU Behavioral and Social Sciences Institutional Review Board. The sign-up sheet and introductory recruitment letter to supervisors are included at the end of this chapter.

Sample size is a perennial issue in qualitative research; a single case may be studied, several cases may be studied, or multiple instances of a process displayed through a variety of cases may be studied (Strauss and Corbin, 1998; Denzin and Lincoln, 2000). This study focused on multiple instances of the process of assessing and treating elder self-neglect displayed through a variety of cases as experienced by several APS workers. It was conducted with a sample size of 16 respondents, each of which described multiple cases. The total number of APS workers in the five participating
central Ohio counties was 20, thus the 16 participants comprised 80% of the target population. Some workers had other job duties in addition to APS.

Strauss and Corbin recommend “theoretical sampling,” which they describe as “sampling on the basis of emerging concepts with the aim being to explore the dimensional range or varied conditions along with the properties of concepts vary” (p. 73). They describe two methods of theoretical sampling when we become sensitive to unique themes emerging from the data: 1) asking questions in further interviews that will give us more specific information and 2) sampling new respondents on the basis of their ability to respond to the emerging concepts. In this study, 100% of the target population (all APS workers in 5 central Ohio counties) was approached to participate, so theoretical sampling of new respondents based on emerging concepts was not possible unless more outlying counties were included, which was not feasible for this study.

Theoretical sampling by asking questions in further interviews to gain more information on emerging themes was done in this study. Selected unique themes that emerged from the data on topics that were not directly included in the original interview schedule for this study were probed with later respondents. These topics included: assessing pet care decisions, not seeking involuntary services for lucid people who may be dying, and working with physicians who are resistant to cooperate in investigations (even though they are state-mandated reporters).

**Data Analysis**

Data analysis for this study followed a *grounded* approach, assuming that the researcher did know what information will be most significant until thematic patterns were revealed through the data collection process (Glaser and Strauss, 1967; Strauss and Corbin, 1998; Padgett, 1998; Charmaz, 2000). The data analyzed for this study were interviews (interview transcripts) and interviewer observations (face sheets and
interviewer reaction sheets). Several procedures exist for qualitative data analysis. This study used *content analysis*, the most common approach used to analyze documents in qualitative research (Padgett, 1998). The qualitative analysis of interview transcripts consisted of the four techniques for content analysis most consistently recommended by leading qualitative researchers: open and selective coding of the data, constant comparative analysis, and memoing (Glaser and Strauss, 1967; Strauss and Corbin, 1998; Padgett, 1998; Locke, Spirduso and Silverman, 1998; Charmaz, 2000; Denzin and Lincoln, 2000). These content analysis techniques are discussed as they relate to the topic and data of this study.

*Open coding* is described by Strauss and Corbin (1998) as an analytic process through which concepts are identified and their properties and dimensions are discovered in data. “In open coding, the analyst is concerned with generating categories and their properties and then seeks to determine how categories vary dimensionally” (Strauss and Corbin, 1998, p. 143). Padgett (1998) explains that open coding reduces the likelihood of data becoming subordinate to preexisting concepts. “At this stage [initial data coding], it is best to use ‘open coding’ and resist the temptation to rely on apriori concepts to understand the data” (Padgett, 1998, p. 76). The first stage of data analysis consisted of open coding where the interview transcripts were analyzed line-by-line and emerging themes and ideas were coded in the margins.

Strauss and Corbin (1998) encourage researchers to code for explanations and to gain an understanding of phenomena. They believe that placing data in discrete boxes during coding tends to prevent the researcher from “capturing the dynamic flow of events and the complex nature of relationships that, in the end, make explanations of phenomena interesting, plausible, and complete” (Strauss and Corbin 1998, p. 129). To address this potential problem, the data were thematically coded during open coding.
using Charmaz’ (2000) model of “action coding” rather than coding for specific conditions such as “bugs” or “fires.” When coding, Charmaz (2000) recommends keeping the codes active by using action codes (for example “deciding to relinquish,” “accounting for costs,” and “making identity trade-offs” [p. 516]). “These action codes give us insight into what people are doing, what is happening in the setting” (Charmaz, 2000, p. 515). In this study, action codes (verbs) were used as much as was feasible when making coding decisions and conceptualizing categories.

Strauss and Corbin’s (1998) approach to coding differs from other qualitative approaches by including axial coding, where properties (i.e. characteristics) and dimensions (i.e. range) within categories of concepts are identified. According to Strauss and Corbin, “axial coding is the act of relating categories to subcategories along the lines of their properties and dimensions” (1998, p. 124). They argue that this offers richer and more in-depth information. Axial coding was used for this study because similar categories of themes and issues emerged in the interviews (e.g. physical and mental conditions needing treatment and unsafe home conditions), therefore the exploration of the specific properties and dimensions of these conceptual categories was an important element of this study.

Selective coding involves integrating and refining categories (Strauss and Corbin, 1998). Selective coding uses initial codes that reappear regularly to sort large amounts of data (Charmaz, 2000). “These codes account for the most data and categorize them most precisely” (Charmaz, 2000, p. 516). According to Strauss and Corbin (1998), in the selective coding stage of data analysis the analyst integrates the data by constructing concepts and relational statements. They explain the process of construction as follows: “By ‘constructed,’ we mean that an analyst reduces data from many cases into concepts and sets of relational statements that can be used to explain, in a general sense, what is
going on” (Strauss and Corbin, 1998, p. 145). Strauss and Corbin emphasized the “process of integrating and refining theory” (1998, p. 143) as the purpose of selective coding. Because the primary emphasis of this study is on discovering the “lived experiences” of how APS workers assess and treat elder self-neglect, the term “selective coding” is used as Charmaz (2000) uses it, which is a coding process used to sort large amounts of data and categorize them precisely.

Strauss and Corbin (1998) explain that the first step in data integration is deciding on a central category that represents the main theme of the research. “Once a commitment is made to a central idea, major categories are related to it through explanatory statements of relationships” (Strauss and Corbin, 1998, p. 161). The central category that emerged in this study was “assessing seniors’ decision-making abilities.” The secondary category that emerged was “approaching intervention with seniors. Both of these categories had several sub-categories that will be discussed later in the “findings” chapter of this dissertation. A third category developed was “themes and issues unique to this interview” which allowed exploration and comparison of unique and outlying themes. Categories and sub-categories were identified, refined, and explored through the analysis of themes, patterns, properties, dimensions, variability, and exceptions (negative case examples/outliers) of assessment and intervention.

*Constant comparative analysis* is a coding technique associated with grounded theory developed by Glaser and Strauss (1967). It is used to compare and contrast themes and concepts (Glaser and Strauss, 1967; Strauss and Corbin, 1998; Padgett, 1998; Charmaz, 2000). Making comparisons is a major technique in grounded theory. Strauss and Corbin explain that comparisons are important because they enable identification of variations in the patterns to be found in the data (1998, p. 67). According to Charmaz,

“The constant comparative method of grounded theory means (a) comparing different people (such as their views, situations, actions, accounts, and
experiences), (b) comparing data from the same individuals with themselves at different points in time, (c) comparing incident with incident, (d) comparing data with category, and (e) comparing a category with other categories.” (2000, p. 515).

Padgett describes constant comparative analysis as follows:

“In practice, it is iterative, beginning as inductive, then becoming deductive, then returning to an inductive approach. As themes emerge from initial coding (inductive phase), one goes back over the data to ensure that it is coded in accordance with these themes (deductive phase). As one combs back through the data, new codes often emerge (inductive phase)” (1998, p. 77).

In this study, constant comparative analysis was conducted throughout the research process by comparing data from different caseworkers, by comparing data from the same APS workers with themselves at different points in time, by comparing data with categories, and by comparing categories with other categories.

Memoing puts into writing the researcher’s thoughts and ideas about what is going on in the data and the researcher’s choices for the direction of research, connections, and interpretations (Emerson, Fretz and Shaw, 1995; Padgett, 1998; Charmaz, 2000). Charmaz describes memo writing as the intermediate step between coding and the first draft of the completed analysis. “Memo writing lead us to explore our codes; we expand upon the processes they identify or suggest. Thus our codes take on substance as well as a structure for sorting data” (Charmaz, 2000, p. 517).

Padgett (1998) suggests that coding decisions should be documented by memoing so that they may be scrutinized later by the researcher or by an auditor. Locke, Spirduso and Silverman (2000) suggest that throughout the process of category development it is important to maintain a record of the exact source for each category. “Not only are advisors often curious about such origins, but the final report will require writing about category development long after immediate memory has dimmed” (Locke, et al, 2000, p. 263). Specific memoing procedures for this study will be explained when discussing an audit trail in the section “methods used to establish trustworthiness.”
Strauss and Corbin (1998) strongly caution researchers to begin data analysis at the start of data collection and continue analysis throughout the collection process rather than waiting until much data have been collected. One reason they give for this is that further data collection should be guided by analysis. They chide a researcher who has not done analysis while interviewing:

“Your plight puts you in exactly the same position as most interviewers who put off analyzing data until most of the data are collected. This situation is precisely what we discourage because further data collection should be guided by analysis” (Strauss and Corbin, 1998, p. 295).

To avoid this pitfall, when scheduling interviews I did not schedule the next interview until the previous one had been transcribed and analyzed. Additionally, the strategy of developing questions for the second round of interviews based on questions emerging from analysis of the first round of interviews promoted analysis throughout the data collection process. Observations were collected at each interview on the interviewer reaction sheets. Loftland (1971) and Fontana and Frey’s (2000) recommended guidelines for collecting data in the field were used to guide the data collection process:

- Take notes regularly and promptly
- Write everything down
- Try to be as inconspicuous as possible in note taking
- Analyze their notes frequently (Fontana and Frey, 2000, p. 656).

**Methods Used to Establish Trustworthiness**

Key issues in qualitative research are *credibility* and *trustworthiness* (Padgett 1998, Guba and Lincoln, 1985). Credibility refers to the believability of the findings. Trustworthiness refers to the rigor of the research methods. According to Padgett, a trustworthy study is one that is carried out fairly and ethically and whose findings represent as closely as possible the experiences of the respondents (Padgett 1998,
Padgett (1998) points out that trustworthiness is earned by rigorous scholarship.

Padgett (1998) identifies that most threats to the credibility and trustworthiness of qualitative research fall under three broad headings: reactivity, researcher biases, and respondent biases. Reactivity refers to the potentially distorting effects of the researcher's presence in the field. Researcher biases refer to the temptation for the researcher to filter observations and interpretations through her own preconceptions and opinions. Respondent biases refer to the temptation for respondents to withhold information, lie, or offer answers that they think the researcher wants to hear (Padgett 1998).

This study utilized five strategies to reduce the threats to trustworthiness suggested by Padgett (1998): triangulation, peer debriefing/support, negative case analysis, member checking, and an audit trail. The term triangulation refers to using two or more sources to achieve a comprehensive picture of a fixed point of reference (Padgett, 1998). As mentioned earlier, site triangulation (collecting data at multiple sites) was used to obtain diverse participants and to guard against reactivity, researcher bias, and respondent bias.

Peer debriefing and support allows researchers to share their emotional ups and downs involved with fieldwork and data analysis and provide mechanisms for researchers to use to avoid imposing their biases (Padgett, 1998; Lincoln and Guba, 1985). Peer support and debriefing was sought from committee members by communicating regularly with individual committee members.

Negative case analysis, another method of guarding against researcher bias, involves testing theories and verifying our findings by searching for falsifying evidence to refute them (Padgett, 1998). Padgett explains: “Just as the peer group challenges a
researcher to explore his or her biases, negative case analysis is a sort of self-imposed ‘devil’s advocate’ position assumed during data analysis. It can lend enormous credibility to a study” (1998, p. 101). In this study, negative case examples that emerged when information arose that differed markedly from existing conceptual themes and categories were analyzed and categorized as “themes and issues unique to this interview.”

Member checking, perhaps the most important strategy used to establish trustworthiness in qualitative research, guards against all three threats to trustworthiness. Member checking involves returning to the field to check data and theories with respondents to ensure that one is on the right track (Lincoln & Guba, 1985; Padgett, 1998). Denzin and Lincoln (2000) point out that an interview is a conversation where both interviewers and interviewees contribute to the text.

“...the interview is a negotiated text, a site where power, gender, race, and class intersect...It is not a neutral tool, for at least two people create the reality of the interview situation. In this situation answers are given. Thus the interview produces situated understandings grounded in specific interactional episodes. This method is influenced by the personal characteristics of the interviewer, including race, class, ethnicity, and gender” (Denzin and Lincoln, 2000, p. 633).

Member checking was used in this study to verify themes, categories, and conceptual conclusions. Each respondent was interviewed twice, with the exception of one respondent who died before the second interview was completed.

Janesick (2000) identifies two methods of member checking: 1) allowing the participants to review the material and 2) having an outsider read the researcher’s interview transcripts and field notes. Both methods were used in this research. Findings and analysis from the first round of interviews were reviewed and discussed with participants at the second interview. During this second interview, respondents were provided with the written transcript analysis of their first interview that included supporting quotes and specific examples of themes. For the 15 respondents participating
in the second interview (1 died during the study), member checking revealed that only
three participants had minor interpretation clarifications they wished made to the
analysis of their interviews (a programmatic spelling correction and two interpretation
clarifications). These corrections were made. A copy of their transcript analysis was
made available to all participants.

Outsider input was sought in two ways: the three members of the researcher’s
dissertation committee each reviewed and commented on the open-coding of one of the
first three interview transcripts, and the committee chair independently analyzed one
additional interview transcript (interview 11), which was randomly selected from
interviews 4 through 16. Her analysis was then crosschecked with my coding to assess
inter-rater dependability. An inter-rater coding agreement rate of 83% was established,
with 109 of the 132 codes assigned by the committee chair being in agreement with my
coding. Most of the coding differences were minor and pertained to interpreting which
category themes should be placed in. For example, inter-rater coding differences
included things such as pet care being coded as a health issue by one rater and a housing
issue by the other, statements about interventions being coded as “intervention actions
needed/taken” by one rater and as “worker’s thoughts and feelings about intervention”
by the other rater, and statements being coded as “assessing housing dangers” by one
rater and as “explaining housing dangers” by the other.

Finally, an audit trail was kept so that others might confirm the findings
(Padgett, 1998; Lincoln and Guba, 1985). The components of an audit include the raw
data, the researcher’s journal, and memos noting decisions made during data collection,
coding, and analysis (Padgett, 1998). As mentioned earlier in the data analysis section of
this study, coding and category development decisions should be documented by
memoing so that researchers, auditors, and advisors can examine them later (Padgett,

“Keep a journal. In it, write about your feelings about your work. This not only frees up your writing, it becomes the ‘historical record’ for the writing of a narrative of the Self or a writing-story about the writing process” (Richardson, 2000, p. 941).

For this study, journal writing followed the above guidelines suggested by Richardson (2000), Padgett (1998), and Locke, Spirduso and Silverman (2000). The journal included memos about research decisions as well as feelings associated with the research process. The frequency of journal entries was determined by the frequency of research decisions and the researcher’s need to document feelings associated with the research process.

**Limitations of the Methodology**

Caution must be used when transferring qualitative research findings to populations outside the study (Locke, et al, 2001). When *purposive* or *theoretical* sampling techniques are used where respondents are selected based on their ability to provide needed information, the findings are not transferable to populations outside of the study (Padgett, 1998). Without random sampling, claims to acquisition of valid knowledge about other groups, either within the study context or external to it, are almost always inappropriate (Locke, at al, 2001). Theoretical sampling of new respondents on the basis of their ability to respond to the emerging concepts was not feasible in this study because 100% of the population of APS workers in the participating counties was initially invited to participate.

Limitations of using interviews to explore sensitive issues include the risks of reactivity and respondent bias. Wide variations in the language and meanings of
Different APS workers make it difficult to uniformly compare the personal and environmental characteristics associated with elder self-neglect. While some objective characteristics can be compared uniformly across different workers’ language, characteristics that are more subjective cannot be uniformly compared. For example, objective characteristics such as the utilities being shut off or the number of pets can be compared with some degree of uniformity, while subjective characteristics such as cleanliness, safety, and suitability of the home environment cannot. Even themes that appear regularly, such as the condition of the home and the elder’s mental states, are subjective by nature. APS worker’s language and meanings are influenced by localized knowledge and traditions, which affects transferability.

Additionally, the absence of discussion about themes, issues, or characteristics does not mean they do not exist. For example, one APS worker might highly value the availability of hygiene supplies in the home and emphasize this in her interview, while another worker might never discuss hygiene supplies in his interview. Some workers might focus on personal characteristics of the elder while others might emphasize assessment of the characteristics of the home. APS workers may not consistently identify situations when elders decline or refuse services, especially if the elder eventually accepts services based on the workers recommendations, educational skills, and powers of persuasion.

Finally, most Adult Protective Service agencies do not use a uniform assessment tool to assess elder self-neglect. The absence of a standardized tool to assess elder self-neglect and the variation of individual APS workers’ language, perceptions, and standards make it difficult to uniformly compare characteristics seen in the field. I attempted to address these limitations by utilizing the five strategies described above to decrease threats to the trustworthiness.
Ethical Considerations

Ethical considerations for this study included *human participants’ protection from harm, informed consent, confidentiality, inclusion of women and minorities, and conflict of interest* (Denzin and Lincoln, 2000; Fontana and Frey, 2000; Locke, et al, 1998; Padgett, 1998, The Ohio State University Institutional Review Board, 2009).

*Human participants’ protection from harm* (physical, emotional, or any other kind) was monitored by submitting this study to The Ohio State University (OSU) Institutional Review Board (IRB) for the protection of human subjects. Additionally, requesting a letter of support from the director/supervisor of each participating APS program promoted respondent protection by ensuring that employers fully sanctioned workers’ involvement in this study. These two methods, IRB approval and official agency sanction, were used to protect participants.

*Informed consent* refers to the right of research subjects to be informed about the nature and consequences of experiments in which they are involved (Denzin and Lincoln, 2000). To assure informed consent in this study, all respondents were asked to sign a written consent form. A standardized consent form recommended by the OSU IRB was used for this study.

*Confidentiality* refers to efforts made to ensure that participants’ identities are never revealed (Padgett, 1998). Respondents in this study were protected from being identified by keeping their names confidential. According to Padgett (1998), confidentiality during data collection requires using code numbers or pseudonyms rather than names on all notes and tapes. Creating respondent identification codes for this study will protect respondent confidentiality. Respondent identification codes were assigned chronologically, with the first respondent being given the code of “01.” The key to these codes was kept in the researcher’s office and will be destroyed upon the
completion of this project. Respondent confidentiality was also protected in this study by only sharing identifying information with the chair of the dissertation committee.

Inclusion of women and minorities occurred naturally to the extent that women and minority APS workers agreed to participate in this research. Of the 16 participants, 13 were women (81%) and 4 were African-American (25%). Respondent demographic characteristics will be discussed in more depth in the “findings” chapter of this dissertation.

Conflict of interest was addressed in two ways. First, no outside funding of any kind was used for this study. Second, conflict of interest was formally monitored by the OSU Office of Research Compliance. An official statement from the OSU Office of Research Compliance is attached to this dissertation.
What is a typical home visit to investigate elder self-neglect like for you?

How do you assess elder self-neglect? Prompts: What areas do you look at? What conditions or thresholds do you look for? (Discuss each area) What behaviors do you look for?

Please describe some home visits where the decision was made to substantiate allegations of elder self-neglect.

Please describe some home visits where the decision was made to not substantiate allegations of elder self-neglect.

Could you describe some home visits where you had mixed feelings about the substantiation of self-neglect allegations? (Where it might have gone either way?)

Please describe an optimal process of care planning for self-neglecting elders. (How would it go in a perfect world?) What services are needed for self-neglecting elders? Which service/treatment recommendations are most accepted? Which are most resisted?

Do you use any particular practice models with self-neglecting elders? If so, what interventions do you use? When are they most effective? Least effective? What direction do you think treatment for elder self-neglect should be going?

How do you assess elders’ satisfaction with their housing and care planning? Prompts: How have elders’ responded to your service recommendations? What roles do elders have in making decisions about their housing and care planning?

When do you override elders’ care planning and housing desires? Prompt: When do you assess the need for/recommend a psychiatric evaluation and/or a competency hearing?

Please describe your experience with seeking involuntary services for self-neglecting elders.

Please describe your experience of the role of kin in care planning for self-neglecting elders. (What roles have kin played in care planning?)

Please describe your experience of care planning for self-neglecting elders without kin. Prompt: Any particular barriers in care planning for self-neglecting elders without kin? How do you see your role in care planning for elders without kin? Prompt: Do you see yourself as a surrogate for society in care planning for elders without kin?

What roles does American society prescribe to elders without kin?

How do you distinguish between elders’ self-determination and self-neglect? How do you balance the NASW Code of Ethics value of client self-determination with the responsibility to protect self-neglecting elders?

What research agenda do you recommend to better understand and treat elder self-neglect? Prompts: What should we be studying? What questions should we be asking about elder self-neglect?
REVISED SEMI-STRUCTURED INTERVIEW SCHEDULE
(Revisions approved by dissertation committee 7/7/08)

First Interview

What is a typical home visit to investigate elder self-neglect like for you?

How do you assess elder self-neglect? Prompts: What areas do you look at? What conditions or behaviors do you look for? (Discuss each area)

Please describe a home visit where the decision was made to substantiate allegations of elder self-neglect.

Please describe a home visit where the decision was made to not substantiate allegations of elder self-neglect.

Please describe a home visit where you had mixed feelings about the substantiation of self-neglect allegations. (Where it might have gone either way.)

Please describe an optimal process of care planning for self-neglecting elders. (How would it go in a perfect world?) Prompts: What services are most needed? Which services are most accepted by elders? Which are most resisted?

Do you use any particular practice models with self-neglecting elders? If so, what interventions do you use?

Please describe your experience with seeking involuntary services for self-neglecting elders. Prompts: When do you override elders’ care planning and housing desires? For example, when would you seek a psychiatric evaluation and/or a competency hearing after an elder has refused these recommendations?

How do you distinguish between elders’ self-determination and self-neglect? How do you balance the NASW Code of Ethics value of client self-determination with the responsibility to protect self-neglecting elders?
Second Interview

Please describe your experience of assessing self-neglecting elders for depression and lethality. Prompts: When do you assess for lethality or depression? What do you consider? What treatment have you recommended?

Please describe your experience of the role of kin in care planning for self-neglecting elders. (What roles have kin played in care planning?)

Please describe your experience of care planning for self-neglecting elders without kin. Prompts: Are there any particular barriers in care planning for elders without kin? Do you see yourself as a surrogate for society in care planning for elders without kin?

What research agenda do you recommend to better understand and treat elder self-neglect? Prompts: What should we be studying? What questions should we be asking about elder self-neglect?
INTERVIEW FACE SHEET

The facesheet is a standardized document for recording the date, time, and location of the interview and the demographic characteristics (age, sex, race or ethnicity, etc.) of the informant.

Name:

First Interview

Date:
Time:
Location:
Time audiotaping began and ended:

Second Interview

Date:
Time:
Location:
Time audiotaping began and ended:

Respondent Characteristics

Job Title at Adult Protective Services:

Hours worked at APS:

Years of related experience:

Education:

Degree(s):

License(s):

Specialized training/classes:

Age:

Sex:

Race/ethnicity:

Marital Status:

Parent Status:
INTERVIEWER REACTION SHEET

The interviewer reaction sheet is a place to log observations about the interviewee and about the setting.

Respondent Name:

Date:

Respondent Process (the manner in which the respondent answers questions and tells her story, including feelings expressed and the connection of feelings to events):

Setting:

Other:
Dear Xxxxx:

Thank you for your interest in my dissertation study on elder self-neglect. The proposal I wrote for members of my dissertation committee is attached. It is a qualitative study exploring themes and issues arising when Adult Protective Service (APS) workers investigate elder self-neglect allegations. I have asked for your participation because you are involved with such investigations. I hope the information obtained from this study will help practitioners better assess and treat older persons experiencing self-neglect.

Data collection will consist of interviews that I will conduct with APS workers. A minimum of 15 APS workers from 6 central Ohio counties will be interviewed. Each interview will last one hour, and each participant will be interviewed twice. Questions for the second round of interviews will be based on information and theories that emerged from the first round of interviews.

Upon receiving responses from the APS agencies contacted for this study, I will submit my dissertation proposal to the Institutional Review Board (IRB) at The Ohio State University. This committee will review the proposal to ensure that procedures for this study protect participants from any physical, emotional or other harm. If you choose to participate, a brief letter of support from the participants’ director or supervisor will be needed for the IRB review. Directors and supervisors will be informed and agree that all participants’ identifying information will remain confidential, known only to me and Dr. Virginia E. Richardson, the chair of my dissertation committee. To protect participants’ identities, I will immediately assign code numbers to each interview to which only I will have code access. To ensure informed consent in this study, all participants will be asked to sign a written consent form prior to being interviewed.

Please contact me after you review the proposal. Findings from this study will be incorporated in my dissertation and will be available to all interested parties. Feel free to call me at (614) 252-9090 if you have any questions. I look forward to hearing from you.

Sincerely,

Brian Bohl, MSW/LISW

Virginia E. Richardson, PhD
Your agency has agreed to allow Adult Protective Service workers to participate in a research study seeking to better understand how APS workers conceptualize, assess, and treat elder self-neglect. The discovery of current APS practices could be helpful to APS workers, agencies, and policy-makers facing the ethical dilemma of balancing freedom and safety when working with self-neglecting elders. Participation is strictly voluntary and will not affect participants’ employment or job performance evaluation. Participation will consist of two one-hour interviews spaced several weeks apart. Interviews will be conducted privately and agencies will not have access to participant’s transcripts. This study has been approved by the Ohio State University Institutional Review Board, and an informed consent form will be reviewed with all participants prior to being interviewed. Study findings will be available to all interested parties. Please provide your name and work telephone number if you are interested in participating. Questions may be directed to Brian Bohl at (614) 252-9090 or bohl.3@osu.edu.

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<tr>
<th>NAME</th>
<th>WORK TELEPHONE NUMBER</th>
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RESEARCHER SIGNATURE_____________________________________
Brian Bohl, MSW/LISW
Ohio State University Doctoral Candidate

SUPERVISOR SIGNATURE_____________________________________

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CHAPTER FOUR: RESULTS

The overarching conceptual approach to data collection and analysis in this study was a person-centered approach, reflecting the researcher’s desire to accurately represent the individual APS workers’ authentic voices and their lived experiences in the field before paraphrasing, summarizing, condensing and interpreting their experiences. The act of interpretation brings in the interpreter’s voice, including his perspectives, values, and biases. A personal goal of this research was to focus on the APS workers’ authentic, actual voices and to describe their lived experiences from their own perspectives as accurately as possible. To this end, there is an emphasis in data analysis on presenting and categorizing direct quotes from individual workers rather than presenting general summaries of the themes that emerged from the data.

The linguistic accuracy of workers’ narratives was emphasized during the transcription of interviews by including workers’ pauses, false starts, word repetitions, mid-sentence revisions or changes of direction, and verbal punctuation. For ease of reading, the pauses, false starts, and word repetitions have been omitted for the presentation of findings. Mid-sentence revisions and changes of direction have been included because these speech patterns shed light on the workers’ thought processes. Suggestions for unfinished words have been added in brackets.

The primary research goal of this study was to gather and to present the voices of front-line APS workers from the field for two purposes: 1) to better understand current practices and concerns of those working directly with self-neglecting elders, and 2) to foster communication within agencies in the form of a “feedback loop” by promoting the
upward flow of information from the agencies’ clinical field workers to the administrators. An underlying assumption of this goal is that the most effective policy and programmatic decisions are informed by the direct experience, knowledge and perspectives of workers in the field. This study was conducted with the hope that an upward flow of information and observations from APS workers in the field might have an influence on Adult Protective Service policy and program development at the macro level. Another research goal of this study was to present APS workers’ thoughts on what constitutes “best practice” in assessing and treating elder self-neglect.

A review of how themes were collected and analyzed is presented here. An interview guide was used that contained an initial set of questions focusing on the researcher’s areas of interest. When a respondent mentioned something that evoked in them an emotional or strong reaction, probes were used to go deeper into his experience (Padgett, 1998, Charmaz, 2000, and Loftland and Loftland, 1995). Data analysis for this study followed a grounded approach, assuming that the researcher did not know what information would be most significant until thematic patterns were revealed through data collection (Glaser and Strauss, 1967; Strauss and Corbin, 1998; Padgett, 1998; Charmaz, 2000). Upon reviewing the data, a central category representing the main theme of the research was chosen (Strauss and Corbin, 1998).

Making comparisons is a major technique in qualitative research. APS workers’ narratives were categorized by themes to compare and to contrast their ideas, voices, and lived experiences. Summary paragraphs of the findings are provided prior to the presentation of workers narratives. The qualitative analysis of interview transcripts consisted of five techniques for content analysis consistently recommended by leading qualitative researchers: open coding, axial coding (i.e. properties and dimensions), and selective coding of the data, constant comparative analysis, and memoing (Glaser and
Strauss, 1967; Strauss and Corbin, 1998; Padget, 1998; Locke, Spirduso and Silverman, 1998; Charmaz, 2000; Denzin and Lincoln, 2000). To capture the dynamic flow of events and provide insight into what workers are doing in the field, action coding (using verbs) was used as much as was feasible when making coding decisions and conceptualizing categories, properties, and dimensions (Charmaz, 2000).
The 16 APS workers who participated in this study were well educated and clinically experienced. Their average age was 41.2 years old, all had college degrees, and they had an average of 13.9 years of related experience. Thirteen women and three men participated. Eleven respondents identified themselves as white, four self-identified as African-American, and one self-identified as being of mixed race. Fifteen of the 16 respondents graduated from Ohio colleges, with eight of these graduating from The Ohio State University. Eleven respondents were currently Licensed Social Workers with one having an Independent License. Twelve respondents worked for Franklin County Adult Protective Services, the most populated county and largest APS agency that participated. One worker from each of four surrounding counties (Fairfield, Licking, Madison, and Pickaway) participated. At the time of this study, these five counties employed a total of 20 APS workers, thus the 16 who participated comprised 80% of the target population.
Overview of Emerging Themes and Categories of Elder Self-neglect

Two major categories emerged during data analysis: “assessing decision-making” and “approaching intervention.” These two major categories corresponded to the research goals of exploring how APS workers assess and treat elder self-neglect. Each category has sub-categories, and each sub-category consists of properties, which are specific themes discussed by workers pertaining to the topic of the sub-category. The discussion of the findings of this study is organized around the categories and their properties that emerged during interviews with APS workers.

“Assessing decision-making” emerged as the central category. Workers often mentioned term “competency.” In developing the central category, the phrase “decision-making” was used to avoid confusion with the legal term “competency.” Competency is a legal term, and only a judge can determine legal competency. APS workers interviewed were aware of this and sometimes used the word informally. Workers assess people’s decision-making, and they may petition the court for a competency hearing if indicated.

Five sub-categories emerged within the central category of “assessing decision-making.” These sub-categories encompassed all assessment themes discussed by APS workers. The five sub-categories of assessing decision-making that emerged were: 1) decision-making capacity, 2) decisions about personal health and hygiene, 3) housing decisions, 4) decisions about relationships, and 5) decisions about finances. Each of these sub-categories consists of properties, which are specific themes discussed by workers within the sub-category. For example, the sub-category of assessing decisions about housing includes the properties of assessing housekeeping decisions, assessing condition of home, assessing health and safety concerns/fire risks, assessing vermin infestation, etc.
A secondary category of “approaching intervention” also emerged. Two sub-categories emerged within the category: 1) actions needed/taken [interventions] and 2) APS workers’ personal feelings about intervention with self-neglecting elders. There was much overlap between these two sub-categories, but transcripts were coded during open and selective coding so that the things workers felt strongly about would be captured for analysis. During selective coding, an orange-colored symbol was used to identify statements as “workers’ feelings” when workers mentioned “feeling” words, when they specifically identified personal values, or when they spoke with passion as evidenced by voice volume, rate of speech, and significant pauses, which were noted in the transcripts.

A third category was developed to identify themes that were unique to one interview. They were coded as unique themes during selective coding (by a brown dot) for purposes of identifying outlying perspectives and practices when analyzing properties. Discussion of unique themes and outlying perspectives captured in the third category (“themes unique to one interview”) has been incorporated into the discussion of the properties of each sub-category. Selected unique themes that do not easily fit into the natural discussion of properties are discussed at the end of the chapter.

Tables are provided for each category and sub-category. These tables include the properties mentioned by the most workers. After each table is a discussion of the dimensions (ranges) of the properties. Properties in the central category mentioned by four or more APS workers are analyzed in depth. Properties in the secondary category mentioned by eight or more workers are analyzed in depth. All references to all properties were compiled and these data are available in the appendix. In summary, the data is presented in a hierarchical format beginning with the identification of overarching themes (categories and sub-categories), then moving to identifying the properties of these categories, then to a discussion of the dimensions of the properties.
Table 2
Central Category: Assessing Decision-making

<table>
<thead>
<tr>
<th>Sub-categories of Assessing Decision-making [see table for each sub-category]</th>
<th>Number of APS workers mentioning sub-category (n=16)</th>
<th>Number of references per sub-category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decision-making capacity</td>
<td>16</td>
<td>427</td>
</tr>
<tr>
<td>Personal health and hygiene decisions</td>
<td>16</td>
<td>411</td>
</tr>
<tr>
<td>Housing decisions</td>
<td>16</td>
<td>285</td>
</tr>
<tr>
<td>Decisions about people and relationships</td>
<td>16</td>
<td>176</td>
</tr>
<tr>
<td>Financial decisions</td>
<td>16</td>
<td>122</td>
</tr>
<tr>
<td><strong>Totals:</strong></td>
<td><strong>16</strong></td>
<td><strong>1421</strong></td>
</tr>
</tbody>
</table>

CENTRAL CATEGORY: ASSESSING DECISION-MAKING

“Assessing decision-making” was the theme mentioned most frequently and emerged as the central category during data analysis. This central thematic category corresponded to the interview schedule developed to explore how APS workers assess and treat elder self-neglect. All 16 participants discussed assessing decision-making and each of its sub-categories, mentioning it 1307 times. The reference count of the five sub-categories equaled 1421 because 114 of the participants’ references pertained to more than one sub-category. Five sub-categories of assessing decision-making emerged: 1) decision-making capacity, 2) hygiene and health care decisions, 3) housing decisions, 4) decisions about other people and relationships, and 5) financial decisions. Tables of the properties of each of these sub-categories are presented here in order of the frequency they were mentioned. A discussion of the dimensions of the properties most frequently mentioned follows each table. Complete group data for all categories are presented in the appendix.
**Table 3**  
**Assessing Decision-making Capacity**  
(A Sub-category of the Central Category “Assessing Decision-making”)

<table>
<thead>
<tr>
<th>Properties of Assessing Decision-making Capacity</th>
<th>Number of APS workers mentioning property (n=16)</th>
<th>Number of references per property</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental capacity [cognitive abilities, mental status, competency]</td>
<td>16</td>
<td>169</td>
</tr>
<tr>
<td>Understanding of current circumstances and risks [via ability to articulate circumstances and risks]</td>
<td>14</td>
<td>110</td>
</tr>
<tr>
<td>Behavior patterns [behavior changes, life-long patterns]</td>
<td>9</td>
<td>21</td>
</tr>
<tr>
<td>Respecting competent people’s rights to make decisions/lifestyle choices</td>
<td>9</td>
<td>21</td>
</tr>
<tr>
<td>Respecting competent people’s rights to decline services</td>
<td>6</td>
<td>15</td>
</tr>
<tr>
<td>Observing “cover-up techniques” being used to mask cognitive impairment</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Observing decision-making impairment when drinking alcohol but no impairment when not drinking alcohol</td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td>Getting to know the person</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Ability to develop adaptive alternatives when barriers arise/ability to “take care of things”</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Observing that the Mini-Mental State exam might not give a clear assessment of someone</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Wandering</td>
<td>1</td>
<td>12</td>
</tr>
<tr>
<td>Compliance with treatment and service recommendations</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Going out at different times of the day to assess mental and physical status</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Other properties [see compiled group data for remaining properties]</td>
<td>6</td>
<td>27</td>
</tr>
<tr>
<td><strong>Totals:</strong></td>
<td><strong>16</strong></td>
<td><strong>427</strong></td>
</tr>
</tbody>
</table>

**ASSESSING DECISION-MAKING CAPACITY**

Assessing decision-making capacity was the most frequently mentioned theme in the entire study, with APS workers making 427 references to 33 different properties of this category. Dimensions are presented here of the six properties of assessing decision-making capacity mentioned by four or more of the respondents participating in this
study. Together these six properties account for 87% of participants’ references to assessing decision-making capacity. These six properties are: 1) assessing mental capacity, 2) assessing understanding of current circumstances/possible consequences and risks to self and others, 3) assessing behavior patterns, 4) respecting competent people’s rights to make decisions/lifestyle choices, 5) respecting competent people’s rights to decline services, and 6) observing “cover-up techniques” being used to mask cognitive impairment. Corresponding with table 3, properties are presented in the order of how frequently they were mentioned by APS workers, with the most frequently mentioned properties being presented first. Complete group data of all 33 properties of assessing decision-making capacity are included in the appendix.

Assessing mental capacity

Within the category of assessing decision-making capacity, the property of assessing mental capacity was discussed most often, being mentioned 169 times and by all 16 workers. This was the only property in the entire central category (assessing decision-making) that was discussed by all 16 participants. Assessing mental capacity was the second most frequently mentioned property in the entire study (second only to “services needed for self-neglecting elders” which was mentioned 173 times), revealing it as the workers’ priority task. Because assessing mental capacity was discussed so frequently and in such detail, each dimension of this property is presented as an individual thematic category. These themes are: assessing cognitive abilities, assessing memory, assessing for dementia, using Mini-Mental State exam questions, assessing competency, seeking an expert psychological evaluation, and case examples ranging from people without cognitive impairment making bad decisions to people with significant cognitive impairment being able to maintain a daily self-care routine.
These dimensions were developed and distinguished by the respondent’s language. For example, assessing memory, assessing dementia, and assessing competency are similar concepts, but they were distinguished as individual dimensions in this study because workers mentioned them separately and with nuances of difference. For example, a worker may assess that a person has memory impairment (such as being unable to recall what she had for breakfast), but her logic and reasoning ability, indicators of her competency, are intact (such as being able to explain what she would do in an emergency). Several workers emphasized that they are not focused on assessing traditional measures of memory (such as MMS questions about date, the president, and ability to recall three items later in a conversation), but rather in assessing peoples reasoning ability and legal competency to understand and articulate risks and consequences of their decisions. The terms competency and dementia are similar in that they both describe a person’s mental abilities, but they are substantively different in that competency is a legal term and is determined by courts, while dementia is a medical term and is diagnosed by medical professionals. These concepts were distinguished in data analysis because workers indicated that the concepts had different meanings for them.

**Assessing cognitive abilities**

Themes workers presented within the dimension of assessing cognitive abilities included: assessing cognitive abilities through conversation, monitoring cognitive decline over time, considering underlying causes of cognitive deficits, substantiating self-neglect allegations when a person is mentally incapacitated, not “forcing things” when a person is alert and oriented, recognizing that people can have cognitive deficits and still understand the consequences of their decisions, and assessing people’s judgment. Examples workers gave of these themes included:
R2: [assessing] “...what this person’s ability is, what this person’s cognition level is to process all of the information that comes at us every day...their ability to decide ‘This is what’s best for me. This is a consequence of this, and I’m choosing to do this anyway.” (p. 12)

R10: “I look at that person’s mental status. So I start evaluating, you know, are they alert and oriented. You know, do they remember things. Are they able to handle their activities of daily living. Do they use the phone. Are they able to pay their bills. ‘Cause the mental status for me plays a part because I need to know if they’re understanding and understand how they’re meeting their needs or how they’re not meeting their needs. So I look and assess for the mental status part of a person, and then I look for their physical capacities.” (p. 2)

R15: “Well, usually when I’m talking to them, I can pretty much tell whether or not they’re oriented that day. Well, their conversation, how they’re dressed, what the house looks like, I’m kinda taking in the whole observation, and kind of gathering my own assessment.” (p. 1)

R12: “And you can determine a lot of capacity and a lot of competence based on just general conversation. Whether their thoughts are clear and lucid, you know, if they followed through on information you might have given them. Do they understand how it works.” (p. 11)

R11: “So, during this conversation, of course, I’m assessing the person, as far as how they’re answering, how much time they need to answer.” (p. 1)

R2: [overriding elders’ desires] “I think when...the person is demonstrating some obvious signs of confusion, inability to process information. You know, when somebody sits there in a conversation with you for twenty minutes, and sometimes it’s that quick that you can see that there’s a problem, and they’re not capable of...[processing information].” (p. 16)

R10: client demonstrating lack of capability if they can’t follow-through with a plan developed together with worker (p. 13)

R1: assessing cognitive decline over time: case example of repeat referral “But this time he has declined cognitively. And medication’s not helpin’. ” (p. 18)

R7: monitoring over time (30-45 days) to assess dementia in 90-year-olds whose competency fluctuates (p. 5)

R3: substantiating self-neglect when the person is mentally incapacitated: “A lot of times that happens when the person is incapacitated mentally. They don’t know the consequences of their behavior, what it’s gonna do to affect neighbors...That’s when it’s substantiated...” (p. 5)

R5: not “forcing things” when people appear alert and oriented (p. 7)

R5: [re: balancing self-neglect with self-determination] “For me it’s all about cognitive status.” p. (18)
R2: “Are they not processing this information because they’re not capable for this reason, that reason. Can it be reversed in any way, which then goes, of course, to the guardianship kind of an issue.” (p. 16)

R7: “I’m one of those who won’t just test people just to be testing. They can still have deficits. And that can either be an education level, that can be they’ve been isolated. It goes back to them not understanding the consequences.” (p. 9)

R9: assessing a person’s request for worker to provide identification information as a sign of good judgment: [when a person says] ‘Just give me some information, I’ll make a call.’ You know, I know right then, you know, that if they say, you know, leave a letter of intent, lettin’ somebody call and check. That’s a sign that they’re somewhat with it. And right there, ‘cause they’re askin’, you know, to prove who you are.” (p. 1)

R14: assessing judgment: substantiated case ex: having poor judgment (p. 3) [overriding elders wishes] if they just really don’t have good judgment and there’s a lot of safety problems (p. 7)

R16: not substantiating self-neglect allegations when they seem cognitively aware of surroundings and they’re making decisions (p. 1)

R10: walking a fine line when determining mental and physical capacity (p. 15)

Assessing memory

Themes workers presented within the dimension of assessing memory included: identifying methods of assessing memory, observing short-term memory loss but intact long-term memory, and specific examples of observed memory impairment. Examples workers gave of these themes included:

R5: testing memory by giving worker’s name and asking for it later (p. 3)

R8: assessing memory by seeing if they can remember the people in the pictures on the wall (p. 1)

R12: asking specific questions to assess memory: “You can ask, ‘Did you eat this morning?’ and they can tell you ‘Yes.’ But if you ask them ‘What did you eat?’ a lot of them won’t remember. So you have to a little bit more specific about what your questions are...” (p. 2)

R15: asking “What did you have for breakfast this morning?” (p. 1)

R11: “Do they appear to not, you know, remember when they ate last? Or you know, how they get their food?” (p. 3)
**R15**: “I wanna know how their memory is. I wanna know if it’s, you know, short-term or not. Some people, even if I ask ‘em what day it is, might refer to a calendar...they might refer to the TV, or they might just say, they didn’t know, or they’re right on top of it and can tell me...” (p. 2)

**R1**: 2 references to observing memory loss, confusion (p. 1, 3)

**R3**: case example of being forgetful and somewhat confused (p. 4)

**R11**: assessing confusion (p. 3); “…finding them to be very confused about certain things.” (p. 7)

**R13**: case example of client not remembering worker from one visit to the next (p. 2)

**R8**: observing short-term memory loss: case example of being able to tell stories about the remote past but not being able to discuss the recent past (p. 4)

**R9**: “A lot of ‘em, the short-term memory is gone. So, can’t hardly remember anything, you know, within almost- some of ‘em, short-term memory’s not there within a five-minute span or somethin’. Or, when you leave, they call you and say, you know, ‘Well what were you doin’ here? I found your card.’ And you had actually talked to ‘em. And thy found your card and they’re callin’ you, you know.” (p. 2)

**R1**: case example of leaving out open food containers but forgetting to eat: “I ask her ‘Did you eat today?’ ‘Yes, I had eggs, and I had bacon, and I made myself a pot of coffee.’ Her stove was disconnected.” (p. 6)

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**Assessing for dementia**

APS workers identified that many people who self-neglect have obvious signs of dementia such as being totally unaware of their home conditions or experiencing psychological symptoms such as delusions or persecutory ideation. Workers consistently identified that dementia alone is not enough to substantiate self-neglect allegations; there must also be a specific safety concern. Workers also identified dementia as a mitigating variable when considering people’s rights to live as they wish versus substantiating self-neglect allegations. For example, workers would not substantiate self-neglect allegations on a cognitively intact person with diabetes who chooses to eat sugar, but if a diabetic has dementia and is unable to understand the possible health
consequences of eating sugar, it may be considered self-neglect. Specific examples

workers shared of the dimension of assessing for dementia included:

**R9**: observing people who are self-neglecting having dementia or Alzheimer’s (p. 1)

**R1**: having dementia influencing the substantiation of self-neglect allegations:
“The tides turn [re: balancing between self-determination and self-neglect] when, I just talked to this man...thirty years ago and that’s what he told me [a diabetic choosing to continue eating sugar] and now it’s thirty years later, and he’s demented. Now...it’s self-neglect.” (p. 25)

**R4**: worker identifying that a person being unaware of home conditions is a “real dead indicator that they’re vacant, or they’ve got some dementia goin’ on, or...” (p. 5)

**R6**: case example of observing delusional thinking in a person who had Parkinson’s and dementia: 90-year-old woman, not paying her rent, thinking there’s a conspiracy, screaming about a conspiracy, being up all night talking to “spirits” and “visions,” worker sometimes having difficulty assessing if some thoughts are real or delusions (p. 6-7)

**R16**: [overriding elders’ desires] “...when you’ve got somebody who’s obviously not competent...” (p. 4) “You know, when you have somebody who’s *obviously* got some sort of a dementia or something goin’ on. And they’re endangering themselves, certainly that’s the other piece.” (p. 4)

**Using Mini-Mental State exam questions**

APS workers consistently shared that they do not formally administer and score the Mini-Mental State exam (MMS). Some workers find using MMS questions to be helpful while others do not. Workers consistently identified assessing mental status and memory from casual conversation rather than formal testing [see the dimensions of “assessing memory” and “cognitive abilities”]. One worker shared that at her agency workers find the clock test to be more helpful in assessing cognitive abilities than the MMS. Specific examples workers gave of their use of the MMS included:

**R1**: using mini-mental state exam: “[mini-mental] gives you that kind of baseline to work off of, you know, about their orientation, and their ability, you know, abilities of *recall*, and all of those, so...” (p. 15)
**R3:** “Can this person really be making decisions? They might tell me in one sense that they know what’s goin’ on, and then you ask ‘em a couple more questions with the mini-mental, say, and they’re confused, they don’t know their birthday, they don’t know who’s the president.” (p. 6)

**R4:** using but not scoring the mini-mental state exam: “We use it to an extent, yes. But not to base it. We prefer the clock test here.” (p. 1) “I usually say three o’clock. Yeah. We prefer the clock test.” And then we also prefer have a little mundane conversation here, talk about what you need to, ok, let’s go back to those mundane things, see if the stories have changed. We prefer doing that. Now yes, we use the mini-mental, do we use it and score it? No.”

**R4:** re: assessing competency: “‘N we don’t use ‘Who’s the president,’ ‘Who’s this,’ ‘Who’s that,’ because…doesn’t give you an adequate—just doesn’t.” (p. 1)

**R9:** “[I] try to assess that they’re oriented and ask some simple questions about, you know, do you know your address, do you know your phone number, know your Social Security number, if it’s on there. Do you know date of birth. Not the date because you’re retired, you know, you might not know what day it is, so I’ll ask the season. And if you watch TV, you know, who’s the president of the United States, pretty much, you know, and phone number really doesn’t—a lot of times, ‘cause you might not, you don’t call yourself, so…” (p. 2)

**R13:** “Also we’re just gonna basically have a conversation with them to see if they can answer any of the MMSE questions, to see where they are competency wise...” (p. 1)

**R13:** “You know, we do a few questions from the MMSE, and it- to be honest, that’s probably about it. You know, we just basically kinda go on our observation, and ask a few of those questions. Yeah, I’d have to say that’s the only tool that I’ve really used.” (p. 6)

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**Assessing competency**

APS workers consistently discussed the importance of assessing people’s competency [see also the dimension of “seeking an expert psychological evaluation”]. Several workers mentioned observing the phenomenon of fluctuating competency, where a person may be lucid one day but confused the next. Workers consistently shared that competency is the main factor they consider when determining whether they consider a person’s behavior to be self-neglect or self-determination. Workers also shared that fluctuating competency is one of the most difficult and frustrating issues they face when investigating and making a determination about the substantiation of elder self-neglect.
Specific examples workers shared about the dimension of assessing competency included:

**R4**: assessing competency (p. 1)

**R1**: competency having a lot to do with it when assessing people’s decisions (p. 25)

**R1**: distinguishing between self-determination and self-neglect “…really has a lot to do with competency.” (p. 25)

**R12**: distinguishing between self-determination and self-neglect “…and again it comes down to competency” (p. 11)

**R4**: “When we’re doing involuntary action, it’s usually based on competency. They are usually so clueless that they don’t even recognize that it’s happening.” (p. 9)

**R4**: worker having mixed feelings about substantiating self-neglect allegations when people demonstrate fluctuating competency: “When they’re right on that border of competency. When they’re just starting that border of competency. It’s like, oh, one day you understand, the other day I don’t think you understand… and you’re yellin’ at me to get out of the house ‘cause you really don’t understand and you don’t want me to know, but the next day I show up you’re sweet as pie, you’ve got your wits about ya, I don’t know, maybe you got a better night’s sleep, I don’t know. Those are the ones that just- and we are lucky in that we are a small county? So those ones that we have mixed feelings? We open, with case management services? And make visits about once a month.” (p. 4)

**R7**: case example of observing fluctuating competency: “…if you saw him today, he’s competent. You see him tomorrow, he’s not competent. He fluctuates.” (p. 4)

**R13**: case example of observing fluctuating competency: “But he was, I wanna say that he had his more lucid moments? And then there’s times that I kind of wondered…” (p. 3) “So that was always kind of hard to get that assessment goin’ because there would be times when he would be under-, you know, medicated, or either he’d be drinkin’ a little too much, so it’s hard to get that assessment, to really know if he really understood the ramifications.” (p. 3)
**Seeking an expert psychological evaluation**

Most workers mentioned seeking expert evaluations when they think a person is not competent to make decisions. Examples of this dimension discussed by workers included consulting with people’s doctors, seeking probate action, and using APS psychologists or Netcare for an expert evaluation. Workers presented a wide range of variation regarding the weight they give expert evaluations, ranging from workers identifying that another professional *must* ultimately make the decision of competency to identifying that another professional’s opinion is used as a factor when considering competency. Specific examples of the dimension of seeking an expert evaluation included:

**R2:** “weighing out” soundness of mind: “And then there’s a determination of why they weren’t of sound mind, which we can’t determine. A doctor needs to determine that kind of thing.” (p. 16)

**R11:** “Well, the competence, competency assessment, I mean, *we* do that. I don’t want to be the sole, responsible person, and I’m *not*, it comes down to a doctor. It’s usually when a client needs help and is refusing. {unintelligible} “It helps”? finding them to be very confused about certain things.” (p. 7)

**R11:** “Yeah, I mean, if you’re a competent person, but who makes that determination? It has to be a doctor. It can’t be *me*. I can say, ‘Look, they really don’t know what they’re doing. You know. I’ve talked to them’ That’s not enough. I’ve got to get a doctor to say ‘This persons is very confused. They probably have beginning dementia or Alzheimer’s.’” (p. 8)

**R15:** referring back to doctor on borderline cases (p. 2); “I always refer back to the doctor.” (p. 7)

**R5:** [re: when does worker seek a psych eval or competency hearing] “Only if we’re seeing, in *my* opinion, if I see what appears to be impaired judgment, either medically or because of some sort of cognitive deficit. And if and only then do we do the assessment and we only move forward [with overriding elder’s desires] once they’ve told me that person can’t make decisions.” (p. 17)

**R9:** “It has to be really severe and the client has to be, I mean evaluated to the point where they can’t function.” [to override client’s self-determination] (p. 8)

**R10** “…it’s not to say that we don’t take in consideration of other collaterals, or professionals, because *we do*. We- that’s why we call you. We wanna know your
opinion. But in the end, it is just an opinion. And we are gonna factor in that along with everything else.” (p. 16)

R12: “If you’ve gotten that far deep, to the place I’m referring you for a psych consult, I’m pretty sure that you’re already incompetent. I just need that piece of paper evaluation to prove it.” (p. 9)

R15: “You can go through the court system and ask for a psych eval to be made.” [if declined by client] (p. 7)

R10: seeking involuntary psychiatric evaluation if after numerous visits client is incapacitated and needs are consistently not being met and client is refusing services without providing alternative to meet need (p. 12)

R10: getting expert psych eval in home if client can’t follow through with plan (p. 14)

R11: if not seeing progress in addressing problems by client, taking it to the “next level” of getting a psychologist out there (p. 9)

R11: getting a doctor involved when they’re pretty confused (p. 9)

R8: contacting a person’s doctor if the person is at risk doesn’t understand what’s going on: “I will first of all contact the doctor, make sure, speak with the doctor to make sure if the older adult is indeed, in their opinion, still capable of making their decisions or not. If the doctor says that they’re not capable of making their decisions, so what they would do is fill out a form called an Expert Evaluation Form, and that will give me the basis to go forth with guardianship if I feel that it’s needed.” (p. 1)

R11: consulting with family physician to get an expert evaluation [regarding competency evaluation] (p. 7)

R7: using people’s doctors for a psych consult: “I’ll go to their doctor, I’ll call their doctor. APS does not require a Release of Information. Because we are investigating.” (p. 8)

R8: not needing client’s consent to release information to their physician due to physicians’ being mandated reports per Ohio Revised Code (p. 3)

R7: re: being able to locate people’s doctors: “I’m gonna say...about 60 to 40 percent. If not, let me get visiting doctors out.” (p. 9)

R7: “Okay, well, a psych eval, I can ask for that at any time. Now just because a senior says, ‘No, I’m not gonna agree to it,’ It may be a waste of money from our standpoint? I may get it from their doctor. Because I would only go for that point if I feel that person’s incompetent. Or incapacitated to make those decisions. So, those are issues that- would I do it? Yes. Have I done it? Yes. Because you- maybe that person is suffering either from strokes or dementia or Alzheimer’s. Maybe that person is suffering from delirium, which can last seven to fourteen days and
they don’t realize it because of an infection that’s going through their bodies.” (p. 7)

R8: physicians not completing expert evaluation if they don’t think APS needs to be involved (p. 3)

R11: using APS psychologist “if we can’t get anywhere with the family physician” (p. 7)

R11: “...if he [psychologist] feels that this person is really confused, doesn’t understand their situation, he sees what we see in terms of their home environment, an’ he’ll recommend a guardian.” (p. 7)

R8: using Netcare for competency evaluation: using Netcare for a competency evaluation if an older adult doesn’t have a physician, making home visits with Netcare worker, Netcare worker may make another visit with Netcare doctor (all p. 1)

R8: Franklin County APS having another doctor besides Netcare if necessary (private pay) (p. 2)

R13: 3 references to having hospital doctors assess mental status and complete expert evaluations while clients are hospitalized (p. 6, p. 7)

R3: leaving the stove on requiring a mental health evaluation (p. 14)

Having minimal mental impairment but making bad decisions/
Having significant mental impairment but being able to maintain daily self-care routine

Finally, APS workers provided specific case examples where mental impairment was not directly correlated with elder self-neglect, including cases where people had minimal mental impairment but were making bad decisions and cases where people had significant impairment but were able to maintain their daily self-care routine:

R1: case example of having minimal mental impairment but making really bad decisions: “Had this little woman and she, she mentally, long-term memory was intact, short-term memory had just some impairment, but, she was making like really bad decisions. She was a gardener, you know, and she would compost in her house.” (p. 11)

R3: case example of having “no clue” about information being asked but being able to sustain daily routine and self-care activities: “He couldn’t tell me anything about anything in his wallet.” (p. 7) “So I looked and, kind of regardless of what his mental state was, he was continuing to do his routine behavior in the house.”[get up, make breakfast, do the dishes, sit on the porch, talk to neighbors,
take a nap] “So then I’m like, ‘Well, he’s kind of in this routine. I can’t really force him out of his home.’” (p. 7)

R5: case example of having serious confusion but being able to manage a daily routine and self-care activities: “The first time I got her the home was in deplorable condition because she’s not able to care for it. Throughout the course of several months, she moved in- we moved her into this beautiful independent senior apartment. So where she could have her dog, which took some work. Serious confusion, but she manages her everyday- she bathes and dresses herself, eats, she takes her little dog for a walk three times a day. She’s just very tangential and repetitive. You hear the same six stories every time you see her. But she’s very able to manage as far as bathing, dressing, she- The apartment’s clean. She and the little dog take their walks and she puts the sweater on the dog when it’s cold, I mean she’s very good at her routine. If you interrupt her routine, that would be a problem. But...she does very well.” (p. 14)

Assessing understanding of current circumstances and risks

Assessing understanding of current circumstances and risks was the fourth most frequently mentioned theme in this study, with 14 APS workers making a total of 110 references to this property. This property was distinguished from the property “assessing mental capacity” because workers specifically mentioned it enough to merit separate analysis. Workers consistently emphasized assessing people’s ability to articulate their current circumstances and risks as being critical when investigating allegations of elder self-neglect. Dimensions of this property included: workers identifying methods of assessing people’s understanding of their circumstances and risks, assessing people’s understanding of their ability to independently manage their lives, and examples of assessing people’s understanding of specific health and safety risks. Examples workers gave of methods of assessing people’s understanding of their circumstances and risks included:

R2: observing that a person is not processing information: “When you can see things that you know she’s not processing. She’s thinking that she’s going to the bathroom properly and that she’s, she’s clean and, when you go into the home and the source of a smell is so horrid, and it’s the person, and the person doesn’t realize it, that’s pretty obvious. There’s an issue and she’s not aware of it. She’s truly not aware of it.” (p. 16-17)
R1: assessing ability to explain decisions (p. 4)

R12: assessing ability to verbalize understanding of current circumstances: “Definitely verbally. They would have to give me a verbal understanding, as well as do their actions meet up with what their words are telling me, you know. (p. 11)

R10: assessing ability to provide details of current circumstances: “Because someone’s giving you enough detail about how they’re managing and what they’re doing and their strategies and their plans? They’re giving you enough of that information that you know they understand it, okay? And then the people who don’t understand it aren’t capable of giving you that history and that detail.” (p. 4)

R11: assessing ability to provide details of how they would respond to an emergency: “They understand what to do in an emergency. That’s a big question. You know, ‘What would happen if a fire started? What would you do?’ ‘Well, I’d call that number.’ ‘Well what number would you call?’ ‘Well, the police.’ ‘Well, what number is that?’ You know, we have to get to do they really know what to do.” (p. 4) “I’d go over to my neighbor’s house. I’d call my neighbor. I’d go to the basement. You know, ‘I’d go out on the back porch.’ You know, things that they think they’re getting, you know, they’re doing something, but they’re really not, you know. Or just ‘I don’t know. I don’t know what I’d do.’ And that’s a real concern.” (p. 4)

R5: asking cause and effect questions: “I ask- you know, we ask real cause and effect questions. An easy ‘What would you do if you had a fire? Or any kind of an emergency, what would you do?’ And I’ll listen to their plan. And even if it isn’t, you know, I’d like- ideally I want them to say ‘I would call 911 and get the hell out.’ Sometimes ‘Well I would call my daughter.’ ‘Where do you keep her number.’ ‘Well I don’t. I’m not sure.’ ‘Okay, well you only have a short amount of time in a fire...how would you really do that? Honest to goodness, living room’s on fire, what do you do?’ ‘Well I guess I’d just run outside.’ ‘Okay.’ [Interviewer: So finally they get to it.] We get to it. An’ so you’re really listening for how logical is the answer. I mean, ‘I would throw a cup of water on it,’ probably not the best answer, but give me the logic, why were you thinking that. Whether I agree with it or not, however disjointed, if it makes sense, if you can eventually get me to where you can explain your reasoning, okay. Why won’t you get rid of the sixteen piles of newspapers. ‘Well the environment’s in trouble and I wanna recycle this newspaper and I just haven’t had time to get it to the guy. I know it’s not clean, I know it can start a fire, but I really feel strongly about recycling it.’ Okay.” (p. 18)

R5: directly asking about understanding of risks: “Depending upon what kind of a rapport you’ve built? I have addressed it directly. I’ve said, you know, ‘Hey I notice there’s some burn marks, you know, what happened?’ They’ll say ‘Oh, I fell asleep.’ ‘Well you know how dangerous that is, that can cause a big fire fast.’ ‘Oh, yeah I know.’ You know, ‘Do you have a smoke detector?’ So that we can a[ssess]- I’m looking for their level of awareness. Do they understand the risk. ‘Cause some people are like, ‘Yeah, who cares.’ Do they understand.” (p. 5)
**R11:** example of directly asking about understanding of risks: [regarding treating gangrenous foot] “You know, do you understand what’s gonna happen if you don’t get that taken care of? You could lose your foot. You could lose your leg.” (p. 8)

**R8:** making sure clients completely understand the repercussions of their situation (p. 13)

**R4:** assessing consistency of understanding: self-determination requires senior’s consistently understanding consequences, not just one time asking them the question “It has to be consistent. And we ask them numerous different ways.” (p. 10); overriding elders desires “when their desires conflict. One day they’re saying this, one day they’re saying that.” (p. 9)

**R5:** assessing if people’s responses are “circular” and they’re unable to answer questions: “And there’s never an answer. It becomes very circular...and we wander around a point but we never actually get to one.” (p. 19)

**R10:** asking client if they can’t clean up clutter or if they don’t want to (p. 14)

Examples workers gave of assessing people’s understanding and perspectives of their ability to independently manage their lives included:

**R15:** “So a lot of the times they do understand that it’s gotten to the point where they can’t manage anymore.” (p. 7)

**R13:** clients still thinking they can do it for themselves although they’ve proven that they can’t (p. 5)

**R7:** “Those are not things that people wanna do, or realize [that they are not able to manage things]. And yes, this maybe has been her lifestyle, but it’s gotten to such a point...There becomes a cross line. People can live like that until it starts affecting other people? Or you don’t even realize how it’s affecting you yourself.” (p. 8)

**R14:** not being realistic about what they can do: “...they can’t use a microwave, can’t cook, but in their mind, they can do it. But...they can’t. Either physically or mentally.” (p. 6)

**R14:** substantiated case example of not having insight into what they can do (p. 3)

Examples workers presented of assessing people’s understanding of their health and safety circumstances and risks included:

**R2:** example of being able to articulate understanding of current circumstances and choices: “Okay, could things be better for me? Probably, but I’m gonna stay
here because I like it better here than going to some place where I would have all the food I’d want, where I would always be warm where I would always get the medicine I want, because it’s more important to me to be here and make these decision on my own than to go there and have somebody tell me what I’m gonna do.” (p. 15)

R11: example of assessing understanding of health risk of not treating gangrene: “Do they really get it?” (p. 8)

R1: example of demonstrating understanding of diabetes risks: “…if you have a diabetic, you know, and they continue to eat the sugar, and they say ‘Well, I’ve always done it, and I understand that if I do it I can go into a diabetic coma and die.’ You’re willing to take the risk? ‘Yes I am.’ ” (p. 25)

R3: example of demonstrating understanding of risk of smoking with oxygen: “Well, then, I need to smoke. I’ve been smokin’ for twenty years, I’ve only had this oxygen on for a year, so I’m gonna quit doin’ the oxygen.” (p. 6)

R12: example of demonstrating understanding of risk of not taking prescribed medication: worker asking “If you don’t take this medication what can happen to you?” client responding “I could die.” (p. 3)

R12: example of demonstrating understanding of risk of not treating gangrene: “‘I don’t believe in amputation. I’m not – ‘ then, you know, ‘It’s my religion.’ ‘And when I die I’m going to leave this world a whole person.’ So, and again, they know the consequences, and they can clearly state their beliefs and why they’re not caring for themselves, and then we have to let it be.” (p. 3-4)

R3: examples of demonstrating understanding of health and fire risks: “Do folks know what their problems are, and know what can happen to them, and, you know, kinda what the consequences are for their behaviors, and a lot of times they do, and they’ll say ‘Well, if my trash gets piled up, it gets piled up. I don’t wanna take it out.’ If, you know, ‘I’ve smoked for fifteen years and now it’s been smokin’ and cookin’ with the oxygen on, and there hasn’t been a fire since, but if there is a fire, it’s gonna go up, you know, pretty quick here.’ Well, ok. If no one else is gonna be harmed, you know, they’re in their own house, you know…” (p. 2)

R7: examples of demonstrating and not demonstrating understanding of current circumstances and risks: “As long as you can say, ‘Yeah, I’m livin’ in filth. This is the way I want to live because da, da, da.’ Guess what? You get to live that way. If they, after I say ‘Do you realize that by smoking, it- drop it on their- your robe, it may burn you?’ ‘No, honey, I’ve never done that…’ you know and then you find burn marks on them. Then they are not understanding the consequences of their actions.” (p. 10)

R14: example of assessing understanding that the client is living in a home where crack is used: if the client knows it’s going on and has insight, worker would probably not do anything other than letting the client know the dangers, if they don’t understand that they’re living in a home where crack is used, worker would step in and do more (p. 7)
**R3**: case example of being able to explain circumstances [wearing stained clothing] “...she was embarrassed about it, she didn’t know...if I wear the same clothes over and over, maybe I had an accident an’ I missed it.” (p. 4)

**R2**: case example of being able to voice safety risks and choices: “She was of very sound mind. She knew the consequences of every decision she made.” (p. 6)
same case: “And she knew if the house caught on fire she was stuck. If somebody broke in, now she could push her button of course, she did have her ERS button, but she knew her limitations in being able to do anything for herself in an emergency. But she knew the consequences, she could voice them to you, discuss them very rationally with you, and put you in your place when you tried to do some[thing], you know, to persuade her to do anything differently.” (p. 7)

**R10**: case example of being able to state possible consequence of huge wound: “I could die” (p. 15)

**R2**: case example of being able to articulate current end-of-life circumstances and desires: “When I walked in, her first thing to me was [worker’s name], I’m going to die. I’m going to die, I’m ready. God is ready for me. He knows I’m comin’. I’m ready to go.’ And she wasn’t hallucinating, there was no dementia talkin’ here, this was very direct, very clear, on what she was tellin’ me.” (p. 14) “She wanted to be free to die at home. And she stated that very clearly, over and over again. I had my boss on the phone so she could hear that. We did contact the doctor, we contacted the squad. She made her wishes known to everybody.” (p. 14) “I’m not suffering. I’m not in pain. I’m breathing, I’m eating, I’m going to the bathroom. This is what I want.’ She wasn’t urinating in the bed. She wasn’t laying in filth. She knew what she wanted.” (p. 15) “…the squad told her, you know, Your vitals are great. The only problem is, is your blood’s not getting enough oxygen’ and she said ‘Well, what’s going to happen?’ and he says, ‘Oh, you might pass out.’ Ok. She goes ‘Can you make me do anything?’ He said ‘No-o-o, unless you’re passed out.’ She goes ‘Well then you wait then till I pass out.’ And, you know, she was very...she understood everything.” (p. 19)

**R13**: case example of being well aware of risks of not taking meds but still choosing home remedies for religious reasons (p. 2)

**R8**: case example of older adult being aware of needing services as evidenced by referring APS worker to older adult’s Senior Options casemanager (p. 8)

**R1**: case example of client winking as a sign of awareness during conversation [non-verbal communication that statements might not be true]: “So I was sittin’ there and I’m like ‘Are you gonna start compostin’ [inside an apartment] again?’ and she just looked at me and winked. And I said all the current issues have been resolved. But I know she’s gonna start composting.” (p. 11) same case: “But I knew she, she didn’t, she basically told me...” (p. 12)

**R2**: case example of being unable to process emergency information: “…but she is not capable of processing the information to know what is goin’ on with her.
...but she’s not capable of understanding bein’ at home and bein’ alone, and processing emergency information, that kind of thing.” (p. 8)

**R10**: case example of being unable to verbally demonstrate understanding of current circumstances when asked “How do you get food?” (p. 5)

**R12**: case example of not understanding risks: denying gangrene (p. 3)

**R6**: case example of explanation of current circumstances not making sense: “Everything was really cluttered and it smelled like old moldy mothballs, ‘n she had tons of boxes out with clothes sittin’ out. And I go ‘What are you doing?’ ‘Oh, church is coming and I’m cleaning out my closets.’ This stuff has been there for years.’ (p. 3)

**R13**: case example of substantiating self-neglect allegations on a person who was unaware of her current circumstances: “...we had called the squad. Got her to the hospital. But she wasn’t even aware of that. Poorly laundered clothing, I mean there was, it was soiled with fecal matter, whether it was hers or her dogs. Well, you know, couldn’t make that determination. Dried food on her lapel. *Shoes,* I mean visibly dirty, food was on there. So *that* one we could actually substantiate that there was some self-neglect, and she was not aware of any of this that was going on.” (p. 2)

**R7**: having dementia and not understanding unmet needs such as getting meds and seeing doctors (p. 2)

**R12**: case example of worker having to seek guardianship for a married couple who were not understanding risks: “I walked in the house one day and the entire kitchen was full of smoke and they weren’t even aware of it.” (p. 9)

### Assessing behavior patterns

Nine APS workers made a total of 21 references to assessing behavior patterns. Workers consistently identified the importance of assessing if behaviors such as wearing dirty clothes or not cleaning the kitchen are new behaviors or are lifelong lifestyle patterns. Workers expressed that they do not consider behaviors such as not performing personal hygiene activities or not keeping a clean house to be signs of reduced decision-making capacity if these behaviors have been lifelong patterns. Dimensions of assessing behavior patterns included: getting a person’s history and background, observing patterns on the second visit, assessing for recent changes in lifestyle, and not substantiating self-neglect allegations when the person has full mental and physical...
capacity and is making a lifestyle choice rather than experiencing a decline because of impaired decision-making capacity. One worker shared that substantiating self-neglect allegations is a “little harder call” when it’s how somebody has always lived. Another worker noted that lifelong lifestyle choices may become a crisis when a person has dementia and is no longer being able to articulate an understanding of risks. Workers gave the following examples of assessing behavior patterns:

**R15**: getting history, background (p. 1)

**R1**: observing patterns on second visit (p. 4)

**R1**: case example of seeing patterns of neglect and confusion (p. 7)

**R1**: case example of observing pattern of over-sleeping: “…he would just sleep, well he could just sleep all day. I mean, I think he could just sleep and not eat.” (p. 22)

Examples workers gave of assessing if behaviors are recent changes in lifestyle or lifelong behavior patterns included:

**R12**: “And you also have to determine if this is something- a new behavior for a client? Or if this is some way they’ve lived their whole life. You might go in, and this person might have dirty clothes on, and their house might be a mess, but that was kind of the conditions they grew up in, and that’s not unusual for them. [Interviewer: Lifestyle.] It’s a lifestyle. It’s a choice that they’ve lived their whole life, and that’s not out of the ordinary for them. To wear the same clothes four days in a row, or, you know.” (p. 3)

**R2**: “…this has been a lifestyle. They might be eighty-four, but when they were twenty-four they lived the exact same way. So there’s no difference to them, they don’t see the issue.” (p. 4)

**R3**: “And then also you have to look at, you know, their lifestyle. Was this kind of a lifestyle choice for them? That they’ve kind of always lived kind of unclean in the kitchen, you know, dishes are always kind of out, after they make a meal?” Have they always maybe had roaches, ’n roaches are not a problem for them? So it’s kind of a lifestyle as well, I think.” (p. 13)

**R4**: “First what we’re gonna look for is, we’re gonna look for how they’re living today compared to how they were living when they were thirty. If there’s no change and they’ve always had a dirt floor, ok, then how you’re living is your...judgment, if you wanna live in dirt, that’s fine. As long as it’s not presenting a health department issue. And then we make the appropriate referral to the health department. Otherwise, we don’t. Then we assess competency. Has
there been a sudden change. But you know, if it’s always been that way, chances are it’s always, it’s gonna remain that way. So is there any competency issue?” (p. 1)

Examples workers gave of not substantiating self-neglect allegations when the person is making a lifestyle choice rather than experiencing a decline because of impaired decision-making capacity included:

**R10**: not substantiating when capable and you gather history that their ADL’s fit a pattern and is the norm for them (p. 4)

**R10**: not substantiating cases when the person has full mental and physical capacity and it’s a lifestyle choice, a pattern, not a decline because of incapacity (p. 3)

**R16**: “And, I think a lot of times, too, if it’s, how somebody has always lived? I think that’s [substantiating self-neglect] a little harder call. If this has been their lifestyle their whole life, this is not a drastic change, it’s not a sign of something going wrong or a cognitive decline.” (p. 2) “Versus somebody who’s maybe always having hygiene issues. ‘N you know, that’s kind of where it gets iffy and do you call it self-neglect or is it, you know, just a lifestyle?” (p. 2)

One worker noted that lifelong lifestyle choices may become a crisis due to having dementia and no longer being able to articulate understanding of risks:

**R7**: “Maybe that is the way they’ve lived all their life, but because they can no longer advocate for themselves and speak for themselves, it still becomes a crisis. And then it’s hard sometimes as an APS, maybe they have lived that whole way, but now because they can’t speak their needs, it becomes...I have to go in and say ‘Well, whether you’ve lived this way or not, this still is not right.’ And try to put some services into place.”(p. 2)

**Respecting competent people’s right to make decisions/lifestyle choices**

Nine APS workers made a total of 21 references to respecting competent people’s right to make decisions and lifestyle choices. Workers consistently expressed the importance of honoring competent peoples’ right to self-determination. [See also “honoring client’s wishes and self-determination” and “honoring people’s right to refuse services” sub-categories under “actions needed” category] Dimensions of this property included: choosing to live in an environment with problems doesn’t mean you’re unsafe,
people having the right to self-determination when they can demonstrate understanding of the risks they’re taking, respecting competent people’s lifestyle decisions even when workers would prefer they make different decisions, and erring on the side of self-determination if you don’t have enough information. Examples workers gave of these dimensions included:

**R7:** choosing to live in an environment with problems doesn’t mean you’re unsafe (p. 3)

**R7:** “As long as they understand the consequences of their actions...that’s their decision.” (p. 1)

**R12:** “If they understand the risk...then, I believe, they have the right to self-determination. And it all comes down to risk and consequences, and their ability to understand that.” (p. 11)

**R2:** “But if the person is capable of understanding the decisions that they making regarding their lives, if they are of their right mind, if they are not putting somebody else at risk, if they’re not putting themselves at risk unknowingly, if they are making theses decisions because this is what they are capable of doing and they understand this, sometimes we have to say we can not force these people to live differently because we’re uncomfortable with it.” (p. 6)

**R5:** “For me it’s all about cognitive status. Even if I disagree with your choices, if you are alert and oriented and are making this decision, whether I agree with it or not, it’s your right to do so. And it’s an ongoing battle.” (p. 18)

**R5:** “If you’re able to make that decision and you understand it...you know? I may think living there is the worst idea ever, but if you’re okay with it and you understand it, I have to support it. Whether I’m comfortable with it or not.” (p. 18)

**R8:** respecting competent client’s right to make decisions: if a person is demonstrating some understanding of APS questions, we have to respect their rights and leave if they ask us to (p. 7)

**R8:** if a senior can articulate a reason for her decisions and you can tell that their cognitive status is intact and you call their doctor to make sure the person is still capable of making their decision, then you have to respect that (p. 13)

**R10:** “They are people that do have the mental and physical capacity, especially mental capacity, to make decisions and are aware of alternatives, but choose not to do that. They want to live their own lives the way they do.” (p. 4) “So when we come across those type of people that have that, you know, more capacity, mental and physical capacities, where they can get out, they can get on the bus line, they can call the cab, they can physically leave their homes, they can walk and, you
know, those are the ones that I would not substantiate because that’s kind of a life choice for them. And it’s not due to a decline or an impairment or some type of incapacity that I felt blocked their ability.” (p. 4)

**R11**: competent clients making bad decisions: “You know, but many times I have a lot of clients who make a lot of bad decisions, but even doctors have found them to be competent. But yet every day someone’s callin’ me about something crazy that they’re doin.’ You know. But they’re competent.” (p. 10)

**R7**: having mixed feelings about substantiating self-neglect allegations in cases where people understand the consequences of their lifestyle choices: “Those are those cases where, again maybe it’s a lifestyle choice? They are living in filth but as long as they understand the consequences. That doesn’t mean I don’t want to help? But I can’t necessarily ‘cause they can still make their own choices.” (p. 4)

**R8**: “…[cognitively intact adults] might be self-neglecting themselves but their own self-determination comes into play and you have to allow them. It may not be agreeable to me, and maybe in beliefs I may feel that this is not my standard way of living? But again, everybody has their own values, their own way that they want to live. So you have to respect that. Especially since they’re adults.” (p. 14)

**R13**: respecting their decision when they’re knowingly self-neglecting (p. 7)

**R8**: respecting competent client’s right to “…choose not to go to the doctor, they choose not to take the medication, they choose to live in a deplorable situation.” (p. 14)

**R3**: “…if they know what the consequences are, then you know, that overrides safety in my eyes.” (p. 16)

**R7**: maybe that’s the way they choose to live (p. 4)

**R10**: erring on the side of self-determination when you don’t have enough info (p. 15)

**Respecting competent people’s rights to decline services**

Six APS workers made a total of 15 references to respecting competent people’s rights to decline services. This property was distinguished from the property “respecting competent people’s right to make decisions/lifestyle choices” because enough workers specifically mentioned it to merit separate analysis. Dimensions of this property included APS not having the authority to intervene when competent people decline help, workers observing people declining specific services, and workers discussing possible underlying
reasons people may have for declining services. These reasons included the current cohort of seniors valuing taking care of themselves, not wanting to ask for help, not wanting to accept welfare, not seeing the need for the services, not wanting to be considered homebound, and not wanting people telling them what to do. One worker implicitly acknowledged the rights of competent people to decline intervention when she described not seeing enough impairment to be able to take action in some cases where people are self-neglecting. Specific examples workers gave of these dimensions of respecting competent people's rights to decline services included:

**R12**: not having the authority to intervene when competent people decline help (p. 4)

**R11**: “[if] the person’s competent ‘n they don’t want any help, we walk away. You know, that’s our job.” (p. 6)

**R3**: “And they can choose to decline that service.” (p. 2)

**R8**: having the right to make the decision to decline cleaning services (p. 8)

**R2**: “…there’s the loopholes of the customer themselves who don’t want the services, don’t need the services.” (p. 9)

**R14**: “I may see that they have no food, that they’re living in squalor and poor conditions, but yet they’re competent and I can see that they’re vehemently saying, ‘I don’t want this stuff. I don’t want the county, I don’t want Meals-on-Wheels. I don’t want a homemaker.’” (p. 3)

**R2**: “We’re dealing with a generation who many, many, many never would have asked for help, never would expect somebody else to step in and take care of a thing that they’ve always been able to take care of.” (p. 4)

**R2**: Sometimes you have people who flat out do not wanna take welfare. Second of all, sometimes you have people who are, it’s- it doesn’t have anything to do with the fact that it’s welfare, but it’s the fact that they’ve always done for themselves, they don’t feel proper in asking for help. And they- sometimes they don’t see that they need the help that we perceive that they need.” (p. 4)

**R2**: “We’ve had people who say ‘No, we don’t want Meals-on-Wheels, there’s other people that need it more than we do.’ It’s not a matter of if you take it somebody else can’t get it... But sometimes there’s no changing their minds.” (p. 5)
**R2**: refusing Meals-on-Wheels due to not wanting to be considered homebound: “I’m not homebound. I don’t wanna be considered homebound.’ That’s a big thing.” (p. 11)

**R2**: “Some people hoard, are aware of the conditions, the smell, that kind of thing, and they don’t want somebody coming in and reporting them or getting them in trouble, or telling them to change their lifestyle.” (p. 12) “And that kind of goes across the board for a lot of hoarders. They don’t want somebody comin’ in tellin’ them to do this and that and that and this.” (p. 12)

**R14**: not seeing enough [impairment] to be able to take action in some cases where people are self-neglecting (p. 2)

**Observing “cover-up techniques” being used to mask cognitive impairment**

Four APS workers made a total of seven references to observing people using cover-up techniques to mask cognitive impairment. Dimensions of this property included workers observing people covering for being unable to answer mini-mental state questions and workers’ identifying possible underlying reasons for people trying to cover cognitive impairment. Workers suggested that people try to cover their cognitive impairment because they don’t want anybody to know self-neglect is occurring or because they are afraid of APS workers. Workers gave the following examples of observing people using cover-up techniques to mask cognitive impairment:

**R3**: “They might tell me in one sense that they know what’s goin’ on, and then you ask ‘em a couple more questions with the...mini-mental, say, and they’re confused, they don’t know their birthday, they don’t know who’s the president. But then they come back with ‘Well, I don’t watch TV,’ ‘Oh, I’m an old person, I don’t keep track of my birthday anymore’ kind of...these cover-up techniques.” (p. 6)

**R12**: “They can follow general conversation, and cover very well, but when you ask for details, they can’t remember.” (p. 2)

**R6**: “...and this one client in particular, is excellent at covering. And she knows how to answer and then how to divert you off to a different subject. So, I mean that’s just the biggest tip-off that there’s self-neglect going on, that she’s really not takin’ care of herself. ‘N she doesn’t want anybody to know or she doesn’t know she’s, she’s neglecting herself.” (p. 5)

**R10**: “They’re afraid of us. So what they do is, and it’s crazy, but they’ll pull it together just enough and they’ll know the answers to give you?” (p. 5)
Table 4
Assessing Decisions about Hygiene and Health Care
(A Sub-category of the Central Category “Assessing Decision-making”)

<table>
<thead>
<tr>
<th>Properties of Assessing Decisions about Hygiene and Health Care</th>
<th>Number of APS workers mentioning property (n=16)</th>
<th>Number of references per property</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appearance/personal care decisions [hygiene/toileting/clothing/grooming]</td>
<td>15</td>
<td>85</td>
</tr>
<tr>
<td>Decisions about medications [compliance, understanding, ability to self-administer medications]</td>
<td>14</td>
<td>75</td>
</tr>
<tr>
<td>Eating decisions</td>
<td>14</td>
<td>71</td>
</tr>
<tr>
<td>Health care decisions/Ability to explain health strategies and possible consequences</td>
<td>14</td>
<td>62</td>
</tr>
<tr>
<td>Physical health and ambulation</td>
<td>6</td>
<td>26</td>
</tr>
<tr>
<td>Decisions about utilizing home-health services</td>
<td>5</td>
<td>16</td>
</tr>
<tr>
<td>Smoking decisions</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td>Possible Urinary Tract Infection (UTI)</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>Possible depression/mental health needs</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Driving decisions</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Imminent medical risk</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Alcohol abuse</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Ability to develop adaptive alternatives when health/hygiene barriers arise</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Decisions about dying at home</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Other properties [see compiled group data for remaining properties]</td>
<td>7</td>
<td>19</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>16</strong></td>
<td><strong>411</strong></td>
</tr>
</tbody>
</table>

ASSESSING DECISIONS ABOUT HYGIENE AND HEALTH CARE

All 16 workers participating in this study mentioned assessing decisions about hygiene and health care. Participants made a total of 411 references to 25 different
properties of this category. Dimensions are presented here of the nine properties of assessing decisions about personal health and hygiene mentioned by four or more of the respondents participating in this study. Together these nine properties account for 87% of participants’ references to assessing decisions about hygiene and health care. These nine properties are: 1) assessing appearance/personal care decisions, 2) assessing decisions about medications, 3) assessing health care decisions/ability to explain health strategies and possible consequences, 4) assessing eating decisions, 5) assessing physical health and ambulation, 6) assessing decisions about utilizing home-health services, 7) assessing smoking decisions, 8) assessing for possible Urinary Tract Infections (UTI’s), and 9) assessing for possible depression/mental health needs. Corresponding with table 4, properties are presented in the order of how frequently they were mentioned by APS workers. Complete group data of all 25 properties of assessing decisions about personal health and hygiene are presented in the appendix.

Assessing appearance/personal care decisions

Assessing appearance and personal care decisions was the most frequently mentioned property in the category of assessing decisions about personal health and hygiene, accounting for 21% of all references in this category. 15 APS workers made a total of 85 references to assessing appearance and personal care decisions. Workers presented seven dimensions of this property: assessing overall physical appearance, assessing personal hygiene decisions, assessing clothing decisions, assessing toileting decisions, assessing level of awareness of personal care, assessing if poor grooming is a life-long lifestyle choice or a lifestyle change, and recognizing that that more affluent communities have higher standards for what they consider to be acceptable personal grooming. Examples workers gave of assessing overall physical appearance included:

R5: assessing physical appearance (p. 3)
R11: “If they let me in, of course the first thing I do is look at the client, their physical condition. If they have any outward medical problems that I can see. How they’re dressed, what they smell like, what they look like, hygiene.” (p. 1)

R13: “Well, we’re- one of the first things we’re gonna look at is their appearance. If they’re poorly laundered clothing, dirty nails, if there’s a body odor, things of that nature, which would indicate things of self-neglect.” (p. 1)

R3: “Are they able to, you know, how are they caring for themselves?” (p. 1)

R15: “Are they taking care of themselves.” (p. 7)

R7: assessing elder self-neglect by looking at the individual themselves (p. 1)

R15: a lot of times on self-neglect they’re not taking care of themselves (p. 4)

R1: typical case of self neglect: “Typically they’ll be dressed inappropriately for the season, they’ll be disheveled, clearly not able to take baths for themselves, you know, as evidenced by their body odors, their hair being matted, things like that.” (p. 1)

R5: sudden weight loss (3 references, p. 8, 8, 10)

R13: observing bite marks from spiders (p. 10)

Workers presented a variety of themes within the dimension of assessing personal hygiene decisions. These themes ranged from smelling people, to looking at their hair, fingernails and teeth, to assessing bathing decisions, to discussing poor hygiene as a factor considered when deciding to substantiate or not substantiate allegations of self-neglect. Specific examples workers gave of these themes included:

R10: assessing alleged medical issues and hygiene issues (p. 1)

R2: “…do they look like they’re maintaining their personal hygiene…” (p. 1)

R14: looking at hygiene (p. 1); looking to see if they’re clean (p. 1)

R16: looking at their personal hygiene; finding poor hygiene (both p. 1)

R2: smelling the person (p. 3); smelling bad (p. 4)

R2: looking at hair and nails (p. 3)

R5: dirt of feces under fingernails (p. 7); long nails (p. 7)
R2: assessing teeth (p. 4)

R5: assessing bathing (2 references, p. 6, 7)

R15: addressing urine odor by asking “How often do you bathe?” (p. 1)

R4: resisting baths (p. 6)

R11: poor hygiene but healthy otherwise is unsubstantiated (p. 4)

R14: “So hygiene and cleanliness is not always a huge factor.” (p. 4)

R16: substantiating for poor hygiene, not substantiating when hygiene is good (p. 1)

When discussing the dimension of assessing people’s clothing, workers consistently described the two dominant themes of observing people wearing soiled clothing and observing people wearing the same clothing for several days. Specific examples workers gave of these themes included:

R1: wearing soiled clothing, poor grooming (p. 6)

R5: wearing soiled clothing (p. 7)

R1: seeing them in same clothes on second visit and asking “How often do you do your laundry?” (p. 4); case example of wearing same soiled clothing on second visit (p. 7)

R2: old food stains on clothing “might indicate they’ve not changed their clothes for quite some time.” (p. 3)

R1: wearing same clothes for many days (p. 3); wearing soiled clothing for days (p. 4)

R2: if “...every day you see them they’re in the same clothes, then you know that there’s an issue there.” (p. 3)

R12: “You’re looking are the clothes clean or dirty? Are they wearing the same clothes they were wearing when you came here last time?” (p. 2)

When discussing dimension of assessing people’s toileting decisions, workers described the themes of assessing toileting ability, assessing how people handle toileting barriers, and assessing how people handle incontinence. Specific examples workers gave of these themes included:
**R2**: case example of a physically ill person demonstrating toileting: “...she could stand up, literally urinated in a cup. And was dumping it out her bedroom window. Yeah. She knew what she was doing.” (p. 14) “She wasn’t urinating in the bed. She wasn’t laying in filth.” (p. 15)

**R2**: case example: depending on aids for toileting “She had to wait on the aids to get there, if the aids didn’t show up, she couldn’t go to the bathroom. She was still in total control of her bodily functions.” (p. 7)

**R8**: case example of assessing for referral concern of incontinence and not observing or smelling evidence of incontinence (p. 7)

**R8**: handling incontinence by getting supplies such as Tucks, Depends (p. 8)

Several workers identified the importance of assessing people’s level of awareness of their personal care, with a lack of such self-awareness being mentioned as an indicator of self-neglect. Specific examples workers gave included:

**R11**: do they know they haven’t bathed and smell bad? (p. 2)

**R8**: case example of a person being totally incontinent and being aware of it (p. 9)

**R6**: not recognizing clothing has holes in it or is falling apart (p. 3)

**R2**: case example: “But you go into the situation and, the woman is saying things like ‘Oh this is my best housecoat’ and it is literally, one, see-through, two, it is, hardened and stained from, uh, bodily functions kind of thing. Fecal and urine. When her- You look at her, her socks and they’re literally attached to her body because they’ve been on there for so long. When you can see things that you know she’s not processing. She’s thinking that she’s going to the bathroom properly and that she’s, she’s clean and- When you go into the home and the source of a smell is so horrid, and it’s the person, and the person doesn’t realize it, that’s pretty obvious.” (p. 16-17) “The hospital took off her clothes, photographed her clothes.” (p. 17) “They actually had to...the socks, you know...They were a part of her skin, pretty much, by the time they went to peel them off of her. Her feet were just...there was...now remember, she had socks on her feet. There was fecal matter under her toenails. And she’s not aware of it. You know. And this woman was in very, very, very bad physical sh[ape]. Her hair was matted to her scalp. They didn’t think they were gonna be able to get her hair clean, it was that attached. And I don’t mean the follicles attached to her hair, I mean the ends of her hair that should have been brushable were attached to her scalp. When you go into a situation and it’s that obvious, and sometimes it might not be that obvious, but you can see after, you know, when you’re talking to people, there are problems.” (p. 17)
Workers also identified the importance of assessing if poor grooming is a lifelong lifestyle choice or a lifestyle change. Specific examples workers gave of this theme included:

**R12**: “And you also have to determine if this is something— a new behavior for a client? Or if this is some way they’ve lived their whole life. You might go in, and this person might have dirty clothes on, and their house might be a mess, but that was kind of the conditions they grew up in, and that’s not unusual for them. [Interviewer: “lifestyle.”] It’s a lifestyle. It’s a choice that they’ve lived their whole life, and that’s not out of the ordinary for them. To wear the same clothes four days in a row…” (p. 3)

**R16**: assessing change in hygiene habits “Versus somebody who’s maybe always had hygiene issues.” (p. 2) personal example: worker’s grandmother who was recently diagnosed with dementia had always been very neat and began having body odor which was a change for her (p. 2)

**R3**: “People are allowed to be dirty. People are never gonna die from bein’ as dirty as however they wanna be.” (p. 4)

Finally, one worker noted that more affluent communities have higher standards for what they consider to be acceptable personal grooming:

**R3**: case example of a person wearing clothing with some stains and urine smell in an affluent neighborhood: “So they [affluent suburban area counseling center] call in ‘n say ‘Hey, she’s confused. She’s, you know, not washing her clothes...’ (p. 4); “I talked to her about some stains on her clothes, she was embarrassed about it, she didn’t know...Well if, you know, I wear the same clothes over and over, maybe I had an accident and that, you know, I missed it.” (p. 4)

**R3**: affluent suburban standards creating a “big problem” when there really isn’t one (p. 4)

**Assessing decisions about medications**

14 APS workers made a total of 75 references to assessing decisions about medications. Themes workers presented of assessing decisions about medications included: assessing a person’s medication regime, assessing a person’s understanding of prescribed medications, and assessing medication compliance. Dimensions of the theme of assessing medication compliance included: assessing a person’s access to getting medication, assessing the ability to self-administer medications, recognizing that
medication compliance is not always a matter of life or death, and recognizing that competent people have the right to not take prescribed medications. Specific examples workers gave of assessing people’s medication regime included:

**R5**: two references to assessing meds (p. 3, 7)

**R9**: trying to find out what medication they’re on (p. 1)

**R12**: “Assessing what kind of medications they’re on.” (p. 2)

**R13**: looking at medications (p. 1)

**R15**: asking “Do you take any kind of medications? What *are* you taking?” (p. 1)

Examples workers gave of assessing people’s understanding of their medications included:

**R8**: making sure clients completely understand the repercussions of their situation, ex: asking “What may happen if you don’t take your medication?” (p. 13)

**R12**: assessing if “They can tell me who their doctor is, if they know what their medications are, if they know why they take them, and those type of things.” (p. 2)

**R6**: case example of an unsubstantiated referral for medical problems and medication non-compliance where the person was actually found to be well aware of her medical treatment needs and medications: “I had an allegation of a woman who was in dire straights, that she wasn’t taking care of her diabetes, *wasn’t* takin’ her medication, *wasn’t* checkin’ her blood sugars.” (p. 5) “And it was just so obvious that she knows exactly what’s going on, she *knows* all her doctors’ names, she *knows* all her medications.” (p. 5)

Dimensions of assessing medication compliance included: assessing people’s access to getting medications, assessing their ability to self-administer medications, recognizing that medication compliance is not always a matter of life or death, and recognizing that competent people have the right to not take prescribed medications.

Examples workers mentioned of assessing access to getting medications included:

**R3**: assessing “are they able to get to their medications.” (p. 1)

**R7**: assessing if they’re getting their medication and getting to the doctor (p. 2)
**R2:** “...are they prescribed, can you get the medications, can you manage them yourself. And a lot of times, if the person is open enough they’ll even talk to us about, you know, ‘We have them set up.’ and ‘This is my way of taking it, make sure I take it...’” (p. 2)

**R16:** “A lot of the self-neglect referrals we get are from med-noncompliance, so talk to them about, you know, medications, how do they get those medicines, you know, does somebody help set them up, that type of stuff. Do they have the money to pay for their prescriptions, ‘cause that’s often a big issue with seniors.” (p. 1)

**R16:** worker having mixed feelings about substantiating self-neglect for medication non-compliance when the underlying cause of the non-compliance is poverty: “I think those are the ones where it’s an issue of some, the medication compliance fees, where you’ve got folks who probably would be very compliant with medications if they could afford them. If they could afford the co-pays, that type of stuff. ‘Cause to me that’s, that’s self-neglect, but it’s based on they really don’t have the resources, so...” (p. 2)

Dimensions of assessing the ability to self-administer medications included:

- assessing how people keep track of their medications, recognizing that the inability to self-administer medications is typical in cases of self-neglect, and case examples of how a person’s inability to self-administer medications might or might not result in the inability to remain living independently in the community. Specific examples of this dimension included:

  **R11:** assessing if they’re able to take meds (p. 4)

  **R13:** assessing ability to self-administer medication: “Also, we’re gonna look at their medications and see if they’re able to- if they have their own system set up? As far as a pill box? Or if they’re dealing with the bottles, to see how those are, and see if they have a full understanding of how its supposed to be administered?” (p. 1)

  **R13:** case example of a person using their homemaker to help with meds (p. 7)

  **R15:** “A lot of times on self-neglect it could be they’re not following through with their meds, they’re not eating very well, or they’re not taking care of themselves.” (p. 4)

  **R4:** [in typical cases of self-neglect] “…medications are a mess.” (p. 1)

  **R3:** case example of not forcing a person with questionable competency out of their home who was not able to take medications as prescribed but was able to keep up a daily routine (p. 7)
R12: “I have a client who was self-neglecting, she was getting’ her medication mixed up and not taking it properly. The difference with her was, she was hallucinating, and thinking that there were demons, and people coming in her house, and doing things to her, and, so when she took her medication? She wasn’t seein’ that. ‘N it was all potassium level. It was all medical.” “And then her levels were off, and I kept trying to get her to take her medicine. She could not take it properly. And so, she couldn’t maintain in that situation [independent living]” (p. 10)

Several workers identified that medication compliance is not always a matter of life or death and that they do not make an issue of it when people’s choice to not take medications does not pose a serious immanent risk. Specific examples of this dimension included:

R11: medication compliance is not always a matter of life or death (p. 5)

R12: “Like if somebody’s not takin’ their medication, and there’s medications that you cannot take and it’s not life or death, so, you know what, I’m not gonna fuss about that. But if it’s something that’s gonna be life or death, and you’re just messin’ up and it’s makin’ you confused...” (p. 10)

R4: “Medications; are you taking your medications? And if you aren’t? Does it really matter if you’re not? Are they life-threatening medications? Because if they’re not...It’s not [self-neglect]. It’s not presenting a serious threat to you, you know? And again, if you’re not taking your medications and there’s no issues of competency, nothin’ I’m gonna- you know.” (p. 1)

Finally, APS workers consistently stated that competent people have the right to not take prescribed medications. Two workers provided examples where self-neglect allegations regarding medication non-compliance were not substantiated because the people were able to explain their decisions to treat themselves with herbal or home remedies rather than physician-prescribed medication. Two workers provided case examples where self-neglect allegations were substantiated in part due to uninformed medication non-compliance. Specific examples workers gave of competent people having the right to not take prescribed medications included:

R8: cognitively intact people can choose to not take medication (p. 14)
**R12**: competent people being competent to neglect themselves by not taking meds (p. 4)

**R12**: “Not taking medications. And people have the right to refuse medication. You just have to see if they know what the medication is, why they’re prescribed it, and again ask ‘Why aren’t you takin’ it?’ “Well, it makes me feel funny.” ‘Did you tell your doctor that? You know, there might be a different alternative you could use.’ Or, it could be that ‘I don’t believe in medicine.’ And you have to determine whether it’s a memory problem? Or whether they actually have a good valid reason for- ‘cause people have a right to refuse. And so, it’s just a matter of determinance of these competencies versus the cognition.” (p. 3)

**R12**: “And so, yeah, if they know what the consequences are? There’s nothing we can do to intervene. If you can say, ‘Well, yeah, you’re not taking this medication. If you don’t take this medication, what can happen to you?’ ‘Oh, doctor said I could die’ or ‘He’s gonna put a pacemaker in me.’ ‘You know what that involves. Are you willing to take that risk?’ ‘I’m not takin’ that medication.’ ” (p. 3)

**R4**: assessing medication non-compliance when medication management assistance is in place: “When we do have somebody in there to sort meds. And at that point, I don’t know so much if it’s resistance, or they’re right on that border again with dementia, or they’ve crossed the line. That they’re not purposely or intending to not be compliant with their medications...” (p. 6)

**R13**: case example of a person understanding the ramifications of selling his pain medications and giving the money to his younger female caretaker but not seeing that he was self-neglecting by not taking his medications as prescribed: “It was some sort of pain medication. And he knew that he needed to take it. But at the same time he also, he would like to sell some part of his medications, and then allow her to have the money, go out on a date, that sort of thing. So, I was kind of torn there, ‘cause I knew that he understood the ramifications of it? But he didn’t see the undue influence that was goin’ on, and the fact that he would be neglecting his self as far as, you know, take- getting his meds the way they were prescribed. You know, I think he was kind of clouded as far as making decisions regarding that matter, but he did not want any intervention from us, as much as I tried to advocate. And I always felt a little torn about that.” (p. 3)

Examples workers provided where self-neglect allegations were not substantiated because the person could explain her medication decisions included:

**R3**: example of not substantiating allegations of self-neglect on a competent person not take prescribed medications [preferring herbal remedies]: “A person not choosing to take their medication. Says ‘You know what, the doctor told me to take this medications for my heart. Well I’m gonna take, you know, some herbal remedies, where I’m drinkin’ my tea everyday.’ Well, you know that person needs some stronger medications, per what the doctor orders. And the person says ‘No, I’m just gonna drink my tea and if I die, I die.’ I’ve had people knowing that they’re gonna die in a certain short amount of time. It’s their right to, you know,
say ‘I don’t wanna continue on with medical care’ or-, because they know what the situation is.” (p. 5)

**R13**: case example of not substantiating self-neglect on a referral allegation that a person wasn’t taking medications [preferring home remedies]: “‘We got a referral, the person was concerned the person wasn’t takin’ their medications. We went out there, the person was very aware of, well aware of whether or not, what the consequences were of taking them versus not taking them. This person preferred to do their home remedies, there were some religious aspects there. So we really understood that they were aware of the consequences, they wanted to take alternative methods, so we allowed them to have their self-determination, and we did not substantiate the self-neglect because they had very justifiable reasons for not wanting to take certain medications and knew what the consequences of those were.” (p. 2)

Case examples workers provided where self-neglect allegations were substantiated due in part to uninformed medication non-compliance (being incapable of taking medications properly as opposed to choosing to not take medications) included:

**R6**: case example of substantiating self-neglect allegations due in part to uninformed medication non-compliance: “And while I was talking to her, I found out, you know, she had medications…but she didn’t know where they were. I went and found them. There’s a doctor’s name on ‘em and the majority of them were old and she wasn’t taking ‘em.” (p. 4) “...it came out that she makes her own decisions on whether she takes her pills or not, ‘n then she hides some of ‘em. For whatever reason, I have not- I do not know why she was hidin’ some of ‘em.” (both p. 4)

**R13**: case example of substantiating self-neglect allegations on person with questionable competency not taking meds as prescribed: “Her medications, because the writing was so small on them she was just goin’ by feel of the pills? And of course, all the pills were about the same size, so she, you know, she was either over or under medication. Also there was an issue with her competency.” (p. 2)

**Assessing eating decisions**

14 APS workers made a total of 71 references to assessing eating decisions.

Dimensions workers presented of assessing eating decisions included: assessing people’s access to food, assessing eating habits, assessing food safety decisions, and assessing decisions about accepting home-delivered meals. Specific examples workers gave of assessing people’s access to food included:
workers presented several themes within the dimension of assessing people’s eating habits. These themes included: observing self-neglecting people not eating, methods they use to assess people’s eating habits, assessing people’s understanding of their eating habits, and trying to figure out reasons why people aren’t eating. Specific examples workers gave of observing that people alleged to be self-neglecting are often not eating well included:

- R15: a lot of times on self-neglect they’re not eating well (p. 4)
- R8: case example of client not eating (p. 9)
- R1: two case examples of clients not eating (p. 6, p. 22)

Workers described three methods of assessing a person’s eating habits: physical observation of the person, physical observation of food in the house (discussed previously), and directly asking the person. One worker noted that when asking people about their eating habits you have to be specific in your questions, for example asking, “What did you eat?” rather than “Did you eat?” Examples included:

- R14: looking at their weight and height to see if they’re getting nourishment (p. 1)
- R1: case example of someone appearing thin and fragile (p. 8)
R15: asking “What did you have for breakfast this morning?” (p. 1)

R12: “You can ask ‘Did you eat this morning?’ and they can tell you, ‘Yes.’ But if you ask them ‘What did you eat?’ a lot of them won’t remember. So you have to be a little bit more specific about what your questions are, ‘cause a lot of ‘em’ll say ‘Oh yeah!’ ” (p. 2)

One worker described how a person’s understanding of his eating habits influence what actions the worker will take:

R14: substantiating self-neglect in part due to having no food: “Well, that I saw that they were, the allegation that I saw there, it did exist. Like they didn’t have any food. Their refrigerator was full of rotten food. Sometimes they may not have insight into what they can do. Poor judgment. So if the referral matches what I’ve seen, then that would be substantiated. And then, it’s the outcome that is sometimes different. So, let’s just say, like, so...I may see that they have no food, that they’re living in squalor and poor conditions, but yet they’re competent and I can see that they’re, they’re vehemently saying ‘I don’t want this stuff. I don’t want the county, I don’t want Meals-on-Wheels. I don’t want a homemaker.’ Then the allegation will be substantiated but there’s really not much I can do about it. So, therefore, the case would then be closed.” (p. 3)

Workers provided several assessment areas to consider when exploring possible underlying reasons for people not eating enough. These assessment areas included:

- assessing access to food, assessing whether not eating well is a new behavior or a life-long pattern, for example exploring if there has been a change in the taste of food,
- assessing if they understand that their eating is unhealthy, and assessing if not eating much food is a choice or an issue of capacity. Workers pointed out that metabolic changes from decreased activity may reduce hunger and that loneliness at mealtime may decrease people’s interest in eating. One worker noted that poor nutrition might be an underlying cause of disordered thinking. Examples of these themes included:

R12: “Some of the other issues with self-neglect we’ve dealt have been just not eating well, not feedings self properly. And you have to figure out is it an appetite thing? Could it be medical? Is it that they’re forgetting to eat? Is it that they don’t have a way to the store to get food? There’s- you just have to ask “Why? Why are you not eating?” And, and you can usually figure out that way. And you also have to determine if this is something- a new behavior for a client? Or if this is some way they’ve lived their whole life.” (p. 2-3)
R11: “Either they just don’t see the need for it, or they’re incapable of. And that’s the crux of what we do is to decide their competency. Do they understand that this is unhealthy? Are they confused? You know, do they appear to not, you know, remember when they la- ate, ate last? Or, you know how they- how do they get their food? They can’t tell me. You know, when I see a level of confusion, and I see the physical signs of neglect, then that together would make me substantiate. Yeah.” (p. 3)

R5: asking “Do you not feel like eating? Have you not felt well? ‘Oh, I just don’t feel like eating,’ or you know, if they’re not, if they’re not moving very much, their metabolism gets very low and they just don’t feel like eating. Or if there’s something that’s changed, the food doesn’t taste good?” I’ve- Lots of times we hear, ‘Well it just doesn’t taste right.’ ” (p. 8)

R15: “…well, the eating. If, if an individual had somebody to prepare a decent meal for them, they would be better off. Nobody want- A lot of times they don’t wanna eat alone. So they choose not to eat at all. But if somebody was there at the time they were eating, and sat down and ate with them, they wouldn’t have a problem with it.” (p. 6)

R15: assessing nutrition as possible cause of disordered thinking (p. 4)

Workers’ discussion of assessing food safety decisions focused on assessing food refrigeration and storage decisions [see property “assessing fire safety risks” under “housing” sub-category for references to unsafe use of the stove]. Examples workers gave of the dimension of assessing food safety decisions included:

R12: “Same thing with food in the house [assessing competence by people’s responses and conversation]. I’m checkin’ to see if it’s spoiled. I have a lot of clients with advanced dementia who will put things in the refrigerator that don’t belong in the refrigerator.” (p. 2) “Well, some people will keep like cold cereal in the fridge. I’ve found the clothes in the fridge before. You know, yeah, just things that don’t really go in the refrigerator. Often times, like crazy stuff. Cans that aren’t opened, or I will find, I know a lot of times, like they’re- you’ll find spoiled meat out on the counters. People aren’t refrigerating things that should be refrigerated. They’ve got milk that’s been in there for over a month, sour, you know, things that they could get really sick off.” (p. 2)

R14: substantiated case example of refrigerator full of rotten food (p. 3)

R14: thinking they can cook when they can’t (p. 6)

Eight workers specifically discussed people’s decision about accepting home-delivered meals. Workers described home-delivered meals as being both the most accepted and the least accepted service offered. Workers identified several reasons for
people not wanting home-delivered meals, including: not liking how they taste, not wanting to pay for them, not understanding that they are eligible to receive them based on their income, thinking that they are for “other [needier] people,” and not wanting to be considered “homebound” or unable to cook for themselves. One worker described offering people two different options of home-delivered meals, delivered fresh daily or delivered frozen weekly. Examples of these themes included:

**R3**: Meals-on-Wheels being the most accepted service (p. 12)

**R4**: most seniors accepting Meals-on-Wheels (p. 7)

**R16**: “And I think the most accepted [service] is always the Meals-on-Wheels.” (p. 3)

**R1**: case example of accepting Meals-on-Wheels (p. 7)

**R15**: “The most accepted [service] is the home-delivered meals. And I give ‘em two choices. We have, we may have the senior center, which they’ll tell us they don’t like. Which is, now our senior center is Monday through Thursday they had to cut a day. There’s also, through Columbus, a place called Simply EZ? And they will come in with a week at a time with frozen meals. Well, a lot of individuals have chosen that it’s better. And then they can choose what they want that day, or what piece of it that they want that day, since they’re not eating as much, and they like it better. So I have brochures, and I give that to them and show them what, what that looks like. So they have that choice.” (p. 5-6)

**R14**: they tend to like Meals-on-Wheels but may not want to pay for it (p. 6)

**R9**: Meals-on-Wheels being the most accepted and most rejected service: “‘Cause either they like ‘em a lot and they’re savin’ ‘em money, or ‘I don’t like ‘em.’ They don’t taste right because they’re diabetic, they don’t have any spices...” (p. 6)

**R1**: “I think the service that’s probably resisted, that they resist, would be, believe it or not, I would say, Meals-on-Wheels.” (p. 14) “People don’t want Meals-on-Wheels because they don’t think that they, they’re not appealing to their palate. I’ll say that.” (p. 14)

**R2**: “If they refuse Meals-on-Wheels it’s for reasons like ‘I don’t like their food.’ ‘I don’t wanna pay the money.’ ‘I don’t- I’m not homebound. I don’t’ wanna be considered homebound.’ That’s a big thing.” (p. 11)

**R2**: [accepting Meals-on-Wheels is] “Half and half. Half and half. Sometimes it’s a matter of ‘Oh, well I never thought about that.’ ‘Oh, well, um...’ A lot of times it- If they want it, it’s not a problem. Sometimes they don’t want it because they
think it’s gonna cost too much money. They don’t understand that it’s a donation-based program. Sometimes they don’t understand that, you know.” (p. 11)

**R14:** “Food is a big issue. ‘Cause a lot of ‘em don’t know they can get Meals-on-Wheels. Or, they think it’s for other people than themselves. Even though their income might be just 500 dollars a month, and by the time you pay utilities that are- that we have in today’s world, that gives them nothing to live on. But they always think it’s for someone else.” (p. 1) “Even though their income would be below, way below, the poverty level.” (p. 1)

**R1:** “Yeah, they don’t like the meals. And I, and most people that I- when I do ask, because sometimes I can just get deep down and dirty and be like ‘Why? Why?’ and it’s like, they just think that-, I believe it’s taking away part of their independence from the cooking. You know what I mean? So, once you, once they get that meal, it’s like ‘What you tryin’ to say, I can’t cook no more?’ And I think that that really kind of affects them.” (p. 15-16)

### Assessing health care decisions

Fourteen APS workers made a total of 62 references to assessing health care decisions. Dimensions workers described of assessing health care decisions included: assessing decisions about treating medical conditions and seeing doctors, assessing people’s understanding of their health conditions and health care decisions, and observing that mental health and chemical dependency services are the most resisted health-related services.

Workers described assessing people’s decisions about treating specific medical conditions such as wounds, gangrene, diabetes, cellulitis, vision impairment, hearing impairment, and kidney dialysis. Workers also described assessing decisions about keeping medical appointments, calling the emergency squad, and discharging against medical advice from a care facility. One worker mentioned assessing health care decisions over time. Specific examples workers gave of assessing medical treatment decisions included:

**R10:** investigating alleged medical and hygiene issues (p.1)
R11: a lot of times probate referrals are based on medical issues, p. 8; ex: untreated open sore getting worse, p. 8

R1: case example of of not caring for wounds (p. 11)

R1: getting a lot of calls about people refusing to treat gangrene (p. 25)

R13: substantiated case example of having untreated medical conditions: untreated vision problems and having a ring imbedded in finger and infected (both p. 2)

R2: two case examples of not treating hearing loss: “I go up and talk to her, and she’s very hard of hearing, so this discussion is being yelled.” (p. 14); different case “The woman was, uh, very hard of hearing, she opened the door.” (p. 16)

R8: case example of client being unable to take care of self and knowing it but not wanting to go to the hospital, being extremely ill and needing medical attention but not wanting to go for it (both p. 9)

R12: case example of substantiating self-neglect allegations for a woman needing but not wanting hospice care (p. 5)

R8: 2 references to refusing medical attention (different cases, p. 9, p. 10)

R3: assessing medical treatment compliance: case example of not keeping medical appointments (p. 7)

R2: case example of not showing up for doctor’s appointments (p. 20)

R5: references to missing medical appointments: missing doctor visits, two references to missing kidney dialysis (p. 7,8, 9)

R6: 2 references to not wanting the emergency squad called: “seniors don’t like to call the squad” (p. 14); client getting mad because squad was called (p. 13)

R2: refusing the emergency squad: “We have been in situations where we’ve called the squad, the squad will come in, but if the person refuses, there’s nothing we can do.” (p. 18)

R2: case example of declining medical treatment from the emergency squad: “She goes [to the squad EMT] ‘Can you make me do anything?’ He said ‘No-o-o, unless you’re passed out.’ She goes ‘Well then you wait then till I pass out.’ ” (p. 19)

R8: case ex: of an older adult choosing to return home from a facility although unable to ambulate, get meals, dress, bathe, toilet self (p. 10)

R13: monitoring health decisions over time: “...there’s a point where you’re allowing them to make the decision, but if you see that it’s dragging on for a week...”
or two, and they’re physically getting worse, their interventions aren’t working, you know, I’ll tell ‘em. ‘Okay, you tried this…but it’s just not working...’” (p. 7)

Dimensions of assessing decisions about seeing doctors included: asking directly about people’s doctors, assessing how people are getting to their doctor, observing people refusing to see a doctor, and following up with people’s doctors to see if people with medical issues have been to see a doctor within the past year. Workers identified that people are often willing to accept home visits from doctors. One worker mentioned APS receiving calls from doctors on high-maintenance patients. Another worker pointed out that cognitively intact people can choose to not go to the doctor. Specific examples workers gave of these themes included:

**R3:** looking at if they’re going to a doctor (p. 1)

**R15:** 2 references to asking about seeing doctors: “Do you have a doctor?” (p. 1); addressing confusion by asking “When have you been to the doctor lately?” (p. 1)

**R2:** [assessing] “Medically whether they’re going to the doctor, do they have a doctor, how often do they see the doctor, when was the last time they saw the doctor...” (p. 2)

**R8:** cognitively intact people can choose not to go to the doctor (p. 14)

**R2:** “You have people who will not go to the doctor, to help with the assessment process, to help with the orders to get home health.” (p. 9)

**R2:** case example of refusing to see a doctor: “They [family client lived with] recognized that she needed to see a doctor. She refused to see a doctor. ...the doctor would not go into the home because the mother would not willingly be a patient. We actually finally talked her into it, but it probably was a month before we could.” (p. 18)

**R1:** case example of client’s sister providing transportation to see a doctor regularly (p. 18)

**R13:** following up with people’s doctors to see if people with medical issues have actually been to see a doctor within say the past year (p. 1)

**R13:** substantiated case example of not knowing where her doctor was located [among other issues] (p. 2)

**R6:** clients usually will talk to a visiting psychiatrist in their home even if previously refusing (p. 12)
**R2**: “And we do have doctors who will go to the home if they’re Medicare. But also those doctors hands are tied if the person’s refusing to see them” (p. 19)

**R7**: doctors calling APS for high-maintenance patients (p. 9)

Workers consistently discussed the importance of assessing clients’ ability to verbally explain their understanding of their medical conditions and the possible consequences of their health care decisions. Workers consistently pointed out that competent people can choose to refuse medical treatment. Workers described seeking court orders of protection for people making life-threatening health care decisions who were not able to explain the possible consequences of their decisions. Examples workers gave of this dimension of assessing health care decisions included:

**R8**: if a senior can articulate a reason for her decisions then you have to respect that, for example: “I don’t wanna go to the doctor...Because I’m not sick.” (p. 13)

**R10**: assessing ability to explain possible consequences of medical decisions: “Knowing the consequences. You know, I had someone who had a, you know, their leg had a huge wound on it and I’m like, you know, ‘Why don’t you go to the doctor.’ ‘Well ‘cause I don’t want to.’ ‘Well why not?’ ‘Because, you know, I’ve been to the doctor, it’s the same thing, it heals up and then it goes away, and I’m, I’m not gonna go.’ And then it’s like, well okay, but, what- and I always say, ‘Okay so if you don’t go to the doctor, what could happen? Tell me the consequence. And they’re like, ‘Well, you know, I could die.’ And I’m like, ‘Okay, so how do you feel about that consequence? I mean that’s a pretty, pretty, you know...’ ‘Well you know, if that’s what happens, that’s what happens, I’m okay with it.’ ” (p. 15)

**R11**: assessing understanding of possible health consequences of not treating gangrenous foot: “You know, do you understand what’s gonna happen if you don’t get that taken care of? You could use your, lose your foot. You could lose your leg. ‘I know that, I don’t care. I’m not goin’ anywhere.’ You know just to refuse it. But then we also have to- You have to have a bigger picture in the context of that, do they really get it. You know.” (p. 8)

**R1**: assessing understanding of possible consequences of not treating gangrenous foot: “Gosh, that’s like almost every other call we get. Someone’s toe’s about to get- it’s black, their leg’s gangrene, everything. And they- and you go over there and they’re like, and they’re sittin’ up there, ‘I’m- I don’t care. Let ‘em take it.’ ” (p. 25)

**R12**: “So, I’ve had other clients I’ve had to go get an order on because they have had gangrene in the legs. ‘You have an infection.’ ‘No I don’t!’ ‘The doctors report it right here,’ I said, ‘You have an infection.’ ‘No, I don’t!’ ‘You know what this
medicine’s for?’ ‘I’m not takin’ that medicine.’ ‘Do you know you could lose your leg?’ ‘I’m not gonna lose my leg.’ Then you can go get an order and force ‘em.” (p. 3)

R12: getting most orders of protection for cellulitis, diabetes, and gangrene: “Most of our severe self-neglect that we end up having to go get an order for? Has everything to do with cellulites, diabetes, and gangrene. And like every single order I think I’ve ever gotten, has had to do with the knees down.” (p. 3)

R12: “A lot of people say, you know, ‘I’m ready to go on. I’m sick of bein’ sick.’ Other people have told us, you know, ‘I don’t believe in amputation. I’m not’—then, you know, ‘It’s my religion.’ ‘And when I die I’m going to leave this world a whole person.’ So, and again, they know the consequences, and they can clearly state their beliefs and why they’re not caring for themselves, and then we have to let it be.” (p. 3-4)

Workers consistently identified that mental health services are the most frequently declined health care services. One worker identified that chemical dependency services are also resisted. Specific examples workers gave of this dimension included:

R3: mental health services being the most declined services: “The hardest one is mental health counseling. You know, talkin’ about...this guy had lost his wife? And I’m like, ‘Well, you know.’ We openly talked about depressions, saying ‘Hey, it’s hard to {unintelligible: ‘be’?} right now. Why don’t you get, you know, maybe some mental health counseling for...just depression?’ ‘Nope, Don’t need it. I’m not crazy. I’m not mentally ill.’ A lot of times even the folks who have schizophrenia, you know, personality disorders...really difficult, really challenging to allow somebody to come into the home...just to build that rapport up.” (p. 12)

R5: refusing mental health referrals (p. 19)

R7: seniors not accepting mental health services (p. 6); current cohort has stigma about receiving mental health services (p. 6)

R9: being evicted again after firing mental health provider (p. 7); getting evicted after refusing mental health treatment (p. 7)

R16: “Easily the most resisted [services] are psychiatric treatment. Chemical dependency. If you’ve got an elder who happens to have a chemical dependency issue, whether it’s alcohol or prescription drugs, tend to be the two things that we see among the seniors, acknowledging that there’s a problem and then getting them access to the help. And a lot of folks don’t want to be seen as, you know- A lot of times when I do an assessment, they’ll say, ‘Well, I’m not crazy, I’m not crazy.’ You know. Self-neglect folks tend to worry that people are gonna see them as crazy, so that, that’s the one that I think is the hardest.” (p. 3)
Assessing physical health and ambulation

Six APS workers made a total of 26 references to assessing physical health and ambulation. Although functional ability (such as ambulation) is technically different than physical health, references to assessing the functional ability of ambulation are presented here with references to assessing physical health because workers often mentioned them together and occasionally appeared to use functional ability and physical health interchangeably. Dimensions workers presented of assessing physical health included: assessing a person's physical capabilities and assessing for health conditions such as urinary tract infections (UTI's), falling, kidney dialysis, diabetes, thyroid conditions, potassium imbalance, untreated wounds, and stroke.

UTI's and falling were the health conditions workers mentioned most often. Several workers observed that UTI's, falling, strokes, thyroid conditions, imbalanced potassium levels, missing kidney dialysis and poor nutrition can produce confusion or cognitive impairment, and that this confusion often clears after medical treatment for these health conditions. Worker's comments on UTI's are counted and discussed later as a separate property. Specific examples workers gave of assessing physical health included:

**R3:** assessing physical health; looking at their health (both p. 1)

**R11:** “If they let me in, of course the first thing I do is look at the client, their physical condition. If they have any outward medical problems that I can see...” (p. 1)

**R5:** assessing physical condition (p. 8); having health issues (p. 8); assessing health conditions (p. 3) including diabetes, swollen ankles (both p. 3), untreated wounds (p. 7), not making it to the toilet (p. 8), toxins from lack of dialysis impairing judgment (p. 9) and confusion clearing after receiving medical treatment (p. 9)

**R12:** [counted under assessing medication decisions] “...she was hallucinating, and thinking that there were demons, and people coming in her house, and doing things to her, and, so when she took her medication? She wasn't seein' that. 'N it was all potassium level. It was all medical.” (p. 10)
Workers described a range of themes regarding falling. Specific examples included:

**R8**: receiving self-neglect referral for falling (p. 7)

**R11**: observing a pattern of falling and being taken to the hospital (p. 5)

**R7**: falling can affect mental status: hitting head can lead to odd behavior (p. 7) case example: getting a court order to make a client go to the hospital after a fall—she had a hematoma which was causing odd (self-neglecting) behaviors such as eating spoiled foods and not realizing it, she didn’t recognize what had happened (p. 7)

Several workers described assessing people’s functional ability to ambulate.

Examples of assessing ambulation included:

**R11**: are they ambulatory (p. 4)

**R3**: “Are they ambulatory throughout the house.” (p. 1)

**R10**: “So I look and assess for the mental status part of person, and then I look for their physical capacities. I wanna make sure that physically, you know, they’re, you know, that they’re [I: “They’re ambulating.”] Right. Are they able to walk, are they able to get to the door, are they able to get out of the home...” (p. 2)

**R8**: 2 case examples of being able to ambulate (p. 8); case example of being unable to ambulate to meet basic needs (p. 10)

**R3**: assessing clutter as cause of ambulation problem (p. 1)

Assessing decisions about utilizing home-health services

Five APS workers made a total of 16 references to assessing people’s decisions about utilizing home-health services. Workers described dimensions of accepting home-health services ranging from people being likely to accept visiting nurses and physicians to people resisting personal care assistance. Dimensions of this property also included workers thoughts on reasons why people might accept or decline these services. One worker described a case where a person fired home health providers and eventually hired
a private male caregiver, which led to referrals from people thinking it was improper for her to have a male caregiver. Specific examples of these dimensions included:

**R1**: people would probably accept visiting nurses if they were available (p. 13)

**R13**: people being more willing to accept homemakers, exterminators, and visiting physicians [than money management assistance]; visiting physicians being accepted because they're easier than getting transportation to their doctors; willing to have a doctor come in; this population may be used to doctors making house calls so they're very accepting [of visiting physicians] (all p. 5)

**R15**: resisting home health services (p. 6); “Sometimes they’re very proud. They don’t wanna have anybody come into their house. They don’t want strangers on a regular basis. They don’t need help cleaning up. So a lot of times, they’re either open or closed to that. Home health is not a biggie to put in there.” (p. 6)

**R16**: resisting personal care assistance: “**Personal** care gets a little harder, ‘cause then you’re asking, you know, to have somebody to help them with the shower and stuff, and I think you know, it’s very hard to let people see you in that vulnerable state, so…” (p. 3)

**R2**: case example of firing home health providers: “...she [physically] deteriorated very quickly within a matter of weeks. It progressed to the point where she, uh, home health services would go into the home, an issue would arise, the home health services did not like the, did not feel that this person was safe, the lady did not **care** for the home health services, she would fire them. Then she...**initiated** contact with an agency, ended up hiring the agency, the agency ended up going under, she hired the aid. Well, then we would get referrals on this **aid**, they didn’t think it was right that this male aid was going in and taking care of this older woman, da da da da da. She was of very sound mind. She knew the consequences of **every** decision she make.” (p. 6)

### Assessing smoking decisions

Four APS workers made a total of 10 references to assessing smoking decisions

This property overlaps with the property “assessing fire risks” under the housing category. See that property for specific examples workers provided of dimensions of assessing smoking decisions. These dimensions included assessing unsafe smoking and smoking with oxygen. In addition to those dimensions, one worker described how the right to decide to smoke is affected by a person’s competency:

**R1**: “People choose to smoke, and understand that you could have all of the things on the side of the package” ... “but when you become incompetent, then
someone has to make that decision for them because there are several things that go along with it that are unsafe, several things that go with it that they can’t do for themselves. If they develop lung cancer, they need an oxygen machine, that person is incompetent, they’re not gonna keep their kendulum in for twenty-four hours a day, they’re not gonna sit up there and you know, check their polsocks and do all that kind of stuff, because they can’t. Before they could, now they can’t.” (p. 25-26)

Assessing for possible Urinary Tract Infection (UTI)

Four APS workers made a total of eight references to assessing for possible Urinary Tract Infections (UTI’s). Workers consistently mentioned observing the severity of symptoms from untreated UTI’s. They noted that untreated UTI’s may be an underlying cause of confusion and that UTI-related confusion clears after simple medical treatment for the UTI. Observations workers shared about UTI’s included:

R2: “I can’t believe the terrible effects I’ve seen from people on a UTI. Then they’re treated for that and they’re a whole new person. It, you know, it might be as simple as that [UTI] as why they’re not processing that information.” (p. 16)

R5: UTI causing confusion (p. 9)

R7: “UTI’s are horrible with seniors. They will distort a senior’s reality base so quickly that it’s not even funny.” (p. 7)

R15: “A lot of times it’s [self-neglect] a urinary tract infection, which is simple, just go to the doctor, get that taken care of, and, you know, then you’re not gonna be as confused any more and you’re gonna remember to eat, and so on and so forth.” (p. 4) “They [UTI’s] can cause major confusion. If left untreated, it gets even worse, even plays havoc on blood pressures and sugar levels and everything. So yeah, it’s always one the things that I’ll ask right away...” (p. 4)

Assessing possible depression/mental health service needs

Four APS workers made a total of five references to assessing for possible depression or mental health service needs. Dimensions of this property included: identifying specific reasons why some seniors need mental health services, observing depression often being undiagnosed, observing that mental health issues are often the
primary diagnosis rather than dementia, and differentiating between actual suicidal ideation versus expressing fatigue. Specific examples included:

**R7**: seniors needing mental health services for depression, isolation, domestic violence, death of a loved one, loss of home or job (p. 6)

**R5**: depression being “often very undiagnosed” (p. 9)

**R10**: a lot of times the primary diagnosis is a mental health issue, not dementia (ex: depression) (p. 11)

**R5**: assessing suicide plan vs. expressing fatigue (p. 20)
### Table 5
Assessing Decisions about Housing
(A Sub-category of the Central Category “Assessing Decision-making”)

<table>
<thead>
<tr>
<th>Properties of Assessing Decisions about Housing</th>
<th>Number of APS workers mentioning property (n=16)</th>
<th>Number of references per property</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housekeeping decisions [cleanliness/clutter]</td>
<td>12</td>
<td>50</td>
</tr>
<tr>
<td>Home environment/condition of home/ home maintenance decisions</td>
<td>10</td>
<td>35</td>
</tr>
<tr>
<td>Health and safety concerns/fire risks</td>
<td>9</td>
<td>28</td>
</tr>
<tr>
<td>Vermin and bug infestation</td>
<td>8</td>
<td>15</td>
</tr>
<tr>
<td>Hoarding/collecting</td>
<td>7</td>
<td>29</td>
</tr>
<tr>
<td>Pet care decisions</td>
<td>6</td>
<td>31</td>
</tr>
<tr>
<td>Utilizing homemaker services</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Getting evicted/property managers/ neighbors/ risk of harm to others</td>
<td>5</td>
<td>15</td>
</tr>
<tr>
<td>Observing many self-neglect referrals living alone [overlap with “relationships” sub-category]</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Observing people refusing to leave their home/ wanting to remain in their home</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Kitchen/bathroom</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Letting strangers enter the home</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Observing many self-neglect referrals living in their own house</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Understanding of home conditions</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Observing people wanting to remain in the same neighborhood</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Recognizing that competent seniors can choose to live how they want</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Issues related to moving from a house to an apartment</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Living in a home where crack is used</td>
<td>1</td>
<td>12</td>
</tr>
<tr>
<td>Ability to develop adaptive alternatives when environmental barriers arise</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Other properties [see compiled group data for remaining properties]</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>16</strong></td>
<td><strong>285</strong></td>
</tr>
</tbody>
</table>
ASSESSING DECISIONS ABOUT HOUSING

All 16 workers participating in this study mentioned assessing decisions about housing. Participants made a total of 285 references to 26 different properties of this category. Workers presented a broader range of properties of assessing decisions about housing than they did with other assessment categories, and their responses were more evenly distributed among these properties than they were in other categories.

Dimensions are presented here of the nine properties of assessing decisions about housing mentioned by four or more of the respondents participating in this study. Together these nine properties account for 76% of participants’ references to assessing decisions about housing. These nine properties are: 1) assessing housekeeping decisions, 2) assessing home environment/condition of home/home maintenance decisions, 3) assessing health and safety concerns/fire risks, 4) assessing vermin, 5) assessing hoarding/collecting, 6) assessing pet care decisions, 7) assessing decisions about utilizing homemaker services, 8) assessing decisions about getting evicted/property managers/neighbors/risk of harm to others, and 9) observing many self-neglect referrals living alone. Corresponding with table 5, properties are presented in the order of how frequently they were mentioned by APS workers. Complete group data of all 26 properties of assessing decisions about housing are presented in the appendix.

Assessing housekeeping decisions [cleanliness/clutter]

Assessing housekeeping decisions was the most frequently mentioned property in the category of assessing decisions about housing, accounting for 18% of all references in this category. 12 APS workers made 51 references to assessing housekeeping decisions. Workers presented five dimensions of assessing housekeeping decisions: assessing housekeeping decisions, observing poor housekeeping conditions, noticing odor, assessing if unclean conditions are a life-long lifestyle choice (which is a competent
person’s right), and substantiating or not substantiating self-neglect allegations based on housekeeping decisions. Specific examples workers gave of assessing housekeeping decisions included:

**R8**: going out unannounced helps assess because you do not give the person the chance to clean up (p. 5)

**R16**: looking at the way the house looks (p. 1)

**R15**: asking “Who does your cleaning?” (p. 1)

Workers shared a wide range of examples of the dimension of observing poor housekeeping decisions. These examples ranged from observing clutter such as papers all over the house, to not taking out the garbage, to deplorable conditions such as a toilet being full of BM. Specific examples included:

**R1**: self-neglectors having poor housekeeping (p. 2)

**R4**: resisting cleaning (p. 6)

**R1**: describing a typical home visit to investigate elder self-neglect: “They usually have papers and things like that strewn about, all over the floor and on the couch. And that’s like, and that’s pretty much throughout the house. It’s just overrun with a lot of paper. The kitchen is usually, the countertops are either covered with dirty dishes or, you know, or with other types of miscellaneous items. You know, you know, like Christmas decorations from seasons, the season before, or you know, things like that, or sometimes like, you know, the cans they’ve opened to cook with are, and trash and things like that are on countertops.” (p. 2)

**R1**: case example of looking in window and seeing paper everywhere (p. 9)

**R5**: clutter to the point of just having little pathways (p. 10)

**R8**: cluttered home as an indicator of self-neglect (p. 7)

**R16**: finding messy homes (p. 1)

**R11**: house being dirty or cluttered (p. 4)

**R11**: there’s a real big difference between clutter and dirt (p. 4)

**R14**: looking at home situation to see if it’s clean, not clean (p. 1)

**R5**: not taking out garbage (p. 8)
**R3**: not taking trash out and having 8 or 10 bags of garbage in the house (p. 2)

**R1**: observing “deplorable” conditions in the home (p. 6)

**R8**: 2 references to home being “deplorable” (both p. 8)

**R8**: finding a deplorable, cluttered home exactly as described in the self-neglect referral (p. 5)

**R13**: case example of filthy home [as one factor considered in substantiating self-neglect allegations] (p. 2)

**R6**: assessing bathroom, example: toilet being full of BM (p. 12)

Specific examples mentioned by workers of the dimension of noticing odor included:

**R1**: case example of noticing odor at the front door (p. 8)

**R4**: typically smelling the house: “Typically I smell. That’s a typical self-neglect.” (excerpted from p. 1)

**R6**: assessing cleanliness, clutter, smells, odors (p. 3)

Several workers identified that competent people have the right to make their own housekeeping decisions, and that for some people it has been a life-long housekeeping decision to not spend their time on housekeeping. Specific examples workers mentioned of assessing if unclean conditions are a lifestyle choice included:

**R3**: “Was this kind of a lifestyle choice for them? That they’ve kind of always lived kind of unclean in the kitchen, you know, dishes are always kind of out, after they make a meal?” (p. 13)

**R15**: “If they’ve got food, they’ve got shelter, they’ve got clothing...I’m pretty much gonna overlook the clutter. Because that’s their right, and it might be the way they lived their whole entire life” (p. 7)

**R15**: “‘N they have the right to choose [clutter].” (p. 7)

**R5**: refusing to recycle when offered assistance (p. 10)

**R7**: “They are living in filth but as long as they understand the consequences.” (p. 4)

**R7**: “People do have the right to live in filth.” (p. 10)
R14: “And then I have people that are incompetent that also live in filth. So, hygiene and cleanliness is not always a huge factor.” (p. 4) [responding to statement about competent people choosing to live in deplorable conditions]

R3: “Professionals saying ‘Well the EMS came in there and it was nasty and they were havin’ a difficult time breathin’ in there ‘cause it smelled so bad.’ Well, maybe the elderly person there, they don’t smell as well as we do, the younger folks do. You know, so it’s like, they’re allowed, it’s allowed to stink in there.” (p. 13)

Specific examples workers gave of their experiences with substantiating or not substantiating self-neglect allegations based on housekeeping decisions included:

R16: not substantiating when house is relatively neat and clean, when “There’s not a lot of clutter and mess and that type of stuff.” (p. 1)

R11: clutter is unsubstantiated in self-neglect (p. 4)

R8: examples of self-neglect: house is a mess, needing major cleaning (p. 7)

R16: substantiating for things like messy homes, poor hygiene (p. 1)

R14: substantiated case example of living in squalor and poor conditions (p. 3)

R7: self-neglect case example of a client “living in a house of filth” with six dogs urinating and defecating all over the house, cats, mice, maggots, bed bugs (p. 8)

Assessing home environment/condition of home/home maintenance decisions

Ten APS workers made a total of 28 references to assessing home maintenance decisions. Workers presented four dimensions of assessing home maintenance decisions: assessing inside and outside home conditions/home maintenance decisions, assessing people’s awareness of their home conditions, assessing if home maintenance problems are related to poverty or disability, and substantiating or not substantiating self-neglect allegations based on home conditions/home maintenance decisions. Examples workers described of assessing inside and outside home conditions/home maintenance decisions included:

R5: assessing home condition inside and outside (p. 7)
workers subtly checking out the kitchen, sinks, TV to assess if utilities are on (p. 3)

R6: assessing the grounds and building while walking to the door (p. 1)

R6: assessing home (p. 1)

R10: looking at the environment; looking at the condition of the home (both p. 2)

R12: assessing environment (p. 2)

R13: assessing the environment; looking at the physical environment (both p. 1)

R6: outside of condo looks beautiful, inside things are different (p. 4)

R10: example: can’t get to bathroom on second floor (p. 2)

R10: really bad living conditions (p. 3), for example having no plumbing (p. 3)

The dimension of assessing people’s awareness of their home conditions included workers considering that people’s understanding of their home conditions reflects their cognitive abilities and noting that people may neglect themselves but not their property.

Specific examples of the range of this dimension included:

R4: senior being unaware of their home conditions is seen by worker as a sign of dementia (p. 5)

R8: looking at the environment first, then determining competency level of the individual (p. 1)

R13: neglecting self but not property (p. 10)

Workers identified the importance of assessing people’s economic and physical abilities to maintain their homes. Examples workers shared of assessing if home maintenance problems are related to poverty or disability included:

R2: “How well maintained is the home? Is the home...you have to determine a lot of times if the home is just old and worn down versus a total neglect, it’s just not taken care of. And, you know, do they live in squalor by choice, by lifestyle...Do they live in a very old, not well-maintained home just because they’ don’t have the money to maintain it....versus a house that’s trashed, literally with trash and, and other things.” (p. 1)

R2: “…you go in and you see, you know, where their house is very well maintained, you know, there’s no clutter, there’s, the carpet’s not all filthy, you
know...” (p. 2) “Other times I’ve gone in and you can see a house that looks pretty well maintained, but like the carpet’s really dirty, it’s not been swept or cleaned or anything. And that might lead to, you know, this person can’t physically sweep the floor, but they can go about picking up their clutter that are, you know, waist level, that kind of thing.” (p. 2-3)

R2: “But they have osteoporosis or something, they can’t scrub their toilet, they can’t sweep their floors, they can’t do some things that, it seems simple, but if you go for three years without being able to do it, imagine the condition of your home.” (p. 10)

R3: case example of having difficulty completing home repairs (p. 3)

R3: case example of relying on son to complete needed home repairs (p. 3)

Specific examples workers gave of their experiences with substantiating or not substantiating self-neglect allegations based on home conditions included:

R4: case example of home conditions which were not good but where self-neglect allegations could not be substantiated: “Dirty home, roaches, dirt floor. Only oven is a old wood oven. Cast iron stuff. Still pumped your water. But had a toilet. So therefore, no health department referral could be made. You know, ‘cause they took care of the sewage appropriately. But that’s the way they always lived.” (p. 3) “Heated with that old, big cast iron stove, just a one room, one, you know, old shack, basically. No fire hazards, didn’t have the trash all over the place, you know like a lot of the houses have? So that was not substantiated, against community [wishes].” (p. 3)

R11: the outside of the house tells a lot (p. 3) “A [substantiated] case would be, you know, I just walk up to the house and the yard is cluttered, and there’s trash on the porch ‘n...there’s dogs or cats running around. You know, apparently unattended. You know, there’s things you see when you first- before you even get into the house.” (p. 2)

Assessing health and safety concerns/fire risks

Nine APS workers made a total of 28 references to assessing health and safety concerns and fire risks. [For more on assessing fire risks see also “assessing smoking decisions” under the “assessing health and hygiene” category.] Respondent 11 explained that APS workers’ purpose is to assess health issues, not “clean or dirty.” (p. 3). Workers presented three dimensions of assessing home health and safety concerns: identifying that workers’ job is to determine if home conditions pose a specific health or safety risk,
assessing fire risks, and assessing people’s understanding of their home safety risks.

Examples workers described of looking for specific health and safety concerns in the home included:

**R11**: “You know, it’s not a matter of clean and dirty. It’s a matter of health. Is it a health issue? Lots of people live in what I would call dirty houses. It doesn’t bother them. They’ve always lived in a dirty house. They grew up in a dirty house. That’s not a big deal to them. Our job is to draw the line between it being just dirty...and unhealthy. Unhealthy would be, old food laying around. You know, bugs, roaches, animal fees, human feces, you know.” (p. 3)

**R7**: looking at the environment and assessing home safety (p. 1)

**R5**: looking for safety concerns and “signs of risk” in the home (p. 2); examples: smoke detectors, clear pathways, cigarette burns (p. 2)

**R3**: assessing clutter as the cause of ambulation problems (p. 1)

**R13**: case example of home condition being so bad client couldn’t follow through on wound care (p. 6)

The dimension of assessing fire risks included observing evidence of unsafe smoking, smoking with oxygen, and unsafe use of the stove. Specific examples of this dimension included:

**R1**: seeing evidence of unsafe smoking (p. 6)

**R1**: case example of having burn holes in clothing (p. 7)

**R1**: having cigarette burns [as a sign of self-neglect] (p. 25)

**R5**: observing cigarette burns where falling asleep (p. 3)

**R3**: smoking with oxygen, setting fires from smoking with oxygen (both p. 2)

**R3**: getting evicted for endangering other apartment residents by smoking with oxygen (p. 6)

**R4**: “just because they’re smoking on oxygen doesn’t make it an APS case” (p.11)

**R3**: leaving the stove on requiring a mental health evaluation (p. 14)

**R11**: having a pattern of burning things on the stove (p. 5)
R12: case example of being unaware of kitchen fires: “I walked in the house one day and the entire kitchen was full of smoke and they weren’t even aware of it.” (p. 9)

R8: clutter being a fire hazard (p. 7)

R5: worker being concerned about piled newspapers as “kindling” (p. 5)

Examples of assessing people’s understanding of the safety risks in their home included:

R7: assessing client’s understanding of home environment safety: “If it’s not a safe environment, do they understand that they’re living not in a safe environment?” (p. 1)

R7: choosing to live in an environment with problems doesn’t mean you’re unsafe (p. 3)

Assessing vermin and bug infestation

Seven APS workers made a total of 15 references to assessing for vermin and bug infestation. Workers presented four dimensions of assessing home infestation: assessing for infestation, assessing people’s awareness of infestation, assessing if infestation is normative for the person, and the range of responses to infestation workers have observed. Specific examples workers gave of assessing for infestation included:

R6: looking for bugs, seeing bugs, (both p. 3)

R11: assessing bugs, roaches [as a health concern] (p. 3)

R13: looking at if there’s infestation in the home: roaches, vermin, bedbugs (p. 1)

R7: case example of having mice, maggots, and bedbugs (p. 8)

R3: case example of rats and raccoons coming in home (p. 3)

R6: seeing rats eating pet food (p. 3)

Examples of assessing people’s awareness of infestation included:

R13: “…so, you know, we’re goin’ in and seein’ if they’re even aware that they have, you know, an infestation or anything like that. And if so, determine if they’ve tried to make any sort of…strides for themselves to link themselves with agencies or somethin’ like that.” (p. 1)
**Assessing hoarding/collecting**

Seven APS workers made a total of 29 references to assessing hoarding and/or collecting. Workers described five dimensions of assessing hoarding/collecting: hoarding behaviors, hoarded items, home conditions of hoarders, hoarders usually resisting visitors and intervention, and explanations of hoarding. Specific examples workers gave of hoarding behaviors and hoarded items included:

- **R13**: [hoarders] bringing items back into the house from the dumpster (p. 8)

- **R13**: case example where a cleaning company took two big dumpsters full of stuff from a client’s basement (p. 8); getting another call the next year on the same person and her house was just as cluttered (p. 9)

- **R1**: case example of a person collecting Styrofoam shipping peanuts (p. 11)

- **R2**: hoarding animals [counted under “assessing pet care decisions” property]

- **R3**: [you see] “a lot of newspapers, and a lot of the junk mail trash.” (p. 11); hoarding newspapers (p. 12)
Workers identified that hoarders' homes usually have reduced living space and “trails” through clutter. [For more on clutter, see also the property “assessing housekeeping decisions.”] Workers description of home conditions of hoarders included:

**R3:** case example of a retired female professor: “...and the path in her home was like two feet wide around. She was sleeping on a coffee table. Her queen size bed was full of paper, full of junk.” (p. 11)

**R9:** having “trails” in the house [walkways through clutter/hoarding] (p. 1)

**R10:** extreme hoarding/cluttering to the point of having no living space [given as an example of bad living conditions] (p. 3)

**R9:** “If they’re hoarders or something, you will get it right away.” (p. 2)

Workers observed that many hoarders resist visitors and intervention:

**R2:** “People, some people who hoard? They hoard and they don’t want anybody near their stuff. It’s their stuff, stay away from it.” (p. 12) “Some people hoard and aren’t aware of it and don’t care if somebody comes in. Some people hoard, are aware of the conditions, the smell, that kind of thing, and they don’t want somebody coming in and reporting them or getting them in trouble, or telling them to change their lifestyle.” (p. 12) “And that kind of goes across the board for a lot of hoarders. They don’t want somebody comin’ in tellin’ them to do this and that and this.” (p. 12)

**R9:** “Pretty much the hoarders don’t wanna let you in.” (p. 1)

Workers discussed explanations people have given for hoarding and also shared their own thoughts on underlying causes of hoarding:

**R3:** case example of a person explaining newspaper hoarding: “One person told me ‘Well, I need to read that one article back there...’ ” (p. 11)

**R3:** “However, if they’re a hoarder, you know, they don’t wanna get rid of their stuff, they know exactly where everything’s at, or they’re attached to it because, you know, ‘Well that was from my mom, and that was last...’ whatever. I don’t know. Whatever thing they have, ‘That was the last thing that that person gave me’ or ‘another person gave me’ or ‘I got that at that vacation. Can’t get rid of that.’ or...an’ some things are just like...people can’t get rid of it. ‘Cause they have a date on it, or somethin’ like that.” (p. 10)

**R9:** hoarders having mental health problems (p. 6)

**R13:** “So it [hoarding] really is one of the hardest cases to work with, because they really feel like those are...there’s some sort of meaning with those possessions. I mean it. It’s like a self- you know, I don’t know, it’s, it’s more than
a possession to ‘em a lot of times. It’s like…that’s their existence, you know. It’s proving that this is who they are because they’ve collected these things. So, and even though they seem meaningless to you and I, I mean they have some sort of worth to these people. So it’s really hard for them to get rid of them” (p. 9)

R13: “And you know, Brian, you know, I’ve had married couples that…they’ve lost children, or, you know, there’s been some great loss. And they may go out thriftin’. You know, goin’ to the thrift stores. And then it just explodes from there. And they both get in-you know, ‘cause it’s an activity, it’s somethin’ to do. It’s something shared. And then, of course, once they’ve purchased all these things not only have they put money into it but, you know, they feel like, ‘If you take that away from me, what else do I have left?’” (p. 9)

R13: case example: “...I did have a coworker and she said, ‘You know, if you went in there, you would swear you were in Macy’s,’ you know, because there’s still the tags on ‘em, they’re in those bags, they’re hanging every- there’s dust about this thick on top of ‘em, but, you know, they were like ‘Well, you know, I will go to a dance, or I will go to a ball’ or something like that. Like you were sayin’ with-[the newspapers], ‘I will finish reading these.’ You know. It’s almost like it gives them some sort of- something to thrive on, so...yeah, it’s interesting.” (p. 9-10)

### Assessing pet care decisions

Six APS workers made a total of 31 references to assessing pet care decisions.

Respondent 6 pointed out that pet care is a tip-off to how things are going (p. 2).

Dimensions of assessing pet care decisions included: assessing pet care by the smell of the home, observing pet care ability ranging from caring well for pets to being unable to care for pets, and observing people having difficulty controlling their dogs. Specific examples workers presented of assessing pet care by the smell of the home included:

R1: “...it might be that they’re not taking care of their animals, or that there might be some odors which sometimes I can smell right from the porch.” (p. 1)

R2: “Smell, you go into a home, an’ if you can smell the animals, which is, you know, so often you go into a home and the animals can’t get out, because the person can’t physically let them out, or because the person is an animal hoarder, so to speak. And [Interviewer: A collector.]” Exactly. And they, you know, they think they’re treating their animal protectively, that kind of thing, but in the long run the animal, who might be very well loved, is not well taken care of because of inability physically to do so, or there’s some dementia or other things going on and they’re not even aware that they’re not taking really good care of the animals.” (p. 3)

R6: assessing pet care/smell (p. 2)
**R1:** pet’s “doing business” in the home; assessing animal feces, human feces [as a sign of health concern] (both p. 3)

Workers described a wide range of dimensions of ability to care for pets, including:

**R2:** case example of caring well for cats: having 30-40 cats but providing well for them by having 17-20 litter boxes, very well maintained. (p. 6) “She actually provided in her will for her cats. She did have people coming in taking care of her animals, and the animals were actually sent to a retirement home for animals, for cats, prior to her death.” (p. 7)

**R1:** taking care of pets but not themselves (p. 2)

**R11:** a lot [of self-neglecting clients] neglect their pets but some take good care of them, better than of themselves (p. 2)

**R3:** “I’ve seen a lot of people have animals that maybe shouldn’t, but then, some people have animals and say ‘Oh, it’s a great companion. Gets me out for a little walk.’ And it’s- you know, if somebody has a small dog, and they’re able to care for ’em in the apartment or whatever, take ’em for a walk every day, that gives ’em a boost of energy at times too. I see many of the times, more so, that the dog or the cats are, you know, a problem for that person. Just elevating the self-neglect. Of not keepin’ the home up, not keepin’ food in for the animal, or too much food in the house, on the back porch, then rats are comin’ in to get the food, you know, so, it could present us some problems.” (p. 11)

**R6:** changing pet care habits (p. 2)

**R3:** having difficulty caring for pets, for example having difficulty changing the cat litter (both p. 11)

**R11:** seeing unattended pets running around outside (p. 2)

**R1:** not taking care of pets (p. 2)

Workers described observing people having difficulty controlling their dogs:

**R1:** being unable to control their dogs (p. 2)

**R3:** having difficulty controlling dogs (p. 11)

**R3:** case example of a woman falling due to her two huge dogs jumping on her and not being able to reach the phone and laying there for 18 hours (p. 10)

Workers described observing some people “hoarding” animals and identified that self-neglecters are more likely to have pets than other people:

**R2:** hoarding animals (p. 2, as quoted above)
R3: letting feral cats in the home: “We get people who...bring in cats. I had a cat lady who had thirteen cats in her home...and just feral cats off the street get in, start tearin up the furniture. Down to the quick of the furniture. Down to the bones, bare bones.” (p. 11)

R4: keeping dead animals (p. 3)

R1: self-neglecters having more pets than others (p. 3)

R11: a lot of self-neglecting clients have pets (p. 2)

Assessing decisions about utilizing homemaker services

Six APS workers made a total of nine references to assessing decisions about utilizing homemaker services. Workers’ experiences with people accepting homemaker services varied widely, with dimensions ranging from some workers finding homemaker services are often easily accepted to other workers finding homemaker services are “more of a sale.” Another dimension of this property involved workers providing reasons for why people might decline homemaker services. Specific examples of the range of workers’ experience with people accepting homemaker services included:

R16: “Housekeeping is more easily accepted.” (p. 3)

R13: clients being more willing to accept homemakers, exterminators, and visiting physicians [than money management assistance] (p. 5)

R3: people whose home is fairly clean accepting homemaker services (p. 12)

R6: homemaker services is “more of a sale” due to trust issues (p. 9)

R8: declining cleaning services (p. 8)

R5: case example of refusing homemaker services: “And he would let me do little things, like bag up some of the trash in the kitchen myself; if it was me. But he would not let me bring people in. We scheduled it two or three separate times, to have the deep cleaning come out and...he would cancel it. Even if I came. Like I would come too, and he would say ‘No, I don’t wanna do this.’ ”(p. 10)

Reasons workers provided for why people might decline homemaker services included:

R3: “if a person has a very dirty home? I think there’s more resistance. Just because, maybe they’re embarrassed...” (p. 13)
**R6**: people complaining that homemakers “don’t clean right” (p.9)

**Assessing decisions about eviction/property managers/neighbors/risk of harm to others**

Five APS workers made a total of 15 references to assessing decisions about eviction/property managers/neighbors/risk of harm to others. Workers presented dimensions of this property ranging from recognizing that seniors have the right to live how they want, including getting evicted, to explaining eviction risks to people, to assessing unintentional risk of harm to other tenants, to apartment managers calling in referrals and being frustrated that APS cannot enforce apartment codes, to examples of reasons for eviction. Specific examples of these dimensions included:

**R7**: seniors can choose to live how they want, including getting evicted (p. 11)

**R4**: case example of worker explaining to an apartment dweller “Hey listen, you know this is bad, you know your neighbors are gonna complain, your neighbors are afraid you’re gonna put this up [set fire to the apartment building from smoking with oxygen], you understand the landlord’ll have every right to kick you out...” (p. 13)

**R11**: assessing risks to other people, for example smoking with oxygen in an apartment building: “The only other thing that would come into play with like a man smoking with oxygen would be, is he just in his own house? Or is he in an apartment building where he’s putting other people at risk?” (p. 3)

**R4**: “Each landlord has different codes to uphold. We don’t. Because...the harm to others...there’s n- In our country, in our court system, there’s no way we could take that to court and do anything against their will, anyway.” (p. 12) “Now harm to others in, you know, you’re goin’ after them to hurt them, yes. Harm to other is you’re [Interviewer interrupts: “Smoking with oxygen in your apartment”] Hm-mm. Not gonna work.’ (p. 12) “That’s an apartment... landlord issue.”(p. 12)

**R4**: “…but like the apartment complexes? We run into a lot of times the mangers will call us. And we’re like...you know, just because they’re smoking on an oxy machine does not make it an APS case. We cannot force them to stop. You can, however. If they wanna live in your facility, and that’s your rule, you need to evict. ‘Well, we don’t wanna evict ‘em.’ I can’t make him stop.” (p. 11)

**R9**: case example of a person getting evicted for threatening neighbors and refusing mental health services: “And the reason they were evicting her, ‘cause she would go off on people in the building. Threaten them and stuff, and...so the
evidence was greatly against her. She went off and tore up the laundry room ’cause they thought- and the police came out, so there was a police report. And, and she was acting crazy. And there was a, this...really raunchy letter that she wrote to the management.” (p. 7) “And then she did weird things with bleach, so, um...I said, ‘The only way I’ll help you,’ ‘cause they were evicting her, ‘will be on is that you agree to mental- uh, elder treatment a focus, and you need a case manager.” And she did. And, recently she fired the case manager, and guess what, she’s bein’ evicted.” (p. 7)

R9: not paying rent (p. 5)

**Observing many self-neglect referrals living alone**

Five APS workers made a total of six references to observing that many self-neglect referrals live alone. This property is also listed in the category “assessing decisions about other people and relationships.” See that category for specific examples of this property.
### Table 6
**Assessing Decisions about Other People and Relationships**
(A Sub-category of the Central Category “Assessing Decision-making”)

<table>
<thead>
<tr>
<th>Properties of Assessing Decisions about Other People and Relationships</th>
<th>Number of APS workers mentioning property (n=16)</th>
<th>Number of references per property</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family relationships</td>
<td>14</td>
<td>45</td>
</tr>
<tr>
<td>Informal support system/relationships with friends</td>
<td>7</td>
<td>29</td>
</tr>
<tr>
<td>Working with families and support systems</td>
<td>5</td>
<td>20</td>
</tr>
<tr>
<td>Responding to visitors or allowing people/service providers in the home</td>
<td>5</td>
<td>18</td>
</tr>
<tr>
<td>Observing many self-neglect referrals living alone [overlap with “housing” sub-category]</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Receiving false reports from children and neighbors</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Living with and/or financially supporting younger drug abusers</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Observing people seeking companionship/interaction with worker</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Socialization/community involvement</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Neighbors calling in referrals</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Risk to others</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Loneliness</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Having enduring marriages</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Other properties [see compiled group data for remaining properties]</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td><strong>Totals:</strong></td>
<td><strong>16</strong></td>
<td><strong>176</strong></td>
</tr>
</tbody>
</table>

### ASSESSING DECISIONS ABOUT OTHER PEOPLE AND RELATIONSHIPS

All 16 workers participating in this study mentioned assessing decisions about other people and relationships. Participants made a total of 176 references to 21 different properties of this category. Dimensions are presented here of the six properties of
assessing decisions about other people and relationships mentioned by four or more of the respondents participating in this study. Together these six properties account for 71% of participants’ references to assessing decisions about relationships. These six properties are: 1) assessing family relationships, 2) assessing informal support system/relationships with friends, 3) working with families and support systems, 4) assessing decisions about responding to visitors or allowing people/service providers in the home, 5) observing many self-neglect referrals living alone, and 6) receiving false reports from children and neighbors. Corresponding with table 6, properties are presented in the order of how frequently they were mentioned by APS workers. Complete group data of all 21 properties of assessing decisions about relationships are presented in the appendix.

Assessing family relationships

Assessing family relationships was the most frequently mentioned property in the category of assessing decisions about other people and relationships, accounting for 26% of all references in this category. Fourteen APS workers made a total of 45 references to assessing family relationships. Dimensions of this property included: assessing the availability of family to help, observing that many seniors have no available family, recognizing families having difficulty with role changes, and recognizing that some seniors rely on their families for help while others don’t want to ask their family for help.

Workers also mentioned observing disgruntled and conflicted families, seniors being exploited by their families, and some seniors choosing to allow themselves to be exploited. Unique themes regarding assessing family relationships included a worker sensing that the family a client described was “mythical” and that homicidal statements made by family caregivers may not be actual threats but rather natural expressions of fatigue. Specific examples of how workers assess availability of family included:
R15: asking “Do you have any family?” (p. 1)

R7: asking about family and friends (p. 1)

R11: asking if they have helpful relatives (p. 2)

R8: seeing if there is family willing to provide care (p. 11)

R2: asking client “What is your family doing for you? ...What are these folks doing to help you? You know, who’s taking you to the grocery store? Who’s doin’ this?” (p. 10)

Examples workers shared of observing that many seniors have no family available to help included:

R1: not having family “…when there is no family…you have no body…” (p. 23)

R1: worker seeing uncaring families, some families not being there for the client (p. 23)

R3: [counted under “assessing informal support system” property] “A lot of times what I see is...a lot of seniors don't have supports. Family members...um, who don't have children, you know, is a problem for them. Their sisters and brothers are elder as well, their parents passed away…” (p. 1)

R10: outliving family, absent family (both p. 9)

Examples workers shared of observing families having difficulties with role changes included:

R2: not wanting to alter family roles; “A threat of asking them to do something that they’ve never done, which is ask their children, or their grandchildren, to do something for them, where there’s been a lifetime doing for them.” (p. 11)

R2: “…you’re gonna have some situations where family really don’t realize that their parents or grandparents need that kind of assistance. Because they see their parents in always as this strong, capable, always doing role. They don’t necessarily see the decline that an outsider would see. Because {spoken softly} it’s their parents. They see them in the same light they’ve always seen ‘em.” (p. 11)

R2: “Well who wants to all of a sudden look weak in front of their children?” (p. 11)

R13: family being willing to help but not wanting to overstep boundaries or have role reversal with parents: “…’cause a lot of times the family is willing to do something but they’re just so afraid that mom and dad is gonna...[claps hands lightly] you know, like the role reversal, you know. They just can’t possibly step in
and, and take over. They just feel like they’re oversteppin’ their *boundaries*...” (p. 4)

**R12**: case example of family following client’s wishes rather than making choices to prevent self-neglect (p. 5)

Workers described a range of willingness on the part of seniors to ask for and/or accept help from their families:

**R1**: case examples of siblings helping: sister cleaning up mess for a client (p. 11); different case ex: of sister taking client to doctor (p. 18)

**R2**: senior wanting family to provide needed care [case ex: family removing elder from nursing home but not providing required 24/7 care] (p. 8)

**R3**: relying on children to complete needed home repairs (p. 3)

**R2**: not wanting to ask family for help: “My family is too busy doing other things, they’re working, they’re taking care of their own.” (p. 5)

**R2**: not wanting to “impose” on family: “Well, they have things of their own to do. They have their own lives. They’re working and raising children, and we don’t want to *ask* them.’ I’ve heard that a lot, ‘I don’t want to ask them.’ And we’ve been flat out told ‘Don’t contact my family. Don’t ask my family to do this.’” (p. 11)

Examples workers shared of observing disgruntled and conflicted families included:

**R10**: receiving calls from disgruntled family members, (p. 7)

**R12**: a lot of calls are angry siblings [senior’s children], for example children disagreeing on parents’ care (both p. 4)

Examples workers shared of observing exploitation by family and some seniors choosing to allow it to continue included:

**R1**: children exploiting parents (p. 23)

**R3**: case ex: of drug-using children moving in on parents with cognitive impairments, (p. 8) case ex: of exploitive child trying to screen APS contact with parent (p. 9)

**R5**: family financial exploitation (p. 17)

**R3**: parents defending exploitive children (p. 8)

**R6**: clients being aware of financial exploitation by family and allowing it to continue (p. 12)
**R16:** case example of senior deferring to mentally ill daughter living in the household and things not getting cleaned up (p. 1)

Examples of unique themes regarding assessing family relationships included:

**R5:** worker suspecting family support system reported by client is “mythical”: “He’ll insist that this mythical nephew is coming to help him...I’ve never even verified that this person exists. I’ve never heard of him actually coming around, nobody seems to know who he is...I don’t believe that’s ever going to happen, if this guy does exist, he’s not involved.” (p. 10)

**R5:** recognizing that homicidal statements made by family caregivers were not actual threats but expressions of caregiver fatigue (p. 21)

**Assessing informal support system/relationships with friends**

Seven APS workers made a total of 29 references to assessing people’s informal support system and/or relationships with friends. Respondent 1 succinctly summarized this property when she described asking “Who’s involved? Who’s helping? Who’s not helping? Who’s more of a hindrance?” (p. 7). Workers presented dimensions of this property ranging from identifying methods used to assess a person’s support system, to assessing a person’s desire for informal (and formal) help, to identifying specific informal support received and from whom, to observing that many seniors lack informal supports. Specific examples workers gave of assessing a person’s support system included:

**R10:** assessing informal supports (p. 1)

**R9:** asking about informal helping systems (p. 2)

**R11:** asking about support system, asking if they have helpful neighbors (both p. 2)

**R15:** asking “Who does your transportation for you?” (p. 1)

**R3:** case example: “You just question, you know, are neighbors really lookin’ out for you or not, or are people just comin’ in off the street, you know prostitutes comin’ in, or the friends, who are these friends that are visiting on your porch? So I had to do some research to kind of find out are these neighbors or people down the street ok? Are they lookin’ in the best interest of him?” (p. 7)
R9: looking at informal and formal helping systems and do they want them (p. 8)

Examples workers provided of specific support received and by whom included:

R9: having friends who help with chores and transportation (p. 3)
R11: having help getting groceries (p. 5)
R9: friends helping with chores but not getting into finances (p. 3)
R1: case example of a person having a friendly relationship with mailman (p. 9)

Workers noted that many seniors don’t have an informal support system. Specific examples of this included:

R10: having few informal supports (p. 9)
R3: “A lot of times what I see is...a lot of seniors don’t have supports. Family members...um, who don’t have children, you know, is a problem for them. Their sisters and brothers are elder as well, their parents passed away, their friends are dying off, neighbors don’t wanna help...” (p. 1)
R14: a lot of people living in the community can no longer live alone and don’t have a support (p. 5)

**Working with families and support systems**

Five APS workers made a total of 20 references to working with families and support systems. Workers consistently described trying to involve family systems to help people. Respondent 8 succinctly summarized this property when she presented the idea of trying to work with families to get the situation resolved (p. 2). Workers presented dimensions of working with families that ranged from identifying methods they used to get families involved, to identifying specific reasons to get families involved, to observing people’s preferences between family involvement and government (APS) involvement, to outcomes of family involvement. Examples of methods workers identified to get families involved included:
**R5:** worker encouraging client to share APS visit information with family and other supports (p. 4)

**R5:** worker calling client’s daughter (p. 5)

Examples of reasons to get families involved included:

**R11:** explaining to family “this is not ok for mom or Grandma to continue living this way” (p. 9)

**R12:** trying to get family involved before seeking guardianship (p. 10)

**R12:** trying to get family, friends to serve as guardian (p. 10)

Dimensions of people’s preferences between family involvement and government (APS) involvement ranged from seniors preferring family involvement over government involvement to families requesting that an outside guardian be appointed so that family doesn’t have to “be the bad guy.” Specific examples of these dimensions included:

**R12:** case example of family requesting guardian “to be the bad guy” so that family doesn’t have to do it (p. 10)

**R13:** APS providing the nudge for a person to say “Oh, Well we don’t really want the government involved. I’d rather have family.” (p. 4)

Workers also described some less than optimal outcomes of family involvement:

**R11:** seeking court orders of protection when client and family “not following through” with making needed changes (p. 9)

**R12:** case example of working with client’s daughter who had Power of Attorney: client appointing daughter as Power of Attorney, daughter’s not accepting that mom was dying and wanting continued chemotherapy for her, worker sympathizing but substantiating self-neglect and insisting daughter’s put mom on hospice to avoid neglect allegations (all p. 5)

**R13:** case example of family getting involved with hoarder, cleaning her house, getting Power of Attorney, APS case being closed, APS getting another call the next year and the house was just as cluttered (p. 8-9)

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**Assessing decisions about responding to visitors or allowing people/service providers into the home**

Five APS workers made a total of 18 references to assessing decisions about responding to visitors or allowing people/service providers into the home. Dimensions
presented by workers included: being concerned when people are too trusting of strangers, recognizing that some people don’t want people in their home, specific reasons why people may not welcome visitors or service providers into their homes, and recognizing that wariness of strangers shows some discernment ability. Respondent 2 succinctly summarized this property: “And sometimes people don’t want somebody comin’ into their home.” (p. 12). Specific examples workers shared of seniors trusting too easily included:

**R1:** worker being concerned when they will let her in so easily (p. 3)

**R1:** trusting people too much (p. 3)

**R5:** case example of letting people into the home/secured apartment who steal (p. 14)

**R9:** “I’m not surprised by how many people don’t let me in? I’m surprised at how many people do. Because they have the rights, it’s not like children, they don’t have to let you in. But I’m really surprised, just from...showing that badge- I wouldn’t let me in so...[laughs]” (p. 1)

Examples of workers’ observations of seniors not wanting people in their home included:

**R10:** not wanting strangers in the house (p. 4)

**R1:** case example of refusing to let worker in the door (p. 8)

Specific examples workers suggested of reasons why people may not welcome visitors or service providers into their homes included:

**R1:** having previously had a bad experience with service providers: “When I talk to seniors about the other services, and why they don’t want them, it’s usually because they’ve had a bad experience, or someone close to them has had a bad experience; somethin’s been stolen, or they don’t do it right...” (p. 14)

**R2:** “People, some people who hoard? They hoard and they don’t want anybody near their stuff. It’s their stuff, stay away from it. Some people hoard and aren’t aware of it and don’t care if somebody comes in. Some people hoard, are aware of the conditions, the smell, that kind of thing, and they don’t want somebody coming in and reporting them or getting them in trouble, or telling them to change their lifestyle. And that kind of goes across the board for a lot of hoarders. They don’t want somebody comin’ in tellin’ them to do this and that and that and this.” (p. 12)
One worker explained how a wariness of strangers shows some discernment ability.

**R9:** “I don’t get my feelings hurt if somebody’ll say, you know, ‘Just give me some information, I’ll make a call.’ You know, I know right then, you know, that if they say, you know, leave a letter of *intent*, lettin’ somebody call and *check*. That’s a sign that they’re, they’re somewhat *with* it. And right there, ‘cause they’re askin’, you know, to prove who you *are*. And they call you back, and, you know.” (p. 1)

**Observing many self-neglect referrals living alone**

Five APS workers made a total of 6 references to observing that many self-neglect referrals live alone. Although this property has only one dimension (living alone), one worker mentioned being self-neglecting and living with others. That reference was not counted under this property. Specific examples of these dimensions included:

**R1:** “...typically they’ll [self-neglect referrals] be living alone...” (p. 1)

**R6:** “Most of our people are living alone.” (p. 1)

**R12:** “With self-neglect, a lot of times there’s not another person in the home...” (p. 1)

**R12:** “So they could still be self-neglecting, but living with somebody.” (p. 1)

**Receiving false reports from children and neighbors**

Four APS workers made a total of seven references to receiving false reports from children and neighbors. Workers presented dimensions of underlying causes of false reports ranging from children using APS as a weapon to children wanting their parent’s money to neighbors feuding over their property line. Specific examples of these dimensions included:

**R5:** children using APS “as a weapon” (p. 12)

**R7:** family members “causing trouble” (p. 4)

**R9:** kids who want parent’s money calling in false referrals (p. 4)

**R12:** getting bogus calls from family or neighbors. case example: bogus call in retaliation by neighbors feuding over bushes on property line (p. 5)
ASSESSING DECISIONS ABOUT FINANCES

All 16 workers participating in this study mentioned assessing decisions about finances. Participants made a total of 122 references to 14 different properties of this category. Dimensions are presented here of the five properties of assessing decisions about finances mentioned by four or more of respondents participating in this study. Together these five properties account for 73% of participants’ references to assessing decisions about finances. These five properties are: 1) assessing bill-paying decisions, 2) observing people not wanting to pay for needed services/accepting free services, 3) assessing decisions about giving money to others/financial exploitation by others, 4) assessing understanding of finances and money management, and 5) assessing
poverty/insurance coverage loopholes. Corresponding with table 7, properties are presented in the order of how frequently they were mentioned by APS workers. Complete group data of all 14 properties of assessing decisions about finances are presented in the appendix.

Assessing bill-paying decisions

Assessing bill-paying decisions was the most frequently mentioned property in the category of assessing decisions about finances, accounting for 25% of all references in this category. Nine APS workers made a total of 30 references to assessing bill-paying decisions. Respondent 15 succinctly stated the importance of assessing bill-paying decisions: “Are they paying their bills. Are they gonna lose their shelter.” (p. 7). Workers described a range of dimensions found in bill-paying decisions. These dimensions included people overpaying bills, paying all their bills, being behind on some bills, paying only some of their bills, bouncing checks, and not paying their bills. Specific examples of these dimensions included:

R9: overpaying bills, for example paying the same bill three times (p. 2)

R2: “Or, and *sometimes* you go into the situation, and they *are* fine. And the environment *is* fine. They have food. Their bills are paid.” (p. 15)

R10: being behind on utilities (p. 3)

R6: having bill-paying problems, for example paying utilities but not rent (p. 4)

R9: having money but not paying the electric bill; not paying rent (both p. 5)

R9: “So, they paid the same bill three *times*, they, uh, they haven’t paid it or, um, they don’t *balance* their checkbook and, um, you know, they keep writin’ checks *anyway*. They get notices from the bank and stuff like that.” (p. 2)

R9: “You know, bouncing checks and everything because they can’t remember doin’ it.” (p. 1)

R11: having a pattern of not paying bills (example: for three months) (p. 5)
**R13:** substantiated case example of client thinking she was paying bills but wasn’t (p. 2)

Workers also identified a range of dimensions in methods they use to assess bill-paying decisions. These dimensions included: directly asking about bill-paying, looking around for shut-off notices/bills/checkbooks, and observing services/utilities being shut-off. Specific examples of these dimensions included:

**R10:** asking “How do you pay your bills?” (p. 4) People that aren’t capable can’t demonstrate to you, people that are capable can describe bill-paying process, produce checkbook ledger (p. 4)

**R10:** asking very personal, detailed questions about finances such as: “How do people help you pay your bills?” (p. 5)

**R6:** asking “Are you having trouble paying your utilities? You know, an’ that’s generally a tip-off that they might be in trouble.” (p. 2)

**R6:** looking at papers lying around for bills/checkbook (p. 5)

**R2:** assessing if they have shut-off notices (p. 2)

**R9:** observing phone service being stopped for not paying phone bill (p. 5)

**R10:** observing utility shut-offs (p. 3)

### Observing people not wanting to pay for needed services/ Accepting free services

Eight APS workers made a total of 17 references to observing people not wanting to pay for needed services and/or accepting free services. Respondent 6 succinctly stated the predominant theme of this property: “They don’t want to pay.” (p. 15). Respondent 11 identified money as the predominant consideration in older adults’ decision-making about service utilization: “The money is the biggest issue.” (p. 7). Workers presented a limited range of dimensions of this property. These dimensions involved reasons for not wanting to pay for services and examples of not wanting to pay for services. Workers identified two underlying reasons for older adults not wanting to pay for services:
preserving assets for their family, and their age cohort not wanting to spend money on themselves.

**R2:** “A lot of people *like* the idea of Passport Medicaid, until they realize ‘Oh. *That’s* the program where if I *belong*, they’re gonna take my house away. And I’ve worked all my life to pay for my house and I want to leave something to my children.’ Resistance is mostly to something that threatens that one thing, whatever it is that they hold very dear and important. And that is, what they’re gonna leave to their family.” (p. 10)

**R11:** “That generation would rather not spend money on themselves.” (p. 6)

Workers presented a few dimensions of not wanting to pay for services. These dimensions included people being more inclined to accept free services, not wanting to pay a co-pay, and wealthy people being court-ordered to pay for services. Specific examples of these dimensions included:

**R1:** “But they would probably be more inclined to accept if they could get it for free.” (p. 16)

**R11:** when you take away the money aspect, most people will accept Meals-on-Wheels, housekeeping, transportation, and the ERS button (p. 6)

**R12:** a lot of people will accept all free services available (p. 12)

**R14:** “They tend to like Meals-on-Wheels, but they may not wanna pay for it.” (p. 6)

**R2:** refusing Meals-on-Wheels for reasons like “I don’t wanna pay the money.” (p. 11)

**R11:** a lot of clients accept services but then decline when they find out there’s a ten dollar co-pay (p. 6)

**R7:** case example of a court ordering wealthy people to pay for services (p. 2)

**Assessing decisions about giving money to others/ Financial exploitation**

Eight APS workers made a total of 16 references to assessing decisions about giving money to others/financial exploitation by others. Respondent 2 succinctly presented this concern: “Because you have elder adults who are *still* using their own
money to help their children, or their grandchildren.” (p. 10). When discussing financial exploitation, respondent 10 pointed out that “a lot of our [APS] stuff is centered around money” (p. 7). Workers identified that giving money to others is a problem when it prevents seniors from meeting their own basic needs. Respondent 11 provided a concrete example of this: “Maybe there’s a grandson that’s coming in and takin’ advantage, or, you know, she’s neglecting herself to buy food for her grandson...” (p. 7).

Workers identified dimensions of seniors’ attitudes about giving away money needed to meet basic needs ranging from seniors knowing it’s wrong, to seniors knowing it’s their right, to seniors not caring what anyone else thinks. Examples of these dimensions included:

R6: “and they’re not paying their own rent and they know that this is, um, wrong.” (p. 12)

R9: elders without dementia giving everything to their adult children stating “It’s my right to give it.” Worker acknowledging “It’s your right to give everything to your children, and...‘I don’t agree, you know, you’re gonna be homeless soon, I don’t think your, your child is on drugs, but...’ You can’t stop it.” (p. 9)

R10: “And then the parents are just like, totally most of them know it? And let it happen. I mean they’re not being exploited, they’re, they’re doing it. They’re giving the money. They’re lettin’ [Interviewer (simultaneously) Which is self-determination, ‘n...] Right, right! [Interviewer: Yeah.] And if they’re alert and oriented and we make that—and they say, ‘Hey, I can give the money if I want, I don’t care what anyone else thinks...’ [Interviewer: That’s the answer.] That’s the answer.” (p. 7)

R13: case example of a senior selling his pain meds and giving the money to his caretaker and understanding the consequences of this decision (p. 3)

Another dimension of assessing seniors’ decisions about giving money away involved workers observing adult children thinking that one sibling is benefiting more from their parent’s money. Two APS workers mentioned this dimension:

R10: siblings being concerned about parents financially favoring other sibling, often the youngest (p. 7)

R12: children thinking one sibling is benefiting more from parents’ money (p. 4)
Assessing understanding of finances and money management

Seven APS workers made a total of 14 references to assessing understanding of finances and money management. This property is similar to the previously mentioned property of assessing bill-paying decisions, but when discussing understanding of finances and money management workers focused more on assessing a person’s underlying understanding of their finances rather than the task-completion focus of assessing bill-paying. Respondent 2 identified possible consequences of not understanding finances and money management: “If they’re not maintaining their finances it might lead into the not getting their food, not getting their medicine...” (p. 2).

Respondent 9 made three references to a direct link between self-neglect and not understanding one’s finances: “You know, in the situation, self-neglect, usually somebody may not be able to take care of their financial situation.” (p. 1), “I think mostly it’s the financial stuff [self-neglect].” (p. 2), and “If it’s self-neglect, but it, a lot of it pertains to, a lot of them, it’s the financial stuff.” (p. 2). Workers described a range of dimensions of understanding about finances and money management. These dimensions ranged from knowing about finances, to not being able to take care of finances, to being totally unaware of finances. Specific examples of these dimensions included:

**R6:** “The seniors seem to know whether they have money or not. They really do. And, you know, they’ve grown up [in the post-depressions era]n they know, like, they know exactly what they need.” (p. 15-16)

**R1:** case example: “...he doesn’t have enough money, or the ability to manage his money to meet his basic needs.” (p. 22)

**R13:** case example: being unaware of leaving signed, blank checks around the house (p. 2)

**R12:** “I’ve had clients before that have gotten so demented that their home has gone into foreclosure...and all their utilities have been turned off. And they’ll tell you, ‘Oh, I’m payin’ the bills.’ ” (p. 9)
Assessing poverty/insurance coverage loopholes

Four APS workers made a total of 12 references to assessing poverty/insurance coverage loopholes. [See secondary category of “actions needed” for more on insurance, eligibility, and funding barriers.] Workers identified dimensions of this property ranging from discriminating between seniors being unable to afford needed services vs. simply not wanting to pay for services, to being ineligible or not enrolled in social insurance programs like Medicaid or Medicare, to insurance program loopholes in which needed services are not covered. Specific examples of workers discriminating between being seniors unable to afford needed services vs. not wanting to pay for services included:

**R4**: “Sometimes they simply, truly, cannot afford to replace their toilet and now they’re pooping in buckets in their tub!” (p. 6)

**R2**: “Do they live in a very old, not well-maintained home just because they don’t have the money to maintain it...” (p. 1)

**R9**: “Or you have people who are poor.” (p. 1)

**R2**: a lot of times the Emergency Response System bracelet costs money that they don’t have; homemakers aren’t used due to cost (both p. 12)

Examples workers presented of being ineligible or not enrolled in social insurance programs like Medicaid or Medicare included:

**R13**: clients’ being willing to accept home-based services but slightly over income and unable to pay for them (p. 4)

**R2**: being ineligible for Medicaid [and being unable to or not wanting to pay for services] (p. 8)

**R2**: “You have people who, for whatever reason aren’t on Medicare.” (p. 9)

Examples workers presented of insurance program loopholes in which needed services are not covered included:

**R4**: experiencing insurance barriers (p. 5)

**R2**: case example of an insurance coverage loophole: “We had a gentleman, wanted to go to a nursing home. Physically, mentally, doctor, customer, everybody was agreeable this person needed it. His coverage, when it went from
Medicaid to HMO to whatever it was, ‘no this won’t pay, no this won’t pay, no this...’ Everybody is ready for this man to go, he needed this. He needed 24-hour care and supervision, and he was in a loophole. And a huge loophole that, it’s terrible. And I think it took probably a month and a half to get this gentleman into a facility. (p. 9)

R2: case example of privately paying for home health services (p. 7)
Table 8
Secondary Category: Approaching Intervention

<table>
<thead>
<tr>
<th>Sub-categories of Approaching Intervention [see table for each sub-category]</th>
<th>Number of APS workers mentioning property (n=16)</th>
<th>Number of references per sub-category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Actions needed/taken [interventions]</td>
<td>16</td>
<td>1324</td>
</tr>
<tr>
<td>APS workers’ feelings about intervention</td>
<td>16</td>
<td>323</td>
</tr>
<tr>
<td><strong>Totals</strong>: [overlap between sub-categories]</td>
<td><strong>16</strong></td>
<td><strong>1359</strong></td>
</tr>
</tbody>
</table>

SECONDARY CATEGORY: APPROACHING INTERVENTION

“Approaching intervention” emerged as the secondary thematic category during data analysis. This secondary category directly corresponded to the interview protocol developed to explore how APS workers assess and treat elder self-neglect. All 16 participants discussed approaching intervention and each of its sub-categories, mentioning it approximately 1359 times. The total includes some references being counted twice because they pertained to more than one sub-category, or property within a sub-category. Two sub-categories of approaching intervention emerged: 1) actions needed or taken [intervention], and 2) APS workers’ feelings about intervention. Tables of the properties of each of these sub-categories are presented here in order of the frequency they were mentioned by APS workers. A discussion of the dimensions of the properties most frequently mentioned follows each table. Complete group data for all categories are presented in the appendix.
### Table 9

**Actions Needed/Taken [Interventions]**

(A Sub-category of the Secondary Category “Approaching Intervention”)

<table>
<thead>
<tr>
<th>Properties of Actions Needed/Taken [Interventions]</th>
<th>Number of APS workers mentioning property ((n=16))</th>
<th>Number of references per property</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identifying services needed for self-neglecting elders</td>
<td>16</td>
<td>173</td>
</tr>
<tr>
<td>Seeking involuntary services/overriding clients’ desires</td>
<td>16</td>
<td>75</td>
</tr>
<tr>
<td>Approaching home visits</td>
<td>14</td>
<td>75</td>
</tr>
<tr>
<td>Linking and consulting with physicians and other service providers [squad, police, court, attorneys, other agencies]</td>
<td>13</td>
<td>125</td>
</tr>
<tr>
<td>Offering information and referrals/encouraging seniors to accept needed services</td>
<td>12</td>
<td>74</td>
</tr>
<tr>
<td>Honoring/acknowledging client’s desires and self-determination</td>
<td>12</td>
<td>65</td>
</tr>
<tr>
<td>Receiving and screening referrals, including bogus calls</td>
<td>11</td>
<td>33</td>
</tr>
<tr>
<td>Using or not using a particular practice model</td>
<td>11</td>
<td>25</td>
</tr>
<tr>
<td>Seeking court orders/guardianship</td>
<td>10</td>
<td>81</td>
</tr>
<tr>
<td>Substantiating allegations</td>
<td>8</td>
<td>38</td>
</tr>
<tr>
<td>Talking/explaining/communicating with clients</td>
<td>7</td>
<td>29</td>
</tr>
<tr>
<td>Approaching mental health services/psychological evaluation</td>
<td>7</td>
<td>28</td>
</tr>
<tr>
<td>Approaching abuse, exploitation, and neglect by others</td>
<td>7</td>
<td>16</td>
</tr>
<tr>
<td>Prioritizing client’s rights/needs [over community desires]</td>
<td>6</td>
<td>44</td>
</tr>
<tr>
<td>Identifying services most easily accepted by seniors</td>
<td>6</td>
<td>19</td>
</tr>
<tr>
<td>Gaining access to homes [including challenges and strategies]</td>
<td>6</td>
<td>18</td>
</tr>
<tr>
<td>Working with clients who resist intervention, including strategies</td>
<td>6</td>
<td>15</td>
</tr>
<tr>
<td>Addressing clients’ desire to know who called on them</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>Advocating for independence [trying to keep people in their homes/community/trying to avoid nursing home placement]</td>
<td>5</td>
<td>29</td>
</tr>
<tr>
<td>Keeping cases open/closing cases</td>
<td>5</td>
<td>25</td>
</tr>
</tbody>
</table>

(continued)
| Involving/working with family | 5     | 21
| Having access to services and financial resources in Franklin County | 5     | 16
| Approaching elder self-neglect gently, “with a softer touch” than neglect or exploitation by others | 5     | 13
| Recognizing that [competent] people are allowed to be dirty, live in filth/clutter | 5     | 8
| Approaching hoarding | 4     | 24
| Approaching ethical dilemmas and decision-making about balancing self-neglect with self-determination | 4     | 22
| Approaching finances with seniors | 4     | 20
| Not having the means to get clients help: experiencing insurance, eligibility, and funding barriers | 4     | 17
| Honoring people’s right to refuse services | 4     | 15
| Utilizing Meals-on-Wheels/other in-home meal program | 4     | 8
| Not substantiating allegations | 3     | 11
| Assessing adequacy of current services | 3     | 5
| Being unable to provide long-term monitoring [APS being a short-term intervention] | 3     | 5
| Providing community education about people’s rights | 2     | 12
| Acknowledging clients’ loss and fatigue | 2     | 10
| Switching to a district case assignment system in Franklin County | 2     | 8
| Allowing people time to address the problems themselves/approaching change gradually | 2     | 5
| Looking at things legally | 2     | 4
| Leaving information with/for client | 2     | 4
| Looking for points listed in the referral | 2     | 3
| Considering extended care facility [ECF] placement | 2     | 3
| Calling health department/code enforcement | 2     | 2
| Other properties [see compiled group data for remaining properties] | 14    | 89
| **Totals:** | **16** | **1324**
ACTIONS NEEDED/TAKEN [INTERVENTION]

All 16 workers participating in this study discussed actions needed or taken. Participants made a total of 1324 references to 72 different properties of actions needed or taken. Dimensions are presented here of the ten topics [properties] in this category that eight or more APS workers discussed. Together these ten properties account for 58% of participants’ references to actions needed or taken. These ten properties are: 1) identifying services needed for self-neglecting elders, 2) seeking involuntary services/overriding clients’ desires, 3) approaching home visits, 4) linking/consulting with physicians and other service providers, 5) offering information and referrals/advocating with seniors to accept needed services, 6) honoring/acknowledging clients’ desires and self-determination, 7) receiving and screening referrals, 8) using or not using a particular practice model, 9) seeking court orders/guardianship, and 10) substantiating allegations. Corresponding with table 9, properties are presented in the order of how frequently they were mentioned by APS workers. Complete group data of all 72 properties APS workers mentioned about actions needed or taken are presented in the appendix.
Table 10
Services Needed for Self-Neglecting Elders

<table>
<thead>
<tr>
<th>Services Needed</th>
<th>Number of APS workers identifying need</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homemaker/shopper</td>
<td>8</td>
</tr>
<tr>
<td>In-home medication assistance and medical monitoring (medication administration, visiting physicians, nurses)</td>
<td>7</td>
</tr>
<tr>
<td>Transportation for all needs (not just medical)</td>
<td>7</td>
</tr>
<tr>
<td>Home-delivered meals</td>
<td>6</td>
</tr>
<tr>
<td>Emergency Response System (ERS button)</td>
<td>4</td>
</tr>
<tr>
<td>Major cleaning</td>
<td>4</td>
</tr>
<tr>
<td>Informal care from family</td>
<td>3</td>
</tr>
<tr>
<td>Financial management assistance</td>
<td>3</td>
</tr>
<tr>
<td>Personal care assistance</td>
<td>3</td>
</tr>
<tr>
<td>Mental health and chemical dependency services</td>
<td>3</td>
</tr>
<tr>
<td>Coordination of care (between formal and informal care providers and needing one single, consistent care coordinator)</td>
<td>2</td>
</tr>
<tr>
<td>Socialization/activity programming (such as congregate lunches, adult daycare)</td>
<td>2</td>
</tr>
<tr>
<td>Wellness checks/companionship</td>
<td>2</td>
</tr>
<tr>
<td>Access to assisted living for all people, not just the affluent</td>
<td>2</td>
</tr>
<tr>
<td>In-home services for people who do not meet the level of care necessary for Passport eligibility or nursing home placement</td>
<td>1</td>
</tr>
<tr>
<td>In-home services for disabled people under the age of 60</td>
<td>1</td>
</tr>
<tr>
<td>Financial assistance to meet basic needs</td>
<td>1</td>
</tr>
<tr>
<td>Free services</td>
<td>1</td>
</tr>
<tr>
<td>Minor home repair</td>
<td>1</td>
</tr>
<tr>
<td>Utilizing multiple services to keep people in their homes</td>
<td>1</td>
</tr>
</tbody>
</table>
Services needed for self-neglecting elders

“Services needed for self-neglecting elders” was the most frequently mentioned property in the entire study, being mentioned 173 times and by all 16 APS workers. Workers were directly asked: “What services are most needed? What services are accepted and what services are rejected?” Workers discussed implementing available services and identified unmet services needs. The available services that workers discussed using the most frequently were homemakers, Meals-on-Wheels, and the Emergency Response System (ERS) button. Other available services workers discussed using were major cleaning, personal care assistance, and minor home repair.

The unmet service needs identified most frequently by workers were in-home medication assistance/medical monitoring and transportation. Other unmet service needs identified by workers included: informal care from family, financial management assistance, mental health and chemical dependency services, coordination of care, socialization/activity programming, and wellness checks/companionship. Workers expressed that some of these services are unavailable (such as in-home medication assistance, transportation for a variety of needs, informal care from family, coordination of care, and wellness checks/companionship), while other services are sometimes available but often resisted by seniors (such as financial management assistance, mental health and chemical dependency services, and socialization/activity programming). Sometimes services are available but unaffordable for most seniors.

Workers consistently identified the dimension of lack of available resources when discussing service needs. Workers identified a variety of specific cost, insurance, eligibility, and funding barriers to putting needed services in place. [See also the property “Not having the means to get clients help: experiencing insurance, eligibility, and funding barriers.”] Specific examples workers gave of needed but unavailable service
resources included: access to assisted living for people of all incomes, in-home services for people who do not meet the level of care necessary for Passport eligibility or nursing home placement, in-home services for disabled people under the age of 60, financial assistance to meet basic needs, and free services. Finally, one worker noted that it takes the utilization of multiple services to keep some people in their homes. Each service area is presented here with specific examples of workers' impressions. Corresponding with table 10, service areas are presented in the order of how frequently they were mentioned by APS workers.

**homemaker/shopper**

Homemaker services were mentioned most often by APS workers describing service needs of self-neglecting elders, with eight workers mentioning it. Specific tasks workers identified that homemaker assistance is needed for included: shopping, housekeeping, cleaning, laundry, and escorting people to medical appointments.

Workers stated that most seniors who are not hoarders will accept homemaker services, but that it is difficult to get hoarders to accept homemaker services.

**R2:** “…a shopper going in and doing the shopping for them once every two weeks, and a homemaker going in once every two weeks to clean their house, sometimes is all that person needed to stay home independently.” (p. 10)

**R3:** “I would say homemaker, if it’s very poor- if the house needs some attention.” (p. 10)

**R5:** “…I think homemaking tends to be the biggest impact? Having someone be able to do the laundry, mop the floor…” (p. 15)

**R7:** “If they need to go grocery shopping, have a home care aid, homemaker come in to do the regular cleaning, also go grocery shopping for them. Or some homemakers will even go to the doctor, you know, with the older adult.” (p. 11)

**R8:** From the major cleaning then have them to- try to get them to agree to have homemaker to come in on a regular basis to help clean up, you know, their- to keep their home maintained.” (p. 11)
R9: “You get a homemaker in there. Somebody come in twice a week and stuff, clean up their home and stuff…” (p. 6)

R10: “…we have homemakers, we have homemaker escorts, where people can take people to the store.” (p. 10)

R11: “They will accept someone maybe helping them with housekeeping.” (p. 6)

**in-home medication assistance and medical monitoring**

such as medication administration, visiting physicians, nurses, podiatrists

The most frequently identified unmet service need for self-neglecting elders was in-home medication assistance and medical monitoring. Seven workers discussed it in depth. Workers were passionate about the unmet need of medication administration assistance being a serious gap in the service delivery system. Several workers shared that they hate to have to place a person in an extended care facility simply because the person is unable to independently manage a complex medication regime. Workers also identified the need for visiting physicians and nurses. They consistently expressed that seniors would accept visiting physicians and nurses if such a service were consistently and dependably available.

R1: “I would like to see them have visiting doctors, first of all, come in. They would have to have a visiting doc position. And any other visiting services, whether it be visiting podiatry, visiting anything else.” (p. 12-13); “…if they could have a visiting nurse or somethin’ I think that they would take that. But you can’t always get that, unfortunately. So med set up would be perfect in that perfect world, but it’s just, you know, but they can’t always get that, so…” (p. 13)

R2: medication monitoring and help getting day started in AM and maybe evenings: “It would be great if somebody could come in in the mornings, help them get started on their day, get their medications started, get them started with breakfast, do this contact…and then, you know, maybe they need the same things in the evenings.” (p. 8)

R6: “And their medical. Making sure they’re taking their medications and going to the doctor.” (p. 8)

R7: “The other services that are taken more often, is the visiting doctor, you know. Maybe they do realize they need to see a doctor, but getting out of the home is hard.” (p. 6)
R10: “But like the one main thing that’s missing, that I complain about all the time, is there’s no services for medical attention. Like for example, there- lots of people have either outlived family or family’s not there or they don’t have a lot of informal supports and there’s no medication management. So they’re not getting their diabetes checked, they’re not gettin’, you know, their blood sugars, they’re not gettin’ their medication, they’re not gettin’- They can’t manage. And they’re not incompetent, they just are a little forgetful. And everything else in their lives they manage. There is absolutely no service, unless you can afford to privately pay a nurse, which is usually an RN, to go to a home to help with med management. There’s no service.” (p. 9); “There’s no county that has it, and that is, to me, a lot of st- I mean it could cut- to me it could cut down on hospital visits, ER visits, doctor visit, if you had some type of system set up to where people could afford some type of nursing. So unless you’re Passport eligible, which they do provide nursing, unless you’re really bad, then, you know, you can get Medicaid, or you’re really, you know, you’re really economically burdened or challenged to where you can get Medicaid and get Passport to provide nursing, or you’re really well off financially and you can afford a nurse, there is a gap in services.” (p. 9); “I mean we have people who cant, don’t- I mean they’re on so many medications. I mean twenty some medications. And they’re different times of the day, who could manage that. I mean it would take a lot for me, I would have to keep on it myself. So, it’s not only med set-up in a pill box, but it’s also the management of, possibly some people just need reminders to take, you know just verbal reminders. They don’t need to physically, just, you know. You have- Like I said, you have diabetes. You have people who need to be seen regularly for Cumadin, because of that medication. You have people, who once the medications run out or don’t keep on top of it, to know they need to re-order. So having someone on top of prescriptions. That, you know, they automatically, you know, and making sure prescriptions get sent. And they have the diabetes and they have the glu[ose], you know, there’s a huge realm that’s missing as far as services.” (p. 9); “… home health agencies are paid by Medicare and/or Medicaid, but usually it’s only two to three weeks and you have to be able to be taught. So, and here’s the other thing. People will like get mad, you know, people will say, ‘Yeah but why don’t you do somethin’?’ We’re supposed to institutionalize someone because they can’t manage their meds? You want to institutionalize someone for that? And then they’re like, ‘Well they need a guardian.’ ” (p. 9-10) “…can an attorney be able to keep up with that as well? Can an attorney call someone [to remind about meds]? How many times a day take their meds, or go over and help them with any. No. So does a guardianship, is that really the answer? Is institutionalization of someone based on just med management?” (p. 10); “So in a perfect world, I would love there to be med management.” (p. 10); “…we have, you know, the home health agencies that do provide the medical part of, but it’s like short-lived. And they won’t stay in, Medicare won’t pay for someone to stay in forever, or med management is not billable.” (p. 10); “…I would want medical issues to be addressed with the elderly so they could stay in their home, and actually develop something.” (p. 10)

R12: “I would say most needed services would be a lot of medication issues. People need somebody to come out and set their pills up for them, and remind them to take them. It would save- it seems so sad to have to send somebody to a
nursing home over this little issue. Because they have nobody to set their medications up, and they can’t do it themselves. Not to mention the amount of money it costs to send somebody to a nursing home for that little service. People would be so much happier at their home. And like, for the most part, that service is not covered by insurance, or...” (p. 8); And to me that is the thing I come in contact with the most that would be the biggest thing would be able to keep people at home.” (p. 8)

R16: “I would love to see if we could somehow get it more covered that...the medication issue. You know, right now you have to have a skilled service to have Medicare pay for a nurse to come in. You have to be homebound. A lot of folks don’t meet that criteria. Our local aging program has nurses on staff, but the cannot do medications. So medications are usually a big- the reason people fall, the reason people wind up in the hospital. Medication problems are one of the biggest issues, and, you know, we have some resources, we have some devices to help with that? But if they’re not on Passport and, you know, they can’t afford to normally pay for that. So that’s a big one.” (p. 3)

**transportation for all needs (not just medical)**

The second most frequently mentioned unmet service need was transportation, with six workers mentioning it. Workers consistently identified the need for expanded transportation services so that seniors can have consistent, dependable transportation to go shopping and visit friends as well as transportation to physician appointments.

Workers also identified transportation needs as the unmet service need that seniors themselves most frequently mentioned.

R1: “I would like to see them have transportation for all of their needs, whether it be for banking, grocery, any minute areas, you know, just like we do, you know. We can hop in our cars and go. I would like to have them have that.” (p. 13); “Yeah. If they wanted to go visit friends, you know, that type of thing. I would love to see that happen for our older adults.” (p. 13)

R2: “We need transportation.” (p. 9) “...when I’m that age, I don’t wanna have to go live in a nursing home because I can’t drive to the store, because I can’t get my groceries or I can’t get my medicines. If this person had transportation.” (p. 9)

R6: case example of a senior self-identifying the need for transportation: “…I said, ‘Well, is there anything I can help you with? You know, we have Franklin County Senior Options here, we have all kinds of services available to seniors, and you’re 78.’ She goes, ‘I do need transportation.’” (p. 6); “Well the optimal would be to be able to get, offer them and have them accept it, that’s the other thing, to like, oh, transportation to the doctor’s, transportation to the grocery store.” (p. 8)
R7: Other services that are *definitely* taken is transportation. They *like* that they can get out and about...” (p. 6)

R9: “…and the escort services, and the *transportation*...” (p. 6)

R11: “A lot of our seniors need transportation. They’ll accept that.” (p. 6)

R15: “And transportation’s one of the big issues. ‘I can’t get to the doctor. I can’t...’ you know, anything like that.” (p. 5)

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**Meals-on-Wheels**  
*(see also property “utilizing Meals-on-Wheels”)*

R6: Meals-on-Wheels (p. 8)

R7: “Meals-on-Wheels are *not* as accepted as much as you think they would be...” (p. 5)

R8: “And then also get them Meals-on-Wheels, if they’re not able to cook, their Meals-on-Wheels.” (p. 11)

R9: [delivered] meals (p. 6)

R10: “…we have Meals-on-Wheels...” (p. 10)

R11: “So when you take away the money aspect, most people will accept Meals-on-Wheels.” (p. 6)

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**Emergency Response System (ERS button)**

R3: “Emergency response buttons are really important.” (p. 10)

R5: “My biggest intervention and the one that I’m- my first go to is the emergency response button. Because it avoids so many of the issues, the falls, the fire risk.” (p. 15); “We live and die by ERS. And you’re often able to get that even if they won’t take meals. It’s an excellent way in the door.” (p. 15)

R7: “Most accepted are the ERS, the Emergency Response Systems, ‘cause that still gives ‘em that independence.” (p. 5)

R11: “And then when we explain the ERS button, ya know, most people will think that that’s a good thing to have.” (p. 6)
major cleaning

R3: “We can also do deep, major cleans. And that’d be great if people- However if they’re a hoarder, you know, they don’t wanna get rid of their stuff…” (p. 10)

R6: “…cleaning services. Major cleaning services plus personal care cleaning.” (p. 8)

R8: “…what we try to do, especially if the person is still capable of living in their own home, let’s say that the person’s home needs major cleaning. Then what we try to do is get major- get services in there to do a major clean. From the major cleaning then have them to- try to get them to agree to have homemaking to come in on a regular basis to help clean up, you know, their- to keep their home maintained.” (p. 11)

R9: “We’ve done major cleanin’s for some, but the hoarders have mental health issues. But if it’s like-, certain ones you do major cleaning.” (p. 6)

informal care from family

R8: “…if we lived in a perfect world, I would say the most desired cases that we have, especially if the person has family and they’re self-neglecting, that the family would step up and actually care for the family member. That is if we live in a perfect world. And that’s what we try to do, to see if there’s any family that is willing to care for their older adult loved one.” (p. 11)

R9: “…even more perfect is that you have a family member that did not know this was going on and is willing to [I; Step up.] Yeah. ‘Ok, I’ll make sure everything is paid,’ you know, and, so they’re able to do that and they become power of attorney and they’re not a perp, ya know. Somebody who just wants to make sure their aunt is ok, their grandmother’s ok…(p. 6); “Those are, the most perfect thing are, are informal helping systems come out of nowhere.” (p. 6)

R14: “Oh, if it was in a perfect world they would have a family. They would have a support system. That you could count on.” (p. 5)

financial management assistance

R1: “I would like to see them have case management. I would like to see them have maybe case management combined with financial, you know, paying- like mainly they need just like some sort of payeeship, because, you know, self-neglect always includes their finances. So I would like to see that happen for them. To have that automatically done and case management.” (p. 13)

R6: “…taking care of their finances, I think is really at the top of the list. If you can get that straightened out you’re- you got a- you’re good to go for quite a while.” (p. 8)
R9: “Or you might get into some financial problems if they will allow it. I think we use First Corp? At one time? For financial things...” (p. 6)

**personal care assistance**

R6: “...personal care cleaning.” (p. 8)

R8: “And if the person needs personal care assistance, have a personal care aide to come out and help ‘em with bathing.” (p. 11)

R11: “Well, we can get you a personal care aide that can come once a week, or three days, as many, as much as you want.” (p. 6)

**mental health and chemical dependency services**

[see also property “approaching mental health services”]

R7: “The services I would like to see taken more often would be mental health services. And they’re not. In our mental health system, they have to be willing to take the services.” (p. 6)

R10: “And the other issue is mental health.” (p. 10); And then to have more in-home mental health. You don’t have a whole lot of, you know, 80-year-old people that are schizophrenic will not usually drive or be able to go to a mental health facility, even if it’s community-based. You need more in-home approach to mental health when you deal with the elderly. Because they’re not gonna come to you and facilitate that. Psychiatrists need to get, I mean if you’re going to work with the community, I feel you need to get out of your office and work with the community. You need to be out there, at least at some point. Because you need to see them in their environment. And we deal with a lot of elderly people that are mentally ill, which is difficult for us ‘cause our expertise is not mental health. And then it’s very difficult to get mental health on board. Because they have their own set of rules and laws and regulations that don’t combine with us, so it’s kinda like, you know, it’s kinda hard to co-exist together. (p. 10) Yea, they don’t really take the initiative. I mean we’ll call, you know, I’ve called mental health before and said, ‘I have this blah, blah, blah.’ Well, if they’re not homicidal or suicidal, then you know, no. And I just, I don’t see that. (p. 11) ...from an outside source, when you’re dealing with someone mentally ill, and that’s not my expertise, I really need for there to be more involvement because it is kinda like, you know, if it doesn’t fit something on their paper, then they’re not really, you know, they’re not in there.”(p. 11) [And a lot of times]...the primary diagnosis is really the mental health issue, not the dementia.” (p. 11) Why not get in there and maintain that. And like I said, I don’t think that they go into the community enough. (p. 11) You know, they don’t really go out there. I mean you have some case managers and agencies that do try to go out and see, but it should be more than that. There’s not enough of that. There needs to be a larger system set aside that really do work with the elderly in mental health because you see a lot of paranoia, lots of anxiety, things like that. And it’s just like, you know, I’m not a counselor, I’m
not mental health, I can’t do that, you know. I can just try to link them the best that I can and try to help ‘em, but that’s not my expertise, so…” (p. 11)

R16: “Easily the most resisted are psychiatric treatment. Chemical dependency. If you’ve got an elder who happens to have a chemical dependency issue, whether it’s alcohol or prescription drugs, tend to be the two things that we see among the seniors, acknowledging that there’s a problem and then getting them access to the help. And a lot of folks don’t want to be seen as, you know-, a lot of times when I do an assessment, they’ll say ‘Well, I’m not crazy, I’m not crazy,’ you know. Self-neglect folks tend to worry that people are gonna see them as crazy, so that’s the one that I think is the hardest. And also lack of resources. It takes a good six months to get in to see a psychiatrist here in the area.”

coordination of care such as between formal and informal care providers and needing one single, consistent care coordinator

R8: “Also, if there’s family members involved and that will actually come over, maybe the home health care agency can actually coordinate, you know, coordinate with one another, you know, some type of time to where the home care agency would come in and perhaps a family member, you know, can come in and work, you know, around the home again.” (p. 11)

R13: “I think probably havin’ someone goin’ out there on a consistent base. Like we can’t do the constant follow-up? You know, we make the referrals, we link them with the services, but someone to kinda be there during the transition of those services being in place. And in monitoring those, as they’re in place to see if they’re appropriate, if there’s more, if there’s less that’s needed. You know, we’re not able to really follow that. And even with the Senior Options programs or Passport, I mean, they’re only out there maybe once a quarter or somethin’ like that. So if we could, you know, have someone that’s consistently goin’ out just to monitor how things are goin’ for them. Seein’ if there’s any change.” (p. 5); “And then there’s so many case managers and social workers that are involved, and a lot of times it’s confusion. So if they just had that one, just for that consistency, I think that would be great. And a lot of times with the homemakers, the services, you have one that’s comin’ in, and then they get used to that person and there’s turnover, so there’s a lot of high turnover with that. I don’t know if that can ever be addressed. I think it’s just the nature of the beast there, but, you know, it’s easy for them to build a rapport with one person, and havin’ them comin’ in. And so I guess if we could do that, that would be good for our clients.” (p. 5-6)

socialization/activity programming such as congregate lunches, adult daycare

R1: adult daycare and other senior programming such as congregate lunches (p. 13); activity programming including challenging minds to keep memory, “keepin’ their mind goin’ ” (p. 26)
R6: “...I would love to take some of these people and get them out of the house. Not in-house, but ‘Hey! Let’s go out and visit people of your same age or in your neighborhood. [I: Like Senior Friends?] Yeah, Yeah, like a dining center. Take ‘em out to a dining center.” (p. 9) “Take ‘em there, get ‘em somethin’ to eat, a little socialization...and if it’s in their neighborhood somebody they might know even, you know, is there havin’ lunch too. And they’ll- they all resist that usually.” (p. 10) “But one – If you have somebody, an escort to take ‘em the first time, like a hostess? And you get ‘em out, they start feelin’ better ‘n they start cleanin’ up, ‘n if physically they’re able to do it, I wish we could do it.”

**wellness checks/companionship**

R1: “Why aren’t there more programs out there that go to just simply check on a person, just a wellness check.” (p. 26): “Because when you do a wellness check, it comes along with companionship, and that companionships is something that older adults really look for. Because sometimes when people are neglecting themselves, they don’t have any stimulus, you know what I mean?”

R15: “Somebody just calling ‘em. They’re lonely. They don’t have somebody checking on them on a regular basis. That and the- well, the eating. If an individual had somebody to prepare a decent meal for them they would be better off. Nobody wants- A lot of times they don’t wanna eat alone. So they choose not to eat at all. But if somebody was there at the time they were eating, and sat down and ate with them they wouldn’t have a problem with it. So I think that is the- being lonely.” (p. 6); “That’s a biggie. I mean, they’ll say to me, ‘You can come back any time.’ And they wanna just have somebody to talk to.” (p. 6)

**access to assisted living for all people, not just the affluent**

R9: few people being able to afford assisted living (case example): “When the time would come, she would be one of those ones, very few ones, who would probably go to assisted living.” (p. 3)

R14: “There would be alternatives between a nursing home and the home life. So they would be, like for poor people, there would be assisted living that’s a medium ground, instead of just putting them- ‘Cause I get a lot of people that live in the community that can no longer live alone, do not, you know, don’t have a support. It’d be nice to be a support. That middle, like an assisted living for people with low income. [Interviewer: Right. Because now only affluent people can get assisted living.] That’s correct. And the waiting lists. They have Medicaid beds? But it’s, [I: (simultaneously) I’ve got a friend on,] it’s ridiculous. [I: on one of those waiting lists. It could take years.] It’s ridiculous. [Yeah. Yeah.] I have many clients right now that could benefit, but instead of the nursing home. They’re physically just not capable of being in the community, but there’s also not appropriated for the nursing home. So I’ve left them in the community, where I think they would thrive in an assisted living. So they’re on a slow decline in the community, whereas in assisted living, I think we would see a steady improvement. So that’s those where you see people say, ‘Well, we have to close it
in like six months.’ Those, a lot of those cases, if we could take- get them into a nice assisted living environment, I think they would thrive.” (p. 5)

_in-home services for people who do not meet the level of care necessary for Passport eligibility or nursing home placement_

R4: “What’s really needed is home services to clean, run errands, and do some personal care need without having to meet the level of care for passport, or for nursing home placement. Without having to meet that level of care. Is what’s really needed. I’m sure that’s said about the- across the board.” (p. 5)

_in-home services for disabled people under the age of 60_

R16: “In our county, we do a really good job through our aging programs of providing a lot of different home-care services? But right now, other than the meals program, there’s a waiting list. You know, and if you happen to be under the age of sixty, and- there’s a real lack of resources. You could be fifty-eight or fifty-nine and disabled, I have a lack of jurisdiction and there’s a lack of resources for that person. But we have a lot of folks that fall in that category. So the perfect world would be the money to treat the problem and the acknowledgment by the client that there is a problem.” (p. 2-3)

_financial assistance to meet basic needs_

R2: financial means to get their food, their medication, pay their utilities (p. 10)

_free services_

R11: “Well, any services that are free are usually accepted.” (p. 6); “’Cause a lot of our clients say, ‘That sounds good.’ And then they found out maybe they have a ten dollar co-pay or something, and that changes everything. ‘I’m not payin’ for anything.’ ” (p. 6); You know, that generation is really hard to part with a dollar and they don’t-, they would rather not spend money on themselves. So that’s a big obstacle.” (p. 6)

_minor home repair_

R10: “...we have minor home repair...” (p. 10)

_utilizing multiple services to keep people in their homes_

R9: You get literally the services in there to keep ‘em in the home that usually- when those work out, that’s really good. And then they’re able to stay there. And you get a multitude of services to keep ‘em there.” (p. 6)
Linking and consulting with physicians and other service providers

Linking and consulting with other service providers was one of the three most frequently discussed themes in the entire study. 13 APS workers made a total of 125 references to linking or consulting with physicians and other service providers, revealing linkage and consultation as their primary intervention activity. Only the themes of identifying services needed for self-neglecting elders and of assessing mental capacity and were mentioned more frequently. Workers discussed linking and consulting with physicians, behavioral health specialists, emergency squad paramedics, police and fire departments, courts, attorneys, guardians, health department/code enforcement, PASSPORT and other agencies.

working with physicians

Consulting with physicians and behavioral health specialists (expert evaluations) was the linkage activity workers mentioned most frequently. Most workers said that to override people’s wishes or force changes, they need an expert evaluation stating that a person is impaired to the point of being unable to rationally make decisions. Other dimensions included: asking people’s primary care physicians or hospital physicians to complete expert evaluations, noting that APS does not need a person’s signed consent to release information during an investigation, discussing conflict between ORC and HIPPA law mandates and differences in physicians willingness to release information, and working with visiting physicians and nurses.

Dimensions of workers thoughts on seeking expert evaluations ranged from worker’s stating that only an expert evaluator can determines a person’s decision-making capacity, to workers consulting expert evaluators for borderline cases, to workers
factoring in collaterals' opinions but recognizing that it is just that, an opinion. Specific examples of workers' thoughts on seeking an expert evaluation included:

**R1**: requesting a cognitive/psych evaluation before overriding elders’ wishes (p. 19)

**R5**: overriding elders’ desires only when impaired judgment has been determined by a Behavioral Health Specialist (BHS) assessment (p. 17), having 2 options in Franklin County, Netcare or private BHS (p. 17)

**R11**: needing an expert evaluation to force changes: “In the eyes of- I can’t go anywhere unless I have that evaluation. I can’t take the next step. (p. 10)

**R5**: getting an outside assessment if worker is unsure of client’s level of understanding: If I’m real fuzzy on it, I’ll ask for an assessment. But I ask-, you know, we ask real cause and effect questions.” (p. 18)

**R10**: getting expert psych evaluation in home if client can’t follow through with plan (p. 14)

**R11**: getting an expert evaluation when a person is not following through or appears confused: “And if I’ve gone through what I think would be a reasonable amount of time to let this person do things for themselves and it hasn’t happened, then I’ve gotta take it to the next level. The next level for me is getting our psychologist out there.” (p. 9); “But when I get to that point where, yeah, I think they’re pretty confused, I need to get the doctor. And then, you know, work with the doctor.” (p. 9)

**R2**: asking other agencies who have nurses and doctors to conduct a mini-mental state exam: “No, I don’t. [use a mini-mental status]. But we’ve often asked other agencies who have nurses and doctors, that, we’ve asked them to do that, yes.” (p. 17)

**R11**: needing an expert evaluator to make the determination of “competency”: “Yeah, I mean, if you’re a competent person, but...who makes that determination? It has to be a doctor. It can’t be me.” (p. 8) “I’ve got to get a doctor to say, ‘This persons is very confused. They probably have beginning dementia or Alzheimer’s.’ ” (p. 8)

**R15**: consulting with doctors: referring back to doctor on borderline cases; explaining to borderline clients that as long as a doctor states they are able to live on their own, unsupervised, worker won’t push any services, (both p. 2)

**R7**: using client’s doctor to get a psychiatric evaluation if needed (p. 7); “I’ll go to their doctor. I’ll call their doctor.” (p. 8)

**R7**: finding client’s doctors 40% to 60% of the time (p. 9); using visiting physicians when client’s physician can’t be found (p. 9)
**R13**: case example of having hospital physicians compete expert evaluations: “...I had the client assessed there, for competency. ‘Cause I was kinda - I was in the process part to her goin’ to the hospital but since she was there, they went ahead and did the psych eval, and they did the- completed a statement of expert evaluation.” (p. 6-7)

**R13**: hospital physicians completing expert evaluations: “Yeah, they’ll do that. They do that quite often, actually. You know especially here with the hospitals, ‘cause they’re very familiar with our program and what we do. We make a lot of referrals though. Yeah, they’re really good about doin’ that.” (p. 7)

Workers consistently stated that they do not need a signed consent to release information when conducting an investigation mandated by state law. Workers also identified conflict between HIPPA laws and the Ohio Revised Code (ORC) mandate to investigate suspected abuse and neglect as presenting an ethical dilemma for physicians and thus a barrier to communicating openly with physicians. Workers discussed strategies for handling this dilemma, including getting people to sign consent forms even though not legally required, developing a form that indicates to physicians that a consent form is not needed according to the ORC, and ways of approaching physicians reluctant to release information.

**R8**: APS not needing a Release of Information to consult with a person’s physician: physicians are mandated reporters per Ohio Revised Code so client consent to release info is not needed because we are investigating the case (p. 3)

**R7**: “APS does not require a Release of Information. Because we are investigating. [I: Right, right.] Yeah. Now that doesn’t mean that doctors don’t wanna throw HIPPA up at us. But if they throw HIPPA at me, I throw the Revised Code at the {unintelligible: ―doctors.‖?}” (p. 8)

**R15**: even though not required by law, needing in practice a consent to release information to speak with physicians: “With individuals here in Pickaway County, I can’t get anywhere by callin’ a doctor and askin’ for information. I have to have a release.” (p. 2) “I don’t even wanna rock the boat ‘cause I want the doctor to cooperate with me, so I’ll just ask the individual up front for a release and not even cross that bridge.” (p. 3) “I’ve done this for eight years now, so when before HIPPA even started, I had no problem at all callin’ the doctor and talkin’ to them. And the nurses, and they were- have been very cooperative, but now everybody’s scared. They don’t wanna give any information without a release.” (p. 3)

**R15**: Cuyahoga county APS having a form they send physicians that explains why APS doesn’t need a release: “And I’ve been to OCAPS, which is Ohio Coalition for
Adult Protective in their workshop, and what they have—kind of information they’ve given me is, the Ohio Revised Code, or your HIPPA law, there’s a line in there. And I’ve asked this one other county, she’s from Cuyahoga, if I’ve pronounced that right. But she’s got a sheet of paper that she can send to a doctor and say, ‘I don’t need to have a release.’ And I said, ‘I need that!’” (p. 3)

R7: approaching physicians who may be reluctant to release information: “I always make it clear to them, ‘Well, if you don’t want to give me the information, when she’s in here twenty times a week and you’re calling me because you want me to come deal with her, then you need to show thought about dealing with me before.’ I will never make it their responsibility, but I’ll put into a light because there is clients who will walk in doctors’ offices, ‘I fell, I need this, I need this, this and this and this’ and drive the doctors up the wall and then they call us. So I’ll put it back on them. ‘Well, that’s what’s gonna happen.’” (p. 9)

R11: some doctors not requiring a signed consent form to release information: “And some doctors don’t require anything. They’ll tell you whatever you need to know.”(p. 10)

Workers discussed differences in physician’s willingness to conduct expert evaluations. They noted that some physicians do not wish to complete expert evaluations due to HIPAA (Health Insurance Portability Accountability Act) laws, not wanting to damage their relationship with their patient, or not wanting to perform psychological assessments.

R11: family physicians sometimes agreeing to complete expert evaluation and sometimes refusing: “…first I’d try with the family physician. Sometimes, if it’s been an ongoing problem and they’ve seen the decline in the person, they will be happy to do the competency eval. That’s [I: That’s expert evaluation.] what we need. Expert evaluation. That’s what we need. Some physicians, they don’t want to wreck the relationship they have with the client? Or they feel they’re not qualified. In terms of if it’s just- you know, a family physician doesn’t feel like he can psychiatrically examine this patient, he’ll say I’d rather not do it. If we can’t get anywhere with the family physician, then we have a physician, actually he’s a psychologist, who we can get to go out. And he has a very high success rate of getting in to talk to the person. And then he does his assessment.” (p. 7)

R11: some doctors not wanting to complete an expert evaluation: “But there are doctors, some doctors that will just say, ‘Look, I’m not their psychologist. I don’t wanna get involved in that side of their life.’” (p. 10)

R8: physicians sometimes not completing expert evaluations: “And like I said, they are one of our required mandators to report abuse to Adult Protective Services. So most of the times the doctors, you know, I really haven’t had any problems at all with some of the physicians cooperating with us? However, we have, I have had experience where maybe a couple of physicians will not complete
the Expert Evaluation because they do not feel that Adult Protective Services need to be involved, or that they feel that the person is not to the point where they are not able to make their decisions anymore. But as far as speaking with us, I really haven’t had a doctor that was not willing to at least cooperate, to speak and explain their reasons why or why not they will not fill out an Expert Evaluation.” (p. 3) “They can fill it out and put deny. Or, ‘cause there is a space for Expert Evaluation. But a lot of them just will not fill it out. And would tell- or the experiences I’ve had, and just tell me the reasons why they won’t fill it out.” (p. 3)

Workers discussion of using visiting physicians and nurses included: noting that visiting physicians and nurses having lower thresholds for recommending involuntary intervention than APS, workers having to explain laws about clients’ rights to other professionals who want involuntary intervention, and using visiting physicians for medical assessments when possible.

R11: visiting physicians and nurses having lower thresholds for wanting involuntary intervention than APS: “Visiting physicians usually visit once a month. So we try to keep a good relationship with them in terms of communication and what they’re seeing and… but the medical law is much different than the way we work. They’re more alarmists. You know, if they see anything wrong, they want something done, and we’re more of, ‘Well, we have to go by the law. We have to do what this person has rights.’ You know, is what it comes down to. And we’re having to explain that all the time.” (p. 5); “They think if a person doesn’t take their medication, oh, they should be in the nursing home. You know, it’s the end of the world, but... There are some, you know, life-threatening medications, and there are medications that, you know, if they don’t take it, they don’t take it. It’s not a matter of life and death. (p. 5).

R2: using visiting physicians for medical assessment when clients will allow it: “And we do have doctors who will go to the home if they’re Medicare. But also those doctors hands are tied if the person’s refusing to see them.” (p. 19); “Ok. Here’s our problem. We do not have a doctor who will go to a home if the patient will not voluntarily say ‘Come to my home.’ ” (p. 17)

R1: case example of using a visiting physician for a medical assessment: “So they came out there and they did everything. They had, like, portable X-ray machines, and portable this, and portable that. So they came out there and they did their thing, and she was ok.” (p. 7)

**working with ambulance paramedics**

APS workers consistently noted that emergency squad paramedics differ in their willingness to transport people and that they will not treat or transport an alert person.
who refuses treatment. Workers shared techniques of handling this dilemma ranging from contacting supervisors to involving physicians to “telling little white lies” so the squad will take a person. Workers shared case examples of working with paramedics and working with dying people. Workers stated that they avoid using an ambulance for transport when possible and noted that seniors do not like to call the squad.

**R5**: avoiding using ambulance (and court orders) when possible: “I convinced a daughter to come and drive here [to the hospital] because I didn’t wanna have to do the big scary ambulance stuff. You don’t want to have to do court orders if you can avoid it. Not only are they unnecessarily frightening, it’s such a big process, if you can just do it more gently. You’re just adding to the stress if you come with police and we come with ambulances, ‘n ‘Ah, it’s terrifying.’ ” (p. 9)

**R6**: “And seniors don’t like to call the squad. Well I wouldn’t wanna call the squad for myself.” (p. 14)

**R8**: paramedics differing on willingness to try to talk people into going to the hospital: “I would have to say, it will also depend on what paramedics that you get that will be able to talk the person into goin’ to the hospital. And in some cases, they have, the- some paramedics have been successful in talking, in persuading and the client says ‘Okay.’ In some cases, no. If they refuse to go...no. They won’t take ‘em. Without an Order [of protection].” (p. 10)

**R13**: working with Emergency Medical Support [emergency squad]: “A lot of times they’ll come out, sometimes they’re more helpful and sometimes they’re a hindrance, because, you know, the first thing they’re gonna do is they’re gonna ask ‘em, ‘Well, do you wanna go?’ ‘No.’ Then they’ll ask ‘em a few things to see where they are competency wise, and they’ll say, ‘Well, we can’t force her.’ So, I’ve had to call like supervisors and say, ‘Listen, this is the situation. I’ve been out here, you know this is what’s going on.’ ‘N they’ll typically say, ‘Okay.’ ” (p. 10); “We’ve had to do that quite a few times because we’re like, ‘Listen. I’ve been involved this long, this is what’s goin’ on.’ ‘You know, it could look kind of amazing, you’re like ‘Well you see that this person, medically...’ I mean, they need to get to a hospital, and they’re flat out refusing, but, you know, like I said, I had to go over their head a couple times. And so that’s worked. I mean sometimes it hasn’t, but for the most part it has. We work in different districts, on different sides of town. And on the west side, I have to say, that those squads, they’re very good in dealing with that. So that helps. A lot.” (p. 10-11)

**R13**: “So we’ve had some good rapport with a lot of the supervisors there with EMS, but sometimes the first responders are very reluctant.” (p. 10)

**R2**: squad being unable to take an alert person who refuses: “We have been in situations where we’ve called the squad, the squad will come in, but if the persons refuses, there’s nothing we can do. Absolutely.” (p. 18)
**R2:** extenuating conditions under which squad will take somebody who refuses treatment: “Unless the person would end up being unconscious right there in front of the squad members. Or if they were in obvious-, if they were obviously not able to, for lack of a better word, if they were incoherent, or crazy, or whatever the word you wanna use.” (p. 18); “Well, ‘cognitively impaired’ won’t even necessarily mean that they- the squad will do anything.” (p. 18) “Yeah, something very dramatic for the squad to be able to say, you know, we’re gonna make this happen. Yeah. And usually I think it’s uncon[scious].” (p. 18)

**R4:** case example where squad would not take a person needing immediate medical care: “Same as with the ER squads’ll come, you know, and they can pass the mi-mental, I’m goin’ ‘No. They’re not competent. You need to take ‘em.’ And...so. Yeah, there’s been one time where a lady, we found her, fetal position, atrophied in it, laying in her own waste for who knows how long. Knew the president, knew the date, her date of birth, and knew today’s date because the newspaper was right there. Squad would not take her. We had already spent two hours with her. Squad said ‘We’ll take her if there’s a diagnosis of dementia.’ I called the doctor, doctor refused to give me it, even after I told him what was goin’ on in the home because of HIPPA. So I gave the doctor the opportunity “What liability are you gonna take? I’ve just informed you of an abuse situation, which liability are you gonna take, HIPPA or not reporting?” [I: And what did he decide?] He decided to not report. [I: Wow!] Yeah, He wouldn’t give me whether or not there was a dementia diagnosis or not.” (p. 2) “But the squad wouldn’t take here ‘cause she would scream every time you went to go pick her up. Well, she was screaming ‘cause she was riddled with- she passed away three days later, she was...cancer.” (p. 2)

**R11:** doctors having a higher success rate [than APS workers] getting squad to take clients who refuse: “But if a doctor sees it, and they call the ambulance when they’re there, sometimes they can get them to be taken in. But we don’t always have a doctor there at the time we need them.” (p. 8)

**R2:** case example of calling a person’s physician and the emergency squad for a dying person who wished to die at home: “We did contact the doctor, we contacted the squad. She made her wishes known to everybody.” (p. 14)

**R6:** case example of telling little white lies to the emergency squad paramedics to get them to transport a person to the hospital: “My experience with the squad is you tell little white lies. Or you don’t tell ‘em certain things. So they will take ‘em. There’s a lady out in Reynoldsburg and she was a cigarette smoker and I said, ‘Okay, you can smoke up until you hear those sirens and you put that out because those guys will not transport somebody that smokes. Or that’s been sitting there puffin’ on a cigarette.’ So she did, but, you know, we had to exaggerate that she had fallen, and she doesn’t remember gettin’ down stairs. Well, she really didn’t, but she could tell them all about this ‘cause we had just been talkin’ about it. So you try to get the squad to take her, and it’s always been for the best when they have.” (p. 14)

**R6:** case example of helping a dying person prepare for the squad to come: “I called the squad, but first...I had to take her into her bedroom, change her, wash
her butt, put on her good underwear, get her ready. [I: She wanted you to do that before the squad came.] Before the squad came. And then when I finally said, ‘It’s called.’ She goes ‘What, what?’ She got all mad because I called it. And then as soon as those cute good-lookin’ firemen walked in you shoulda heard her performing. And do you know that she died two hours later. [I: No kidding!] Yeah, she had me sittin’ there holding her hand and all that stuff. And I had just gotten up and left and she coded.” (p. 13) “Oh yeah, they took her. She died in the hospital.” (p. 14)

**working with police and fire departments**

Workers noted that the use of police differs in different communities, with smaller communities using the police more often in cases of elders self-neglect. Workers noted that the police will not “pink slip” a competent person (take a person into custody for their own safety) unless the person is expressing immediate intent to harm. Workers shared case examples of working with the police and fire departments, including cases where the police or fire departments have asked APS to intervene.

R3: use of police back-up being different in different counties: “In Delaware, it was more frequent. I haven’t every used it here in Columbus in the last two and a half years. In Delaware, more frequent. An’ I only think if it because, maybe just the Council for Older Adults or the community up there was like, ‘Oh, we wanna help you out. We wanna make sure you’re safe.’ And anything- it seemed like, maybe, any seedy house up there? It was like, ‘Oh, you better be careful, we’re comin’ out with ya.’ I’m like, ‘That’s great, but you know, do you really need to be there involved, an’ lights and siren up there, an’...” (p. 9)

R4: rural mental health agency sending police out: “They don’t make home visits.” (p. 8) “They’ll send the police department out. ‘N then the police department goes ‘Oo-o-o, we don’t know what to do. And then the police department calls me! Whether they’re sixty or not!’” (p. 8)

R2: “If we go to a home and we have an elder adult who is refusing to see a doctor, and there is nothing anywhere stating that this person is not competent, they need intervention...there’s no police interaction. Sometimes the police can be involved where there’s a pink slip situation. But the police will only pink slip if the person is right then and there expressing the- they’re gonna hurt somebody, or they’re gonna hurt themselves, that kind of thing. Seldom does that ever happen, when you need it to happen, of course.” (p. 18)

R9: case example of fire department chief asking APS to place client due to excessive 911 calling: worker explaining to fire chief that the court found client competent and asking them “What would you do with a competent person?” [They’d charge her with something] (p. 5); “Well, that’s what you’ll have to do
because they’re sayin’ that she is competent. I can’t stop her from doin’ it.’ So they say, ‘Yeah, next time we will do that.’” (p. 5)

R9: police not taking client in because her son was a deceased cop: “He was a cop, and when I got the report from the police, they said the only reason we didn’t take her in, when she was goin’ off, we knew her son. …He was on the police force with us.” (p. 7)

**working with the courts: judges, attorneys, and guardians**

Workers shared their experiences of working with court personnel. [see the discussion of the property “seeking court orders/guardianship” for more information on this topic.]

R2: case example of person experiencing severe self-neglect having police and court involvement (p. 16)

R9: working with attorney (guardian) to have a person transferred to Boston where she has family (p. 5)

R9: working with attorneys (guardians) “you find out more information,” (p. 5)

R13: case example of working with court-assigned attorney (p. 7)

**working with the health department and other agencies**

Workers mentioned working with the health department (code enforcement), linking with other agencies, and consulting on cases with APS colleagues. One worker in a smaller community described a more personal relationship between the health department worker and the APS worker than exists in larger communities. She noted that they sometimes make home visits together. This does not typically happen in larger communities.

R4: making referrals to health department when there is a health department issue (p. 1)

R4: “But if it’s not fixable, because we’re a small community, we have the health department. And we actually, due to a lack of better words, we’ll go in, ‘Okay, you’re the bad guy, I’m the good guy.’” (p. 11) “And I’ll need them to do that sometimes. And a lot of times that’s how we keep ‘em out of court.” (p. 11)
R2: initiating passport (p. 8)

R2: getting peer feedback from APS colleagues (p. 12)

Seeking involuntary services/overriding clients’ desires

APS workers were asked to describe their experience with seeking involuntary services for self-neglecting elders. Sixteen workers made a total of 75 references to seeking involuntary services or overriding clients’ wishes. Workers consistently identified competency and safety as their central concerns when considering overriding clients’ wishes. Workers identified petitioning the courts for court-ordered services as a “last choice” method of implementing needed but unwanted services. [See property “seeking court orders/guardianship” for more on the specific process and issues involved with seeking involuntary services through the court.] Workers consistently emphasized that they prefer to try to convince people of the need for services rather than seek involuntary services and that they rarely seek court orders for involuntary services. Three workers mentioned the probate court standard of imminent risk as being potential loss of life or limb within a 24 to 72-hour period if intervention does not occur.

Some workers provided case examples where they felt compelled to override clients’ wishes. Other dimensions workers presented of seeking involuntary services included: noting that often times something bad has to happen before they can intervene, allowing the clients time to try their interventions before seeking involuntary services whenever possible, and acknowledging people’s fears about being institutionalized against their will. One worker noted that an APS home visit itself is an involuntary service and another worker shared that it is uncomfortable asking people with cognitive impairment to sign a case plan informing them that they are going to be taken to court. Examples of workers’ thoughts on seeking involuntary services included:

R1: seeking involuntary services when they’re “hitting rock bottom” (p. 22)
R2: something bad having to happen before involuntary intervention takes place: “A lot of times those situations come down to, sometimes something bad has to happen before we can [intervene].” (p. 18)

R3: overriding elders’ desires: “Probably when I see that they are in danger themselves. Or they’re puttin’ somebody else in danger. That’s the main thing. N’ that I can clearly see that, you know, they’re really not understanding consequences.” (p. 14)

R3: example of reason for overriding elders’ desires: “...if he was doin’ somethin’, leavin’ the stove on, you know, I’d have to say, that’s when you need to have the mental health evaluation competed.” (p. 14)

R3: “Involuntary services. I’d have a pro-you know, protection orders, even though people didn’t want those. Just to provide safety for that client. Other ones would be the guardianships that I’ve done.” (p. 14)

R4: court-ordered services are rarely sought: “We really don’t do too much. One to three a year. Yeah. So, and by the time we go to court, we’ve got neighbors, and everything, you know. We don’t go in empty-handed. Our judge won’t like that. But, in regards to the elders, when we’re doing involuntary action, it’s usually based on competency. They are usually so clueless that they don’t even recognize that it’s ha- And I hate to say that about somebody, I really do. But they’re usually so clueless they don’t recognize it’s even happening. And I feel funny havin’ ‘em sign the case plan, saying that I’m gonna do this, and this is that I did explain it to you, ‘cause I know full well they’re not grasping what I’m saying. You know? ‘N I come pick ‘em up, ‘n I’m a happy face, ‘n they get in the car ‘n they go to court with me!” (p. 9)

R5: rarely seeking guardianship: seeking guardianship one time in four years in case of family financial exploitation “I am not prone to doing it.” (p. 17)

R6: worker being directive with client when “something is not gonna work” (p. 11)

R6: examples of forcing services: being directive with a client needing emergency medical care (p. 13); forcing client to move from unsanitary, unsafe home: “Yeah, I bet she just wanted to die. But...and, and she was, but I told her she wasn’t gonna die in that mess.” (p. 12); worker forcing services when clients know conditions are wrong, for example financial exploitation by granddaughter or grandson when seniors “...are giving them money, and they’re not paying their own rent and they know that this is wrong. I mean they, they do understand what they’re doing.” (p. 12)

R7: case example of involuntary removal from vermin infested home filled with animals and animal feces: “I had to tell the grandson, you had to come get her out of this house. She didn’t want to leave this house. I said, ‘Well I’ll be willing to work with you to get this hose cleaned up. If she can pass an expert evaluation
and tell me she’s competent. But in the meantime, she can’t be here.’ Because I know City Code was coming to close that house down.” (p. 8)

**R8:** having to override client’s decisions when they are unable to care for self (p. 10)

**R8:** case examples of overriding client’s decisions: insisting client get medical assessment immediately (p. 9), “...she was really in a situation where I truly felt at that time that she really needed medical attention. However, she was refusing to seek medical attention. So in this particular case, what I did, is I explained to her that if she did not seek medical attention at all, then I would have no other choice, but to go and get a court order to have- to make here go to the hospital to seek medical attention. ‘Cause I couldn’t just leave her there in her situation. And her friend was there also to help encourage her. [ I: That was lucky.] Right, that was a lucky situation. In that particular case, she did decide to go so I wouldn’t have to actually go and get a court order.” (p. 9); different case example of having to get a court order of protection for client to go to hospital: “She refused. At that time there was no family members, friends or anybody to help encourage her to get the services. So what I ended up having to do at that particular time was go to court, and seek the assistance of our Prosecuting Attorney, get a court order to have her removed from the home by force, if necessary with the police help as well as be able to call the paramedics.” (p. 10)

**R9:** to override client’s self-determination: “It has to be really severe and the client has to be, I mean evaluated to the point where they can’t function.” (p. 8)

**R9:** having no choice [but to override elder’s desires] when people are really bad off and won’t use helping systems (p. 8)

**R9:** examples of involuntary services: stopping seniors from driving (p. 3); having to move a client (p. 7); worker saying to client who didn’t want mental health services: “The only way I’ll help you, (‘cause they were evicting her)...is that you agree to...elder treatment and focus.” (p. 7)

**R9:** APS worker showing up is an involuntary service (p. 6)

**R10:** seeking involuntary psychiatric evaluation if after numerous visit a client is incapacitated and their needs are consistently not being met and the client is refusing services without providing an alternative to meet need (p. 12)

**R11:** seeking involuntary services: “Well, the competence, competency assessment, I mean, we do that. I don’t want to be the sole responsible person, and I’m not, it comes down to a doctor. It’s usually when a client needs help and is refusing. It helps finding them to be very confused about certain things.” (p. 7)

**R12:** “I definitely, in an emergency level has to be loss of life or limb, to go seek an order to override their wishes. Otherwise, I just feel like if somebody was in danger of their safety. But I know usually when we do go seek a guardianship, you know, I’m pretty confident that they’re incompetent. And they’re just not seeing the outcome of their decisions.” (p. 9)
**R12:** examples of reasons for seeking involuntary services: health, finances, dementia, utilities turned off, unaware of kitchen fires (p. 9) “So, things like that, you just can’t be out there anymore. You know, if it’s an unsafe situation.” (p. 9)

**R13:** seeking involuntary services: “Well, wh- if I feel there’s an imminent danger there. If they’re, you know, I’ve had to have a few of the emergency orders to have them just receive medical care. You know, I mean there’s times when you’re goin’ there and you’re seein’ that there’s a deep wound infection, and there’s maggots in there, and they’re sayin’, ‘Well, you know, I can treat-’ No, you know you really need to have someone intervene here. If I feel that they’re gonna lose a limb, or their life, within 24 to 72 yours I’m goin’ right up there to Probate Court, you know, sayin’ what I saw.” (p. 6)

**R13:** case example of the process of seeking involuntary services: “…but since she was there [hospital], they went ahead and did the psych eval, and they did the – completed a statement of expert evaluation. And they were, they suggested that, you know, she does need to have a guardian established. So at that point I went ahead and approached Probate Court, and then an attorney picked up the case and so I’ve been workin’ with him ever since.” (p. 6-7)

**R13:** acknowledging people’s fears about being institutionalized against their will: “…because there’s a point where you’re allowing them to make the decisions, but if you see that it’s dragging on for a week or two, and they’re physically getting worse, their interventions aren’t working ri-, you know, I’ll tell ‘em. ‘Okay, you tried this.’ You know, ‘We’ve allowed you to go this route. But it’s just not working. When you’re- you know, I see you declining.’ And, you know, there’s been a lot of resistance, but in the end, you know, if we’ve had to get involved to get orders of placement or for, for the medical care, typically, after that they’ll say, you know. ‘Thank you, ‘ because I think a lot of times there’s that fear there? You know, if I’m goin’ into the hospital, what’s the next step? You know, I’m older, I don’t have any family members, you know, what are you gonna do? Put me in the system, leave me there?” (p. 7)

**R13:** having to “come there very abrupt” in some situations (p. 10): for example, getting people out of home for medical conditions, explaining to client “Okay, obviously you’re not able to see the scope of this, and we’re gonna take you to the emergency room. Now, when you get there, you know, that’s on you, but we have to take you because we’re seeing you in this condition.” (p. 10)

**R14:** seeking involuntary services: “Again, case-by-case. But I tend to do it if they just really don’t have good judgment, and it’s just come to point where I just think there’s lot of safety problems.” (p. 7) “And if they have zero insight into it, then I tend to take more of a control.” (p. 7)

**R15:** overriding elder’s desires: “When they’re at risk. If a doctor’s telling me that they-, I always refer back to the doctor. And tell them, you know, ‘I understand that you want to remain in your own home. That’s what I want for you, too. But I have a doctor stating to me that you are at risk if you stay here. If you don’t have the services in place. So you can choose on your own...those services. If you don’t
choose those services, and I still have the doctor saying you can’t remain in your own home, then I will have to go to court.’ And I will be happy to say that in the years that I have done this, for eight years, I’ve only had to go to court three times. So, a lot of the times they do understand that it’s gotten to the point where they can’t manage anymore.” (p. 7)

R16: seeking involuntary services sparingly: “Really, that only-, the two times that’s gonna come into play is when you’ve got somebody who’s obviously not competent, and then you start looking at, speaking with their family physician or the family members about pursuing guardianship. You know, when you have somebody who’s obviously got some sort of a dementia or something goin’ on. And they’re endangering themselves, certainly that’s the other piece. With the folks who are alert and competent and oriented and stuff, while we do have the adult protective orders, we use them very sparingly because, you know, it is an invasion on somebody’s rights. So we use what the court designates as ‘imminent danger.’ Potential loss of life or limb within a twenty-four hour period if we don’t intervene. Typically, we don’t use those. Again they’re very invasive. It’s- we try to use least restrictive, and also it’s just, I can generally talk folks into? You know, ‘Okay, let’s try this, try this.’ ” (p. 4)

Approaching home visits

Fourteen APS workers made a total of 75 references to approaching home visits. Workers discussed two main dimensions of this property: identifying APS procedures for the first visit and describing positive ways of approaching clients. Workers consistently pointed out the importance of building rapport with clients and approaching self-neglect concerns gently. Two workers identified the strategy of initially identifying themselves as workers from Office on Aging or Job and Family Services, not Adult Protective Services to help reduce people’s anxiety.

Procedures on the first visit include going out unannounced within 3 business days of receiving the referral, making the first visit in pairs (in large counties), explaining the referral process and referral concerns, confirming demographic information and completing initial paperwork, assessing/offering smoke detectors, and beginning to strategize and offer help/referrals. Examples workers shared of this dimension included:

R11: having 3 business days to make face-to-face contact (p. 2)

R9: making first visit unannounced (p. 1)
R16: first visit being unannounced (p. 1)

R12: making unannounced visits: “So a *typical* visit, the very first visit, you go in pairs. And you go unannounced. I typically make all my visits, whether they’re follow-ups or not, unannounced.” (p. 1); [worker being agreeable to making appointments in some situations] “But the majority of mine are unannounced. Don’t wan give ‘em time to clean up or cover things up. Don’t want them to put on a little show because they know I’m comin’.” (p. 1)

R13: “We *basically* respond to the allegations which is made in a report to our office. We go out unannounced. Typically we go in, we’re tryin’ to see what the environment is like, we go over the allegations of the referral with our client, and then we determine whether or not there is anything to substantiate as far as the self-neglect.” (p. 1)

R10: going on initial visit with partner unannounced (p. 1)

R7: making first home visit in pairs (p. 1)

R6: making initial home visit with a partner for safety and “having two pairs of eyes” (p. 1)

R12: going on first visit in pairs: “…because we are a large county and we have fifteen case managers, we always go out in pairs.” (p. 1); going out in pairs for safety; to separate client and alleged perpetrator; wanting to interview the person alone; second worker providing a diversion; second worker can be checking things such as meds, food supply; “…the very first visit, you go in pairs.” (all p. 1)

R9: first visit: telling client where you’re from, explaining APS (p. 1)

R12: “Typically, you know when I’m there, it’s to introduce myself, start building a relationship. I am obligated to tell them what office I work for, and the reason that I’m there. I specifically kinda read off all the allegations that were made. I describe my role in that I’m kind of a neutral party, we’re mandated by law to be here, I’m not stating everything in here is true, going out to get the other half of the story. Kind of do my own assessment, and see how things are going. Give them a chance to respond.” (p. 1-2)

R16: first visit: telling them where worker is from and letting them know agency has received referral and worker would like to talk to them about community resources (p. 1)

R11: confirming demographic info on first visit (p. 2)

R2: going through the assessment and initial paperwork on first visit whenever possible such as the waiver, the consent, the rights and responsibilities (p. 1)

R11: assessing/offering smoke detectors on the first visit: policy is asking about smoke detectors on first visit, arranging for smoke detectors if requested (p. 2)
**R10:** strategizing what resources would be helpful and formulating a plan on the first visit: “A lot happens for me in the first visit” (p. 1); starting strategy and start throwing options out there (p. 1); for example, calling Meals-on-Wheels from the house on the first visit (p. 1)

**R11:** offering help (p. 1)

The dimension of approaching clients included: the importance of building rapport, not being critical, gently explaining the reason for visit, recognizing the importance of demonstrating courtesy and not shaming or embarrassing people, strategies for assessing people who are resistant to engage, keeping the first visit short, and usually making several home visits to get a feel for somebody. [See also the property in this category “approaching elder self-neglect gently, ‘with a softer touch’ than neglect or exploitation by others.”] Workers also identified the importance of remembering that allegations may or may not be true. Examples workers shared of the dimension of approaching clients included:

**R11:** recognizing that allegations may be true or not (p. 1)

**R5:** building rapport: being a “friendly visitor” to engage (p. 3)

**R3:** building rapport: “…just tryin’ to build rapport right at the door” (p. 1) “Kinda startin’ that rapport building.” (p. 1); building rapport [to encourage mental health services] (p. 12)

**R9:** building rapport: worker finding common ground to “put ‘em at ease,” for example, discussing Western films, John Wayne (p. 2)

**R14:** “Well, immediately I knock on the door, and because it’s their space, not mine, I try to identify myself right away. And then immediately start to build rapport and respect them and, just try to get in the house as much as possible. Probably have 99 percent rate as far as getting in.” (p. 1)

**R11:** developing rapport (p. 7); “After I’ve known the person for a while, I think I know, you know, how they think or, you know, what they’re thinking, and what their expectations are.” (p. 10)

**R15:** “I usually knock on the door and walk in, introduce myself as being from Job and Family Services. I don’t mention Adult Protective Services. And then I explain to them the reason why I’m there. That there has been a referral into our office. And then I explain to them what the referral was. They generally will ask if
I can say who called? I tell ‘em I’m sorry, that’s confidential information and I can’t reveal that, however, I am a very resourceful person and so my objective is to place services in here to eliminate any kind of risks that might be involved. So that usually calms them down. I do have paper that says I have an intent to investigate. I’m obligated by the State to give that to them. I usually don’t give that to them until I’m ready to leave? So it’s not something up front and gonna embarrass them or intimidate ‘em.” (p. 1)

R14: “I’m up-front. I’m up-front with ‘em a hundred percent. So there’s no sneaking around. And I just try to build a rapport as quickly as possible. So I don’t come on strong. So immediately, I use ‘I’m from Franklin County Office on Aging, and I’m here-‘ and I use what I can to try to get in the door, and immediately, then, we start going over the concerns. So a little bit of rapport building, and letting them- or, and giving them the referrals. I think people like referrals. Giving, like, information. They like information. If you come there and just wanna allege, allegation of drug use, and a variety of activity, ‘n...That’s not gonna get you anywhere.” (p. 6-7)

R11: trying to explain APS role to clients in a non-threatening way (p. 1)

R9: recognizing the importance of demonstrating courtesy: not going in until invited, not sitting down until asked, not touching anything unless you ask (all p. 2)

R11: always asking permission to do things, for example asking permission to look in fridge (p. 2)

R16: recognizing the importance of not being critical: “I tell people ‘I’m not the Good Housekeeping lady, I have dishes in my own sink.’ You know, I’m not gonna come in and be critical of that. I’m gonna come and offer help, and if they want help, we’ll hook ‘em up.” (p. 5)

R7: offering services without shaming or embarrassing (p. 6) [counted under “advocating with clients to accept needed services”]

R6: keeping the first visit short: usually the initial interview is short. Staying 30 minutes to an hour on the first visit “and then I find that’s enough” (p. 2)

R9: strategies for assessing people who are resistant to engage: talking in doorway if not let in (p. 1); getting help from another agency that already has trust (p. 1)

R10: making numerous home visits to “get a feel” for somebody (p. 4); going back several times to assess (p. 6)

R1: visiting 4-5 times to complete the investigation (p. 4)

R10: sometimes you can tell in one visit that it’s bogus (p. 6)
Offering information and service referrals/encouraging seniors to accept needed services

Twelve APS workers made a total of 74 references to offering information and referrals and encouraging seniors to accept services. Dimensions included: promoting service utilization, describing techniques used to advocate with seniors to accept needed services, and specific examples of services and adaptive equipment workers recommend. Examples workers gave of promoting service utilization included:

R11: educating people about available services (p. 6)
R15: letting them know what kind of resources are out there (p. 1)
R10: improving quality of life by linking to resources (p. 3)
R3: recommending services (p. 6)
R2: encouraging service utilization (p. 2)
R14: “It’s my job to facilitate the client understanding, getting at least to try. I try to get them to try the service.” (p. 3)
R3: “You know, overall I think they enjoy the [services.] Once they get set up with services they say, you know, ‘Oh, it’s a lot of, less kind of job duties, housework duties,’ in the home that they can, you know, really benefit from. I think they stay with the program for a long time.” (p. 13)

Several workers shared techniques they use when encouraging seniors to accept needed services or intervention:

R5: framing intervention as “steps we can take to get people off your back/make the outside world happy” (p. 5)
R7: offering services without shaming or embarrassing; “I come in more as, ‘I’m here as a helping hand, I’m not here to embarrass you, I’m not here to shame you. I’m here to say, this is what’s available and you have the choice to take them. This is what can make your life better.” (p. 6)
R7: providing resource information to seniors and advocating for their needs: It’s being an advocate for their needs and see if there is anything we can do to assist them” (p. 1)
R12: “I still offer the services, you know, and I’m like, ‘Well, these are here. And if you wanna try it, you don’t have to stick with it.’ You know, I don’t ever give up on my own agenda?” (p. 11)
**R12**: A lot of people are willing to take services if you’re the person who sets ‘em up. You just have to determine what type of personality they have. If they’re kinda like ‘Well yeah, if you do all the work ’n I just get to sit here.’” (p. 11-12)

**R12**: “A lot of things are based on ‘What can you do for me? What are you gonna give me?’ And then people will accept everything you can give ‘em, as long as it’s free.” (p. 12)

**R15**: recommending and setting up home-based services: “Well, in a perfect world, we’ll set up someone that’s gonna check up on them on a regular basis. If they don’t have home-delivered meals, I will ask, you know, ‘Would you be interested in that?’ And I’ll even explain to them, ‘If you don’t have family, that this is the perfect thing to do.’ ‘Can I call for home health for you? Do you have any help in your home?’ If they don’t, then I’ll explain to them about home health, and if they have Medicaid and Medicare, we’ll touch on all those bases. Set up what we can, or give them- I’ll make phone calls. I don’t have any problem doing that. I’ll set this up for you.’ And follow through in a couple days and make sure it got started.” (p. 5)

Examples of services recommended by workers included Meals-on-Wheels, deep cleaning, homemaker, medication monitoring, senior housing, and personal care. [See discussion on “services needed by self-neglecting elders” for more on these services.]

Specific examples and case examples workers gave included:

**R12**: putting other agency’s services in place when client willing to allow it, for example home health, Senior Options monthly drop-in (p. 6)

**R1**: case example of making a Meals-on-Wheels referral for a person not having any food in her home (p. 6)

**R3**: offering deep cleaning service (p. 10)

**R8**: case example of offering cleaning services (p. 8)

**R3**: case example of getting homemaker services to help with cleaning: “So [we] finally worked in to getting him some homemaker services to help take that stuff out.” (p. 2)

**R14**: case example of linking to senior housing: person not wanting to move from home of 40 years that’s full of rats and feces, worker working out agreement with person for him to take taxi and go look at a couple of senior housing sites (p. 3)

**R13**: 1 reference to making referrals for a nurse or someone to assist with medications (p.1)

**R11**: usually being able to talk people into getting medical intervention (p. 8)
**R8**: service utilization in a perfect world: “...let’s say that the person’s home needs *major* cleaning. Then what we try to do is get major services in there to do a major clean. From the major cleaning then have them try to get them to agree to have homemaker to come in on a regular basis to help clean up, you know their to keep their home maintained. If they need to go grocery shopping, have a home care aid, homemaker come in to do the regular cleaning, also go grocery shopping for them. Or some homemakers will even go to the *doctor*, you know, with the older adult. And if the person needs personal care assistance, have a personal care aide to come out and help ‘em with bathing. And then also get them Meals-on-Wheels, if they’re not able to cook, their Meals-on-Wheels. I would say *that* would be kind of if we lived in a perfect world.” (p. 11)

Examples of equipment APS workers recommended included the Emergency Response System (ERS) button, an electronic medication box, and a walker. The ERS button was the equipment mentioned most often by workers. Examples included:

**R3**: advocating for the Emergency Response button (p. 10)

**R6**: promoting the Emergency Response button (p. 14)

**R11**: encouraging self-neglect people to get the Emergency Response System (ERS) (p. 4)

**R1**: case example of getting a person a walker: “Got him a walker and stuff like that, and that’s helped tremendously...” (p. 22)

**R3**: “A lot of people who forget with, like medication set up? They can get a electronic *med* box. That really helps people out and they’re like ‘Wow!...that’s perfect!’” (p. 14)

**Honoring/acknowledging clients’ wishes and self-determination**

Twelve APS workers made a total of 65 references to honoring clients’ wishes and self-determination. 40 of these references involved worker’s personal thoughts and feelings about intervention, and those references will be discussed in that category. The remaining 25 references were about actions taken to honor clients’ wishes and self-determination. Dimensions included: making appointments per clients’ request, leaving if asked to by competent clients, honoring peoples’ wishes to remain in the same part of town, honoring peoples’ decisions to remain in a neglect or abuse situation, and allowing
competent people who are not endangering themselves or others to determine how they want to live. Examples workers gave of these dimensions included:

**R1:** making appointments per client request for follow-up visits after initial unannounced visit (p. 1)

**R12:** “I typically make all my visits, whether they’re follow-ups or not, unannounced. Sometimes you have those clients who prefer that you come and you make an appointment, and, depending on the situation, I’m agreeable to that.” (p. 1)

**R1:** honoring client’s desire to remain in the same area (p. 18)

**R8:** if a person is demonstrating some understanding of questions, we have to respect their rights and leave if asked to (p. 7)

**R8:** older adults who are sharp sometimes wanting to stay in a neglect or abuse situation: “However, if you have a situation where the older adult is competent or you feel that they’re clearly able to make their own decision, some of- cases that you get, the older adult may want to stay in that situation. And in that case it’s kinda very difficult you know, to take their rights away and you wouldn’t want to take their rights away if they’re- ‘Cause a lot of times what I found, especially in neglect or abuse cases, that sometimes the older adult may know that this is goin’ on, because of their cognitive status, that they’re still sharp and able to make their decisions, but a lot of times they do not want to leave that type of situation.” (p. 2)

**R8:** case example of an older adult choosing to return to her apartment from a facility although unable to care for self (unable to ambulate, get meals, dress, bathe, toilet, self) (p. 9, 10)

**R10:** There’s absolutely nothing you can do when people know what’s going on and are making bad decisions. You have to wait for a physical or mental decline. (p. 8); “you’ve gotta sometimes walk away” (p. 8); sometimes you have to just let go (p. 8)

**R10:** “I also think you know, you don’t wanna force anything and you don’t wanna try to say, ‘Well this needs to be done’ because really that’s not what APS is about. We’re about self-determination, participation, freedom over safety is a huge principle that we utilize.” (p. 8) “And because we rely on self-determination, freedom over safety, and we really try to respect the client’s self-participation and decision-making all these things that social work’s all about, sometimes that puts us having to just let it go. I don’t think people understand that. Especially with self-neglect. People don’t get that aspect of it.” (p. 8)

**R16:** “I think if you don’t have that endangerment, if there’s not a real endangerment, you not gonna force yourself in there. ‘Cause you’re gonna allow them to determine how they live, and if that’s messy, that’s messy.” (p. 5)
R16: worker using Havemeyer’s theory to make decisions and start where the client is (p. 2); trying to find out “what their perception is.” (p. 2)

**Receiving and screening referrals, including bogus calls**

Eleven APS workers made a total of 33 references to receiving and screening referrals, including getting bogus calls. Dimensions of this property included: receiving calls from family members, neighbors, and landlords, getting bogus calls and exaggerated referrals, referral sources perceiving neglect and desiring change but sometimes being unable to identify specific allegations of self-neglect, getting repeat referrals, getting a lot of holiday referrals and describing the referral process. Getting bogus and exaggerated referrals was the dimension of receiving referrals mentioned most often by workers. Themes within this dimension ranged from receiving malicious bogus calls to receiving exaggerated calls to receiving calls from well-intentioned people who do not have good information. Examples included:

**R5**: false reports wasting APS time (p. 13)

**R11**: receiving lots of bogus calls (p. 1)

**R14**: getting totally bogus calls (p. 2); getting very *clearly* bogus calls (p. 4)

**R14**: “There’s a lot of people that make malicious referrals, and just because you’re older, they think, you know, they have other motivations behind making the referral. Besides helping that person. Or, they think they’re helping when it in all actuality they’re making judgments on that person. That if they were a 40 or 30-year-old, it’d be no one’s business how they lived. But suddenly, because you’re 80 or 90, everybody wants to make it their business. So, there’s a lot of referrals that we go out on that are completely unsubstantiated.” (p. 4)

**R2**: getting bogus referrals such as malicious calls from feuding children (p. 21)

**R5**: receiving calls from posturing family, children making false referrals (p. 12); kids using APS as a “weapon” (p. 12)

**R12**: Case example of bogus call: retaliation by neighbor’s feuding over bushes on property line (p. 5)

**R5**: well-intentioned people not having good info (p. 11)
**R5:** people tend to overstate on referrals (p. 10), including people “beef stuff” so APS will come (p. 11)

**R14:** worker not needing to decide [about substantiation of allegations] on totally bogus calls where there is no self-neglect (p. 2)

Examples workers gave of the referral source perceiving neglect and desiring change but sometimes being unable to identify specific allegations of self-neglect included:

**R10:** referral sources having the “perception” that something should be done but not being able to explain any specific allegations of self-neglect (p. 6)

**R2:** referral source desires change (p. 6)

**R4:** apartment managers making referrals: worker must explain that APS can’t make elders stop doing things and the managers may evict tenants if rules aren’t being followed; managers don’t want to evict seniors (both p. 11)

Examples workers gave of receiving repeat referrals, describing the referral process, getting holiday referrals, and receiving referrals from neighbors included:

**R3:** assessing service utilization and making adjustments when APS gets another referral (p. 14)

**R15:** reinvestigating repeat referrals to see if services are working or not (p. 2)

**R8:** description of referral process: All APS workers are online taking intakes (referrals) then the referral is submitted to the supervisor to determine if it will be investigated. Referrals to be investigated are then assigned to workers who read them and make a home visit to assess and either substantiate or not substantiate the allegations (p. 1)

**R16:** getting a lot of holiday referrals: “‘Cause people are comin’ home and seein’ how bad things have gotten, and then they’re callin’.” (p. 4)

**R3:** neighbors calling in referrals (p. 2)

**Using or not using a particular practice model**

All 16 APS workers were asked if they use any particular practice models. Some of their responses were counted under other more applicable properties. All responses are included here with notation regarding where they were counted. When asked if they use
a particular model, 11 APS workers made 25 specific references to using or not using a particular practice model and three workers mentioned using assessment tools such as the Mini-Mental State exam or a risk-assessment form. The remaining workers mentioned being honest, building rapport, and listening to clients.

Five workers stated that they do not use any particular practice model and other workers hesitated in identifying a practice model they use consistently. Reasons for not using a practice model or not consistently using one model included the ideas that all clients do not fit into any given model and that using a particular model may pre-set workers’ expectations. One worker explained, “no one fits in your theories perfectly. No one fits in all those. You’re dealing with human beings...” The most frequently used practice model was a client-centered approach, with three workers mentioning it. Other models workers mentioned using were a systems approach, a problem-solving approach, reality therapy, and a self-preservation/educational approach.

**R4:** “Don’t think I use any particular, ’cause to me, if you go in with a model, or anything, you’re pre-setting what you’re expecting.” (p. 7)

**R3:** The main thing I just try to go in an’ have an open mind. There’s no real, no real set thing that I try to use.” (p. 13)

**R11:** “I don’t really use any interventions. I think that I try to develop a rapport with the client.” (p. 7)

**R12:** “We don’t have a specific name of a model that we follow.” (p. 9)

**R16:** “You know, I don’t use an actual model, I just, you know, after thirteen years of doin’ it you kind of get the hang for how, how- I think the- a client centered approach. Looking at helping them frame what the problem is, instead of it being my idea. And just explaining to them the different services. So it’s very-, you know, you try to get in there, help identify the problem and help identify the resources, and connect them up. You know.” (p. 4)

**R8:** “I would say, the- and it kinda varies, but I would say, in regards to if I would have to apply any, it would be client-centered. Because the client is always the center point of our investigation. A lot of cases we try to do what’s in the best interest of the clients, try to let the clients have some type of say, if all possible, in what we can put in. What are your goals? What would you like to see happen.
How can we help resolve, you know, this issue. So I would more or less say the client-centered approach.” (p. 12, 13)

R9: “Always err on the rights of the client.” (p. 8) “We’re all client-centered!” (p. 8)

R5: “Wright State very much centered the systems approach about understanding people are part of a larger system, so. I’m happy to involve church groups, families, you know, whatever people offer them support. I’m very- a strong believer in people meeting people where they are. I cannot put you to where I think you should be, that’s a gradual process. But the systems approach with Wright State, that was a big deal and it definitely stuck. I very much believe we are in concentric rings, parts of larger- you know.” (p. 16); “What in their lives creates the whole picture and not just...your not bathing isn’t your biggest issue. It may be the pinpoint issue at the moment, but you are more than this old person who isn’t bathing. You are, you know, a member of the Moose Lodge, and a grandfather, and blah, blah, blah, all these things that make you who you are. I think it’s extraordinarily key to recognize that if we have any shot at getting people to accept intervention.” (p. 16)

R5: framing intervention as “steps we can take to get people off your back/make the outside world happy” (p. 5)

R10: “I’ll tell you the model I use and I’ve used ever since I’ve been a social worker. It’s just problem-solving. It just is. I mean you, you gather information, you identify the issues, and then you start developing a plan and formulating it, and tryin’ to figure out, you know, where can- is the resource that you can get to either minimize, you know, minimize it or resolve it.” (p. 11)

R2: “When you talk about models, I hate going back to that. I, you know, I did go through all of that stuff in school, and I think it really probably fluctuates. I have always been a very strong, I don’t wanna say believer in so much as a lover of, like reality therapy kind of thing? You know, my bottom line is when I go in and talk to somebody is – What is this person aware of? What are they capable of deciding?” (p. 12) “I hate to talk about models because it’s just, I think they’re just, they just kind of, they cross lines sometimes depending on the person you’re dealing with.” (p. 13)

R7: “I’m here to say ‘this is what’s available and you have the choice to take them. This is what can make your life better.’ So the model I probably use is more of that self-preservation model. I use it more as a, I hate to say a teacher to a child.” I can give you, you can choose to take it a learn off of it, and that’s a wonderful thing.” (p. 6)

R1: “The only one that comes to mind would be like the mini-mental.” (p. 15) [counted under assessment]

R13: “You know, we do a few questions from the MMSE, and it- to be honest, that’s probably about it. You know, we just basically kinda go on our observation
and ask a few of those questions. Yeah, I’d have to say that’s the only tool that I’ve really used.” (p. 6) [counted under assessment]

R15: “Like a risk-assessment form? Okay. I have a risk assessment. I’ve just recently got a new one. Last week I went to the OCAPS workshop and got a new one. The one I had before I didn’t particularly care for, but, again, we had somebody that had some tools out there, and it was like, I monitored it, or altered it so it would fit our county.” (p. 7) [counted under “using a risk-assessment form” property]

R14: “I don’t know, I mean, I think that the best thing to do is…I’m up-front. I’m up-front with ‘em a hundred percent. So there’s no sneaking around. And I just try to build a rapport as quickly as possible. So I don’t come on strong.” (p. 6) [counted under “approaching home visits” property]

R6: “I usually go in just waiting for the client to tell me. That’s how I do it.” (p. 11) [counted under “approaching elder self-neglect gently” property]

**Seeking court orders/guardianship**

Ten APS workers made a total of 81 references to seeking court orders or guardianship. Conceptually similar to “seeking involuntary services,” the property of “seeking court orders” was distinguished by the workers’ specific linguistic legal references to the court, guardianship, attorneys, etc., and by the specific description of the legal process of seeking court orders. Seeking court orders was also distinguished as a separate property from “seeking involuntary services” because it is a specific, sanctioned method of seeking involuntary services that workers mentioned enough to merit separate analysis. It is presented here (rather than with the property “seeking involuntary services”) in keeping with the data analysis pattern established for this study of discussing properties in order of the frequency they were mentioned by respondents.

Dimensions workers presented of seeking court orders included: workers seeking court orders and guardianship only as a last resort, describing the process and results of seeking court-ordered services, describing the process and results of seeking guardianship, identifying circumstances and conditions that lead workers to seek court orders, and noting that different counties having different attitudes about seeking
guardianship. Workers consistently expressed that they try to avoid seeking court orders and guardianship. Specific examples workers shared of this dimension included:

**R5:** avoiding court orders when possible (p. 9)

**R8:** trying to put interventions in home before going to court to take rights away (p. 2)

**R6:** worker feeling she’s not really working for the client when seeking guardianship “Because nobody wants guardianship.” (p. 11)

**R11:** “Guardianship, for me, is an absolute last, last resort. I will do anything and wait as long as I can to avoid that. But, there’s cases where you have to step in. The person is really in danger, if they don’t either A, get some help, or B, be removed from that environment. So then we make the probate court referral.”

**R12:** exhausting all avenues before seeking guardianship (p. 1)

**R10:** people not knowing the “finality” of guardianships (p. 12)

**R10:** worker trying really hard to get clients to address problems without court involvement, talking and working hard with a client before filing petition to the court (p. 13)

**R5:** “At which point we can petition the probate court for assistance with that. [forcing medical treatment]. I’ve never actually had to do that myself, I just talked her into it. I talked and talked and talked and talked and talked until I convinced her, ‘Let’s just make sure you’re okay.’ “ (p. 9)

**R10:** worker not doing too many guardianships (p. 12, 13)

**R5:** “I’ve one time have sought a guardianship in four years. I am not prone to doing it.” (p. 17)

**R15:** worker being happy that she’s only gone to court three times in eight years doing this (p. 7)

Workers described the process of seeking court orders. They consistently stated that they seek court orders only when people are demonstrating a lack of understanding of health consequences and that seeking court orders is rare. Workers identified different types of court orders available to APS and provided several case examples where they sought court orders.

**R12:** getting an order of protection when people demonstrate a lack of understanding of health consequences (p. 3)
**R3**: needing probate action only when a person is not able to make decisions on their care, turning into a guardianship when people don’t allow court-ordered services (p. 5)

**R7**: “And if it becomes, you know, where it’s a fight, we do have orders available to Adult Protective Services. That is what makes us different than anybody else. Those orders are there to help protect our seniors and to give them a dignity and a life free of abuse and neglect and exploitation.” (p. 2)

**R11**: [seeking court involvement] when examples of not following through pile up “and I have a real case” (p. 9) ex: client and family “not following through” with meeting needs (p. 9)

**R12**: getting supervisor’s permission for seeking emergency court orders (p. 10)

**R7**: types of court orders available to APS: “We can go to court for guardianships and conservatorships. We help clients going to courts for sanitation needs. We’ve gone to courts for evictions. We’ve gone to courts for restraining orders. When I talk about the orders, the orders are what makes APS individual. They’re types of- there’s a restraining order, where we can, you know, they have to let us-maybe they won’t even let us into the house. That order will get us into the house. We have an order of- that will allow us to put services into that home. We have orders that we can take that person out of the home and send them to a hospital or to a facility that can meet their needs. And then the last order is if we did order those services to be put into place, they’ll be ordered to pay for those services.” (p. 2)

**R8**: description of process of getting court orders: APS worker calling prosecuting attorney before magistrates leave at 5:00 PM, worker usually getting to probate court magistrate to give testimony same day as order sought, getting court order in 2-3 hours, getting court order before 5:00 PM or getting court order next day if after 5:00 pm, worker has always been “fortunate” to get court orders the same day (p. 10, 11)

**R8**: Columbus Police Dept. or Franklin Co. Sheriff’s office enforcing order of protection, paramedics called to transport client to hospital per order of protection (p. 10)

**R11**: seeking court orders to get medical intervention is rare, having to be life or death to get a court order for medical intervention (p. 8)

**R11**: seeking court order for medical intervention: a lot of times probate referrals are based on medical issues, for example untreated open sore getting worse (p. 8)

**R12**: “Most of our severe self-neglect that we end up having to go get an order for? Has everything to do with cellulites, diabetes, and gangrene. And like every single order I think I’ve ever gotten has had to do with the knees down.” (p. 3)
**R8:** getting court order of protection to force medical assessment: case example of worker telling client she will get order of protection to make client go to emergency room for medical assessment (p. 9); getting order to force medical assessment (different case (p. 10)

**R7:** case example of getting a court order to make a client go to the hospital after a fall—she had a hematoma. It was self-neglect because she didn’t recognize what had happened. (p. 7)

**R7:** example of court order for something other than medical intervention: court ordering wealthy people and spouses to pay for needed services (p. 2)

**R8:** client being angry with worker for order of protection (p. 10)

Workers described the process of seeking guardianship. They consistently stated that guardianship is only sought when a person is demonstrating that they are unable to make informed decisions and that seeking guardianship is rare. Workers discussed consulting with family, doctors, and magistrates about guardianship. Workers noted that magistrates ask them what less restrictive measures have already been tried prior to seeking guardianship. Workers shared that they consider whether or not seeking guardianship will improve a person’s situation.

**R11:** “But then you have to be thinking, what I’m thinking is how is the guardian gonna make this any better?” (p. 9)

**R5:** sometimes getting a guardian wouldn’t improve the situation (p. 14)

**R11:** guardians can get services in there even against their will (p. 9); guardian being able to force services (p. 10)

**R8:** guardianship taking place if person is not able to make decisions ex: dementia, Alzheimer’s (p. 2)

**R11:** showing a pattern of decline in decision-making to get a court order (p. 8)

**R11:** getting a guardian when a doctor says “they really can’t make decisions” (p. 9)

**R12:** being confident they’re incompetent when seeking guardianship, for example not seeing outcomes of decisions (p. 9)

**R12:** seeking guardianship when “you’re puttin’ out fire, after fire, after fire.” (p. 9)
R12: presenting cases to clinical review prior to seeking guardianship or nursing home placement (p. 10)

R11: guardianship application process: making probate court referral, documenting “actions tried” in probate court referral, explaining why guardianship is needed in probate referral (p. 8)

R12: regular guardianship process taking 6-8 weeks to get on docket (p. 11); having to know the person is safe enough to be in the house 2 more months when seeking regular guardianship (p. 10)

R1: guardianship taking about 3 months from initial worker assessment to a guardian becoming involved (p. 7)

R1: worker can request guardianship be expedited (p. 7)

R12: trying to get family involved before seeking guardianship (p. 10)

R12: trying to get family, friends to serve as guardian, going through probate court for attorney guardian if no family/friends available, (p. 10)

R12: case ex: of family requesting guardian to “be the bad guy” (p. 10)

R8: magistrate asking what least restrictive measures have been tried (p. 2)

R12: magistrates asking what’s been tried (p. 10); case example of getting guardian for a person unable to take meds properly, being able to tell magistrate worker tried timed med box (p. 10)

R12: getting a guardian to manage money when a financial emergency occurs, being able to remain in the community with money management from a guardian (for example moving from house to an apt.) (p. 9)

R12: case example: getting guardians for a married couple who were unsafe, this case broke worker’s heart because she know they’d probably be removed from home (p. 9)

R3: requesting guardianship doesn’t happen often in Franklin County: worker never having filed for guardianship in Franklin Co., worker filing like seven times in two years working in Delaware Co., Delaware Co. pushing guardianship (p. 14-15)

Substantiating self-neglect allegations

Eight APS workers made a total of 38 references to substantiating self-neglect allegations. Several workers explicitly pointed out that substantiating allegations doesn’t necessarily mean that any intervention will occur. Other dimensions workers presented
of substantiating self-neglect allegations included: assessing mental capacity, identifying conditions leading to the substantiation of self-neglect, noting that there are more substantiated cases than unsubstantiated, and explaining the substantiation process.

Workers emphasized the importance of assessing mental capacity when deciding about substantiating self-neglect. This dimension is discussed in the property “Assessing mental capacity” under the assessment category “Assessing decision-making capacity.”

Respondent 3 neatly summarized this dimension of substantiating self-neglect allegations:

“A lot of times that happens when the person is incapacitated mentally. They don’t know the consequences of their behavior, what it’s gonna do to affect neighbors...That’s when it’s substantiated...” (p. 5)

Workers identified conditions that lead them to substantiate self-neglect allegations. Examples of these conditions included:

**R2:** “I think bottom line is- to substantiate is when somebody is going without food, medicine, heat, when they are *noticeably* going without something and it can be changed, and *should* be changed for their well-being.” (p. 5)

**R10:** substantiating if there’s a protective need: “…we substantiate what, you know, if there’s a protective need.” (p. 3) “If I was gonna substantiate a case, it would be someone who would probably be somewhat incapacitated, possibly mental status as well as physical status to where they *could not* be able to have someone come in or them be able to leave.” (p. 3)

Workers consistently pointed out that substantiating allegations does not necessarily mean that any intervention will occur:

**R5:** substantiating but closing case due to person refusing services: “…I had him open the first time probably three or four months. And eventually- He consistently refused the help, he liked the visits but he didn’t want the help. And I had to say, at this point I’m going to end up, you know, I’m going to close out my part, but, you know, you can all me anytime. And be *aware* it’s possible someone may call me again, because they’re concerned. At which point I’ll come out and talk to you again, nothin’ scary, it’s just me again.” (p. 11)

**R12:** substantiating allegations on competent self-neglecters: “The way I approach it, I believe, even if they’re *competent*, I can still *substantiate* that you’re neglecting yourself. However...yes, it’s substantiated, you are neglecting
yourself, however, you are competent and you understand the consequences and
the outcomes of this neglect.” (p. 4)

R12: not having authority to intervene when competent people decline help:
“However, they have proved to me they’re competent to do so [self-neglect].
So I feel like the allegation is substantiated. However, we don’t have any
authority to intervene.” (p. 4)

R7: allegations being substantiated doesn’t mean that we’re going to fix it: “And
it’s substantiated. That doesn’t mean that it’s, that we’re going to fix it, it just
means that it’s substantiated. (p. 3) “I can substantiate even cases that I don’t do
anything in. Substantiation just means that, yes, that problem is there. Now
whether we choose to act upon that is whole ‘nother issue when we’re doin’
investigations.” (p. 3) “APS, really what the job of APS is just to say whether it’s
true or not true, not to necessarily fix it. And to society that’s very hard to digest.”
(p. 3)

R14: substantiating allegations but being unable to take action: “So if the referral
matches what I’ve seen, then that would be substantiated. And then it’s the
outcome that is sometimes different.” (p. 3) [if they’re competent and refuse
services] “Then the allegation will be substantiated but there’s really not much I
can do about it. So therefore, the case would be closed.” (p. 3)

R14: substantiating allegations not always leading to desired outcomes: worker
wanting to do more for people whose competency is impaired but they have a
clean home, good hygiene, and a support system (p. 4)

R14: case example: worker getting a lot of calls about a client who has end-stage
Alzheimer’s that she needs to be in a nursing home, but to worker she was doing
very well. Allegations were substantiated but the outcome was not what referral
source(s) wanted (p. 4) “I mean, the findings are there, but [not] the outcome.”
(p. 4)

Two workers identified that there are more substantiated cases than
unsubstantiated ones:

R2: “There’s plenty more substantiated than unsubstantiated.” (p. 6)

R6: substantiating most cases: “Let me think of a [substantiated] case. Which is
the majority of mine.” (p. 4)

One worker summarized the substantiation and case closing process:

R15: substantiating allegations at the end of the investigation: “That’s
[substantiating] usually probably the end of the investigation. I give it- if I think
that it’s gonna take me that thirty days, or even forty-five days, I go back in and
make sure. Most of the people at that point, I’ve either put some services in there
and they’ve worked, and we have at least eliminated whatever had been the risk

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, and everything’s good, and I basically tell ‘em I won’t be coming back unless there’s another referral to my office.” (p. 2)

**R15**: documenting substantiation of allegations in report to the state and that services were put in place (p. 4)
Table 11
APS Workers’ Feelings about Intervention
(A Sub-category of the Secondary Category “Approaching Intervention”)

<table>
<thead>
<tr>
<th>Properties of APS Workers’ Feeling about Intervention</th>
<th>Number of APS workers mentioning property (n=16)</th>
<th>Number of references per property</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valuing honoring self-determination and client’s rights</td>
<td>12</td>
<td>40</td>
</tr>
<tr>
<td>Struggling with difficult case decisions/ethical dilemmas re: balancing self-determination with obligation to protect</td>
<td>8</td>
<td>23</td>
</tr>
<tr>
<td>Wanting seniors to accept services</td>
<td>8</td>
<td>18</td>
</tr>
<tr>
<td>Valuing independence/keeping people in their homes/in the community [out of nursing homes]</td>
<td>6</td>
<td>21</td>
</tr>
<tr>
<td>Genuinely caring/going the extra mile to help</td>
<td>6</td>
<td>18</td>
</tr>
<tr>
<td>Workers in Franklin County appreciating having access to good programs and funding available to put services in place</td>
<td>5</td>
<td>16</td>
</tr>
<tr>
<td>Wishing that more people had supportive families/having strong feelings against exploitive families</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Experiencing frustration with lack of willingness of other service systems to become involved</td>
<td>4</td>
<td>15</td>
</tr>
<tr>
<td>Experiencing frustration when referral concerns are legit but all available services are in place and nothing else can be done</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Keeping own values in check</td>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>Not valuing using a treatment model/Mini-Mental State exam</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>Expressing empathy for respecting peoples private space</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Wishing to avoid seeking guardianship going to court</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Having strong feelings about the lack of home-based medical management services</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Valuing being a social worker, having social work values, ex: self-determination</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Recognizing importance of patience in giving client’s time to make changes on their own</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Valuing/recognizing importance of keeping cases open</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Experiencing difficulty/frustration assessing if some thoughts are real or delusions</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Other properties [see compiled group data for remaining properties]</td>
<td>16</td>
<td>100</td>
</tr>
<tr>
<td><strong>Totals:</strong></td>
<td><strong>16</strong></td>
<td><strong>323</strong></td>
</tr>
</tbody>
</table>
APS WORKERS’ FEELINGS ABOUT INTERVENTION

All 16 workers participating in this study shared personal feelings about intervention. Participants made a total of 323 references to 59 different properties of their feelings or values about intervention. There was much overlap between the two intervention sub-categories of “actions needed/taken” and “workers’ feelings about intervention,” but transcripts were coded during selective coding by using a symbol indicating “worker expressing feelings” so that the themes workers felt strongly about would be captured for analysis. Statements were coded as “workers’ feelings about intervention” when workers mentioned feeling words, when they specifically identifying personal values, or when they spoke with passion as evidenced by voice volume, rate of speech, and significant pauses.

Dimensions are presented here of the five topics [properties] that six or more APS workers shared feelings about. Together these five properties account for 37% of participants’ references to their feelings about intervention. These five properties are: 1) valuing honoring self-determination and client’s rights, 2) struggling with difficult case decisions/ethical dilemmas regarding balancing self-determination with the obligation to protect people, 3) wanting seniors to accept services, 4) valuing independence/keeping people in their homes in the community/out of nursing homes, and 5) genuinely caring going the extra mile to help. Corresponding with table 11, properties are presented in the order of how frequently they were mentioned by APS workers. Complete group data of all 59 properties of APS workers’ feelings about intervention are presented in the appendix.
Honoring self-determination/client’s rights

Honoring client’s rights and self-determination were the themes that elicited the strongest feelings from the most APS workers participating in this study. 12 APS workers made a total of 40 specific references to their feelings about honoring client’s rights and self-determination. Workers consistently identified establishing a person’s ability to make decisions as a prerequisite for honoring risky or unsafe choices.

Dimensions of honoring client’s rights and self-determination mentioned by more than one worker included: respecting competent adults’ rights to live how they wish, particularly their right to be dirty, live in a dirty home, or neglect themselves, workers experiencing frustration with wanting to help but needing to respect client’s choices, and honoring people’s housing and treatment desires. [See the property “balancing between self-determination and the obligation to protect” for more on balancing self-determination with the need for intervention.] Other dimensions workers mentioned included: just because they are 60 does not mean every right gets stricken from them, endangerment being a mitigating factor when considering competent people’s right to decline services, and not wanting to put people in nursing homes or take away their rights by getting a guardian.

Specific examples workers shared of valuing and respecting competent people’s rights to live how they wish included:

R9: always erring on side of client’s rights (p. 8)
R8: “They are adults, they’re not children.” (p. 13)
R16: valuing people’s right to live how they wish (p. 2)
R12: “I think that is optimal. That we live in a country that you have the right to determine how you’re gonna live life the way you want to.” (p. 6)
R12: “If they understand the risk...then, I believe, they have the right to self-determination.” (p. 11)
**R8:** adults can make their own decision about staying in their environment or not (p. 1)

**R3:** “I really think that people are allowed to live however they wanna live.” (p. 13)

**R5:** “It is your right to live as you choose and I am happy to support that.” (p. 7)

**R12:** “It’s really hard to case plan anything for another individual who has the right to live the way they want. ‘N I believe in people’s rights, so I would say it is ideal that we all get to choose to live how we want to.” (p. 7)

**R14:** “I always go on self-determination first. So, I tend to go with their rights first. And all clients, I try to involve in any change that occurs. So, even if they’re against it, we’ll talk it out. And if they have zero insight into it, then I tend to take more of a control. I mean I move clients probably a lot more than some people?” (p. 7)

Workers consistently noted that competent people have the right to live in filth or deplorable conditions. Examples included:

**R3:** “People are allowed to be dirty.” (p. 4)

**R7:** “People do have the right to live in filth.” (p. 10)

**R8:** respecting competent senior’s right to choose to live in a deplorable situation (p. 14)

Several workers specifically mentioned respecting competent people’s right to neglect themselves. Examples included:

**R6:** “Self-determination would generally with me always win out on trying to force somebody because they’re self-neglecting themselves.” (p. 14)

**R13:** wanting to respect their decision when they’re knowingly self-neglecting (p. 7)

**R8:** “…they might be self-neglecting themselves but their own self-determination comes into play and you have to allow them. It may not be agreeable to me, and maybe in beliefs I may feel that this is not my standard way of living? But again, everybody has their own values, their own way that they want to live. So you have to respect that. Especially since they’re adults.” (p. 14)

**R16:** “You know, I think it’s really easy to allow people to self-determine when it’s a self-neglect issue. I think the only time it really becomes a struggle is more when you’ve got that endangerment issue. I think if you don’t have that endangerment, you’re not gonna force yourself in there. You’re gonna allow them to determine how they live, and if that’s messy, that’s messy.” (p. 5)
Examples workers shared of wanting to help but needing to respect competent people’s choices included:

**R7**: worker wanting to help but needing to respect client choices (p. 4)

**R10**: there’s absolutely nothing you can do when people know what’s going on and are making bad decisions. You have to wait for a physical or mental decline. (p. 8) “…you want people to have what they need. And it’s really hard to walk away.” (p. 8)

Examples workers gave of respecting specific housing and treatment desires included:

**R1**: “some people, they request an appointment, so I have no problems with doin’ that.” (p. 1)

**R2**: “*He wants the west side.* I got him on **every** waiting list I can possibly get him on, ‘cause I’m not movin’ him nowhere but where he wants to be.” (p. 18)

**R12**: honoring people’s right to die at home: worker allowing people to remain at home to die; worker not wanting to die in a hospital or nursing home; worker taking into account what she would want, what her grandparents would want (all p. 6)

Other dimensions workers presented of their feelings about the importance of honoring competent people’s rights and self-determination included:

**R7**: “Just because they’re 60 doesn’t mean every *right* gets stricken from them. By no means.” (p. 11)

**R16**: “If they choose to not *have* that help, I’m really okay with that unless it’s an endangerment issue.” (p. 5)

**R12**: worker not wanting to put people in nursing homes or take away their rights by getting a guardian (p. 6)

**Struggling with difficult case decisions/ethical dilemmas**
**Regarding balancing self-determination with the obligation to protect**

Eight APS workers made a total of 23 references to struggling with balancing between honoring self-determination and protecting people from self-neglect. Workers consistently identified assessing mental competency as a primary factor in balancing
people’s self-determination to live how they wish with the APS obligation to protect people from abuse and neglect. Dimensions of this property mentioned by more than one worker included: workers having difficulty walking away from capable people who aren’t meeting their needs or are making unsafe choices, making decisions on a case-by-case basis, and self-neglect having to be severe in order to override people’s self-determination. Other dimensions workers discussed included: having the most difficulty finding this balance with clients who are only a little bit confused, taking a gradual approach whenever possible, talking to seniors about bad decisions being difficult, and having mixed feelings about substantiating when people would probably be compliant with medications if they could afford them. Specific examples workers shared of these dimensions included:

R5: balancing self-neglect with self-determination: “It’s an ongoing battle, it’s a tough. For me it’s all about cognitive status.” (p. 18) “And it’s an ongoing battle. It’s something I question myself. During a case I question myself, months later, I question myself if it comes back. Because you’re always concerned. I don’t ever wanna apply my own yardstick to someone else’s values, but I also want to understand that if they’re in a position to not be able to make decisions, they need someone to do that for them. But that’s the balance between are you able to make the decision, even if they’re poor ones.” (p. 18)

R3: “Yeah, it’s a challenge to do so.” [distinguishing between self-determination and self-neglect] (p. 16)

R5: balancing self-neglect with self-determination: “I am forever on the fence with myself about how much of this is lifestyle, how much is a problem.” (p. 13)

R13: having difficulty finding the balance between client self-determination and the worker’s obligation to protect: “You know, in my nine years here it’s been very hard to find that balance.” (p. 7)

R14: having to make difficult decisions: “So sometimes you have to make a decision. So it falls on me. I guess.” (p. 5)

R10: No one can understand what it’s like to face the tons of ethical dilemmas in the job unless you’ve done it because you constantly walk a fine line (p. 14)

R3: having difficulty making decision to remove seniors from their home, even when they’re “mentally gone” (p. 7)
R13: feeling torn about not intervening: case example of feeling torn when a client understood the ramifications of him selling his pain meds and giving the money to his caretaker but was not seeing that he was self-neglecting by not taking his medications as prescribed [did not substantiate] (p. 3); “he did not want any intervention from us, as much as I tried to advocate” (p. 3)

R10: It’s hard when they’re capable but not meeting needs (p. 7)

R10: “…you want people to have what they need. And it’s really hard to walk away.” (p. 8)

R14: having to make difficult decisions: “…so you have to look at it on a case-by-case basis.” (p. 4) “It is tough because there’s a lot of gray areas. So, sometimes I’m leaving people in unsafe situations that could go bad rather quickly.” (p. 4)

R9: “Mainly, it’s all a case-by-case situation.” (p. 8)

R9: “It has to be really severe.” (p. 8) [to override clients’ self-determination]

R9: having no choice when people are really bad off and won’t use helping systems (p. 8)

R13: “But it is, it’s hard finding those boundaries between the self-determination and knowin’ they’re self-neglecting and, you know, by law, we have to go in there, ‘n we have to intervene in a lot of cases, but I try ‘n take the gradual approach?” (p. 10)

R6: it’s hardest to try to help when clients are only a little bit confused; “My job I see, is to try and form a relationship with them to try and let them see it is for their best interest to...just accept an emergency response system...It, it’s one of the hardest things to do. If they’re confused...it’s not...but if they know what they’re talkin’ about...and they’re maybe only a little confused, that’s when it’s really tough and you just keep goin’ back and trying to see what you can do to help them. And I try to say, “I’m here to help you, to protect you, make sure you’re okay.”” (p. 14)

R10: talking to seniors about bad decisions is difficult because the worker is allowed to make bad decisions at her age (p. 8)

R16: having mixed feelings about substantiating when people “…probably would be very compliant with medications if they could afford them.” (p. 2)

**Wanting seniors to accept services**

Workers consistently expressed a strong desire for seniors to accept needed services. Eight APS workers made a total of 18 specific references to wanting seniors to accept services. When asked to describe an optimal process of care planning for self-
neglecting elders, many workers identified client’s willingness to accept needed services as the primary factor in optimal care planning. Dimensions of this property included: workers thinking it’s in the best interest of self-neglecting clients to have services, preferring to talk people into services rather than forcing services, noting that cost is a barrier to people accepting services, and acknowledging that some people will not accept needed services. [See “actions needed/taken” property “not having the means to get clients help: experiencing insurance, eligibility, and funding barriers” for more on financial barriers to putting services in place.] Specific examples workers shared of wanting seniors to accept services included:

R14: worker thinking it’s always in a self-neglecting client’s best interest to have services: “I mean, there is incidences where I would push, even though they are in a situation where I could close it. But I then make the judgment to push a little harder. ‘Cause I always think it would be in their best interest to have this. It’s my job to facilitate the client understanding, getting at least to try. I try to get them to try the service.” (p. 3)

R12: worker not wanting clients to die from self-neglect: “In a perfect world, everybody would do what they need to do for themselves.” (p. 6)

R11: clients’ being receptive to offered services is the perfect outcome (p. 6)

R5: preferring to “talk ‘em into into it” rather than forcing treatment or petitioning probate court for services (p. 9)

R15: worker wanting clients to accept home-based services: “Well, in a perfect world, we’ll set up someone that’s gonna check up on them on a regular basis. I’ll, if they don’t have home-delivered meals, I will ask, you know ‘Would you be interested in that?’ And I’ll even explain to them, ‘If you don’t have family, that this is the perfect thing to do. Can I call for home health for you? Do you have any help in your home?’ If they don’t, then I’ll explain to them about home health, and if they have Medicaid and Medicare, we’ll touch on all those bases.” (p. 5) “If they agree to all that, that’s the perfect world.” (p. 5)

R6: “Well the optimal would be to...be able to get, offer them and have them accept it, that’s the other thing...” (p. 8)

R16: “In a perfect world they would see that there’s a problem and they’d want help. That’s the first piece. ‘Cause that’s often the hardest, just convincing them that they need the help.” (p. 2); “So the perfect world would be the money to treat the problem and the acknowledgement by the client that there is a problem.” (p. 3)
R7: In a perfect world client’s accept services, the services are in place, and they’re all paid for. “but okay, let’s be real, that’s not happening.” (p. 5)

Valuing independence/keeping people out of nursing homes

Six APS workers made a total of 21 references to valuing independence and keeping people out of nursing homes. Dimensions included: recognizing that some people with cognitive impairment can remain living independently, refuting the misperception that APS workers’ goal is to put people in nursing homes, trying to honor people’s desire to remain independent in their own homes, and workers feeling sad about having to put people in a nursing home just for an issue like needing medication assistance. Specific examples workers gave of these dimensions included:

R3: “Well, he’s kind of in this routine. I can’t really force him out of his home. ‘Cause sometimes I think the home environment’s gonna be better, I think, than a nursing home that he is not familiar with. He doesn’t like talkin’ with a lot of people, so maybe the crowd’s gonna be worse for this person. He likes kinda bein’ a homebody, nobody in his business. But got along really well at home.” (p. 7)

same case: “[He] was gone mentally, but he showed me that, you know, he’s livin’ his life how he wants to, he’s not hurtin’ anybody else. Ok. He can stay in the community.” (p. 14)

R3: “You can’t just put everybody into a nursing home.” (p. 15)

R5: “...they think we’re just gonna drag everybody off to a nursing home...but my mission really is to keep people in the community” (p. 6)

R7: “...nothing beats bein’ in you own home and bein’ independent.” (p. 3)

R7: “I know as a caregiver [for mother and grandfather with Alzheimer’s], I know how it is. I know that they want to maintain their independence, and I will push for their independence.” (p. 9)

R9: “I always think that I don’t want to be in a nursing home, so how can we work this. Even if I have to- it has to be the absolute last thing for me. A nursing facility. Yeah, I’ll try if there’s a guardian and we’re able to keep them in the community a little longer. And I know it’s gonna happen eventually, but the client has rights. I usually ask ‘em what they want. And, you know, a lot of time they don’t want a nursing home. Unless they’re just too far gone. And that’s- But, so mainly the whole thing is to err on the rights of the client and try to respect them. And try to find any means they can remain in the home, you know.” (p. 8)
R9: “If I can help ‘em remain in the community, with services. They can do that.” (p. 8)

R12: “People would be so much happier at their home.” (p. 8); “And to me...the biggest thing would be able to keep people at home.” (p. 8)

R12: case example: “And it broke my hear to get ‘em both guardians, because I know the guardians would probably take ‘em from the home. Because that’s where they really wanted to be.” (p. 9)

R13: trying to keep people home with services (p. 4); worker typically trying to not do ECF (extended care facility) placement unless really necessary (p. 4)

R12: worker feeling that it’s sad to send someone to a nursing home over a “little” med assistance issue (p. 8)

Genuinely caring/going the extra mile

All 16 APS workers expressed caring for the clients. Six workers made a total of 18 specific references regarding genuinely caring and/or going the extra mile. There were two main dimensions to this property: workers’ viewing their primary job as being to take care of people and help them meet their basic needs and workers sharing specific case examples where they provided care above and beyond the requirements of their job description. Specific examples workers shared of viewing their primary job as being to take care of people and help them meet their basic needs included:

R1: “It’s, it’s really, it’s really difficult, because, you know, you go into some of these houses and just really (brief pause) you really want them to know, you know, ‘Look, we’re out here?’ You know what I mean? ‘We’re, we’re, we’re really tryin’ to help you with stuff’ and you take on a lot, you know.” (p. 23)

R2: viewing referrals as “somebody is needing something” (p. 1); needing help (p. 5)

R6: “it’s not just, you know, go to court and then assess ‘em for court. It’s taking care of the client.” (p. 16)

R2: worker having difficulty leaving home of sick/dying client [2 case examples] (p. 7, 14)

R8: 2 references (different cases) to “I could not leave her there”: worker insisting client get medical assessment immediately (p. 9); couldn’t leave client in home unable to care for self (p. 10)
Specific examples of workers going the extra mile included:

**R1**: worker buying fast food for client for several days (p. 7)

**R3**: worker personally checking out neighbors and house guests (p. 7)

**R3**: taking personal risks by confronting exploitive children: “So I kind of like havin’ the conversation with the, you know, deadbeat kids. A lot of times that’s intimidating, though, for me to do, just because, you know, you don’t know if they’re under the influence of any alcohol or drugs so…” (p. 9) “It’s kind of intimidating just to have a conversation like “Man, what are you doin’ for this person?” (p. 9)

**R6**: worker providing personal care for a client before squad comes (p. 13); holding client’s hand in ER prior to death (p. 13)

**R6**: worker presenting three insurance plans for senior to choose from (p. 15)

**R9**: working with a client’s attorney to arrange client being moved to a nursing home in Boston near her family: “…from there she ended up in a nursing home. And I was ambivalent about it ‘cause she had nobody here. Her family was in Boston. But then it was like working with the attorney to see that she got into a nursing facility in Boston. Nobody would visit her here. You know. Her sisters were kinda elderly, and all the family was in Boston originally, so…” (p. 5)
Table 12
Themes [perspectives/properties/dimensions] Unique to One Interview

<table>
<thead>
<tr>
<th>Unique themes/perspectives/properties/dimensions</th>
<th>Number of APS workers mentioning theme (n=16)</th>
<th>Number of references per theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identifying influence of community standards</td>
<td>1</td>
<td>21</td>
</tr>
<tr>
<td>Assessing wandering</td>
<td>1</td>
<td>12</td>
</tr>
<tr>
<td>Approaching elders living in a home where crack is used</td>
<td>1</td>
<td>12</td>
</tr>
<tr>
<td>Providing details of getting a court order of protection</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>Needing assisted living alternative for people who can’t live at home but are not appropriate for the nursing home</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>Assessing alcohol abuse</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Worker wishing clients could have a single, consistent care coordinator</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Identifying strategies for handling dogs/other dangers identified by referral source on home visits</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Consulting with pre-existing Senior Options case manager/seniors preferring Senior Options casemanagers</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Basing APS decisions in Franklin County on client needs, not community desires</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Looking at the “three biggies” to distinguish self-neglect from self-determination (food, shelter, clothing)</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Worker acknowledging and problem-solving regarding male client’s sexual needs to avoid conflict with prostitutes</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Understanding and explaining hoarding</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Educating clients about the importance of nutrition for healthy brain function</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Worker passionately wanting to get seniors out of the house for socialization, such as at a senior dining center</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Working with banks regarding elder self-neglect (banks are not mandated reporters)</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Having hospital doctors complete expert evaluations</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Calling EMS [emergency squad] supervisors when EMS first responders won’t transport clients</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Recognizing grief/grieving recent loss of spouse</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>References to other unique themes [see compiled group data for remaining themes]</td>
<td>14</td>
<td>107</td>
</tr>
<tr>
<td><strong>Totals:</strong></td>
<td><strong>16</strong></td>
<td><strong>264</strong></td>
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</table>
THEMES UNIQUE TO ONE INTERVIEW

All 16 APS workers participating in this study mentioned unique themes. Participants made a total of 249 references to 98 different unique themes. Many of these themes were unique perspectives on properties that were mentioned by several workers. Those unique perspectives of established properties were presented with their corresponding properties. Selected unique themes that did not fit into established properties are presented here. Corresponding with table 12, unique themes are presented in the order of how frequently they were mentioned by APS workers. Complete group data of all 98 unique themes are presented in the appendix.

assessing wandering

R12: “One of the big ones [self-neglect behaviors] that gets reported is wandering. So people are wandering. They might- and then you have to determine whether or not there’s a purpose for their wandering? Or if they’re just wandering ‘cause they don’t know what they’re doing and got lost. Or if it gets dangerous. I’ve had clients that wander away from their building. Some people, like, have a purpose. ‘I wasn’t wandering, I was going to the store,’ or ‘I take a walk every day at this time. That’s my routine.’ And somebody else, a neighbor, might see them and think, because they’re old, they’re wandering. Or if they didn’t have purpose. Others just wander and get lost, and don’t have a purpose. And I had a client end up, they wandered into a pond...in a residential apartment. They have those nice ponds with the ducks? And the client ended up in the pond. So you have to determine how dangerous it is, if they’re carrying I.D., if they can tell you how to get home?” (p. 2)

needing as many laws for seniors as for children

R7: Worker wishing there was a log for adult abusers like there is for children. Example: multi-county “sweetheart swindler” might have been caught had we been able to share that information. “Maybe we could have stopped one?” (p. 12); The lack of a national exploitation log for seniors “tells you that we de-value our seniors.” (p. 12); “But there should be just as many laws for our seniors. And there’s not.” (p. 13)

wishing banks would become mandated reporters

R11: “Banks are not mandated reporters, but yet, sometimes I can call a bank, and I can explain the situation, and that manager will give me access to anything.
Some banks will say, ‘Absolutely not. Unless you get permission from the client.’ So- because they’re not mandated reporters. I can’t wait for the day that they are. Because- yeah. That would really be helpful. You know, the bank teller sees this woman come up to the counter with her grandson and takes out 10,000 dollars, and she’s never done that. Come on. You know, that’s red flags. Red flags are everywhere, but...no one calls us about it, we can’t help, you know.” (p. 10-11)

wishing to be deputized

R7: “I at times wish APS could become deputized. I truly do.” (p. 12); “And at times I wish I was deputized. You’d be amazed the things that we can see. I’ve walked in and there’ll be drugs all over the-...Oh! I mean, I’ve seen coke lines, weed, I’ve seen weapons. And they’ll leave it out there, ‘cause I’m not- ‘n I’ll make it clear to them if I ever see it again, I’m gonna have the police here. But I won’t get back in. But at times I wish I was deputized because I’ve walked in on abuse cases where people have been abused so badly, and I can’t get a police officer here quick enough. They’ll be gone. Yeah.” (p. 12)

health department standards differing between private homes and apartments, APS standards not differing

R4: regarding having different standards for people living in their own home and people living in apartments: “Now the health department standards are different. Yes. But our standards aren’t. The health department, they’ve got different codes to withhold. Each landlord has different codes to uphold. We don’t.” (p. 12)

observing a naturally occurring but less than optimal senior housing community

R2: “I went into a home of a customer that I’d had for a while, ninety-five-year-old lady...ah, she’s so funny. Wonderful little lady. In this little tiny house that was built years and years and years ago as a vacation cottage kind of thing. And unfortunately this area has developed into, um, all these older adults are living in them because it’s cheap housing...but they’re also not built to accommodate year-round living.” (p. 14)

older adults not realizing how nice senior housing is now

R14: “I think sometimes people don’t know- The old view, if you’re dealin’ with an 80-year-old or a 90-year-old, senior housing is something that would be...not better than where they live. And I think sometimes they don’t realize how nice our senior housing is.” (p. 3)
observing an increase in people going to the hospital after the hospital’s home-based health and medication management services were discontinued

R16: “I mean, we used to have case management, outpatient case management through our hospital, and while they still do it, they’re making the people come to them now. But they used to go to the homes, set up meds, check their blood pressure. We had a lot of success with that, but then I guess it wasn’t cost effective, so they started cutting out those visits, and we saw an increase in people goin’ to the hospital again.” (p. 3-4)

educating clients about the importance of nutrition for healthy brain function

R15: “…and one of the things that I’ll say to them, standard spech, is, you know, another reason why I ask ‘Did you have any- What did you have to eat this morning. Because, if you’re not feeding your brain you’re not gonna be able to think. And, a lot of times, because we are inactive, we’re sitting around all day long, you don’t feel hungry, but you still have to feed you brain. You still have to do that so you’re gonna be thinking clearly. And those are things that you can do for yourself, you do that for yourself, and you’re never going to have to leave this house.’ So you know, it’s an incentive, you know, to, ‘even if you don’t’ feel hungry, get yourself somethin’ to eat anyway.’ So that’s kind of my little standard speech.” (p. 4-5)

problem-solving about intimacy needs to help avoid abuse by prostitutes

R9: “…there are a group of elders that are choosin’ to be with, um…Men that are choosin’ to be with younger women that are not- That are drug abusers and junkies.” (p. 8); “A woman who’s definitely on crack, younger, came in, lost it on him, threatened him, because he had had a business arrangement with her.” (p. 9); “And he wrote her a check, and stopped payment on it. She literally went off, while they were there gettin’ the services.” (p. 9); “He told me what had happened. So I said, well, I said, ‘Well, you’re a good looking guy in a wheelchair.’ I said, ‘Hey, how about adult daycare.’ Because, I said, ya’ know, men, women, the ratio is like eight to one. Maybe meet a woman your age that likes you for who you are and there won’t have to be any payment involved.” (p. 9); “I was like, the guy’s lonely, you know? Like, you know, she went off, I said, dude, I saw her. And I was like- He’d say ‘I don’t know if I like women my age.’ I said, ‘Dude, I saw her. I’d take a 70-year-old over her, so…But he was thinkin’ like ‘Really?’ I said, ‘Yeah, why don’t you try that for three days or so, ‘n…” ‘I don’t believe-’ He was {unintelligible}. But where is he gonna meet somebody?” (p. 9); “I’m saying, so, that’s self-determination, helping the client.” (p. 9)
explaining new national “light bulb call-for-help” program

R7: new national “light bulb” program every county can get federal funds for where a special bulb is put in the window that can flash if help is needed (p. 10)
CHAPTER FIVE: DISCUSSION

This discussion is organized in five sections. The first section is a response to the initial research questions, integrating the findings from this study with existing theory and research. The second section is a discussion of ethical dilemmas faced by APS workers in the field. The third section is an evaluation of strengths and limitations of current APS service-delivery systems for assessing and treating elder self-neglect. The fourth section is a discussion of strengths and limitations of this study. The fifth section is a discussion of implications for future practice and research.

Research Questions

- What themes and issues arise when Adult Protective Service (APS) workers investigate allegations of elder self-neglect?
- How do APS workers conceptualize elder self-neglect?
- How do workers approach older adults alleged to be self-neglecting?
- What themes and issues arise when workers assess elder self-neglect?
- What decisional factors emerge when workers discuss their decision about whether or not to substantiate allegations of elder self-neglect?
- What kinds of treatment and service recommendation themes and issues arise?
- What themes and issues arise in cases where older adults decline services?
- When are involuntary services sought?
- What services are needed by older adults found to be self-neglecting?
- What are the gaps in service delivery?
- What services do older adults accept and what services do they reject?
- How do workers distinguish between elder self-determination and self-neglect?
What themes and issues arise when Adult Protective Service workers investigate allegations of elder self-neglect?

Five dominant themes arose when APS workers discussed investigating allegations of elder self-neglect: assessing decision-making capacity and awareness of current risks and circumstances, recommending and implementing needed services, consulting and linking with service providers, honoring competent people’s right to live as they wish, and approaching elder self-neglect with a “softer touch” than allegations of abuse or exploitation. Four major problematic issues also emerged: working with seniors who are reluctant to accept needed services, seeking involuntary services, struggling with difficult case decisions and ethical dilemmas, and getting into homes to assess conditions. These major themes and issues will be discussed in detail as they relate to the following research questions. Consistent with the literature (Iris, 2010; Fulmer, 2008; Dyer et al, 2008; Liebbrandt, 2008; Kutame, 2008; Teasler et al, 2006; Heisler and Bolton, 2006), workers in this study identified that the majority of referrals they investigate are for cases of elder self-neglect.

The process of investigation begins with receiving and screening referrals, some of which are “bogus” calls where the caller may have inadequate or false information, may exaggerate conditions, or may have malicious intent. A common concern that arises during investigation is the clients’ desire to know who called APS on them. Workers protect referral source confidentiality in a variety of ways, including explaining confidentiality laws to the client, not looking at the name of the referral source so the worker can honestly say “I don’t know,” not taking referral source info to a home visit to avoid slipping and telling, and emphasizing to the client that somebody cared enough to call. Two workers noted that some clients will ask them to leave or will refuse to talk due to the worker not telling them who made the referral.
The process of investigation ends with closing cases. Workers identified that they sometimes need to keep cases open longer than the 30-day guideline to get a solid assessment or for pending court action, which can take months. Sometimes workers can keep cases open under a different classification for monitoring. Workers feel most comfortable closing “borderline” cases (where there is some risk present) when services are in place. One worker noted, “You can’t keep a case open for potential.”

The issue of clients’ legal rights arises when APS workers investigate elder self-neglect. As mentioned above, workers consistently stressed the importance of acknowledging and honoring competent people’s legal right to live as they wish. Two workers mentioned the importance of APS providing community education about competency laws and client’s rights to the public. Additional themes and issues that arise during investigations are discussed in the following responses.

**How do APS workers conceptualize elder self-neglect?**

APS workers interviewed for this study consistently operationalized self-neglect as people not taking care of themselves and their environment to the degree that they are causing or risking physical harm. Workers identified unsafe medical and hygiene decisions, unsafe housing decisions, and harmful financial decisions as primary indicators of elder self-neglect. This conceptualization is consistent with the range of conceptualizations found in the literature. It is particularly similar to the National Center on Elder Abuse (NCEA) definition:

“Self-neglect is characterized as the behavior of an elderly person that threatens his/her own health or safety. Self-neglect generally manifests itself in an older person as a refusal or failure to provide himself/herself with adequate food, water, clothing, shelter, personal hygiene, medication (when indicated) and safety precautions.

The definition of self-neglect excludes a situation in which a mentally competent older person, who understands the consequences of his/her decision,
makes a conscious and voluntary decision to engage in acts that threaten his/her health or safety as a matter of personal choice” (NCEA, 2005).

Also consistent with the NCEA definition of elder self-neglect, workers in this study repeatedly noted that competent people have the right to live as they wish, including neglecting themselves. Several workers described the common phenomenon of substantiating allegations of elder self-neglect but closing the case without intervention because the person refused recommended services. Two workers mentioned the importance of acknowledging the underlying issues of clients’ losses and treatment fatigue when considering self-neglect.

It is important to note that APS workers’ conceptualization of self-neglect may be influenced by their unique role of having to make decisions for other people. Unlike sociologists, researchers, policy-makers, and the general public, practitioners are personally responsible for deciding whether or not to seek involuntary services for self-neglecting elders. APS workers interviewed for this study consistently identified laws and ethical principles (from as the NASW Code of Ethics and their agencies’ mission statements) as their guiding principles in defining and approaching elder self-neglect. This construction of self-neglect through the lens of ethical and legal considerations appears to be influenced by the workers’ need for practical guidelines in their unique role as decision-makers.

Workers consistently stated that their conceptualization of elder self-neglect is often in contrast to community opinions and desires. For example, a neighbor of a self-neglecting elder might construct self-neglect as an untreated health issue, a property value issue, or a character defect rather than as a lifestyle choice permitted by law. Community members might construct their ideas of desired intervention for self-neglecting elders from a perspective of beneficence, such as “people in need should helped,” rather than from a perspective of acknowledging and protecting individual’s
legal and ethical rights. Workers consistently and repeatedly pointed out that families, neighbors, landlords, police and fire personnel, and local community leaders want to see change occur and are often unaware of or do not agree with laws protecting citizen’s rights. Workers described the typical community response to elder self-neglect as being “You need to do something about this.” Several workers described educating the public about people’s legal rights as an important part of their job.

A literature review on conceptualizing elder self-neglect revealed that elder self-neglect is not an objective phenomenon but rather a socially constructed concept resulting from a series of social judgments (Lauder, et al, 2001). Authors consistently noted that a wide range of variation exists in conceptualizing self-neglect among scholars, practitioners, cultural groups, age cohort groups, and older adults identified by others as self-neglecting (Iris, 2010; McDermott, 2010; Skelton, 2010; Gibbons, 2009; Lauder, 2009; Kelly et al, 2008; Fulmer, 2008; Naik, et al, 2008; Pavlou and Lachs, 2008). Gaining a better understanding of the social construction of the concept of elder self-neglect will be discussed further in the “Implications for future practice and research” section that follows.

An in-depth discussion of various conceptualizations and theoretical perspectives of elder self-neglect was presented in chapter two. In summary, the most common deficit of theoretical perspectives of elder self-neglect is their lack of attention to the underlying economic concerns of aging associated with elder self-neglect. All 12 theories on aging reviewed for this study, with the exceptions of Exchange Theory and Productive Aging perspectives, identify the need for meaningful relationships and activities as the foundational elements of successful aging (and, by implication, avoiding self-neglect). Only Exchange Theory and Productive Aging identify the necessity of having adequate resources to exchange for needed goods and services as an essential element of
successful aging. The other theories assume economic stability, or at least that basic human needs are being met. This is usually not the case for older adults experiencing self-neglect.

The APS workers interviewed for this study did not specifically mention any theoretical perspectives on elder self-neglect, however they did mention themes consistent with four theories: Exchange Theory, Productive Aging, Role Theory, and Continuity Theory. Consistent with Exchange Theory and a Productive Aging perspective, workers identified the lack of goods and services to exchange as a contributing factor of self-neglect. Productive Aging theorists and Exchange Theory proponents argue that the problems of aging come about because the aged have little to exchange, leading to their increased dependence and need to comply with others (Turner, 1992; Bengston and Dowd, 1981; Dowd, 1979). From a social exchange theory perspective, elder self-neglect may be viewed as resulting from the inability to produce goods and services to exchange.

Choi, et al (2009) found that elder self-neglect and neglect is, in large part, attributable to the lack of resources to pay for essential goods and services and to inadequate healthcare and other formal support programs rather than individual risk factors. This finding supports an exchange theory explanation of elder self-neglect. Choi, et al (2009) recommend that inadequate public policy coverage needs to be considered as a significant cause of elder self-neglect and neglect. Consistent with this finding, workers interviewed for this study also identified that elder self-neglect is often due to a lack of resources, inadequate healthcare coverage, and unaffordable formal support services. For example, workers stated that property neglect may be due to poverty, financial and eligibility barriers prevent many seniors from receiving needed healthcare
and formal support services, and that assisted living support is unavailable for poor people.

“...you have to determine a lot of times if the home is just old and worn down versus a total neglect, it’s just not taken care of. And, you know, do they live in squalor by choice, by lifestyle...Do they live in a very old, not well-maintained home just because they don’t have the money to maintain it....versus a house that’s trashed, literally with trash and other things.”

“There’s also the income eligibility issue. You know, sometimes they’re willing to accept the services, but they may be slightly over income, and then that’s-, you know, by them paying for that, they wouldn’t be able to accept them.”

“What’s really needed is home services to clean, run errands, and do some personal care need without having to meet the level of care for passport, or for nursing home placement. Without having to meet that level of care. Is what’s really needed. I’m sure that’s said about the- across the board.”

Re: rural counties lacking funding from city taxes that some larger cities have: “We have none. None. If you don’t qualify for Medicare or Medicaid for any home health services, there’s nothing unless you private pay.”

“You have people who aren’t eligible for Medicaid... You have people who for whatever reason aren’t on Medicare... So they might have a skilled need, but they don’t have Medicare. They might have a skilled need but they don’t have Medicaid.”

“I have a real hard time keeping track of Medigold, Medicare, Medicaid, private insurance, what they will do... Right now there’s a huge problem with the Medicare/Medicaid nursing home situation. I can’t even remember the names of em! The one where- the HMO stuff. you know, And who’s gonna pay. We’ve had people who want. We had a gentlemen, wanted to go to a nursing home. Physically, mentally...doctor, customer, everybody was agreeable this person needed it. His coverage, when it went from Medicaid to HMO to whatever it was...no, this won’t pay, no this won’t pay, no this...Everybody is ready for this man to go, he needed this. He needed 24-hour care and supervision, and he was in a loophole. And a huge loophole that, ah...it’s terrible. And I think it took probably a month and a half to get this gentleman into a facility.”

“I’d like to see more programs accepting a wider array of insurance and health care. Because, you know, if someone has Medigold, then they can’t have the same things that I just got for a person who has Medicare. And, or somebody who’s got Humana can’t get the same things as you got somebody who’s Medigold, or...Medicaid, then they got everything, and, you know what I mean? And it’s frustrating.”

“They have that spenddown. And sometimes the spenddown is just so atrocious. I mean, just the amount is-‘cause sometimes I’ll look and I’ll say ‘Oh! You only get, you know, eight hundred dollars, right?’ And I’m thinking, is it, you
know, in my mind, and they’re like ‘Yeah, my spenddown is like two hundred and eighty-five’ and I’m like…”

“So you’d have to be Medicaid eligible to get free homemaker services.”

“There would be alternatives between a nursing home and the home life. So they would be, like, for poor people, they would be assisted living that’s a medium ground, instead of just putting them [in nursing homes].”

Consistent with Role Theory and Continuity Theory, several workers identified seniors resisting role changes as a factor contributing to elder self-neglect. Workers described seniors not wanting to change their role status from independent roles to dependent roles. For example, workers specifically described seniors who are parents resisting asking their children for support because they do not want a role reversal from caregiver to care-receiver.

“…you’re gonna have some situations where family really don’t realize that their parents or grandparents need that kind of assistance. Because they see their parents in always as this strong, capable, always doing role. They don’t necessarily see the decline that an outsider would see. Because {spoken softly} it’s their parents. They see them in the same light they’ve always seen ‘em.”

“’cause a lot of times the family is willing to do something but they’re just so afraid that mom and dad is gonna...[claps hands lightly] you know, like the role reversal, you know. They just can’t possibly step in and, and take over. They just feel like they’re oversteppin’ their boundaries...”

“A threat of asking them to do something that they’ve never done, which is ask their children, or their grandchildren, to do something for them, where there’s been a lifetime doing for them.”

“Well who wants to all of a sudden look weak in front of their children?”

Consistent with Continuity Theory, workers described seniors wanting to continue living in the same environment, sometimes even when the environment is unsafe. From a Role Theory perspective, this could be viewed as resisting the change from the independent role of head of household/homeowner to the more dependent role of houseguest, renter, or nursing home resident.

“And so, because she didn’t wanna leave, she was a case that I had to go check every day. Had to make sure she was ok every day.” “...it all took place
from September to December, and she was so sweet. But...She had everything. If there were the animals, she had everything. She had the odor at the front door, she had the same soiled clothing on. She had the poor hygiene. She had the cigarette smoking. She had the burn holes...She smoked outside. That was the saving grace with cigarettes, right? Smoked outside. She had roach and mice infestation, and she refused to leave. And that's one of the, you know, they refuse to leave.” “I got this case in September, and this was like about five years ago. That's how they stick with you though, some of those cases. I got it in September, and I think we had her guardian and had her placed in December.”

“This lady, this was some years ago, but I believe that she was discharged, I can’t remember if it was from a nursing facility or a hospital, back home. However, in this situation she wanted to be in her own apartment. She has a son, but her son did not live there with her. In this particular situation, she was not able to get her meals, she was weak, could not get up to really ambulate, to actually get her meals or even dress or bathe herself, or even go to the bathroom. In this particular situation I asked her and tried to talk her into going back to the hospital because it was totally, completely apparent that she was not able to take care of herself, and I could not leave her there. She refused.” “So what I ended up having to do at that particular time was go to court and seek the assistance of our Prosecuting Attorney, get a court order to have her removed from the home by force, if necessary, with the police help as well as be able to call the paramedics.” “And she was angry, you know, with me. She asked me if I would be able to sleep at night, you know, because she was extremely angry with me having to get the Order. But again, I had no choice but to get the Order. And that was a case where I had to override. Override the decision.”

“I have a client right now who does not want to move. He’s lived in his home for 40 years. It is horrible. It’s horrendous, it’s full of rats, feces, it’s disgusting. It’s really not even- I recently went through the whole hose and was shocked, okay? He does not want to move. But...he cannot stay there. He’s competent. But...I’m working out an agreement with him, that he has agreed to go look at senior housing.” “And so we have reached a compromise, and he is going to take a taxi and go look at a couple of place. ‘Cause currently he has no water. And I think that’s not gonna work.”

“Sometimes it’s bad from the beginning [of the investigation], but they want to be in there. That’s their lives. So, sometimes you have to make a decision. So it falls on me. I guess.”

How do workers approach older adults alleged to be self-neglecting?

Workers consistently pointed out the importance of building rapport with clients and approaching self-neglect concerns gently. They shared that they approach investigations of self-neglect allegations with more patience and a “gentler touch” than they do when investigating abuse allegations. Five workers specifically discussed this
approach. One worker described her approach to older adults alleged to be self-neglecting as “Very soft, very ‘just concerned about you.’” Workers mentioned being “slow and careful” and “working your way in slowly.” They discussed trying to explain their role to clients in a non-threatening way, going “gently” into the reasons for the home visit, and “not coming on too strong.” Two workers specifically mentioned trying to not be “scary,” for example avoiding “I’m here with the government and we’re doing things my way.”

A technique several workers mentioned using in order to be less threatening is to initially identify themselves as “we’re from the office on aging” and then later specifically identifying Adult Protective Services. Workers emphasized the importance of demonstrating courtesy and not shaming or embarrassing people. Three workers specifically expressed having personal empathy for respecting people’s private space. Workers also emphasized the importance of remembering that allegations may or may not be true.

Workers described the utility of approaching people alleged to be self-neglecting by listening to them rather than directing them. One worker explained: “I usually go in just waiting for the client to tell me.” Workers described approaching people by talking, explaining, and communicating with them. They described offering information and referrals, encouraging seniors to accept needed services, and leaving printed information for the client. Workers recommended approaching change gradually and recommended patience in giving people time to address the problems themselves and making changes on their own.

Another theme that emerged about approaching self-neglect referrals was workers consciously trying to keep their own values in check when assessing other people’s lifestyles. One worker demonstrated this by stating “I don’t have the right to
adjust people’s lifestyle.” She also stated “I don’t ever wish to make decisions for anyone if at all avoidable, and 99 percent of the time it is avoidable.” Another worker described keeping her values in check by thinking about the APS principle of “Freedom over Safety” every time she goes out and always trying to err on the part of the client unless there’s significant harm or danger.

This principle of “Freedom over Safety” appears to strongly influence APS workers’ approach to self-neglecting elders. Five workers expressly stated that people are allowed to be dirty and live in filth or clutter. Six workers emphasized prioritizing client’s needs and rights over community desires. One worker noted that it can be a challenge getting people to acknowledge that there’s a problem. Another noted “it’s tricky” trying to have a person quit a behavior.

As discussed previously, assessing decision-making capacity emerged as the dominant theme of assessing elder self-neglect. Workers may substantiate allegations of self-neglect but be unable to take any action if the older adult verbally demonstrates an understanding of possible consequences of their decisions and refuses services. Four workers specifically mentioned honoring people’s right to refuse services. Workers discussed their strategies for approaching people who resist intervention, including strategies for gaining access to homes. These strategies are discussed in the “Implications for future practice and research” section that follows. Finally, one worker noted that she approaches seniors referred for self-neglect by letting them know that “somebody cares” because somebody cared enough to make a referral.

An in-depth discussion comparing and contrasting theoretical perspectives on treating elder self-neglect is presented in chapter two. In summary, the most frequently represented treatment approaches to elder self-neglect found in the literature were the medical model (including mental health, hygiene, nutrition, medications, disease, and
functional impairments) and an ecological perspective (including the effect of community and formal and informal support networks). Workers interviewed for this study were not specifically asked about their theoretical approaches to explaining or treating elder self-neglect. They were, however, asked if they use any particular practice models when approaching elder self-neglect.

Workers were asked “Do you use any particular practice models with self-neglecting elders? If so, what interventions do you use?” Five workers stated that they do not use any particular practice model and several other workers hesitated in identifying a practice model they use consistently. Reasons for not using a practice model or not consistently using one model included the ideas that all clients do not fit into any given model and that using a particular model may pre-set workers’ expectations. One worker explained, “no one fits in your theories perfectly. No one fits in all those. You’re dealing with human beings...” The most frequently used practice model was a client-centered approach, with three workers mentioning it. Other models workers described using were a systems approach, a problem-solving approach, reality therapy, and a self-preservation/educational approach. Specific practice recommendations for approaching self-neglect found in the literature and in this study are presented in the following “Implications for future practice and research” section.

**What themes and issues arise when workers assess elder self-neglect?**

As mentioned throughout this study, researchers have observed that there is no standardized definition of elder self-neglect and that no tool exists for characterizing elder self-neglect. This gives rise to conceptual, assessment, and intervention problems for health and social care workers (Iris, 2010; McDermott, 2010; Skelton, 2010; Gibbons, 2009; Fulmer, 2008; Kelly, et al, 2008; Naik, et al, 2008; Pavlou and Lachs, 2008, Lauder, et al, 2005). Researchers have recently focused on developing standardized

Workers who participated in this study consistently identified their primary assessment task as assessing seniors’ decision-making abilities. Workers particularly emphasized assessing seniors’ abilities to verbally demonstrate their understanding of possible consequences of their decisions. For example, workers typically assess people’s ability to explain what might happen if they do not take prescribed medications, undergo recommended medical treatment, or maintain their home environment to meet applicable city or apartment housing code standards.

In addition to assessing decision-making capacity, workers described assessing people’s decisions about health and hygiene, housing, relationships, and finances. Workers described assessing elder self-neglect allegations by looking for points listed in the referral. They described keeping the first visit short and usually making several home visits to get an accurate assessment of somebody. One worker shared her approach of seeing all clients once a week “regardless of how busy it gets.”

APS workers identified issues of competency, self-determination, and available resources regularly arising when they assess elder self-neglect. They also identified several sensitive issues that may arise when assessing elder self-neglect. These included: assessing and approaching the need for mental health services, recommending psychological evaluations, approaching finances with seniors, approaching unintentional risk of harm to others, and assessing abuse, exploitation, and neglect by others. One worker noted sometimes finding self-neglect to really be exploitation by others.
Another theme that emerged was workers preferring to evaluate self-neglect on a case-by-case basis. One worker noted that assessment and intervention differs among APS workers. Only one worker identified utilizing a specific standardized risk assessment form that she found through the Ohio Coalition of Adult Protective Services. She shared that she did not care for the previous one she got from somebody else and that she had had to alter it for use in her community. Workers were, generally speaking, not enamored with standardized assessment tools or practice models. They consistently expressed that standardized assessment tools such as the Mini-Mental State Exam do not provide an accurate or useful measure of a person’s ability to make real-life decisions about housing, health, hygiene, and activities of daily living.

Workers’ expressed preference for case-by-case assessment is in direct contrast to the current research agenda of seeking to develop standardized assessment tools and treatment protocols for elder self-neglect (McDermott, 2010; Kelly, et al, 2008; Naik, et al, 2008; Pickens, et al, 2007). This contrast is discussed further in the “Implications for future practice and research” section. Workers’ thoughts on standardized tools and practice models are discussed in more detail in the “Evaluation of current practices” section.

**What decisional factors emerge when workers discuss their decision about whether or not to substantiate allegations of elder self-neglect?**

APS workers substantiate allegations when they observe the conditions of self-neglect alleged in the referral. Workers do not substantiate self-neglect allegations when the alleged conditions are not found. False or exaggerated allegations may be made by feuding neighbors, feuding children, or children or service providers who are overreacting to perceived risks.
Workers identified two primary factors they consider when deciding whether or not to substantiate allegations of elder self-neglect: the condition of the person and the condition of their environment. When assessing a person’s condition, workers consider if self-care decisions such as hygiene, medical, and eating decisions are putting a person’s health at serious risk. When assessing a person’s environment, workers consider if housekeeping and home maintenance decisions present serious health and safety risks. They may also consider, when possible, if bill-paying decisions are jeopardizing continued housing or leading to utility shut-offs.

Self-neglect allegations are only substantiated when workers assess that a person’s self-care or housing decisions present serious risks to her health or safety. One worker framed it as “we substantiate...if there’s a protective need.” Another worker explained:

“I think bottom line is- to substantiate is when somebody is going without food, medicine, heat, when they are noticeably going without something and it can be changed, and should be changed for their well-being.”

Substantiating allegations is decided on a case-by-case basis, with competency being considered as a mitigating factor in deciding whether or not to substantiate. Workers may or may not substantiate self-neglect allegations when competent people are neglecting themselves, depending on the specific conditions and the person’s responses. Workers described sometimes deciding to not substantiate self-neglect allegations when people understand the consequences of how they’re living: when the person has full mental and physical capacity, is making a lifestyle choice, and their Activity of Daily Living (ADL) skills fit a lifelong pattern and are the norm for them rather than a decline because of incapacity. Workers also described sometimes deciding to substantiate self-neglect allegations when competent people are neglecting themselves, but closing the case if they decline intervention.
“The way I approach it, I believe, even if they’re competent, I can still substantiate that you’re neglecting yourself. However...yes, it’s substantiated, you are neglecting yourself, however, you are competent and you understand the consequences and the outcomes of this neglect.”

Workers consistently and repeatedly noted that conditions such as poor hygiene, poor health choices like smoking or poor nutrition, and poor housekeeping are not enough to substantiate allegations of elder self-neglect. However, poor health choices such as not treating gangrene or ulcerous wounds, obvious malnutrition to the point of starvation, or poor housekeeping and home maintenance decisions that create current, immediate health or fire hazards such as not having a functional toilet or available fire exits usually are enough to substantiate self-neglect allegations. Two workers identified that there are more substantiated cases than unsubstantiated ones.

*What kinds of treatment and service recommendation themes and issues arise?*

Researchers have observed that there are no specific interventions or intervention trials to date for elder self-neglect, and that there is little empirical data available to guide medical practice in cases of elder self-neglect, particularly with self-neglecting patients who resist interventions (Pavlou and Lachs, 2008; Torke and Sachs, 2008). A literature review revealed that in-home services, court-appointed guardianship, and institutionalization are the most common formal interventions for elder self-neglect. Consistent with literature review findings, workers participating in this study identified in-home services, court-appointed guardianship, and institutionalization as the most common interventions for elder self-neglect. Workers consistently identified linkage to in-home services as their primary approach to treating elder self-neglect. They also identified court-ordered services other than guardianship, such as court-ordered cleaning, as an option in some communities. The problem with such court-ordered services is that unless people have a court-appointed legal guardian who can force
compliance, they do not actually have to accept the court-ordered services. Workers consistently emphasized trying to avoid institutionalization as much as possible.

Workers consistently and repeatedly noted that substantiating allegations does not necessarily mean that any intervention or treatment will occur beyond recommending services and offering linkage and advocacy assistance. Because they are adults, seniors have the legal right to live as they wish, including neglecting themselves and declining services that they do not wish to pay for. Intervention may not occur because APS workers do not have the legal authority to intervene when competent adults decline help, or because resources for needed interventions are unavailable.

The only two mitigating circumstances that allow workers to pursue involuntary services are: 1) concerns that the person might not be legally competent to make lifestyle decisions, and 2) imminent risk of harm to self or others, usually defined as risk of loss of life or limb within 24 to 72 hours. Workers may substantiate self-neglect allegations but close the case due to the person refusing services. One worker described this phenomenon as follows:

“And it’s substantiated. That doesn’t mean that it’s, that we’re going to fix it, it just means that it’s substantiated. I can substantiate even cases that I don’t do anything in. Substantiation just means that, yes, that problem is there. Now whether we choose to act upon that is whole ‘nother issue when we’re doin’ investigations. APS, really what the job of APS is just to say whether it’s true or not true, not to necessarily fix it. And to society that’s very hard to digest.”

APS workers consistently described their frustration with wanting seniors to accept treatment and service recommendations but acknowledged that ultimately, competent seniors have the right to decline all service recommendations. Workers identified their primary intervention activities as being to recommend and/or implement needed services and consulting/linking with other service providers (such as physicians, emergency squad personnel, police, court personnel, attorneys, and other agencies). Workers mentioned many other treatment and service recommendation themes. Some
are listed here with more detail available on each in chapter four and in the raw data from the secondary category “Approaching intervention with seniors” available in the appendix.

**clinical treatment and service recommendations themes**

- Workers advocating for independence [trying to keep people in their homes or community and trying to avoid nursing home placement]
- Involving and working with families
- Approaching hoarding
- Considering extended care facility [ECF] placement
- Calling health department/housing code enforcement
- Acknowledging and addressing client’s intimacy needs
- Educating clients about the importance of nutrition for healthy brain function
- Referring clients to a volunteer organization for assistance
- Working with banks
- Working with landlords
- Recommending driving suspension or re-test to the Bureau of Motor Vehicles (BMV)

**workers’ expressed feelings about treatment and service recommendations**

- Wanting seniors to accept services
- Valuing independence/keeping people in their homes
- Having strong feelings about gaps in service delivery
- Workers in Franklin County appreciating having access to good programs and funding available to put services in place
- Wishing more people had supportive families
What themes and issues arise in cases where older adults decline services?

As mentioned by APS workers throughout this study, assessing a person’s decision-making capacity is a primary issue that arises in cases where older adults decline services. If a worker assesses that a senior may not be legally competent to make decisions, she may petition the probate court for a competency hearing. Making this decision can be challenging, and two workers noted that it can be difficult and frustrating assessing if some of client’s thoughts are real or delusions. If a person is judged to be not competent by the probate court, the court may appoint a guardian to make decisions for the person, including implementing services the person is declining.

In some jurisdictions, courts have the authority to order services without appointing a guardian. The problem with court-ordered services is that people may continue to decline the services and there is not much recourse other than to seek guardianship. Guardians are legally able to enforce their decisions, for example utilizing the police or sheriff’s department to assist in getting in the house or protecting service providers from angry seniors.

Workers also identified assessing imminent risk of harm to self or others as an issue that arises when older adults decline services. If they find imminent risk of harm, workers may petition the courts to seek temporary guardianship or to order services. In communities that have specific housing or health department codes, workers may
contact code enforcement to investigate and perhaps mandate housing maintenance, repair, or clean up.

Workers are sometimes hesitant to involve code enforcement, particularly in larger counties, because they do not want a person to lose their housing. In contrast, an APS worker in a smaller county (that does have housing and health codes) knows the code inspector and contacts him to visit the senior with her to help “enforce” needed changes. She described it as a “good cop-bad cop” kind of approach. In larger counties with larger numbers of workers and code inspectors, the APS workers do not personally know the code inspectors and shared visits and consultations cannot be arranged.

Finally, workers identified strategies for working with older adults who decline or resist services. These strategies include clearly explaining the services (“putting everything out in black and white”), compromising about needed changes, and monitoring people over time (“keep tryin’”). These strategies are discussed in more detail in the “Implications for future practice and research” section that follows.

**When are involuntary services sought?**

People lacking capacity who are endangering themselves or others will likely need some form of temporary or permanent guardianship (Pavlou and Lachs, 2008). Although legal interventions such as guardianship may serve to protect vulnerable older people, it is critical to ensure that such interventions do not inappropriately infringe on the older person’s civil liberties or result in exploitation (Connolly, 2008). Consistent with the literature, workers in this study consistently identified competency and safety as their central concerns when considering seeking involuntary services. One worker summarized it succinctly:

“Probably when I see that they are in danger themselves. Or they’re puttin’ somebody else in danger. That’s the main thing. N’ that I can clearly see that, you know, they’re really not understanding consequences.”
Workers noted that often times something bad has to happen before they can seek involuntary intervention. One worker identified seeking involuntary services when people are “hitting rock bottom.” Another worker mentioned the importance of assessing suicidal or homicidal statements and noted that all suicidal or homicidal statements are not actual threats but are often just expressions of grief and fatigue, and that clients need to feel safe to express grief and fatigue.

Workers seek involuntary services by petitioning the probate court for a competency hearing for guardianship or for court-ordered services. In some counties, the courts can order involuntary services without mandating a guardianship. Workers described the probate court standard of imminent risk as being potential loss of life or limb within a 24 to 72-hour period if intervention does not occur. Workers consistently emphasized that they wish to avoid seeking court orders for involuntary services and that they prefer to try to convince people of the need for services rather than seek involuntary services.

One worker noted that unintentional risk of harm to others is “not gonna work” in court as a reason for seeking involuntary services and identified unintentional risk of harm to others as a landlord issue. Unintentional risk of harm to others may be a housing code enforcement issue in communities that have established housing codes, but many rural communities do not have housing codes.

Several workers shared their clinical approaches to working with people who might need involuntary intervention. They emphasized the importance of acknowledging people’s fears about being institutionalized against their will, and they described taking the clinical approach of allowing people time to try their own interventions before seeking involuntary services whenever possible. One worker shared that it is
uncomfortable asking cognitively impaired people to sign a case plan informing them that they are going to be taken to court.

**What services are needed by older adults found to be self-neglecting?**

This topic is discussed in more depth in the results chapter. [See property “Identifying services needed for self-neglecting elders,” the first property in the category “Actions needed/taken.”] As mentioned previously, a literature revealed in-home services, court-ordered services such as guardianship, and institutionalization as the most common services used with self-neglecting elders. Workers in this study addressed needed services in two ways: they discussed implementing available services and they identified unmet services needs. The available services that workers discussed using the most frequently were homemakers, Meals-on-Wheels, and the Emergency Response System (ERS) button. Other available services workers discussed using were major cleaning, personal care assistance, and minor home repair.

The unmet service needs identified most frequently by workers were in-home medication assistance/medical monitoring and transportation. Other unmet service needs identified by workers included: informal care from family, financial management assistance, mental health and chemical dependency services, coordination of care, socialization/activity programming, and wellness checks/companionship. Workers expressed that some of these services are unavailable (such as in-home medication monitoring, transportation for a variety of needs, informal care from family, coordination of care, and wellness checks/companionship), while other services are sometimes available but often resisted by seniors (such as financial management assistance, mental health and chemical dependency services, and socialization/activity programming). Sometimes services are available but unaffordable for most seniors.
**What are the gaps in service delivery?**

APS workers interviewed for this study expressed strong feeling about the gaps in service delivery. Choi, et al (2009) found that elder self-neglect is, in large part, attributable to the lack of resources to pay for essential goods and services and to inadequate healthcare and other formal support programs rather than individual risk factors. Consistent with the literature, APS workers described the lack of available resources as a major gap in service delivery and identified this lack of resources as a contributing factor to elder self-neglect (Choi, et al, 2009; Schaefer, 2004). Workers were passionate about sometimes not having the means to get clients help due to insurance, eligibility and funding barriers. Workers explained that some needed services are unavailable or unaffordable, while other services are available but resisted by seniors.

Workers pointed out that APS is a short-term crisis intervention service and that they are unable to provide needed long-term monitoring. The gaps in service delivery identified most frequently by APS workers were in-home medication assistance, in-home medical monitoring, and transportation for a variety of needs (not just medical transport). Other gaps in service delivery identified by workers included informal care from family, coordination of care between formal and informal helping systems, home-based wellness checks/individual companionship, and assisted living for poor people.

In addition to identifying actual gaps in service delivery, workers also identified two other major barriers to service delivery: 1) seniors’ lack of trust and willingness to accept services, and 2) their lack of willingness to pay for needed services. Workers suggested that a lack of trust is often a result of the person previously having a bad experience with service providers or hearing reports from others of bad experiences. Workers suggested that the lack of willingness to pay for services may be a cohort-related phenomena related to valuing frugality and/or the desire to preserve assets for family
members. Services that are available but often resisted by seniors include financial management assistance, mental health and chemical dependency services, and socialization and activity programming.

**What services do older adults accept and what services do they reject?**

APS workers were asked to identify what available services older adults accept and what services they reject. Workers noted that older adults are typically most likely to accept the least personally invasive services (such as the Emergency Response System button, transportation, visiting physicians and nurses, in-home medication monitoring, home-delivered meals, and exterminators) and most likely to reject the most personally invasive services (such as personal care or an attorney or third party handling their finances). Moderately invasive services (such as major cleaning, homemakers, and adult daycare) are moderately accepted. One worker noted that APS intervention is the least accepted service due to the investigative, personal nature of Adult Protective Services.

Workers consistently said that older adults are most likely to accept the Emergency Medical System button. Workers expressed that most seniors would accept transportation services and in-home medical services such as medication administration, visiting physicians or visiting nurses if they were readily and consistently available. According to workers, Meals-on-Wheels are not as accepted as one would think because some seniors don’t like the taste of them and others value independent cooking. Estimates of how many seniors accept Meals-on-Wheels ranged from “about half” to “most of them.” “‘Cause either they like ‘em a lot and they’re savin’ ‘em money, or...They don’t taste right because they’re diabetic, they don’t have any spices...”

Homemaker and major cleaning services are a “harder sell” because many seniors do not want strangers in their homes, have previously had a bad experience with homemakers, or know friends who have had bad experiences with homemakers. Workers
pointed out that hoarders particularly resist homemaker and major cleaning services. Personal care services are also often rejected. Workers noted the extremely personal, invasive nature of such services and suggested that seniors may not want to be so vulnerable with strangers.

Workers consistently expressed that older adults usually reject financial management services, mental health services, and chemical dependency services. Workers consistently shared that older adults typically do not want people meddling with their finances. Mental health and chemical dependency services are generally resisted due to the stigma the current cohort of older adults has against them. Several workers shared that when they have suggested counseling, perhaps for depression, a recent loss, or adjustment to a life transition, seniors have declined and told them “I’m not crazy.” Several workers suggested that this stigma will decline in future cohorts who appear less likely to stigmatize mental health services and more likely to self-identify as “consumers.”

Finally, workers shared that older adults will usually accept free services but often reject services that have any associated cost, even a nominal co-pay. Workers’ explanations of this ranged from poverty, to cohort-related frugality, to people wanting to preserve assets for their families. An implication of this phenomenon is that an effective strategy to increase service utilization would be to develop and fund programs that are universal (available to all, such as Medicare) with need-based eligibility requirements rather than income-based eligibility requirements.

**How do workers distinguish between elder self-determination and self-neglect?**

APS workers consistently identified competency as the primary factor they consider when balancing self-neglecting elders’ right to self-determination with the legal
mandate to protect seniors from self-neglect. They also consistently identified the dilemma of balancing seniors’ rights with their health and safety needs as one of the biggest and most common ethical dilemmas they face in the field. In addressing this dilemma, Franklin County APS policy-makers have formally identified “Freedom over Safety” and “Self-determination” as their agencies primary guiding principles, providing ethical direction and support for workers. Facing the dilemma of freedom versus safety is particularly difficult when clients demonstrate “fluctuating competency.” Specific examples of this dilemma and others are discussed in the “Facing Ethical Dilemmas in the Field” section that follows.

Adult Protective Services is qualitatively different from Child Protective Services. In the United States, children under the age of 18 do not have the legal right to choose to self-neglect or to choose to remain in a neglectful environment. Therefore, in Child Protective Service investigations, conditions found during the investigation will determine whether the allegations are substantiated and what outcomes will occur. Unlike children under the age of 18, competent adults over 60 have the right to self-determination, including the right to self-neglect and the right to refuse treatment and services. Therefore, for APS workers, substantiating self-neglect allegations and deciding what course of action to pursue are more complicated because the client’s competency, legal rights, and personal preferences mitigate these decisions. Typically, APS workers will respect an adult’s decisions as self-determination if the person appears competent, demonstrates the ability to articulate the possible risks of her decisions, and other people are not being put at risk by her decisions.

Workers’ views on honoring self-determination differed somewhat from literature review findings in that workers firmly believe in honoring people’s right to refuse services. For example, in contrast to workers’ approach to definitively honoring a
competent self-neglecting elder’s right to refuse intervention, Bergeron (2006) suggested that honoring client choice might not necessarily mean honoring the overt refusal for intervention. He implied that accepting a client’s refusal-for-services is akin to patient abandonment, which he viewed as a clear violation of a social worker’s professional Ethical Code. He recommended the idea of “negotiated consent” in which practitioners offer differing degrees of assistance to minimize the elder abuse or neglect.

In contrast to Bergeron’s (2006) view that accepting a client’s refusal for services is akin to patient abandonment, workers interviewed for this study identified accepting a client’s refusal for services as a sign of respect. Somewhat similar to Bergeron’s idea of “negotiated consent,” several workers in this study emphasized seeking “compromise” with clients regarding service implementation. Bergeron concluded that laws about elder abuse and neglect need to be reexamined and revised:

“Laws that only allow for investigating and substantiating allegations of abuse, but then allow exclusive rights to the victims to remain in serious, life-threatening situations because of his or her ‘right to choose’ begs our immediate attention.” (Bergeron, 2006, p. 100)

In contrast to this view, no workers participating in this study expressed the concern that laws protecting senior’s rights need to be re-examined. Bergeron (2006) observed that in practice, competent older adults’ right-to-refuse intervention appears to override APS workers’ duty-to-protect. Findings from this study are consistent with Bergeron’s observation, although Bergeron presented it as a negative outcome bordering on unethical while workers participating in this study presented it as a positive outcome guided by the ethical principles of self-determination and “Freedom over Safety.”

Regarding the determination of decision-making capacity, Torke and Sachs (2008) questioned if it is possible to give adequate justifications for living in squalor or ignoring one’s basic needs. They suggested that a failure to provide for one’s basic human needs might provide enough evidence that a person lacks capacity. In contrast to
Torke and Sachs (2008) conceptualization of decision-making capacity as being related to providing for one’s basic needs, workers interviewed for this study consistently conceptualized decision-making capacity as the ability to identify possible consequences of one’s decisions.

Torke and Sachs (2008) conceptualization of decision-making capacity suggests that people do not have the legal right to neglect themselves or to “live in filth” because these lifestyle choices indicate a lack of decision-making capacity. By implication, Torke and Sachs (2008) appear to recommend that involuntary services should be sought for people making such choices based on their lack of decision-making capacity. In direct contrast, APS workers interviewed for this study consistently identified acknowledging people’s legal right to live how they choose unless they have been evaluated as lacking decision-making capacity by expert evaluators and deemed legally incompetent by a judge. Workers consistently described considering the guiding ethical principle of “Freedom over Safety” when approaching the dilemma of balancing older adults’ right to refuse intervention and APS workers’ duty to protect. Workers shared personal feelings about highly valuing self-determination and client’s rights more frequently than they shared feelings about any other topic.

Summary of findings from this study as compared to previous literature

Findings from this study consistent with and in contrast to previous literature are provided here in bullet point format.

Findings consistent with previous literature

- The majority of allegations investigated by APS are cases of self-neglect. (Iris, 2010; Fulmer, 2008; Dyer et al, 2008; Liebbrandt, 2008; Kutame, 2008; Teasler et al, 2006; Heisler and Bolton, 2006)

- Although self-neglect may be viewed differently by different people and in different communities, there is general agreement in the operationalization of
self-neglect as being some variation of the theme of people not taking care of themselves and/or their environment to the degree that they are causing or risking physical harm. (National Center on Elder Abuse, 2005; Day, 2010; Pavlou and Lachs, 2008; Sherman 2008; Leibbrandt, 2008)

- The primary interventions for elder self-neglect are currently in-home services, court-ordered services such as a court-appointed guardianship, and institutionalization. (Pavlou and Lachs, 2008; Torke and Sachs, 2008; Anetzberger and Balaswamy, 1994)

- People lacking capacity who are endangering themselves or others will likely need some form of temporary or permanent guardianship. Although legal interventions such as guardianship may serve to protect vulnerable older people, it is critical to ensure that such interventions do not inappropriately infringe on the older person’s civil liberties or result in exploitation. (Pavlou and Lachs, 2008; Connolly, 2008).

- In practice, competent older adults’ right-to-refuse intervention appears to override APS workers’ duty-to-protect. (Bergeron, 2006; Torke and Sachs, 2008)


**Findings in contrast to previous literature**

- APS workers in this study consistently expressed that a case-by-case approach to assessing and treating elder self-neglect is optimal. This is in contrast to the direction of current researchers who are seeking to develop standardized assessment tools and treatment protocols for elder self-neglect in the belief that standardized assessment and treatment of elder self-neglect is optimal. (McDermott, 2010; Kelly, et al, 2008; Naik, et al, 2008; Pickens, et al, 2007)

- APS workers in this study consistently expressed the perspective that honoring competent people’s rights to self-determination, including their right to decline services, is a sign of respect and is legally and ethically required. Workers consistently identified some variation of “Freedom over Safety” as a guiding ethical principle in their work with self-neglecting elders. This is in contrast to Bergeron’s suggestion that simply honoring competent seniors’ right to decline services it is akin to client abandonment and that laws protecting seniors rights need to be revised. (Bergeron, 2006)

- APS workers interviewed for this study consistently conceptualized informed decision-making capacity as the ability to identify possible consequences of one’s decisions. This is in contrast to Torke and Sachs (2008) conceptualization of informed decision-making capacity as being related to providing for one’s basic needs. They suggested that a failure to provide for one’s basic human needs might provide enough evidence that a person lacks decision-making capacity.
Facing Ethical Dilemmas in the Field

APS workers acknowledged that they often face ethical dilemmas in the field. They must regularly make difficult decisions about how to best address self-neglect while still respecting self-determination. Sometimes they must make serious, life-altering decisions for other people. One worker stated, “There’s tons of ethical dilemmas in this job.” Another worker noted, “It is tough because there’s a lot of gray areas.” She went on to explain, “So, sometimes I’m leaving people in unsafe situations that could go bad rather quickly.” She acknowledged the burden of being ultimately responsible for making these difficult ethical decisions: “…so it falls on me. I guess.” Workers identified several specific ethical dilemmas they face in the field, and some workers shared how they approach ethical dilemmas.

Situations in the field where workers may experience stressful ethical dilemmas often involve the issue of how to best respond to medical issues that may be causing imminent risk of harm. For example, some workers shared that they sometimes experience stress when facing ethical decisions about whether to force involuntary services on lucid dying people. Other workers shared that they sometimes face the dilemma of whether or not to tell “white lies” to emergency squad Emergency Medical Technicians (EMT’s) to get them to transport people to hospital. Workers expressed significantly deeper frustration with facing the ethical dilemma of whether or not to seek involuntary services for lucid dying people than they did about having to tell “white lies” to EMT’s. This might be because seeking involuntary services has a deep personal impact on clients, while exaggerating circumstances to EMT’s has a much smaller personal impact on the EMT’s.

Several workers described a significant ethical dilemma affecting their investigations that is faced not by themselves, but by physicians. This dilemma involves
physicians having to choose which of two conflicting laws to honor: the Health Insurance Portability and Accountability Act of 1996 (HIPAA) or the Ohio Revised Code (ORC). HIPAA provides strict laws about protecting their patient’s confidentiality, while the Ohio Revised Code identifies physicians as mandated reporters of abuse and neglect who are therefore required to participate in APS investigations, with or without their patient’s consent. This ethical dilemma for physicians affects APS workers’ investigations because it determines how much information workers will receive from clients’ physicians. Medical and historical information can be crucial in making decisions about borderline cases because it may reveal if the client’s behavior has been a lifelong pattern, a gradual decline, or an abrupt change in behavior.

Physicians can address this dilemma by asking their patients to sign a form consenting to the release of information, however, according to APS workers interviewed for this study, most physicians do not do this. Physicians typically opt to release patient information to APS, refuse to release patient information, or direct APS investigators to obtain patients’ consents to release information, which may not be possible. Workers deal with this dilemma in different ways, including trying to get the client to sign a consent form, trying to get physicians to release the information, or accepting that they will not be able to get that information for their investigation. Workers thoughts on this topic were presented in greater detail in the section “working with physicians” from the property “Linking and consulting with physicians and other service providers” in the Secondary Category “Approaching intervention.”

Some workers described how they approach ethical dilemmas. One worker described having to keep honestly looking at APS principles and asking “…what am I doing as a social worker, how am I handling this?” She further noted that by trying to control every risk for everybody you take away his or her “freedom over safety.” Another
worker explained that she operates off the “do no harm” mandate, always considering if her actions will cause harm. She noted as an example that putting some people in a nursing home would “crush them and they would die.” Another worker described making difficult decisions on a case-by-case basis. Another worker described her process as looking at the “three biggies” (food, shelter, self-care/clothing) to distinguish self-neglect from self-determination:

“Well, you look at the three biggies. Are they paying their bills, are they gonna lose their shelter. Are they eating, are they bein’ able to get food? And, are they taking care of themselves. If they’ve got food, they’ve got shelter, they’ve got clothing...I’m pretty much gonna overlook the clutter.”

**Evaluation of Current APS Service-Delivery Systems for Elder Self-Neglect**

It was notable that APS workers consistently expressed satisfaction with the current system of case-by-case assessment of elder self-neglect. Workers did not express a desire to implement a standardized assessment tool. Some workers specifically expressed that they prefer not trying to standardize assessment or treatment. One worker explained, “if you go in with a model, or anything, you’re pre-setting what you’re expecting.” Another noted “people don’t fit in boxes.”

This is in contrast to the results from the literature review, which suggested that there is a critical need to develop a standardized tool for assessing elder self-neglect. Interestingly, researchers have had difficulty developing an effective, reliable instrument to assess self-neglect in individuals, although much time and money have been spent in this direction (for example, the Self-Neglect Severity Scale (SSS) developed by Kelly, et al, 2008, and the Capacity Assessment and Intervention model (CAI) developed by Skelton, et al, 2010). In contrast to this current research agenda, APS workers interviewed for this study appear to have decided that it is neither feasible nor clinically sound to try to standardize the assessment of elder self-neglect. Implications of this
finding are discussed further in the “Implications for future practice and research” section that follows.

Some workers described the Mini-Mental State exam (MMS), the most commonly used standardized instrument for assessing mental status, as being ineffective in assessing people’s actual day-to-day ability to provide adequate self-care. Other workers described a limited use of an adapted MMS by sometimes asking a few questions from it. One worker pointed out that it is normal for retired people to not be oriented to the exact date and suggested that this is not an indicator of impairment. Another worker explained that using the Mini-Mental exam might not give a clear assessment of someone. She provided a case example of a person who scored 28 of 30 on the MMS but was completely unable to manage daily affairs. She described not caring if person knows the year, but more importantly, are they eating and paying bills? She stated unequivocally that the MMS and most models are “hogwash.”

APS workers generally expressed little interest in using particular practice models to approach elder self-neglect. Five workers stated that they do not use any particular practice model and other workers hesitated in identifying a practice model they use consistently. Reasons for not using a practice model or not consistently using one model included the ideas that all clients do not fit into any given model and that using a particular model may pre-set workers’ expectations. The most frequently used practice model was a client-centered approach, with three workers mentioning it. Other models workers mentioned using were a systems approach, a problem-solving approach, reality therapy, and a self-preservation/educational approach. [See discussion of the property “Using or not using a particular practice model” under the “Actions Needed/Taken” sub-category in Chapter 4.]
Strengths and limitations of APS service-delivery systems are presented here as bullet points with a discussion of selected themes following.

**Strengths of current APS service-delivery systems for addressing elder self-neglect**

- An abundance of caring, qualified, field-experienced workers
- Workers are consistently and conscientiously aware of people’s legal rights
- Workers consistently review previous interventions when cases are re-opened
- Workers are satisfied with current methods of case-by-case assessment
- Workers are satisfied with available peer consultation and supervision opportunities and actively engage in case consultation and clinical supervision
- Home-delivered meals can usually be arranged for all seniors at little or no cost and they can continue to receive the meals even if they do not pay for them
- Franklin county workers have access to services and financial resources due to a local tax for senior services
- In some rural counties APS workers can coordinate services with Health Department and Housing Code inspectors and can even visit clients together

**Limitations of current APS service-delivery systems for addressing elder self-neglect**

- Workers identified a need for ongoing long-term monitoring and advocacy that APS, which is a crisis intervention service, cannot provide
- Free resources (other than meals) are often not available, especially in smaller counties. Some counties have no access to resources to cover the cost of any services, even the Emergency Medical Response system
- Not having the means to get clients help: experiencing insurance, eligibility and funding barriers to implementing needed services
- Time constraints: often times the established investigation period of 30 days is often not enough time to build a relationship, get a solid assessment of a person, and develop enough trust to implement services or talk about financial concerns
- Service eligibility should be need-based and universal, not income-based. Workers consistently described seniors declining to pay for or being unable to pay for needed in-home services such as homemakers
• Lack of a single, consistent, ongoing care advocate/case manager to coordinate, monitor, and advocate for seniors with needed in-home service providers, especially after business hours

• Banks are not mandated reporters. If banks were mandated reporters, much financial exploitation and financial self-neglect could be uncovered and reduced

• Not having housing codes to enforce interior home changes in rural counties

• In urban counties such as Franklin County, APS workers cannot establish working relationships with individual Health Department and Housing Code inspectors; thus there is no way to coordinate care on specific cases between APS and Code inspectors

In assessing the strengths of the current APS service-delivery system, the most notable observation was the high level of compassion demonstrated by the workers. Workers consistently explained that they view their primary job as being to take care of people and help them meet their basic needs. They also shared specific case examples where they provided care above and beyond the requirements of their job description. [See discussion of the property “Genuinely caring/going the extra mile” under the “Workers feelings about intervention” sub-category in Chapter 4.] Case examples of workers genuinely caring and going the “extra mile” included:

• buying fast food and taking it to a client for several days until other arrangements could be made

• taking safety risks by personally checking out neighbors and house guests

• taking personal safety risks by confronting exploitive children

• providing personal care for a client before the emergency squad arrived (per the client’s request)

• accompanying sick and dying clients to the hospital; holding client’s hand in ER prior to death

• researching and presenting three insurance plans for client to choose from

• working with a client’s attorney to arrange client being moved to a nursing home in Boston near her family
Workers consistently demonstrated genuine empathy for seniors’ circumstances, property, privacy, rights, and preferences. Eight workers expressed a strong personal desire for seniors to accept needed services. Several workers were passionate in expressing their concern and frustration about the lack of needed available resources such as in-home medication administration, assisted living for people of all incomes, and lack of companionship.

Some seniors develop a history of case openings and closings. Workers in all counties described reviewing previous interventions when cases are re-opened for investigation. In smaller counties, the same worker is usually re-assigned when cases are re-opened. Franklin County APS, the largest agency participating, has switched to a district case assignment system where it is more likely a senior will get the same worker when a case is re-opened. This was identified as a strength by Franklin County APS workers. Workers described it being optimal for purposes of better assessment and relationship building for seniors to have the same worker when cases are re-opened.

Three major limitations emerged when workers discussed the service-delivery systems for assessing and treating elder self-neglect: 1) insurance, eligibility, and funding barriers to implementing needed services, 2) investigation time constraints, and 3) the lack of a single, permanent care advocate to coordinate and monitor ongoing care. Workers passionately described their frustration with sometimes not having the means to get clients help due to insurance, and eligibility, and funding barriers. One worker explained these barriers as follows:

“I’d like to see more programs accepting a wider array of insurance and health care, because, you know, if someone has Medigold, then they can’t have the same things that I just got for a person who has Medicare. And, or somebody who’s got Humana can’t get the same things as you got somebody who’s Medigold, or... Medicaid, then they got everything, and, you know what I mean? And it’s frustrating.”
Workers described the following funding, insurance, and eligibility barriers to implementing needed services:

- clients being willing to accept services but slightly over income and unable to pay for them
- income eligibility barriers: for example, middle-class and lower middle-class people being over income eligibility requirements for programs if they’ve got some resources
- problems with Medicaid ineligibility (such as having an “atrocious” spenddown before being eligible, or being Medicaid eligible for homemaker services only if you’re impoverished)
- program financial eligibility issues such as some service programs not accepting some insurances (such as Medicare, Medigold, Humana)
- workers themselves having some difficulty keeping track of complicated insurance programs
- home support resources sometimes being unavailable
- not qualifying for needed services: for example, needing home services without having to meet passport level of care
- rural counties having no funding for services: “We have none. None. If you don’t qualify for Medicare or Medicaid for any home health services...there’s nothing unless you private pay.” (including Emergency Response buttons)

Workers consistently described seniors declining to pay for or being unable to pay for needed in-home services such as homemakers. One way to address this gap in service delivery would be to reorganize service eligibility requirements so that service eligibility becomes need-based and universal, rather than income-based as it currently is. This recommendation will be discussed in further detail in the following “Implications for future practice and research” section.

The second most frequently mentioned limitation of current APS service delivery systems was the time constraints of workers having only 30 days to complete an investigation. Workers consistently noted that 30 days is often not a sufficient amount of time to get a solid assessment of a person, particularly a person who demonstrates
fluctuating competency. Workers also noted that 30 days is not always sufficient time to develop enough trust to get people to try services, or to get them to open up and talk about financial concerns and engage in problem-solving. Workers and agencies address this problem in a variety of ways. Some agencies allow workers to keep cases open longer under certain conditions, some agencies have longer monitoring programs (90-120 days) that workers can refer clients to, and some individual workers simply do not close cases until they are reasonably certain they have an accurate assessment of the situation.

Lastly, several workers noted the limitation that APS is a crisis-intervention service and is unable to provide needed long-term monitoring. Even when clients are referred to long-term programs such as Senior Options, their case manager is likely to visit once every three months and is unable to provide ongoing, day-to-day monitoring and advocacy. One worker specifically identified the need for at-risk seniors to have a single, consistent, ongoing care coordinator to advocate for them with in-home service providers, especially after business hours. This recommendation will be discussed in further detail in the following “Implications for future practice and research” section.

**Strengths and limitations of this study**

One potentially unique theoretical contribution of this study is to contribute to theory development in the area of conceptualizing self-neglect by exploring the social construction of elder self-neglect from the perspective of APS investigators. This study focused on a group of practitioners with the unique role expectation of having to make decisions for other people regarding elder self-neglect. The construction and operationalization of elder self-neglect by these practitioners is influenced by their role as decision-makers in that it is primarily constructed by ethical and legal considerations. Practitioners are bound by codes of ethics such as the NASW Code of Ethics and their
agencies’ guiding ethical principles. It is a unique contribution to the literature on elder self-neglect to provide empirical evidence that APS investigators’ conceptualization of self-neglect and their investigation decisions are informed by the consideration of seniors’ legal rights and the ethical principle of self-determination.

Discussion helps people clarify their values, perspectives, and approaches. A practical contribution of this study is that having APS workers discuss and clarify their views on what constitutes “best practice” in working with self-neglecting elders may ultimately benefit elders being investigated for self-neglect. Exploration and discussion of best practice methods may also benefit workers in the field by supplying support and guidance to workers who regularly face the ethical dilemma of balancing seniors’ freedom with their safety.

Methodological strengths and limitations of this study are discussed in more depth in chapter three. To summarize, strengths of this study include triangulation of research sites (5 counties including urban and rural communities) and triangulation of sources used in exploring elder self-neglect (literature review, interviews with workers in the field, and analysis of existing assessment tools and new tools under development). Additionally, the analysis for this study is grounded in data collected for the specific purposes of this study rather than secondary data analysis of data collected for another study. The data collected for this study, interviews with APS investigators, were treated reverently with every effort made to accurately present the workers’ authentic perspectives. Careful attention was paid to phonetically transcribing the data to accurately capture workers’ stories and thought processes.

To assure that the workers’ perspectives were accurately represented, in-depth second interviews focusing on member checking were conducted. Member checking was done after completing the coding and analysis of the initial interview, and the completed
coding and analysis of the initial interview were presented to the workers for their approval. Member checking involved reviewing with the workers’ the accuracy of the coding decisions, thematic categorization, and the overall representation of their perspectives from the initial interview. Any changes or corrections were then integrated into the analysis of the initial interview. Only three workers identified any corrections: one program title correction and two minor interpretation clarifications (“fear factor” referring to the client, not the worker, and “crack house” referring to a home where crack was smoked, not a place where crack was cooked and distributed).

A methodological strength of this study was using five strategies suggested by Padgett (1998) to reduce the threats to trustworthiness, particularly the threat of researcher bias (the temptation for the researcher to filter observations and interpretations through her own preconceptions and opinions). These methods were: triangulation, peer debriefing/support, negative case analysis, member checking, and an audit trail.

Additionally, outsider input was sought in two ways: the three members of the researcher’s dissertation committee each reviewed and commented on the open-coding of one of the first three interview transcripts, and the committee chair independently analyzed one additional interview transcript (interview 11), which was randomly selected from interviews 4 through 16. Her analysis was then crosschecked with my coding to assess inter-rater dependability. An inter-rater coding agreement rate of 83% was established, with 109 of the 132 codes assigned by the committee chair being in agreement with my coding. Most of the coding differences were minor and pertained to interpreting which category themes should be placed in.

A limitation of this study is that due to using purposive sampling (where respondents were selected based on their knowledge and location), the findings are not
generalizable to other groups of APS workers. Without random sampling, claims to acquisition of valid knowledge about other groups, either within the study context or external to it, are almost always inappropriate (Locke, at al, 2001). Limitations of using interviews to explore sensitive issues also include the risks of reactivity (the potentially distorting effects of the researcher’s presence in the field) and respondent bias (the temptation for respondents to withhold information, lie, or offer answers that they think the researcher wants to hear) (Padgett, 1998).

Another limitation of this study was the inability to utilize theoretical sampling of participants to further explore new themes that emerged. This inability to increase sample size was due to already including 100% of the possible sampling frame of investigators in the five participating counties. To utilize theoretical sampling of participants (such as seeking less experienced workers to interview), it would have been necessary to invite participation from more counties, which was not feasible in this study due to time, geographic, and financial constraints. A strength of this study was that another form of theoretical sampling, theoretical sampling by asking questions in further interviews to gain more information on emerging themes, was done in this study.

Another possible limitation of this study occurred when describing the context of the research to participants. Although unavoidable, my legal obligation to disclose to respondents my stance as an LISW mandated reporter of suspected abuse and neglect might have contributed to an initially negative or punitive research context. Although my interviewer stance of mandated reporter did not appear to cause respondents to be guarded, it is not possible to know what kind of impact this stance might have had on participants’ decisions about disclosing revealing information. Another interviewer stance that gave context to the research was my choice to reveal my previous professional experience as an abuse and neglect investigator for Franklin County Children’s Services.
I revealed this background information to create rapport and to situate myself as a colleague and somewhat of an “insider.” This stance appeared to help create rapport and give me some credibility. Both of these interviewer stances provided context to the study that could have influenced the results.

**Implications for future practice and research**

Social workers need more information on current practices that practitioners use to identify, assess, and treat elder self-neglect. In conducting this research, I sought to accomplish the following goals:

- **Increase awareness of the nature of public policies and interventions regarding elder self-neglect**
- **Increase awareness of clients’ rights**
- **Promote discussion about what constitutes best practice**
- **Produce practical “benchmark” information regarding how APS workers balance the ethical dilemma of “safety vs. freedom” when working with self-neglecting elders**
- **Provide guidance to policy-makers interested in devising state-of-the-art laws and policies on elder self-neglect.**

This study was conducted with the hope that an upward flow of information, observations, and experiences from APS workers in the field can have a positive influence on policy development at the macro level. The following ideas are best practice ideals, not suggestions based on actual available funding. The emphasis here is on best practices for improving the safety and quality of life for self-neglecting elders living in the community. These ideas are presented simply to identify needs and generate ideas of best practice, with the acknowledgment that funding availability is a critical reality in any program development.
Implications for future practice

Because elder self-neglect is a complex topic, social workers must evaluate their biases and pre-conceived notions regarding this condition. Social workers must learn more from empirically-based research to guide their decisions when working with potentially self-neglecting older persons. Presented here is a review of clinical “best practice” recommendations found in the existing literature on elder self-neglect. Most of these are experience-based recommendations from practitioners in the field rather than empirically-based recommendations. This may be due, in part, to the challenges of acquiring research approval for treatment on human subjects and to a lack of funding for treatment research that is not focused on cost containment.

Summary of results from a literature review of best practice recommendations for self-neglecting elders

- Assess the other person’s risk of imminent harm to self or others, competency, self-maintenance, and home environment. (Torke and Sachs, 2008)
- Honestly explain your purpose and hear the others wishes, needs and values. (Greene and Blundo, 1999; Mixson, 1991)
- Engage the other person in treatment planning and seek compromise. (Pavlou and Lachs, 2008; Karpinski, 1997)
- When offering referrals and services, always explain costs and eligibility. Display consistency and dependability by specifying follow-up, including date and time. (adapted from Amilla, 1999; Mixson, 1991)
- Consider using a strengths approach rather than or in addition to a deficits approach. (Kivnick and Murray, 2001; Chapin and Cox, 2001)
- Maintain conscious awareness of the balance between person, tasks, and resources. Each element exerts significant influence on outcomes. (Rogers, 1961; Green and Blundo, 1999; Epstein, 1988, 1992; Germain and Bloom, 1999; Choi, Kim, and Asseff, 2009)
- Practitioner self-awareness includes a conscious recognition of one’s own values (particularly regarding freedom and safety) and wishes for the other person. (Lauder 2009; Robbins, Chatterjee, & Canda, 2006; Lauder, Scott, and Whyte, 2001; Wadley & Haley, 2001)
Consistent with the literature review, the APS workers in this study echoed all of these clinical “best practice” recommendations with the exception of specifically identifying using a strengths approach. In addition, workers made the following “best practice” clinical recommendations for working with clients who resist intervention:

- Call a client who has declined home visits
- Keep the first visit short if sensing resistance
- Monitor clients over time
- Talk clearly about services with resistant clients (“putting everything out in black and white”)
- Provide resource information, particularly printed material they can review later
- Be careful to avoid shaming or embarrassing when offering services
- Compromise with clients, particularly about housing (for example, trying to keep a person in the same neighborhood if relocation is necessary)
- Involve a client’s family and friends to encourage needed medical treatment or services (no release of information is needed because it is a state-mandated investigation; some workers seek releases anyway)
- Openly acknowledge their right to decline services
- Keep trying
- Strategy for getting a person to undergo an unwanted psychological evaluation: explain “If you go to a doctor and the psych eval comes back fine, you have the right to still refuse these services. So it would be to your benefit to go ahead and have a psych done.”
- Strategies for getting in homes:
  - building rapport and respecting people to get in the house
  - being willing to have door slammed in face several times
  - whistling to get a dog’s attention when observing “beware of dog” signs on gated fences
  - taking dog treats on home visits
  - calling a client before visiting if there’s a dog that needs to be put out or some other type of danger identified by the referral source
  - using “I’m from Franklin County Office on Aging” (rather than APS) to get in the door
Strategies for working with seniors who refuse to leave their home: home-delivered meals, visiting physicians, expedited guardianship

Petition the courts for assistance (as a last resort)

The following recommendations for needed changes in service eligibility requirements and for needed services that are currently unavailable emerged from this study:

Universal, needs-based eligibility requirements for in-home services and assisted living facilities rather than income-based eligibility requirements

In-home medication monitoring and administration assistance, such as someone to help get the day started and then making reminder phone calls for medication monitoring when the following doses are due

A single, consistent, on-call 24/7 care coordinator. Optimally, seniors would have a primary on-call care coordinator who is ultimately responsible for care coordination and is available 24/7 for emergencies or to actually provide necessary care when gaps in service-delivery arise such as a no-show nurse or personal care assistant [a group of coordinators could share on-call duties]

Increased transportation services, including transportation for socialization, such as a monthly voucher program, or something like COTA’s mainstream transportation program for the disabled

Implications for future research

Social workers need empirical knowledge based on the lived experiences and perspectives of older persons deemed as self-neglectful. The sensitive and socially charged nature of adult self-neglect presents several barriers to exploring the lived experience of elders experiencing self-neglect. These include: barriers to accessing the target population (such as elder self-protection, mistrust of strangers, and refusals to participation), differing interpretations of laws about client confidentiality (a barrier experienced in this study), and the fact that the concept of self-neglect is socially constructed and thus presents difficulties in interpretation, measurement, and self-identification. These challenges must be faced to gain knowledge about the personal experiences of self-neglecting elders. Such knowledge will improve practitioners’
effectiveness when working with these vulnerable people and guide those concerned with improving services to develop more appropriate and effective methods of assessment and treatment for the growing population of self-neglecting older adults.

More research is also needed on comparing the financial costs of in-home care versus extended care facility (ECF) placement for people with a wide range of conditions and service needs. Although conventional wisdom suggests that it is more expensive to provide in-home skilled nursing care (the highest level of nursing care) than it is to provide skilled nursing care in an extended care facility, a multi-database literature review found no empirical evidence of this. Additionally, many seniors that APS workers seek to place in extended care facilities do not need round-the-clock skilled nursing care to remain in their homes. Although there was no recent empirical research found on directly comparing the costs of in-home care to ECF care, a multi-database literature review revealed some empirical evidence that suggests in-home care is a cost-viable alternative to nursing home care. For example, in 1998 New Hampshire Health and Human Service commissioner Terry Morton told legislators that it costs $36,000 annually to care for an elderly Medicaid recipient in a nursing home, compared with $12,000 for home-based care (AHA News, 1998).

Schwab, et al (2003) analyzed costs to maintain nursing home eligible individuals at home and found that the costs of maintaining a person who has an HMO policy at home are modest and affordable, yet offer a substantial benefit, particularly to low- and moderate-income older people. They found that these individuals would spend an average of $4,900 (in 2003) out-of-pocket per year to purchase equivalent home and community-based services if they were not enrolled in the Social HMO.

Grabowski (2006) reviewed the cost-effectiveness of noninstitutional long-term care services (such as Medicaid waiver programs, consumer-directed care, capitated
models that blend acute and long-term care services, and case management and subsidized community services for individuals with dementia) and found that these new care models were more expensive but yielded greater client and caregiver welfare than institutional care services. He noted, however, that recent cost evaluations of noninstitutional long-term care have relied on confounded research designs that may be biased across treatment and comparison groups.

Currently, Medicare, Medicaid, and private insurances pay for hospital-based, office-based, and extended care facility care, but not for in-home care unless people are eligible for specific, limited, special programs with rigid eligibility requirements (such as being diagnosed by a physician as permanently home-bound, being severely financially impoverished, and/or meeting hospice eligibility requirements). Thus, there is no currently available “pool of money” to draw from to implement in-home care. Workers interviewed for this study identified that systemic changes from office-based, hospital-based, and extended care facility services to home-based services could possibly save money in the long run. This field observation should be empirically explored by future researchers. Comparing the actual cost of an experimental program of home-based care to the cost of comparable office, hospital, and extended care facility-based care might provide empirical evidence of the cost-efficiency of in-home care for seniors at risk of being institutionalized for self-neglect.

Perhaps the most important implication for future research to emerge from this study is the finding that practitioners interviewed for this study unequivocally expressed that self-neglecting elders are best served by individualized assessment and intervention methods rather than by standardized methods. Workers described relying on peer consultation and supervision for challenging cases rather than seeking standardization of assessment instruments and protocols. This individualized treatment approach reflects a
postmodern perspective in its focus on case-by-case, client-centered, locally contextualized (e.g. local community standards, health and housing codes, and available resources), assessment and treatment (Greene, 2008).

Also similar to a postmodern perspective, workers described trying to avoid taking a “one-up, one-down” approach, with its implied power imbalance, where the worker takes a one-up position by self-identifying as the “expert” (Hepworth, et al, 2009). Without specifically identifying it as a tenet of postmodernism, workers consistently described taking a “one-down” approach where they recognize the legitimacy of individual knowledge and thus give some of their power to the client.

“I think it helps a lot for us, at least when I approach people, to try to not be scary or to make them seem like ‘I'm here with the government and we’re doing things my way’ and that, you know.”

“I have never on an initial visit just busted out like a mini-mental status or anything like that because I think it’s scary enough to have someone you don’t know knock on your door. It’s intimidating enough to feel like someone’s assessing you and your environment. If it feels more like a friendly visitor, than somebody who’s got a clipboard checking off what they think is wrong with you, you’re more likely to get people to engage. And if I just shut up and listen? We get so much, they’ll offer more if they’re comfortable. As opposed to feeling like they’re getting rapid-fire questions: ‘Do you, do you, do you, do you have, have you done...?’”

“Try to make it as non-threatening as possible.”

“I just try to build a rapport as quickly as possible. So I don’t come on strong.”

Workers repeatedly emphasized using the National Association of Social Workers (NASW) Code of Ethics and their agencies’ practice principles as guides for their work with self-neglecting elders. Workers specifically mentioned the NASW value of honoring the dignity and worth of each person, the NASW ethical principle of self-determination, and the Franklin County Principle of “Freedom over Safety.”

**NASW Value: Dignity and Worth of the Person**

**Ethical Principle: Social workers respect the inherent dignity and worth of the person.**
Social workers treat each person in a caring and respectful fashion, mindful of individual differences and cultural and ethnic diversity. Social workers promote clients’ socially responsible self-determination. Social workers seek to enhance clients’ capacity and opportunity to change and to address their own needs. Social workers are cognizant of their dual responsibility to clients and to the broader society. They seek to resolve conflicts between clients’ interests and the broader society’s interests in a socially responsible manner consistent with the values, ethical principles, and ethical standards of the profession.

**NASW Ethical Standard 1. Social Workers’ Ethical Responsibilities to Clients**

1.02 Self-Determination: Social workers respect and promote the right of clients to self-determination and assist clients in their efforts to identify and clarify their goals. Social workers may limit clients’ right to self-determination when, in the social workers’ professional judgment, clients’ actions or potential actions pose a serious, foreseeable, and imminent risk to themselves or others.

**Franklin County APS Principles**

Freedom over Safety: The client has a right to choose to live at risk of harm, providing he/she is capable of making that choice, harms no one, and commits no crime.

Self-determination: The client has a right to personal choices and decisions until such time that he/she delegates or the court grants the responsibility to someone else.

In operationalizing these guiding principles, workers consistently described using a *legal* definition of imminent risk of harm when considering limiting client’s right to self-determination, which they described as being “the risk of loss of life or limb within 24 to 48 hours.” Workers repeatedly noted that the general public has a much lower standard when conceptualizing “risk of harm.” For example, poor hygiene, not maintaining one’s home, and isolating oneself do not in themselves present an imminent risk of loss or life or limb.

Workers described educating the public about laws as their primary approach when they “seek to resolve conflicts between clients’ interests and the broader society’s interests in a socially responsible manner consistent with the values, ethical principles,
and ethical standards of the profession” (NASW Code of Ethics). In contrast to community values and current literature, workers firmly believe “The client has a right to personal choices and decisions until such time that he/she delegates or the court grants the responsibility to someone else” (Franklin County APS Principle). These guiding principles, in conjunction with a knowledge of and sensitivity to state and local laws, are the underpinnings of how APS workers construct elder self-neglect.

Workers in this study emphasized the treatment principles of honoring clients’ self-determination and legal rights, recognizing the dignity and worth of the individual, compromising with clients, and utilizing professional “team” consultation with peers and supervisors for challenging cases. The individualized, postmodern treatment approach favored by these APS workers raises questions about the utility of seeking to develop and utilize a standardized approach to elder self-neglect. Further research is needed regarding APS workers preferring case-by-case assessment. Perhaps this preference for a case-by-case approach reflects the unique characteristics of the APS workers interviewed for this study. Workers interviewed for this study were well educated, experienced (avg. experience was 13.9 years), and described having adequate access to meaningful peer consultation and supervision. APS workers with less education, experience, or access to adequate consultation and supervision might prefer a standardized tool.

Finally, it is important to note that understanding how APS investigators conceptualize, assess, and treat elder self-neglect is only one piece of the puzzle. To gain a fuller understanding of the phenomenon of elder self-neglect, we also need to explore the perspectives of seniors found to be self-neglecting and other interested parties such as families, neighbors, judges, guardians, police and fire personnel, administrators, policy-makers, in-home and office-based service providers, and the general public.
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Appendix: Compiled Group Data

**Central Category:** Assessing decision-making—(1307 references) [total of sub-categories equals 1421 because 114 references pertained to more than one sub-category]

(R1: 126 references) (R2: 126 references) (R3: 100 references) (R4: 38 references) (R5: 81 references) (R6: 66 references) (R7: 46 references) (R8: 61 references) (R9: 81 references) (R10: 114 references) (R11: 109 references) (R12: 106 references) (R13: 104 references) (R14: 54 references) (R15: 59 references) (R16: 36 references)

**Sub-category:** Assessing decision-making capacity—(427 references)

(R1: 28 references) (R2: 38 references) (R3: 32 references) (R4: 15 references) (R5: 17 references) (R6: 18 references) (R7: 22 references) (R8: 21 references) (R9: 27 references) (R10: 57 references) (R11: 53 references) (R12: 40 references) (R13: 21 references) (R14: 11 references) (R15: 15 references) (R16: 12 references)

Assessing mental capacity [cognitive abilities/mental status/competency] (169 references by 16 APS workers) (R1: 14 references: observing memory loss, confusion, p. 1; being confused, p. 3; case ex: of leaving out open food containers but forgetting to eat, p. 6; same case: “I ask her ‘Did you eat today?’ ‘Yes, I had eggs, and I had bacon, and I made myself a pot of coffee.’ (pause) Her stove was disconnected.” p. 6; case ex: of having intact long-term memory, short term having “just some impairment” p. 11; same case ex: of having minimal mental impairment but making “really bad decisions” [composting in house], p. 11; same case ex: of having a good long-term memory but making bad decisions, p. 11; same ex: of being oriented and up on current events, p. 11; using mini-mental status exam, p. 15 “[mini-mental] gives you that kind of baseline to work off of, you know, about their orientation, and their ability, you know, abilities of recall, and all of those, so...” p. 15; assessing cognitive decline over time: case example of repeat referral “But this time he has declined cognitively. And medication’s not helpin’. ” p. 18; distinguishing between self-determination and self-neglect “…really has a lot to do with competency.” p. 25; case ex: of having dementia, p. 25; competency having a lot to do with it when assessing people’s decisions, p. 25) (R2: 5 references: [assessing] “...what this person’s ability is, what this persons’ cognition level is to process all of the information that comes at us every day...their ability to decide ‘This is what’s best for me. This is a consequence of this, and I’m choosing to do this anyway.’” p. 12; “weighing out” soundness of mind, p. 16; a doctor needs to determine why a person is not of sound mind (workers can’t), p. 16; [re: when does worker recommend a psych eval against elder’s desires] “I think when...the
person is demonstrating some obvious signs of confusion, inability to process information. You know, when somebody sits there in a conversation with you for twenty minutes, and sometimes it’s that quick that you can see that there’s a problem, and they’re not capable of...[processing information].‖ p. 16; “Are they not processing this information because they’re not capable for this reason, that reason. Can it be reversed in any way, which then goes, of course, to the guardianship kind of a issue.” p. 16) (R3: 11 references: case ex: of being forgetful and somewhat confused, p. 4; being unable to make decisions on their care p. 5; needing probate action, p. 5; being mentally incapacitated, p. 5; refusing court-ordered services, p. 5; turning into a guardianship when they refuse needed care, ex: the person still doesn’t let the homemaker or nurses come in, p. 5; “Can this person really be making decisions?” p. 6; “They might tell me in one sense that they know what’s goin’ on, and then you ask ‘em a couple more questions with the mini-mental, say, and they’re confused…” p. 6; case ex: of having “no clue” about information being asked [ex: “He couldn’t tell me anything about anything in his wallet.”], p. 7; same case ex: of man with cognitive deficits continuing routine self-care activities [get up, make breakfast, do the dishes] “Well, he’s kind of in this routine. I can’t really force him out of his home.” p. 7; leaving the stove on requiring a mental health evaluation, p. 14) (R4: 8 references, including 3 references to strategies for assessing mental status: preferring the “clock test” to the MMS, p. 1, using the MMS but not scoring it, p. 1; assessing memory by discussing “mundane” things, changing topic, then going back to assess memory of the “mundane” things discussed, p. 1; assessing “competency” p. 1; 2 to worker having mixed feelings about substantiating when client’s demonstrate fluctuating competency: “When they’re right on that border of competency.” p. 3, “When they’re just starting that border of competency. It’s like, oh, one day ya’ understand, the other day I don’t think you understand…” p. 3; worker identifying that a person being unaware of home conditions is a “real dead indicator that they’re vacant, or they’ve got some dementia goin’ on, or…” p. 5; “When we’re doing involuntary action, it’s usually based on competency. They are usually so clueless that they don’t even recognize that it’s happening.” p. 9) (R5: 8 references, including 3 references to not “forcing things” when someone appears alert and oriented, p. 7; 2 to having another mental health professional make a mental status assessment, both p. 17; testing memory by giving worker’s name and asking for it later, p. 3; case example of having serious confusion but being able to manage a daily routine and self-care activities, p. 14 “it’s all about cognitive status,” p. 18) (R6: 10 references, including 8 references to observing delusional thinking/dementia, including thinking there’s a conspiracy, screaming about a conspiracy, being up all night talking to “spirits,” worker sometimes having difficulty assessing if some thoughts are real or delusions, p. 6-7; and 2 to assessing memory by seeing if they can remember the people in the pictures on the wall, p. 1. being able to tell stories about the remote past but not the recent past [short-term memory problems], p. 4) (R7: 10 references, including 5 references to getting a psychiatric evaluation/consultation: using a person’s doctor to get a psychiatric evaluation, p. 7, only seeking a psych
eval if the worker feels the clients incompetent or incapacitated to make decisions (ex: strokes, dementia, Alzheimer’s, delirium from infection), p. 7, using client’s doctor for psych consult, p. 8, being able to find clients’ doctors 40% to 60% of the time, p. 9, using visiting doctors for psych eval if unable to find clients’ doctor, p. 9; observing “fluctuating competency” ex: “...if you saw him today, he’s competent. You see him tomorrow, he’s not competent. He fluctuates.” p. 4; monitoring over time (30-45 days) to assess dementia in 90-year-olds whose competency fluctuates (p. 5); worker not testing people “just to be testing,” p. 9; reference to they can still have deficits and be able to make decisions, p. 9; examples of deficits: educational level, isolation, p. 9) (R8: 12 references, including 9 to consulting a physician and 3 to using Netcare: contacting their doctor first about their decision-making ability, p. 1, “you may make calls to the doctor to make sure that this person is still capable of making their decision” p. 13, the doctor may complete an expert evaluation form for the APS to go forth with guardianship, p. 1, APS having another doctor besides Netcare if necessary (private pay) p. 2, not needing client’s consent to release information to their physician due to physicians’ being mandated reports per Ohio Revised Code, p. 3, physicians not completing expert evaluation if they don’t think APS needs to be involved (4 references, all p. 3); using Netcare for a competency evaluation if an older adult doesn’t have a physician, p. 1, making home visits with Netcare worker, p. 1, Netcare worker may make another visit with Netcare doctor, p. 1) (R9: 16 references, including 5 to assessing orientation, including asking address, phone number, social security number, birth date (2 references, p. 1, p.2); “Not the date because you’re retired, you might not know what day it is, so I’ll ask the season.” p. 2; Not asking phone number (2 references) “cause you don’t call yourself” p. 2, this retiree isn’t out there fillin’ out applications and forms, p. 2; 4 references to “It has to be really severe and the client has to be, I mean evaluated to the point where they can’t function.” [to override client’s self-determination], p. 8; 3 to experiencing loss of short-term memory: “A lot of ‘em, the short-term memory is gone” p. 2; “short-term memory’s not there within a five-minute span” p. 2; ex: client calling the number on the card you just gave them and asking “What were you doin’ here?” p. 2; 2 to Clients asking worker to prove identity shows they’re somewhat “with it”: as stated, p. 1; it’s a sign that clients are “with it” if they ask for info to call and check on the worker, p. 1; having dementia or Alzheimer’s (p. 1); writing “raunchy” letter to apartment management and later denying that she wrote the letter while at the same time recognizing her own handwriting and signature in the letter, p. 7) (R10: 10 references, including 4 references to assessing mental status: as stated, p. 2; are they alert and oriented, p. 2; do they remember things, p. 2; can the handle ADL’s, p. 2; 2 references to worker seeking involuntary psychiatric evaluation if after numerous visits client is incapacitated and needs are consistently not being met and client is refusing services without providing alternative to meet need, p. 12; 2 references to getting expert psych eval in home if client can’t follow through with plan: as stated, p. 14; client demonstrating lack of capability if they can’t follow-through with a plan developed together with worker, p. 13; 1 reference to consulting with collaterals to factor in their opinion, but
it’s just that an opinion, p. 16; 1 reference to walking a fine line when determining mental and physical capacity, p. 15) (R11: 21 references, including 12 references to getting a doctor/psychologist expert evaluation regarding competency: worker not wanting to be solely responsible for competency assessment, p. 7; competency assessment coming down to a doctor, p. 7; consulting with family physician, p. 7; getting an expert evaluation, p. 7; using APS psychologist “if we can’t get anywhere with the family physician, p. 7; “...if he [psychologist] feels that this person is really confused, doesn’t understand their situation, he sees what we see in terms of their home environment, an’ he’ll recommend a guardian.” p. 7; doctor having to make determination of competency, p. 8; “...who makes that determination? It has to be a doctor. It can’t be me...that’s not enough.” p. 8; getting a doctor to say “This person is very confused, they probably have beginning dementia or Alzheimer’s.” p. 8; doctor seeing a decline over several visits, p. 8; if not seeing progress in addressing problems by client, taking it to the “next level” of getting a psychologist out there, p. 9; getting a doctor involved when they’re pretty confused, p. 9; and 7 references to assessing mental status: including 2 references to assessing memory: “When did you eat last?” p. 3, “How do you get your food?” p. 3, 2 references to assessing answers during conversation: assessing answers, p. 1, example: assessing how much time do they need to answer, p. 1, assessing confusion, p. 3; being very confused, p. 7; assessing competency, p. 7; “It’s [incompetency] usually when a client needs help and is refusing.” p. 7; needing a pattern of not understanding consequences or refusing needed help to prove incompetency, p.8) (R12: 12 references to assessing competence, including 7 references to assessing conversation as part of determining competence: as stated, p. 2; can they follow conversation, p. 2; being important for worker to “not do all the talking” p. 11; determining a lot of capacity and competence by general conversation, p. 11; 3 examples: clear and lucid thoughts, follow-through on info provided previously, understanding how it works [APS process, referrals], all p. 11; 2 references to asking specific questions to assess competence: example: asking “What did you eat today?” rather than “Did you eat today?” p. 2; being confident they’re incompetent when seeking guardianship, p. 9; ex: husband calling police on wife for not having dinner ready on time, p. 9; being pretty sure client is incompetent when referring to psych consult, p. 9; “...again it comes down to competency” p. 11) (R13: 13 references, including 6 references to assessing competency through conversation and a few MMSE [Mini-Mental Status Exam] questions: having a conversation and seeing if they can answer any of the MMSE questions to assess competency, p. 1; “Basically, it’s just a conversation.” p. 1; case ex: of client demonstrating competency issue of very poor recall [not remembering worker from one visit to the next], p. 2; asking a few questions from the MMSE, p. 6; going on observation and asking a few of those [MMSE] questions, p. 6; MMSE being the only tool worker has really used, p. 6; 4 references to observing fluctuating competency: case example where client would have lucid moments but sometimes the worker wondered [about his thinking], p. 3; same case ex: worker wondering if medications were affecting the client’s mind, p. 3; same ex: hard getting assessment due to medication or drinking too
much, p. 3; same ex: “So that was always kind of hard to get that assessment goin’ because there would be times when he would be under-, you know, medicated, or either he’d be drinkin’ a little too much, so it’s hard to get that assessment, to really know if he really understood the ramifications.” p. 3; and 3 references to having hospital doctors assess mental status and complete expert evaluations while clients are hospitalized, p. 6, 2 on p. 7) (R14: 3 references: substantiated case ex: having poor judgment, p. 3; [overriding elders wishes] if they just really don’t have good judgment and there’s a lot of safety problems, p. 7; and 1 reference to identifying that both competent and incompetent people can live in filth: “And then I have people that are incompetent that also live in filth. So, hygiene and cleanliness is not always a huge factor.” p. 4) (R15: 12 references, including 6 references to assessing orientation: “Well, usually when I’m talking to them, I can pretty much tell whether or not they’re oriented that day.” p. 1; assessing orientation from conversation, dress, house, whole observation, p. 1; asking if they have any questions, p. 1; “So just try to see how well they’re oriented for that day.” p. 1; asking what day it is, p. 2; “Some people, even if I ask ‘em what day it is, might refer to a calendar...they might refer to the TV, or they might just say, they didn’t know, or they’re right on top of it and can tell me...” p. 2; 3 references to assessing memory: asking “What did you have for breakfast this morning?” p. 1; assessing memory, p. 2; assessing short-term memory, p. 2; and 3 references to consulting with a doctor: referring back to doctor on borderline cases, p. 2; “I always refer back to the doctor.” p. 7; “You can go through the court system and ask for a psych eval to be made.” [if declined by client], p. 7) (R16: 4 references to assessing awareness/competence: not substantiating when they seem cognitively aware of surroundings and they’re making decisions, p. 1; overriding elders’ desires when they are obviously not competent, p. 4; [overriding elder’s desires] when somebody obviously has dementia or something going on, p. 4; [overriding desires] when they’re endangering themselves, p. 4)

Assessing understanding of current circumstances and risks [via ability to articulate circumstances and risks] (110 references by 14 APS workers) (R1: 6 references to assessing ability to communicate understanding of circumstances/risks: being able to explain decisions, p. 4; case ex: of winking [non-verbal communication that statements might not be true] as a sign of awareness during conversation, “So I was sittin’ there and I’m like ‘Are you gonna start compostin’ again?’ and she just looked at me and winked.” p. 11; same ex: “And I said all the current issues have been resolved. (pause) But I know she’s gonna start composting.” p. 11; same case ex: of communicating subtly, indirectly “But I knew she, she didn’t, she basically told me...” p. 12; understanding risks, p. 25; ex: of communicating understanding of risks: “...if you have a diabetic, you know, and they continue to eat the sugar, and they say ‘Well, I’ve always don it, and I understand that if I do it I can go into a diabetic coma and die.’ You’re willing to take the risk? ‘Yes I am.’ ” p. 25) (R2: 19 references to assessing awareness of problems [via ability to discuss current circumstances and decisions]: “Some people...can’t really make
themselves say, ‘I, I can’t take a bath,’ ‘I can’t do this,’ ‘I’m afraid to get in the tub,’ ‘I’m afraid to get in the shower.’” p. 2;
“Sometimes they’re very eager for help. They know that they don’t smell good, they know that they’re not eating right, they know these things, and they’re willing for help, they just didn’t know how to get it.” p. 3;
being unaware of cognitive decline, p. 5; ex: they’re living in an environment they would not have lived in when they were younger, but they don’t recognize the decline they’re now living in, p. 5; “...are they aware of the consequences of the decisions they’re making and can they make that decision understanding that the decision they’re making is going to lead them to this consequence.” p. 5; case ex: “She was of very sound mind. She knew the consequences of every decision she made.” p. 6; same case ex: “And she knew if the house caught on fire she was stuck. If somebody broke in, now she could push her button of course, she did have her ERS button, but she knew her limitations in being able to do anything for herself in an emergency.” p. 7; same case ex: “But she knew the consequences, she could voice them to you, discuss them very rationally with you, and put you in your place when you tried to do some[thing], you know, to persuade her to do anything differently.” p. 7; case ex: of being unable to process info: “...but she is not capable of processing the information to know what is goin’ on with her. ...but she’s not capable of understanding bein’ at home and bein’ alone, and processing emergency information, that kind of thing.” p. 8; some people aren’t aware that they are hoarding, others are, p. 12; “My bottom line is when I go in and talk to somebody is ‘What is this person aware of? What are they capable of deciding?’” p. 12; case ex: of being able to communicate desire to die at home: “When I walked in, her first thing to me was [worker name], I’m going to die. I’m going to die, I’m ready. God is ready for me. He knows I’m comin’. I’m ready to go.’ And she wasn’t hallucinating, there was no dementia talkin’ here, this was very direct, very clear, on what she was tellin’ me.” p. 14; case ex: of being able to communicate desires: “She made her wishes known to everybody.” p. 14; case ex: of person understanding her health problems and choosing to die at home: “I’m not suffering. I’m not in pain. I’m breathing, I’m eating, I’m going to the bathroom. This is what I want.” She wasn’t urinating in the bed. She wasn’t laying in filth. She knew what she wanted.” p. 15; being able to communicate understanding of current circumstances: “Sometimes we go in...and they can tell us that they’re satisfied and we know that they really understand everything,” p. 15; making conscious decisions: “...it’s more important to me to be here and make these decisions on my own than go there [a supervised facility] and have somebody tell me what I’m gonna do.” p. 15; “When you can see things that you know she’s not processing. She’s thinking that she’s going to the bathroom properly and that she’s, she’s clean and, when you go into the home and the source of a smell is so horrid, and it’s the person, and the person doesn’t realize it, that’s pretty obvious. There’s an issue and she’s not aware of it. She’s truly not aware of it.” pp. 16-17; case ex: of person understanding health risks and declining medical treatment from emergency squad: “...the squad told her, you know, ‘Your vitals are great. The only problem is, is your blood’s not getting enough oxygen’ and she said ‘Well, what’s going to happen?’
and he says, ‘Oh, you might pass out.’ Ok. She goes “Can you make me do anything?” He said “No-o-o, unless you’re passed out.” She goes “well then you wait till I pass out.” And, you know, she was very...she understood everything.” p. 19) (R3: 12 references: knowing problems and consequences, p. 2; ex: of knowing risks “Well, if my trash gets piled up, it gets piled up. I don’t wanna take it out.” p. 2; ex: of knowing risks “I’ve smoked for fifteen years and now it’s been smokin’ and cookin’ with the oxygen on, and there hasn’t been a fire since, but if there is a fire, it’s gonna go up, you know, pretty quick here.” p. 2; case ex: of being able to explain things [wearing stained clothing] “…she was embarrassed about it, she didn’t know...if I wear the same clothes over and over, maybe I had an accident an’ I missed it.” p. 4; not knowing consequences (ex: how their decisions affect neighbors), p. 5; primacy of not inflicting harm on others, p. 6; ex: endangering other apartment residents by smoking with oxygen on in an apartment building, p. 6; example of demonstrating understanding of risk: “Well, then, I need to smoke. I’ve been smokin’ for twenty years, I’ve only had this oxygen on for a year, so I’m gonna quit doin’ the oxygen.” p. 6; case ex: still driving with severe cognitive deficits, p. 7; overriding elder’s desires when they are in danger or they’re putting somebody else in danger, p. 14; [overriding elder’s desires] when “I can clearly see that, you know, they’re really not understanding consequences.” p. 14; “I always take it back to, you know, does this person understand the decisions that they’re gonna make. Do they truly understand that the roaches could cause them some asthma, could cause them, you know, more filth. The trash, if they don’t take it out it’s gonna cause ‘em more…” p. 16) (R4: 2 references: overriding elders desires “when their desires conflict. One day they’re saying this, one day they’re saying that.” p. 9; self-determination requires senior’s consistently understanding consequences, not just one time asking them the question “It has to be consistent. And we ask them numerous different ways.” p.10) (R5: 6 references, including methods used to assess understanding like asking “cause and effect” questions such as “What would you do in a fire?” “Why won’t you get rid of piles of papers?”(p. 18), looking for “logical” (p. 18) answers to questions, and assessing a problem if elders responses are “circular” (p. 19) and they’re unable to answer questions; 3 references to assessing level of awareness about risks, including by observing smoking in home with piled newspapers and by asking directly about burn marks and fire risks) (R6: 5 references, including 2 case examples of assessing if their explanations are not making sense: stuff has obviously been in disarray for years and client saying the church is coming and she’s cleaning her closets, p. 3; being able to explain things, p. 5 2 references to “knowing what’s going on”; “being sharp as a tack”) (R7: 6 references to understanding the consequences of their actions: having dementia and not understanding unmet needs (exs: meds and seeing doctors) p. 2; understanding the consequences that they’re living in,” p. 4; people not realizing their lifestyle has gotten to a crisis point “cross-line,” p. 8; it [freedom to make lifestyle choices] goes back to them not understanding the consequences of their actions, p. 9; understanding consequences of actions ex: living in filth, p. 10; not understanding the consequences of their actions, ex: burn marks on robe, denies doing it, p. 10) (R8: 2
references, 1 reference to making sure clients completely understand the repercussions of their situation, p. 13; 1 reference to older adult being aware of needing services as evidenced by referring APS worker to older adult’s Senior Options casemanager, p. 8) (R10: 7 references, including 5 to client demonstrating understanding by giving enough detail about how they’re managing, their strategies and plans: as stated, p. 4; people who don’t understand aren’t capable of giving detail, p. 4; ex: of being unable to verbally demonstrate understanding re: “How do you get food?”, p. 5; ex: of knowing the consequences: client being able to tell worker possible consequence of huge wound “I could die” p. 15; 1 reference to asking client if they can’t clean up clutter or if they don’t want to, p. 14; 1 reference to self-determination is capable people making reasoned decisions, p. 15)

(R11: 26 references: assessing the person’s understanding of the situation p. 2; “Do they get it?” p. 2; example: deciding competency regarding home conditions “Do they understand that this is unhealthy?” p. 3; understanding what to do in case of emergency, p. 4; assessing understanding of what to do if a fire started, p. 4; ex: asking “What exact number would you call?” p. 4; “We have to get to do they really know what to do?” p. 4; exs: of not knowing what to do if fire: “I’d call my neighbor” p. 4; “I’d go to the basement” p. 4; “I’d go to the back porch” p. 4; “I don’t know what I’d do” [“And that’s a real concern.”] p. 4; many people are “right on the edge” of competency, p. 5; examples: pattern of burning things on the stove, p. 5; pattern of falling and being taken to the hospital, p. 5; pattern of calling police a lot, p. 5; pattern of not paying bills for 3 months, p. 5; having a pattern of trying to do something that’s not working or a pattern of decline, p. 8; sometimes cases are not quite bad enough to force intervention, p. 5; “They’re getting by. It’s not a great situation, but they’re getting by.” p. 5; examples: being able to tell what they’d do in an emergency, p. 5; having help getting groceries, p. 5; refusing medical treatment “just to refuse it” ex: not treating gangrene, p. 8; worker assessing the bigger picture re: decision-making. “Do they really get it?” ex: not treating gangrene, p. 8; showing a pattern of decline in decision-making to get a court order, p. 8; [seeking court involvement] when examples of not following through pile up “and I have a real case” p. 9; ex: client and family “not following through” p. 9; “So it comes down to competency, really for me” p. 10) (R12: 8 references, including 5 references to demonstrating lack of ability to understand consequences and risks: ex: denying gangrene, p. 3; ex: not seeing outcomes of decisions, p. 9; ex: being unaware kitchen was full of smoke, p. 9; being able to verbally demonstrate understanding, p. 11; “it all comes down to risk and consequences, and their ability to understand that.” p. 11; and 3 references to not intervening if people can demonstrate they know what the consequences are: example: worker asking “If you don’t take this medication what can happen to you?” client responding “I could die.” p. 3; having to “let it be” when they know consequences and can clearly state their beliefs, ex: not treating gangrene due to not believing in amputation, p. 3-4; substantiating self-neglect allegations sometimes when people are competent and don’t want to do anything about it, exs: roaches, not taking meds, p. 4) (R13: 5 references to assessing understanding of current situation: case example of being unaware of being taken by the squad to
the hospital, p. 2; “she was not aware of any of this that was going on,” p. 2; case ex: of being well aware of consequences of not taking meds but still choosing home remedies for religious reasons, p. 2; case ex: of having clouded decision-making regarding selling medications but not wanting intervention no matter how hard worker tried, p. 3; clients still thinking they can do it for themselves although they’ve proven that they can’t, p. 5) (R14: 6 references: substantiated case example of not having insight into what they can do, p. 3; not being realistic about what they can do, p. 6; ex: “...they can’t use a microwave, can’t cook, but in their mind, they can do it. But...they can’t. Either physically or mentally.” p. 6; assessing if they understand some of the stuff that’s going on, p. 7; if a client knows it’s going on and have insight, worker would probably not do anything other than letting them know the dangers [ex: living in a home where crack is used], p. 7; if they don’t understand [that they’re living in a home where crack is used], worker would step in and do more, p. 7) (R15: 1 reference: “So a lot of the times they do understand that it’s gotten to the point where they can’t manage anymore.” p. 7)

Assessing behavior patterns [changes in behavior/lifelong patterns] (21 references by 9 APS workers) (R1: 3 references: observing patterns on second visit, p. 4; case ex: of seeing patterns of neglect and confusion, p. 7; case ex: “…he would just sleep, well he could just sleep all day. I mean, I think he could just sleep and not eat.” p. 22) (R2: 1 reference: “…this has been a lifestyle. They might be eighty-four, but when they were twenty-four they lived the exact same way. So there’s no difference to them, they don’t see the issue.” p. 4) (R3: 4 references: “And then also you have to look at, you know, their lifestyle. Was this kind of a lifestyle choice for them?” p. 13; “That they’ve kind of always lived kind of unclean in the kitchen, you know, dishes are always kind of out, after they make a meal?” p. 13; “Have they always maybe had roaches, ’n roaches are not a problem for them? p. 13; “So it’s kind of a lifestyle as well, I think.” p. 13) (R4: 2 references: assessing for recent changes in lifestyle: “First what we’re gonna look for is we’re gonna look for how they’re living today compared to how they were living when they were thirty.” (p. 1); right to make lifestyle decisions: “If there’s no change and they’ve always had a dirt floor, ok, then how you’re living is your...judgment, if you wanna live in dirt, that’s fine. As long as it’s not presenting a health department issue. And then we make the appropriate referral to the health department. Otherwise, we don’t.” p. 1) (R7: 1 reference: lifestyle becoming a crisis due to dementia and not being able to articulate needs, p. 2) (R10: 2 references: not substantiating cases when the person has full mental and physical capacity and it’s a lifestyle choice, a pattern, not a decline because of incapacity, p. 3; not substantiating when capable and you gather history that their ADL’s fit a pattern and is the norm for them, p. 4; (R12: 2 references to assessing if something is a new behavior or lifelong way of living: as stated with examples of not eating, wearing dirty clothes, p. 3; lifelong choices not being out of the ordinary, ex: wearing same clothes 4 days in a row, p. 3) (R15: 1 reference to getting history, background, p. 1) (R16: 5 references to differentiating between life-long lifestyle and self-neglect: it’s a little harder call to substantiate when it’s
how somebody has always lived, p. 2; [being a harder call] “If this has been their lifestyle their whole life, this is not a drastic change, it’s not a sign of something going wrong or a cognitive decline...” p. 2; personal ex: worker’s grandmother recently been diagnosed with dementia who was always neat started having body odor which was a change for her, p. 2; [worker’s grandmother ex:] “Versus somebody who’s maybe always having hygiene issues.” p. 2; “…that’s kind of where it gets iffy and, do you call it self-neglect or is it, you know, just a lifestyle?” p. 2)

Respecting competent people’s right to make decisions/lifestyle choices (21 references by 9 APS workers) [see also “honoring client’s wishes and self-determination” and “honoring people’s right to refuse services” subcategories under “actions needed” category] (R2: 1 reference: “But if the person is capable of understanding the decisions that they making regarding their lives, if they are of their right mind, if they are not putting somebody else at risk, if they’re not putting themselves at risk unknowingly, if they are making theses decisions because this is what they are capable of doing and they understand this, sometimes we have to say we can not force these people to live differently because we’re uncomfortable with it.” p. 6 ) (R3: 1 reference: “…if they know what the consequences are, then you know, that overrides safety in my eyes.” p. 16) (R5: 2 references to worker supporting poor decisions if the person is able to make decisions/is alert and oriented, both p. 18) (R7: 4 references: “As long as they understand the consequences of their actions...that’s their decision.” p. 1; choosing to live in an environment with problems doesn’t mean you’re unsafe, p. 3; maybe that’s the way they choose to live, p. 4; worker having mixed feelings about substantiating when people understand the consequences of their lifestyle choices, p. 4) (R8: 5 references to respecting competent client’s right to make decisions, including: if a person is demonstrating some understanding of APS questions, we have to respect their rights and leave if they ask us to (p. 7), if a senior can articulate a reason for her decisions and you can tell that their cognitive status is intact and you call their doctor to make sure the person is still capable of making their decision, then you have to respect that (p. 13), respecting competent client’s right to “…choose not to go to the doctor, they choose not to take the medication, they choose to live in a deplorable situation.” (p. 14), self-determination comes into play and you have to allow competent adults [to self-neglect] (p. 14), having to respect how competent adults want to live, p. 14) (R10: 4 references, 2 references to not substantiating when people have the physical and mental capacities and make life choices, both p. 4; making life choices not being due to decline, impairment, or incapacity, p. 4; and 1 reference to erring on the side of self-determination when you don’t have enough info, p. 15) (R11: 2 references to competent clients making bad decisions: “You know, but many times I have a lot of clients who make a lot of bad decisions, but even doctors have found them to be competent” p. 10; getting calls every day on competent people doing crazy things, p. 10) (R12: 1 reference: “If they understand the risk...then, I believe, they have the right to self-determination.” p. 11) (R13: 1 reference: wanting to respect their decision when they’re knowingly self-neglecting, p. 7)
Respecting competent people’s rights to decline services (15 references by 6 APS workers)  

**R2:** 9 references: some people having difficulty asking for help, p. 4; valuing doing for self, p. 4; “Sometimes they don’t see that they need the help that we perceive that they need.” p. 4; “We’ve had people who say ‘No, we don’t want Meals-on-Wheels, there’s other people that need it more than we do.’ It’s not a matter of if you take it somebody else can’t get it... But sometimes there’s no changing their minds.” p. 5; “…there’s the loopholes of the customer themselves who don’t want the services, don’t need the services.” p. 9; refusing Meals-on-Wheels due to not wanting to be considered homebound “‘I’m not homebound. I don’t wanna be considered homebound.’ That’s a big thing.” p. 11; not interpreting needing transportation assistance as being homebound, p. 11; “Some people hoard, are aware of the conditions, the smell, that kind of thing, and they don’t want somebody coming in and reporting them or getting them in trouble, or telling them to change their lifestyle.” p. 12; “And that kind of goes across the board for a lot of hoarders. They don’t want somebody comin’ in tellin’ them to do this and that and this.” p. 12)  

**R3:** 1 reference: “And they can choose to decline that service.” p. 2  

**R8:** 1 reference to declining APS intervention: ex: having the right to make the decision to decline cleaning services, p. 8)  

**R11:** 1 reference: “[if] the person’s competent ‘n they don’t want any help, we walk away. You know, that’s our job.” p. 6)  

**R12:** 1 reference: not having the authority to intervene when competent people decline help, p. 4)  

**R14:** 2 references: not seeing enough [impairment] to be able to take action in some cases where people are self-neglecting, p. 2; “I may see that they have no food, that they’re living in squalor and poor conditions, but yet they’re competent and I can see that they’re vehemently saying, ‘I don’t want this stuff. I don’t want the county, I don’t want Meals-on-Wheels. I don’t want a homemaker.”’ p. 3)  

Observing “cover-up techniques” being used to mask cognitive impairment (7 references by 4 APS workers)  

**R3:** 3 references: “they come back with these kind of cover-up techniques [for not knowing president, birthday] p. 6; ex: “Well, I don’t watch TV.” p. 6; ex: “Oh, I’m an old person, I don’t keep track of my birthday anymore.” p. 6)  

**R6:** 2 references to being excellent at “covering,” including diverting subject is the “biggest tip-off” of self-neglect, p. 5)  

**R10:** 1 reference re: They’re afraid of us, so they’ll pull it together just enough and know the answers to give you, p. 5)  

**R12:** 1 reference: “They can follow general conversation, and cover very well, but when you ask for details, they can’t remember.” (p. 2)  

Observing decision-making impairment when drinking alcohol but no impairment when not drinking (13 references by 2 APS workers)  

**R9:** 11 references [see also “alcohol abuse” under assessing decisions about health/hygiene sub-category]: as stated, p. 4; case ex: driving drunk and damaging car, p. 4; same case: falling off curb drunk and getting arm broken by car hitting her, p. 4; being disoriented in cout, ending up in nursing home due to alcoholism, p. 5; making 911 calls all the time from falling down drunk, p. 5; calling 911 for pizza when drunk, p. 5; calling 911
to pick her up after passing out on floor in own urine, p. 5; police/fire dept. asking APS worker to place client due to excessive 911 calls, p. 5; APS worker explaining to fire/police personnel that court found client competent, asking them “what would you do with a competent person?” [they’d charge her with something], p. 5; “getting lucky,” 2 mentions p. 5, ex: 911 calls stopped when phone was cut off due to not paying bill, p. 5) (R13: 2 references: case example where it was hard getting assessment due to medication or drinking too much, p. 3; same ex: “So that was always kind of hard to get that assessment goin’ because there would be times when he would be under-, you know, medicated, or either he’d be drinkin’ a little too much, so it’s hard to get that assessment, to really know if he really understood the ramifications.” p. 3)

Getting to know the person (9 references by 2 APS workers) (R10: 8 references to getting to know people by going out often: getting to know the person and what their norm of living is, p. 5; sometimes taking many visits to assess understanding, p. 5; going back several times to assess, p. 6; most workers tying to use best practice of 2-3 visits, p. 6; sometimes you can tell in one visit that it’s bogus, p. 6; visiting 2-3 times to see if they can hold it together, p. 6; the more you go out, the more you know a person, p. 14; getting to know people by going out often, p. 14) (R11: 1 reference to getting to know the person. “After I’ve known the person for a while, I think I know, you know, how they think or, you know, what they’re thinking, and what their expectations are.” p. 10)

Assessing ability to develop adaptive alternatives when barriers arise/ability to “take care of things” (8 references by 2 APS workers) (R10: 5 references to assessing ability to develop alternatives when barriers arise: as stated, p. 2; examples: 2nd floor bathroom, p. 2; being mentally unable to develop plan to have groceries/meds delivered, p. 3; are they capable of thinking of alternatives, p. 3; if people are capable of meeting needs in alternative ways, that’s fine p. 3) (R16: 3 references to assessing ability to take care of things: “It’s typically going to be where you do find that the senior’s maybe not taking care of things as good as they should be.” p. 1; ex: senior deferring to mentally ill daughter living in the household and things not getting cleaned up, p. 1; not substantiating when “...it looks like they’re pretty well taking care of themselves.” p. 1)

Observing that the Mini-Mental State exam might not give a clear assessment of someone (7 references by 2 APS workers) (R4: 3 references: “And somebody can pass the mini-mental... and totally obliterate the clock test.” p. 2; “Because I’m sayin’ there’s something wrong...but they’re passing the mental. Clock test it goin’ ‘Okay, I was right.’ ” p. 2; “Same as with the ER squad’ll come, you know, and they can pass the mini-mental, I’m goin’ ‘No. They’re not competent. You need to take ‘em.’ ” p. 2) (R10: 4 references, as stated, p. 11; case ex: senior completely unable to manage but scored 28 of 30 on Mini-mental exam, p. 11; worker not caring if person knows the year, but are they eating? Paying bills? p. 12; worker observing other people basing decisions on the mini-mental status exam and questioning this practice, p. 12)
Assessing wandering (R12: 12 references: wandering; assessing wandering; are they getting lost; is it dangerous; wandering away from their building; being able to explain purpose such as “I wasn’t wandering, I was going to the store’ or ‘I take a walk every day at this time. That’s my routine.’”; neighbors might think because they’re old they’re wandering; wandering without purpose and getting lost, case ex: client wandered into apartment complex pond; determining how dangerous the wandering is; are they carrying id?; can they tell you how to get home? all p. 2)

Assessing compliance with treatment and service recommendations (R1: 5 references: refusing help, p. 1; worker hypothesizing that a person might be making decisions that didn’t make sense as an act of rebellion, p. 11; “...for the most part, they follow through.” p. 17; “there’s just a kind of a, a rogue few, you know, that, um, that are just like...‘No,’ ” p. 17; case ex: of client refusing to see a psychiatrist, p. 20)

Going out at different times of the day to assess mental and physical status (R10: 3 references: as stated, p. 5; some people are better in the morning, p. 5; seeing them at different times of the day to see where they struggle and where they don’t, p. 5)

Worker having mixed feelings about substantiating when a senior is not incapable but is not making good decisions (R10: 3 references: as stated, p. 7; it’s hard when they’re capable but not meeting needs, p. 7; case ex: eating out every day instead of paying bills and not wanting to change, p. 7)

Accepting life as it is (R2: 2 references: “I don’t know how to use the word, ‘cause martyr is not the right word. Because they’re really ok with the fact that they’re older, they don’t need much anymore, and they’re ok with status quo. Its, it’s ok.” p. 5; “Other things are a priority over their needs, even if they see it that they have a need.” p. 5)

Seniors valuing freedom over safety (R2: 2 references: customers valuing freedom over safety, p. 13; “...they do value their freedom over safety.” p. 14)

Substantiating cases on people who lack both mental and physical capacity and have really bad living conditions (R10: 2 references, p. 3)

No textbook teaches how to assess understanding (R10: 2 references: as stated, p. 4: getting a feeling that something’s not right, even when they can answer questions, from being a social worker and experience. It’s not in books, it’s something you learn the longer you do it, p. 6)

Most self-neglecting people don’t think they need help (R11: 2 references: as stated, p. 1; ex: saying “I’m fine” when confronted about health risk of having no passageways in home due to clutter, p. 1)
Assessing ability to follow-through (R12: 2 references: giving clients info on Senior Options program without making official referral to see what they will do, p. 11; clients independently calling Sr. Options demonstrates if they will follow through, p. 11)

Assessing lethality versus expressing fatigue (R5: 1 reference, p. 20)

“Nobody wants guardianship.” (R6: 1 reference, p. 11)

“Seniors don’t like to call the squad.” (R6: 1 reference, p. 14)

Determining competency level of the individual after looking at the environment (R8: 1 reference, p. 1)

Getting a court order of protection when clients are unable to care for themselves (meals, dress, bathe, bathroom) and refuse medical intervention (R8: p. 10)

There are usually several different concerns (R10: 1 reference, p. 1)

Assessing ADL’s (R10: 1 reference, p. 1)

Breaking assessment down into 3 categories: mental, physical, collaterals supports (R10: 1 reference, p. 2)

Unintentionally self-neglecting due to not knowing resources out there (R10: 1 reference, p. 3)

Not getting a clear picture of some people no matter how hard you try (R10: 1 reference, p. 5)

Telling supervisor “something ain’t right” and he's like “keep goin’ out there” it’ll eventually work its way out (R10: 1 reference, p. 6)

Assessing are their actions meeting up with what they’re saying (R12: 1 reference, p. 11)

Looking at the “three biggies” to distinguish self-neglect from self-determination [food, shelter, clothing/self-care] (R15: 1 reference, p. 7)


Assessing hygiene, toileting, clothing, grooming decisions/appearance (85 references by 15 APS workers) (R1: 9 references to assessing clothing/grooming decisions: “…typically…they’ll be dressed
inappropriately for the season, they'll be disheveled, clearly not able to take baths for themselves, you know, as evidenced by their body odors, their hair being matted, things like that.” p. 1; wearing same clothes for many days, p. 3; seeing them in same clothes on second visit, p. 4; asking “How often do you do your laundry?” [after seeing in same clothes at second visit], p. 4; wearing soiled clothing for days, p. 4; “But the second visit will clearly show you because if they have on the same soiled clothing...” p. 5; showing improvement on second visit “...and I go out there and, you know, the house it just, it smells of Pine-sol, or, you know, the client just came back from the beauty shop!” p. 5; wearing soiled clothing, poor grooming, p. 6; case ex: of wearing same soiled clothing on second visit, p. 7) (R2: 18 references including 16 references to assessing hygiene: using sight and smell to assess physical characteristics “…how do they look...are they feeble, are they ambulatory, do they look like they’re maintaining their personal hygiene...” p. 1; smelling the person and pets, p. 3; old food stains on clothing “might indicate they’ve not changed their clothes for quite some time.” p. 3; if “…every day you see them they’re in the same clothes, then you know that there’s an issue there.” p. 3; looking at hair and nails, p. 3; assessing teeth, p. 4; smelling bad, p. 4; UTI being possible cause of a person smelling bad, p. 4; case ex: “…the woman is saying things like ‘Oh this is my best housecoat’ and it is literally, one, see-through, two, it is, hardened and stained from, uh, bodily functions kind of thing.” p. 16; same case ex: “You look at her, her socks and they’re literally attached to her body because they’ve been on there for so long.” p. 16; same case: not recognizing big hygiene problems: “When you can see things that you know she’s not processing. She’s thinking that she’s going to the bathroom properly and that she’s, she’s clean and, when you go into the home and the source of a smell is so horrid, and it’s the person, and the person doesn’t realize it, that’s pretty obvious.” pp. 16-17; same case ex: not realizing incontinence, fecal/urine stains on clothing, p. 17; same case ex: not changing clothes, socks: hospital having to peel socks of her, “They were a part of her skin, pretty much, by the time they went to peel them off of her.” p. 17; same case ex: having severely matted hair “…the ends of her hair that should have been brushable were attached to her scalp.” p. 17; and 4 re: assessing decisions about toileting: case ex: depending on aids for toileting “She had to wait on the aids to get there, if the aids didn’t show up, she couldn’t go to the bathroom. She was still in total control of her bodily functions.” p. 7; case ex: of demonstrating toileting “…she could stand up, literally urinated in a cup. And was dumping it out her bedroom window. Yeah. She knew what she was doing.” p. 14; case ex: demonstrating eating, drinking, and toileting, p. 15; same case ex: “She wasn’t urinating in the bed. She wasn’t laying in filth.” p. 15) (R3: 8 references: “Are they able to, you know, how are they caring for themselves?” p. 1; case ex: wearing clothing with some urine smell in an affluent neighborhood, p. 4; same case ex: going out in stained clothing in an upscale neighborhood, p. 4; same case ex: “She’s not washing her clothes” p. 4; same ex: client explaining stained clothing “I talked to her about some stains on her clothes, she was embarrassed about it, she didn’t know...Well, if, you know, I wear the same clothes over and over, maybe I had an accident and that, you know, I missed it.” p. 4;
“People are allowed to be dirty.” p. 4; “People are never gonna die from bein’ as dirty as however they wanna be.” p. 4; “I guess in Upper Arlington, if a person’s out at the bank and they shouldn’t maybe be smelling the way they might, or maybe have a little small stain on them, they’re gonna be like ‘Well what’s this elderly person out here driving? She’s a little bit confused how can she be driving? etc.’” p. 4; affluent suburban standards creating a “big problem” when there really isn’t one, p. 4) (R4: 1 reference to resisting baths, p. 6) (R5: 9 references to assessing physical appearance, as stated, p. 3; including 3 references to sudden weight loss, p. 8,8,10; 2 to bathing, p. 6,7; dirt or feces under fingernails, p.7; long nails p. 7; wearing soiled clothing, p.7) (R6: 5 references, including not recognizing clothing has holes in it, or is falling apart, p. 3; looking for boots in wintertime to assess if they’ve gone somewhere, p. 3) (R7: 1 reference: [assessing elder self-neglect by] looking at the individual themselves, p. 1) (R8: 4 references to incontinence: referral concern of incontinence (p. 7); assessing for incontinence: worker not observing or smelling evidence of incontinence (p. 7), handling incontinence by getting supplies such as Tucks, Depends, p. 8; case ex: of person being totally incontinent and being aware of it, p. 9) (R10: 1 reference to investigating alleged medical issues and hygiene issues, p. 1) (R11: 6 references: assessing how they’re dressed, p. 1; what they smell like, p. 1; what they look like, p. 1; hygiene, p. 1; do they know they haven’t bathed and smell bad? p. 2; poor hygiene but healthy otherwise is unsubstantiated, p. 4) (R12: 4 references to assessing clothing: “are the clothes clean or dirty?” p. 2; “Are they wearing the same clothes they were wearing when you came her last time?” p. 2; assessing if wearing dirty clothes is a new behavior or a lifelong way of living, p. 3; lifelong choices not being out of the ordinary, ex: wearing same clothes 4 days in a row, p. 3) (R13: 7 references to looking at their appearance, p. 1; looking for poorly laundered clothing, p. 1; dirty nails, p. 1; body odor, p. 1; malnourishment, [previous 4 “would indicate things of self-neglect”] p. 1; seeing physically if they haven’t been eating properly, p. 1; neglecting self but not property, ex: bite marks from spiders, p. 10) (R14: 3 references to assessing hygiene: looking at hygiene, p. 1; looking to see if they’re clean, p. 1; “So, hygiene and cleanliness is not always a huge factor.” p. 4) (R15: 3 references to assessing hygiene: addressing urine odor by asking “How often do you bathe?” p. 1; a lot of times on self-neglect they’re not taking care of themselves, p. 4; “Are they taking care of themselves.” p. 7) (R16: 6 references to assessing personal hygiene decisions: looking at their personal hygiene, p. 1; finding poor hygiene, p. 1; substantiating for poor hygiene, p. 1; not substantiating when hygiene is good, p. 1; personal ex: worker’s grandmother recently diagnosed with dementia had always been very neat and began having body odor which was a change for her, p. 2; assessing change in hygiene habits “Versus somebody who’s maybe always had hygiene issues.” p. 2)

Assessing decisions about medications [medication compliance, understanding of medications, ability to self-administer medications] (75 references by 14 APS workers) (R1: 2 references: case example of getting better and closing case after getting back on medications for high blood pressure and
hyper-lucademia, p. 18; same case ex: of depression lifting after getting on Zoloft, p. 18) (R2: 2 references: “...are they prescribed, can you get the medications, can you manage them yourself.” p. 2; “...and a lot of times, if the person is open enough they’ll even talk to us about, you know, ‘We have them set up.’ and ‘This is my way of taking it, make sure I take it...’” p. 2) (R3: 7 references, including 6 to having the right to not take meds: choosing to not take meds, p. 5; choosing to take herbal remedies instead of prescribed medication, p. 5; “No, I’m just gonna drink my tea and if I die, I die.” p. 5; knowing death is near, p. 5; having the right to not continue medical treatment, p. 5; case example of not taking meds, p. 7; assessing “are they able to get to their medications.” p. 1) (R4: 4 references: “medications are a mess,” p. 1; assessing medication compliance, p. 1; assessing if not taking meds is life-threatening “Are they life-threatening medications? Because if they’re not...it’s not. It’s not presenting a serious threat to ya, you know?” p. 1; resisting medications, p. 6) (R5: 2 references to assessing meds, p. 3, 7) (R6: 5 references, including 4 to assessing knowledge of meds and doctors, including not taking meds, p. 4; not knowing where meds were, p. 4; hiding meds, p. 4; knowing meds and doctor’s names, p. 5; and 1 reference to receiving allegations of neglecting health [exs: meds, diabetes]) (R7: 1 reference to assessing if they’re getting their medication and getting to the doctor, p.2) (R8: 2 references: making sure clients completely understand the repercussions of their situation, ex: asking “What may happen if you don’t take your medication?” p. 13; cognitively intact people can choose to not take medication, p. 14) (R9: 1 reference to trying to find out what medication they’re on, p. 1) (R11: 2 references: assessing if they’re able to take meds, p. 4; medication compliance is not always a matter of life or death, p. 5) (R12: 21 references, including 17 references to assessing medication compliance: not taking medications, p. 3; having the right to refuse medication, p. 3; asking “Why aren’t you taking it?” p. 3; determining if it’s a memory problem or whether they have a reason for not taking, p. 3; examples of reasons: “It makes me feel funny” p. 3; “I don’t believe in meds.” p. 3; a lot of elderly people haven’t seen a doctor in years and “don’t believe in doctors” p. 3; not intervening if people can demonstrate they know what the consequences are, p. 3; asking “If you don’t take this medication, what can happen to you?” p. 3; examples of being able to state consequences: “Oh, doctor said I could die” p. 3; “He’s gonna put a pacemaker in me.” p. 3; competent people being competent to neglect themselves by not taking meds, p. 4; worker not “fussing” about client not taking meds that are not “life or death,” p. 10; not taking some meds can be serious, p. 10; case exs: hallucinations caused by low potassium level, thyroid problems, p. 10; case ex: medical issues causing mental health symptoms, p. 10; case ex: being unable to take meds properly creating mental inability to maintain independent living, p. 10; and 4 references to assessing understanding of meds: assessing meds they’re on, p. 2; do they know who their doctor is, p. 2; do they know their meds and why they take them, p. 2; “You just have to see if they know what the medication is, why they’re prescribed it...” p. 3) (R13: 16 references, including 8 references to assessing ability to self-administer medications: assessing ability to administer meds, p. 1; ex: having their
own system set up as far as a pill box, p. 1; how they’re dealing with the bottles, p. 1; assessing understanding of how medication is supposed to be administered, p. 1; assessing if they’re able to administer their own meds, p. 1; substantiated case ex: of not taking meds as prescribed, p. 2; same case ex: of person with untreated vision problems “just going by the feel of the pills” p. 2; case ex: of using homemaker to help with meds, p. 3; and 7 references to respecting competent people’s decision to not take meds: case example of not substantiating referral allegation that person wasn’t taking meds, p. 2; same case ex: of person being well aware of consequences of not taking meds, p. 2; same person preferring home remedies for religious aspects, p. 2; same ex: of person being aware of consequences and choosing alternative methods, p. 2; same ex: of having justifiable reasons for not taking certain medications and knowing the consequences, p. 2, case ex: of a person selling his pain meds and giving the money to caretaker, p. 3; same person not seeing that his was self-neglecting by not taking his medications as prescribed, p. 3; 1 reference to looking at medications, p. 1) (R15: 3 references, including 2 references to asking about medications: “Do you take meds?” p. 1; “What are you taking?” p. 1; and 1 reference to not taking meds as prescribed: “A lot of times on self-neglect it could be they’re not following through with their meds, they’re not eating very well, or they’re not taking care of themselves.” p. 4) (R16: 7 references: “A lot of the self-neglect referrals we get are from med noncompliance…” p. 1; talking to them about medications, p. 1; asking how they get medicines, p. 1; asking if somebody helps set them up, p. 1; asking if they have money to pay for prescriptions “‘cause that’s often a big issue with seniors.” p. 1; having mixed feelings about substantiating when people “…probably would be very compliant with medications if they could afford them.” p. 2; “‘Cause to me that’s [medication non-compliance] self neglect, but it’s based on they really don’t have the resources, so…” p. 2)

Assessing health care decisions/ability to explain health strategies and possible consequences of medical decisions [including treating medical conditions, seeing doctors, calling emergency squad, discharging from rehab/care facility, psychiatric and mental health services, chemical dependency services] (62 references by 14 APS workers) (R1: 4 references: case example of not caring for wounds, p. 11; case ex: of client’s sister providing transportation to see a doctor regularly, p. 18; case ex: of being taken to Netcare [psychiatric emergency services], p. 18; getting a lot of calls about people refusing to treat gangrene, p. 25) (R2: 8 references, including 6 about assessing decisions about seeing doctors: [assessing] “Medically whether they’re going to the doctor, do they have a doctor, how often do they see the doctor, when was the last time they saw the doctor…” p. 2; “You have people who will not go to the doctor, to help with the assessment process, to help with the orders to get home health.” p. 9; case ex: “They [family client lived with] recognized that she needed to see a doctor. She refused to see a doctor. …the doctor would not go into the home because the mother would not willingly be a patient. We actually finally talked her into it, but it probably was a month before we could.” p. 18; refusing the squad: “We have been in situations where we’ve
called the squad, the squad will come in, but if the person refuses, there's nothing we can do." p. 18; case ex: of declining medical treatment “She goes [to the squad EMT] ‘Can you make me do anything?’ He said ‘No-o-o, unless you’re passed out.’ She goes ‘Well then you wait then till I pass out.’ ” p. 19; “And we do have doctors who will go to the home if they’re Medicare. But also those doctors hands are tied if the person’s refusing to see them” p. 19; case ex: of not showing up for doctor’s appointments, p. 20 ; and 2 about not treating hearing loss: case ex: “I go up and talk to her, and she’s very hard of hearing, so this discussion is being yelled.” p. 14; different case ex: “The woman was, uh, very hard of hearing, she opened the door.” p. 16) (R3: 4 references, including 3 re: mental health services being the most declined services: “The hardest on is mental health counseling” p. 12; case ex: this guy had lost his wife, worker recommended counseling for depressions “Nope, Don’t need it. I’m not crazy. I’m not mentally ill.” p. 12; “A lot of times even the folks who have schizophrenia, you know, personality disorders, really difficult, really challenging to allow somebody to come into the home...just to build that rapport up.” p. 12 and 1 re: assessing medical treatment compliance: case ex: of not keeping medical appointments, p. 7) (R5: 4 references, including 3 references to missing medical appointments, exs: doctor visits, dialysis, dialysis again, p. 7,8, 9; refusing mental health referrals, p. 19) (R6: 3 references: 1 to clients usually will talk to a visiting psychiatrist in their home even if previously refusing, p. 12, 2 re: not wanting emergency squad called: “seniors don’t like to call the squad” p. 14, client getting mad because squad was called, p. 13) (R7: 3 references, including 2 to mental health services: seniors not accepting mental health services, p. 6, current cohort has stigma about receiving mental health services, p. 6; doctors calling APS for high-maintenance patients, p. 9) (R8: 7 references, including 2 references to being unable to take care of self and knowing it but not wanting to go to the hospital: as stated, p. 9, being extremely ill and needing medical attention but not wanting to go for it, p. 9; 2 references to refusing medical attention (different cases, p. 9, p. 10); cognitively intact people can choose not to go to the doctor, p. 14; if a senior can articulate a reason for her decisions then you have to respect that, ex: “I don’t wanna go to the doctor...Because I’m not sick.”, p. 13; case ex: of an older adult choosing to return home from a facility although unable to ambulate, get meals, dress, bathe, toilet self, p. 10) (R9: 2 references to refusal of mental health treatment leading to eviction (being evicted again after firing mental health provider [elder treatment focus], p. 7; getting evicted after refusing mental health treatment, p. 7) (R10: 3 references, including 2 to assessing client’s ability to explain health strategies and possible consequences of medical decisions ex: “Why don’t you go to the doctor?” “It’s the same thing, it heals up and then it goes away” p. 15; ex: “If you don’t go to the doctor, what could happen?” “I could die.” p. 15; and 1 reference to investigating alleged medical and hygiene issues, p.1) (R11: 4 references: a lot of times probate referrals are based on medical issues, p. 8; ex: untreated open sore getting worse, p. 8; refusing medical treatment “just to refuse it” ex: not treating gangrene, p. 8; worker assessing the bigger picture re: medical decision-making “Do they really get it?” ex: not treating gangrene, p. 8) (R12: 8 references to
assessing ability to understand health consequences: example: denying or not understanding gangrene. “You have an infection” “No I don’t!” “Do you know you could lose your leg?” “I’m not gonna lose my leg.” p. 3; getting an order of protection when they demonstrate a lack of understanding of health consequences, p. 3; getting most orders for cellulites, diabetes, and gangrene, p. 3; “And like every single order I think I’ve ever gotten has had to do with the knees down.” p. 3; a lot of people refusing treatment say “I’m ready to go on. I’m sick of bein’ sick.” p. 3; not believing in amputation, p. 4; exs: “it’s my religion” “I’m going to leave whole.” p. 4; case example of substantiating self-neglect allegations for a woman needing but not wanting hospice care, p. 5) (R13: 7 references, including 4 references to assessing if they’re seeing a doctor: following up with people’s doctors to see if people with medical issues have actually been to see a doctor within say the past year, p. 1; looking at if they’re going to a doctor, p. 1; substantiated case ex: of not knowing where her doctor was located [among other issues], p. 2; 2 references to having untreated medical conditions: substantiated case example of untreated vision problems, p. 2; same case ex: having a ring imbedded in finger and infected, p. 2; and 1 reference to monitoring health decisions over time: “...there’s a point where you’re allowing them to make the decision, but if you see that it’s dragging on for a week or two, and they’re physically getting worse, their interventions aren’t working, you know, I’ll tell ‘em. ‘Okay, you tried this...but it’s just not working...’” p. 7) (R15: 2 references to asking about seeing doctors: “Do you have a doctor?” p. 1; addressing confusion by asking “When have you been to the doctor lately?” p. 1) (R16: 4 references to resisting psychiatric and chemical dependency services: “Easily the most resisted [services] are psychiatric treatment.” p. 3; chemical dependency acknowledgment and treatment being resisted, p. 3; folks not wanting to be seen as crazy, p. 3; “Self-neglect folks tend to worry that people are gonna see them as crazy, so that, that’s the one that I think is the hardest.” p. 3)

Assessing eating decisions (71 references by 14 APS workers) (R1: 8 references: case ex: of not eating, p. 6; case example of accepting Meals-on-Wheels, p. 7; case ex: of someone appearing thin and fragile, p. 8; resisting Meals-on-Wheels “I think the service that’s probably resisted...would be believe it or not, I would say, Meals-on-Wheels.” p. 14; “People don’t want Meals-on-Wheels because they don’t think that they, they’re not appealing to their palate.” p. 14; resisting Meals-on-Wheels due to valuing independent cooking: “I believe it’s taking away part of their independence from the cooking.” p. 14; valuing being able to cook: “...once the get that meal [Meals-on-Wheels] it’s like ‘What you tryin’ to say, I can’t cook no more?’” p. 15; case ex: of male client not eating, p. 22) (R2: 2 references to assessing decisions about Meals-on-Wheels: accepting or declining Meals-on-Wheels is about half and half, p. 11; “If they refuse Meals-on-Wheels it’s for reasons like ‘I don’t like their food.’ ‘I don’t wanna pay the money. ‘I’m not homebound. I don’t wanna be considered homebound. That’s a big thing.” p. 11) (R3: 1 reference to Meals-on-Wheels being the most accepted service, p. 12) (R4: 2 references: not a whole lot of food in the house or rotten food, p. 1; most
seniors accepting Meals-on-Wheels, p. 7) (R5: 5 references to eating: as stated, p. 3;7; asking “Have you got enough to eat?” p. 3; not feeling like eating, p. 8; food not “tasting right” p. 8) (R7: 1 reference to checking to see if they have food, p. 1) (R8: 1 reference: case ex: of client not eating, p. 9) (R9: 3 references to Meals-on-Wheels being the most accepted and most rejected service: including “ ‘Cause either they like ‘em a lot and they’re savin’ ‘em money, or ‘I don’t like ‘em. They don’t taste right because they’re diabetic, they don’t have any spices...” p. 6) (R10: 1 reference: Client being unable to explain how they get food, p. 5) (R11: 10 references: asking to look in fridge, p. 2; assessing food supply, p. 2; asking about food supply on first visit, p. 2; if there’s no food asking why there’s no food, p. 2; asking how do they get food, p. 2; asking who helps get food, p. 2; asking how do they pay for food, p. 2; “When did you eat last?” p. 3; “How do you get your food?” p. 3; having help getting groceries, p. 5) (R12: 13 references, including 7 references to checking food in house: as stated, p. 2; checking to see if it’s spoiled, p. 2; putting things in fridge that don’t belong, p. 2, ex: keeping cereal, clothes, unopened cans in fridge, p. 2; not refrigerating things that need to be, p. 2, exs: spoiled meat on the counter, p. 2, sour milk over a month old, p. 2; and 6 references to assessing eating: asking “What did you eat this morning?” not “Did you eat this morning?” p. 2; not eating well [as indicator of self-neglect], p. 2; not feeding self properly, p. 2; assessing causes of malnourishment, p. 3; asking “why are you not eating?” p. 3; assessing if not eating is something new or a lifelong way of living p. 3) (R14: 12 references to assessing nourishment/food decisions: looking at their weight and height to see if they’re getting nourishment, p. 1; “Food is a big issue.” p. 1; a lot of them don’t know they can get Meals-on-Wheels, p. 1; thinking Meals-on-Wheels is for other people, p. 1; ex: even if their income is only 500 dollars a month, p. 1; “they always think it’s [Meals-on-Wheels] for someone else.” p. 1; [thinking Meals-on-Wheels is for other people] even though their income may be way below the poverty level, p. 1; substantiated case ex: not having any food, p. 3; substantiated case ex: refrigerator full of rotten food, p. 3; substantiated case ex: having no food, p. 3; they tend to like Meals-on-Wheels but may not want to pay for it, p. 6; thinking they can cook when they can’t, p. 6) (R15: 11 references, including 6 references to assessing eating habits: asking “What did you have for breakfast this morning?” p. 1; assessing nutrition as possible cause of disordered thinking, p. 4; a lot of times on self-neglect they’re not eating well, p. 4; “A lot of times they don’t want to eat alone.” p. 6; “So they choose not to eat at all.” p. 6; “But if somebody was there at the time they were eating, and sat down and ate with them, (softly) they wouldn’t have a problem with it.” p. 6; “Are they eating, are they being able to get food?” p. 7; and 4 references to accepting home-delivered meals: home-delivered meals being the most accepted service, p. 5; clients telling workers they don’t like senior center meals, p. 5; a lot of individuals have chosen that frozen meals home-delivered once a week through “Simply EZ” are better than hot meals delivered daily from the senior center, p. 6; “And then they can choose what they want that day, or what piece of it that they want, since they’re not eating as much, and they
like it better.” p. 6) (R16: 1 reference to accepting Meals-on-Wheels: “And I think the most accepted [service] is always the Meals-on-Wheels.” p. 3)

Assessing physical health and ambulation (26 references by 6 APS workers) (R3: 4 references: assessing physical health, p. 1; “Are they ambulatory throughout the house.” p. 1; assessing clutter as cause of ambulation problem, p. 1; looking at their health, p. 1) (R5: 9 references: assessing health conditions, p. 3; including diabetes/“sugar,” p. 3, swollen ankles, p. 3, assessing physical condition, p. 8; untreated wounds, p. 7, not making it to the toilet, p. 8; having health issues, p. 8; toxins from lack of dialysis impairing judgment, p. 9; and confusion clearing after receiving medical treatment, p. 9) (R7: 2 references: falling can affect mental status: hitting head can lead to odd behavior, p. 7; getting a court order to make a client go to the hospital after a fall—had a hematoma (self-neglect because she didn’t recognize what had happened, p. 7) (R8: 3 references: receiving self-neglect referral for falling, p. 7; 2 case ex: of being able to ambulate p. 8, case ex: of being unable to ambulate to meet basic needs, p. 10) (R10: 4 references to assessing physical capabilities: as stated, p. 2; can they walk, p. 2; can they get to the door, p. 2; can they get out of the home, p. 2) (R11: 4 references, to assessing the person’s physical condition: as stated, p. 1; obvious medical problems, p. 1; are they ambulatory, p. 4; observing a pattern of falling and being taken to the hospital, p. 5)

Assessing decisions about utilizing home-health services (16 references by 5 APS workers) (R1: 1 reference: people would probably accept visiting nurses if they were available, p. 13) (R2: 3 references: firing home health providers “...the lady did not care for the home health services, she would fire them.” p. 6; case ex: “…she [physically] deteriorated very quickly within a matter of weeks” and initiated contact with a home health agency, then hired the male aid when the agency ended up going under, she hired the aid, p. 6; same case ex: “Well, then we would get referrals on this aid that people didn’t think it was right that this male aid was going in and taking care of this older woman, da da da da da. She was of very sound mind. She knew the consequences of every decision she made.” p. 6) (R13: 4 references to accepting visiting physician services: being more willing to accept homemakers, exterminators, and visiting physicians [than money management assistance], p. 5; visiting physicians being accepted because they’re easier than getting transportation to their doctors, p. 5; willing to have a doctor come in, p. 5; this population may be used to doctors making house calls so they’re very accepting [of visiting physicians], p. 5) (R15: 7 references to resisting home health services: home health being resisted, p. 6; “Sometimes they’re very proud.” p. 6; “They don’t wanna have anybody come into their house.” p. 6; “They don’t want strangers on a regular basis.” p. 6; “They don’t need help cleaning up.” p. 6; they’re either open or closed to that [home health], p. 6; “Home health is not a biggie to put in there.” p. 6) (R16: 1 reference to resisting personal care services: “Personal care gets a little harder, ‘cause then you’re asking, you know, to have somebody to help them with the shower and stuff, and I
think you know, it’s very hard to let people see you in that vulnerable state, so…” p. 3)

Assessing smoking decisions (10 references by 4 APS workers) [see also “assessing fire risks” under housing category] (R1: 5 references: seeing evidence of unsafe smoking, p. 6; case ex: of having burn holes in clothing, p. 7; having cigarette burns [as a sign of self-neglect], p. 25; people may understand the consequences of smoking when they first choose to smoke, but once the become incompetent, someone has to make that decision for them because there are several things that go along with it that are unsafe, that they can’t do for themselves, pp. 25-26; “…if they develop lung cancer, they need an oxygen machine, that person is incompetent, they’re not gonna keep their kendulum in for twenty-four hours a day, they’re not gonna sit up there and you know, check their polsocks and do all that kind of stuff, because they can’t. Before they could, now they can’t.” p. 26) (R3: 3 references to smoking with oxygen: smoking with oxygen, p. 2; setting fires from smoking with oxygen, p. 2; choosing to quit using the oxygen to continue smoking, p. 6) (R4: 1 reference: “just because they’re smoking on oxygen doesn’t make it an APS case” p. 11) (R5: 1 reference to observing cigarette burns where falling asleep)

Assessing for possible Urinary Tract Infection (UTI) (8 references by 4 APS workers) (R2: 2 references: “I can’t believe the terrible effects I’ve seen from people on a UTI. Then they’re treated for that and they’re a whole new person.” p. 16; “It might be as simple as that [UTI] as why they’re not processing that information.” p. 16) (R5: 1 reference to UTI causing confusion, p. 9) (R7: 1 reference: “UTI’s (urinary tract infections) are horrible with seniors. They will distort a senior’s reality base so quickly that it’s not even funny.” p. 7) (R15: 4 references: “A lot of times it’s a urinary tract infection, which is simple, just go to the doctor, get that taken care of, and, you know, then you’re not gonna be as confused any more and you’re gonna remember to eat, and so on and so forth.” p. 4; “They [UTI’s] can cause major confusion.” p. 4; “If left untreated, it gets even worse, even plays havoc on blood pressures and sugar levels and everything.” p. 4; “So yeah, it’s [UTI] always one the things that I’ll ask right away…” p. 4)

Assessing possible depression/mental health service needs (5 references by 4 APS workers) (R5: 2 references: depression being “often very undiagnosed” p. 9; assessing suicide plan vs. expressing fatigue, p. 20) (R6: 1 reference to client’s disposition improving after moving from an uninhabitable house to an apartment, p. 13) (R7: 1 reference to seniors needing mental health services for depression, isolation, domestic violence, death of a loved one, loss of home or job, p. 6) (R10: 1 reference to a lot of times the primary diagnosis is a mental health issue, not dementia (ex: depression), p. 11)

Assessing decisions about driving (3 references by 3 APS workers) (R2: 1
Assessing for imminent medical risk (10 references by 2 APS workers) [see also “seeking court orders” under “Actions needed” category] (R8: 5 references, including insisting client get medical assessment immediately “I could not leave her there” (2 references, different cases, p. 9, 10); client deciding to go to emergency room so APS worker wouldn’t have to get court order (p. 9), worker getting court order of protection to force medical assessment (different case), (p. 10); worker having to override client’s decisions when they are unable to care for self, p. 10) (R13: 5 references: overriding elders’ desires if there’s an imminent danger, p. 6; having to get a few emergency orders to have them receive medical care, p. 6; ex: deep wound infection with maggots and they’re saying “I can treat it” p. 6; case ex: client in hospital and really reluctant to get needed follow-up care, p. 6; getting people out of home first [involuntarily] for medical conditions, p. 10)

Assessing alcohol abuse (R9: 10 references, including having problems when drinking alcohol but ok when not, p. 4; sobering up in a nursing facility after falling due to drinking, p. 4; stopping driving due to damaging car while driving drunk, p. 4; being unable to stop drinking, p. 4; falling off curb drunk and getting arm broken when hit by car, p. 4; being disoriented in court, ending up in nursing home due to alcoholism, p. 4; making 911 calls all the time from falling down drunk, p. 5; calling 911 while drunk for pizza or volunteer opportunities, p. 5; calling 911 to pick her up after passing out on floor in own urine, p. 5, police/fire personnel requesting that APS place client due to excessive 911 calls [while drunk], p. 5)

Assessing ability to develop adaptive alternatives when health/hygiene barriers arise (R10: 6 references, including adapting to being unable to get to 2nd floor bathroom (3 references, p. 2 [see housing decisions]); being unable to have someone come in and unable to leave to get groceries, meds, p. 3; being unable to physically go out to get food/meds and also mentally unable to develop a plan to have groceries/meds delivered, p. 3; substantiating cases on people who lack both mental and physical capacity and have really bad living conditions, ex: human waste backing up in plumbing and senior being unable to think of alternatives, p.3)

Assessing decisions about dying at home (R2: 5 references: case ex: of self-determining to die at home, p. 14; “When I walked in, her first thing to me was ‘[worker name], I’m going to die. I’m going to die, I’m ready. God is ready for me. He knows I’m comin’. I’m ready to go.’ And she wasn’t hallucinating, there was no dementia talkin’ here, this was very direct, very clear, on what she was tellin’ me.” p. 14; dying person demonstrating eating, drinking, and toileting: “Yeah. She knew what she was doing.” p. 14; “She wanted to be free to die at home. And she stated that very clearly, over and over and over again. ...We did contact the doctor, we contacted
the squad. She made her wishes known to everybody.” p. 14; (same case) declining medical assistance from emergency squad: “...the squad told her, you know, ‘Your vitals are great. The only problem is, is your blood’s not getting enough oxygen’ and she said ‘Well, what’s going to happen?’ and he says, ‘Oh, you might pass out.’ Ok. She goes “Can you make me do anything?” He said “No-o-o, unless you’re passed out.” She goes “well then you wait then till I pass out.” And, you know, she was very...she understood everything.” p. 19)

Assessing Emergency Response Button decisions (R1: 3 references: case ex: of someone repeatedly accidentally pressing the ER bracelet and calling the squad, p. 9; same case ex: of accidentally hitting the ERS button repeatedly and causing false alarms, p. 10; usually accepting ERS button, p. 13)

Assessing decisions about using air conditioner (R1: 2 references: case example of being dehydrated, not using air conditioning, p. 18; same case ex:, repeat referral “‘Got him again this summer. Same problem. Didn’t turn on the air, he’s dehydrated.” p. 18)

Assessing sleeping patterns (R1: 2 references: case example “…he would just sleep, well he could just sleep all day. I mean, I think he could just sleep and not eat.” p. 22; same case ex: client falling asleep during home visits, p. 22)

Assessing ability to do activities of daily living (R2: 2 references: assessing activities of daily living and “their ability to do their daily care stuff.” p. 2; “Or, and sometimes you go into the situation, and they are fine. And the environment is fine. They have food. Their bills are paid.” p. 15)

Assessing willingness to accept help (R6: 2 references: client identifying need for transportation p. 6; clients usually accepting medical/grocery transportation services, meals services, and personal care assistance, p. 9)

Making sure the basic needs are addressed ASAP ex: shelter, food, clothing, utilities (R10: counted as 2 references: [1) food, 2) clothing], p. 1)

Needing help with medical management (R10: 2 references: client being able to manage everything in life but medical management, p.9; needing medication management, p. 9)

Assessing compliance fatigue (R5: 1 reference: “I’m tired of being sick” p. 20)

Seniors don’t want to call the squad (R6: 1 reference, p. 14)

If a client refuses to go to the hospital paramedics won’t take her without a court order of protection (R8: 1 reference, p. 10)

Cycle resuming upon returning home from the hospital after getting medical
**Sub-category:** assessing decisions about housing—(285 references)

(R1: 34 references) (R2: 18 references) (R3: 34 references) (R4: 14 references) (R5: 21 references) (R6: 19 references) (R7: 12 references) (R8: 14 references) (R9: 11 references) (R10: 15 references) (R11: 27 references) (R12: 5 references) (R13: 23 references) (R14: 28 references) (R15: 4 references) (R16: 6 references)

Assessing housekeeping decisions [cleanliness/clutter] (50 references by 12 APS workers) (R1: 14 references: “If I’m having a really difficult time getting in the house? I pretty much know that their house is in bad shape.” p. 1; when having difficulty getting in their house] “That their house is gonna be in bad housekeeping conditions.” p. 1; “...it might be that they’re not taking care of their animals, or that there might be some odors which sometimes I can smell right from the porch.” p. 1; self-neglecters having poor housekeeping, p. 2; “They usually have papers and things like that strewn about, all over the floor and on the couch. And that’s like, and that’s pretty much throughout the house.” p. 2; “It’s just overrun with a lot of paper.” p. 2; “The kitchen us usually, the countertops are either covered with dirty dishes or, you know, or with other types of miscellaneous items.” p. 2; showing improvement on second visit “...and I go out there and, you know, the house it just, it smells of Pine-sol, or, you know, the client just came back from the beauty shop!” p. 5; observing “deplorable” conditions in the home, p. 6; having infestation with mice and roaches, p. 6; case ex: of noticing odor at front door, p. 7; case ex: of roach and mice infestation, p. 8; case ex: of looking in window and seeing papers everywhere, p. 9; case ex: of not seeing roaches due to poor eyesight, p. 11) (R3: 4 references to assessing cleanliness: not taking trash out and having eight or ten bags of garbage in the house p. 2; “Was this kind of a lifestyle choice for them? That they’ve kind of always lived kind of unclean in the kitchen, you know, dishes are always kind of out, after they make a meal?” p. 13; “Well maybe the elderly person there, they don’t smell as well as we do, the younger folks do.” p. 13; “So it’s like, they’re allowed, it’s allowed to stink in there.” p. 13) (R4: 2 reference: typically smelling the house: “Typically I smell...That’s a typical self-neglect.” (excerpted p. 1); resisting cleaning, p. 6) (R5: 3 references including not taking out garbage, p. 8; clutter to the point of just having little pathways, p. 10, refusing to recycle when offered assistance, p. 10) (R6: 2 references: assessing cleanliness, clutter, smells, odors, p. 3; assessing bathroom, ex: toilet being full of BM, p. 12) (R7: 4 references to living in filth, including “They are living in filth but as long as they understand the consequences.” p. 4, “People do have the right to live in filth.” p. 10, self-neglect case example of a client “living in a house of filth,” p. 8, exs: six dogs urinating and defecating all over the house, cats, mice, maggots, bed bugs, p. 8) (R8: 6 references: including going out unannounced helps assess because you do not give the person the chance to clean up, (p. 5); 2 references to home being “deplorable” (p. 8); cluttered home as indicator of self-neglect (p. 7); finding a deplorable, cluttered home exactly as described in self-neglect referral (p. 5); example of self-neglect: house being a mess, needing major cleaning, p. 7) (R11: 3
references: house being dirty or cluttered, p. 4; there’s a real big difference between clutter and dirt, p. 4; clutter is unsubstantiated in self-neglect, p. 4) (R13: 1 reference to case example of filthy home [as one factor considered in case ex: of substantiating self-neglect allegations], p. 2) (R14: 3 references: looking at home situation to see if it’s clean, not clean, p. 1; substantiated case example of living in squalor and poor conditions, p. 3; [responding to statement about competent people choosing to live in deplorable conditions] “And then I have people that are incompetent that also live in filth. So, hygiene and cleanliness is not always a huge factor.” p. 4) (R15: 3 references, including 2 references to having the right to live in clutter: “If they’ve got food, they’ve got shelter, they’ve got clothing...I’m pretty much gonna overlook the clutter. Because that’s their right, and it might be the way they lived their whole entire life.” p. 7; “N they have the right to choose [clutter].” p. 7); and 1 reference to asking “Who does your cleaning?” p. 1) (R16: 5 references: looking at the way the house looks, p. 1; finding messy homes, p. 1; substantiating for messy homes, p. 1; not substantiating when house is relatively neat and clean, p. 1; not substantiating when “There’s not a lot of clutter and mess and that type of stuff.” p. 1)

Assessing home environment/condition of home/home maintenance decisions (35 references by 10 APS workers) (R2: 6 references: “Taking in the environment” (p. 1); “How well maintained is the home?” p. 1; “…you have to determine a lot of times if the home is just old and worn down versus a total neglect, it’s just not taken care of.” p. 1; “Do they live in a very old, not well-maintained home just because they don’t have the money to maintain it, versus a house that’s trashed, literally with trash and, and other things.” p. 1; “…you go in and you see, you know, where their house is very well maintained, you know, there’s no clutter, there’s, the carpet’s not all filthy, you know…” p. 2; ex: “…you can see a house that looks pretty well maintained, but like the carpet’s really dirty, it’s not been swept or cleaned or anything. And that might lead to, you know, this person can’t physically sweep the floor, but they can go about picking up their clutter that are, you know, waist level, that kind of thing.” pp. 2-3; “But they have osteoporosis or something, they can’t scrub their toilet, they can’t sweep their floors, they can’t do some things that, it seems simple, but if you go for three years without being able to do it, imagine the condition of your home.” p. 10) (R3: 2 references to assessing ability to make needed home repairs: case example of having difficulty completing home repairs, p. 3; case ex: relying on son to complete needed home repairs, p. 3) (R4: 3 references: 2 to case example of home conditions which were not good but where self-neglect allegations could not be substantiated: “Dirty home, roaches, dirt floor. Only oven is a old wood oven. Cast iron stuff. Still pumped your water. But had a toilet. So therefore, no health department referral could be made.” (p. 3); (same case) taking care of sewage appropriately, “that’s the way they always lived.” single man, never been married, appeared healthy, Heated with a big cast iron stove. Just a one-room old shack, basically. No fire hazards, no trash all over, self-neglect allegations not substantiated, against community wishes (p. 3); 1 reference to senior being unaware of home conditions is seen by worker as
a sign of dementia, p. 5) (R5: 2 references: assessing home condition inside and outside, p. 7; worker subtly checking out the kitchen, sinks, TV to assess if utilities are on, p. 3) (R6: 3 references: assessing the grounds and building while walking to the door, p. 1; assessing home, p. 1; outside of condo looks beautiful, inside things are different, p. 4) (R8: 1 reference to looking at the environment first, then determining competency level of the individual, p. 1) (R10: 7 references to assessing living conditions: including as stated, p. 1; looking at the environment, p. 2; looking at the condition of home, p. 2; ex: can’t get to bathroom on second floor, p. 2; really bad living conditions, p. 3; having no plumbing, p. 3) (R11: 8 references, including 5 references to assessing the outside of the home: seeing things before you even get into the house, p. 2, having a cluttered yard, p. 2, having trash on the porch, p. 2; the outside of the house tells a lot, p. 3; assessing the home, p. 1; assessing [home] conditions, p. 1; assessing the condition of the house, p. 3) (R12: 1 reference to assessing environment, p. 2) (R13: 3 references: assessing the environment, p. 1; looking at the physical environment, p. 1; neglecting self but not property, p. 10)

Assessing health and safety concerns/ fire risks (28 references by 9 APS workers) [see also “assessing smoking decisions” under health and hygiene category] (R1: 3 references: seeing evidence of unsafe smoking, p. 6; case ex: of having burn holes in clothing, p. 7; having cigarette burns [as a sign of self-neglect], p. 25) (R3: 5 references, including 4 re: fire risks: smoking with oxygen, p. 2; setting fires from smoking with oxygen, p. 2; getting evicted for endangering other apartment residents by smoking with oxygen, p. 6; leaving the stove on requiring a mental health evaluation, p. 14; 1 re: assessing clutter as cause of ambulation problems, p. 1) (R4: 1 smoking reference: “just because they’re smoking on oxygen doesn’t make it an APS case” p. 11) (R5: 5 references, including 3 to worker looking for safety concerns and “signs of risk” in the home p. 2, examples: smoke detectors, clear pathways, cigarette burns, p. 2, observing cigarette burns where falling asleep, p. 3; and 2 re: worker being concerned about piled newspapers as “kindling,” p. 5) (R7: 5 references, including 2 to looking at the environment and assessing home safety, p. 1; 2 to assessing client’s understanding of home environment safety, exs: “If it’s not a safe environment, do they understand that they’re living not in a safe environment?” p. 1; choosing to live in an environment with problems doesn’t mean you’re unsafe, p. 3) (R8: clutter being a fire hazard, p. 7) (R11: 6 references, including 5 to assessing health issues, not “clean or dirty”: as stated, p. 3; lots of people live in a dirty house. “Our job is to draw the line between it being just dirty and unhealthy” p. 3; examples of unhealthy: old food laying around, p. 3; bugs, roaches, p. 3; animal feces, human feces, p. 3); and 1 reference to having a pattern of burning things on the stove, p. 5) (R12: 1 reference to being unaware of kitchen fires: “I walked in the house one day and the entire kitchen was full of smoke and they weren’t even aware of it.” p. 9) (R13: 1 reference to case example of home condition being so bad client couldn’t follow through on wound care, p. 6)
Assessing infestation of bugs and vermin (15 references by 7 APS workers) (R3: 3 references: case example of rats and raccoons coming in home, p. 3; case ex: of having roaches and agreeing to a “deep clean,” p. 5; “Have they always maybe had roaches, ‘n roaches are not a problem for them?” p. 13) (R5: 1 reference: some families have always had infestations and poor home conditions, “this is how this family works” p. 7) (R6: 3 references: looking for bugs, p. 3; seeing bugs, p. 3; seeing rats eating pet food, p. 3) (R7: 1 reference: case example of having mice, maggots, and bedbugs, p. 8) (R11: 1 reference: assessing bugs, roaches, [as a health concern] p. 3) (R12: 1 reference to being competent and not wanting to do anything about roaches, p. 4) (R13: 4 references: looking at if there’s infestation in the home: roaches, vermin, bedbugs, p. 1; seeing if they’re aware of infestation, p. 1; determining if they’ve tried making any strides for themselves to link to agencies or something [re: infestation], p. 1; substantiated case example of person with untreated vision problems being unaware of roaches on rim of cup she was drinking coffee from, p. 2) (R14: 1 reference: client not wanting to move from home of 40 years that’s full of rats and feces, p. 3)

Assessing hoarding/collecting (29 references by 7 APS workers) (R1: 1 reference: case example of a person collecting Styrofoam shipping peanuts, p. 11) (R2: 3 references: “People, some people who hoard? They hoard and they don’t want anybody near their stuff. It’s their stuff, stay away from it.” p. 12; “Some people hoard and aren’t aware of it and don’t care if somebody comes in. Some people hoard, are aware of the conditions, the smell, that kind of thing, and they don’t want somebody coming in and reporting them or getting them in trouble, or telling them to change their lifestyle.” p. 12; “And that kind of goes across the board for a lot of hoarders. They don’t want somebody comin’ in tellin’ them to do this and that and that and this.” p. 12) (R3: 7 references: “...if they’re a hoarder, you know, they don’t wanna get rid of their stuff, they know exactly where everything’s at, or they’re attached to it because, you know, ‘Well that was from my mom, and that was last...’ whatever.” p. 10; “Whatever thing they have, ‘That was the last thing that that person gave me’ or ‘another person gave me’ or ‘I got that at that vacation. Can’t get rid of that.” p. 10; “Some things are...just like...people can’t get rid of it. ‘Cause they have a date on it, or...somethin’ like that.” p. 10; [you see] “A lot of newspapers, and a lot of the junk mail trash.” p. 11; case ex: retired female professor, “…and the path in her home was like two feet wide around. She was sleeping on a coffee table. Her...queen size bed was full of paper, full of junk.” p. 11; case ex: of explaining hoarding newspapers “One person told me ‘Well, I need to read that one article back there...’” p. 11; hoarding newspapers, p. 12) (R5: 1 reference to hoarding) (R9: 4 references, including having “trails” in the house [walkways through clutter/hoarding], p. 1; “Pretty much the hoarders don’t wanna let you in.” p. 1;“If they’re hoarders or something, you will get it right away.” p. 2; hoarders having mental health problems, p. 6) (R10: 1 reference to extreme hoarding/cluttering to the point of having no living space as an example of bad living conditions, p. 3) (R13: 12 references to assessing hoarding: hoarders being hardest to deal with because they have an attachment to their possessions, p. 8; [hoarders]
bringing items back into the house from the dumpster, p. 8; case ex: cleaning company took 2 big dumpsters full of stuff from clients basement, p. 8; same case: getting another call the next year and the house was just as cluttered, p. 9; hoarders feeling like there's meaning with those possessions, p. 9; “It’s more than a possession to ‘em a lot of times. It’s like that’s their existence, you know. It’s proving that this who they are because they’ve collected these things.” p. 9; [possessions] have worth to them, so it’s really hard for them to get rid of them, p. 9; married couples having had a great loss [ex: children] going to thrift stores together then it explodes from there, p. 9; thrifting [collecting] as shared activity, p. 9; “If you take that away from me, what else do I have left?” p. 9; case ex: of hoarding new clothes with tags still on them in garment bags covered with dust, p. 9; same case: client explaining “I will go to a dance, or I will go to a ball...” p. 9; “It’s almost like it [hoarding] gives them something to thrive on.” p. 9

Assessing pet care decisions (31 references by 6 APS workers) [overlap with health and hygiene decisions sub-category] (R1: 6 references: “…it might be that they’re not taking care of their animals, or that there might be some odors which sometimes I can smell right from the porch.” p. 1; being unable to control their dogs, p. 2; taking care of pet but not self, p. 2; not taking care of pets, p. 2; pet’s “doing business” in home, p. 3; self-neglecters having more pets than others, p. 3) (R2: 6 references: going into the home and smelling the animals, p. 3; hoarding animals, p. 3; “So often you go into a home and the animals can’t get out, because the person can’t physically let them out, or because the person is an animal hoarder, so to speak.” p. 3; And they, you know, they think they’re treating their animal protectively, that kind of thing, but in the long run the animal, who might be very well loved, is not well taken care of because of inability physically to do so, or there’s some dementia or other things going on and they’re not even aware that they’re not taking really good care of the animals.” p. 3; case ex: having 30-40 cats but providing well for them, p. 6; same case ex: having 17-20 litter boxes, very well maintained, p. 6; same case ex: of caring well for cats: “She actually provided in her will for her cats. She did have people coming in taking care of her animals, and the animals were actually sent to a retirement home for animals, for cats, prior to her death.” p. 7) (R3: 9 references: case ex: falling and not being able to reach the phone and laying there for 18 hours due to her two huge dogs jumping on her, p. 10; having difficulty caring for pets, p. 11; difficulty changing cat litter, p. 11; bringing feral cats into home, p. 11; having difficulty controlling dogs. p. 11; “I’ve seen a lot of people have animals that maybe shouldn’t, but then, some people have animals and say ‘Oh, it’s a great companion. Gets me out for a little walk.” p. 11; “I see...many of the times, more so, that the dog or the cats are, you know, a problem for that person. Just elevating the self-neglect.” p. 11; not keeping food for the animal, p. 11; pet food drawing rats, p. 11) (R4: 1 reference to keeping dead animals: “dead animals, rotting floor, the only piece of furniture was a lawn chair, bed, n’ God knows how long they’ve changed their clothes...um, no food.” p. 3) (R6: 4 references: Looking for pets, p. 2; pet care is a tip-off to how things are going, p. 2; assessing pet
Assessing decisions about utilizing homemaker services (9 references by 6 APS workers) (R3: 2 references: people whose home is fairly clean accepting Homemaker services, p. 12; “If a person has a very dirty home? I think there’s more resistance. Just because, maybe they’re embarrassed...” p. 13) (R5: 2 references to refusing home intervention, case ex: canceling scheduled cleanings: “And he would let me do little things, like bag up some of the trash in the kitchen myself, if it was me. But he would not let me bring people in. We scheduled it two or three separate times, to have the deep cleaning come out and he would cancel it. Even if I came. Like I would come too, and he would say ‘No, I don’t wanna do this.’ ”p. 10) (R6: 2 references: homemaker services is “more of a sale” due to trust issues, p. 9; complaining that homemakers “don’t clean right,” p. 9) (R8: 1 reference to declining cleaning services, p. 8) (R13: 1 reference: Clients being more willing to accept homemakers, exterminators, and visiting physicians [than money management assistance], p. 5) (R16: 1 reference: “Housekeeping is more easily accepted.” p. 3)

Assessing decisions about eviction/property managers/neighbors/risk of harm to others (15 references by 5 APS workers) (R4: 4 references, including 3 to unintentional risk of harm [to other tenants]: unintentional risk to others is “not gonna work in court” (p. 12), unintentional risk to other tenants is an apartment landlord issue (p. 12), explaining “Hey listen, you know this is bad, you know your neighbors are gonna complain, your neighbors are afraid you’re gonna put this up [smoking w/ oxygen], you understand the landlord’ll have every right to kick you out...” (p. 13); and 1 reference to apt. managers calling in referrals, p. 11) (R7: 1 reference: seniors can choose to live how they want, including getting evicted, p. 11) (R9: 7 references, including 2 references to getting evicted upon refusal of mental health services, as stated, p. 7, getting evicted for threatening neighbors, p. 7; police being called to apartment for threatening neighbors and property destruction, p. 7; writing “raunchy” letter to apartment management, p. 7, being evicted again after firing mental health provider [elder treatment focus], p. 7; Not paying rent, p. 5; property damage (tearing up laundry room), p. 7) (R11: 2 references: assessing risks to other people, p. 3; ex: smoking with oxygen in an apartment building, p. 3) (R15: 1 reference: “Are they paying their bills, are they gonna lose their shelter.” p. 7)

Observing many self-neglect referrals living alone (6 references by 5 APS workers) [overlap with “decisions about relationships”] (R1: 1 reference, p. 1) (R4: 1 reference, case ex: p. 3) (R5: 2 references to living alone, p. 1,8) (R6: 1 reference: “Most of our people are living alone” p. 1) (R12: 1 reference: “With self-neglect, a lot of times there’s not another person in the home...” p. 1)
People refusing to leave their home/wanting to remain in their home (9 references by 3 APS workers) (R1: 2 references to refusing to leave home: case example p. 7; another case ex: p. 8) (R8: 1 reference to refusing to leave the home: case ex: of an older adult choosing to return home to her apartment from a facility although unable to care for self, p. 9) (R14: 6 references to wanting to remain in the home, including 4 references to a case example of competent client not wanting to move from home but can’t stay in home due to horrendous conditions: client not wanting to move from home of 40 years that’s full of rats and feces, p. 3; same case: home is horrible, horrendous, disgusting, p. 3; same case: worker being shocked at home conditions, p. 3; same case: competent client not wanting to move from home but can’t stay in home due to horrendous conditions, p. 3; people wanting to remain in their home, p. 5; “That’s their lives.” p. 5)

Assessing the kitchen/bathroom (7 references by 3 APS workers) (R2: 2 references: “…I always, if possible, on the initial visit...get a glimpse of the kitchen.” p. 3; “The counters are wiped down, there’s not dirty dishes, could be one, a good sign, that they’re pretty well maintaining the care of themselves and their kitchen, but it also could mean you know, they’re not eating so they’re not makin’ a mess.” p. 3) (R6: 4 references, including food out on counters, p. 4; kitchen cupboards open, p. 4; having outdated (expired) food, p. 4; having no food in fridge, p. 4) (R11: 1 references to assessing bathroom and kitchen, p. 3)

Assessing decisions about letting strangers enter the home (4 references by 3 APS workers) (R3: 1 reference to not wanting worker to enter home, p. 1) (R5: 2 references to letting strangers into the home: letting strangers in who then stole checkbook, p. 14; letting strangers into security building, p. 15) (R10: 1 reference to not wanting strangers in the house, p. 4)

Observing many self-neglect referrals living in own house (3 references by 3 APS workers) (R3: 1 reference, p. 2) (R4: 1 reference: case example of one-room shack, p. 3) (R5: 1 reference re: Self-neglecters often living in an apt. or free-standing home, p. 1)

Assessing understanding of home conditions (5 references by 2 APS workers) (R8: 2 references: demonstrating understanding of needing major cleaning (p. 8); making sure clients completely understand the repercussions of their situation, ex: “Do they have a very good understanding of what may happen if you don’t get the house cleaned.” p. 13) (R11: 3 references, including 2 to assessing clients’ responses to allegations of clutter in the home: some clients denying problems in the home, ex: saying “I’m fine” when confronted about health risk of having no passageways in home due to clutter, p. 1; some clients acknowledging clutter, saying “Well, yeah, it does look a little cluttered. You know, maybe I should do something about that.” p. 2; deciding competency regarding home conditions: “Do they understand that this is unhealthy?” p. 3)
Observing people wanting to remain in same part of town/neighborhood (4 references by 2 APS workers) (R1: 2 references: case example: “I was raised here, born here, raised here, gonna die here...” p. 11; case ex: of wanting to stay in same area, p. 18) (R5: 2 reference, older adults valuing and knowing their neighborhood, being comfortable and wanting to remain in their community, both p. 16)

Recognizing that [competent] seniors can choose to live how they want (3 references by 2 APS workers) (R7: 1 reference, ex: getting evicted p. 11) (R8: 2 references: 1 to adults can make their own decisions about staying in their environment or not, (p. 1), 1 reference to respecting competent senior’s right to choose to live in a deplorable situation, p. 14)

Assessing issues related to moving from house to an apartment (3 references by 2 APS workers) (R1: 2 references: case example of composting in an apartment [after living in a private home], p. 11; same ex: of moving from house to apt. “...she was like, 'This is how I always did it when I had a house, I’m not changin’ it.’” p. 11) (R14: 1 reference: some people don’t mind moving to an apartment and others are so steadfast in their home and their possessions, p. 5)

Assessing decision to live in a home where crack is used (R14: 12 references: [they demonstrate understanding] by talking about living in a crack house, p. 7; living in a crack house is very common, p. 7; there’s a lot of drug activity, p. 7; “Drugs doesn’t necessarily make a bad caregiver.” p. 7; “Like a lot of the caregivers are on drugs.” p. 7; “That’s a reality.” p. 7; getting a lot of referrals about that, p. 7; people making judgments that crack is worse than alcohol, p. 7; “I mean there’s nothing that makes a crack addict a bad caregiver.” p. 7; if a client knows it’s going on and have insight, worker would probably not do anything other than letting them know the dangers, p. 7; if they don’t understand, worker would step in and do more, p. 7; “They may wanna stay there, but that’s not gonna work.” [if they don’t understand they’re living in a crack house], p. 7)

Assessing ability to develop adaptive alternatives when environmental barriers arise (R10: 5 references, including 4 references to adaptive strategies for being unable to get to second floor bathroom: using Depends, crawling up steps, using a potty chair, males using a milk jug, going to business across the street, sponge bathing in kitchen (all p. 2); having plumbing problems with human waste backing up and senior not capable of thinking of alternatives, p. 3)

Observing people not using parts of the home (R1: 3 references: case example of not using part of the home “The part that was unorganized was the front of the house that he never used.” p. 9; same case ex: of watching TV in the kitchen, p. 9; “…a lot of times where they just sit in the kitchen, where they have a little TV. A lot of older adults have that kind of TV in the kitchen thing.” p. 9)
Assessing utilities [see also “assessing bill-paying decisions” under “finances” Section] (R14: 3 references: seeing if they have utilities, p. 1; sometimes they might not have any lights, water, gas, heat, p. 1; case example: “‘Cause currently he has no water. And I think that’s not gonna work.” p. 3)

Older adults not realizing how nice senior housing is now (R14: 2 references: older adults (80-90) having old view of senior housing as something not better than where they live, p. 3; older adults (80-90) not realizing how nice our senior housing is, p. 3)

Having same APS standards whether it’s a home or apartment (R4: 1 reference, p. 12)

Making sure basic needs are addressed ASAP (shelter, food, clothing, utilities) (R10: 1 reference, p. 1)

Not substantiating self-neglect allegations for home in poor repair, dirty, roaches, but pathways are clear (R12: 1 reference, p. 4)

Neighbors calling code enforcement (R13: 1 reference, p. 10)

**Sub-category:** assessing decisions about other people and relationships—(176 references)


Assessing family relationships (45 references by 14 APS workers) (R1: 7 references: case example of sister cleaning up mess for a client, p. 11; different case ex: of sister taking client to doctor, p. 18; worker seeing uncaring families, p. 23; children exploiting parents, p. 23; not having family, p. 23; “...when there is no family...you have no body...” p. 23; some families not being there for the client, p. 23) (R2: 10 references to not wanting to ask family for help: “My family is too busy doing other things, they’re working, they’re taking care of their own.” p. 5; wanting family to provide needed care [case ex: family removing elder from nursing home but not providing required 24/7 care] p. 8; asking client “What is your family doing for you?” p. 10; “Because you have elder adults who are still using their own money to help their children, or their grandchildren.” p. 10; asking “What are these folks doing to help you? you know, Who’s taking you to the grocery store? Who’s doin’ this?” p. 10; not wanting to “impose” on family, p. 11; not wanting to alter family roles “A threat of asking them to do something that they’ve never done, which is ask their children, or their grandchildren, to do something for them, where there’s been a lifetime doing for them.” p. 11; “Well, they have things of their own to do. They have their own lives. They’re working and raising children, and we don’t want to ask them.’ I’ve heard that a lot, ‘I don’t

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want to ask them.’” p. 11; “And we’ve been flat out told ‘Don’t contact my family. Don’t ask my family to do this.’” p. 11; family not realizing need for help, “…they see their parents in always as this strong, capable, always doing role. They don’t necessarily see the decline that an outsider would see.” p. 11; parents not wanting to look weak in front of their children, p. 11) (R3: 4 references to assessing relationships with children: relying on children to complete needed home repairs, p. 3; case ex: of drug-using children moving in on parents with cognitive impairments, p. 8; parents defending exploitive children, p. 8; case ex: of exploitive child trying to screen APS contact with parent, p. 9) (R5: 3 references: suspecting family support system reported by client is “mythical,” “He’ll insist that this mythical nephew is coming to help him…I’ve never even verified that this person exists. I’ve never heard of him actually coming around, nobody seems to know who he is…I don’t believe that’s ever going to happen, if this guy does exist, he’s not involved.” p. 10; family financial exploitation, p. 17; recognizing that homicidal statements made by family caregivers were not actual threats but expressions of caregiver fatigue, p. 21) (R6: 1 reference to clients being aware of financial exploitation by family and allowing it to continue, p. 12) (R7: 1 reference to asking about family and friends, p. 1) (R8: 1 reference to seeing if there is family willing to provide care, p. 11) (R9: 7 references, including 4 references to elders (without dementia) giving everything to adult children: as stated, p. 9, “It’s my right to give it.” p. 9, acknowledging “it’s your right to give everything to your children” p. 9, “You can’t stop it.” p. 9; asking about kids, p. 2; “Can you get a number? Can you call them? Will they respond to this?” p. 2; parent being aware kids are trying to get financial guardianship, p. 4) (R10: 3 references to assessing family relationships: getting calls from disgruntled family members, p. 7; outliving family, p. 9; absent family, p. 9) (R11: 1 reference: asking if they have helpful relatives, p. 2) (R12: 4 references to assessing relationships with children: children disagreeing on parents’ care, p. 4; a lot of calls are angry siblings, p. 4; ex: they think one child is benefiting more from parents’ money, p. 4; case example of family following client’s wishes rather than making choices to prevent self-neglect, p. 5) (R13: family being willing to help but not wanting to overstep boundaries with parents, ex: role reversal “…‘cause a lot of times the family is willing to do something but they’re just so afraid that mom and dad is gonna...[claps hands lightly] you know, like the role reversal, you know. They just can’t possibly step in and, and take over. They just feel like they’re oversteppin’ their boundaries...” p. 4) (R15: 1 reference to asking “Do you have any family?” p. 1) (R16: 1 reference to case example of senior deferring to mentally ill daughter living in the household and things not getting cleaned up, p. 1)

Assessing informal support system/relationships with friends (29 references by 7 APS workers) (R1: 2 references: case example of having a friendly relationship with the mailman, p. 9; case ex: of client wanting to use worker [who was at the time a Senior Friend when in college] as a homemaker more than a friend, p. 26) (R3: 7 references to assessing support system: Assessing support system, p. 1; “Do they have family nearby? Do neighbors come in and check on ‘em. A lot of times what I see
is a lot of seniors don’t have supports.” p. 1; not having family members, not having children, is a problem for them, p. 1; “their sisters and brothers are elder as well, their parents passed away, their friends are dying off, neighbors don’t wanna help because they say ‘Well, she’s kinda cranky, you know really she doesn’t’ get out a lot so we don’t know her...or him.’” p. 1; lacking support system, p. 1; assessing decisions about friends and neighbors: “You know, you just question, are neighbors really look’in out for ya or not, or are people just comin’ in off the street, you know prostitutes comin’ in, or the friends, who are these friends that are visiting on your porch?” p. 7; worker assessing support system: “So I had to do some research to kind of find out are these neighbors or people down the street ok? Are they look’in in the best interest of him?” p. 7)

(R9: 10 references to assessing informal helping systems and decisions about using informal and formal helping systems, including asking about informal helping systems, p. 2; keeping a person in the community who has informal helping systems [3 mentions], p. 3; having friends who help with chores and transportation (4 references) as stated, p. 3; helping with cleaning, shopping, and yard work, p. 3; friends helping with chores but not getting into finances, p. 3; looking at informal and formal helping systems and do they want them, p. 8; having no choice [but to override elder’s desires] when people are really bad off and won’t use helping systems, p. 8) (R10: 4 references to assessing supports: as stated, p. 2; assessing services involved and informal supports, p. 1; assessing collaterals p. 2; having few informal supports, p. 9) (R11: 4 references: asking about support system, p. 2; asking if they have helpful neighbors, p. 2; having help getting groceries, p. 5; asking “Who’s involved? Who’s helping? Who’s not helping? Who’s more of a hindrance?” p. 7) (R14: 1 reference: a lot of people living in the community can no longer live alone and don’t have a support, p. 5) (R15: 1 reference to asking “Who does your transportation for you?” p. 1)

Working with families and support systems (20 references by 5 APS workers) (R5: 3 references, including 2 references to worker involving families, churches, supports, for ex: calling client’s daughter, p. 5; and 1 reference to worker encouraging client to share APS visit information with family and other supports, p. 4) (R8: 1 reference to trying to work with family to get situation resolved, p. 2) (R11: trying to get family involved, p. 9; explaining to family “this is not ok for mom or Grandma to continue living this way” p. 9; seeking court orders of protection when client and family “not following through” with making needed changes, p. 9) (R12: 6 references, including 3 references to assessing family relationships re: guardianship: trying to get family involved before seeking guardianship, p. 10; case ex: family requesting guardian “to be the bad guy” p. 10; trying to get family, friends to serve as guardian, p. 10; 3 to case ex: of working with client’s daughter who had Power of Attorney: client appointing daughters as Power of Attorney, p. 5; daughter’s not accepting that mom was dying. Ex: wanting chemotherapy for her, p. 5; worker sympathizing but substantiating self-neglect and insisting daughter’s put mom on hospice to avoid neglect allegations, p. 5) (R13: 8 references to working with family: working with family, p. 4; having helpful family involvement
being optimal in care planning process, p. 4; APS providing nudge for person to say “Oh. Well we don’t really want the government involved. I’d rather have family.” p. 4; worker would like to see parents allowing their children to assist them, p. 4; ex: family taking to doctor’s appointments, p. 4; ex: family setting up home nursing services, p. 4; case ex: of family getting involved with hoarder, cleaning her house, getting POA, APS case being closed, APS getting another call the next year and house was just as cluttered, p. 8-9)

Assessing decisions about responding to visitors, allowing people/service providers into the home (18 references by 5 APS workers) (R1: 8 references, including 4 about responding to visitors/trusting people: worker being concerned when they will let her in so easily, p. 3; trusting people too much, p. 3; case ex: of refusing to let worker in the door, p. 8, ignoring worker knocking on front door “…if they’ll only let you in through the garage, so you go to knock on the front door, an so they, like, ignore you, and stuff…” p. 8; and 4 references to assessing decisions about allowing service providers in the home: people would probably accept visiting nurses if they were available, p. 13; resisting other service providers: “They’re not gonna have anybody givin’ ‘em a bath. They’re not gonna have anybody washin’ their clothes and goin’ through their stuff.” p. 14; having had a bad experience with service providers “When I talk to seniors about the other services, and why they don’t want them, it’s usually because they’ve had a bad experience, or someone close to them has had a bad experience; somethin’s been stolen, or they don’t do it right…” p. 14; case ex: of accepting a mental health case manager, p. 18) (R2: 5 references: “You have people who won’t allow somebody to come into their home.” pp. 8-9; “And sometimes people don’t want somebody comin’ into their home?” p. 12; “People, some people who hoard? They hoard and they don’t want anybody near their stuff. It’s their stuff, stay away from it.” p. 12; “Some people hoard and aren’t aware of it and don’t care if somebody comes in. Some people hoard, are aware of the conditions, the smell, that kind of thing, and they don’t want somebody coming in and reporting them or getting them in trouble, or telling them to change their lifestyle.” p. 12; “And that kind of goes across the board for a lot of hoarders. They don’t want somebody comin’ in tellin’ them to do this and that and that and this.” p. 12) (R5: 2 references re: letting strangers into the home/secured apartment who steal, p. 14) (R9: 2 references: “I’m not surprised by how many people don’t let me in? I’m surprised at how many people do. Because they have the rights, it’s not like children they don’t have to let you in. But I’m really surprised, just from…showing that badge- I wouldn’t let me in so…[laughs]” p. 1; “I don’t get my feelings hurt if somebody’ll say, you know, ‘Just give me some information, I’ll make a call.’ You know, I know right then, you know, that if they say, you know, leave a letter of intent, lettin’ somebody call and check. I, uh, that’s a sign that they’re, they’re somewhat with it. And right there, ‘cause they’re askin’, you know, to prove who you are. And they call you back, and, you know.” p. 1) (R10: 1 reference to not wanting strangers in the house, p. 4)

Receiving false reports from children/neighbors (7 references by 4 APS workers) (R5: 2 references: children using APS “as a weapon,” and making false reports both p. 12) (R7: 1 reference to family members causing trouble, p. 4) (R9: 3 references to family making false referrals: as stated, p. 4; kids who want parent’s money calling in false referrals, p. 4; case ex: parent alert and well-oriented, did not sell house as alleged, p. 4) (R12: 1 reference: getting bogus calls from family or neighbors, example: retaliation by neighbor’s feuding over bushes on property line, p. 5)

Assessing decision to live with and/or financially support younger drug abusers (9 references by 3 APS workers) (R9: 1 reference to older men choosing to be with younger female drug abusers, p. 8) (R13: 3 references: case example of older man allowing younger woman to move in as “caretaker,” p. 3; same case ex: of him selling his pain meds and giving money to caretaker, p. 3; same case ex: understanding consequences of selling meds for caretaker but not seeing that he was self-neglecting by not taking meds as prescribed, p. 3) (R14: 5 references to assessing decision to live with drug abusers: [they demonstrate understanding] by talking about living in a crack house, p. 7; living in a crack house is very common, p. 7, if a client knows it’s going on and have insight, worker would probably not do anything other than letting them know the dangers, p. 7; if they don’t understand, worker would step in and do more, p. 7; “They may wanna stay there, but that’s not gonna work.” [if they don’t understand they’re living in a crack house], p. 7)

Observing people seeking companionship/interaction with worker (6 references by 3 APS workers) (R1: 4 references: “I’ve had a woman yesterday tell me, self-neglect, um, ‘Don’t forget me! Don’t forget me!’ ” p. 17; “And to me that was the, the acknowledgement of satisfaction, you know, that she wanted me to come back.” p. 17; “...and that companionship is something that older adults really look for. Because sometimes when people are neglecting themselves, they don’t have any stimulus, you know what I mean?” p. 26; “...they don’t have any social interactions, and they want to talk to people.” p. 26) (R12: 1 reference: a lot of people being lonely and wanting visits, p. 11) (R15: 1 reference: “They’ll say ‘You can come back any time.’ ” p. 6)

Assessing socialization/community involvement (6 references by 3 APS workers) (R5: 1 reference: “...we ask, ‘Does anybody visit you regularly?’ ” p. 4) (R6: 4 references: “you’re here by yourself all day...Are you going to church? Is your son, daughter, neighbor coming over? I try to get them to tell us.” p. 2; “I look around for boots in the winter time, just to see if they’ve been
out. Anything that’ll tip you off that they’ve gone somewhere.” p. 3; “There’s this other group that may have neighbors that stop by, or a family member that stops, by, but not every day.” p. 10; “the only thing they’re hearin’ is that TV goin’. You know, or they have nobody to talk to so...” p. 10) (R10: 1 reference to assessing client’s community involvement, p. 2)

Neighbors calling in referrals (3 references by 3 APS workers) (R3: 1 reference, p. 2) (R7: 1 reference to not substantiating allegations made because neighbors don’t get along, p. 4) (R13: 1 reference {counted under “assessing housing”} to neighbors calling code enforcement p. 10)

Assessing risk to others (8 references by 2 APS workers) (R3: 6 references: assessing if anyone else is going to be harmed by their actions [ex: smoking with oxygen], p. 2; being unaware that their behavior is affecting neighbors, p. 5; primacy of not inflicting harm on others, p. 6; endangering other apartment residents, ex: smoking with oxygen on in an apartment building, p. 6; case ex: of driving with severe cognitive deficits, p. 7; [overriding elders desires] when they are in danger or they’re putting somebody else in danger, p. 14) (R4: 2 reference to unintentional risk of harm to others: unintentional risk of harm is “not gonna work” in court, (p. 12); [unintentional risk of harm] “That’s an apartment... landlord issue.” p. 12)

Assessing loneliness (R15: 6 references: “They’re lonely.” p. 6; “They don’t have somebody checking on them on a regular basis.” p. 6; “So I think that is the- [biggest service need] being lonely.” p. 6; “A lot of times they don’t wanna eat alone. So they choose not to eat at all. But if somebody was there at the time they were eating, and sat down and ate with them, {softly} they wouldn’t have a problem with it.” p. 6; “That’s a biggie.” [loneliness], p. 6; “And they wanna just have somebody to talk to.” p. 6)

Having enduring marriages (R1: 3 references: case example of being married 75 years, p. 10; “It was great visiting them, they had all these stories and histories, you know.” p. 10; recognizing grief from loss of spouse can be debilitating, p. 10)

Assessing decisions about neighbors and property managers (R9: 2 references:
getting evicted for threatening neighbors, p. 7; writing “raunchy” letter to apartment management, p. 7)

Assessing dependence on others (R13: 2 references: case example of using homemaker to help with meds, p. 3; same case ex: of being totally dependent on homemaker [exploitation case] p. 3)

Appreciating that somebody cares (e.g. person who reported) (R2: 1 reference: “...when they’re like ‘Who turned me in?’ ‘Who turned you in? Somebody cared about you. For whatever reason, right or wrong, maybe they saw
something and misinterpreted it, but right or wrong, somebody cared about you. And a lot of older adults really appreciate that.” (p. 21)

Having the most problems’ with people that have been “reclusives” for years (R4: 1 reference)

Having no children (R5: 1 reference)

Having no caretakers (R5: 1 reference)

Not substantiating allegations made by children overreacting to parent’s conditions [but offering linkage to services in such cases] (R7: 1 reference, p. 4)

Living with others and being self-neglecting (R12: 1 reference: “So they could still be self-neglecting, but living with somebody.” p. 1)

Sub-category: assessing decisions about finances—(122 references)
(R1: 10 references) (R2: 20 references) (R3: 1 reference) (R4: 2 references) (R5: 1 reference) (R6: 10 references) (R7: 2 references) (R8: 1 reference) (R9: 21 references) (R10: 14 references) (R11: 7 references) (R12: 6 references) (R13: 12 references) (R14: 8 references) (R15: 3 references) (R16: 4 references)

Assessing bill-paying decisions (30 references by 9 APS workers) (R1: 1 reference: case ex: of a man paying his bills at the kitchen table, p. 9) (R2: 3 references: assessing if they’re getting their bills paid, p. 2; assessing if they have shut-off notices, food, medication, p. 2; “Or, and sometimes you go into the situation, and they are fine. And the environment is fine. They have food. Their bills are paid.” p. 15) (R6: 4 references, including 3 to assessing utility bill paying: assessing utility bill paying, p. 2; asking “Are you having trouble paying your utilities? You know, an’ that’s generally a tip-off that they might be in trouble.” p. 2, having bill-paying problems, for example paying utilities but not rent, p. 4, and 1 reference to looking at papers lying around for bills/checkbook, p. 5) (R7: 1 reference to asking about finances and bills, p. 1) (R9: 10 references, including 6 references to not paying bills/overpaying bills, including paying the same bill three times, p. 2; not paying bills, p. 2; not paying electric bill, p. 3; having money but not paying the electric bill, p. 3; not paying rent, p. 5; phone service being stopped for not paying phone bill, p. 5; and 4 references to writing bad checks, including not remembering bouncing checks, p. 1; continuing to write checks without keeping a balance, p. 2; getting notices from the bank, p. 2; writing bad checks, p. 3) (R10: 8 references to assessing if they’re paying bills and knowledge of bill-paying procedures: as stated, p. 2; utility shut-offs, p. 3; being behind on utilities, p. 3: assessing if finances are in disarray, for ex: having no clue about their checkbook, p. 3; asking “How do you pay your bills?” (2 references) p. 4, p.5; people that aren’t capable can’t demonstrate to you, people that are capable can describe bill paying process, produce checkbook ledger, p. 4; asking very personal, detailed questions about finances, ex: “How do
people help you pay your bills?” p. 5) (R11: 1 reference to having a pattern of not paying bills (ex: for three months), p. 5) (R13: 1 reference to not paying bills: substantiated case example of client thinking she was paying bills but wasn’t, p. 2) (R15: 1 reference: “Are they paying their bills, are they gonna lose their shelter.” p. 7)

Observing people not wanting to pay for needed services/accepting free services (17 references by 8 APS workers) (R1: 2 references to accepting free services: “But they would probably be more inclined to accept it if they could get it for free.” p. 16; “Which all of us would be more inclined to accept things if we could get it for free.” p. 16) (R2: 4 references to not wanting to pay for needed services/ wanting to preserve assets for children: “A lot of people like the idea of Passport Medicaid, until they realize ‘Oh. That’s the program where if I belong, they’re gonna take my house away. And I’ve worked all my life to pay for my house and I want to leave something to my children.’” p. 10; “Resistance is mostly to something that threatens that one thing, whatever it is that they hold very dear and important. And that is, what they’re gonna leave to their family.” p. 10; “Sometimes they don’t want it [Meals-on-Wheels] because they think it’s gonna cost too much money.” p. 11; refusing Meals-on-Wheels for reasons like “I don’t wanna pay the money.” p. 11) (R3: 1 reference to not wanting to pay for services, p. 10) (R6: 2 references, 1 to seniors not wanting to pay for services: “They don’t want to pay.” p. 15; 1 reference that most seniors will accept free services, p. 16) (R7: 1 reference to court ordering wealthy people to pay for services, p. 2) (R11: 5 references: a lot of clients accept services but then decline when they find out there’s a ten dollar co-pay, p. 6; that generation would rather not spend money on themselves, p. 6; free services are usually accepted, p. 6; when you take away the money aspect, most people will accept Meals-n-Wheels, housekeeping, transportation, and the ERS button, p. 6; “The money is the biggest issue.” p. 7) (R12: 1 references: a lot of people will accept all free services available, p. 12) (R14: 1 reference to not wanting to pay for services: “They tend to like Meals-on-Wheels, but they may not wanna pay for it.” p. 6)

Assessing decisions about giving money to others/financial exploitation by others (16 references by 8 APS workers) (R2: 1 reference: “Because you have elder adults who are still using their own money to help their children, or their grandchildren.” p. 10) (R5: 1 indirect reference to family financial exploitation) (R6: 1 reference to giving money to family “and they’re not paying their own rent and they know that this is, um…wrong” p. 12) (R9: 4 references to elders without dementia giving everything to adult children: as stated, p. 9; “It’s my right to give it.” p. 9; acknowledging “it’s your right to give everything to your children” p. 9; “You can’t stop it.” p. 9) (R10: 5 references to assessing financial exploitation: financial exploitation, p. 7; “a lot of our [APS] stuff is centered around money,” p. 7; siblings being concerned about parents financially favoring other sibling, often the youngest, p. 7; most parents know it—they’re not being exploited, they’re giving the money, p. 7; parents denying financial exploitation “Hey I can give that money if I
want, I don’t care what anyone else thinks.” p. 7) (R11: 1 reference: case example: “Maybe there’s a grandson that’s coming in and takin’ advantage, or, you know, she’s neglecting herself to buy food for her grandson…” p. 7) (R12: 1 reference: children thinking one sibling is benefiting more from parents’ money, p. 4) (R13: 2 references to assessing decision to financially support others: case example of selling his pain meds and giving the money to his caretaker, p. 3; same case ex: of a person understanding the consequences of selling his pain meds to give money to his caretaker, p. 3)

Assessing understanding of finances and money management (14 references by 7 APS workers) (R1: 2 references: case ex: of 85-year-old man living beyond means, p. 21; same case ex: “...he doesn’t have enough money, or the ability to manage his money to meet his basic needs.” p. 22) (R2: 1 reference: “If they’re not maintaining their finances it might lead into the not getting their food, not getting their medicine...” p. 2) (R6: 1 reference: “The seniors seem to know whether they have money or not. They really do. And, you know, they’ve grown up [in the post-depression era] ’n’ they know, like, they know exactly what they need.” p. 15-16) (R9: 3 references re: in self-neglect situations, usually somebody may not be able to take care of finances: as stated. p. 1; “I think mostly it’s the financial stuff” p. 2; “If it’s self-neglect...a lot of it pertains to...a lot of them, it’s the financial stuff.” p. 2) (R10: 1 reference to assessing money understanding, p. 5) (R12: 4 references to being unaware of finances: example: utilities turned off, p. 9; being unaware that home is in foreclosure, p. 9; “I’ve had clients before that have gotten so demented that their home has gone into foreclosure...and all their utilities have been turned off. And they’ll tell you, ‘Oh, I’m payin’ the bills,’” p. 9; being unaware their home’s been sold at sheriff’s auction, p. 9) (R13: 2 references to leaving signed, blank checks around the house: substantiated case example of leaving signed, blank checks around the house, p. 2; being unaware of leaving signed blank checks around, p. 2)

Assessing poverty/insurance coverage loopholes (12 references by 4 APS workers) [see secondary category of “actions needed” for more on insurance, eligibility, and funding barriers] (R2: 8 references to assessing poverty/insurance coverage loopholes [vs. simply not wanting to pay for services]: “Do they live in a very old, not well-maintained home just because they don’t have the money to maintain it...” p. 1; case ex: of privately paying for home health services, p. 7; being ineligible for Medicaid [and being unable to or not wanting to pay for services], p. 8; “You have people who, for whatever reason aren’t on Medicare.” p. 9; “There’s the financial loopholes, there’s the loopholes of the customer themselves who don’t want the services, don’t need the services.” p. 9; case ex: of experiencing insurance coverage loophole: “We had a gentleman, wanted to go to a nursing home. Physically, mentally, doctor, customer, everybody was agreeable this person needed it. His coverage, when it went from Medicaid to HMO to whatever it was, ‘no this won’t pay, no this won’t pay, no this...’ everybody is ready for this man to go, he needed this. He needed 24-hour care and supervision, and he was in a
loophole. And a huge loophole that, it's *terrible*. And I think it took probably a month and a *half* to get this gentleman into a facility.” p. 9; a lot of times the Emergency Response System bracelet costs money that they don't have, p. 12; homemakers aren’t used due to cost, p. 12) (R4: 2 references: experiencing poverty “Sometimes they simply, truly, cannot afford to replace their toilet and now they’re pooping’ in buckets in their tub!” p. 6; experiencing insurance barriers, p. 5) (R9: 1 reference to finding poverty: “Or you have people who are poor.” p. 1) (R13: 1 reference to clients’ being willing to accept home-based services but slightly over income and unable to pay for them, p. 4)

Observing people resisting financial services [money management assistance]/not wanting to disclose income (12 references by 3 APS workers) (R6: 2 references: being secretive about finances, p. 5, often resisting financial services, p. 9) (R13: 6 references to resisting money management services: resisting financial [money management] assistance, p. 4; example: resisting third party they’re unaware of coming in to assist with finances, p. 4; being reluctant to hand over account information to someone they haven’t known, p. 5; financial assistance being most resisted service, p. 5; [resisting] accepting an attorney or third party to com in [and assist with finances], p. 5; being more reluctant about an attorney or third party handling their finances, p. 5) (R14: 4 references, including 2 references to resisting financial management services: elders resisting people being in their finances, p. 5; that’s number one: “What do they don’t like the most. Well, people being in their finances. I think that would be number one.” pp. 5-6; and 2 references to not wanting to divulge income: “And in order to get services, you have to give up your income amount, and sometimes *that* is something they will *never* part with.” p. 6; leaving people [without services] that would benefit from services and are probably eligible but won’t share [income verification], p. 6)

Observing people resisting participating in social welfare programs/declining “welfare” (9 references by 3 APS workers) (R1: 3 references: ‘Cause I’m a social worker, I think they hear the word first ‘social’; ‘I don’t need welfare.’ ” p. 15; resisting Medicaid “God forbid you introduce *Medicaid*, you know, and that truly is a state-funded program. That is, that *is* a welfare program. And then they *really* fight ya, they really fight ya.” p. 16; “...there’s a lot that goes into getting an application put in and stuff, and they’re like ‘I don’t wanna do it.’ ” p. 16) (R2: 3 references to declining “welfare”: not wanting “welfare,” p. 4; perceiving services as welfare, p. 5; “They don’t need it. ‘Somebody else needs it more than I do’ I’ve heard that many, many, many times.” p. 5) (R14: 3 references: thinking Meals-on-Wheels is for other people, p. 1; ex: even if their income is only 500 dollars a month, p. 1; “they always think it’s [Meals-on-Wheels] for someone else.” p. 1; [thinking Meals-on-Wheels is for other people] even though their income may be *way* below the poverty level, p. 1)

Assessing decisions about paying for medications (R16: 4 references: “Do they
have the money to pay for their prescriptions, ‘cause that’s often a big issue with seniors.” p. 1; having mixed feelings about substantiating when people “…probably would be very compliant with medications if they could afford them.” p. 2; not being able to afford co-pays, p. 2; “ ‘Cause to me that’s [medication non-compliance] self neglect, but it’s based on they really don’t have the resources, so...” p. 2)

Observing people not using air conditioning (R1: 2 references: case example of not using A.C. and becoming dehydrated, p. 18; same case, repeat referral next year, “Same problem. Didn’t turn on the air, he’s dehydrated.” p. 18)

Assessing transportation (R15: 2 references: Asking “How do you get back and forth transportation?” p. 1; “And transportation’s a big issue. ‘I can’t get to the doctor. I can’t...'” p. 5)

APS workers asking more personal questions than Senior Options because it’s an investigation [ex: financial questions], p. 12) (R8: 1 reference)

Observing people giving money to many charities (R9: 1 reference, p. 3)

People having financial difficulties don’t know it and usually let you in (R9: 1 reference, p. 1)

Credit Union putting rent and electric bills on auto-pay (R9: 1 reference, p. 5)
**Secondary Category:** Approaching intervention w/ seniors - (1359 references)  
(R1: 72 references) (R2: 65 references) (R3: 82 references) (R4: 27 references)  
(R5: 100 references) (R6: 65 references) (R7: 82 references) (R8: 70 references)  
(R9: 69 references) (R10: 122 references) (R11: 107 references) (R12: 111 references)  
(R13: 110 references) (R14: 104 references) (R15: 99 references) (R16: 75 references)

**Sub-category:** actions needed/taken - (1278 references)  
(R1: 62 references) (R2: 56 references) (R3: 73 references) (R4: 33 references)  
(R5: 103 references) (R6: 56 references) (R7: 67 references) (R8: 71 references)  
(R9: 70 references) (R10: 88 references) (R11: 106 references) (R12: 111 references)  
(R13: 107 references) (R14: 104 references) (R15: 99 references) (R16: 72 references)

Services needed for self-neglecting seniors (173 references by 16 workers) **(R1):**  
10 references, including 3 references to being involved with activity programming, including challenging minds to keep memory; “keepin’ their mind goin’” (p. 26); needing visiting doctors: “I would like to see them have visiting doctors, first of all, come in. They would have to have a visiting doc position. And any other visiting services, whether it be visiting podiatry, visiting anything else.” p. 13; clients needing transportation to visit friends, help with finances, service availability outweighing issue of whether or not client will accept services (p. 13), case management combined with some sort of financial payeeship, because self-neglect always includes their finances, p. 13; adult daycare and other senior programming such as congregate lunches, p. 13; home visits for “wellness checks”) **(R2):** 10 references, including transportation “We need transportation.” p. 9 [2 references], financial means to meet needs, p. 10; shopper [2], homemaker [2] medication monitoring, AM help “help them get started on their day” p. 8) **(R3):** 3 references {2 of which are mentioned and counted elsewhere} Emergency Response button, homemaker, “deep clean,” all p. 10) **(R4):** 1 reference: needing personal care, home repairs, and transportation services. p. 5) **(R5):** 5 references {mentioned and counted elsewhere} homemaker having biggest impact (p. 15), 2 references to ERS button, Meals-on-Wheels most accepted (p. 15). Personal care least accepted, p. 15) **(R6):** 20 references, 5 to needing socialization, getting “out of the house” ex: dining center (p. 9) [see overlap with worker’s feelings about intervention re: getting elder’s out of the house]; 4 to Meals-on-Wheels; ex: needing Meals-on-Wheels, p. 8, accepting Meals-on-Wheels but getting rid of them, not liking Meal’s on-Wheels “And then they get rid of them ‘cause they don’t like ‘em, yeah.” p. 9, 3 to needing transportation, ex: client identifying need for transportation, p. 6, needing transportation to the doctor’s, to the grocery store (p. 8), “They always seem to accept transportation and meals” p. 9; 3 to needing cleaning/homemaker services (p. 8) ex: homemaker services aren’t readily accepted (p. 9), biggest complaint is that “They don’t clean right.” p. 9; 2 to needing personal care services, p. 8, ex: personal care assistance is often accepted, p. 9, 2 to needing financial services, exs: needing financial services is “at the top of the list” (p. 8), financial help is generally resisted, p. 9, needing medical monitoring, p. 8) **(R7):** 7 references {mentioned and counted elsewhere} including 3 references to needing but not accepting mental health services, (p. 6), ERS being most
accepted (p. 5), Meals-on-Wheels not accepted as much, (p. 5), accepting visiting doctor, (p. 6), definitely accepting transportation, (p. 6) (R8: 8 references {mentioned and counted elsewhere}: informal care from family, major home cleaning, homemaker to keep home maintained, homemaker to go grocery shopping, some homemakers even go to the doctor with them, personal care assistant, Meals-on-Wheels, coordination of care between formal and informal support systems, all p. 11) (R9: 8 references: {including 6 mentioned and counted elsewhere} major cleaning, hoarders having mental health issues, homemaker, transportation, meals, financial management services if allowed by senior, all p. 6; 1 reference to having a family member willing to become involved and monitor finances, become power of attorney, p. 6; 1 reference to few people being able to afford assisted living, p. 3) (R10: 33 references, including 18 to needing med management services that aren't available: “...there’s no services for medical attention” p. 8; having no med management examples: not getting meds, not getting blood sugar checked, p. 9; seniors being able to manage everything in life but medical management, p. 9; no service except private pay nursing to help with med management, p. 9; worker worked in Delaware Co. too and there is no med management service in any county, p. 9; unless you’re really poor and Medicaid/passport eligible or really well-off to afford a nurse, this is a gap in services, p. 9; examples of needing med management: setting up pill box, verbal reminders, keeping track of and re-ordering prescriptions (2 references p. 9); missing med management services, p. 9; Medicare/Medicaid home health agencies are not long-term, you have to be able to be taught, p. 9; worker not wanting to institutionalize someone because they can’t manage their meds, p. 9; guardians not providing med management, p. 10; guardianship is not the answer for needing medication management, p. 10; Medicare not paying for long-term medication management, p. 10; Med management is not Medicare billable, p. 10; 14 references to needing home-based mental health services: wishing psychiatrists would make home visits for ongoing mental health services, p. 10; APS expertise is not mental health (2 references) as stated, p. 10, worker is not a M.H. counselor, p. 11; difficulty getting mental health services on board due to contrasting laws, rules, and regulations, p. 10; Mental Health services not taking initiative to provide services unless the client is homicidal or suicidal, p. 10, 11; A lot of times the primary diagnosis is mental health, not dementia, ex: depression, p. 11; wanting M.H. services to go into the community more, p. 11; there should be more community-based M.H. services “set aside” to work with the elderly, p. 11; and 1 reference to having meal services, minor home repair, personal care assistance, homemakers, escorts, senior friends, and short-term health agency services available, p. 10) (R11: 6 references to to Franklin County having services and some money to help clients: as stated, p. 6; ex: APS helping out with paying for house cleaning, p. 6; being able to provide services in Franklin County, p. 6; examples: homemaker, meals-on-Wheels, personal care aides, all p. 6) (R12: 6 references to clients needing home-based medication help to remain in home: example: pill set-up and reminders to take, p. 8; worker feeling that it’s sad to send someone to a nursing home over a “little” med
assistance issue, p. 8; having nobody to set up meds and being unable to do it themselves, p. 8; “Not to mention the amount of money it costs to send somebody to a nursing home for that little service” p. 8; “People would be so much happier at their home.” p. 8; “And, like, for the most part, that service is not covered by insurance...” p. 8) (R13: 12 references to needing a single, consistent care coordinator: needing home visits on a consistent bases, APS can’t do the constant follow-up, p. 5; needing someone to be there during transition into services and monitoring when in place, p. 5; “We’re not able to follow that” p. 5; even programs like Senior Options and Passport only come out maybe once a quarter, p. 5; worker wishing for a service where someone’s consistently going out to monitor how things are going, p. 5; a lot of time people won’t contact APS if things aren’t working out because they’re glad APS is out of the picture, p. 5; a lot of times it’s confusion to have so many casemanagers and social workers involved, p. 5; if they just had one for consistency, that would be great, p. 5; there’s a lot of turnover with homemakers and service people, p. 5; worker acknowledging that high provider staff turnover is just the nature of the beast, p. 6; being easy for clients to build rapport with one person coming in, p. 6; [having one consistent worker] would be good for our clients, p. 6) (R14: 12 references, including 11 references to needing assisted living alternative for people who can’t live at home but are not appropriate for the nursing home: [in a perfect world] there would be alternatives between nursing home and the home life, p. 5; there would be a medium ground of assisted living for poor people, p. 5; a lot of people living in the community can no longer live alone, and don’t have a support, p. 5; “It’d be nice to be a support.” p. 5; wishing for middle ground [level of care] for people with low income, p. 5; waiting lists for Medicaid assisted living beds being ridiculous, p. 5; having many clients that could benefit [from assisted living] instead of a nursing home p.5; they’re physically not capable of being in the community but they’re also not appropriate for the nursing home, p. 5; “So I’ve left them in the community, where I think they would thrive in as assisted living.” p. 5; “So they’re on a slow decline in the community, whereas in assisted living, I think we would see a steady improvement.” p. 5; a lot of cases that have to be closed would thrive in a nice assisted living environment, p. 5; and one reference to “Oh, if it was in a perfect world they would have a family. They would have a support system. That you could count on.” p. 5) (R15: 12 references, including 11 references to the most needed service being regular social contact, especially at mealtime: “Somebody just calling ‘em.” [being the most needed service], p. 6; “They’re lonely.” p. 6; “They don’t have somebody checking on them on a regular basis.” p. 6; “If an individual had somebody to prepare a decent meal for them, they would be better off.” p. 6; “Nobody want- A lot of times they don’t wanna eat alone.” p. 6; “So they choose not to eat at all.” p. 6; “But if somebody was there at the time they were eating, and sat down and ate with them, {softly} they wouldn’t have a problem with it.” p. 6; “So I think that is the [biggest need], being lonely.” p. 6; “That’s a biggie.” [loneliness], p. 6; “They’ll say ‘You can come back any time.’ ” p. 6; “And they wanna just have somebody to talk to.” p. 6; and 1 reference to transportation being a big problem: “And transportation’s one of the big issues. ‘I can’t get to the
Seeking involuntary services/overriding client’s desires (75 references by 16 workers) (R1: 2 references, including clients’ wishes being overridden when they’re “hitting rock bottom” p. 22) (R2: 1 reference about something bad having to happen before involuntary intervention takes place: “A lot of times those situations come down to, sometimes something bad has to happen before we can [intervene].” p. 18) (R3: 4 references to overriding elder’s desires: “Probably when I see that they are in danger themselves. Or they’re puttin’ somebody else in danger. That’s the main thing.” p. 14; “And that I can clearly see that, you know, they’re really not understanding consequences.” p. 14; ex: leaving the stove on would require a mental health evaluation, p. 14; [filing protection orders] “...even though people didn’t want those. Just to provide safety for that client.” p. 14) (R4: 3 references to involuntary services, including that they are rarely sought [1-3 times per year]; usually based on competency, by that point “They are usually so clueless that they don’t even recognize that it’s happening.” p. 9) (R5: 1 reference to seeking guardianship one time in 4 years in case of family financial exploitation “I am not prone to doing it.” (p. 17) {mentioned and counted elsewhere}) (R6: 4 references to worker being directive with client: when “something is not gonna work” p. 11, being directive with a client needing emergency medical care, p. 13, forcing client to move from unsanitary, unsafe home. ex: “Yeah, I bet she
just wanted to die. But...and, and she was, but I told her she wasn’t gonna die in that mess.” p. 12, worker forcing services when clients know conditions are wrong. ex: financial exploitation by granddaughter or grandson when seniors “...are giving them money, and they’re not paying their own rent and they know that this is wrong. I mean they, they do understand what they’re doing.” p. 12 (R7: 2 references to involuntary removal from home: Telling grandson “you had to come get her out of this house” (p. 8), City Code closing house down, p. 8) (R8: 5 references to worker having to override client’s decisions when they are unable to care for self (p. 10) including forcing involuntary medical services such as insisting client get medical assessment immediately (p. 9), worker telling client she will get a court order to make her go to hospital (p. 9), client deciding to go to emergency room so APS worker wouldn’t have to get court order (p. 9), getting court order of protection for client to go to hospital (different case) (p. 10) (R9: 9 references, including 8 references to overriding client’s wishes, including “It has to be really severe.” [to override client’s self-determination] (stated 4 times on p. 8) ex: “It has to be really severe and the client has to be, I mean evaluated to the point where they can’t function.” p. 8; stopping seniors from driving, p. 3; having to move a client, p. 7; worker saying to client who didn’t want mental health services: “The only way I’ll help you, (‘cause they were evicting her)...is that you agree to...elder treatment and focus.” [mental health services], p. 7; having no choice [but to override elder’s desires] when people are really bad off and won’t use helping systems, p. 8; 1 reference to APS worker showing up is an involuntary service, p. 6) (R10: 2 references to seeking involuntary psychiatric evaluation if after numerous visit a client is incapacitated and their needs are consistently not being met and the client is refusing services without providing an alternative to meet need, p. 12) (R11: 1 reference: “Well, the competence, competency assessment, I mean, we do that. I don’t want to be the sole responsible person, and I’m not, it comes down to a doctor. It’s usually when a client needs help and is refusing. It helps finding them to be very confused about certain things.” p. 7) (R12: 4 references to overriding elder’s wishes only when danger exists: having to be risk of loss of life or limb to override elder’s wishes, p. 9; safety must be in danger [to override], p. 9; removing people from home if it’s an unsafe situation, p. 9; exs: health, finances, dementia: utilities turned off, unaware of kitchen fires, p. 9) (R13: 27 references to approaching overriding elders’ decisions: overriding elders’ desires if there’s an imminent danger, p. 6; worker having to get a few emergency orders to have them receive medical care, p. 6; ex: deep wound infection with maggots, p. 6; going to probate court if it seems they’re going to lose limb or life within 24-72 hours, p. 6; case ex: client in hospital and really reluctant to get follow-up care, p. 6; same case: home conditions so bad client couldn’t follow through with wound care, p. 6; same case: consensus with attending physician and nurses that client needed after care and rehab at a nursing home, p. 6; same case ex: worker not having to get court order because at last minute client listened to her cousin and agreed to go to nursing home for a few weeks, p. 6; taking a gradual approach, p. 7; wanting to respect their decision when they’re knowingly self-neglecting, p. 7; [confronting
client’s decision-making] after allowing them to make the decision but if you see it’s dragging on for a week or two and they’re physically getting worse, p. 7; having to confront clients [who are getting worse] and getting orders of placement or for medical care, p. 7; meeting a lot of resistance when overriding their decisions, p. 7; typically they’ll say ‘thank you’ after that [after health improves from overriding their health decisions], p. 7; worker recognizing there’s fear about “…if I’m going’ into the hospital, what’s the next step?” [after court orders for medical treatment are granted], p. 7; recognizing client’s fear of being abandoned in the system “I’m older, I don’t have any family members…what are you gonna do? Put me in the system, leave me there?” p. 7; building rapport and taking that gradual approach, p. 7; making them feel that they’re part of the decision-making, p. 7; consistently identifying concerns to the clients [about their decisions], p. 7; worker constantly repeating herself [re: concerns], p. 7; getting pretty stern when it gets to a point [where their interventions aren’t working and they’re getting worse], p. 7; having to intervene in a lot of cases, p. 10; trying to take a gradual approach, p. 10; having to “come there very abrupt” in some situations, p. 10; [having to be very abrupt] quite a few times, p. 10; getting people out of home first for medical conditions, p. 10; ex: explaining to client “Okay, obviously you’re not able to see the scope of this, and we’re gonna take you to the emergency room. Now, when you get there, you know, that’s on you, but we have to take you because we’re seeing you in this condition.” p. 10) (R14: 4 references to overriding elders wishes: determining need to override elders’ wishes on a case-by-case basis, p. 7; [overriding] if they just really don’t have good judgment and there’s a lot of safety problems, p. 7; taking more control if they have zero insight into it, p. 7; ex: worker moving clients a lot more than some people, p. 7) (R15: 6 references: [overriding elder’s desires] “When they’re at risk.” p. 7; “I always refer back to the doctor.” p. 7; explaining to clients that a doctor is stating that they are at risk if they stay home without services in place, p. 7; explaining to clients “I understand that you want to remain in your own home. That’s what I want for you, too. But I have a doctor stating to me that you are at risk if you stay here. If you don’t have the services in place. So you can choose on your own…those services. If you don’t choose those services, and I still have the doctor saying you can’t remain in your own home, then I will have to go to court.” p. 7; worker being happy to say she’s only gone to court 3 times in 8 years doing this, p. 7; “So, a lot of the times they do understand that it’s gotten to the point where they can’t manage anymore.” p. 7) (R16: 10 references to seeking involuntary services sparingly: [(overriding elder’s desires] in two situations, “…when you’ve got somebody who’s obviously not competent,” p. 4; “…when you have somebody who’s obviously got some sort of a dementia or something goin’ on.” p. 4; “And they’re endangering themselves, certainly that’ the other piece.” p. 4; speaking with their family physician or family about pursuing guardianship, p. 4; using Adult Protective Orders sparingly with competent adults because it’s an invasion on rights, p. 4; using court designate “eminent danger” [sic], “Potential loss of life or limb within a twenty-four hour period if we don’t intervene.” p. 4; typically not using Adult Protective orders because they’re very invasive, p. 4; trying to use
least restrictive services, p. 4; worker can generally talk folks into services: “Okay, let’s try this, try this.” p. 4; still going with least restrictive alternative, p. 5)

Approaching home visits (75 references by 14 workers) (R1: 1 reference to visiting 4-5 times to complete the investigation, p. 4) (R2: 3 references, including 2 to going through the assessment and initial paperwork on first visit whenever possible such as the waiver, the consent, the rights and responsibilities, p. 1; respecting clients by being non-confrontational, p. 3) (R3: 3 references to building rapport: “...just tryin’ to build rapport right at the door,” p. 1; “Kinda startin’ that rapport building.” p. 1; building rapport [to encourage mental health services], p. 12) (R5: 3 references to building rapport, including being a “friendly visitor” to engage, p. 3) (R6: 6 references, including 4 to making initial home visit with a partner for safety and “having two pairs of eyes” p. 1; 2 references to keeping the first visit short; usually the initial interview is short. Staying 30 minutes to an hour on the first visit “and then I find that’s enough” p. 2) (R7: 1 reference to making first home visit in pairs, p. 1) (R9: 8 references, including making first visit unannounced p. 1; telling client where you’re from, p. 1; explaining APS, p. 1; talking in doorway if not let in, p. 1; getting help from another agency that already has trust, p. 1; not going in until invited, p. 2; not sitting down until asked, p. 2; not touching anything unless you ask, p. 2; worker finding common ground to “put ‘em at ease,” p. 2 [exs: Western films, John Wayne]) (R10: 8 references, including 3 references to strategizing what resources would be helpful and formulating a plan on the first visit: “A lot happens for me in the first visit” (p. 1); starting strategy and start throwing options out there, p. 1; ex: calling Meals-on-Wheels from the house on the first visit, p. 1; and 3 references to making numerous home visits to “get a feel” for somebody: 2 on p. 4; going back several times to assess, p. 6; 1 reference to going on initial visit with partner unannounced, p. 1; 1 reference re: sometimes you can tell in one visit that it’s bogus, p. 6) (R11: 11 references, including 9 references to approaching the first visit, including 2 references to assessing/offering smoke detectors: policy is asking about smoke detectors on first visit, p. 2, arranging for smoke detectors if requested, p. 2; recognizing that allegations may be true or not, p. 1; trying to explain role to clients in a non-threatening way, p. 1; offering help, p. 1; confirming demographic info on first visit, p. 2; having 3 business days to make face-to-face contact, p. 2; always asking permission to do things, p. 2; example: asking permission to look in fridge, p. 2; and 2 references to getting to know the person: developing rapport, p. 7; “After I’ve known the person for a while, I think I know, you know, how they think or, you know, what they’re thinking, and what their expectations are.” p. 10) (R12: 17 references, including 7 references to going on first visit in pairs: “…because we are a large county and we have fifteen case managers, we always go out in pairs.”; going out in pairs for safety; to separate client and alleged perp; wanting to interview the person alone; second worker providing a diversion; second worker can be checking things, exs: meds, food supply; “…the very first visit, you go in pairs.” (all p. 1); 6 references to approaching the first visit: introduce self and start building a
relationship, p. 1; being obliged to identify the agency and explain reason for visit, p. 1; specifically reading off all allegations, p. 1; describing role as neutral party, mandated by law to visit, “going out to get other half of the story.” p. 1; assessing things, p. 2; giving client chance to respond, p. 2; and 4 references to making unannounced visits: making first visit unannounced, p. 1; worker typically making all visits unannounced, p. 1; making unannounced visits because “don’t wanna give ‘em time to clean up or cover things up.” p. 1; “Don’t want them to put on a little show because they know I’m comin’.” p. 1 (R13: 5 references to making first visit: responding to reported allegations, p. 1; going out unannounced, p. 1; going over the allegations with our client, p. 1; determining whether or not there is anything to substantiate as far as self-neglect, p. 1; looking at it [self-neglect] on different levels: physical living environment, ability to administer meds, if they’re going to a doctor, p. 1) (R14: 10 references: building rapport and respecting them to get in the house, p. 1; worker probably having a 99 percent rate of getting in, p. 1; worker respecting that the client’s home is their space, not his, p. 1; “I think that the best thing to do is...I’m up-front. I’m up-front with ‘em a hundred percent.” p. 6; not “sneaking around” p. 6; trying to build rapport as quickly as possible, p. 6; not coming on too strong, p. 6; using “I’m from Franklin County Office on Aging” to get in the door, p. 6; immediately starting to go over concerns after getting in the door, p. 6; “I think people like referrals. Giving, like, information. They like information. If you come there and just wanna allege, allegation of drug use, and a variety of activity, ‘n...That’s not gonna get you anywhere.” p. 6-7) (R15: 5 references to making first visit: not mentioning APS initially but rather “introducing myself as being from Job and Family Services. I don’t mention Adult Protective Services.” p. 1; explaining referral to client, p. 1; not sharing referral source, p. 1; identifying “…my objective is to place services in here to eliminate any kind of risks that might be involved.” p. 1; usually giving obligatory ‘intent to investigate’ paper when ready to leave to avoid embarrassing or intimidating them, p. 1) (R16: 4 references, including 2 references to making first visit: first visit being unannounced, p. 1; telling them where worker is from and letting them know agency has received referral and worker would like to talk to them about community resources, p. 1; and 2 references to not being critical: ‘I tell people I’m not the Good Housekeeping lady, I have dishes in my own sink.’ ” p. 5; “You know, I’m not gonna come in and be critical of that.” p. 5)

Linking and consulting with physicians and other service providers (squad, police, court, passport, specialists, other agencies) (125 references by 13 workers) (R1: 5 references, including 2 references to requesting a cognitive/psych evaluation before overriding elders’ desires, p. 19; arranging home visit by a doctor for medical assessment: “So they came out there and they did everything. They had, like, portable X-ray machines, and portable this, and portable that. So they came out there and they did their thing, and she was ok.” p. 7; using psych info for guardianship, convincing clients to allow a home psychiatric evaluation by a psychiatrist) (R2: 14 references, including squad [6], exs: calling squad
for a person who wished to die at home, p. 14, “We have been in situations where we’ve called the squad, the squad will come in, but if the persons refuses, there’s nothing we can do. Absolutely.” p. 18; “Unless the person would end up being unconscious right there in front of the squad members. Or if they were in obvious-, if they were obviously not able to, for lack of a better word, if they were incoherent, or crazy, or whatever the word you wanna use.” p. 18; “Well, ‘cognitively impaired’ won’t even necessarily mean that they- the squad will do anything.” p. 18; “Yeah, something very dramatic for the squad to be able to say, you know, we’re gonna make this happen. Yeah. And usually I think it’s uncon[scious].” p. 18; doctors [5], for ex: “And we do have doctors who will go to the home if they’re Medicare. But also those doctors hands are tied if the person’s refusing to see them.” p. 19; “Ok. Here’s our problem. We do not have a doctor who will go to a home if the patient will not voluntarily say ‘Come to my home.’ ” p. 17; police: “If we go to a home and we have an elder adult who is effusing to see a doctor, and there is nothing anywhere stating that this person is not competent, they need intervention...there’s no police interaction...Sometimes the police can be involved where there’s a pink slip situation. But the police will only pink slip if the person is right then and there expressing the- they’re gonna hurt somebody, or they’re gonna hurt themselves, that kind of thing. Seldom does that ever happen, when you need it to happen, of course.” p. 18; other agencies: “No, I don’t. [use a mini-metal status]. But we’ve often asked other agencies who have nurses and doctors, that, we’ve asked them to do that, yes.” p. 17; worker getting peer feedback from APS colleagues, p. 12; initiating passport, p. 8; and court involvement, p. 16) (R3: 4 references to using police back-up: “In Delaware, it was more frequent. I haven’t every used it here in Columbus in the last two and a half years.” p. 9; “In Delaware, more frequent.” p. 9; “…it seemed like, maybe, any seedy house up there? It was like, “Oh, you better be careful, we’re comin’ out with ya.” p. 9; “That’s great, but you know, do you really need to be there involved, and lights and siren up there…” p. 9) (R4: 6 references, including 5 about referrals to health department (code enforcement), including using the health department (code enforcement) in a small community when they know a living arrangement is not “fixable,” using “good cop/bad cop” approach with health dept. worker being “bad cop,” using health department to keep people out of court; and 1 re: confronting doctors about needing dementia diagnosis for squad to take client) (R5: 4 references, including 3 to having a behavioral health specialist (BHS) make a mental status assessment: overriding elders desires only when impaired judgment has been determined by a BHS assessment (p. 17), having 2 options, netcare or private BHS (p. 17), getting an outside assessment if unsure of client’s level of understanding, (p. 18); and 1 about avoiding using ambulance when possible, p. 9) (R6: 10 references to using the emergency squad: exs: calling squad for client falls, client sent right back home (p. 14), needing to tell “little white lies” to get the squad to take client (p. 14), exaggerating conditions to get squad to take client (p. 14), case examples of calling the squad (p. 13-14), 2 references to seniors not liking to call the squad) (R7: 9 references, including 8 references to contacting client’s physician; including using client’s doctor to get a psychiatric evaluation
(p. 7), not needing client consent to contact her doctor due to Oho Revised Code mandate to investigate (p. 8), some physicians throw Hippa, worker throws Revised Code back at them (p. 8), approaching physician about helping APS now to promote future APS assistance to the physician (2 references, p. 8, p. 9), physicians calling APS for high-maintenance patients (p. 9), finding client’s doctors 40% to 60% of the time (p. 9); 1 reference using visiting physicians when client’s physician can’t be found, p. 9) (R8: 13 references, including 11 references to consulting with client’s physicians including: physicians are mandated reporters per Ohio Revised Code so client consent to release info is not needed (p. 3); not having problems with physician cooperation (2 references) (p. 3); physician’s not completing expert evaluation if they don’t think APS needs to be involved (p. 3) (4 references) including: physicians can put “deny” on Expert Evaluation or just not fill it out (p. 3), a lot of physician’s not filling out evaluation and telling APS worker the reasons, (p. 3); and 2 references to paramedics transporting clients to hospital: some paramedics will talk people into going, others won’t (p. 10), if client refuses, paramedics won’t take without court order of protection, p. 10) (R9: 6 references, including 4 references to working with police/fire departments, including police/fire depts. asking APS to place client due to excessive 911 use, p. 5; worker explaining to police/fire personnel that the court found client competent and asking them “What would you do with a competent person?” [They’d charge her with something], p. 5; police telling worker that a client’s only son who was a cop was killed, p. 7; police not taking client in because they knew her son (deceased cop), p. 7; and 2 references to working with guardians: working with attorney (guardian) to transfer client to Boston where she has family, p. 5; working with attorneys (guardians) “you find out more information,” p. 5) (R10: 4 references, including 2 references to getting expert psych eval in home if client can’t follow through with plan: as stated, p. 14; client demonstrating lack of capability if they can’t follow-through with a plan developed together with worker, p. 13; 1 reference to consulting with collaterals to factor in their opinion, but it’s just that an opinion, p. 16; 1 reference to walking a fine line when determining mental and physical capacity, p. 15) (R11: 22 references, including 22 references to working with physicians/APS psychologist: communicating with visiting physicians, p. 5; visiting physicians usually visit once a month, p. 5; visiting physicians and nurses having different [lower] thresholds for involuntary intervention than APS, p. 5; ex: medication compliance is not always a matter of life or death, p. 5; having to explain the law that “this person has rights” [to physicians] all the time, p. 5; worker not wanting to be solely responsible for competency assessment, p. 7; competency assessment coming down to a doctor, p. 7; consulting with family physician, p. 7; getting an expert evaluation, p. 7; some physicians don’t want to wreck their relationship with the client, p. 7; some family physicians feel they’re not qualified to do a psychiatric evaluation, p. 7; using APS psychologist “If we can’t get anywhere with the family physician, p. 7; APS psychologist having a very high success rate of getting in [to the home], p. 7; doctors having a higher success rate [than APS workers] getting squad to take clients who refuse, p. 8; getting a doctor to say “This person is very confused, they probably
have beginning dementia or Alzheimer’s.” p. 8; doctor seeing a decline over several visits, p. 8; if seeking no progress by the client, taking it to the “next level” of getting a psychologist out there, p. 9; getting a doctor involved when they’re pretty confused, p. 9; needing an expert evaluation to force changes, p. 10; some doctors requiring consent forms, p. 10; some doctors don’t require anything and will tell whatever you need to know, p. 10; some doctors wanting to not get involved in the psychological side of people’s lives, p. 10) (R13: 19 references, including 13 references to working with EMS [emergency medical support]/squad: calling the squad, p. 2; squad sometimes being helpful and sometimes being a hindrance, p. 10; EMS workers asking first “do you wanna go?” p. 10; EMS workers asking a few questions to assess competency and then saying “We can’t force her.” p. 10; worker calling squad supervisors and explaining situation, p. 10; supervisors typically saying “okay” p. 10; having good rapport with a lot of EMS supervisors, p. 10; EMS first responders being very reluctant sometimes, p. 10; having to call EMS supervisor quite a few times and explaining case “I’ve been involved this long, this is what’s goin’ on.” p. 10; worker being amazed that EMS workers can see that person needs to get to a hospital but refusing to transport, p. 10; going over their heads a couple of times, p. 11; that works for the most part, sometimes it hasn’t, p. 11; squads on the west side being very good in dealing with that [getting clients to go to the hospital], p. 11; and 5 references to having hospital doctors complete expert evaluations: having hospital doctor do psych evaluation to assess competency while client’s there and completing expert evaluation, p. 6; case ex: of expert evaluation done by hospital staff recommending guardianship, p. 7; same case: worker approaching probate court with hospital’s expert evaluation, p. 7; hospital doctors completing expert evaluations quite often, p. 7; “they’re really good about doing that” p. 7; and 1 reference to case example of working with court-assigned attorney, p. 7) (R15: 9 references to consulting with doctors: referring back to doctor on borderline cases, p. 2; needing a release in Pickaway County to get information from doctors, p. 2; explaining to borderline clients that as long as a doctor states they are able to live on their own, unsupervised, worker won’t push any services, p. 2; worker learning in Ohio Coalition of Adult Protective Service Workers [OCAPS] workshop that there’s a line in the Ohio Revised Code or HIPPA law that says no release is needed [when APS is investigating], p. 3; worker telling Cuyahoga County worker who has a form she can send to a doctor that says no release is needed “I need that!” p. 3; not ever wanting to rock the boat with doctors because worker wants the doctors to cooperate, p. 3; asking clients for a release to avoid conflict with doctors, p. 3; worker doing this for 8 years and before HIPPA, having not problem calling doctors and nurses for information, but now everybody’s scared, p. 3; they don’t want to give any information without a release, p. 3)

Offering information and referrals/encouraging seniors to accept needed services (74 references by 12 workers) (R1: 2 references, case example of getting a person meals on wheels who had no food, p. 6; case example getting a person a walker, p. 22) (R3: 9 references: case ex: “So [we]
finally worked in to getting him some homemaker services to help take that stuff out.” p. 2; encouraging service utilization, p. 2; recommending services, p. 6; advocating for Emergency Response button, p. 10; offering deep cleaning service, p. 10; “Overall I think they enjoy the [services.]” p. 13; once they get set up with services they say it’s a lot less housework in the home [and] it’s something in the home that they can really benefit from, p. 13; [once they get set up with services] “I think they stay with the program for a long time.” p. 13; “A lot of people who forget with, like medication set up? They can get a electronic med box. That really helps people out and they’re like ‘Wow!...that’s perfect!’” p. 14) (R5: 2 references to framing intervention as “steps we can take to get people off your back/make the outside world happy” p. 5) (R6: 1 reference to promoting the Emergency Response Button, p. 14) (R7: 3 references: providing resource information to seniors, p. 1; offering services without shaming or embarrassing, p. 6; advocating for their needs, p. 1) (R8: 5 references to offering services, including cleaning services (2 references) (p. 8), getting services in for a major clean, then homemakers for maintenance (p. 11), homemakers will clean, go to grocery, and some will even go to doctor with older adult (p. 11), getting a personal care assistant if bathing help is needed (p. 11), getting Meals-on-Wheels if they can’t cook meals, p. 11) (R10: 1 reference to improving quality of life by linking to resources, p. 3) (R11: 6 references, including 2 references to encouraging self-neglect people to get the Emergency Response System (ERS), p. 4; educating people about available services, p. 6; walking away if the person is competent and they don’t want help, p. 6; clients’ being receptive to offered services is the perfect outcome, p. 6; usually being able to talk people into getting medical intervention, p. 8) (R12: 11 references to advocating for services/making referrals: putting other agency’s services in place when client willing to allow it, exs: home health, Senior Options monthly drop-in, p. 6; worker continuing to offer services, p. 11; recommending trial basis, p. 11; giving clients info on Senior Options program without making official referral to see what they will do, p. 11; clients independently calling Sr. Options demonstrates if they will follow through, p. 11; consulting with Sr. Options, p. 11; some clients preferring workers to handle referrals, p. 11; a lot of people will take services if you set them up, p. 11; determining personality type re: referral process, p. 11; some clients accepting services if “you do all the work” p. 12; a lot of clients will accept all free services, p. 12) (R13: 1 reference to making referrals for a nurse or someone to assist with medications, p.1) (R14: 15 references, including 10 references to trying to get clients to try services: worker “pushing” [for services] in some cases where the case could be closed, p. 3; worker making the judgment to push a little harder, p. 3; worker thinking it’s always in a self-neglecting client’s best interest to have services, p. 3; worker facilitating client understanding [of services], p. 3; getting clients to try services, p. 3; “I try to get them to try the service.” p. 3; case ex: client not wanting to move from home of 40 years that’s full of rats and feces, p. 3; same case ex: competent client not wanting to move but can’t stay in home [due to with rats and feces], p. 3; same case ex: worker working out agreement with client for client to go look at senior housing, p. 3; same case ex: client is going to take taxi and
go look at a couple of senior housing sites, p. 3; and 5 references to focusing on giving referrals and information rather than just the allegations: giving referrals, p. 6; “I think people *like* referrals.” p. 6; giving information, p. 6; “They like information.” p. 6; “If you come in there and just wanna allege, allegation of drug use, and a variety of activity, n’...That’s not gonna get you anywhere.” pp. 6–7) (R15: 18 references to recommending and setting up home-based services: letting them know what kind of resources are out there, p. 1; “Well, in a perfect world, we’ll set up someone that’s gonna check up on them on a regular basis,” p. 5; recommending home-delivered meals, p. 5; “And I’ll even explain to them, ‘If you don’t have family, that this is the perfect thing to do.’ ” [re: home-delivered meals] p. 5; recommending home health services: “Can I call for home health for you? Do you have any help in your home?” p. 5; “If they don’t [have home health services], then I’ll explain to them about home health, and if they have Medicaid and Medicare, we’ll touch on all those bases.” p. 5; worker setting up services, p. 5; “I’ll make phone calls. I don’t have any problem doing that.” p. 5; “I’ll set this up for you.” p. 5; following up: “And follow through in a couple days and make sure it got started.” p. 5; “With our [Pickaway Co.] home health or home-delivered meals, it’s from the senior center and they usually will have it started within two days.” p. 5; setting up assessment through Central Ohio Area Agency on Aging to set up Passport services, p. 5; “If they agree to all that, that’s the perfect world.” p. 5; giving clients 2 choices re: home-delivered meals: the senior center or “Simply Easy” through Columbus, p. 5; senior center open only M-Th, they had to cut a day, p. 5; “Simply Easy” from Columbus coming in with a week at a time with frozen meals, p. 6; worker providing brochures to show people what the meals look like, p. 6; having a choice of home-delivered meal programs, p. 6)

Honoring/acknowledging client’s wishes and self-determination (65 references by 12 workers) (R1: 9 references, including 3 references to making appointments per client request for follow-up visits after initial unannounced visit, p. 1; honoring client’s desire to remain in same area; getting on waiting lists for housing in that area, both p. 18) (R3: 2 references; “People are allowed to be dirty.” p. 4; “I really think that people are allowed to live however they wanna live.” p. 13) (R5: 3 references to advocating for people’s choices if competent, including “It is your right to live as you choose and I am happy to support that.” p. 7) (R6: 1 reference: “Self-determination would generally with me always win out on trying to force somebody because they’re self-neglecting themselves.” p. 14) (R7: 3 references: worker wanting to help but needing to respect client choices, p. 4; “People do have the right to live in filth.” p. 10; “Just because they’re 60 doesn’t mean every *right* gets stricken from them. By no means.” p. 11) (R8: 12 references, including 4 references to client rights coming first: “They are adults, they’re *not* children.” (p. 13), self-determination comes into play and you have to allow them [to self-neglect] (p. 14), their lifestyle may not be agreeable to the APS worker but you have to respect how they want to live, (p. 14); respecting competent senior’s right to choose to live in a deplorable situation, (p. 14); adults can
make their own decision about staying in their environment or not, p. 1; and 3 references to clients refusing to speak to APS, asking APS to leave including if a person is demonstrating some understanding of questions, we have to respect their rights and leave if they ask us to (all p. 7), 2 to older adults who are sharp sometimes wanting to stay in a neglect or abuse situation (p. 2), and 2 to an older adult choosing to return to her apartment from a facility although unable to care for self (unable to ambulate, get meals, dress, bathe, toilet self), p. 9, p. 10) (R9: 3 references to always erring on side of client’s rights, p. 8) (R10: 6 references, including There’s absolutely nothing you can do when people know what’s going on and are making bad decisions. You have to wait for a physical or mental decline, p. 8; getting cases back in 6 months after a decline, p. 8; “you’ve gotta sometimes walk away” p. 8; sometimes you have to just let go, p. 8; “...you want people to have what they need. And it’s really hard to walk away.” p. 8; not wanting to force anything because that’s not what APS is about. We’re about self-determination, freedom over safety, client participation—all those things social work is about, p. 8) (R12: 11 references, including 2 to some client’s preferring follow-up appointments: as stated, p. 1; worker agreeing to make appointments depending on the situation, p. 1; and 4 references to worker not wanting to put people in nursing homes or take away their rights by getting a guardian, p. 6; “I think that is optimal. That we live in a country that you have the right to determine how you’re gonna live live the way you want to.” p. 6; “It’s really hard to case plan anything for another individual who has the right to live the way they want.” p. 7; “And I believe in people’s rights, so I would say it is ideal that we all get to choose to live how we want to.” p. 7; and 4 references to honoring the right to die at home: as stated, p. 6; worker allowing people to remain at home to die, p. 6; worker not wanting to die in a hospital or nursing home, p. 6; [when considering allowing people to die at home] worker taking into account what she would want, what her grandparents would want, p. 6; “If they understand the risk...then, I believe, they have the right to self-determination.” p. 11) (R13: 1 reference: wanting to respect their decision when they’re knowingly self-neglecting, p. 7) (R14: 4 references: going on self-determination first, p. 7; going with their rights first, p. 7; trying to involve all clients in any change that occurs, p. 7; “So even if they’re against it, we’ll talk it out.” p. 7) (R16: 10 references to honoring self-determination: worker often using Havemeyer’s theory: a person has a God-given right to live how they wish, no matter how others are offended, p. 2; worker using Havemeyer’s theory to make decisions and start where the client is, p. 2; trying to find out “...what their perception is.” p. 2; “Do they think there’s a problem, you know?” p. 2; “A lot of times they’re like, ‘I don’t know why you’re here.’ ” p. 2; “...it’s easy to allow people to self-determine when it’s a self-neglect issue.” p. 5; “I think the only time it really becomes a struggle is more when you’ve got that endangerment issue.” p. 5; “I think if you don’t have that endangerment, if there’s not a real endangerment, you’re not gonna force yourself in there.” p. 5; “You’re gonna allow them to determine how they live, and if that’s messy, that’s messy.” p. 5; “I’m gonna come and offer help, and if they want help, we’ll hook ‘em up. If
they choose to not have that help, I’m really okay with that unless it’s and endangerment issue.” p. 5)

Receiving/screening referrals, including bogus calls (33 references by 11 workers) (R2: 3 references: referral source desires change, p. 2; getting bogus/inappropriate referrals such as malicious calls from feuding children, p. 21; getting referrals on a home health aid, p. 6) (R3: 4 references, including 3 to assessing service utilization and making adjustments when APS gets another referral p. 14, and 1 reference to neighbors calling in referrals, p. 2) (R4: 2 references about apartment managers making referrals, including worker must explain that APS can’t make elders stop doing things and the managers may evict tenants if rules aren’t being followed; managers don’t want to evict seniors, both p. 11) (R5: 8 references; including 6 to making inaccurate/false referrals: posturing family, not having good info, wanting to assure APS visit (p. 11), kids using APS as a “weapon” (p. 12), children making false referrals (p. 12), false reports wasting APS time (p. 13); and 2 references to people tend to overstate on referrals, including people “beef stuff” so APS will come, p. 11) (R8: 1 reference to describing referral process: All APS workers are online taking intakes (referrals) then the referral is submitted to the supervisor to determine if it will be investigated. Referrals to be investigated are then assigned to workers who read them and make a home visit to assess and either substantiate or not substantiate the allegations, p. 1) (R10: 3 references to referral source having “perception of neglect”: referral sources having the “perception” that something should be done but not being able to explain any specific allegations of self-neglect p. 6) (R11: 1 reference to receiving lots of bogus calls, p. 1) (R12: 1 reference to getting bogus calls: Example: retaliation by neighbor’s feuding over bushes on property line, p. 5) (R14: 8 references to getting/approaching bogus calls: getting totally bogus calls, p. 2; worker not needing to decide [about substantiation of allegations] on totally bogus calls where there is no self-neglect, p. 2; getting very clearly bogus calls, p. 4; ex: a lot of people make malicious referrals, p. 4; ex: referral source having other motives besides helping that person, p. 4; ex: or they think they’re helping but they’re in actuality making judgments on that person, p. 4; for a 30-40-year-old it’s no one’s business how they live, but for 80-90-year-olds everybody wants to make it their business, p. 4; a lot of referrals being completely unsubstantiated, p. 4) (R15: 1 reference to reinvestigating repeat referrals to see if services are working or not, p. 2) (R16: 1 reference to getting a lot of holiday referrals: “‘Cause people are comin’ home and seein’ how bad things have gotten, and then they’re callin’.” p. 4)

Using or not using a particular intervention model/treatment approach: (25 references by 11 workers) [workers not represented here mentioned using MMSE or relationship-building: references to using the MMSE counted under “assessment” category] (R2: 2 references to worker “hating” to discuss treatment models) (R3: 2 references: “They might tell me in one sense that they know what’s goin’ on, and then you ask ’em a couple more questions with the, uh, mini-mental, say, and they’re confused, they don’t
know their birthday, they don’t know who’s the president.” p. 6; The main thing I just try to go in an’ have an open mind. There’s no real, no real set thing that I try to use.” p. 13) (R4: 1 reference to not using a particular practice model to avoid “pre-setting” expectations, p. 7) (R5: 6 references, including 4 to using the systems approach, including “people are part of a larger system” (p. 16), involving families, churches, supports; looking at whole picture, not just the pinpoint issue at the moment; “…you are more than this old person who isn’t bathing,” (p. 16); and 2 references to framing intervention as “steps we can take to get people off your back/make the outside world happy” p. 5) (R7: 1 reference to using a self-preservation” model, like a teacher to a child, p. 6) (R8: 3 references to worker using a client-centered approach when investigating self-neglect allegations, including “…the client is always the center point of our investigation.” (p. 12) and “…[we] try to let the clients have some type of say, if all possible, in what [services] we can put in.” (p. 12) (R9: 1 reference to using a client-centered approach, p. 8) (R10: 1 reference to using a problem-solving model p. 11) (R11: 1 reference: “I don’t really use any interventions. I think that I try to develop a rapport with the client.” p. 7) (R12: 1 reference to not following a specific treatment model: “We don’t have a specific name of a model that we follow.” p. 9) (R14: “I don’t know, I mean, I think that the best thing to do is…I’m up-front. I’m up-front with ‘em a hundred percent. So there’s no sneaking around. And I just try to build a rapport as quickly as possible. So I don’t come on strong.” (p. 6) [counted under “approaching home visits” property]) (R15: “Like a risk-assessment form? Okay. I have a risk assessment. I’ve just recently got a new one. Last week I went to the OCAPS workshop and got a new one. The one I had before I didn’t particularly care for, but, again, we had somebody that had some tools out there, and it was like, I monitored it, or altered it so it would fit our county.” (p. 7) [counted under “using a risk-assessment form” property]) (R16: 6 references to approaching treatment from client’s perspective: not using a specific treatment model, p. 4; after 13 years of experience you get the hang of it, p. 4; using a client-centered approach, p. 4; “Looking at helping them frame what the problem is, instead of it being my idea.” p. 4; explaining available services, p. 4; “…you try to get in there, help identify the problem, and help identify the resources, and connect them up.” p. 4)

Seeking court orders/guardianship (81 references by 10 workers) (R1: 3 references about seeking guardianship, expediting guardianship p. 7) (R3: 7 references: needing probate action only when a person is not able to make decisions on their care, p. 5; turning into a guardianship when people don’t allow court-ordered services, p. 5; doing guardianships, p. 14; requesting guardianship doesn’t happen often in Franklin County, p. 14; worker never having filed for guardianship in Franklin Co., p. 14; worker filing like seven times in two years working in Delaware Co., p. 14; pushing guardianship in Delaware Co., p. 15) (R5: 4 references: 2 about petitioning probate court for medical treatment, including worker never having to do it but being able to talk people into things, p. 5; including avoiding court orders when possible (p. 9); 2 references about seeking guardianship, including sometimes getting a guardian wouldn’t improve
the situation (p. 14), “I’ve one time have sought a guardianship in four years.” (p. 17) (R6: 1 reference to worker feeling she’s not really working for the client when seeking guardianship “Because nobody wants guardianship.” p. 11) (R7: 4 references to court orders being available to APS to protect seniors, including guardianship, conservatorship, evictions, restraining orders, service orders, financial orders (ex: sanitation, getting in the house, court ordering wealthy people and spouses to pay for needed services (all p. 2), “And if it becomes, you know, where it’s a fight, we do have orders available to Adult Protective Services. That is what makes us different than anybody else. Those orders are there to help protect our seniors and to give them a dignity and a life free of abuse and neglect and exploitation.” p. 2; getting a court order to make a client go to the hospital after a fall—she had a hematoma. (self-neglect because she didn’t recognize what had happened) p. 7) (R8: 16 references, including 11 references to getting court order of protection, including worker telling client she will get order of protection to make client go to emergency room for medical assessment (p. 9), getting order to force medical assessment (different case, p. 10), Columbus Police Dept. or Franklin Co. Sheriff’s office enforcing order of protection (p. 10), paramedics called to transport client to hospital per order of protection (p. 10), client being angry with worker for order of protection (p. 10), APS worker calling prosecuting attorney before magistrates leave at 5:00 PM (p. 10), worker usually getting to probate court magistrate to give testimony same day as order sought (p. 10), getting court order in 2-3 hours (p. 11), getting court order before 5:00 PM (p. 11), getting court order next day if after 5:00 pm (p. 11), worker has always been “fortunate” to get court orders the same day (p. 11); 3 to trying to put interventions in home before going to court to take rights away (p. 2); and 1 reference to guardianship taking place if person is not able to make decisions ex: dementia, Alzheimer’s, (p. 2), and 1 to magistrate asking what least restrictive measures have been tried, p. 2) (R10: 5 references to worker not doing too many guardianships: as stated, p. 12, 13; people not knowing the “finality” of guardianships, p. 12; worker trying really hard to get clients to address problems without court involvement. p. 13; talking and working hard with a client before filing petition to the court, p. 13) (R11: 18 references, including 14 references to seeking guardianship: “Guardianship, for me, is an absolute last, last resort” p. 7; “I will do anything and wait as long as I can to avoid that.” p. 7; having to step in when a person is in danger if they don’t get help or are removed from the environment, p. 7; making probate court referral, p. 8; documenting “actions tried” in probate court referral, p. 8; explaining why guardianship is needed in probate referral, p. 8; a lot of times probate referrals are based on medical issues, p. 8; showing a pattern of decline in decision-making to get a court order, p. 8; [seeking court involvement] when examples of not following through pile up “and I have a real case” p. 9; ex: client and family “not following through” with meeting needs, p. 9; getting a guardian when a doctor says “they really can’t make decisions” p. 9; “But then you have to be thinking, what I’m thinking is how is the guardian gonna make this any better?” p. 9; guardians can get services in there even against their will, p. 9; guardian being able to force services, p. 10;
and 4 references to seeking medical intervention: a lot of times probate referrals are based on medical issues, p. 8; ex: untreated open sore getting worse, p. 8, seeking court orders to get medical intervention is rare, p. 8; having to be life or death to get a court order for medical intervention, p. 8) (R12: 22 references, including 18 references to seeking guardianship: being confident they’re incompetent when seeking guardianship, p. 9; ex: not seeing outcomes of decisions, p. 9; [seeking guardianship] when “you’re puttin’ out fire, after fire, after fire.” p. 9; case ex: getting guardians for a married couple who were unsafe, p. 9; this case broke worker’s heart because she know they’d probably be removed from home, p. 9; getting a guardian to manage money when a financial emergency occurs, p. 9; being able to remain in the community with money management from a guardian (ex: moving from house to an apt.) p. 9; trying to get family involved before seeking guardianship, p. 10; case ex: of family requesting guardian to “be the bad guy” p. 10; trying to get family, friends to serve as guardian, p. 10; going through probate court for attorney guardian if no family/friends available, p. 10; magistrate asking what’s been tried, p. 10; case ex: of getting guardian for a person unable to take meds properly, p. 10; being able to tell magistrate worker tried timed med box, p. 10; exhausting all avenues before seeking guardianship, p. 10; presenting cases to clinical review prior to seeking guardianship or nursing home placement, p. 10; regular guardianship process taking 6-8 weeks to get on docket, p. 11; having to know the person is safe enough to be in the house 2 more months when seeking regular guardianship, p. 10; and 4 references to getting an order of protection: getting an order of protection when they demonstrate a lack of understanding of health consequences, p. 3; getting most orders for cellulites, diabetes, and gangrene, p. 3; “And like every single order I think I’ve ever gotten has had to do with the knees down.” p. 3; getting supervisor’s permission for seeking emergency court orders, p. 10) (R15: 1 reference: worker being happy that she’s only gone to court 3 times in 8 years doing this, p. 7)

Substantiating allegations (38 references by 8 workers) (R2: 2 references, “I think bottom line is- to substantiate is when somebody is going without food, medicine, heat, when they are noticeably going without something and it can be changed, and should be changed for their well-being.” p. 5; “There’s plenty more substantiated than unsubstantiated.” p. 6) (R5: 1 reference to substantiating but closing case due to person refusing services: “...I had him open the first time probably three or four months. And eventually- He consistently refused the help, he liked the visits but he didn’t want the help. And I had to say, at this point I’m going to end up, you know, I’m going to close out my part, but, you know, you can all me anytime. And be aware it’s possible someone may call me again, because they’re concerned. At which point I’ll come out and talk to you again, nothin’ scary, it’s just me again.” p. 11) (R6: 1 reference to substantiating most cases: “Let me think of a [substantiated] case. Which is the majority of mine.” p. 4) (R7: 8 references, including 7 to allegations being substantiated “doesn’t mean that we’re going to fix it”; including “That doesn’t mean that it’s...that we’re going to fix it, it just means that it’s substantiated.” (p. 3); “I can substantiate even cases that I don’t do
anything in.” (p. 3); choosing to act is a whole nother issue (p. 3); APS’ job is to say if it’s true or not, not to fix it. That’s hard for society to digest. (p. 3); APS is not about monitoring. Our job is to investigate and put services in place. (p. 10); APS is not code enforcement. (p. 11); It’s not APS worker’s job to “bail them out.” (p. 11) (ex: getting evicted), and 1 reference to substantiating allegations for a lot of different reasons) (R10: 2 references to substantiating if there’s a protective need: as stated, p. 3; substantiating due to mental and/or physical incapacitation, p. 3) (R12: 2 references to substantiating allegations on competent self-neglecters: substantiating self-neglect allegations sometimes when people are competent and don’t want to do anything about it. exs: roaches, not taking meds, p. 4; not having authority to intervene when competent people decline help, p. 4) (R14: 17 references, including 13 references to substantiating allegations but being unable to take action if the person is competent: not seeing enough to be able to take action, p. 2; “Okay, it would be substantiated, but yet there’s nothing I could do about it.” p. 2; seeing that the allegation did exist, p. 3; ex: like they didn’t have any food, p. 3; ex: refrigerator full of rotten food, p. 3; ex: not having insight into what they can do, p. 3; ex: having poor judgment, p. 3; substantiating allegations if the referral matches what the worker sees, p. 3; substantiating allegations but client being competent and refusing services, p. 3; ex: having no food, p. 3; ex: living in squalor and poor conditions, p. 3; client not wanting county involvement or services, p. 3; closing substantiated cases where there’s really not much worker can do about it, p. 3; and 4 references to substantiating allegations not always leading to desired outcomes: worker wanting to do more for people whose competency is impaired but they have a clean home, good hygiene, and a support system, p. 4; case ex: worker getting a lot of calls about a client who has end-stage Alzheimer’s that she needs to be in a nursing home, but to worker she was doing very well, p. 4; same ex: allegations substantiated but outcome was not what referral source(s) wanted, p. 4; same ex: the findings are there but [not] the outcome, p. 4) (R15: 5 references: substantiating allegations at the end of the investigation, p. 2; going back in 30-45 days to make sure, [things are good] p. 2; having put services in and eliminating risk [within 30-45 days] in most cases, p. 2; reassessing after putting services in and if everything’s good telling them “I won’t be back unless there’s another referral.” p. 2; documenting substantiation of allegations in report to the state and that services were put in place, p. 4)

Talking/explaining/communicating with clients (29 references by 7 workers)
(R1: 4 references to communicating with clients, including “Making clients understand,” not misleading clients, being truthful (p. 20), just giving information) (R2: 6 references to talking with clients, including recommending Meals-on-Wheels: “Aside from other reasons, it’s a contact that walks in the door every day.” p. 11, sitting down to talk with people, seniors misunderstanding APS worker intentions, looking at things on a personal level, respecting clients by being non-confrontational, asking seniors what services family is providing them ) (R4: 2 references, including identifying and explaining possible
consequences to seniors during home visits, for example “You understand the landlord'll have every right to kick you out” p. 13) (R5: 2 references: 1 about listening and avoiding rapid-fire questions (p. 3), 1 reference to talking with elders about housing and care planning) (R10: 6 references to explaining things to the client: explaining APS, p. 1; explaining in detail the nature of concerns, going step-by-step (2 references) as stated, p. 1, addressing all issues one at a time, p. 1; explaining why worker is seeking a psychiatric evaluation for the client, p. 13; explaining that if the case goes to court the client and worker can’t participate in the decision and “that alleviates your self-determination” p. 13; telling the client if worker is going to file a court petition, p. 13) (R11: 6 references to explaining concerns to client, including 3 references as stated, p. 1; explaining dangers, p. 2; examples: no pathways through home, p. 2; fire hazards, p. 2) (R16: 3 references to getting people to acknowledge that there's a problem: “In a perfect world they would see that there's a problem and they’d want help. That’s the first piece.” p. 2; “ ‘Cause that's often the hardest, just convincing them that they need the help.” p. 2; “So the perfect world would be the money to treat the problem and the acknowledgement by the client that there is a problem.” p. 3)

Approaching mental health services/psych evaluation (34 references by 7 workers) (R3: 4 references, including mental health services being the most declined service: “The hardest on is mental health counseling” p. 12; case ex: this guy had lost his wife, worker recommended counseling for depressions “Nope, Don’t need it. I’m not crazy. I’m not mentally ill.” p. 12; “A lot of times even the folks who have schizophrenia, you know, personality disorders, really difficult, really challenging to allow somebody to come into the home...just to build that rapport up.” p. 12) (R4: 4 references: “So I kind of like try to keep that case open as long as possible, so I can try to build that rapport and say ‘Hey, look, you know, I know somebody else...’ maybe not phrase it as ‘You need some mental health counseling.’” p. 12; “Hey, somebody who has more time in talking can come ‘n see you. Kinda slip it in that way.” p. 12; Usually it doesn’t work even that way. Very, very rarely.” p. 12; filling out the large quantity of required paperwork being a barrier to accepting mental health services “There’s so much paperwork to fill out, that the person’s like ‘Why do I have to fill out fifty pages of,’ you know, Hippa violations, all the regular papers. Insurance. They’re like, ‘No. Forget it.”’ p. 12) (R5: 6 references: working with clients who decline health/mental health assessments: “we’ll keep trying” “we’ll get ‘em in.” (p. 17), APS having limited ability to work with mental health issues (p. 18), Making referrals to physicians for depression (p. 19), “Mentally ill is not incompetent” (p. 19), “There’s not a whole lot we can do...you can make referrals...often their absolutely opposed and we end up essentially not being able to intervene like we’d like to.” (p. 19 excerpted), having had training about depression, p. 20) (R7: 9 references to mental health services: not accepting mental health services, p. 6; “In our mental health system, they have to be willing to take the services.” (p. 6); current cohort has stigma about receiving mental health services (p. 6); mental health services needed for depression, isolation, domestic violence, death of loved one, loss of home
or job, (all p. 6) (R10: 3 references: approaching need for psychiatric evaluation with client by framing it as “prove me wrong” p. 13; trying to avoid a court order for a psychiatric evaluation (2 references) (as stated, p. 13; explaining to the client that if it goes to court the client and worker can’t participate in the decision and ‘that alleviates your self-determination’ p. 13) (R15: 4 references to getting reluctant client’s to agree to a psych evaluation: you can ask the courts for a psych evaluation [if declined by the client], p. 7; worker is usually successful talking to them, p. 7; explaining to clients “If you go to a doctor and the psych eval comes back fine, you have the right, the right to still refuse these services.” p. 7; telling clients “So, you know, it would be to your benefit to, to go ahead and have a psych done.” p. 7) (R16: 4 references to resisting psychiatric and chemical dependency services: “Easily the most resisted [services] are psychiatric treatment.” p. 3; chemical dependency acknowledgment and treatment being resisted, p. 3; folks not wanting to be seen as crazy, p. 3; “Self-neglect folks tend to worry that people are gonna see them as crazy, so that, that’s the one that I think is the hardest.” p. 3)

Approaching abuse, exploitation, and neglect by others (16 references by 7 workers) (R1: 2 references to assessing helpfulness of kin, including “family can be crap” (p. 23), “family is not always good” p. 23) (R2:4 references re: worker can’t be as direct if senior lives w/ perpetrator, “fear factor” ) (R3: 3 references about confronting exploitive children or housemates: “You need to help.” p. 8; “I kind of like havin’ the conversation with the, you know, deadbeat kids.” p. 9; case ex: of adult child trying to screen worker’s contact with parents, p. 9) (R5: 1 reference to family members financially exploiting elders) (R7: 2 references to abusers leaving quickly, including “Yes, I can take care of that client, but…that abuser is gone.” p. 12) (R8: 1 reference to taking measures to remove older adults who are confused about abuse or neglect going on, p. 1) (R9: 3 references to approaching seniors about their giving everything to their adult children: acknowledging “it’s your right to give everything to your children” p. 9; pointing out possible consequence of homelessness to client giving all his/her money to children, p. 9; “You can’t stop it.” p. 9)

Prioritizing client’s rights/needs [over community desires] (44 references by 6 workers) (R3: 22 references: Delaware County almost “forcing” services, p. 2; [honoring client’s rights to take risks] “If no one else is gonna be harmed.” p. 2; small communities having “skewed” ideas about letting people live how they want, p. 2; people in small communities being more likely to know somebody in government, p. 3; case example of worker defending client’s right to live how he wants to supervisor: client living on an acre of land in the country, no one else was around in that neighborhood area in a different township, so they couldn’t have city code come in, code saying “Well, it’s on his [land].” p. 3; giving client the “benefit of a doubt” re: time to make needed home repairs, p. 3; worker getting pressure from APS and community to evict a person, p. 3; recognizing there are different APS standards in different communities [ex: Franklin vs. Delaware Counties], p. 4; getting more referrals from
professionals in affluent communities “However we treat ‘em all the same.” p. 4; case ex: of wearing clothing with some urine smell in an affluent neighborhood, p. 4; same case ex: going out in stained clothing in an upscale neighborhood, p. 4; same case ex: of getting referrals from Upper Arlington [affluent suburb] five times about a lady not washing her clothes, p. 4; “I guess in Upper Arlington, if a person’s out at the bank and they shouldn’t maybe be smelling the way they might, or maybe have a little small stain on them, they’re gonna be like ‘Well what’s this elderly person out here driving? She’s a little bit confused how can she be driving? etc.” p. 4; affluent suburban standards creating a “big problem” when there really isn’t one, p. 4; affluent communities throwing community morals/standards at people, p. 5; requesting guardianship doesn’t happen often in Franklin County, p. 14; worker never having filed for guardianship in Franklin Co., p. 14; worker filing like seven times in two and a half years working in Delaware Co., p. 14; pushing guardianship in Delaware Co., p. 15; the community expecting results in Delaware County, p. 15; professionals calling in referrals in Columbus usually don’t second-guess APS investigations, “…we don’t hear from ‘em again. Like, ‘Alright, they did their job. They must be ok.’ Whereas in Delaware it’s a whole different mindset of, you know, this person cannot live like this.” p. 15; “That’s why I switched from Delaware to come down here, ‘cause I thought, you know, I’m tired of doin’ what the community wants rather than what the client wants.” p. 15; “You can’t just put everybody in a nursing home. However, that was a typical thing to do in Delaware.” p. 15)

(R4: 4 references to case ex: of not substantiated against community wishes: single man, never married, dirty home, roaches, dirt floor, cast iron old wood oven, pumped own water, had a toilet, taking care of sewage appropriately, so no health dept. referral could be made, “that’s the way they always lived.” (p. 3), one room, basically an old shack, no fire hazards, no trash all over, “that was not substantiated against community wishes” p. 3) (R5: 4 references, including 2 to APS having a difference consideration of risk than the community including “ a couple of roaches won’t kill you” (p. 2) and 2 references on p. 7 that people in the community/family sometimes want APS to “force” things, but they won’t if the person is alert and oriented, frequently telling other professionals and community members “This is their right, this is their choice...etc.” {great quote p. 7}) (R9: 3 references to always erring on side of client’s rights, p. 8) (R10: 8 references, including 7 to basing APS decisions in Franklin County on client needs, not community desires: in Franklin Co. the APS principles tell you you don’t worry about what the community thinks, the client comes number one, p. 15, 16; worker consulting with collaterals to factor in their opinion, but it’s just that, an opinion, p. 16; when you worry about what everybody else thinks you lose the focus of advocating for your client, p. 16; Having 2 great supervisors in Franklin Co. who have that philosophy, p. 16; client coming first over family, friends, neighbors, community, p. 16; Franklin Co. being a great place to work because workers all share innate kind of social work thinking [principle that client comes first], p. 16; sympathizing with workers in counties who get more pressure from what the perception of the community will be, p. 16; and 1 reference to people not understanding
APS principles of self-determination and Freedom over Safety, p. 8) (R16: 3 references to community members desiring change: “I get a lot of “How can you let somebody live like that?” p. 4; “...I often say it’s not disruptive to them. It’s more disruptive to clean everything up.” p. 4; “We get a lot of police officers, fire fighters, and stuff saying, ‘Oh, you’ve gotta go condemn this house.’” p. 4)

Identifying services accepted by seniors (19 references by 6 workers) (R4: 1 reference to most seniors accepting Meals-on-Wheels) (R5: 1 reference to ERS button and Meals-on-wheels are accepted, homemakers are a “tougher sell” than meals, personal care is least accepted, p. 15) (R7: 4 references: Emergency Response System being accepted by seniors because it gives independence, (p. 5); Meals-on-Wheels not being accepted as much because “they’re not cooked the way I cook.” (p. 5), transportation services are “definitely” accepted by seniors (exs: Red Cross, Senior options), (p. 6); visiting physician services are usually accepted by seniors, p. 6) (R8: 4 references to seniors accepting service recommendations, including homemaker services, personal care, and an emergency response button being the most accepted services (p. 12), Meals-on-Wheels and adult daycare being accepted by some (p. 12), APS intervention being least accepted due to the investigative, personal nature of APS, p. 12) (R9: 3 references to delivered meal services being the most accepted and most rejected service, mentioned twice as stated, p. 6, “Cause either they like ‘em a lot and they’re savin’ ‘em money, or ‘I don’t like ‘em. They don’t taste right because they’re diabetic, they don’t have any spices...” p. 6) (R13: 6 references to clients accepting formal supports: clients allowing formal supports [being optimal in care planning process], p. 4; exs: passport visiting physician, p. 4; nurses to monitor, administer medication, p. 4; clients optimally being willing to allow formal supports to remain as independent as possible, p. 4; being more willing to accept homemakers, exterminators, and visiting physicians, p. 5; being more reluctant about an attorney or third party handling their finances, p. 5)

Gaining access to homes (including challenges and strategies) (18 references by 6 workers) (R1: 4 references, including 3 references to strategies for handling dogs on home visits: worker whistling to get dog’s attention when she sees “beware of dog” signs on gated fences, p. 2; getting dog treats to take, p. 2; “Let me give ‘em a little something. Maybe they can eat in the dining room.” p. 2; gaining access to the home) (R2: 2 references to having door slammed in face, including willingness to have it happen several times) (R3: 3 references to it being challenging to get into homes: “It’s a challenge right at first, from the start. Basically even trying to get into the home itself is a challenge.” p. 1; “…it’s always just a hassle tryin’ to get in.” p. 1; “So it’s always a challenge.” [to get in], p. 1) (R4: 2 references to not having problems getting in the house [unlike larger counties]) (R9: 4 references to calling a client before visiting if there’s a dog that needs to be put out or some other type of danger identified by referral source: 2 references to dogs, p. 1; 2 references some other type of danger, p. 1) (R14: 3 references {counted under “approaching home visits”})

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rapport and respecting them to get in the house, p. 1; worker probably having a 99 percent rate of getting in, p. 1; using “I’m from Franklin County Office on Aging” to get in the door, p. 6)

Working with clients who resist intervention, including strategies (15 references by 6 workers) (R1: 5 references, including 2 about compromising with clients [including compromising about housing]; calling a client who has declined home visits, strategies for working with seniors who refuse to leave their home such as getting home-delivered meals, visiting physicians, and expediting guardianship, monitoring clients over time) [2 references]) (R2: 2 references: talking about services with resistant clients, “putting everything out in black and white”) (R5: 1 reference {mentioned and counted elsewhere} to working with clients who decline health/mental health assessments “we’ll keep trying” “we’ll get ‘em in.” p. 17) (R7: 2 references: providing resource information to seniors, offering services without shaming or embarrassing) (R11: 1 reference to keeping first visit short if sensing resistance, p. 2) (R15: 4 references to getting reluctant client’s to agree to a psych evaluation {counted under “approaching mental health services”}: you can ask the courts for a psych evaluation [if declined by the client], p. 7; worker is usually successful talking to them, p. 7; explaining to clients “If you go to a doctor and the psych eval comes back fine, you have the right, the right to still refuse these services.” p. 7; telling clients “So, you know, it would be to your benefit to, to go ahead and have a psych done.” p. 7)

Addressing clients’ desire to know who called on them (12 references by 6 workers) (R2: 3 references: referrals asking “who turned me in?” p. 1; responding to “Who turned me in” by explaining someone cared about you, p. 21; protecting referral source confidentiality, p. 21) (R5: 2 references including worker not looking at the “screen” so she can honestly say “I don’t know.”) (R6: 1 reference: “They always want to know who did it, who called us” and it’s anonymous, so we cannot tell them, p. 2) (R8: 1 reference to APS workers being asked to leave due to not telling who made the referral, p. 8) (R9: 2 references to not identifying referral source: as stated, p. 1; worker not taking info on referral source to home visit so he never slips and tells, p. 1) (R11: 3 references to explaining confidentiality laws: not identifying referral source, p. 1; some people refusing to talk because worker won’t identify referral source, p. 1; some people not understanding confidentiality laws, p. 1)

Advocating for independence [trying to keep people in their homes and/or in the community/trying to avoid nursing home placement] (29 references by 5 workers) (R2: 3 references to advocating for independence: worker discussing concept of independence with seniors, advocating for independence) (R3: 6 references about trying to keep people in their homes: case ex: of man with cognitive deficits continuing routine self-care activities “Well, he’s kind of in this routine. I can’t really force him out of his home.” p. 7; “Cause sometimes I think the home environment’s gonna be better, I think, than a nursing home that he is not familiar with.” p. 7; same case ex: “He doesn’t like talkin’ with a lot of people, so maybe the
crowd's gonna be worse for this person.” p. 7; “He likes kinda bein’ a homebody, nobody in his business. But got along really well at home. “ p. 7; same case: “[He] was gone mentally, but he showed me that, you know, he’s livin’ his life how he wants to, he’s not hurtin’ anybody else. Ok. He can stay in the community.” p. 14; “You can’t just put everybody into a nursing home.” p. 15) (R9: 18 references, including 13 references to providing services to keep people in the community, including putting services in place, p. 3; providing services to keep people in the community, p. 6; “You get literally the services in there to keep ‘em in the home...” p. 6; doing major cleaning, p. 6; home making, p. 6; escort services, p. 6; transportation, p. 6; meals, p. 6; using “First Corp” for financial services, if they’ll allow it, p. 6; trying to help people remain in the community with services, p. 8; getting a guardian for finances (3 references) as stated, p. 3; being able to remain in the community with an attorney’s (guardian) assistance with finances, p. 3; friends helping with chores but not getting into finances, p. 3; and 5 references to trying to avoid nursing home placement: as stated, p. 8; trying to keep people in community a little longer, p. 8; a lot of times they don’t want a nursing home, p. 8; trying to find any means they can remain in the home, p. 8; trying to help people remain in the community with services, p. 8) (R12: 2 references: “People would be so much happier at their home.” p. 8; “And to me...the biggest thing would be able to keep people at home.” p. 8) (R13: 1 reference to trying to keep people in home with services, p. 4)

Keeping cases open/closing cases (25 references by 5 workers) (R1: 3 references, including “You can’t keep a case open for potential” (p. 12), finding reasons to keep cases open, example of case closing) (R5: 7 references, including 4 references re: It’s rare that one visit spurs change, including usually not closing case on one visit (p. 13), “Cause people put up a good front, I always go at least twice, of not three times.” (p. 13); and 3 references to keeping cases open, including keeping open under a different classification for monitoring, keeping same APS worker for monitoring, keeping cases open for pending court action can take months) (R7: 2 references to having 30 days in Franklin County to determine if allegation is true, can push it to 45. Ex: monitoring over time (30-45 days) to assess dementia in 90-year-olds whose competency fluctuates, p. 5) (R11: 3 references: having 30 days to make the determination to close the case, p. 5; closing cases if not adding services, p. 5; keeping cases open another 30 days for monitoring, p. 5) (R15: 10 references, including 7 references to closing borderline cases when services are in place: worker feeling more comfortable closing borderline cases when services are in place: “...and I feel pretty good about [it when] there’s eyes involved, there’s somebody in there that’s seeing this person each day.” p. 4; “Somebody there is gonna see them every day.” exs: home health agency, home-delivered meals, p. 4; worker thinking she’ll get another report if this is happening [service providers are observing client] p. 4; “So with those [borderline cases], I really pretty much close them? And I know that I’m going to get another referral.” p. 4; backing out when home-based services are in place, p. 5; “the home-health agency’s gonna let me know whether or not things have been good.” p. 5; “If they’re non-
compliant, and they pull out, then I get a call.” p. 5; and 3 references to opening ongoing 6-month cases: asking at-risk clients that need more help than can be provided in 30-45 days if they want to continue to work with her on a monthly basis for 6 months, p. 5; state requiring case plan for a 6-month ongoing case, p. 5; listing with ongoing clients what worker can do, p. 5)

Involving/working with family (21 references by 5 workers) (R1: 2 references: calling family and doctors to consult/confirm information, receiving calls from children) (R5: 6 references: trying to be more open with family in cases of self-neglect (p. 4), encouraging client to share info with family, others (p. 4), getting verbal consent to speak to family (p. 5), worker calling daughter (p. 5), family can be “panicky” about conditions that aren’t that bad to APS (p. 7) having family come to assist with crisis rather than using ambulance or court orders when possible, p. 9) (R8: 3 references, including trying to work with family to get situation resolved (p. 2), Seeing if there is family willing to provide care (p. 11), in a perfect world family and home health agencies would coordinate with each other, p. 11) (R11: 3 references to working with family: trying to get family involved, p. 9; explaining to family “this is not ok for mom or grandma to continue living this way” p. 9; having a “real case” [for seeking court involvement] when client and family “not following through” p. 9) (R13: 7 references: working with family, p. 4; helpful family involvement being optimal care in care planning process, p. 4; APS providing nudge for person to say “Oh. Well we don’t really want the government involved. I’d rather have family.” p. 4; Family being willing to help but not wanting to overstep boundaries with parents. Ex: role reversal, p. 4; worker wishing to see parents allowing children to assist them, p. 4; ex: family having access to services and financial resources in Franklin County (16 references by 5 workers) (R5: 1 reference to Franklin County has a sliding fee scale for services through “Options” program) (R7: 8 references including: smaller counties (Ex: Monroe) are unable to put services in place (2 references, p. 3, p. 10), Franklin Co. is very lucky to have a contract with a psychiatric services company (p. 9), Franklin Co. contracting with competent psychological services, p. 9) (R10: 1 reference: There’s never enough services, but Franklin County Office on Aging and other Franklin Co. agencies try very hard to fill the gaps, p. 8) (R11: 1 reference: being blessed in Franklin County to have many services and some money to help clients, p. 6) (R14: 5 references to clients benefiting from free access to Meals-on-Wheels in Franklin County: being able to get Lifecare Alliance [Meals-on-Wheels] without paying for it in Franklin County, p. 6; worker having many clients that would have a co-pay otherwise, p. 6; Lifecare Alliance waiving co-pay, p. 6; “So the Meals-on-Wheels keeps them going.” [people who can’t cook] p. 6; “That one day a meal [sic] keeps them in reality.” p. 6)
Approaching elder self-neglect gently, “with a softer touch” than neglect or exploitation by others (13 references by 5 workers) (R5: 6 references, including worker being “Very soft, very ‘just concerned about you.’”) (p. 1), APS worker being “slow and careful” in approach to elder self-neglect (p. 1), “working your way in slowly” (p. 2) and 3 references to trying to not be “scary,” including avoiding “I’m here with the government and we’re doing things my way.” (p. 2), and “It’s scary enough without checking off a clipboard.” (p. 3) (R6: 3 references; going “gently” into the reasons for the home visit, p. 2, letting clients know “we’re from the office on aging” and then later specifically identifying Adult Protective Services, p. 1, worker waiting for the client to tell them problems or needs. Ex: “I usually go in just waiting for the client to tell me.” p. 10) (R7: 2 references: 1 reference to approaching self-neglect with a “softer touch” than neglect/exploitation, p. 6; 1 reference to listening to their problems “Maybe they don’t wanna necessarily do anything about it, but no one has ever listened to them to hear what their problems are.” p. 1) (R11: 1 reference {counted under “explaining to clients”} to trying to explain role to clients in a non-threatening way, p. 1) (R14: 1 reference {counted under “approaching home visits”} to not coming on too strong, p. 6)

Recognizing that [competent] people are allowed to be dirty, live in filth/clutter (8 references by 5 workers) (R3: 2 references: “People are allowed to be dirty.” p. 4; “I really think that people are allowed to live however they wanna live.” p. 13) (R7: 1 reference to “People do have the right to live in filth.” p. 10) (R8: 2 references: adults can make their own decision about staying in their environment or not (p. 1), respecting competent senior’s right to choose to live in a deplorable situation, p. 14) (R14: 1 reference {counted under “assessing decision-making”}: recognizing that both competent and incompetent people can live in filth: “And then I have people that are incompetent that also live in filth. So, hygiene and cleanliness is not always a huge factor.” p. 4) (R15: 2 references: “Because that’s their right [clutter], and it might be the way they lived their whole entire life.” p. 7; “... ‘n they have the right to choose.” p. 7)

Approaching hoarding (24 references by 4 workers) (R3: 2 references: case ex: “She didn’t trust anybody to go in her home and throw out stuff. I did, one day, for six hours, stood there and went through this narrow walkway to clear a spot for her to sleep in her bed. Six hours, but holding up each individual paper and saying...Do you want it?” p. 11; worker thinking they need to stop newspaper delivery, p. 12) (R5: 2 references to hoarders sometimes “fearing” outsiders, p. 1) (R13: 17 references: explaining beforehand to hoarders that if their approach [to improve home conditions] isn’t working APS will intervene, p. 8; “...it’s kind of a give and take.” p. 8; hoarders being hardest to deal with because they have an attachment to their possessions, p. 8; “...that’s really been difficult in working with them.” p. 8; trying to clear a pathway in one room at a time, p. 8; explaining risk to community, neighbors, p. 8; ex: “vermin can go next door,” p. 8; ex: “I have to look out not only for you, but I have to look out for those that are around you.” p. 8; worker bringing up to possibility of calling code enforcement for health issues, p. 8; explaining “I’m willing
to work with you but only to a certain point.” p. 8; hoarders being one of the hardest cases to work with because they feel like there’s meaning with those possessions, p. 9; “It’s more than a possession to ‘em a lot of times. It’s like that’s their existence, you know. It’s proving that this is who they are because they’ve collected these things.” p. 9; [possessions] having worth to them so it’s really hard for them to get rid of them. p. 9; married couples having a great loss [ex: children] going to thrift stores then it explodes from there, p. 9; thrifting as shared activity, p. 9; “If you take that away from me, what else do I have left?” p. 9; “It’s almost like it gives them something to thrive on.” p. 9; [possessions] having worth to them so it’s really hard for them to get rid of them. p. 9; married couples having a great loss [ex: children] going to thrift stores then it explodes from there, p. 9; thrifting as shared activity, p. 9; “If you take that away from me, what else do I have left?” p. 9; “It’s almost like it gives them something to thrive on.” p. 9) (R16: 3 references to approaching change gradually: “I don’t think you can come in and just change the whole life around. Especially like with the hoarders.” p. 4; “What we know about that is, you know, that [abrupt change] doesn’t work.” p. 4; case example of abrupt changes not working: family brought in a garbage bin, “...as they’re hauling stuff out and throwing it away, mom and dad are coming back in through the front door with the stuff, and it caused them a lot of anxiety, and the family couldn’t understand that.” p. 4)

Approaching ethical dilemmas and decision-making about balancing self-neglect with self-determination (22 references by 4 workers) (R10: 7 references: worker having to keep honestly looking at APS principles [freedom over safety] and asking “…what am I doing as a social worker, how am I handling this?” p. 8; “There’s tons of ethical dilemmas in this job.” p. 14; By trying to control every risk for everybody you take away freedom over safety, p. 15; worker thinking about “Freedom over Safety” every time she goes out, p. 15; worker thinking about worker liability (2 references) p. 15; always trying to err on the part of the client unless there’s significant harm or danger, p. 15) (R12: 3 references to worker operating off the “do not harm” mandate: as stated, p. 11; worker considering if her actions will cause harm, p. 11; ex: putting some people in a nursing home would crush them and they would die, p. 11) (R14: 5 references to making difficult decisions on a case-by-case basis: looking at it on a case-by-case basis, p. 4; “It is tough because there’s a lot of gray areas.” p. 4; ex: “So, sometimes I’m leaving people in unsafe situations that could go bad rather quickly.” p. 4; worker having to make a difficult decision, p. 5; “so it falls on me. I guess.” p. 5) (R15: 7 references to looking at the “three biggies” to distinguish self-neglect from self-determination (food, shelter [including bill paying], clothing [self-care]): “Well, you look at the three biggies.” p. 7; “Are they paying their bills, are they gonna lose their shelter.” p. 7; “Are they eating, are they bein’ able to get food?” p. 7; “And, are they taking care of themselves.” p. 7; “If those three things. If they’ve got food, they’ve got shelter, they’ve got clothing...I’m pretty much gonna overlook the clutter.” p. 7; “So if those three biggies hit me, that ‘Well, you’re gonna be evicted. You know? You, you aren’t making the good choices for yourself, therefore you’re not paying you’re bills, therefore you’re gonna lose your place to live and, and I ca-I have to help you. Let’s work on this together.” p. 7; “I just go right back to three biggies, ’n make sure that that’s what they have...” p. 7)

Approaching finances with seniors (20 references by 4 workers) (R6: 5
references including: Seniors don’t want to pay for services (p. 15), treatment approach to seniors who don’t want to pay: worker presents 3 insurance plans, asks senior to decide. (p. 15), treatment approach to seniors with no money: “Some of them that have no money will refuse the services, then you can say ‘you know I can help you with that, we’ve got a program that would put that in here for nothin’!’ And then, then they’ll accept it.” (p. 16), explaining conservatorship to seniors (2 references) ex: “You will know this person. This person will be talking to you.” (p. 16), ex: you can tell the conservator how much spending money you need, p. 16) (R11: 7 references to addressing financial concerns: a lot of clients accept services but then decline when they find out there’s a ten dollar co-pay, p. 6; explaining the need for services to the client and discussing finances. “You can afford it.” p. 6; free services are usually accepted, p. 6; when you take away the money aspect, most people will accept Meals-n-Wheels, housekeeping, transportation, and the ERS button, p. 6; nothing’s free unless you’re eligible, p. 6; for most seniors, if it’s not free it’s a low co-pay, a few dollars for each hour of service and they can afford it, p. 6; “The money is the biggest issue.” p. 7) (R13: 2 references to being only able to offer clients conservatorship or money management assistance for financial management needs in Franklin County: Franklin Co. Probate Court being only willing to do conservatorships now (used to do POA’s but quit because they needed more oversight), p. 4; being only able to offer conservatorship or money management agencies like First Corp. or Pauline Home, p. 4) (R14: 6 references to resisting financial involvement [e.g. divulging income, paying for services] being a barrier to getting services: resisting people being in their finances, p. 5; “I think that would be number one.” [most resisted service], p. 6; needing to give up income amount to get services, p. 6; “…and sometimes that is something they will never part with.” p. 6; leaving people [without services] that would benefit from services and are probably eligible but won’t share [income verification], p. 6; ex: “They tend to like Meals-on-Wheels, but they may not wanna pay for it.” p. 6)

Not having the means to get clients’ help: experiencing insurance, eligibility, and funding barriers (17 references by 4 workers) (R1: 6 references to experiencing program financial eligibility issues: including service programs not accepting insurance, Medicaid ineligibility, being Medicaid eligible for homemaker services only if you’re impoverished, having an “atrocious” Medicaid spenddown, being over income for programs, clients more inclined to accept free services) (R2: 3 references, including not having a visiting doctor program, not having enough funding, worker having difficulty keeping track of insurance programs) (R4: 4 references to insurance/ eligibility/ funding barriers to getting services, including not qualifying for services, needing home services without having to meet passport level of care, other counties (ex: Franklin) having more services and funding than [rural] counties, “We have none. None. If you don’t qualify for Medicare or Medicaid for any home health services...there’s nothing unless you private pay.” (p. 6), ex: lacking funding for Emergency Response Buttons) (R13: 4 references to home support resources sometimes being unavailable: as stated, p. 4; ex: income eligibility
barriers, p. 4; client being willing to accept services but slightly over income and unable to pay for them, p. 4; clients ideally fitting within income eligibility requirements and having resources available in community to remain as independent as possible, p. 4)

Honoring people’s right to refuse services (15 references by 4 workers) (R8: 4 references, including having the right to make decision to decline cleaning services (p. 8), refusing to go to hospital (worker got order of protection) (p. 10), APS intervention is the least accepted service (compared to Senior Options, homemakers, personal care, etc.), p. 12) (R9: 2 references to refusing services: elders not accepting services, p. 3; dropping case due to client refusing services, p. 8) (R12: 7 references to worker understanding clients not allowing for services: as stated, p. 7; people typically either accepting all available services or none, p. 8; “And sometimes you can’t even blame people for not wantin’ people in their home. They’ve been stolen from before.” p. 8; ex: “My neighbor, they had their mother living with them for a while, and their help would come and be on the phone the whole time, and not work.” p. 8; “I’ve had cases I’ve investigated where it’s the home health aide who has stolen a book of checks, and exploited them.” p. 8; people resisting change, p. 8; resisting upheaval of what you don’t know, p.8) (R15: 2 references: having the right to refuse services, p. 2; “…I tell ‘em up front that they have a right to refuse any services that I have to offer as long as I find they’re in their right mind.” p. 2)

Utilizing Meals-on-Wheels/other in-home meal program (8 references by 4 workers) (R4: 1 reference: Having easy access to Meals-on-Wheels due to working in a small community “We don’t necessarily have to make a formal MOU like everybody else does”) (R7: 1 reference to new meals that are “catering” being available where the client can pick what they want. (frozen, delivered weekly) (R14: 5 references to introducing Meals-on-Wheels: a lot of them don’t know they can get Meals-on-Wheels, p. 1; thinking Meals-on-Wheels is for other people, p. 1; ex: even if their income is only 500 dollars a month, p. 1; “they always think it’s [Meals-on-Wheels] for someone else.” p. 1; [thinking Meals-on-Wheels is for other people] even though their income may be way below the poverty level, p. 1) (R16: 1 reference to having levy funds [in rural county] to pay for Meals-on-Wheels if someone can’t pay a donation, p. 3)

Not substantiating allegations (11 references by 3 workers) (R7: 6 examples of reasons for not substantiating: neighbors don’t get along, children overreacting, clients understanding consequences that they’re living in (p. 4), some mandated reporters reporting non-stop (ex: nurses reporting dirty home), reporters lying, family members causing trouble) (R10: 3 references to not substantiating cases when the person has full mental and physical capacity and it’s a lifestyle choice, a pattern, not a decline because of incapacity: as stated, p. 3; not substantiating when capable and you gather history that their ADL’s fit a pattern and is the norm for them, p. 4; making life choices not being due to decline, impairment, or incapacity, p. 4) (R15: 2 references to finding allegations unsubstantiated: worker not going back if she doesn’t feel there’s anything they need and
there wasn’t a risk, p. 3; closing case, informing client, leaving card, and offering help if anything changes, p. 3)

Assessing adequacy of current services (R3: 3 references to assessing service utilization and making adjustments when APS gets another referral: “I hope they’re still gettin’ services, but when they do come back, we can look ‘em up in the system and it still says ‘Oh yeah, they’re gettin’ homemaker, and home-delivered meals, and emergency response.’” p. 14; “…I see that once they get the service, they stay with the service.” p. 14; adding new services upon getting new referrals, p. 14) (R7: 1 reference) (R10: 1 reference to gathering info regarding collateral sources, support systems, services involved, past services, informal supports, p. 1)

APS being unable to provide long-term monitoring [APS being a short-term intervention] (5 references by 3 workers) (R3: 2 references: APS workers visit and leave, so they can’t provide ongoing monitoring, p. 2; “I can [only] see their long-term once they come back into the system? ‘Cause we only have ‘em for thirty days.” p. 14) (R12: 2 references to APS being a short-term intervention: as stated, p. 6; [short-term intervention] being optimal for self-neglecters who are competent, p. 6) (R13: 1 reference: APS can’t do the constant follow-up, p. 5)

Providing community education about people’s rights (12 references by 2 workers) (R3: 3 references: “Just that they have the rights to live however they want to. Yeah. It’d be great to talk to the professionals about it, and then also to just people who are living in the community. Neighbors, family members.” p. 13; “So I think we do that somewhat now, talkin’ to neighbors and professionals.” p. 13; “So I think we try to educate the community.” p. 13) (R11: 9 references to explaining competency laws and client’s rights to the public: referral sources wanting APS to take action, p. 3; explaining competency to other people is the hardest thing, p. 3; going by the law [that people have rights] p. 5; having to explain the law that “this person has rights” [to physicians] all the time, p. 5; a lot of competent people make bad decisions, p. 10; getting calls every day on competent people doing crazy things, p. 10; the average person doesn’t realize the law, p. 10; the average person and referral sources not understanding that competent people can make their own decisions and might not want help, p. 10; “You are your own person ‘til the court says you’re not” p. 10)

Acknowledging clients’ loss and fatigue (10 references by 2 workers) (R1: 4 references, including 2 to case example where client’s wife had just passed away, p. 9; case ex: of normal grieving process including “I’m not gonna do the laundry today’ issues,” p. 10) (R5: 6 references: recognizing “seasons of loss” (p. 20), expressing empathy for losses and treatment fatigue (p. 20), worker expressing importance of clients being free to express fatigue and sadness and suicidal/homicidal thoughts (ex: “I’m tired of being sick” (p. 20), “I swear to you I could just kill him” (p. 21) “I’ll just tie her to the bed, she won’t get up.”(p.21), such statements are often not threats but expressions of client/caregiver fatigue, p. 21)
Switching to a district case assignment system in Franklin County (8 references by 2 workers) (R12: 7 references: as stated, p. 7; assigning cases to same APS worker, p. 7; worker happy about district system, p. 7; “pro” to getting same client reassigned is having an established baseline, p. 7; “con” is worker might have preconceived notion and not have as open mind as with somebody unfamiliar, p. 7; “con” is workers’ having different work ethics, p. 7; “con” is that if you get a crummy worker you might not get the same service or intervention as from a different worker, p. 7) (R13: 1 reference to APS workers working in different districts on different sides of town, p. 11)

Allowing people time to address the problems themselves/approaching change gradually (5 references by 2 workers) (R11: 3 references to allowing people time to address the problems themselves: being patient with clients and giving them the opportunity to do what they think they can do to make it better, p. 9; waiting a “reasonable amount of time to let this person do things for themselves...” p. 9; “So I take it as far as I can in my eyes, to help, and to give them time...” p. 9) (R16: 2 references to approaching change gradually: approaching change gradually, p. 4; “I don’t think you can come in and just change the whole life around.” p. 4)

Looking at things legally (4 references by 2 workers) (R2: 2 references, including “we can’t legally make them talk to us”) (R10: 2 references to worker thinking about her own liability, p. 15)

Leaving information with/for client (4 references by 2 workers) (R5: 3 references, including explaining it in a non-threatening way, encouraging client to share info with family, others, p. 4) (R6: 1 reference to leaving a card if no answer unless there’s an alleged perpetrator involved, p. 1)

Looking for points listed in the referral (3 references by 2 workers) (R5: 2 references, including finding things not listed on referral, p. 11) (R7: 1 reference to assessing referral accuracy, p. 1)

Considering extended care facility [ECF] placement (3 references by 11 workers) (R6: 1 reference to placing a person with dementia in a nursing home, p. 7) (R13: 2 references to considering ECF placement: looking at ECF placement if clients’ not allowing needed home support services, p. 4; worker typically trying to not do ECF placement unless really necessary, (trying to keep people in home with services), p. 4)

Calling health department/code enforcement (2 references by 2 workers) (R6: 1 reference to worker threatening to contact the health department “‘Cause she’s a hoarder and refusing any kind of help, and the ceilings are fallin’ down and the house is actually fallin’ down around her. So I was gonna pull that card out.” p. 11) (R13: 1 reference to neighbors calling code enforcement, p. 10)

Approaching elders living in homes where crack is used (R14: 12 references:
they demonstrate understanding] by talking about living in a crack house, p. 7; living in a crack house is very common, p. 7; there’s a lot of drug activity, p. 7; “Drugs doesn’t necessarily make a bad caregiver.” p. 7; “Like a lot of the caregivers are on drugs.” p. 7; “that’s a reality.” p. 7; getting a lot of referrals about that, p. 7; people making judgments that crack is worse than alcohol, p. 7; “I mean there’s nothing that makes a crack addict a bad caregiver.” p. 7; if a client knows it’s going on and have insight, worker would probably not do anything other than letting them know the dangers, p. 7; if they don’t understand, worker would step in and do more, p. 7; “They may wanna stay there, but that’s not gonna work.” [if they don’t understand they’re living in a crack house], p. 7)

Assessment and intervention differing among APS workers [and between APS and other disciplines] (R12: 10 references: “It’s not a science” p. 7; “it’s kind of an art, not a science” p. 7; workers having different philosophies on freedoms, choices, competency, p. 7; assessment/intervention is not standard, p. 7; workers trying to make it as standard as possible, p. 7; nurses and doctors operating from a medical model will think something is terrible while APS worker might thing it’s comparably clean, p. 7; APS case managers having different standards, ex: looking for exploitation, p. 8; intervention is not a science, p. 8; there’s not a formula you can follow to get the same outcome, p. 8; everybody has a different approach, p. 8)

Keeping a person in the community who has informal helping systems (R9: 8 references, including 4 references to an optimal outcome being when informal helping systems arise: “more perfect” is when family member is willing to become power of attorney and make sure everything is paid and they’re not a perp, p. 6, most perfect thing is when “informal helping systems come out of nowhere” p. 6, ex: family [niece, granddaughter] who had no idea there was a problem, p. 6, case ex: son came and took his dad back to Texas with him, p. 6; 3 references, p. 3; looking at formal and informal helping systems and do they want them, p. 8)

Seniors already having/preferring a Senior Options casemanager (R8: 7 references, including consulting with Sr. Options CM (p. 8), older adult referring APS worker to Senior Options casemanager, p. 8) seniors perceiving Senior Options as helping, APS not (p. 12), seniors preferring senior options services because they’re less intrusive than APS services (p. 12), APS asking more personal questions than senior options because it’s an investigation. Ex: financial questions, p. 12)

Acknowledging and addressing client’s intimacy needs (R9: 6 references: worker acknowledging and problem-solving regarding male client’s sexual needs to avoid conflict with prostitutes, p. 9; ex: recommending adult daycare as a way to meet women, p. 9; worker getting “flack” from another agency regarding honoring men’s desire for sex, p. 9; workers at another involved agency being “pissed” about worker suggesting adult daycare as away to meet women and making a complaint to worker’s supervisor, p. 9; worker’s supervisor supporting worker problem-solving
Educating clients about the importance of nutrition for healthy brain function  
(R15: 6 references: making standard speech “Because, if you’re not feeding your brain, you’re not gonna be able to think.” p. 4; “And, a lot of times, because we are inactive, we’re sitting around all daylong, you don’t feel hungry, but you still have to feed your brain.” p. 4; “You still have to do that [eat] so you’re gonna be thinking clearly.” p. 4; “And those are things that you can do for yourself, you do that for yourself, and you’re never going to have to leave this house.” p. 4; using remaining at home as incentive for eating, “So, you know, it’s an incentive…” p. 4; making standard speech “even if you don’t feel hungry, get yourself somethin’ to eat anyway.” p. 4)

Referring client to a volunteer organization for assistance (R15: 6 references: identifying “Circle of Caring” organization, p. 6; it has about 89 volunteers, p. 6; they kinda got locked into two things: providing transportation and building ramps to code, p. 6; they provide retired manpower, you pay for materials, p. 6; ramps quickly became their main service vs. making regular visits, p. 6; worker still referring people but it doesn’t seem to be happening like she thought the program would, p. 6)

Assessing suicidal/homicidal statements (R5: 5 references, including “Netcare is very specific… I will go a little beyond that” (p. 19 excerpted), talking about suicidal statements, asking about direct death wish statements “would you actually hurt yourself?” (p. 19), assessing suicide plan vs. expressing fatigue (p. 20), recognizing that clients need to feel safe to express grief and fatigue and that all suicidal/homicidal statements are not actual threats but often just expression of grief and fatigue (pp. 20-21)

Working with banks (R11: 5 references: banks are not mandated reporters, p. 10; some banks will share info without permission, some won’t, p. 10; worker hoping banks become mandated reporters, p. 10; ex: “…the bank teller sees this woman come up to the counter with her grandson and takes out $10,000, and she’s never done that. Come on. You know, that’s red flags.” p. 10-11; “Red flags are everywhere, but…no one calls us about it, we can’t help…” p. 11)

Not having housing codes to enforce interior home changes in rural counties (R16: 5 references: not having housing codes in Licking County to address the inside of somebody’s dwelling, p. 5; not having anything like Franklin County’s environmental court, p. 5; “…they can make ‘em clean up the yard and the grass.” p. 5; “Can’t really do a lot about the inside dwelling of someone’s home unless it’s sewage issue and it’s a public health hazard, so…” p. 5; “…it really limits what you can do with it.” p. 5)

Using a risk assessment form (R15: 4 references: using a new risk assessment form, p. 7; getting the new form last week at an OCAPS [Ohio Coalition of Adult Protective Services] workshop, p. 7; worker not caring for the
previous one she was using, p. 7; worker altering previous one gotten from somebody else to “fit our county,” p. 7)

Getting people to acknowledge that there’s a problem (R16: 4 references: “In a perfect world they would see that there’s a problem and they’d want help. That’s the first piece.” p. 2; “Cause that’s often the hardest, just convincing them that they need the help.” p. 2; “So the perfect world would be the money to treat the problem and the acknowledgement by the client that there is a problem.” p. 3; acknowledging that there’s a psychiatric or chemical dependency problem being resisted, p. 3)

Seeing all clients once a week regardless of how busy it gets (R10: 3 references: as stated p. 4; not letting anybody go past one week, p. 5; going out every week even for protective need cases, p. 5)

APS being a crisis intervention service (R11: 3 references: “We’re always looking at the life or death aspect, because technically we’re crisis intervention.” p. 5; APS trying to resolve crisis, p. 6; {counted under “seeking court orders”} having to be life or death to get a court order, p. 8)

Recognizing limits of what APS workers can do (R1: 2 references, including nothing could be done because it wasn’t an emergency, “you can only do so much”)

Approaching unintentional risk of harm to others (R4: 2 references: unintentional risk of harm to others is “not gonna work” in court for involuntary services, unintentional risk of harm to others is a landlord issue)

APS standards differing from Health Department standards (R4: 2 references: APS has the same standards whether person lives in their own home or an apartment. Health dept. standards [code enforcement] are different between private homes and apartments)

People getting over their initial resistance to services (R11: 2 references) (―And many times, our clients are against something and when they try it they love it‖ p. 9; “it’s just getting over that hurdle of ‘I don’t want anybody in my house.’” p. 9)

Working with landlords (R12: 2 references: landlords don’t want to call the police, p. 4; explaining to landlords that they have to treat seniors like any other tenant because until they have a guardian they’re their own person, p. 3)

Informing clients about improved quality of senior housing (R14: 2 references: older adults (80-90) having old view of senior housing as something not better than where they live, p. 3; older adults (80-90) not realizing how nice our senior housing is, p. 3)

It’s “tricky” trying to have a person quit a behavior (R3: 1 reference, p. 6)
Recommending driving suspension or re-test to BMV (R3: 1 reference, p. 7)

Finding self-neglect to be really exploitation (R5: 1 reference, p. 11)

Offering feeding suggestions (“tricks”) to caregivers (R5: 1 reference, p. 8)

Keeping people in the same community if possible (R5: 1 reference)

New national “light bulb” program every county can get federal funds for (special bulb in window that can flash if help is needed) (R7: 1 reference, p. 10)

Getting the same case a second time (R9: 1 reference, p. 7)

Evaluating on a case-by-case basis (R9: 1 reference, p. 8)

Making sure the basic needs are addressed ASAP (shelter, food, clothing, utilities) (R10: 1 reference, p. 1)

Worker insisting daughters with Power of Attorney put dying mom on hospice to avoid neglect allegations [self-neglect already substantiated] (R12: 1 reference, p. 5)

Sub-category: worker’s personal thoughts and feelings about intervention [some overlap with “actions needed” category] (306 references)

(R1: 19 references) (R2: 9 references) (R3: 24 references) (R4: 13 references) (R5: 21 references) (R6: 15 references) (R7: 28 references) (R8: 9 references) (R9: 15 references) (R10: 34 references) (R11: 10 references) (R12: 21 references) (R13: 24 references) (R14: 33 references) (R15: 19 references) (R16: 12 references)

Honoring self-determination/client’s rights (40 references by 12 workers) (R1: 3 references: “some people, they request an appointment, so I have no problems with doin that.” p. 1; and 2 to honoring client’s desire to remain living in same community, ex: “He wants the west side. I got him on every waiting list I can possibly get him on, ’cause I’m not movin’ him nowhere but where he wants to be.” p. 18) (R3: 2 references; “People are allowed to be dirty.” p. 4; “I really think that people are allowed to live however they wanna live.” p. 13) (R5: 3 references to advocating for people’s choices if competent, including “It is your right to live as you choose and I am happy to support that.” p. 7) (R6: 1 reference: “Self-determination would generally with me always win out on trying to force somebody because they’re self-neglecting themselves.” p. 14) (R7: 3 references; worker wanting to help but needing to respect client choices, p. 4; “People do have the right to live in filth.” p. 10; “Just because they’re 60 doesn’t mean every right gets stricken from them. By no means.” p. 11) (R8: 5 references, including 4 references to client rights coming first: “They are adults, they’re not children.” (p. 13), self-determination comes into play and you have to allow them [to self-neglect] (p. 14), their lifestyle
may not be agreeable to the APS worker but you have to respect how they want to live, (p. 14); respecting competent senior’s right to choose to live in a deplorable situation, (p. 14); adults can make their own decision about staying in their environment or not, p. 1) (R9: 3 references to always erring on side of client’s rights, p. 8) (R10: 2 references re: there’s absolutely nothing you can do when people know what’s going on and are making bad decisions. You have to wait for a physical or mental decline. (p. 8) “...you want people to have what they need. And it’s really hard to walk away.” p. 8) (R12: 9 references, including 4 references to worker not wanting to put people in nursing homes or take away their rights by getting a guardian, p. 6; “I think that is optimal. That we live in a country that you have the right to determine how you’re gonna live life the way you want to.” p. 6; “It’s really hard to case plan anything for another individual who has the right to live the way they want.” p. 7; “And I believe in people’s rights, so I would say it is ideal that we all get to choose to live how we want to.” p. 7; and 4 references to honoring the right to die at home: as stated, p. 6; worker allowing people to remain at home to die, p. 6; worker not wanting to die in a hospital or nursing home, p. 6; [when considering allowing people to die at home] worker taking into account what she would want, what her grandparents would want, p. 6; “If they understand the risk...then, I believe, they have the right to self-determination.” p. 11) (R13: 1 reference: wanting to respect their decision when they’re knowingly self-neglecting, p. 7) (R14: 4 references: going on self-determination first, p. 7; going with their rights first, p. 7; trying to involve all clients in any change that occurs, p. 7; “So even if they’re against it, we’ll talk it out.” p. 7) (R16: 4 references: valuing people’s right to live how they wish, p.2; “I think it’s really easy to allow people to self-determine when it’s a self-neglect issue. I think the only time it really becomes a struggle is more when you’ve got that endangerment issue. p.5; “I think if you don’t have that endangerment, you’re not gonna force yourself in there.” p.5; “If they choose to not have that help, I’m really okay with that unless it’s an endangerment issue.” p. 5)

Worker struggling with difficult case decisions/ ethical dilemmas regarding balancing self-determination with obligation to protect (23 references by 8 workers) (R3: 2 references; worker having difficulty making decision to remove seniors from their home, even when they’re “mentally gone,” p. 7; “Yeah, it’s a challenge to do so.” [distinguishing between self-determination and self-neglect], p. 16) (R5: 2 references to thoughtfully balancing self-neglect with self-determination; “I am forever on the fence with myself about how much of this is lifestyle, how much is a problem.” p. 13; “It’s an ongoing battle, it’s a tough [decision?], For me it’s all about cognitive status.” p. 18) (R6: 1 reference: worker expressing that it’s hardest to try to help when clients are only a little bit confused; “My job I see, is to try and form a relationship with them to try and let them see it is for their best interest to...just accept an emergency response system.....It, it’s one of the hardest things to do. If they’re confused...it’s not...but if they know what they’re talkin’ about...and they’re maybe only a little confused, that’s when it’s really tough and you just keep goin’ back and trying to see what you can do to help them. And I try to say, “I’m here to
help you, to protect you, make sure you’re okay.” (p. 14) (R9: 4 references to “It has to be really severe.” [to override clients self-determination], including having no choice [but to override elder’s desires] when people are really bad off and won’t use helping systems p. 8) (R10: 4 references: It’s hard when they’re capable but not meeting needs, p. 7; talking to seniors about bad decisions is difficult because the worker is allowed to make bad decisions at her age, p. 8; No one can understand what it’s like to face the tons of ethical dilemmas in the job unless you’ve done it because you constantly walk a fine line, p. 14; “...you want people to have what they need. And it’s really hard to walk away.” p. 8) (R13: 4 references, including 2 references to worker feeling torn about not intervening: case example of feeling torn when a client understood the ramifications of him selling his pain meds and giving the money to his caretaker but was not seeing that he was self-neglecting by not taking his medications as prescribed [did not substantiate], p. 3; feeling torn in same case ex: because “he did not want any intervention from us, as much as I tried to advocate” p. 3; and 2 references to having difficulty finding the balance between client self-determination and the worker’s obligation to protect them: “You know, in my nine years here it’s been very hard to find that balance.” p. 7; “But it is, it’s hard finding those boundaries between the self-determination and knowin’ they’re self-neglecting and, you know, by law, we have to go in there, ‘n we have to intervene in a lot of cases, but I try ’n take the gradual approach?” p. 10) (R14: 5 references to having to make difficult decisions: looking at it on a case-by-case basis, p. 4; “It is tough because there’s a lot of gray areas.” p. 4; ex: “So, sometimes I’m leaving people in unsafe situations that could go bad rather quickly.” p. 4; worker having to make [a difficult] decision, p. 5; “so it falls on me. I guess.” p. 5) (R16: 1 reference: Having mixed feelings about substantiating when people “…probably would be very compliant with medications if they could afford them.” p. 2)

Workers wanting seniors to accept services (18 references by 8 workers) (R5: 3 references to preferring to “talk ‘em into into it” rather than forcing treatment or petitioning probate court for services, p. 9) (R6: 1 reference: “Well the optimal would be to...be able to get, offer them and have them accept it, (smiling) that’s the other thing...” p. 8) (R7: 1 reference: In a perfect world client’s accept services, the services are in place, and they’re all paid for. “but okay, let’s be real, that’s not happening.” p. 5) (R11: 1 reference: clients’ being receptive to offered services is the perfect outcome, p. 6) (R12: 1 reference to worker not wanting clients to die from self-neglect: “In a perfect world, everybody would do what they need to do for themselves.” p. 6) (R14: 4 references: making the judgment [in some instances] to push a little harder, p. 3; worker thinking it’s always in a self-neglecting client’s best interest to have services, p. 3; “It’s my job to facilitate the client understanding, getting at least to try.” p. 3; “I try to get them to try the service.” p. 3) (R15: 4 references to worker wanting clients to accept home-based services: “Well, in a perfect world, we’ll set up someone that’s gonna check up on them on a regular basis.” p. 5; recommending home-delivered meals: “And I’ll even explain to them, ‘If you don’t have family, that this is the perfect thing to do.’” p. 5;
recommending home health services: “Can I call for home health for you? Do you have any help in your home?” p. 5; “If they agree to all that [service recommendations], that’s the perfect world.” p. 5) (R16: 3 references to getting people to acknowledge that there’s a problem: “In a perfect world they would see that there’s a problem and they’d want help. That’s the first piece.” p. 2; “‘Cause that’s often the hardest, just convincing them that they need the help.” p. 2; “So the perfect world would be the money to treat the problem and the acknowledgement by the client that there is a problem.” p. 3)

Valuing independence/keeping people in their homes/in the community [out of nursing homes] (21 references by 6 workers) (R3: 6 references: “Well, he’s kind of in this routine. I can’t really force him out of his home.” p. 7; “Cause sometimes I think the home environment’s gonna be better, I think, than a nursing home that he is not familiar with.” p. 7; same case ex: “He doesn’t like talkin’ with a lot of people, so maybe the crowd’s gonna be worse for this person.” p. 7; “He likes kinda bein’ a homebody, nobody in his business. But got along really well at home.” p. 7; same case: “[He] was gone mentally, but he showed me that, you know, he’s livin’ his life how he wants to, he’s not hurtin’ anybody else. Ok. He can stay in the community.” p. 14; “You can’t just put everybody into a nursing home.” p. 15) (R5: 1 reference: “...they think we’re just gonna drag everybody off to a nursing home...but my mission really is to keep people in the community” p. 6) (R7: 2 references: “...nothing beats bein’ in your own home and bein’ independent.” p. 3; “I know as a caregiver [for mother and grandfather with Alzheimer’s], I know how it is. I know that they want to maintain their independence, and I will push for their independence.” (by trying to get services and monitoring in place), p. 9) (R9: 6 references to worker trying hard to keep people in community a little longer [and avoid nursing home placement]) (as stated, p. 8; trying to avoid nursing home placement, p. 8; worker not wanting to be in a nursing home, p. 8; a lot of times they don’t want a nursing home, p. 8; trying to find any means they can remain in home, p. 8; trying to help people remain in community with services, p. 8) (R12: 4 references to worker valuing keeping people in their home: worker feeling that it’s sad to send someone to a nursing home over a “little” med assistance issue, p. 8; “People would be so much happier at their home.” p. 8; “And to me...the biggest thing would be able to keep people at home.” p. 8; case ex: “And it broke my hear to get ’em both guardians, because I know the guardians would probably take ’em from the home. Because that’s where they really wanted to be.” p. 9) (R13: 2 references: trying to keep people home with services, p. 4; worker typically trying to not do ECF placement unless really necessary, p. 4)

APS worker genuinely caring/going extra mile (18 references by 6 workers) (R1: 3 references, including buying fast food for client for several days, p. 7; “It’s, it’s really, it’s really difficult, because, you know, you go into some of these houses and just really (brief pause) you really want them to know, you know, ‘Look, we’re out here?’ You know what I mean? ‘We’re, we’re, we’re really tryin’ to help you with stuff’ and (brief pause) you take on a
lot, you know.” p. 23) (R2: 4 references, including worker having difficulty leaving home of sick/dying client [2 case examples] p. 7, 14; viewing referrals as “somebody is needing something” [2 references] (p. 1, 5) (R3: 4 references, including personally checking out neighbors and house guests, p. 7; taking personal risks by confronting exploitive children, p. 8; “So I kind of like havin’ the conversation with the, you know, deadbeat kids. A lot of times that’s intimidating, though, for me to do, just because, you know, you don’t know if they’re under the influence of any alcohol or drugs so…” p. 9; “It’s kind of intimidating just to have a conversation like “Man, what are you doin’ for this person?” p. 9) (R6: 4 references; Exs: providing personal care for a client before squad comes (p. 13), holding client’s hand in ER prior to death (p. 13), presenting three insurance plans for senior to choose from (p. 15), “it’s not just, you know, go to court and then assess ‘em for court. It’s taking care of the client.” p. 16) (R8: 2 references (different cases) to “I could not leave her there”: worker insisting client get medical assessment immediately, p. 9; couldn’t leave client in home unable to care for self, p. 10) (R9: 1 reference: “..from there she ended up in a nursing home. And I was ambivalent about it ‘cause she had nobody here. Her family was in Boston. But then it was like working with the attorney to see that she got into a nursing facility in Boston. Nobody would visit her here. You know. Her sisters were kinda elderly, and all the family was in Boston originally, so…” p. 5)Workers in Franklin County appreciating having access to good programs and funding available to put services in place (16 references by 5 workers) (R5: 1 reference to Franklin County has a sliding fee scale for services through “Options” program) (R7: 8 references including: smaller counties (Ex: Monroe) are unable to put services in place (2 references, p. 3, p. 10), Franklin Co. is very lucky to have a contract with a psychiatric services company (p. 9), Franklin Co. contracting with competent psychological services, p. 9) (R10: 1 reference: There’s never enough services, but Franklin County Office on Aging and other Franklin Co. agencies try very hard to fill the gaps, p. 8) (R11: 1 reference: being blessed in Franklin County to have services and some money to help clients, p. 6) (R14: 5 references to clients benefiting from free access to Meals-on-Wheels in Franklin County: being able to get Lifecare Alliance [Meals-on-Wheels] without paying for it in Franklin County, p. 6; worker having many clients that would have a co-pay otherwise, p. 6; Lifecare Alliance waiving co-pay, p. 6; “So the Meals-on-Wheels keeps them going.” [people who can’t cook] p. 6; “That one day a meal [sic] keeps them in reality.” p. 6)

Worker wishing that more people had supportive families/having strong feelings against exploitive families (9 references by 5 workers) (R1: 4 references: “…family can be crap…” p. 23; “…family can be uncaring, and family can be lazy, family can be, um, exploitive, you know, family can just simply not care.” p. 23; “…you wish that they had that theoretical good family. You know, you wish that, you know, somebody was comin’ along.” p. 23; “family is not always a good thing.” p. 23) (unidentified respondent: 1 reference by purposely unidentified worker stating after tape recorder had been turned off “I hate families.”) (R8: 1 reference to worker wishing
family would “Step up” and provide care [in a perfect world], p. 11) (R13: 2 references to workers wanting helpful family involvement: having helpful family involvement being optimal in care planning process, p. 4; in a perfect world worker would like to see parents allowing their children to assist them, p. 4) (R14: 1 reference: “Oh, if it was in a perfect world they would have a family. They would have a support system. That you could count on.” p. 5)

Frustration with lack of willingness of other service systems to become involved (15 references by 4 workers) (R4: 5 references, Exs: mental health system refusing home visits, MD refusing to give dementia diagnosis, Police not knowing what to do, squad refusing to take seniors, worker leaving seniors needing mental health treatment in the mental health waiting room) (R7: 3 references to Confronting physicians who want to “pass the buck”) exs: Many clients’ physicians want to “pass the buck” on mental health issues saying “that’s not our field.” (p. 9), Worker says “but you are their doctor. It’s your responsibility to link them with someone.” p. 9) (R10: 6 references to worker wishing for more in-home mental health services, including wishing psychiatrists would make home visits for ongoing mental health services, p. 10; “And then it’s very difficult to get mental health on board. Because they have their own set of rules and laws and regulations that don’t combine with us, so it’s kinda like, you know, it’s kinda hard to co-exist together.” p. 10; worker not “seeing” Mental Health position, p. 11; wishing for more mental health involvement, p. 11; wanting M.H. services to go into community more, p. 11) (R13: 1 reference: worker being amazed that EMS [emergency squad] workers can see that a person needs to get to a hospital but refusing to transport, p. 10)

Being frustrated when referral concerns are legit but all available services are in place and nothing else can be done differently (9 references by 4 workers) (R1: 2 references: nothing could be done because it wasn’t an emergency, “you can only do so much”) (R5: 1 reference: “And so I’m on the fence about that because I don’t disagree with the concerns. Every time they come in, I’m like, ‘Mm, yeah.’ ” p. 14) (R7: 2 references to worker getting aggravated when she sees news reports that no services were in place: “No! Maybe somebody was in place. They just chose to live that way. And people have the right. ‘N you get to make bad choices, that’s why we live in the United States.” (p. 11); “And just because something happens to them doesn’t mean that society didn’t react. It’s just that we didn’t give you the reaction that you wanted us to react to.” p. 11) (R14: 4 references to worker wishing some substantiated cases could have better outcomes: worker wanting to do more for people whose competency is impaired but they have a clean home, good hygiene, and a support system, p. 4; case ex: worker getting a lot of calls about a client who has end-stage Alzheimer’s that she needs to be in a nursing home, but to worker she was doing very well, p. 4; same ex: allegations substantiated but outcome was not what referral source(s) wanted, p. 4; the findings are there but [not] the outcome, p. 4)
Worker keeping own values in check (13 references by 3 workers) (R3: 6 references: “...once I get in, it’s kinda like ‘Wow, this is pretty dirty.’ So kind of goin’ through my own, like, ‘Well, I don’t have to live here’ I guess, in a sense.” p. 1; “So kinda workin’ that through my own mind.” [acknowledging personal values/biases], p. 1; “I always have to check myself. ‘Cause it’s like, wow, can this person really live in this much filth, and I'm goin’ home to a clean home, and kinda putting my ideals onto somebody else...” p. 6; worker comparing his standards of taking care of family to what he sees in the community, p. 8; worker checking own values regarding what’s “valuable” to hoarders, p. 11; approaching people with an open mind, p. 13) (R5: 3 references: “I don’t ever wanna apply my own yardstick to someone else’s values...” p. 18; Even if I disagree with your choices, if you are alert and oriented and are making this decision, whether I agree with it or not, it’s your right to do so.” (p. 18), I may think living there is the worst idea ever, but if you’re okay with it and you understand it, I have to support it. Whether I’m comfortable with it or not.” p. 18) (R10: 4 references to worker thinking about how her decisions affect the client: as stated, p. 15; worker having to keep honestly looking at APS principles [freedom over safety] and asking “…what am I doing as a social worker, how am I handling this?” p. 8; thinking about “Freedom over Safety” every time she goes out, p. 15; always trying to err on the part of the client unless there’s significant harm or danger, p. 15)

Not using a treatment model/Mini-mental exam (11 references by 3 workers) (R2: 2 references to worker “hating” to discuss treatment models) (R4: 1 reference to not using a particular practice model to avoid “pre-setting” expectations) (R10: 8 references, including to worker thinking mini-mental exam and most models are “hogwash” because people don’t fit in boxes: as stated, p. 11; using the Mini-Mental Exam might not give a clear assessment of someone p. 11; case example: person completely unable to manage but scored 28 of 30 on MME, p. 11; worker not caring if person knows the year, but are they eating? Paying bills? p. 12; worker questioning other workers basing decisions on the mini-mental exam, p. 12; and 3 reference to worker feeling that no one fits a theory perfectly: people don’t fit into boxes, p. 11; “...no one fits in your theories perfectly. No one fits in all those. You’re dealing with human beings...” p. 12; No one fits in all those things, p. 12)

Expressing empathy for respecting peoples private space (6 references by 3 workers) (R5: 2 references: “I feel like anything outside of that entryway really does require permission.” (pp. 3-4) “how would I feel if...” p. 4) (R12: 3 references to worker empathizing with clients not wanting people in their home: “And sometimes you can’t even blame people for not wantin’ people in their home. They’ve been stolen from before.” p. 8; ex: “My neighbor, they had their mother living with them for a while, and their help would come and be on the phone the whole time, and not work.” p. 8; “I’ve had cases I’ve investigated where it’s the home health aide who has stolen a book of checks, and exploited them.” p. 8) (R14: 1 reference to worker respecting that the client’s home is their space, not his, p. 1)
Wishing to avoid seeking guardianship/go to court (4 references by 3 workers) (R6: 1 reference to worker feeling she’s not really working for the client when seeking guardianship “Because nobody wants guardianship.” p. 11) (R11: 2 references: “Guardianship, for me, is an absolute last resort. p. 7; “I will do anything and wait as long as I can to avoid that.” p. 7) (R15: 1 reference: worker being happy that she’s only gone to court 3 times in 8 years doing this, p. 7)

Worker having strong feelings about lack of home-based medical management services (6 references by 2 workers) (R10: 5 references: “…the one main thing that’s missing, that I complain about all the time, is there’s no services for medical attention.” p. 8; guardianship is not the answer for needing medication management, p. 10; worker not wanting to institutionalize someone because they can’t manage their meds, p. 9; worker not wanting to be institutionalized herself for problems with med management, p. 10; worker wishing there was med management service available, p. 10) (R16: 1 reference: worker would “love to see” widely available home-based medication management services, p. 3)

Valuing being a social worker, having social work values, ex: self-determination (5 references by 2 workers) (R1: 4 references: honoring clients’ desire to remain in same neighborhood, p. 18; “…‘cause I’m not movin’ him nowhere but where he wants to be.” p. 18; honoring self-determination: “What he said is still his right, to self-determine what he wants to do. So in the time, I just have to…monitor it a little more closely…” p. 19; wanting to be helpful: “That’s the kind of mindset that we have, we’re just social workers, come on!” p. 23) (R10: 1 reference to not wanting to force anything because that’s not what APS is about. We’re about self-determination, freedom over safety, client participation—all those things social work is about, p. 8)

Recognizing importance of patience in giving client’s time to make changes on their own (4 references by 2 workers) (R4: 1 reference: taking “baby steps” with cleaning “I mean, honestly, it’s a long haul, you gotta be patient... but... they usually do.”) (R11: 3 references: being patient with clients and giving them the opportunity to do what they think they can do to make it better, p. 9; waiting a “reasonable amount of time to let this person do things for themselves...” p. 9; “So I take it as far as I can in my eyes, to help, and to give them time...” p. 9)

Valuing/recognizing importance of keeping cases open (3 references by 2 workers) (R4: 2 references, 30 days (standard) is not enough to build rapport with some seniors, importance of keeping cases open until worker is sure elder truly understands consequences) (R5: 1 reference; “Because I did case management that was community-based...I’m more likely to wanna keep things open...to try to keep following up and, you know...” p. 11)

Worker sometimes experiencing difficulty/frustration assessing if some thoughts
are real or delusions (2 references by 2 workers) (R6: 1 reference: “So we were on the fence with that for quite a while, ‘cause we kept saying, “Is she telling the truth or isn’t she telling the truth? Does she have dementia? Confusion? What is it? But it was delusions with Parkinson’s and…” p. 8) (R10: 1 reference to the hardest part is to have to rely on what people tell you when you can’t get a clear picture of their understanding and you have no evidence that they’re not being honest, you can’t really find anything, p. 5)

Worker caring about senior’s being lonely (R15: 11 references: “Somebody just calling ’em.” [being the most needed service], p. 6; “They’re lonely.” p. 6; “They don’t have somebody checking on them on a regular basis.” p. 6; “If an individual had somebody to prepare a decent meal for them, they would be better off.” p. 6; “Nobody want- A lot of times they don’t wanna eat alone.” p. 6; “So they choose not to eat at all.” p. 6; “But if somebody was there at the time they were eating, and sat down and ate with them, {softly} they wouldn’t have a problem with it.” p. 6; “So I think that is the [biggest need], being lonely.” p. 6; “That’s a biggie.” [loneliness], p. 6; “They’ll say ‘You can come back any time.’ ” p. 6; “And they wanna just have somebody to talk to.” p. 6)

Worker wishing clients could have a single, consistent care coordinator (R13: 10 references: needing home visits on a consistent basis, p. 5; “Like we can’t do the constant follow up?” p. 5; “We’re not able to really follow that” [monitoring services and utilization], p. 5; needing someone to be there during transition into services and monitoring when in place, p. 5; even programs like Senior Options and Passport only come out maybe once a quarter, p. 5; worker wishing for a service where someone’s consistently going out to monitor how things are going, p. 5; a lot of times people won’t contact APS if things aren’t working out because they’re glad APS is out of the picture, p. 5; “And then there’s so many case managers and social workers that are involved, and a lot of times it’s confusion.” p. 5; “So if they just had that one, just for that consistency, I think that would be great.” p. 5; [having one consistent worker] would be good for our clients, p. 6)

Worker wishing there was assisted living available for all people, not just the affluent (R14: 8 references: [in a perfect world] there would be alternatives between nursing home and the home life, p. 5; there would be a medium ground of assisted living for poor people, p. 5; “Cause I get a lot of people that live in the community that can no longer live alone, do not, you know, don’t have a support. It’d be nice to be a support.” [middle-ground level of care] p. 5; wishing for assisted living for people with low income, p. 5; having many clients that could benefit from assisted living instead of a nursing home, p. 5; “So I’ve left them in the community, where I think they would thrive in an assisted living.” p. 5; “So they’re on a slow decline in the community, whereas In assisted living, I think we would see a steady improvement.” p. 5; a lot of cases that have to be closed would thrive in a nice assisted living environment, p. 5)
Worker passionately wanting to get people out of the house for socialization (R6: 5 references, including “…I would love to take some of these people and get them out of the house. Not, not in-house, but ‘Hey! Let’s go out and visit people of your same age or in your neighborhood...’ ” (p. 9), “and you get ’em out...they start feelin’ better ‘n they start cleanin’ up, ’n if physically they’re able to do it, I wish we could do it.” p. 10, “And sometimes we don’t wanna sit down because of the environment we’re in.” p. 1)

Worker perceiving that seniors need but resist Mental Health services (R7: 4 references) Worker would like to see mental health services taken more often (p. 6), “...I think sometimes mental health service doesn’t push enough. They’re too wishy-washy.” (p. 6), not explaining what they do after senior declines services. (p. 6), current cohort has stigma about mental health, future cohorts won’t (p. 6)

Valuing not making decisions for others (R5: 4 references: “I don’t have the right to adjust people’s lifestyle.” p. 7; valuing “working it out together.” p. 15; “I don’t ever wish to make decisions for anyone if at all avoidable, and 99% of the time it is avoidable.” p. 15; “I don’t know that you can make that decision for someone else.” p. 16)

Working with hoarders being difficult (R13: 4 references: hoarders being hardest to deal with because they have an attachment to their possessions, p. 8; “That’s really been difficult in working with them” [hoarders], p. 8; explaining “I’m willing to work with you but only to a certain point.” p. 8; Hoarders being one of the hardest cases to work with because they feel like there’s meaning with those possessions, p. 9)

Letting referrals know that “somebody cares” (R2: 3 references, including somebody cared enough to make a referral, making several home visits)

Wanting to provide community education about people’s rights (R3: 3 references: “Just that they have the rights to live however they want to. Yeah. It’d be great to talk to the professionals about it, and then also to just people who are living in the community. Neighbors, family members.” p. 13; “So I think we do that somewhat now, talkin’ to neighbors and professionals.” p. 13; So I think we try to educate the community.” p. 13)

Frustration with insurance barriers/lack of coverage (R4: 3 references)

“A lot happens for me in the first visit” (R10: 3 references (p. 1), including start strategizing and start throwing options out there, p. 1; ex: calling Meals-on-Wheels from the house on the first visit, p. 1)

Worker losing sleep or having dreams about clients as “litmus test” that she needs to “push it a little further” (R16: 3 references: “…if I start losing sleep over it and if I start having dreams about having dreams about this, you know, client? If I start having like, ‘Oh, my God, what if they got
caught in a fire?‘ kind of thing, ‘they, could they get out?’ I think that’s when I usually know that I need to push it a little further.” p. 5; “...like I said, my litmus test is when I start losin’ sleep at night, ‘cause I’m good at leavin’ stuff here at work. p. 5; “I start havin’ dreams about Mrs. Smith or whoever, (laughs) then I know that maybe we need to push it a little further.” p. 5)

Expressing deep empathy for client’s losses and fatigue (R5: 2 references: not all suicidal/homicidal statements are actual threats but rather may be expressions of grief and fatigue. Clients’ and caregiver’s needs to be allowed to express grief and fatigue without assuming lethal intent. (She does ask directly about intent.) p. 20)

Worker not liking to call the emergency squad (R6: 2 references: Worker expressing that its “scary” to call the squad. “That’s very scary for me to do that.” [call the squad] p. 13; worker feeling that it’s optimal for the squad to take seniors to the hospital: “So you try to get the squad to take her, and it’s always been for the best when they have.” p. 14)

Worker “coming down hard” on neglect by others (R7: 2 references, p. 11)

Needing as many laws for seniors as for children (R7: 2 references) Worker wishing there was a log for adult abusers like there is for children. Ex: multi-county “sweetheart swindler” might have been caught had we been able to share that information. “Maybe we could have stopped one?” (p. 12). The lack of a national exploitation log for seniors “tells you that we de-value our seniors.” (p. 12); “But there should be just as many laws for our seniors. And there’s not.” (p. 13)

Worker being surprised at how many people let him in “just from showing that badge” because they have rights, they don’t have to (R9: 2 references, p. 1)

Worker thinking about her own liability (R10: 2 references, p. 15)

Worker not wanting to be solely responsible for competency assessment (R11: 2 references: as stated, p. 7; “It has to be a doctor. It can’t be me...that’s not enough.” p. 8)

Worker wishing there was a way to follow-up (R12: 2 references: “But there are people that you do worry about, even though you’ve closed the case. And it would be nice sometimes to have something that was more ongoing.” [worker tries to put another agency in there when clients are willing to allow it] p. 6; worker wishing there was a way to follow-up, ex: family, somebody would call back if things got worse, p. 7)

Recognizing that drug addicts can be adequate caregivers (R14: 2 references: “Drugs doesn’t necessarily make a bad caregiver.” p. 7; “There’s nothing that makes a crack addict a bad caregiver.” p. 7)
Worker feeling more comfortable substantiating allegations and closing the case when there are service providers involved (R15: 2 references “...if there’s a home health agency involved, and I feel pretty good about I’m- there’s eyes involved, there’s somebody in there that’s seeing this person each day.” p. 4; “Or I also feel like the individual has home-delivered meals, and so somebody there is gonna see them every day.” p. 4)

Seniors usually express their level of satisfaction with services without being asked (R4: 1 reference)

Worker stating that it’s “comforting” to visit with a partner (R6: 1 reference, p. 1)

APS worker not testing people just to be testing (R7: 1 reference: ex: date or time- “Half the time I don’t know what day it is” p. 9)

A lot of times allegations are based on caller’s morals and values. That’s why they think we should do something. (R7: 1 reference, p. 4)

Importance of being honest and telling why you’re there is the biggest issue. (R7: 1 reference: “You got to be honest with them and tell them why you’re there. It’s the biggest issue because...you’re not gonna be able to do you job if you’re not honest with them.” p. 4)

“They can still have deficits” (and remain independent) (R7: 1 reference: examples: educational deficits, isolation, p. 9)

The first thing worker taught her children was the consequences of their actions (R7: 1 reference, p. 10)

Worker perceiving APS and Child Protective Services a “pretty different” because “...an adult is a competent human being. A child is not.” (R7: 1 reference, p. 11)

Worker wishing she could be deputized (R7: 1 reference: example of seeing drugs all over, weapons, cases where “people have been abused so badly, and I can’t get a police officer her quick enough. They’ll be gone.” (abusers leaving quickly), p. 12)

Worker expressing concern over funding dependability (R7: 1 reference: How can we deal with elder self-neglect without having laws and funding to stand behind us? p. 13)

Worker feeling “fortunate” to have always gotten court orders of protection the same day as sought (R8: 1 reference, p. 11)

APS worker showing up is an involuntary service (R9: 1 reference, p. 6)

Worker not liking the APS title, preferring being an “advocate” (R10: p. 14, 3 mentions of “advocate,” including “I am their biggest advocate, I’m gonna be there with them”)
Worker trying really, really hard to get client to address problems without court involvement (**R10**: 1 reference, p. 13)

No textbook teaches how to assess understanding (**R10**: 1 reference, p. 4)

Explaining competency to other people is the hardest thing (**R11**: 1 reference, p. 3)

Worker sympathizing with daughters who have Power of Attorney not accepting that mom was dying (**R12**: 1 reference: “And I felt really torn to say...They really did not want her on hospice, they wanted to have hope. And I hated to substantiate ‘cause, I said, Who am I to go in there and tell people, take away their hope for their mother, and say, ‘Well, whether you hope for her or not, she's dying and you have to put her on hospice.’ You know, I really sympathized with those daughters...” p. 5)

Worker being happy about new district system of assigning cases in Franklin County (**R12**: 1 reference, p. 7)

Worker wanting form used in Cuyahoga County that informs a doctor that no release of information is needed for an APS investigation (**R15**: 1 reference: “I need that!” p. 3)
**Themes or perspectives (properties/dimensions) unique to one interview:**

(264 references)

(R1: 10 references) (R2: 8 references) (R3: 21 references) (R4: 16 references) (R5: 21 references) (R6: 15 references) (R7: 23 references) (R8: 17 references) (R9: 28 references) (R10: 13 references) (R11: 20 references) (R12: 1 reference) (R13: 26 references) (R14: 25 references) (R15: 14 references) (R16: 6 references)

Identifying influence of community standards (R3: 21 references): small communities having “skewed” ideas about letting people live how they want, p. 2; people in small communities being more likely to know somebody in government, p. 3; Delaware County almost “forcing” services, p. 2; case example of worker defending client’s right to live how he wants to supervisor: client living on an acre of land in the country, no one else was around in that neighborhood area in a different township, so they couldn’t have city code come in, code saying “Well, it’s on his [land].” p. 3; giving client the “benefit of a doubt” re: time to make needed home repairs, p. 3; worker getting pressure from APS and community to evict a person, p. 3; recognizing there are different APS standards in different communities [ex: Franklin vs. Delaware Counties], p. 4; getting more referrals from professionals in affluent communities “However we treat ‘em all the same.” p. 4; case ex: of wearing clothing with some urine smell in an affluent neighborhood, p. 4; same case ex: going out in stained clothing in an upscale neighborhood, p. 4; same case ex: of getting referrals from Upper Arlington [affluent suburb] five times about a lady not washing her clothes, p. 4; “I guess in Upper Arlington, if a person’s out at the bank and they shouldn’t maybe be smelling the way they might, or maybe have a little small stain on them, they’re gonna be like ‘Well what’s this elderly person out here driving? She’s a little bit confused how can she be driving? etc.’” p. 4; affluent suburban standards creating a “big problem” when there really isn’t one, p. 4; affluent communities throwing community morals/standards at people, p. 5; requesting guardianship doesn’t happen often in Franklin County, p. 14; worker never having filed for guardianship in Franklin Co., p. 14; worker filing like seven times in two and a half years working in Delaware Co., p. 14; pushing guardianship in Delaware Co., p. 15; the community expecting results in Delaware County, p. 15; professionals calling in referrals in Columbus usually don’t second-guess APS investigations, “…we don’t hear from ‘em again. Like, ‘Alright, they did their job. They must be ok.’ Whereas in Delaware it’s a whole different mindset of, you know, this person cannot live like this.” p. 15; “That’s why I switched from Delaware to come down here, ‘cause I thought, you know, I’m tired of doin’ what the community wants rather than what the client wants.” p. 15; “You can’t just put everybody in a nursing home. However, that was a typical thing to do in Delaware.” p. 15)

Assessing wandering (R12: 12 references) (wandering; assessing wandering; are they getting lost?; is it dangerous?; wandering away from their building; being able to explain purpose such as “I wasn’t wandering, I was going to the store’ or ‘I take a walk every day at this time. That’s my routine.”);
neighbors might think because they’re old they’re wandering; wandering without purpose and getting lost, case ex: client wandered into apartment complex pond; determining how dangerous the wandering is; are they carrying id?; can they tell you how to get home? all p. 2)

Approaching elders living in a home where crack is used (R14: 12 references: [they demonstrate understanding] by talking about living in a crack house, p. 7; living in a crack house is very common, p. 7; there’s a lot of drug activity, p. 7; “Drugs doesn’t necessarily make a bad caregiver.” p. 7; “Like a lot of the caregivers are on drugs.” p. 7; “that’s a reality.” p. 7; getting a lot of referrals about that, p. 7; people making judgments that crack is worse than alcohol, p. 7; “I mean there’s nothing that makes a crack addict a bad caregiver.” p. 7; if a client knows it’s going on and have insight, worker would probably not do anything other than letting them know the dangers, p. 7; if they don’t understand, worker would step in and do more, p. 7; “They may wanna stay there, but that’s not gonna work.” [if they don’t understand they’re living in a crack house], p. 7)

Details of getting court order of protection (R8: 11 references: worker telling client she will get order of protection to make client go to emergency room for medical assessment (p. 9), getting order to force medical assessment (different case, p. 10), Columbus Police Dept. or Franklin Co. Sheriff’s office enforcing order of protection (p. 10), paramedics called to transport client to hospital per order of protection (p. 10), client being angry with worker for order of protection (p. 10), APS worker calling prosecuting attorney before magistrates leave at 5:00 PM (p. 10), worker usually getting to probate court magistrate to give testimony same day as order sought (p. 10), getting court order in 2-3 hours (p. 11), getting court order before 5:00 PM (p. 11), getting court order next day if after 5:00 pm (p. 11), worker has always been “fortunate” to get court orders the same day (p. 11)

Needing assisted living alternative for people who can’t live at home but are not appropriate for the nursing home (R13: 11 references: [in a perfect world] there would be alternatives between nursing home and the home life, p. 5; there would be a medium ground of assisted living for poor people, p. 5; a lot of people living in the community can no longer live alone, and don’t have a support, p. 5; “It’d be nice to be a support.” p. 5; wishing for middle ground [level of care] for people with low income, p. 5; waiting lists for Medicaid assisted living beds being ridiculous, p. 5; having many clients that could benefit [from assisted living] instead of a nursing home p.5; they’re physically not capable of being in the community but they’re also not appropriate for the nursing home, p. 5; “So I’ve left them in the community, where I think they would thrive in as assisted living,” p. 5; “So they’re on a slow decline in the community, whereas in assisted living, I think we would see a steady improvement.” p. 5; a lot of cases that have to be closed would thrive in a nice assisted living environment, p. 5)

Assessing alcohol abuse (R9: 10 references) (having problems when drinking
alcohol but ok when not, p. 4; sobering up in a nursing facility after falling due to drinking, p. 4; stopping driving due to damaging car while driving drunk, p. 4; being unable to stop drinking, p. 4; falling off curb drunk and getting arm broken when hit by car, p. 4; being disoriented in court, ending up in nursing home due to alcoholism, p. 4; making 911 calls when drunk (3 references), p. 5; police/fire dept. asking APS to place client due to excessive 911 calls [when drunk], p. 5)

Worker wishing clients could have a single, consistent care coordinator (R13: 10 references: {see “actions needed” category} (exs: worker wishing for a service where someone’s consistently going out to monitor how things are going, p. 5; “And then there’s so many case managers and social workers that are involved, and a lot of times it’s confusion. So if they just had that one, just for that consistency, I think that would be great.” p. 5; [having one consistent worker] would be good for our clients, p. 6)

Strategies for handling dogs/ other dangers identified by referral source on home visits (R1: 3 references to dogs, including worker whistling to get dog’s attention when she sees “beware of dog” signs on gated fences, p. 2; getting dog treats to take, p. 2; “Let me give ‘em a little something. Maybe they can eat in the dining room.” p. 2) (R9: 4 references: 2 references to calling a client before visiting if there’s a dog that needs to be put out, p. 1; 2 references to some other type of danger, p. 1)

Consulting with pre-existing Senior Options casemanagers/seniors preferring Senior Options casemanagers (R8: 7 references, including consulting with Sr. Options CM (p. 8), older adult referring APS worker to Senior Options casemanager, (p. 8) seniors perceiving Senior Options as helping, APS not helping (p. 12), seniors preferring senior options services because they’re less intrusive than APS services (p. 12), APS asking more personal questions than senior options because it’s an investigation. Ex: financial questions, p. 12p. 8)

Basing APS decisions in Franklin County on client needs, not community desires (R10: 7 references: in Franklin Co. the APS principles tell you you don’t worry about what the community thinks, the client comes number one, p. 15, 16; worker consulting with collaterals to factor in their opinion, but it’s just that, an opinion, p. 16; when you worry about what everybody else thinks you lose the focus of advocating for your client, p. 16; Having 2 great supervisors in Franklin Co. who have that philosophy, p. 16; client coming first over family, friends, neighbors, community, p. 16; Franklin Co. being a great place to work because workers all share innate kind of social work thinking [principle that client comes first], p. 16; sympathizing with workers in counties who get more pressure from what the perception of the community will be, p. 16)

Looking at the “three biggies” to distinguish self-neglect from self-determination (food, shelter [including paying bills], clothing [self-care]) (R15: 7 references: “Well, you look at the three biggies.” p. 7; “Are they paying their bills, are they gonna lose their shelter.” p. 7; “Are they eating, are
they bein' able to *get* food?‖ p. 7; “And, are they taking care of themselves.” p. 7; “If those three things. If they’ve *got* food, they’ve *got* shelter, they’ve *got* clothing...I’m pretty much gonna overlook the clutter.” p. 7; “So if those three biggies hit me, that ‘Well, you’re gonna be evicted. You know? You, you aren’t making the good choices for yourself, therefore you’re not paying you’re bills, therefore you’re gonna lose your place to live and, and I ca- I have to help you. Let’s work on this together.” p. 7; “I just go right back to three biggies, ‘n make sure that that’s what they *have...‖ p. 7)

Acknowledging and problem-solving about intimacy needs to help avoid abuse by prostitutes (R9: 6 references: as stated, p. 9; ex: recommending adult daycare as a way to meet women, p. 9; worker getting “flack” from another agency regarding honoring men’s desire for sex, p. 9; workers at another involved agency being “pissed” about worker suggesting adult daycare as a way to meet women and making a complaint to worker’s supervisor, p. 9; worker’s supervisor supporting worker problem-solving re: client’s sexual needs, p. 9; “I’m saying, so, that’s self-determination, helping the client.” p. 9)

Understanding hoarding (R13: 6 references: hoarders being hardest to deal with because they have an attachment to their possessions, p. 8; hoarders being one of the hardest cases to work with because they feel like there’s meaning with those possessions, p. 9; “It’s more than a possession to them a lot of times. It’s like that’s their existence, you know. It’s proving that this is who they are because they’ve collected these things.” p. 9; [possessions] have worth to them, so it’s really hard for them to get rid of them, p. 9; “...they feel like, ‘If you take that away from me, what else do I have left?’” p. 9; “It’s almost like it gives them some sort of something to thrive on.” p. 10)

Educating clients about the importance of nutrition for healthy brain function (R15: 6 references: making standard speech “Because, if you’re not feeding your brain, you’re not gonna be able to think.” p. 4; “And, a lot of times, because we are inactive, we’re sitting around all daylong, you don’t feel hungry, but you still have to feed your brain.” p. 4; “You still have to do that [eat] so you’re gonna be thinking clearly.” p. 4; “And those are things that you can do for yourself, you do that for yourself, and you’re never going to have to leave this house.” p. 4; using remaining at home as incentive for eating, “So, you know, it’s an incentive...” p. 4; making standard speech “even if you don’t feel hungry, get yourself somethin’ to eat anyway.” p. 5)

Worker passionately wanting to get seniors out of the house for socialization, such as at a senior dining center. (R6: 5 references) ex: “the ones I really wish would- I could get out are the ones......the only thing they’re *hearin’* is that TV goin’. You know, or they have nobody to talk to so...” (p. 10)

Working with banks (R11: 5 references: banks are not mandated reporters, p. 10;
some banks will share info without permission, some won’t, p. 10; worker hoping banks become mandated reporters, p. 10; ex: “…the bank teller sees this woman come up to the counter with her grandson and takes out $10,000, and she’s never done that. Come on. You know, that’s red flags.” p. 10-11; “Red flags are everywhere, but…no one calls us about it, we can’t help…” p. 11

Having hospital doctors complete expert evaluations (R13: 5 references: having hospital doctor do psych evaluation to assess competency while client’s there and completing expert evaluation, p. 6; case ex: of expert evaluation done by hospital staff recommending guardianship, p. 7; same case: worker approaching probate court with hospital’s expert evaluation, p. 7; hospital doctors completing expert evaluations quite often, p. 7; “they’re really good about doing that” p. 7)

Calling EMS [emergency squad] supervisors when EMS first responders won’t transport clients (R13: 5 references: worker calling squad supervisor and explaining situation, p. 10; supervisors typically saying “okay,” p. 10; having to call EMS supervisors quite a few times and explaining case, p. 10; going over EMS first responders heads a couple of times, p. 11; that works for the most part, sometimes it hasn’t, p. 11)

Recognizing grief/grieving recent loss of spouse (R1: 4 references, including 2 to case example where client’s wife had just passed away, p. 9; case ex: of normal grieving process including “ ‘I’m not gonna do the laundry today’ issues,” p. 10)

Worker in a small community using the health department when they know a living arrangement is not “fixable” (R4: 3 references, including “good cop/bad cop,” using health department to keep people out of court)

Asking “cause and effect” questions to assess people’s understanding of possible risks (R5: 3 references, including “What would you do in a fire?” “Why are you keeping these papers?” (p. 18) and looking for “logical” answers to questions vs. not having an answer or “circular” responses, pp. 18-19)

Overriding elder’s desires only when impaired judgment has been determined by a behavioral health specialist’s assessment (R5: 3 references: getting an outside assessment if unsure of client’s mental status (p. 18) Having a behavioral health specialist make an assessment, using Netcare or a private BHS,p. 17)

Addressing mental health issues (R5: 3 new references) “Mentally ill is not incompetent.” (p. 19), making referrals to physicians for depression (p. 19), having had training about depression, p. 20)

Using a systems approach learned at Wright State. (R5: 3 references: “people are part of a larger system” (p. 16), involving families, churches, supports; looking at whole picture, (p. 16) “Your not bathing isn’t your biggest
issue. It may be the pinpoint issue at the moment, but you are more than this old person who isn’t bathing.” (p. 16)

Confronting physicians who want to “pass the buck” (R7: 3 references) Many clients’ physicians want to “pass the buck” on mental health issues saying “that’s not our field.” (p. 9), Worker says “but you are their doctor. It’s your responsibility to link them with someone.” (p. 9); If they throw Hippa worker throws Ohio Revised Code back (p. 8)

Funding problems (R7: 3 references) Politicians tried to remove APS from the law. (p. 13), “Two years ago we about lost every bit of funding we had. We almost got taken off of the state budget line. If that happened, APS would not have been about.” (p. 13) How can we deal with elder abuse without having laws and funding to stand behind us? (p. 13)

Difficulty getting home-based mental health services (R10: 3 references: “And then it’s very difficult to get mental health on board. Because they have their own set of rules and laws and regulations that don’t combine with us, so it’s kinda like, you know, it’s kinda hard to co-exist together.” p. 10; Mental Health services not taking initiative to provide services unless client is homicidal or suicidal (2 references, pp. 10,11)

APS being a crisis intervention service (R11: 3 references: “We’re always looking at the life or death aspect, because technically we’re crisis intervention.” p. 5; APS trying to resolve crisis, p. 6; having to be life or death to get a court order, p. 8)

Allowing people time to address the problems themselves (R11: 3 references: being patient with clients and giving them the opportunity to do what they think they can do to make it better, p. 9; waiting a “reasonable amount of time to let this person do things for themselves...” p. 9; “So I take it as far as I can in my eyes, to help, and to give them time...” p. 9)

Needing as many laws for seniors as for children. (R7: 3 references) Worker wishing there was a log for adult abusers like there is for children. Ex: multi-county “sweetheart swindler” might have been caught had we been able to share that information. “Maybe we could have stopped one?” (p. 12). The lack of a national exploitation log for seniors “tells you that we de-value our seniors.” (p. 12); “But there should be just as many laws for our seniors. And there’s not.” (p. 13)

Clients accidentally repeatedly pushing ERS button (R1: 2 references to case example, pp. 9, 10)

Clients valuing independent cooking vs. meals on wheels (R1: 2 references, including client saying “What you tryin/ to say, I can't cook no more?” And I think that really kind of affects them.” p. 15)

Communicating with elder’s who have [untreated] hearing loss (R2: 2 references)
Worker not having any problems “getting in the door,” perhaps because it’s a “smaller county,” elders in farm country want to “Be nice to strangers” (R4: 2 references)

APS and Health department standards differing: APS has the same standards whether person lives in their own home or an apartment. Health dept. standards (code enforcement) are different between private homes and apartments (R4: 2 references) (p. 12)

Unintentional risk of harm to others is “not gonna work” in court [as grounds for involuntary services]. Unintentional harm to others is an apartment landlord issue (R4: 2 references)

Other counties (ex: Franklin) having more services and funding (R4: 2 references) including “We have none. None. If you don’t qualify for Medicare or Medicaid for any home health services...there’s nothing unless you private pay.” (p. 6) ex: lacking funding for Emergency Response Buttons

“A lot of our caregivers are women.” (R5: 2 references, p. 6; (ex: divorced daughter-in-law, p. 6)

Asking about direct death-wish statements while recognizing the need to express grief and fatigue (R5: 2 references: “Would you actually hurt yourself?” (p. 19), Suicidal/homicidal statements are often expressions of grief/fatigue rather than plans, pp. 20-21)

The concept of “Seasons of loss” (R5: 2 references) including “When you have lost in periods of your life your spouse, children siblings, friends.” (p. 20); “I’ve met a lot of people who say, ‘I’m it, I’m the last one.’” p. 20)

Needing to tell “little white lies” to the squad EMT’s to get them to take the client. (exaggerating actual conditions) (R6: 2 references, p. 14)

Worker getting “aggravated” when she sees news reports that no services were in place. (R7: 2 references) “No! Maybe somebody was in place. They just chose to live that way. And people have the right. ‘N you get to make bad choices, that’s why we live in the United States.” (p. 11); “And just because something happens to them doesn’t mean that society didn’t react. It’s just that we didn’t give you the reaction that you wanted us to react to.” (p. 11)

Abusers getting away (R7: 2 references) not being able to get police to home before abuser leaves (p. 12); “Yes, I can take care of that client, but...that abuser is gone.” (p. 12)

Older adult choosing to return to apartment from a facility although unable to care for self (unable to ambulate, get meals, dress, bathe, toilet self) (R8: 2 references, p. 9, p. 10)
Discussing the affordability of services with seniors (R11: 2 references: explaining the need for services to the client and discussing finances. “You can afford it.” p. 6; for most seniors, if it’s not free it’s a low co-pay, a few dollars for each hour of service and they can afford it, p. 6)

Worker not wanting to be solely responsible for competency assessment (R11: 2 references: “I don’t want to be the sole, responsible person, and I’m not, it comes down to a doctor.” p. 7; “...who makes that determination? It has to be a doctor. It can’t be me...that’s not enough.” p. 8)

People getting over their initial resistance to services (R11: 2 references: “And many times, our clients are against something and when they try it they love it” p. 9; “it’s just getting over that hurdle of ‘I don’t want anybody in my house.’” p. 9)

Older adults not realizing how nice senior housing is now (R14: 2 references: older adults (80-90) having old view of senior housing as something not better than where they live, p. 3; older adults (80-90) not realizing how nice our senior housing is, p. 3)

Using Havemeyer’s theory to guide decisions (R16: 2 references: Havemeyer’s theory: a person has the God-given right to live how they wish, no matter how others are offended, p. 2; worker using Havemeyer’s theory to make decisions and start where the client is, p. 2)

Observing an increase in people going to the hospital after the hospital’s home-based health and medication management services were discontinued (R16: 2 references: “...they used to go to the homes, set up meds, check their blood pressure.” pp. 3-4; “We had a lot of success with that, but then I guess it wasn’t cost effective, so they started cutting out those visits, and we saw an increase in people goin’ to the hospital again.” (p. 4)

Observing chemical dependency (R16: 2 references: “…alcohol or prescription drugs, tend to be the two things that we see among the seniors...” p. 3; seniors resisting acknowledging that there’s a problem, p. 3)

Older males and females looking the same (R1: 1 reference)

Client avoiding self-incrimination, ex: communicating meta-messages by winking as sign of awareness, non-verbal communication to indicate awareness (R1: 1 reference, p. 11)

Roles society perceives of elders without kin as “sole-survivor” (R1: 1 reference)

Recognizing that the worker might be putting a person at risk by talking with them if a perpetrator is living in the home (clients experiencing “fear factor”) (R2: 1 reference)

Urinary Tract Infection (UTI) being possible cause of a person smelling bad (R2:
1 reference)

Seniors firing home health providers (R2: 1 reference)

Worker describing a naturally occurring senior housing community (former summer cottages, not really adequate for winter, not all winterized) (R2: 1 reference) (p. 13-14)

Comparison of different APS practices re: taking referrals (R2: 1 reference)

Service resistance due to fearing loss of assets for family (R2: 1 reference)

Worker recommending driving suspension or re-test to BMV (R3: 1 reference, p. 7)

Preferring the “clock test” to Mini-Mental Status Exam (R4: 1 reference)

Adapting MMS (by discussing “mundane” things, changing topic, then going back to re-assess memory of the “mundane” things discussed) (R4: 1 reference)

Comparing funding health insurance for the elderly to funding health insurance for children...elders need funding as much as children (R4: 1 reference)

Having easy access to Meals-on-Wheels due to “working in a small community” “We don’t necessarily have to make a formal MOU like everybody else does” (R4: 1 reference)

Worker leaving seniors in mental health waiting room saying “You need to deal with him, don’t you return him home.” (R4: 1 reference)

Seeing self-neglect more with men (R5: 1 reference, p. 1)

Offering feeding suggestions (“tricks”) to caregivers from own experience with caregiving for family members with dementia (R5: 1 reference, p. 8)

Franklin County has a sliding fee scale for services through “options” program (R5: 1 reference)

Worker providing personal care for a client before the squad comes (per client request) and accompanying client to hospital, holding her hand while dying. (“I had to take her into her bedroom, change her, wash her butt, put on her good underwear, get her ready.” p. 13) (R6: 1 reference)

Family (granddaughter) wanting to handle dementia, taking demented client into her home (R6: 1 reference, p. 7)

Worker observing that mental illness runs in families (R6: 1 reference, p. 7)

Worker not allowing client to die in home in unsanitary conditions. (“...and she
was [dying], but I told her she wasn’t gonna die in that mess. So we
moved her into an apartment.” p. 12) (R6: 1 reference)

Worker identifying that the client’s disposition improved after moving out of
uninhabitable house to apartment. (R6: 1 reference, p. 13)

Holding client’s hand in ER prior to death “Yeah, she had me sittin’ there
holding her hand and all that stuff. And I had just gotten up and left and
she coded.” (R6: 1 reference, p. 13)

Worker calling squad for client falls and the client is sent right back home. (R6: 1
reference, p. 14)

Unique approach to working with seniors who don’t want to pay for insurance.
“Okay, look it, her I’m gonna find you three things, three insurance
programs that’s gonna be the best for you. And I’m gonna present ‘em to
you and I’ll tell you my pros and cons and you look at it and you decide.
You decide which one you want.” (R6: 1 reference, p. 15)

“Fluctuating competency” (R7: 1 reference) “…if you saw him today, he’s
competent. You see him tomorrow, he’s not competent. He fluctuates.”
(p. 4)

Falling is worse for seniors due to loss of cushion and fluids. (R7: 1 reference)
(p. 7)

Worker being a caregiver for her mother who has Alzheimer’s (and grandfather),
having to place mother in a facility (R7: 1 reference) “I know as a
caregiver, I know how it is. I know that they want to maintain their
independence, and I will push for their independence.” (by trying to get
services and monitoring in place) (p. 9)

New national “light bulb” program every county can get federal funds for.
(special bulb in window that can flash if help is needed) (R7: 1 reference)
(p. 10)

Worker wishing she could be deputized. (R7: 1 reference) Ex: seeing drugs all
over, weapons, cases where “people have been abused so badly, and I can’t
get a police officer here quick enough. They’ll be gone.” (abusers leaving
quickly) (p. 12)

In a perfect world family and home health agencies would coordinate with each
other (R8: 1 reference, p. 11)

Getting help from another agency that already has trust (R9: 1 reference, p. 1)

Friends helping with chores but not getting into finances (R9: 1 reference, p. 3)

Credit Union putting rent and electric bills on auto-pay (R9: 1 reference, p. 5)
APS worker showing up is an involuntary service (R9: 1 reference, p. 6)

Older men choosing to be with younger female drug abusers (R9: 1 reference, p. 8)

Worker having strong feelings about lack of services for medical management (R10: 1 reference, p. 8)

Worker not wanting to institutionalize someone because they can’t manage their meds (R10: 1 reference, p. 9)

People not knowing the “finality” of guardianships (R10: 1 reference, p. 12)

Worker not liking the APS title, preferring being an “advocate” (R10: 1 reference, p. 14)

By trying to control every risk for everybody you take away “Freedom over Safety” (R10: 1 reference, p. 15)

Consulting with collaterals to factor in their opinion, but it’s just that an opinion (R10: 1 reference, p. 16)

Explaining competency to other people is the hardest thing (R11: 1 reference, p. 3)

Clutter is unsubstantiated in self-neglect (R11: 1 reference, p. 4)

“It’s [incompetency] usually when a client needs help and is refusing.” (R11: 1 reference, p. 7)

Worker wanting form used in Cuyahoga County that informs a doctor that no release form is needed for an APS investigation: “I need that!” (R15: 1 reference, p. 3)