MIAMI UNIVERSITY
The Graduate School

Certificate for Approving the Dissertation

We hereby approve the Dissertation

of

Karen E. Joseph-Kent

Candidate for the Degree

DOCTOR OF PHILOSOPHY

Suzanne Kunkel, Ph.D.
Chair

Kate de Medeiros, Ph.D.
Co-Chair

Robert Applebaum, Ph.D.
Reader

Amie Duncan, Ph.D.
Reader

Cameron Hay-Rollins, Ph.D.
Graduate School Representative

ABSTRACT

AUTISM SPECTRUM DISORDERS AND THE HEALTHCARE EXPERIENCES OF AGING ADULTS

by

Karen E. Joseph-Kent

This qualitative, descriptive study illuminates the experiences of adults diagnosed with Autism Spectrum Disorders (ASD) and Intellectual Disabilities (ID) and their challenges and successes in receiving quality healthcare services. This population is challenged by a triple jeopardy of age, intellectual disability and autism symptomology (social/sensory/behavioral/communication challenges) and may experience negative health outcomes and suboptimal relationships with healthcare providers due to their communication deficits and behavioral impairments. Additionally, this population may suffer from increased morbidity and even premature death. Through semi-structured interviews with adults diagnosed with ASD and/or their guardians/caregivers, this study explored their perspectives and impressions of their healthcare experiences for 12 adults. In addition to their ASD diagnosis, many of the adults were impacted by major physical and mental health co-morbidities that require regular medical attention such as epilepsy, diabetes, sleep disturbances, depression, sedentary lifestyle and gastrointestinal problems. Individuals with developmental disabilities, such as ASD, often experience health issues associated with aging at earlier ages and at higher rates than the general population. The goals of this project were to understand how well their health care providers understand autism, including the sensory, behavioral, social and communication needs required of an adult with autism; explore their experience with how well their care is coordinated between primary health care and other specialty or ancillary services, and identify factors which could impact access to care; and to discover what other barriers (e.g. access to available health services, policy concerns, such as health insurance and residency location, advocacy, aging guardians and others) which may potentially influence the health for ASD adults.

Some of the adults interviewed experienced negative health outcomes and suboptimal relationships with healthcare providers; others seemed to have very positive relationships, with good preventive care and monitoring of health. Clinical and communications accommodations were absolutely necessary to make healthcare provision more comfortable for this population of adults. Coordination of care was seen as an imperative, with most family members taking on this responsibility, with support from residential caregivers and some primary care physicians. Barriers to accessing healthcare services were identified, including insurance concerns. The societal and healthcare costs of adults with ASD/ID are growing and are anticipated to be significant. This challenge will likely be further exacerbated given there are few trained healthcare providers who are prepared or dedicated to serve this population. Continuing to deepen the healthcare industry's understanding of the characteristics and circumstances that enable these positive relationships and successful outcomes will be critical in the future.

A DISSERTATION

Presented to the Faculty of
Miami University in partial
fulfillment of the requirements
for the degree of

Doctor of Philosophy

Department of Sociology and Gerontology

by

Karen E. Joseph-Kent

The Graduate School
Miami University
Oxford, Ohio

2016

Dissertation Directors: Suzanne Kunkel, PhD (chair) and Kate de Medeiros, PhD (co-chair)

©

Karen E. Joseph-Kent

2016

Table of Contents

CHAPTER 1: INTRODUCTION.....	1
Specific Aims:.....	3
 CHAPTER 2: LITERATURE REVIEW.....	 9
Background	9
Health Outcomes of Adults with ASD/ID	10
Determinants of Health for ASD/ID Adults	14
Biology.....	15
Individual Behavior	16
Social Factors.....	18
Policymaking	23
Family Relationships: Parental and Sibling.....	23
Parental/Family Stresses in the Transition to Adulthood	24
Sibling Relationships with Individuals with ASD/ID.....	25
Neurodiversity Movement	26
Summary of Literature Review.....	28
 CHAPTER 3: RESEARCH METHOD	 29
Rationale for Exploratory Qualitative Methods.....	29
Feasibility/Focus Group Guidance	29
Participant Recruitment	30
Interview Strategy	34
Data Collection	36
Field Notes and Memos	38
Data Analysis	38
Data Interpretation	40
Positioning of Researcher	41

CHAPTER 4: FINDINGS	42
Informant Characteristics	42
Specific Aim 1:	47
Clinical Accommodations	47
Communication Practices	52
Patient Social/Behavioral Requirements	55
Transitioning On/Off Psychotropic Medications	58
Double Jeopardy Stigma of Ageism/Disability	61
Specific Aim 2:	63
PCP Serving as Coordinator of Care/Services: Positive Experiences	64
Role of Family Members in the Coordination of Care	68
Reliance on Caseworkers in Coordination of Care	70
Coordination of Care Challenges: Emergency Rooms	71
Coordination of Care Challenges: Preventive Health Services	72
Specific Aim 3:	73
Barriers to Health: Access to Available Services	73
Barriers to Health: Medicaid Coverage	74
Barriers to Health: Group and Supported Residential Living	76
CHAPTER 5: DISCUSSION	80
Autism as Viewed Through a Life Course Perspective	81
Challenges to Access to Care	82
Importance of the Family Physician	83
Independent Living vs. Group Living: Does it Make a Difference for Health?	84
Implications of Communication Challenges	85
Access to Preventive Health Screenings	86
Limitations	86
Conclusions and Future Work	87
The Provider Perspective and Sharing Best Practices	88
Alternative Care Settings To Prevent Injury and Reduce Emergency Room Use	88
Exploring the Medical Home Concept for Adults with ASD/ID	89
Understanding the Long-Term Impact of Using Psychotropic Medications	90
Potential Application of Life Course Perspective and the Neurodiversity Movement on Adults with ASD/ID	90

Critical disability studies: More and better research.....	91
REFERENCES.....	92
Appendix A: INFORMED CONSENT (Guardian who will participate in Interview)	103
Appendix B: INFORMED CONSENT (Legal Guardian who will not participate in Interview, but must provide consent for participation)	105
Appendix C: INFORMED CONSENT (Caregivers who are not Legal Guardians).....	107
Appendix D: INFORMED ASSENT	109
Appendix E: RECRUITMENT ANNOUNCEMENT: KAREN KENT	112
Appendix F: IRB APPROVAL.....	113
Appendix G: DRAFT INTERVIEW GUIDE FOR Caregivers.....	114
Appendix H: DRAFT INTERVIEW GUIDE FOR ADULTS	116
Appendix I: DEMOGRAPHIC FORM	117

LIST OF TABLES

Table 1: Characteristics of ASD/ID Subjects under study	43
Table 2: Social characteristics of ASD//ID adults	45
Table 3: Guardian characteristics	46

DEDICATION

This dissertation is dedicated to my family for their enduring support and love. It is also dedicated to the strong and brave adults with ASD and their families and caregivers who love them. They inspire me to continue to learn and share with others their path in the journey of life.

As I reflect upon the personal journeys shared with me from the people I interviewed, I am uplifted by their perseverance, emotional resilience and positive outlook for the future. They were so generous in sharing their stories in the hopes that it would help others who are facing similar challenges in managing their health. The parents and siblings, who are so dedicated to ensuring the best quality of life for their sons, daughters, sisters and brothers, are remarkable people who balance much in their lives to safeguard their loved ones from stress and potential danger. There is so much that needs to be accomplished to serve this important and growing population. On a personal note, as my son is about enter the age of “adulthood,” I am privileged to have the experiences of these amazing people to help guide me and my family through many upcoming decisions and important life events.

ACKNOWLEDGEMENTS

I most whole heartedly thank my chairs, Drs. Kate de Medeiros and Suzanne Kunkel for their encouragement, critical analysis and advice throughout this process. Also, I am thankful for the exceptional guidance from Drs. Robert Applebaum, Cameron Hay-Rollins and Amie Duncan, who make up the rest of my dissertation committee. I share my gratitude to the ASD community in Cincinnati for their assistance in promoting and advising my project, especially Nancy Kopnick, Jennifer Brown, Amanda Tipkemper and Sue Radabaugh. Thank you to Kaylynne Adleta for her excellent transcription work. My deep appreciation and love to William Kent for his editing skills and unending support, encouragement and love, as well to Ian Kent for sending me on this lifelong journey to advocate for others and for Lauren Kent who always exemplifies social justice and concern for others. Also, thanks to the Joseph and Kent families for always being there for me during my all of my academic studies. Finally, I thank my academic colleagues at Xavier University and Miami University of Ohio, especially Dr. Ida Schick, Dr. Nancy Linenkugel, Tina Farrell and Tom Ruthemeyer and many other colleagues who encouraged me to complete this dissertation.

CHAPTER 1: INTRODUCTION

This dissertation shares the results of an exploratory study of aging adults with Autism Spectrum Disorders (ASD) and Intellectual Disabilities (ID) and their experiences in accessing and receiving healthcare services. This study was based on direct interviews with adults diagnosed with ASD/ID, their parents/sibling guardians and residential caregivers. The first chapter of the dissertation presents a background on the complex healthcare concerns of this expanding population, identifies the specific aims the study will consider, explains the significance of this issue and presents an overview of the methodology used. The chapter concludes by noting the limitations of the study and offers a glimpse into the rest of the dissertation.

Background of the Study

ASD is a lifelong neurodevelopmental disorder and is among the most common of the identified developmental disabilities (Volkmar, Paul, Rogers and Pelphrey, 2014). ASD is associated with ID, problems with motor coordination, difficulties with social interaction, sensory impairments and attention deficits. In addition to autism symptoms, nearly half of those diagnosed with ASD have major physical and mental health co-morbidities that require regular medical attention, such as epilepsy, diabetes, falls, sleep disturbances, depression, sedentary lifestyle and gastrointestinal problems (Happé and Charleton, 2011). Individuals with developmental disabilities, such as ASD, often experience health issues associated with aging at earlier ages and at higher rates than the general population (Haveman, et al, 2010, Heller and Sorenson, 2013). This higher risk is due to the combination of biological factors, suboptimal access to adequate healthcare and lifestyle and environmental issues (Heller and Sorenson, 2013). Often people with ASD are underdiagnosed with chronic illnesses because of the impediments they face with respect to identifying and communicating symptoms of ill health (Mouridsen, Rich and Isager, 2016). Many of these conditions could be better managed and perhaps prevented through more effective screening and prevention services provided by healthcare professionals.

Autism is often portrayed by advocacy groups and the media as strictly a childhood disorder. In fact, over four hundred million dollars are spent annually in the United States on autism research, which is primarily focused on autism prevalence, potential etiologies, early identification strategies and possible treatments in children (Nicoladis, et al., 2012). The prevalence of ASD significantly increased since 2002, when rates were 1:150, to rates as high as 1:68 children and 1:102 in adults (Cheak-Zamora and Teti, 2014, Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010). Over the next six years, nearly half a million children diagnosed with ASD will turn 18 (CDC, 2015) and will begin transitioning to adult healthcare providers. The numerous and complex needs of this growing adult population are not well understood, in particular their healthcare needs. The combined impact of an aging population in Western countries, an increasing rate of diagnosis of ASD and the escalating use of healthcare services for ASD will impose special and significant demands on our already strained healthcare system.

Based on the limited literature, it seems reasonable to conclude that aging adults with ASD experience health disparities and may also experience challenges in navigating the complex healthcare environment. One very recent study on 45 adults diagnosed with ASD and their informal and formal caregivers by Mukaetova-Ladinska and Stuart-Hamilton (2016) found 60% of all respondents felt ASD adults age differently than people without autism and require a different approach to care provision. This lack of research and knowledge regarding aging in ASD adults was recognized as one of the major barriers in delivery of quality care for people aging with ASD. The societal and healthcare costs of adults with ASD/ID are growing and are anticipated to be significant, while there are few trained healthcare providers who are prepared to serve this population. It is critical to research the experiences and concerns shared by adults with ASD and their families in order to find methods that facilitate communication, decrease patient anxiety, improve care and medication compliance and ultimately improve patient satisfaction, and perhaps, positively impact patient outcomes.

In order to better understand the needs of adults, this study focused on the population of adults with ASD who were also diagnosed with ID. The presence of ID in ASD is estimated to be 50-60% (Baird, et al., 2006); this population is challenged by a triple jeopardy of age, ID and social/behavioral challenges. According to the most recent literature on adults with an ID

diagnosis, there is a lack of a coordinated response to ensure the best possible health and social care is provided to this special population in later life (Lin, Lin, and Hsu, 2016). In addition, premature deaths are recognized in the ID population. Helsop, et al., (2014) conducted a study in England which found that nearly one quarter of people with ID died prior to the age of 50 and the median age of death for men and women was 64 years old. This was 13-20 years younger than in the general population. Most importantly, Helsop, et al. found that good quality healthcare could prevent these deaths in 37% of adults with ID (as compared to 13% of the general population). Through proper identification of disease and more effective management of illness, we might achieve reduced mortality and improve quality of life during old age.

The role of the physician is key in early recognition and evaluation of ASD and associated co-morbidities and in effective disease management of these chronic disorders. The primary goals of medical treatment for this population are to maximize functional independence and quality of life by minimizing the core autism spectrum disorder features, facilitating development and learning, promoting socialization, reducing maladaptive behaviors and educating and supporting families (Myers and Johnson, 2007). The studies on healthcare providers thus far report a lack of self-perceived competency by primary care providers (PCPs) in treating and diagnosing adults with ASD (Bruder, et al. 2012; Golnik, et al. 2009). There is very limited literature on best practices for optimal compliance and enhanced comfort in the clinical setting for adults with ASD/ID. Therefore, it is essential to identify innovative and individualized ways to serve this population in the clinical setting and to remove barriers to care. Because so much focus has been on children with ASD, transitioning effective techniques proven in the pediatric environment to the adult care delivery setting needs to occur, thus enabling a seamless and successful transition of care. It is important for adult medical providers to understand the clinical experience of their patients with ASD/ID special needs in order to reach these previously mentioned goals for medical treatment.

Specific Aims:

The goal of this exploratory study is to describe the experiences of adults with ASD and their caregivers in navigating the healthcare system to receive healthcare services.

Specific Aim 1: To understand the perception of patients and their caregivers about how well their healthcare providers understand autism, including the sensory, behavioral, social and communication needs required of an adult with autism.

Specific Aim 2: To explore ASD-impacted adults and their guardians' experience with the coordination between primary health, other specialty or ancillary services and factors which could impact access to care.

Specific Aim 3: To discover what other barriers (e.g. access to available health services, policy concerns, such as health insurance and residency location, advocacy, aging guardians and others) can potentially influence the health for ASD adults.

Significance of the Study/Innovation

This project is highly innovative as it is the first attempt to understand how the adult autism population accesses care and perceives their healthcare interactions. The intention of this project is to sensitize the reader to the plight of people with ASD and how they navigate a complex and fragmented healthcare system that is often not appropriately prepared and designed for them. The study reviewed their healthcare successes and challenges, as described by the adults, their family and their residential caregivers. Through learning from the lived experience of this special population, new opportunities for further research, intended to improve their current health status, are suggested. Based on the literature, healthcare professionals admit to limited preparation in serving the adult ASD/ID community; by investigating the three specific aims, the study offers understanding on ways the healthcare delivery system, with the support of family and residential care coordinators, may better serve this growing population of adults.

The results of this study illuminate the inherent challenges in accessing and receiving coordinated healthcare services for the ASD/ID population. Utilizing the defined determinants of health as outlined by groups like the World Health Organization (WHO, 2016) and Healthy People 2020 (2016), this study explored the biological, social, behavioral, health services and policy factors which influence health outcomes. As a result, healthcare providers, including physicians and clinical/administrative staff, as well as leaders in the social services sector, may begin to understand ways to enhance understanding and sensitivity to ASD adult needs, recognize opportunities to coordinate care and remove barriers to providing quality care.

The focus of this project on ASD adults with ID is also of significance to a large population of adults and those adolescents who are in transition to adulthood. The cohort of individuals initially given the diagnosis of ASD recently turned 70 years old, when the incidence rate of ASD was estimated to be 1:100,000. As the rate of diagnosis exponentially increased, the older individuals with ASD have much to share in anticipation of the growing cohort of younger adults, especially those with the combined diagnosis of ASD/ID. The ASD/ID combination tends to increase the severity of both disorders, leading to less functional ability, more need for community services and more subjective distress (Patel, et al., 2010). Adults with ASD/ID need ongoing medical care and support for behavioral symptoms. According to Patel, et al., there is a paucity of data and research on the best approach for managing adults who have ASD.

The process of transition of adolescents to adult healthcare providers for special needs patients is a relatively new phenomenon, which has been under study primarily over the last 20 years. Transition planning is the purposeful, planned movement of adolescents and young adults with chronic conditions from child-centered to adult-centered care (Cheak-Zamora and Teti, 2014). Transitions, as related to life course theory, may have a substantial impact on trajectories, as in the case of the ASD adult's ability to be comfortable and willing to see their adult physician. A major transition which has yet to be studied to any great degree is the transition of aging families with adult children with ASD. Individuals who have received decades of able assistance from informal supports provided primarily by a caregiver within their own family are destined to outlive their caregiving parents. As a result, older adults with ASD may become vulnerable when those primary caregivers die or are no longer able to provide care, and alternatives or siblings may not be available in the same way. At this point, either individuals transition into the formal support system for the first time or are hidden or overlooked until a major crisis occurs (Perkins and Beckman, 2012). The primary care medical provider may serve as a key player in the process of planning for the medical care services during this important transition period. Knowledge derived from both the caregiver and the adult with ASD through these interviews informs their perspective on the ability of healthcare providers to be active participants in planning for this transition. Healthcare providers who understand these transitions and are active participants in preparing for this significant transition will help adults maintain continuity of care and ultimately better health.

A special report offered by the Autism-In-Older Adults Working Group in the November 2011 *Journal of the American Geriatrics Society* (Piven and Rabins, 2011, p. 2151) states that older adults with ASD “could impose tremendous humanistic and economic burdens on the healthcare system and society.” This working group suggested the need for conducting “cross-sectional descriptive studies in adults of phenomenology, including current symptoms and behaviors...associated medical conditions and descriptions of available service and support networks” (Piven and Rabins, 2011, p. 2154). This group identified a gap in understanding; this project is the first attempt to fill that gap of knowledge. As this first generation of those diagnosed with autism are now reaching their 60s and 70s, understanding their obstacles to good health is essential to avoiding those burdens referred to by the geriatric work group.

This older population, now facing the loss of parents who often advocated for their healthcare, will need careful attention for both their physical and psychological well-being. Little funding has been devoted to projects exploring the impact of health systems and services for people with ASD (Bennett, 2016, Singh, Lazzeroni and Hallmayer, 2009). The knowledge gained from this generation will be important in planning for the needs of the very large cohort of adolescents with ASD now entering adulthood.

Theoretical Framework

Several sociological/aging theories support the specific aims of this study. First, the life course perspective provides a valuable framework for examining the intersection of aging, ASD and ID. Focusing on dynamic processes between people and their social worlds (Elder, 1995; George, 1993), the life-course approach provides a way of examining the interplay of life stages and transitions in relation to life outcomes (Coyle, Kramer and Mutchler, 2014). Transitions from previous states to future states, such as the transition from pediatric to adult medical care, are integral events that influence life-course trajectories. The “linked lives” principle, central to the life-course paradigm, highlights the fact that events experienced by one member of a family may have implications for the life course of another family member (Hogan, 2012). Parents and sibling guardians, who are part of this study, have many details and experiences to share from their own perspectives on how the primary care provider and their offices serve their family and how they represent those whom they care for. According to Ferraro and Kelley-Moore (2003), early risk factors shape trajectories in short-term outcomes, but also long-term outcomes as well.

These adults have lived with their disabilities and associated co-morbidities throughout their lives; their caregivers have often taken the lead in the management of these challenges. As a result, the pair (adult and caregiver) continue to navigate through systems not well designed and customized for their myriad needs.

Overview of Research Methodology

This project relied on qualitative data gathered through interviewing a purposive sample of adults with ASD/ID and their parents/guardians, as well as residential caregivers, when appropriate. A qualitative approach of enquiry was needed to learn about the specific aims and to meet the objectives outlined above; it was determined direct interviews were the most sensitive and direct methods to gain this information. The strength of this method was that it offered depth and detail to create a constructive understanding of the healthcare experiences of this population. This exploratory, descriptive method provided a straightforward look at the phenomenon, which was required due to the lack of information on the subject (Lambert and Lambert, 2013). The full discussion of the researched methods is disclosed in Chapter 3.

Assumptions/Limitations and Scope

Utilizing qualitative interviews as a research method enabled a richer and more descriptive understanding of adults with ASD/ID and their caregivers' shared relationship and life journey. Also, as a relatively unexplored area of research, interviews allow the interviewee to respond from their own experiences and provide context and explanation to their responses (Coyle, et al., 2014). This method of data collection allowed for deeper insights into their reality and lays a rich foundation of data for future research.

The challenge in finding older adult participants was evident, but realizable as the project moved along and connections began to "snowball". Initially, the study attempted to focus on adults with ASD/ID above the ages of 40. Many people who potentially fit into that category may not have been officially diagnosed with ASD, but were called a variety of other diagnoses during childhood. Rarely do adults go through the process of reevaluation for ASD as an adult. It became apparent that many adults, even those in their 20s, experience significant medical and mental health needs, and are often challenged in finding adult physicians and healthcare providers who can support their ASD needs. Given the life course perspective of this research, the subjects under study expanded from the ages of mid 20s all the way into the early 60s. This

group of cases offered a wide variety of health status levels, health service needs, residential setting experiences and sources of social and healthcare support. Twelve total adult cases were studied, which included interviews with four ASD adults, twelve parents or guardians (siblings), and several caseworkers/caregivers from supported living or group living environments. In total, 19 people were interviewed.

Summary

The population of adults diagnosed with ASD and ID is growing exponentially. This population often experiences health issues associated with aging at earlier ages and at higher rates than the general population (Haveman, et al., 2010, Heller and Sorenson, 2013), including premature death (Helsop, et al., 2014). In order to identify methods to eliminate the current gaps in care, this project defined the following goals:

- To understand how well their health care providers understand autism, including the sensory, behavioral, social and communication needs required of an adult with autism;
- To explore their experience with how well their care is coordinated between primary health care and other specialty or ancillary services and to identify factors which could impact access to care; and finally,
- To discover what other barriers (e.g. access to available health services, policy concerns, such as health insurance and residency location, advocacy, aging guardians and others) can potentially influence the health for ASD adults.

By understanding these important elements of healthcare access and utilization, healthcare providers, healthcare policy makers, ASD advocates, parents and families will learn new information regarding the needs of adults in the clinical settings. This project will conclude with a comprehensive “call to action” to continue to investigate the needs and concerns for this growing and largely ignored population of adults.

CHAPTER 2: LITERATURE REVIEW

Background

This dissertation utilized a life course perspective as applied to the health of ASD adults. Life course suggests that a complex interplay of biological, behavioral, psychological and social protective and risk factors contribute to health outcomes across the span of a person's life (Pies and Kotelchuck, 2014). The experiences of all of these factors impact the life span of the subjects under study. In addition, important life stage transitions (such as the transition to living away from family and the loss of caregivers) often impact an individual's health trajectory.

Given this perspective, this literature review is organized in four sections. First, the literature review considers current research on health outcomes for adults diagnosed with developmental disabilities/ID and autism spectrum disorders. Understanding current health outcomes speaks to important chronic diseases which adults with ASD/ID experience. Understanding these associated diseases is important for health screening purposes for this population. Next, in section two, a deeper understanding of the determinants of health and potential barriers to positive healthy aging is identified. Section two illuminates not only the biological and behavioral aspects to health outcomes, but the psychological and social protective and risk factors. Adults with ASD/ID are complex in their healthcare, social, behavioral and mental health needs. Uncovering their determinants of health and identifying barriers will be helpful for healthcare providers to appreciate the challenges which these adults and their families handle on a regular basis. In section three, the literature review considers the role of the caregiver in serving individuals with a combined ASD/ID diagnosis. This information is important since the guardian (parent or sibling) serves as an active participant in facilitating access to healthcare services for the adult. The "linked lives" of the adult and the family member share important life trajectories together, impacting the health of the adult with ASD (and vice-versa, actually). Related to the role of the caregiver is the environment in which the ASD/ID adult resides, which ranges from living with family, living in a supported or supervised environment to group/residential environments. These environments and communities have a major influence on access to healthcare services. Finally, in section four, the concept of neurodiversity, which promotes the idea of autistics as their own culture, was reviewed in the context of studying ASD individuals actively involved in receiving medical services. The neurodiversity movement, a new

and developing notion of self-advocacy for autistics, may have growing influence on interactions with healthcare professionals and other support providers, therefore an important consideration in the context of healthcare delivery. As this study entered an unexplored area of research, going in with a broad perspective on the health, social interactions and advocacy needs of people with ASD/ID was essential.

Health Outcomes of Adults with ASD/ID

Understanding health outcomes of adults with ASD/ID is important in targeting potential chronic health concerns and planning for health services delivery needs. Very little literature exists on the health outcomes or developmental trajectories of adults with ASD (Magiati, Tay and Howlin, 2013). Given there is no central reporting on the health services utilization of this population, epidemiological and health services research is complex and costly (Taylor and Seltzer, 2011). Given that this study focuses on adults with a combined diagnosis of ASD and ID, it is necessary to look at the life expectancy and health outcomes literature to scan the environment for anticipated health concerns. This first section will look at mortality rates and specific medical, psychiatric and oral health concerns impacting adults with ASD/ID. This information is essential in understanding the types of illness this population commonly manages in addition to their ASD/ID disability.

Life Expectancy

Unfortunately, there is limited information regarding the life expectancy of people with ASD (Tyler, et al., 2011). Shavelle, Strauss and Pickett (2001) reported mortality data on over 13,000 ambulatory Californians with autism, followed between 1983 and 1997, of whom 202 died during the study interval. In this analysis, the overall standardized mortality ratio (SMR) — the ratio of observed deaths in persons with autism compared with the expected number of deaths in a general population of persons with similar demographic characteristics—was calculated as 2.4 (meaning the mortality risk for those with ASD is nearly two and half times more than the general population). For persons with little or no ID, the SMR was 1.4; for those with moderate, severe or profound ID, the rate is much higher at 3.1. Women, in particular, had a much higher rate at 5.5. Drowning and epilepsy were often cited as cause of death in younger people, with the rate of death decreasing over time for those causes. Mouridsen, Brønnum-Hansen, Rich and Isager, et al. (2008) reported on a clinical group of 341 Danish individuals

with autism who were followed for an average of 35 years, with a mean age of 43 years; their group SMR was 1.93. In this study, the two most common causes of death were epilepsy and cardiovascular disease. Although the average life expectancy of individuals with autism spectrum disorder is unknown, it is likely that many will survive to an age where chronic diseases such as diabetes, hypertension, coronary heart disease and cancer could occur and potentially impact health and mortality.

In more recent work, Mouridsen (2013) found the most important risk factors associated with reduced life expectancy in people with ASD are moderate to profound ID, having epilepsy and female gender. In a similar study which evaluated an all-cause and cause-specific mortality in ASD using nationwide Swedish population-based registries, the authors concluded they were unable to differentiate whether the increased mortality in ASD was because of shortcomings in care provision, increased biological vulnerability, or both (Kogen, et al., 2008). This supports the need for continuous and coordinated care for this high-risk sub-population of individuals (people with ID) within the population of people with ASD. Mouridsen concluded that measures to reduce inequalities in people with ASD need to focus on reducing mortality from preventable causes of death such as infectious diseases and accidents.

Mental Health Disorders

Co-occurring mental health disorders are often part of an ASD diagnosis. Some of these disorders include attention-deficit/hyperactivity disorder, oppositional defiant disorder, conduct disorder, tic disorders, disorders of impulse control, sleep, feeding, elimination and mood (i.e. depression and bipolar-related disorders). All can be difficult to accurately diagnose, especially when nonspecific symptoms are present and when the individuals are not able to fully express themselves (Mazzone, Ruta and Reale, 2012). This overlap highlights the need to carefully consider the qualitative aspects of ASD and comorbid presentations. Mental health needs remain very high during adulthood and seem to be frequently undetected and untreated, and more often identified as “just part” of ASD (Hassoi and Turk, 2012). Some of the mental health symptoms that can occur with core autistic symptoms include hyperactivity, aggression, irritability, and/or self-injurious behaviors (Park, S. Y., et al., 2016). For some adults with ASD, the mental health concern becomes an even more challenging health concern than their autism symptoms.

For people diagnosed with ASD who exhibit psychiatric comorbidity, psychiatric concerns are managed by several different types of interventions (Ghaziuddin, et al., 1992). In addition to behavioral and psychological interventions, medications are increasingly used for the control of mood and behavioral symptoms in autism. However, despite the current popularity of psychopharmacologic agents, little systematic research has focused on their use in persons with autism (Ghaziuddin, Ghaziuddin and Greden, 2002, Park, et al., 2016). Ideally, medications are used as part of a comprehensive treatment plan, using other types of treatments as well. As a result, it is difficult to pinpoint the effective intervention. There is a high rate of psychotropic medication usage in adults with ID (Robertson, et al., 2000). Types of psychotropic medications include anti-depressants (including selective serotonin reuptake inhibitor (SSRIs) and non-SSRIs) and neuroleptics (also known as anti-psychotic medication) (Ghaziuddin, Ghaziuddin and Greden, 2002). One study found that adults with ASD and ID were more likely to be prescribed psychotropic medication, and in particular antipsychotics, compared to matched controls with ID who do not have ASD (Tsakanikos, et al., 2007). Overall there is limited evidence about the use of psychotropic medication in adults with autism and intellectual disabilities. Also, there are no long-term longitudinal studies of the use of these medications in children/adolescents and their impact on adult health. Some of these psychotropic and neurological medications may cause higher risk for other conditions. Antipsychotics have been associated with weight gain; neuroepileptic drugs have been associated with osteoporosis and sleep problems, and psychoactive medications are associated with cardiovascular risk and hyperlipidemia (Croen, et al., 2015, Park, et al., 2016). Today, the only medications which are approved for children with ASD by the U.S. Food and Drug Administration (FDA) for reducing agitation and irritability are risperidone (brand name Risperdal) and aripiprazole (Abilify) (Park, et al., 2016).

In the Croen, et al. study (2016), more than half of adults with ASD were diagnosed with a mental health condition - 29% diagnosed with anxiety, 26% with depression, 11% with bipolar disorder, 8% with schizophrenia and 8% with OCD. After adjusting for sex, age and race/ethnicity, the risk of most psychiatric conditions was significantly elevated in adults with ASD - from 2.9-times higher for depression to 22-times higher for schizophrenia - compared to controls. The risk of suicide attempts was 5-times higher in adults with ASD compared to typical controls, indicating the depth of the depression in the ASD population. This study did not

control for ID and included a larger number of those without an ID; thus, the study was not able to ascertain if these trends are indicative of the ID population.

Seizure Disorders/Epilepsy

An association between ASD and epilepsy is consistently reported in the literature, with a wide range of estimates from as little as 5 percent to as much as 46 percent (Spence and Schneider, 2009). Data from the literature suggest that age, gender and comorbid medical conditions all increase epilepsy risk in the ASD population. Also, there appears to be a correlation with severity of ID and epilepsy; the more severe the ID, the higher the rate of observed epilepsy. The clinical identification of seizures may be difficult in some cases, especially partial complex seizures, which can be largely complicated by the presence of atypical body movements (tics) and behavioral patterns often seen in association with ASD (Bauman, 2010). It is likely that the co-occurrence of ASD and seizures may reflect a shared underlying neurobiology (Bauman, 2010). According to Woolfenden, et al., (2012), in their systematic study of all literature on ASD and epilepsy for people over the age of 12, 23.7% of those with ASD/ID had epilepsy, as compared the 1.8% in the population without ID. Based on Woolfenden's review, the SMR was found to be 2.8 higher than among peers of the same age and sex in the general population. For women, the SMR was even higher. The need for consistent health surveillance is key to managing the health of those ASD impacted individuals who also have seizure disorders.

Oral Health/Dental Care

The connection between oral care and overall well-being, as well as general physical health is well established in the literature (Scully, 2000). Oral health problems can result in pain and discomfort, causing devastating complications to an individual's well-being, with financial and social costs that can cause significant stress to the patient and the family. In addition, research indicates associations between periodontal disease and other significant health issues including diabetes (Löe, 1993), heart disease and stroke (Wu, et al., 1999), and adverse pregnancy outcomes (Hillier et al., 1988, 1995).

The literature related to oral health for those with ASD is even more limited than the literature related to physical health. A search of the *Journal of the American Dental Association*

indicated no articles related to adult dentistry and ASD. There were a few articles related to children with ASD and dental care, mostly focused on the methods for effective care in the operatory environment. In an article by Friedlander, Yagiela, Paterno and Mahler (2006), the authors encouraged dentists to be familiar with the medications used to treat the associated features of ASD, as many psychotropic drugs cause orofacial and systemic side effects and may trigger adverse interactions with dental therapeutic drugs, such as analgesics. Also, the inability to communicate effectively also can complicate obtaining information on pain and discomfort. Most people with moderate to profound ID and behavior problems require sedation to perform even the most basic dental cleanings, and the degree of sedation can be difficult to control. Most dentists prefer to conduct any long and involved treatment and procedures in a surgical center or hospital center under general anesthesia (Ananthanarayan, Sigal and Godlewski, 1998).

Given the limited literature on health outcomes, what can be gleaned from the literature is that adults with ASD/ID do have much higher rates of chronic physical illness, complicating mental health issues and even premature deaths. Obviously, more research is needed in this area to gain a complete picture of health outcomes. The next section will review the context of determinants of health in this population, which sheds some insight into why adults with ASD/ID have such negative health outcomes.

Determinants of Health for ASD/ID Adults

The health status of aging people with ASD/ID is adversely compromised by a collection of disparities, which ultimately impact health outcomes. Utilizing the report *Healthy People 2020* model of determinants of health (US Department of Health and Human Services, 2016), this dissertation applied an ecological approach to help identify the individual challenges to health status experienced by ASD adults and their relationship with the external influences which impact optimal health. Determinants of health utilized by *Healthy People 2020* encompass five broad categories:

- Biology
- Individual Behavior
- Social Factors

- Health Services Delivery
- Policymaking

The interrelationship among these factors can determine an individual's (or population's) health. Each factor will be explored in this section and should be viewed in the context of how a healthcare provider can influence the prevention and management of some of these health determinants.

Biology

Biology has a major influence on health. Given this, we do have some limited understanding of the biological associations with ASD and other co-morbidities. As mentioned in Chapter One, it is estimated that more than half of children with ASD have an ID (Baird, et al., 2006; van Engeland and Buitelaar, 2008). There is evidence that people with lower cognitive abilities and people have poorer health than their peers (Krahn, et al., 2006). This situation is likely due to the interplay of other determinants of health, including their lower health literacy levels, inability to identify poor health, limited problem solving abilities and weak communication skills to negotiate our complex healthcare system (Emerson, et. al., 2001). As a result, this may lead to missed or late diagnosis and lost opportunities for prevention of disease or timely treatment (Croen, et al., 2015).

Also, dietary challenges are seen in adults and children with ASD. Evidence suggests there is a link between ASD and compromised immune systems, such as gluten allergies, and other medical causes (van Engeland and Buitelaar, 2008; Pessah, et al., 2008). Restricted diet is a common issue for many people with ASD, due to sensory preferences, and often leads to poor nutrition and weight concerns (Heller, et al., 2013). PCPs, in conjunction with psychologists may be able to create clinical environments where food sensitivities are managed and nutritional deficits are addressed.

Many ASD individuals may have medically relevant disorders that can potentially negatively impact their developmental progress and behavior, but which frequently go undetected (Bauman, 2010). Many of these chronic conditions are treatable, often resulting in improved developmental gains and quality of life for the patient and family. ASD individuals can

and do have many of the same medical disorders and diseases that affect neurotypical persons, although they may present differently. Some of the more common disorders include gastrointestinal dysfunction, sleep irregularities, metabolic disorders and hormonal imbalances (Bauman, 2010). Given the susceptibility for chronic illnesses, screening for chronic diseases requires measurement of weight, height, blood pressure, and venipunctures for blood glucose, kidney function and lipid testing; these seemingly routine experiences may trigger panic, aggression, fear, or other overwhelming reactions in persons with autism spectrum disorders (Tyler, et al., 2011). Some individuals require desensitization techniques, such as sedation, to allow these requisite screenings to be conducted (Shabani and Fisher, 2006). Management of chronic disease in the ASD/ID requires creative, thoughtful, individually tailored care, especially for those with cognitive disabilities.

As mentioned in the previous section, gender has an impact on health status and longevity in ASD. Women tend to have a shorter lifespan than men with ASD, which is atypical from the general population. Why this is the case is unclear and worthy of future exploration.

Individual Behavior

Features and habits intrinsic to ASD may make individuals inclined to engage in behaviors that may lead to chronic diseases. For example, tactile, gustatory and olfactory sensitivity in children with autism spectrum disorders may lead to diets that are limited in nutritional value and social challenges interfere with participation in organized sports and physically oriented recreational activities (Pan and Frey, 2006). Given these behaviors, concern is growing about the health habits of adults with ASD. Rates of obesity in children with ASD were found to be above nationally representative prevalence estimates for children (Egan, Dreyer, Odar, Beckwith and Garrison, 2013). Among children with ASD, 17.16% had a body mass index (BMI) percentile in the overweight range and 21.89% had a BMI percentile in the obese range. Obesity increases the risk of many chronic diseases including diabetes, cardiovascular diseases, sleep disorders, musculoskeletal conditions and cancer (Guh, et al., 2009)

As in the obesity study above, information about medical comorbidities in children with autism spectrum disorders is rapidly accruing in the literature, yet much is unknown about the

health of adults with ASD. In a study conducted by Tyler, et al. (2011) a cohort of 108 young adults with autism spectrum disorders, rates of chronic disease were 34.9% for obesity, 31.5% for hyperlipidemia and 19.4% for hypertension. Based on this information, Tyler hypothesizes that without behavior intervention initiated in childhood and continued through adolescence and early adulthood, serious health conditions, including diabetes, coronary heart disease, heart failure, osteoarthritis and cancer will likely ensue.

Persons with disabilities often experience difficulties in communication and social interaction with health professionals. They also may have difficulties in participating in examinations they do not understand, or of which they are fearful. Additionally, health professionals may lack, or feel they lack the necessary specialized skills and knowledge to provide adequate care services to this special population. Physical barriers such as inaccessibility of healthcare facilities to people with physical, cognitive or sensory impairments can be challenging. Sensory overload from noise, smells, lights and crowded busy waiting rooms could exacerbate their behavior problems (Olivie, 2012). Tactile sensitives may interfere with physical exams, and may result in lost opportunities to identify disease (Croen, et al., 2015). Barriers to health screenings and health services include individual and environmental factors which makes delivery of care challenging, such as when ASD/ID individuals exhibit physically aggressive behaviors.

Behavior management, through the use of prescription drugs is very common in adults with ASD/ID, beginning at very young ages. Most medications prescribed to ease autism's disabling symptoms are used "off label," meaning their Federal Drug Administration approval is for other, sometimes-related conditions such as ADHD, sleep disturbances or depression. Such off-label use is common in many areas of medicine and is usually done to relieve significant suffering in the absence of sufficiently large and targeted studies. The long-term impact on these medications on individuals with ASD has not been determined (Grondhuis and Aman, 2014). The intersection of social demands for appropriate behavior and the biological impacts of medications on a population which may metabolize drugs in a different way demonstrates the complexity of understanding anticipated health outcomes for people with ASD.

Social Factors

Social determinants of health reflect the social factors and physical conditions of the environment in which an individual is born, works, lives, relaxes and ages. Social and physical determinants contribute to our quality of life, health outcomes and overall functioning (U.S. Health and Human Development, 2016). Social determinants include many important concerns for adults with ASD/ID:

- Availability of resources to meet daily needs, such as educational and job opportunities, living wages, or healthful foods
- Social support and social interactions
- Residential segregation
- Social norms and attitudes, such as discrimination

As noted by several authors, (Gerhardt and Lainer, 2011, Howlin, Goode, Hutton and Rutter, 2004), social determinants such as employment, community and residential needs of ASD individuals continue to far exceed the available resources. Although a minority of adults achieve relatively high levels of independence, most remain very dependent on their families or other support services. According to the Howlin et al. study of 68 adults on the ASD spectrum and who had an IQ of at least 50, few people lived alone, had close friends, or held permanent employment. Communication impairments still persisted, and reading and spelling abilities were poor. Stereotyped behaviors including obsessive/compulsive tendencies, physical “tics” (rocking, hand flapping, pacing, etc.), repetitive language, mood changes to interruptions in daily routines, or verbal and physical reactions to sensory stimulation frequently continue into adulthood. In addition, 10 of the 68 individuals developed epilepsy. Overall, only 12% were rated as having a ‘very good’ outcome; 10% were rated as ‘good’ and 19% as ‘fair’. The majority were rated as having a ‘poor’ (46%) or ‘very poor’ (12%) outcome. Individuals with a childhood performance IQ of at least 70 had a significantly better outcome than those with an IQ below this.

For many of the social factors above, disparities in attention to care needs seem to be at the root of many of these concerns. People with ID, especially moderate and severe disabilities, often rely on their support providers for the routine activities for their daily lives. These include

support to identify health concerns, communication with health providers and engagement in health promoting behaviors (Krahn, Hammond and Turner, 2006). Living arrangements and environment play a vital role in maintaining health, and recent literature recognizes that differences in health status vary with the nature of the caregiving arrangement for people with ID.

In Western countries, the trend has been for people with ID to move out of the family home to live in the community in individual or smaller group homes, not in large congregate care facilities, as once was the norm. Healthcare providers have expressed concerns about compromised healthcare quality for individuals living in the community without constant family supervision. Smaller group home situations may lack access to healthcare in these homes and finding clinicians who are knowledgeable about the person and their condition can be challenging, resulting in inadequate recognition of potentially life-altering conditions (Krahn, et al., 2006). A study conducted by Lewis, Lewis, Leake, King and Lindemann (2002) evaluated health status of individuals living in three types of community living centers in California. Compared with persons with ID living at home with family or friends or living in the community on their own, persons living in community-based group homes were more likely to have a personal dentist or physician, more likely to have a normal body mass index and less likely to be obese. In contrast, a study from Israel by Lifshitz and Merrick (2003) found community residence adults displayed more medical problems and individuals living at home exhibited more dental problems. The challenge in understanding health outcomes based on residence has been the availability of large sample sizes and great variability in settings to evaluate the health of adults. What we do know is socialization, access to safe living environments and availability of resources will have an impact on health outcomes.

Social norms and attitudes are also a social determinant of health. According to the Disability Rights Commission in 2006, people with ID are at risk of systemic discrimination in access to timely and effective healthcare (Disability Rights Commission, 2006). As a result, people with ID and ASD are at risk of exposure to social exclusion and exposure to episodes of disability-related discrimination. As seen in racially based discrimination, health inequalities may result from long term stigmatization. In addition, there is some evidence to suggest exposure to disability-related discrimination and bullying is associated with poorer physical health and mental health among people with learning disabilities (Emerson, 2010).

Stigma, a sociological concept developed by Goffman (1963), is often experienced by people with autism and their caregivers. Stigma is a mark of disgrace that sets people and groups apart from the rest of society and often results in negative actions and discrimination. Inherent in this definition of stigma is the acknowledgement that stigma is imposed by others who negatively evaluate and make assumptions about the person with the stigmatizing characteristic. Perhaps more importantly, the feelings and perceptions of being stigmatized affect the lives, opportunities, and experiences of those being negatively judged. Gray (2002) shows that parents of children diagnosed with ASD experience considerable stigmatization due to the socially inappropriate behavior of their children. Gray argues that the normal physical appearance of those diagnosed with ASD makes these behaviors more stigmatizing for parents; ASD is often known as the “invisible disability”. The literature on how those within the ASD population experience stigma is now being documented. Articles range from how the media portrays autism (Stevenson, J. L., Harp, B., & Gernsbacher, M. A., 2011) to the study of parents and siblings and their felt or enacted stigma (Gray, 2002, 2004). Stigma is at play in any social interaction for those with disabilities and is compounded by those who are aging. The impact of both realities, recognized as “double jeopardy” (McGrew, Groger & Kunkel, 2002), places the adult with autism and their aging caregivers at risk in two significant ways: the individual with a developmental disability requires care and support, while the older family member(s) may require care and support for their own aging-related conditions. It is assumed stigma reaches all facets of social interaction, including the interactions those stigmatized groups have in receiving healthcare services. Rarely would stigma towards age and disability be overt in institutionalized settings; however, insidious discrimination exists in forms such as challenges in accessing services, difficulties in communicating needs and expectations and subjective decision making by healthcare workers.

Healthcare Services

Access to healthcare and the quality of health services impact health outcomes, especially in an acute episode. Access to care is challenging for ASD/ID adults and their caregivers, as so few providers are trained and willing to serve people with special needs. Although specialized training exists for developmental pediatricians in serving this population, no such specialty exists in adult medicine. For many, it is very challenging to find a PCP who is focused on the needs of those with ASD or ID, in addition to caring for a broader population of patients in their general

practice. Undoubtedly, for the practicing physician in today's healthcare world where they are expected to see patients quickly and efficiently, they are challenged to offer extended time to comprehensively examine patients who have the physical limitations, communication difficulties or behavioral issues that often coexist in persons with ASD/ID. This can potentially result in limited clinical consultation, poor rapport and perhaps suboptimal treatment choices.

According to Nicolaidis, et al. (2013), adults with ASD are just as likely as other adults to have a primary care provider, but are more likely to have unmet physical and psychiatric needs. In addition, they are less likely to receive preventive care and more likely to end up in the emergency room. Routine primary care screenings for chronic health concerns are increasingly needed as people age. Research indicates that adults with developmental disabilities receive fewer and less timely screening and diagnostic services than the general population (Haveman, et al., 2010). In the Nicolaidis study, perceptions of the quality of doctor-patient communication are uniformly poorer among adults with ASD, which is potentially related to the communication impairments associated with the disorder. For most ASD patients, psychiatrists manage the psychotropic medications, with little input or interaction from primary care physicians.

The role of an adult PCP is to serve as the patient's first point of entry into the healthcare system and as the continuing focal point for all needed healthcare services (American Association of Family Practitioners, 2014). There are very few PCPs trained to serve the ASD community. Additionally, PCPs are not reimbursed to serve this more complicated population. According to a qualitative study conducted by Carbone, Behl, Azor and Murphy (2010) pediatricians indicate a desire to provide high quality care to their ASD patients, but lack of time, training and resources serve as significant barriers to optimal care. However, no studies on adult PCPs have been conducted to understand the experience of serving the adult ASD population.

Further, pediatric patient-centered medical homes (PCMH), originally organized to serve special needs children in the 1960's, are now considered the standard of care for all children (American Academy of Pediatrics, 2002; Homer, et al., 2008). Special needs children are often challenging for medical providers to address as their healthcare needs, utilization and cost have a substantial impact on the healthcare system. Often care is less than ideal as there are no incentives to orchestrate the myriad of health needs or to anticipate future care requirements. Medical homes are designed to provide care that is "accessible, comprehensive, continuous,

coordinated, compassionate, culturally competent and family-centered” (Berry, Agrawal, Cohen and Kuo, 2013). Providers organized to serve as a medical home tend to demonstrate more comprehensive and coordinated care and greater success at meeting needs when compared to the broader cohort of children and youth with special needs (Volkmar, Paul, Rogers and Pelphrey, 2014). In Homer’s meta-analysis (2008), the preponderance of evidence supported a positive relationship between the medical home and desired outcomes, such as better health status, timeliness of care, family centeredness, and improved family functioning. It is suspected, but not proven, that providing care through a PCMH results in substantial cost savings from reducing unnecessary healthcare utilization (Barry, Agrawal, Cohen and Kuo, 2013). Although the pediatric literature indicates the value of medical homes for the special needs population, no evidence exists on medical homes for adult ASD patients.

For many people with ASD with complex co-morbidities, especially ID, the lack of coordination across a variety of healthcare and social support specialists can be a daunting challenge (Marks, Siserak and Heller, 2010). Given the wide variety of clinical needs of this population, coordination of care with specialists is required for good health. For both primary care and specialists, their training in serving this population is largely “on the job” in finding what works or does not work for their special needs patient population. McGhee and Dorsett (2011) found the training of frontline staff is widely accepted as an effective strategy for increasing organizational capacity to improve quality of life. Unfortunately, there is a scarcity of US studies on programs designed to improve clinician training on ID; the modest existing literature regarding clinician preparation indicates inadequate or absence of formal training on ID. Currently, there is no curriculum requirement for US medical schools specifically to teach competency in the provision of care to persons with ID (Perkins and Moran, 2010). Training issues related to ID are still not commonly presented in the context of a life span, instead remaining largely the domain of pediatrics. In fact, numerous pediatricians provide care to patients with ID long after the transition to adult medical services should have occurred. This challenge for physicians is compounded for adults with ID who live in supervised residential settings who experience frequent turnover of clinical staff; this lack of continuity of care may result in failure to recognize emerging health issues (Perkins and Moran, 2010). Hence this speaks to the need for interdisciplinary training, including primary care physicians, specialists and the providers of ID services (Lin, Lin and Hsu, 2016).

Policymaking

Aging is influencing ID policy issues (Fujiura and Parish, 2007). In the EU countries, there is emerging discussion focused on the changing needs of the aging ID population. In Europe, the needs for the ID population is considered within the backdrop of the broader political environments including changes in economic conditions, legal precedent, political conditions, medical technology and philosophies of governance, which historically alter the landscape of supports and services for persons with cognitive disabilities. As caregivers and adult siblings age, policymaking for caregiving support is a significant worry for families. The International Association for the Scientific Study of Intellectual Disabilities (2002) proclaimed adults with ID have the same needs and rights as the typical population to receive quality medical care, access to good nutrition and housing, employment, social interactions and access to leisure activities. This goal is equitable and just, however, it is not yet a reality.

There is a lack of organized public and private sector systems to address the needs of the ASD/ID population, and this is universal for most developed countries. Even aging people with mild ID are often unable to gain successful full-time employment. Vocational services are often difficult to sustain for those with moderate or more severe disabilities. The 2002 report from the US Surgeon General's Conference on Health Disparities and Mental Retardation "Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation" set forth a vision to improve the health of individuals with ID (Perkins and Moran, 2010). The report highlighted disparities in health status, access to care and healthcare quality, and called attention to the lack of training of physicians and other healthcare professionals in the needs of individuals with ID across their life span. Since this report, progress is slow, and efforts affecting the well-being of older adults have come under budgetary pressures. Furthermore, there is limited coverage for health promotion and preventive care programs targeted specifically for older adults with lifelong disabilities (Perkins and Moran, 2010).

Family Relationships: Parental and Sibling

Family members (parents or other family members/formal guardians) are often key in supporting adults with ASD. These parents experience an altered life course as both a "perpetual parent" caring for children with developmental disabilities and as a "stigmatized parent" caring for an individual with behavior concerns (Kropf and Kelly, 1995). Siblings often step in when

parents are unable to continue to serve in this role. This study focused on the experiences of the individual with ASD; however the role and actions of the caregiver is absolutely integral in understanding the healthcare experience.

The literature related to caring for children/siblings with ASD is very important to the approach of this study. Although the focus of this dissertation was on the individual with ASD/ID, the family member actively participated in the interview process and shared the healthcare experiences. It was essential to have someone familiar with the healthcare encounters of the adult. In a few instances, supportive and group home caregivers would accompany the adult to medical visits when the family members were not available, due to age, location or schedule. Several supportive and group home caregivers were interviewed as part of this study.

Parental/Family Stresses in the Transition to Adulthood

For individuals with ASD, the normative challenges associated with the transition to adulthood are compounded with the social and behavioral difficulties unique to ASD. The experience of adulthood often involves transitions in educational, occupational, residential and relational arenas, and the development of new roles and identities. These transitions are particularly stressful for adults with ASD and their families because difficulties coping with change is a fundamental part of ASD. Also, the heterogeneity of ASD may make it challenging for families to develop expectations for the future. Families of individuals with ASD also face stress related to changes in the service system following graduation from high school, which exacerbates the normal worries associated with supporting a child's transition to adulthood (Smith, et al., 2012). These worries are legitimate given the bleak range of opportunities for the ASD population. A study by Shattuck, et al. (2012) revealed that after young adults with ASD left the public school system at the age of 22, 80% continued to live at home, only 32% attended postsecondary education, just 6% had competitive jobs and 21% had no employment or education experiences at all. Further, 40% reported having no friends. As a result, adults with ASD/ID are very dependent on their families to fill every level of need.

Particularly stressful for families is the management of physically and verbally aggressive behaviors presented by many children on the spectrum; these behavior problems can continue into adulthood and remain a barrier for adult independence and community involvement (Smith, et al. 2012). Although there is some improvement in behavior problems and autism

symptoms as ASD children age, there is also evidence that improvements in behavioral functioning slow down once the young adult leaves school (Shattuck, 2012).

The years of high stress experienced by families, also takes a toll on the physical well-being of parents. A study by Selzer, Greenberg and Hong (2010) indicated that mothers of adults with ASD have significantly more physical health symptoms including joint pain, headaches, fatigue and gastrointestinal problems than mothers of adults without disabilities. Social, occupational and financial strains, which are additionally experienced by family caregivers, often lead to elevated levels of health problems and psychological distress particularly in mothers. It is estimated at least 40% of adults with ASD live with their aging parents or siblings (Taylor and Seltzer, 2011). The significance of these parental and sibling relationships is often overlooked in policy, practice and research and social service providers. This raises the question of what families need for adequate support and intervention strategies (Mukaetova-Ladinska and Stuart–Hamilton, 2016). Aging parents often have no choice but to continue in an active caregiver role.

In the Mukaetova-Ladinska and Stuart–Hamilton study (2016) their findings present an urgent need to address both the unmet and increasing needs of both ASD subjects and their families. Aging parents of adults with ASD face the unknown futures for their adult children when they are unable to look out for them any longer. For ASD adults over the age of 40, they will likely require a “new generation” of caregivers, who may be siblings or other family or close friends. This will place pressures on quality of life for the guardians and the older person with ASD, as well as the social service systems which are offered to meet the needs of the ASD adult population.

Sibling Relationships with Individuals with ASD/ID

Sibling relationships over the life course are an important thing to bear in mind in studying this population. Since the study placed special emphasis on interviewing adults age forty and beyond, several interviews included siblings who serve as caregiver or guardian upon the passing of a parent.

Seltzer, et al. (2002), not only studied the parent as caregiver, but also the sibling as caregiver. Among the general population, the sibling relationship has significant life course variation, as the intense involvement that characterizes sibling interactions during childhood gives way to more disengaged relationships during the young adult years, followed by a

rekindling of the sibling bond during midlife and older age. A growing body of research on adult sibling relationships when one individual has a developmental disability suggests that, in general, these siblings tend to maintain high levels of positive involvement across the life course, although there is variability in the degree of contact and closeness. Severity of disability was also a factor in the relationship; siblings whose brother or sister with less severe functional impairments and behavior problems were more likely planning to co-reside in later years. Finally, there was a greater expectation that the siblings would co-reside when the mother was already in poor health. Interestingly, even among those who planned to live apart, at least half had weekly contact with the brother or sister, have had discussions with their parents during the preceding year about future plans and plan to be the legal guardian of the sibling with the disability after the parents were no longer able to fill this role. Although this research is focused more broadly on individuals with developmental disabilities, it is helpful in understanding how the presence of cognitive impairment affects sibling wellbeing and sibling relationships (Orsmond and Seltzer, 2007).

Orsmond and Seltzer (2007) offered the only focused study on the sibling pairs when one sibling was diagnosed with ASD. Compared with siblings of adults with developmental disabilities, siblings of adults with ASD conveyed lower levels of engagement with their brother or sister, reported lower levels of positive feelings about the relationship, felt more pessimistic about their brother or sister's future and were more likely to report that their relationships with their parents had been affected. The authors noted that much more research needs to be done with siblings to better understand the relationships, especially with the growing cohort of young adults transitioning into adulthood.

Neurodiversity Movement

Many ASD self-advocates, including Sinclair (1993), and Davidson (2008), argue for the acceptance of the autistic experience from the perspective of the neurodiversity movement (Silverman, 2008). Self-advocates believe autism represents an acceptable cognitive style or mode of interaction and should be treated as a form of diversity, rather than a disorder. The neurodiversity movement is inspired by the disability rights movement and specifically, deaf culture. Further, neurodiversity advocates espouse their condition is not a disease to be treated and, if possible, cured, but rather a natural human specificity (like sex or race) that must be equally respected (Ortega, 2009). According to Baker (2006) autism is a valid identity that

ought to be protected against the encroachment of aggressive behavioral therapies or genetic tests to identify ASD that might be developed in the future. Self-advocates tend to invoke a social model of disability, in which disabilities largely result from a lack of social accommodations to human difference, as opposed to a medical model that conceives of disabilities primarily in terms of the physical, behavioral and cognitive disorders of individuals (Chamak, Bonniau, Jaunay and Cohen, 2008). Self-advocates also argue that basic medical and psychological claims about autism represent unfounded assumptions on the part of researchers (Silverman, 2008). From their point of view, disability is defined using deficiency models, which stigmatize people as impaired or diminished (Caldwell, 2014).

In contrast, the neurodiversity perspective calls for focus directly on the world of people with autism, absent the assumptions and comparisons inherent in deficiency models. Consistent with the approach used by Seltzer (2007), the current study utilized the experience of the parents of children with autism from a discipline known as critical disability studies (CDS). Disability studies have made an impact on the research agendas of many disciplines, including social sciences and medicine. This interdisciplinary and multidisciplinary discipline challenges societal notions of disability and the position of people with disabilities in the world by fully supporting the rights of the individual (Meekosha and Shuttleworth, 2009). This dissertation utilized a central theme of critical disability studies by attempting to understand the lived experiences of the individual and identifying how we can improve their quality of life through improved health. The Society for Disability Studies has a goal that “disability studies should interrogate the connections between medical practice and stigmatizing disability” (The Society for Disabilities Studies, 2016, <http://disstudies.org/index.php/about-sds/what-is-disability-studies/>). The CDS discipline helped to shape the specific aims and methods of this dissertation.

Utilizing a dyadic interview design supports the critical disability study discipline by recognizing the interdependent relationship between people to safeguard the rights of the individual (Caldwell, 2014). The methods section details some of the techniques of dyadic interviewing which potentially facilitates the participation of the adult with ASD/ID in the most meaningful and participatory way possible.

As the neurodiversity movement gains more traction as an accepted form of social identity, it does make one pause to consider if this will impact the range of therapies and treatments ASD adults will seek and what impact this may have on health policy. As this is an

emerging notion, a few of the interview participants were aware of the concept, while others may not have mentioned this as a factor, but mentioned behavior which fit into the model. Knowledge of this movement is important to healthcare practitioners and any professional who serves this population.

Summary of Literature Review

This project utilized the life course approach to health experiences of adults with ASD/ID, as their healthcare needs changes throughout their lifetime. The relationship with family and other social support will change over the lifetime, and that linked life experience also impacts the healthcare delivery experience. The complex interplay of biological, behavioral, psychological and social protective factors contribute to health outcomes across the span of a person's life and directly impact the determinants of health. As noted from the literature, adults with ASD/ID have shorter lifespans, are more susceptible to chronic diseases including mental illness and require ongoing support from guardians and supported living environments. The neurodiversity movement is changing the thinking about the approach to research through the development of the CDS discipline, which aims to include those with a diagnosis of ASD to be directly included in research, especially in a dyadic model with their guardians and caregivers. Gaining a better understanding of the interactions with healthcare providers is essential to removing barriers to delivering needed healthcare services. The next chapter will describe the methods used to study the experiences of this unique population.

CHAPTER 3: RESEARCH METHOD

Rationale for Exploratory Qualitative Methods

The research question and specific aims of this project, as it is exploratory in nature, utilized qualitative data methods. Exploratory qualitative interviews allow for detailed exploration and deep understanding of the research questions, and allow the voice and story of the participants to be told (Patton, 2002). An exploratory approach is suggested when a topic has not been researched extensively and a deeper understanding of an issue is desired (Patton, 2002). As the specific aims attempt to ascertain the perceptions of caregivers and ASD adults, direct interviews are the most sensitive and direct methods to gain this information. The goal was to interview enough people to reach a point of credibility in describing the uniqueness of this population. Therefore, achieving true “data saturation” (Lambert and Lambert, 2013) would be difficult given the diversity of intellectual disabilities, health status levels and ASD severities. The strength of this method is it yields the depth and detail to create a holistic understanding of the healthcare experiences of this population. Exploratory research is used when problems are in a preliminary stage, which is exactly where research on ASD adults is in many respects. This research method is flexible, provides a rich and detailed report on a small number of participants and can address research questions of all types (what, why, how) (Shields and Tajalli, 2006).

The dyadic model, supported by CDS discipline, allows the individual with ASD/ID the opportunity to make the choice to answer the question or have the support person to answer for the person with ID (if in their best interest). The perspectives and experience of how caregivers support their loved ones with autism in utilizing healthcare services is also important to understand. The goal of this method was to capture in greater clarity the emergent and intrinsic properties of “healthcare experiences” that are shaped by a unique complexity of health conditions and health status. Based on other qualitative research conducted on people with learning disabilities (McCarthy, 1998, Finlay and Lyons, 2002), flexibility and the ability to offer follow-up questions is needed for this special population.

Accordingly, weight was given to the person with ID as the primary source of information. The data collected from the key support person functions as a secondary source that parallels their supportive role and is contextualized accordingly during analysis. The goal of this project was to involve adults with ASD/ID in a way that participation is not only done in

accordance with ethical practices, but is also meaningful and representational. The researcher's role was to facilitate people with ID in sharing their experiences and having their perspectives and voices heard, when possible. For those ASD/ID adults who were not comfortable or able to participate in the interview process, the guardian or caregiver served as the voice for the ASD adult. The challenge in the population under study is that some possess very limited oral communication abilities, and some were non-verbal, thus eliminating the opportunity to fully participate in the interview. Additionally, if the guardian suggested a social service caregiver participate in the interview, instead of, or in addition to the guardian, that served as the additional voice of the ASD adult.

Choosing the appropriate method is not only a methodological concern, but an ethical concern when interviewing people with special needs and their caregivers. Finlay and Lyons (2002) recommend that interviewers must be acutely aware of the tendency for individuals with ID/ to acquiesce during interviews. Questions were carefully crafted to avoid creating situations that may promote agreement and acquiescence to statements or questions, regardless of the content of the items. To further help to mitigate this concern, a focus group of ASD professionals and parents assisted in crafting these questions.

Morse (2003) suggests other concerns regarding bias, including the setting and the abilities of participants, need to be considered when developing a qualitative study. Home settings or other very familiar, convenient and comfortable locations were utilized for the comfort and convenience of the ASD and guardian participants. Participants (parents/guardians) were asked to confirm the intellectual disability level and the diagnosis of ASD. The interview appointment allowed for breaks as needed and lasted a length that was comfortable for both the adult and their guardian.

Feasibility/Focus Group Guidance

The researcher conducted one focus group with ASD professionals and parents to gain their feedback regarding interview questions, identify potential contacts to assist with finding research participants and receive suggestions on what questions to ask in the demographic questionnaire. Four participants were part of the focus group. All were ASD professionals and one was an ASD professional as well as a parent of an adult diagnosed with ASD/ID. The contacts asked questions regarding the scope of the research (what type of healthcare experiences

would be discussed) and offered many ideas for the recruitment of potential participants. In particular, several group homes were suggested and personal contacts were offered to enable the researcher to network in the ASD field. The researcher took notes during the focus group and utilized an agenda, draft interview questions and a draft demographic form as tools to focus the discussion. The session was not audiotaped. The focus group was used as advice prior to proceeding with data collection.

There was general agreement by the focus group members that the research design, which allowed for the voices of the older ASD/ID adult and their caregivers, was appropriate to answer the research questions defined in the project. Several suggestions were made regarding the demographic data elements, including financial status and extended medical specialist identification. Employment was important to note for both the ASD/ID adult and the caregiver. Also, asking if the caregiver was also caregiving for any other individuals in the family was included. The focus group made suggestions for the content of the recruitment video, which was created for the ASD/ID adult so they could make a personal connection with the researcher and understand the format of the interview. The focus group participants suggested that social services caregivers could also be included in the interview process when appropriate. As a result, new consent forms were created to include these caregivers/caseworkers, and to receive consent from guardians if they did not participate in the interviews. Please see Appendix A - Appendix D for all consent and informed assent forms.

Participant Recruitment

According to Noy (2008) sampling procedures are unique facets within any paradigm in which empirical research is pursued. Recruitment efforts amount to crucial moments within the overall research design; moments where the type of contact between researcher(s) and informants is conceptualized and later personified. As the primary researcher, I am also a parent of a teenager with ASD/ID. As a member of the ASD community, membership can have privileges of knowing a network of community leaders and caregivers and also, be part of the language, advocacy and educational groups and social networks. This certainly made a difference in identifying potential participants. A broad range of recruiting locations was made, as suggested by Finlay and Lyons (2001). This included contacting group living environments, the local autism society and local autism support groups. At no time were the agencies or

organizations asked to provide names or contact information of potential informants to the PI. They were asked only to distribute recruitment flyers containing information on how to contact the PI, in order to maintain the privacy of those who chose to participate. Other strategies included the use of snowball sampling by asking participants to refer acquaintances who might be interested in participating and by asking group leaders in the organizations to contact individuals they knew who might be interested in participating.

Accommodations for Participant Recruitment

People with a high incidence of receptive and expressive language problems were offered further accommodations, including using innovative disclosure methods such as a YouTube video (Dressler, 1996, Capron, 1999). A short video was prepared specifically for the adults with ASD. In the video, the researcher explained the goals of the project, any risks or challenges they might encounter, the understanding that they could stop the interview at any time and any benefits they may receive from the interview. This video was listed on all flyers and was attached to any promotional or recruitment emails. The video was very helpful for participants, both ASD adults and caregivers, so they could “meet” the researcher prior to the actual meeting time. The link to the video is <https://youtu.be/F-FrCUAh5BE>.

Sampling

The sample was purposive, meaning that all informants met the criteria of being diagnosed with ASD, as well as ID, and adults must have an adult primary care physician. As this was a study on aging adults, the initial criteria included that individuals needed to be age 40 and above. In reality, finding enough adults at that age was challenging. For those born prior to 1976, the ASD diagnosis was a rare occurrence (1:10,000 was the incidence rate at that point in time), and it is rarely offered during adulthood (Hertz-Picciotto and Delwiche, 2009). For many of these individuals, they were diagnosed with other disabilities such as multiple handicaps or mental retardation, but not ASD. Interestingly, the younger cohorts and guardians of the local ASD community were interested in participating in this study, to share their experiences, both good and bad. As this is a life course perspective study, the sample was broadened to include participants who saw adult physicians and were at least age 20, with special emphasis on adults who had multiple chronic disorders. Realizing there could be potential cohort differences found in ASD adults from such a broad age range, it is believed the experiences found from these

adults are important to explore in order to consider the life course impact to healthy aging. Therefore, a stratified sampling method was employed to consider cohort differences. The goal was to find a range of ages including those from ages 20-35, 36-50 and ages 50+. Adults with ASD were recruited from a variety of sources. A recruitment flyer was prepared to announce the study (Appendix E). With the goal of sampling cases to represent a combination of pre-selected variables – intellectual disability, age and ASD diagnosis, reaching out to a variety of targeted audiences was an important goal (Trost, 1986). Adult ASD support groups in the greater metropolitan region was an initial source of contact. The ASD community has many support/social/training groups for ASD adults and caregivers and a convenience sample through the process of “snowballing” helped to identify potential informants (Richards and Morse, 2013). A sampling procedure may be defined as snowball sampling when the researcher accesses informants through contact information that is provided by other informants. This process is, by necessity, repetitive: informants refer the researcher to other informants, who are contacted by the researcher and then refer her or him to yet other informants, and so on (Noy, 2008). Hass, et al. (2016) noted recruitment is often best achieved through direct contact from service provider staff members to the adult or a third party contact. This proved to be true in this study, where focus group members, other professionals and friends familiar with the researcher assisted in making initial contacts with many participants. Through snowballing techniques, adults beyond the geography of the greater local area were interviewed and informants came from three other states. This lead to some interesting information, as social service delivery varied from state to state. Prior to recruitment, the research study proposal was approved by the Miami University Institutional Review Board (IRB) approval # 01075r (Appendix F) for protection of human subjects.

Human Subjects Consideration

Good qualitative research demands building on the strengths of people with disabilities, while understanding their (and our own) limitations (McCarthy, 1998). People with ID who are recruited as informants could be considered vulnerable if their ability to provide assent is compromised (Robert and Roberts, 1999). People with learning/intellectual disabilities are valid sources of information about their lives, and often are the best sources. Allowing for the most sensitive approach to communication to ensure the purpose of this study is clearly and

thoughtfully articulated to the adults with ASD, along with receiving consent from the caregiver (guardian), was key to achieving informed assent. Guidelines for informed consent and proxy decision-making procedures for people with ID were designed into the informed assent consent document and were followed in this study (Iocono and Murray, 2002).

The unique social-communicative abilities associated with autism spectrum can contribute to the reluctance of some adults with ASD to be involved with new people and experiences or to disclose personal information (Haas, et al., 2016). In addition, some adults are reluctant to identify with a particular condition (autism), as they do believe it was a childhood condition, something they have “grown out of.” One of the participants indicated they no longer had autism; however, the guardian confirmed that that diagnosis was still very relevant (most people do not lose that diagnosis over time).

The latest literature on research participation recognizes that what usually motivates people to join a project is either personal or social (Clark, 2010). According to Clark, one of the primary motivators is the opportunity to benefit directly from the experience, which could include receiving medical care, joining a group or receiving compensation. This study included a \$25 gift card or cash, which all ASD/ID participants were very happy to receive. Interestingly, three of the four ASD/ID participants indicated they were very happy to help others by participating in this study. Also, all were familiar with research studies and experienced in sharing their ideas and experiences with others.

People with ID who were part of this study were provided information about this study in a way that was comprehensible, in plain language and free of jargon or technical terms. Asking an individual to indicate their reason for agreeing to participate also supports their ability to articulate their interest in participating (Dressler, 1996). Each informant was evaluated to best ascertain their communication needs. According to Haas (2016), offering choice, flexibility and sensitivity are likely to be important success factors in engaging adults with ASD in research. Dressler (1996) indicates a minimal standard for assent would include the demonstrated ability to understand information that is relevant to the choice being made to participate in a study. To meet this standard, a participant needed to have a preference between options to participate or not participate and be able to communicate his/her choice between options. Also, they were encouraged to ask questions and seek clarification.

Saturation

Patton (2002) suggests that the richness of the data drives the sample size and that saturation can be achieved with as few as one informant. Saturation in data collection means that the sample size is adequate to fully explore the issue, and data collection can cease when no new data or information is being obtained in the interviews. Given the exploratory nature of this study and the uniqueness of the population, saturation, in the traditional sense, would be difficult to achieve. Instead, the goal was to find as many participants as possible to illustrate a variety of informant characteristics, while also finding common categories of data. As a guideline, sample size was estimated based on the formula suggested by Maykut and Morehouse (1994) that 12 to 20 informants should allow for saturation in most qualitative studies. The initial goal of this study was to interview 12-15 adult cases, and the final number was 12. However, the total number of interviews, which included adults with ASD, parents/guardians and residential caseworkers, totaled 18 participants. This offered triangulation by gaining perspectives of all three types of participants. Of the 12 adult cases, 2 were female, and 10 were male. All of the informants were white and came from middle income or higher income families. After the 12th case, consistent categories of experiences emerged in the data. At this point it was appropriate to conclude, no further interviews would be required. Given the wide variability in communication, health, social and behavioral abilities, even in this defined population of adults with ASD, the sample achieved a useful range of participants to inform this analysis. In addition, the demographic questionnaire was completed to collect general information useful in stratifying the sample and developing life course data for each participant.

Interview Strategy

When the adult was available and willing to participate, the interview process began by asking questions directly to the adult with ASD. When introducing the interview, ground rules were clearly explained. For some adults with ASD/ID, their attention span for the interview was limited. Therefore, questions were prioritized for the ASD/ID adult, as to first get details regarding their impression of interacting with their physician. For some higher functioning ASD adults, they participated in the interview quite fully, working with the researcher for well over an hour. The general goal was to have active participation by the adult for a 30 minute interview. For the caregivers, interviews usually took around 60 minutes. Both the caregiver and adult were

offered a \$25 stipend for completing the entire interview. Interestingly, more than half of the caregiver participants refused the stipend, and were very glad to offer their story to help develop the research project. All of the participants expressed relief that someone was interested in the plight of ASD adults and their families. All participants fully participated in their interviews.

Two participants were the parents of adults who prematurely passed away. In planning for this study, premature deaths were understood to happen in this population. However, it was not fully anticipated there would be participants in the study that fit this category. Their stories were important to share, as they both had a significant medical and mental health history which highlighted their interactions with healthcare providers.

Given this research approach, there may be concern over respondents speaking for people with ASD/ID, rather than allowing them to speak for themselves. By asking participants with ID to identify the key support person, this removed an element of paternalism on the part of the researcher and facilitated the role of those individuals with ID in the study to have a choice of who represented them. Their support role in research mirrored their social role. This neutralized the power dynamics at play in research interactions. During the interview, if a topic caused any emotional distress or anxiety associated with recalling experiences, the topic ended and other topics were discussed. In general, even in the cases where the ASD adult had passed away, this did not occur and guardians were able to tell their loved one's stories in great detail.

Interview Guide Development

The specific aims were the starting point in the generation of interview questions. As outlined in chapter one, the research aims are focused on how well the healthcare providers serve their unique needs, the degree of service fragmentation/coordination of care managed in the primary care setting and the barriers (e.g. environmental, sensory and others) experienced by ASD adults in the medical environment. In addition, all available literature regarding the concerns of adult medicine practitioners and their ability to serve this unique population of adult patients was reviewed to help guide the initial list of questions. Over time, questions needed to be reworded, reordered or redesigned when appropriate to clarify concepts introduced by the participants. In particular, it became quite clear that social determinants of health, including group and supported living arrangements, transportation, leisure activities and other lifestyle factors were important to learn about for this study and questions were added to expand on this

information. Techniques such as probing questions, asking for clarification, repeating questions, active listening, summarizing and the use of silence were utilized to augment discussion (Creswell, 2013; Roulston, 2010). Interview questions are listed in Appendix G and H.

Demographic Form

Each interview “group” (ASD/ID adult and their guardian and/or caregiver) were asked to complete a demographic form to provide descriptive information which was helpful for the interviewer to quickly gain some background information on their health, living situation, financial and educational status. The value in gaining this information was three-fold during the time of the interview: First, it helped to initiate potential new lines of questioning that relate to the specific aims of the project; this information corroborated information shared during the interview; and finally, it elaborated and provided richness and detail (Clarke, 2009). In addition, it served as a very helpful source to compare and contrast all participants in the study, to be sure a wide variety of characteristics were considered and conveyed as part of the study. A copy of this form is provided in Appendix I.

Data Collection

A single semi-structured interview was conducted with each informant, each lasting between forty-five minutes to two hours in length. Consent forms were sent prior to the interview for the informant to review, as well as the demographic form. Consent forms were signed before each interview session began, with participants acknowledging that they would be audio recorded, that all personal information would be changed to protect their privacy and that they could stop the interview at any time if they became uncomfortable. One informant asked that they not have their responses audio recorded, which was respected. Hand written notes were taken in great detail, instead, to record that informant’s responses. Informed consent (or informed assent for ASD/ID participants) was acknowledged in writing by all informants, with verbal recorded consent utilized for interviews that needed to be conducted by phone. Nineteen total people were interviewed as part of the study. Four adults with ASD/ID were interviewed in the study. Two ASD/ID adults were deceased and parents offered to tell their stories. Eight other parents or siblings were interviewed to tell the stories of their ASD loved ones. In these eight cases, ASD/ID informants had severe communication challenges and were not comfortable in participating in the study. As a result, their guardians did not recommend participation for their

loved ones. Finally, it was suggested that three group home or supportive living professionals be interviewed as part of the study. The guardians of the ASD/ID adult suggested their points of view were helpful to understand healthcare experiences.

The location of the interviews was selected by the informants. Most interviews were conducted in office locations, homes, or discreet public locations (library, restaurant). Three interviews were completed over the phone, as they lived in locations greater than 200 miles from the researcher. Basic demographic data were collected and are summarized in Chapter 4.

At the start of each interview, the researcher thanked the informants for their willingness to participate in the study. Informants were told that the outcomes of the study would be used to inform healthcare providers and administrators of how ASD/ID individuals experience using the healthcare system, identify any barriers to services and also point out where program improvements might be needed. A casual, conversational style was used with each interview in order to build rapport, as suggested by Patton (2002). The interview guides, for both ASD/ID adult and caregiver, were structured to begin the interview with general information, and as a connection was built, to elicit deeper and more personal thoughts and insights (Erlandson, et al., 1993). The interview guide served as a reference to assist the researcher in probing for descriptions of experiences, concerns about determinants of care and coordination issues with healthcare specialists and social service needs. As qualitative interviewing requires a natural progression of conversation, some informants told their stories without probing, while others needed significant encouragement to provide detail to some questions. It is common practice in qualitative interviews for the researcher to determine the need to develop or amend the planned questions as the interviews progress. The interview guides served as a tool to prompt story telling by asking questions like “Tell me about how you ...”, or “Could you tell me more about what you mean by that?” (Roulston, 2010). Open ended questions on the interview guides provided basic structure for the questions, while allowing the participants to describe and discuss experiences within the context most meaningful for them (Creswell, 2007). While the interview guides were used as a basic structure to the session, the researcher followed the informants lead and discussed topics that they determined were important and pertinent to them.

To clarify understanding of the informants’ stories, frequent restating of comments was ongoing throughout the interviews. This strategy involved the use of rich details with deep

interconnected descriptions in the findings and member checking with participants (Creswell, 2013). Repeating back informant's responses and asking for clarification, assured that the researcher clearly represented the participant's contributions, and provided validation of the data collected. Significant discussion took place regarding the informant's personal life, with respondents sharing stories, incidents and anecdotes about their healthcare experiences. In order to improve credibility, member checking was conducted throughout the interview (especially when questioning around a specific aim was near completion) and also near the conclusion of the interview. Using statements like "So what you are telling me is...", was a way to validate the message/data being collected. In all cases, important historical review of the informant's medical, mental health, educational, social and family background took place in order to understand the context of where they are today in their life.

Field Notes and Memos

Extensive, descriptive field notes and memos were written and/or recorded before and/or after the interviews and served as supplemental sources of data (Patton, 2002). These notes included descriptions of the family history, observations of the interactions between ASD/ID adults and their guardians/caregivers, facial expressions and body language, a summary of conversations and other related observations that could not be captured on the audio tape. Memos were also captured following the interviews by writing thoughts and noting questions, insights and reflections in memo form (Patton, 2002). Field notes and memos were treated as data, and were protected as all other data.

Data Analysis

Patton (2002), reports two primary sources of data to be analyzed: the data actually collected in the study, as well as the insights, interpretations, and discoveries made during data collection. Digital recordings were transcribed verbatim by a professional transcriber trained in confidentiality, and included the transcripts of the interviews, memos, and field notes. All identifying information anonymized; titles such as Mrs. X (for mothers/guardians) or Mr. X (for fathers/guardians) or fictitious names were given to adults with the ASD/ID diagnosis. Interviews were transcribed into text documents and imported into Excel software for data management. Not only is the script of the conversation part of the analysis, but observations of

the way the dyad interacted during the interview was part of the analysis. Field notes were written immediately after the interview with those observations.

Data analysis for qualitative descriptive research does not require strict procedures of analysis, but rather encourages finding the method based on the research question/specific aims and literature which guides the analysis. For this study, conventional content analysis was utilized to guide data analysis. Conventional content analysis is described as “as a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns” (Hsieh and Shannon, 2005). Conventional content analysis method allows the researcher to gain a richer understanding of a phenomenon, especially when existing theory or research literature on a phenomenon is limited. Researchers avoid using preconceived categories (Kondracki and Wellman, 2002), instead allowing the categories and names for categories to flow from the data. Researchers immerse themselves in the data to allow new insights to emerge (Kondracki and Wellman, 2002).

Initial or first phase categorization began with the PI carefully reading each transcript, numerous times. Following initial readings, content analysis began, where transcripts were searched to discover salient patterns that were used to develop initial meaningful units of discussion (Patton, 2002). For example, descriptions about special accommodations in the clinical environment were coded as “environmental adaptations”; all types of anxiety/attention and mood altering medications (many mentioned by name), were coded as “psychotropic medications”; all descriptions of novel approaches to physical examination and medical testing were coded as “clinical accommodations.” This is also known as open coding because there were no pre-determined categories to be assigned. As the analysis developed, a preliminary code book developed as a reference. The code book listed the names for all of the codes, and the definitions of the codes as they were assigned. Having an ongoing directory improves the consistent application of codes (Schoenberg, Kruger, Bardach and Howell, 2013) and demonstrates rigor in qualitative research. The code book underwent continual revision throughout the coding process, sometimes teasing apart complex stories, and other times combining codes that became apparent were more closely related as the data was analyzed. Initial or first phase coding continued until all data was coded into appropriate categories or into deviant categories when it could not be fit with other codes (Patton, 2002). This stage is also referred to as the testing/authenticating of

inductive content. It involves comparing the codes and themes developed in phase one for appropriate placement, and/or determining if other placement opportunities exist (Patton, 2002).

To show rigor and assure the study was trustworthy, Patton's (2002) recommended steps were taken in this study: a purposive sampling, focused on informants who could provide insight into the research questions; comprehensive memos and detailed field notes were documented noting any information that might be helpful during later stages of the project; interviews continued until saturation in data collection was reached; the code book was used to assure the consistent application of codes; and identification of confirming and disconfirming patterns assured careful analysis. To clearly represent the informants' experiences, direct quotes were included in the coding procedures.

Data Interpretation

Data interpretation is the process of "attaching significance to what was found, making sense of findings, offering explanations, drawing conclusions, extrapolating lessons, making inferences, considering meanings, and otherwise imposing order on an unruly but surely patterned world" (Patton, 2002). This develops through careful reading, coding, and analysis, as well as writing and reflecting on the data. The advantage of the conventional approach to content analysis is gaining direct information from study participants without imposing preconceived categories or theoretical perspectives. Knowledge generated from the content analysis is based on participants' unique perspectives and grounded in the actual data. As the project's sampling technique was designed to maximize diversity of healthcare experiences, the analysis techniques were structured to capture that complexity. The use of direct quotations and anecdotes capture the true character of the informants. The data presentation focuses on sensitivity toward the experiences that the informants shared. Their shared experiences and detailed descriptions allow the reader to better understand their healthcare experiences and their ability to manage health determinants.

All informants received fictitious names after the data were transcribed. The transcripts were modified to include additional changes to protect the privacy of the informants. Cities and specific healthcare providers are not mentioned by name. In the transcription, a non-descript set of letters (e.g., XXXX) were typed instead of a person's name to protect anonymity when the participant talked about other persons involved in care of the individual. All physicians and other

healthcare providers are referred to as “Dr. XX.” Any other identifying information was indicated by XXXX in the transcript. Residences were all referred to as “group home” or “my home” if people lived independently. Careful management of these notes assures that disclosure of participants is not discovered through deductive means by outsiders. In addition, the transcribed individual document files were assigned file codes to protect the identity of participants.

Positioning of Researcher

I have a very interesting perspective on this study. My professional background includes serving as a healthcare administrator, including working in an academic hospital, but also managing a large specialty physician practice. Although I did not work for a specialty area which served the ASD/ID population, we did serve the hearing impaired population, well known for their strong deaf culture in their community. This population is quite akin to the neurodiversity movement. I am the parent of a teenager who is diagnosed with both ASD and a mild intellectual disability. I believe my unique perspective added to my understanding of the challenges parents, guardians and caregivers face in ensuring their loved one receives respectful, accessible and high quality healthcare. Since I am part of the ASD community, it did come in handy in terms of recruitment and rapport with informants. As my son is still accessing pediatric healthcare providers, I was not well informed of adult needs in this population. In an effort to avoid bias and remain neutral in the research process, I attempted to be careful during the data collection and analysis phases. Although I have knowledge of adult healthcare services as a patient and as an administrator, specific details regarding existing adult services for ASD/ID adults was not investigated, especially in the area where I live. Staying open to understanding the perspectives of the informants was a central concern. Lacking specific information on the adult healthcare providers allowed for a clearer understanding of what each informant was describing. My intent was to take a neutral position, to focus on what was important and meaningful to the informants.

CHAPTER 4: FINDINGS

In this chapter, the three specific research aims are presented with corresponding findings. Major categories of responses were identified through the informant interviews, which include direct quotes from informants. Given the complexity and specificity of individual needs for each case included in this study, categories and descriptions of experiences described here are not necessarily distinct and exclusive to each specific aim. The opinions and experiences described by the informants are often multifaceted, and have been assigned categories thought to best express and demonstrate their beliefs in a logical sequence. In addition, as the ASD/ID adults' medical needs are complex, they often discuss their total healthcare experiences including those beyond the primary care environment, such as dental procedures, specialist office visits and inpatient hospital experiences.

Informant Characteristics

Informants fell into three categories: adults with ASD/ID, family members/guardians and caseworkers/caregivers who support them in their residence. For those adults with ASD/ID who possessed the social and communication skills to participate in interviews, those individuals were included as active participants. There were four adult participants diagnosed with ASD/ID. All ASD/ID adults were interviewed along with their family member/guardians. There were six cases where individuals who were not willing or able to be active in the interviews. Based on the CDS discipline, family members/guardians were utilized instead as the primary source of information. In some cases, caseworkers/caregivers were suggested to be part of the interview in order to give a complete picture of the healthcare experiences. Especially in group home situations, caseworkers/caregivers are the individuals who often accompany ASD/ID adults to their physician or hospital visits.

In total, twelve ASD/ID adults (n=12) were studied as part of this analysis, with an average age of 41.5 years. All twelve adults included interviews with their parent or sibling guardian. The four individuals with ASD/ID who participated in the study were identified by family as those with mild to moderate intellectual disabilities. Those adults with severe intellectual disabilities were either nonverbal or lived with significant communication challenges which made inclusion in the interview difficult. All parents or guardians were offered the opportunity to include their ASD/ID adults in the interviews, if they so desired.

Table 1 provides details on the ASD/ID adults enrolled in the study. Ten men and two women were included in the study. All participants reported their race as white. As ASD is identified in 20 percent of females, and less frequently in older aged cohorts, fewer women were anticipated to be enrolled in the study. There was a wide range of intellectual disability from mild to profound, most diagnosed with an ID at an early age, as reported by their family member. Several were not identified with ASD until an older age (often diagnosed with other labels such as mentally retarded, emotionally disturbed, “limp baby” and other disabilities), even into adulthood. This is not a surprise given the changing criteria for diagnosis over the last forty years. Most in this study reported being in good to fair health. Two cases included adults who were deceased, with their parents reporting their healthcare experiences.

Table 1: Characteristics of ASD/ID Subjects Under Study

Informant ID	Current Age	Sex	Age of ASD Diagnosis	Level of ID (reported)	Health Status (reported)
Subject 1	40	M	5	Medium	Good
Subject 2	32	F	5	Medium	Good
Subject 3	53	M	Adult	Severe	Fair
Subject 4	45	M	42	Mild	Good
Subject 5	31	M	3.5	Medium	Good
Subject 6	53	M	5	Mild-Med	Good
Subject 7	25	M	4	Severe	Good
Subject 8	34	M	1	Severe	Good
Subject 9*	24	F	3	Mild	Deceased
Subject 10*	41	M	4	Severe	Deceased
Subject 11	59	M	10	Severe	Fair
Subject 12	61	M	4	Severe	Good

*deceased

Table 2 offers more details regarding additional social attributes of the ASD/ID adults who were enrolled in the study. All participants had medical coverage either under Medicare, Medicaid through a state waiver program or through their parents’ medical coverage, while

several participants who had employment also had access to commercial insurance to supplement their healthcare coverage at some point in their lives. All reported they had “just enough” financial resources to get by in life. Participants were nearly split in terms of their residence. Half lived independently with various levels of support while the rest lived in a group home setting. Most reported being in relatively good health, yet all reported at least three chronic concerns, most often psychiatric/behavioral, gastric and weight/dietary issues. Other significant reported diseases included epilepsy, vertebrae and other orthopedic challenges, sleep disorders, diabetes, dental and hyperlipidemia. Nearly all individuals in the study were hospitalized at least once in their lives, if not more than once. Finally, all reported a relationship with a primary care provider (PCP), although all had some difficulties in maintaining that relationship at times due to challenges with finding a physician who accepts Medicaid patients. Most notably, five of the twelve participants reported using the same PCP as a family member which allowed for a longer relationship with that provider, than those who did not have a familial relationship. Very few held a high school diploma, and as a result, few had sustainable employment. A few participants were covered by Medicare, which makes the dual eligible. Those who had a high school diploma did have some successful employment and at times, medical benefits through their employer, which allowed them broader access to medical care as they did not have to find physicians who would accept Medicaid.

Table 2: Social Characteristics of ASD/ID Adults

Informant ID	Residence Status	Educational Attainment	Ever Hospitalized	See same physician as family?	Medical Needs
Subject 1	Independent with Support	No HS Diploma	Yes	Yes	GI, Dietary, weight concerns
Subject 2	Independent with Support	No HS Diploma	Yes	Yes	Diabetes, weight, mental health
Subject 3	Group Home	No HS Diploma	Yes	No	GI, dietary, dental
Subject 4	Independent	Some College	Yes`	No	GI, dietary, weight, dental, mental health, vertebrae
Subject 5	Group Home	No HS Diploma	Yes	No	Epilepsy, mental health, diet
Subject 6	Family Home	HS Diploma	Yes	Yes	Club feet, orthopedic, speech
Subject 7	Group Home	HS Diploma	Yes	No	Epilepsy, sleeping, history of GI surgery, mental health
Subject 8	Group Home	No HS Diploma	Yes	Yes	Food intolerance, mental health
Subject 9*	Group Home	No HS Diploma	Yes	No	GYN, GI, Mental Health, Sleep, Weight, Ear Infections
Subject 10*	Group Home	No HS Diploma	Yes	No	GI, Prolapsed Rectum, Sleep, Diabetes, Weight issues, Dental
Subject 11	Group Home	No HS Diploma	Yes	No	GI, Weight, Dental, Dietary Restrictions
Subject 12	Group Home	No HS Diploma	No	No	Spinal, cardiac, mental health

*deceased

Table 3 offers information regarding the guardians who participated in each interview. Guardians' demographic data and information were collected on both their lifestyle and healthcare status. Parent participants who actively supported their adult children ranged in ages from 49-94, with an average age of 67. As most were reaching older ages, many not only supported their adult child, but also attended to their own chronic illnesses. All participants had a higher level of education with a college degree and some with advanced or terminal degrees. All reported to be in relatively good health ranging from good to fair. Some were also caregiving to other adult children, some with special needs and some were caregiving to spouses. Three adults with ASD/ID had siblings who were very involved in supporting their needs as guardians. These guardians ranged in age from 49-60 with an average age of 56.

Table 3: Guardian Characteristics

Informant ID	Current Age	Guardian?	Relationship	Accompany ASD/ID adult to doctor's visits?	Caregiving for other family members?	Health Status (reported)
Guardian 1	65	Yes	Mother	Yes	No	Good
Guardian 2	49	Yes	Brother	No	No	Good
Guardian 3	94	No	Mother	No	No	Fair/Poor
Guardian 4	75	No	Father	Sometimes	Yes	Good
Guardian 5	66	Yes	Mother	Yes	Yes	Good
Guardian 6	60	No	Sister	Yes	No	Good
Guardian 7	66	Yes	Father	Yes	Yes	Good
Guardian 8	68	Yes	Mother	Yes	No	Good
Guardian 9*	49	Yes	Mother	Yes	Yes	Good
Guardian 10*	73	Yes	Mother	Yes	No	Good
Guardian 11	79	Yes	Mother	Yes	No	Fair
Guardian 12	60	Yes	Brother	No	No	Good

*Adult with ASD is now deceased

Specific Aim 1:

To understand the perception of patients and their caregivers about how well their healthcare providers understand autism, including the sensory, behavioral, social and communication needs required of an adult with autism.

The first aim of this study was to learn, in the words of ASD/ID adults and their caregivers, how well their healthcare providers worked to accommodate their needs. There were many stories of positive impressions of healthcare providers having a complete understanding of autism and the needs that come with it. However, there were other stories that explained less than positive or suboptimal experiences. The healthcare environment can be a very distracting and sensory stimulating experience. As a result, ASD/ID adults may need additional customer service attention, special treatment in the clinical setting and extra time to have procedures explained to them. Communication and physical approach to examinations must be planned in a careful way, as not to startle or upset the patient. Also, a feeling of respect towards the adult with ASD/ID is important to both the adult and their caregivers. Behavioral needs were a significant care management challenge, as well as dental needs were often cited as one of the most challenging areas for providers to understand the needs for an adult with ASD/ID. A variety of accommodations, clinical decision making and communication methods were reported, and could be identified in five major categories of needs. These include clinical accommodations, environmental adjustments, communication practices, transitioning on psychotropic medications, specific social needs requirements and the double jeopardy stigma of ageism/disability.

Clinical Accommodations

Clinical accommodations run a gamut of sensory and behavioral concerns, including changing the clinical room arrangements, adapting the typical patient flow process, shortening the interactions in waiting and examination rooms and utilizing pediatric providers. All of these accommodations are adaptations to allow the adult with ASD/ID to successfully handle the medical environment with the least amount of stress possible, for them, the providers of care and for the family.

Clinical accommodations: Sensory needs. As mentioned in the literature review, pediatric providers have access to helpful literature and training opportunities to help ASD/ID

children in the clinical setting. Developmental pediatric physicians are trained to accommodate disabled individuals in the clinical setting. Adult healthcare providers are not provided the same level of training. Often the clinical environments are not friendly to people with ASD and family/guardians must serve as the primary advocates for accommodations in the clinical setting. A major source of frustration is the waiting room experience. For adults with ASD/ID, especially those with behavior challenges, waiting can add to anxiety, heighten frustration and result in negative physical or verbal behavior. Several families shared their frustration with long waits in waiting rooms. For one individual, her behavior (shrieking, rocking, physical gestures) caused upset and stress for the staff and other patients, that the patient and her family were asked to leave the specialist's office. Here, Sarah K's mother shared her experience, as her daughter had an intense interest in desk calendars.

Mrs. K: A lot of the times they wouldn't accommodate, especially when you are dealing with a typical adult office setting. When we went to the hospital for the GI stuff, it was not a children's hospital.... They wouldn't do anything to minimize (the wait) or get her separated (from other patients) so finally the staff, not sure if it was a clerk or nurse said she has to leave, she is disturbing our other clients.

This comment illustrated the challenge of having to wait even short lengths of time for physicians and the distraction of the waiting room environment. Many other participants echoed this concern, including Mrs. J who mentioned her son saw the only PCP in the area who specialized in seeing adults with developmental disabilities. She acknowledged the special needs community was lucky to have this professional in the marketplace; however, this was not a good match for her son because of the crowded environment and long waits times:

Mrs. J: We waited for long periods in a large waiting room to see him. Our waits were usually at least two hours, just too long for anyone with autism. I just decided that wasn't a good match. So we went to (her PCP) instead.

These examples indicate environmental concerns, like waiting room environments, the length of wait times and the exam room environment make a difference to adults with ASD/ID. Guardians of lower functioning adults with ASD/ID noted the challenge of needing advocacy and supervision in the clinical settings. For those adults, most needed their guardians or representatives from their group home accompany them to the office. Here is a story of why that supervision is so important, and it also indicates the challenges clinical staff may have in serving this population:

Mrs. W: One time, I remember when (the doctor) was on our board of directors, and we had a meeting this one evening and I'm on the board. He said well, (your son) destroyed my office today. His caregiver had taken him and she told (him) to "stay right here, I have to go to the bathroom, OK." So out the door she goes and he just trashed everything. Just smashed the place up.

Often, people with ASD will destroy objects when they are anxious and uncomfortable. This story illustrates the need for extra support which is needed in the clinical environment, especially for adults who have significant disabilities.

Others tell of clinical and administrative staff that clearly bent the usual rules and offered as much accommodations as possible, as they do understand the esoteric needs of each individual:

Mrs. S: Yes, as a matter of fact they do (find ways to meet her son's needs)...Any time he had to go to the hospital I went. The manager would let me know and everything and I went with him too. They let me dress up in the scrubs and go into the operating room with (her son)...

In pediatric environments, there are often helpful ways to distract during long waits, including video players, books and other helpful distractions. Staff is trained to remove objects which may be dangerous to the child with ASD/ID and specially trained staff, such as Child-Life Specialist can support the child in the environment. Since these sensory supports are lacking in the adult environment, flexibility is needed to allow family to care for adults in the clinical environment.

Clinical accommodations: Environmental adjustments. Another mother mentioned her son's serious fear of examination or operating room tables. In their internist's office, the office staff understood this concern well, and moved office furniture around to allay the fears of this patient. However, this was challenging in other environments, where the physical environment is more difficult to reorganize. She recalled one stressful episode where her son was going in for surgery. In addition, the excerpt speaks to the utilization of a pediatric provider:

Mrs. F: There is a whole episode about (her son) having severe gastritis and to make it really brief, we had a really good gastroenterologist because our doctor picked him out. (Our son) can't get in a bed to be sedated; he is terrified of it, so they have to do it in a chair. So we talked to the nursing crew, we had to call people so we were ready and at the last second the anesthesiologist came in and refused, so everything went to hell.

Mrs. F also shared the accommodations her son's PCP offered in his office. The entire family saw the same PCP, and the family has been with this office for many years. Hence, her son is very comfortable in the office environment:

Mrs. F: They know he will not sit on the exam table, so everything is done when he is sitting in a chair. The doctor has a chair, so they bring the chair in for the blood pressure. (My son) likes to tease him, the doctor, so he starts writing on his prescription pad, and getting on and off the table. The doctor commented "this is the happiest I have ever seen him." ... They (the staff) all go out of their way to be loving and friendly. They talk directly to (him),

This story exemplifies the success this family found in developing this relationship with their primary care physician. The physician's office accommodates their son's unique needs and ensured he had a positive and comfortable experience in the clinical environment.

Clinical accommodations are welcomed by families to ensure the best experience possible for their loved one. Mrs. J, who developed several effective strategies for her son with the assistance of her son's physician, offered several suggestions for PCPs who serve adults with ASD/ID:

Mrs. J: They need to find more ways to conduct tests more comfortably and less invasively. For example, using finger sticks instead of blood draws. Also, be sure to work with speech therapists so that those with weak communication skills can identify pain through pictures or other descriptions. Also, it is essential to have community supports, like service coordinators, to enable access to care and good coordination of care.

All of these examples point to the need for special accommodations to meet the behavioral and sensory needs of the adult ASD/ID population. Long waits in exam rooms, lack of supervision and other distracting environments should be avoided to ensure a successful healthcare encounter. Also, creativity in allowing for special accommodations, including bending the usual rules of visitors or the common way of conducting examinations should be considered.

Clinical accommodations: Utilizing pediatric providers. Some of the younger participants continued to see pediatric providers, as the choices for adult practitioners were very limited. Most children "age out" of pediatric providers between the ages of 18 and 22. For the ASD population, this transition time can be very challenging to find adult providers who understand ASD needs. A limited choice of clinical providers is a concept that will be discussed at a later point; however, clinical accommodations are often made by pediatric providers to ensure continuity of care in an environment which is sensitive to ASD/ID needs. Pediatric

providers have more training in serving those with developmental disabilities. Mrs. K described the positive experiences with her daughter's long-time pediatric dentist:

Mrs. K: There have been so many other experiences that were fine. The parents at (our group home) are so envious that I could take her to a regular dentist because she will cooperate and they have to have their children sedated and do procedures down at (a specific hospital, where they offer adult Medicaid dental services). But maybe because she is verbal and she can understand, she does well, and of course we are bribing her all of the time. You know, with a Disney toothbrush and stuff like that. Well the pediatric dentist that she had originally said they would continue to see (her daughter) for as long as she wants to, although generally they would want to phase them out at 18 or 21.

Some specialty providers, like dentists, will continue to see adults on the autism spectrum. In this case, the parent was told there were no general dentists in their area they could refer to, and as a result, the pediatric dentist was willing to continue to see her as a patient. This option is not always available to all patients, leaving many in a quandary where to go for services.

One parent of a younger participant felt continuing to see a pediatric provider was going to be the plan for his child, well into the future:

Mr. L: I think the whole society has changed. I don't perceive this as being a problem like it has been in the past. The people who are going into the field know. So I think it is really different now.

Whether this will be an accepted practice in the field of medicine remains to be seen. Most of the participants in this project reported they were required to leave their pediatric provider at the time of adult transition. Mrs. K made the suggestion for pediatric providers to continue their relationship with adults with ASD/ID. After the inappropriate placement of her daughter in the adult inpatient psychiatric ward, she strongly indicated the need of the local pediatric hospital to take adults ASD/ID patients:

Mrs. K: Well my first thing would be that they need to have a different wing at (their local) children's hospital for adults with autism because it is not appropriate to put a person who thinks like a 3 year old in with 40 or 50 year olds in a psychiatric setting. Their needs are not the same. For example you go to the (adult academic medical center); they don't have Disney videos in the adult psychiatric unit. I think they just need some place to serve these people and not in an adult setting. That would be a solution for so many of us. Other parents have horror stories about, out of desperation, having to admit their adult child into a hospital and it is just horrid. They are just mistreated and not understood.

Pediatric hospitals are facing increasing pressure to serve adults who have a gap in service once they leave the pediatric specialists, especially related to all developmental disabilities because of the lack of expertise in adult medicine. Pediatric health providers may be an option for many who find those physicians who are willing to accommodate the needs of an adult. Some specialty physicians, such as dentists and psychologists, seemed to be more willing to accommodate these adult requests from the people interviewed in this study. However, as adults age, pediatricians may not be the most appropriate medical providers, given the expertise needed for adults.

Communication Practices

Communication in the clinical environment. Mrs. S. mentioned the importance to approach her son with a calm and deliberate approach. Although her son has expressive language issues, his receptive language is well developed and he is compliant with directions if approached by medical professionals in the right way. Mrs. S offered the following comment:

Mrs. S: Well he has gone to different doctors, you know, and he is not a guy you can go to and say “hi how are you doing”? It startles him when someone is really loud. You have to explain in detail this is what we are going to do, now you give me your finger and we will get a little blood out of it...The funny thing of it is, he does not initiate a conversation but if anybody asks him a question, he knows exactly what the person is saying; he knows everything that I say to him. I can tell him things that I would think he would never do...

This comment should serve as reminder to healthcare providers that many people with ASD do have receptive language skills, even when their expressive skills are modest. It is best when the parent/guardian or residential caregiver clearly explains the communication skill level to the healthcare worker. In fact, many adults with ASD/ID expect clear explanations. Many parents and siblings mentioned the need for their loved ones to understand what is happening in the healthcare environment. Compliance improved when adults with ASD/ID were given clear descriptions of what to expect; not only did it provide instruction, it offers a level of respect which is palpable to them.

Nancy, an adult with ASD/ID also reiterated the importance of clear explanations and for written instructions:

Nancy: Yeah, he tells me what is going to happen and he writes things down so I can look at it later. He tells me what I need to do. You know, some people scream when they go to the doctor, they do not like shots (mentioning something that bothers her).

Nancy's comment, as someone with ASD/ID, indicates she appreciates the effort her doctor takes to explain things and to give her a written document to remind her of important directions. Also, she indicates her frustration in the environment, at the same time. Her brother, her guardian, echoes his appreciation for her physician's approach for communications:

Nancy's guardian: Yes, (Nancy's doctor) does all of that and he tries to teach her things that will help her health and so does the team. They will tell her behavioral stories to encourage her in certain behaviors, when she is not being cooperative or she doesn't understand why it is helpful, so they do that too, one of the people on the staff, so that is good.

The story of Nancy reinforces the importance of utilizing "teaching moments" and having appropriate educational information and directions for people with ASD/ID. Obviously, these materials need to be at a level which can be understandable and useful to the patient.

Mrs. S also mentioned the challenge for nurses and other clinical personnel in how they approached and spoke to her son. Tone and physical approach have imbedded messages, especially to people with sensory challenges. As her son is non-verbal, she believes when her son is spoken to, the medical staff often times speak in a loud voice. Loud, shrill voices are very difficult for her son to process, and it often frightens him. Mrs. M echoed the concern, especially in dealing with the non-verbal population with ASD/ID:

Mrs. M: They have a Medicaid clinic there (hospital where son receives dental services) and they know they have people with disabilities and I think the staff has been really good. I think they need training particularly with a non-verbal person. I have had a few situations where they really don't get it. If you approach someone that isn't all there and you startle them, or you start to do something, you know. I mean our guys are anxious and they are going to get an anxious response if they don't ease in and say what they need to do and my name is so-and-so...

This illustrates how important it is to approach the adult with ASD/ID in a gentle, normal tone and comforting manner. Staff may confuse adults who are non-verbal as adults with a hearing impairment; this was identified by several participants as an issue.

Communication in the administrative environment. Poor customer service was echoed by several study participants. Mrs. W mentioned her son experienced poor customer service at an academic hospital, which was the only choice for the surgical procedure for their son. The

mother actually worked for the hospital, and was very insulted by the treatment they received from administrative staff, which she likened to how Medicaid (indigent) patients were treated. Often, at academic hospitals, Medicaid patients are followed by medical residents and can be seen in different, sometimes less desirable environments. Her comments here reflect her indignation:

Mrs. W: Yes, he had that done at (the academic medical center) because I remember that is when I was working there and I was with him. I think I know what you are talking about with the environment because they treated him like a Medicaid patient. And I took an attitude. I told them I work here, you know.

She also mentioned her indignation on the location of the adult services in the academic hospital when referencing their positive experience at the local children's hospital:

Mrs. W: Well this was at the point where he wasn't eligible to be operated on at (a children's hospital) and that was part of my problem because I loved children's (hospitals). All through his childhood I loved (the hospital). And we didn't have to go to the doctor in some basement somewhere.

This section highlights the importance of respectful communications, tailored to the abilities of the adult with ASD/ID, is absolutely essential to ensuring compliance and positive experiential outcomes. It also speaks to the Medicaid payor stigma experienced by the family and the patient.

Communication with guardians and residential caregivers. Communications with guardians and residential caregivers (group home and supported living situations) is also key in order to develop an integrated plan with healthcare providers. In particular for guardians who live a distance from their loved one, the coordination between the guardian, caregiver and medical professional is essential to ensure proper consent and coordinated care planning. Nancy's brother, who serves as her guardian, lives about 200 miles from Nancy. Both he and his wife have been integral to communicating with providers and attempting to reduce her psychotropic medications, increasing her physical activities, changing her diet and providing her with more social interaction. However, it has taken a great deal of patience and time to achieve this level of care and health for his sister:

Wife: They have seen a tremendous change in her because we are working together because we really want her to have a full life.

Nancy's Guardian: They have, over time figured out what she likes and what she doesn't like. Right now things are fairly status quo for her and pretty much everything she is doing she is comfortable with...it has taken five years.

Nancy's guardian also shared his concerns regarding communications from the medical professionals. Consent was not always received for some of the procedures during visits. In addition, medication changes were made without his input.

Nancy's Guardian: The main problem I have with the healthcare professionals is making decisions without consulting us. I mean, I have never gone the legal route because it has never got to that point, but that has been very hard. I mean they all have letters, they all have the information, but they just don't think about it.

This example illustrates how important it is for healthcare providers to clearly understand the legal relationship of the adult diagnosed with ASD/ID and their guardian. Especially in group and supportive living situations, residential caregivers are not allowed to consent for medical procedures.

Patient Social/Behavioral Requirements

An interesting thing to note for two of the ASD/ID participants was their reluctance to be recognized as having a disability. They did not view themselves as "autistic" and one adult indicated he "grew out of it". It is not clear if they avoid the diagnosis because of the stigma associated with it, or the adult feels they live a fine life without having the label of "autistic". Others who received the ASD diagnosis as an adult, recognized the ASD diagnosis with a sense of relief (as it explained and verified their behavior and feelings which were not understood previously). This presents challenges to healthcare providers to know how to approach each ASD/ID client about their developmental diagnosis. The role of the caregiver is very helpful in interpreting these perspectives to healthcare providers. In order to develop a trusting relationship, this psychosocial approach to the patient's disability is quite important. The neurodiversity movement may change the view of the disability, for those with the diagnosis and for those who serve them.

Mrs. K noted how challenging it is for healthcare providers to be ready for the challenges that may present themselves in the clinical setting. Although she would try to prepare the office for her daughter's challenging behavior, sometimes it was not enough:

Mrs. K: They don't really understand what they are up against until they actually see her. You would think at a pediatric (hospital) they would be the best trained, but that's not always the case. I mean we have had a lot of bad experiences, especially when she was in the emergency room setting, just no accommodations. The nurses were afraid to touch her... They saw the struggles I was going through and nobody would help.

Mrs. K's story illustrates the frustrating experiences both she and her daughter shared in the emergency room, where the providers were not familiar with her daughter's needs. As mentioned in the literature review, the use of emergency rooms is very high in the ASD population. Even in a pediatric hospital, where staff are trained to work with people with developmental disabilities, staff may be left bewildered on how to best approach someone with ASD/ID.

In contrast, Mrs. M noted how well her son's PCP approached her son during office visits. His social needs are met in the current primary care environment:

Mrs. M: They are friendly and they greet him. And Dr. (his PCP) he is a character. He is like a child, so he has this bubbly personality and he greets (my son) and (he) is comfortable with him. (He) will let him listen to his chest or look at him. And if (he) is not into it that day, (the doctor) will just back off. He doesn't have to have hands on so much, just wants to see what's going on and make (him) comfortable. If (my son) just wants to get up and walk around that's ok too.

This vignette exemplifies the flexibility the PCP and his staff have in serving this man. As adults with ASD have "good" and "not so good days", having flexibility for their needs is also a helpful lesson for healthcare practitioners.

Mrs. S explained a "catch 22" scenario her son experienced with dental procedures. While he was a teenager and young adult, he received his dental services from the local pediatric hospital. He was compliant and settled in this setting. As he grew older, the hospital made a policy decision that dental patients could only be seen if they had a staff pediatric physician. As he is now an adult, he did not have a pediatrician any longer, thereby losing the ability to access the pediatric dentist. When he transferred to an adult dentist, the pediatric dentist noted he was "moderately compliant" which turned out to preclude him from going to an inpatient dental practice in an adult hospital (which would have been a similar environment). He was considered higher functioning, thus, his only option was to go to a private dentist who accepted Medicaid payment, which is difficult to find in this area. Here is what happened to Mrs. S's son:

Mrs. S: So then we were wondering what we were going to do because at that point there was some dental work that he actually needed. So the group home hooked him up with a dentist who

supposedly treated special needs people, and he ended up slugging the hygienist in the breast and she had just had a mastectomy so they stopped right then and said we can't deal with this.

As a result, her son ended up at the inpatient dental office due to his challenging behavior in the office setting. In the meantime, he developed some serious dental issues, which required him to be sedated for the procedure. After this, he was sedated for all dental procedures including cleanings. His mother expressed dismay that his ability to tolerate dental cleanings was lost due to the stressful transition from the pediatric provider to the adult practitioner.

Related to communications is the challenge of understanding how the person with ASD/ID expresses their feelings of pain or discomfort. Working with this population is challenging in ascertaining how they experience or identify symptoms. Some interviewed were very capable of managing their health and asking questions. However, for lower functioning ASD/ID individuals, it is their caregiver who must serve as the interpreter to the clinician. Each individual with ASD/ID should be evaluated for their capabilities of expressing their understanding of their health:

Mrs. J: The difficult thing is (her son) cannot explain what his symptoms are, he cannot tell us how he feels. Now that he had that experience (he was hospitalized for gut pain), whenever he does not feel well, he tells us it his stomach, but often, it is not. This is the words he has learned to describe not feeling well.

Mr. Z echoed Mrs. J's assessment of the challenge his brother has in understanding his health or communicating his symptoms:

Researcher: How would he rate his health status?

Mr. Z: The question wouldn't even be relevant to him. He would say great. He couldn't think that through.

These stories explain the inherent challenge in serving these older adults, who may not have the benefit of some of the more recent speech therapy training which is available to younger adults with ASD/ID. However, developing innovative ways to work with older adults may offer some methods to solve these problems. Mrs. J noted how she and his in-home caregivers would get "creative" in approaching her son's anxiety, and his ability to handle his emotions and behavior. They would utilize a placebo (vitamin) to convince her son he could handle stressful events, thereby avoiding the use of medications:

Mrs. J: He hasn't been on anything for years but right now he takes Buspar (a psychotropic drug used to treat anxiety). We have that as a back-up if we have a problem at home. It is the last resort. When we went to the wedding, a staff member recently got married, it was out on a farm, and outside, and very different for (her son). So as long as I have a small Diet Coke it seems to work just as well. The other we have, but they just use it at (his) work is the placebo, which is B-12...we tell him it is calming medicine.

This mother, who is also a healthcare professional, developed innovative tactics to improving her son's healthcare experiences, and accomplished this in concert with the PCP. This exemplifies a successful approach to managing her son's stress in clinical and other life situations. Each of the stories in this section illuminates the need for communication between the healthcare provider and the parent/guardian (as well as the residential caseworker) to ensure providers have the best preparation to serve the adult with ASD/ID.

Transitioning On/Off Psychotropic Medications

All participants, including those adults with ASD/ID, expressed serious concerns regarding the medical management of ASD with psychotropic medications. All but one participant was taking at least one, if not more, psychotropic medications. The balancing act of the right medications and the right dosage is something that is a life-long challenge for every individuals interviewed. Several spoke of the need to start medications at very young ages, especially in order to function in the educational environment. Many of these medications have not been tested on children, thus, the medical literature has little information on the long-term use of these medications. Every parent/guardian discussed the early use of medications, the most striking stories are shared here:

Mrs. K: In about the third grade she just started, you know, terrible sleeper, tons of anxiety and nothing you could do would make her happy and she would just have these complete meltdowns. She developed these repetitive activities that disturbed other people. She would rub her face until it was red and raw, she would bite herself and when she was really frustrated she would spit on people. So we started down a path of taking all of these wild medications.

Mrs. W: Well when (my son) was young and he went to the (the children's hospital) psychiatric center, not even in school, I think he was about 3 years old they had him on Haldol.

Mrs. J: (My son) was never on a big dose of Risperdal, he is on the lowest dose. We tried Paxil, we tried two SSRIs and it was like giving him speed. It was horrible. That is the reason he went on Risperdal. I think it was (his pediatric ASD specialist) that put him on Paxil and he was so bad that I couldn't leave him with anybody; we had to take him with us.

These stories speak to several issues. Severe behavior problems, present for many of these individuals at young ages, gave many families the difficult choice to utilize some very powerful psychiatric medications. Behavioral therapy was not available for many of the adults that took part in this study, and prescription drugs were really the only option. These prescriptions are used “off label,” meaning that their FDA approval is for other, related conditions such as attention deficit hyperactivity disorder (ADHD), sleep disturbances or depression. Off-label use is common in nearly all areas of medicine and is usually done to relieve significant suffering in the absence of sufficiently large and targeted studies. These medications were not tested on children, and their long term use is still not well understood. For many of these adults, the life-long use of psychotropic medication are appearing to cause physical consequences as adults. In particular, the family of the adults who died prematurely attributed their many of their children’s health problems to psychotropic medications:

Mrs. W: ...He was on so many psychotropic medications. In fact, I wonder sometimes if that didn’t do him in. He developed diabetes when he moved out to the (group home).....They used food to control his behavior. He ballooned up to 260 pounds and it was after that that he developed the diabetes. There was a family history plus some of the medications tend to raise his sugar.

Mrs. K noted her daughter’s early indication of heart failure was passed off as “due to her medications”:

Mrs. K: Not that she was expressing to us (her symptoms) in a way that we could understand. But in hindsight, she had all of the classic symptoms that the doctors overlooked. The classic weight retention, her legs and they just passed it off as the medications.

Both of these stories share a similar concern that psychotropic medications caused chronic health conditions which contributed to the demise of their children. All family members/guardians shared their ongoing worries related to these medications, including issues around weight gain, drowsiness, gastrointestinal upset, elevated cholesterol levels and diabetes. Mr. Z expressed what he referred to as the “freaky balance” in ensuring his brother’s behavior was well managed, in order to remain at the care facility which he has lived in for over twenty years. The medications offered an important relief to aggressive behavior, but it brought serious concerns regarding health implications to several guardians:

Mr. Z: It is a very freaky balance really. Risperdal is very powerful anti-psychotic and you probably know what it is but it has been linked over time to shrinkage of brain volume. It is

really a horrifying med but when I try to get them to reduce the dose, which they were happy to do because they don't like it either, to their credit, he flipped out. So yes, it is a choice made for keeping him there and relatively happy. It is a lousy choice but that is such a reality.

Among the frustrations related to medications was the mixed advice they received regarding safety and effectiveness. In the end, the families were hoping for relief for their loved ones:

Mrs. S: Well anyway, it (the psychiatric admission) was a hideous experience. They put him in there and they started taking him off of his drugs. Because he was an adult they wouldn't talk to us because we weren't his guardians (the group home was the guardian). They would not even confirm that he was there and I said, look, I know he is here. He got so bad during that stay because of being off the medication and they couldn't deal with it. They didn't know what to do for him....He cried the whole time. I mean he never cried...so when you hear him cry it was just heartbreaking. We had an experience where we took him to a doctor up in Columbus who did the opposite. He just bombed him with medication..... the poor guy was drugged his entire life for the most part because of his behavior.

As indicated by Mrs. S in her comment above, several participants noted the challenge of changing medications or attempting to reduce high dosages. Often participants were hospitalized for a significant period of time, as they went through very difficult periods, which heightened anxiety and produced very challenging physical and emotional behaviors:

Mr. L: I think it was that summer there were two things that led to great destruction of his bedroom and his things. At one time I think it was backing him off of his medications. I can't remember how I was encouraged, but we finally took him off of the last medication and he was miserable, a bundle of nerves and anxiety. There was a lot of destruction that summer. (This young man ripped two mattresses, exposing springs and ripped a wooden door off his wardrobe in his room).

Mr. L's comments point to the challenge of keeping anxiety in check to keep the adult with ASD/ID safe in their residential environment, including the safety for themselves and the people around them. This "balancing act" of ensuring socially appropriate behavior was articulated by Mr. Z, as one that could impact the ability to live in the most desirable circumstances for his aging brother. Thus, the management of medications was essential for his brother's all around well-being:

Mr. Z: It is a tough process. With my brother you are dealing with a terminal condition. He is not going to change; he is not going to get any better. He has reached that stage where all I really care about is that he stays at this place. It is the best place in the world...So I just can't allow that to happen. He is very happy overall and they love him very much. They show him a tremendous amount of affection, the staff does, but he is volatile and I don't want him to blow it.

Essentially, the use of psychotropic medications frustrated many, and was seen as something of an inescapable issue for adults with ASD/ID. One interviewee was pursuing Functional Medicine and avoiding the use of medications. This approach will be discussed in the next section, related to Specific Aim 2.

Double Jeopardy Stigma of Ageism/Disability

As indicated in the literature review, stigma is a mark of disgrace that sets people and groups apart from the rest of society and often results in negative actions and discrimination. Even though overt discrimination towards age and disability is rare in institutionalized settings, insidious discrimination is evident in challenges accessing services, difficulties in communicating needs and expectations and subjective decision making by healthcare workers. As mentioned in the literature review, Gray (2002) found that children diagnosed with ASD and their parents experience considerable stigmatization due to what is perceived as socially inappropriate behavior; it is reasonable to anticipate that stigma would continue as people age, and perhaps be compounded by age-related stigmatizing attitudes. All three specific aims shed light on the issues surrounding accessing services and difficulty in communicating needs that may result in stigmatized interaction within the healthcare system. Subjective decision making and judgements are highlighted here to illustrate the impact healthcare providers' actions can have on an ASD/ID individual and their family.

Mrs. F mentioned an early interaction with a pediatric neurologist when her son was in the process of being diagnosed with ASD. She mentioned this was a significant event in her family's process of understanding their son's disability, an event which is still with her nearly three decades later. For many of these guardians, they have lived with perceived bias throughout their loved one's lifetime. This feeling of stigmatization not only impacts the person with ASD/ID, but the guardian as well. As mentioned in the literature review, the "linked lives" principle, central to the life-course paradigm, highlights the fact that events experienced by one member of a family may have implications for the life course of another family member. These interactions certainly highlight the impact these comments made on the informants of this study.

Mrs. F: We took (her son) to see a pediatric neurologist at children's hospital. And, (he) was 2.5 to 3. And (the doctor), immediately, this guy was so cold. (Her son) was playing with his

telephone, and put it up to the doctor's ear and put by his own ear. The doctor said, "See he is optic oriented, he is not interested in people." (She pauses) "What? He is trying to play with you?" Then he says "does he flap his hands?" (which is a common feature in young children with ASD) and I said yes he does, so he wrote that down. So he was only writing down things that fit the (ASD) stereotype....And he said "well, I will tell you my diagnosis, I hold out no hope out for this child." I couldn't help myself, I said "Well, that's why God didn't make you his mother then, isn't it?"

Several informants told stories similar to Mrs. F, which indicated that healthcare providers sometimes focus on expected or stereotypic behavior of ASD in their patients. At times, age related stigma could be coupled with the stigma of disability. Mrs. K told two stories related to disability stigma and age related stigma (although in the latter case, the symptoms were discounted because of her daughter's young age, not older age). The first story was associated with her daughter's monthly reoccurring abdominal cramps. Miss K was prescribed Depo- Provera, a long-acting reversible hormonal contraceptive birth control drug that is injected every three months. It is a progestin-only medication. This drug is commonly used in women with intellectual disabilities as it reduces or eliminates the menstrual bleeding. Miss K was experiencing significant pain symptoms, which were discounted because of her ASD diagnosis by healthcare providers:

Mrs. K:I knew something was medically wrong with her. I convinced them to do some medical testing on her, so they had to transfer her back to (the academic medical center) so they could do ultrasounds and stuff, because she was always complaining about belly pain. But they didn't find anything they just said it was because she had autism....We finally realized she had some gynecological problems. She was on the depo shot and it caused a (decidual) cast form in her uterus and when she would have a period it would be so painful because her body was trying to expel that cast. Everyone dismissed me, you know, there's nothing wrong here. The gynecologist did not want to examine her. They didn't want to put their hands inside somebody with Autism...This went on for a year and she would get very violent and the Ibuprofen wasn't working. Here let's deliver a baby with Ibuprofen.

Miss K passed away at the age of twenty-four. As described by her mother, the autopsy indicated one chamber of her heart was enlarged, causing the cardiac wall to thin and dilate, resulting in cardiomyopathy. It is believed this was caused by a viral infection. Mrs. K expressed her concern to her physician about her daughter's shortness of breath. In addition, she was on a significant number of prescription drugs, which caused drowsiness. All of these symptoms were not recognized as a cardiac condition:

Mrs. K: ...Because nobody thinks a young female is going to have heart issues... a simple chest x-ray would have shown an enlarged heart, but they are just not thinking heart issues when they see a young female.

Mrs. K viewed her daughter's death as a tragedy that could have been avoided. Several parents/caregivers also shared a similar concern that healthcare providers have predisposed mindsets regarding their family member's disabilities. Mrs. J expressed concern regarding the perspective of healthcare providers on how much care they will offer her son, especially as he ages, and when the time comes, when she may not be able to influence his access to services:

Mrs. J: No we are not at that point yet (of worrying about "end of life issues"). He is still young, only 41. This is the most horrible thing; when I was interviewing pediatricians, this one pediatrician said that he wouldn't take any heroic measures to save (her son). I said if he had appendicitis you wouldn't do anything? So we didn't go with him!

This story illustrates the worry some parents and guardians feel about the attitudes by some healthcare providers towards their loved one. The dual stigma of disability and age can potentially impact access to care based on the experiences shared by the informants. As a result, families often must maintain a protective and vigilant attitude to ensure their loved ones receive appropriate care.

Mr. Z, who is his brother's guardian, offered an interesting comment regarding his brother's significant curvature of the spine. The discussion was related to his brother's ability to exercise, however his comment indicates an internalized stigma:

Mr. Z: Not only does he not enjoy doing it (exercise) but he has that characteristic horrible slump that you see in older people with autism, where the head hangs way lower and the spine is curved or stooped and I think it is partly a shame response. He has that and his posture is terrible.

This comment may indicate an internalized stigma which can actually be internalized more by the family member, than by many adults with ASD/ID. The "linked lives" experience of years of perceived stigmatization and social judgement is shared by many families who live with ASD as part of their family experience.

Specific Aim 2:

To explore ASD-impacted adults and their guardians' experience with the coordination between primary health, other specialty or ancillary services, and factors which could impact access to care.

The primary care physician is often counted on to serve as the "gatekeeper" for specialist services and medication coordination. As examined in the literature review, pediatric literature

is full of supporting data related to the value of medical homes for the special needs population, yet little evidence exists on patient centered medical homes for adult ASD patients. This specific aim wanted to better understand the degree of fragmentation and coordination of medical services received by ASD adults. Several of the adults with ASD/ID shared the same PCPs as other family members, and this “family doctor” scenario will be explored. It became clear from the interviews that it is often not a physician who coordinates services, but often the family is responsible for this coordination, with support (sometimes leading support) of caseworkers from residential settings. None of the informants indicated they participated in a medical home. All but a few of the younger informants had Medicaid as a payor, as most had Level 1 Waivers from their County Developmental Disabilities provider. Given this lack of formal coordination, and reality of chronic illness in this population, the medical home model represents a potentially useful approach to health management.

There were several situations where coordination of care was challenging, in particular, in emergency rooms. Several stories will be shared of the challenge in this environment. In addition, preventive medical screenings, usually coordinated through the primary care physician, can also be a challenge for some adults with ASD/ID. Those stories are also shared in this section.

PCP Serving as Coordinator of Care/Services: Positive Experiences

All but one of the participants had a dedicated PCP, and most were followed by their physician for some time (greater than three years). Five of twelve adults with ASD/ID had the same primary care physician as their family member. These five reported very strong and confident relationships with their physicians, often in more positive terms than those who saw

different physicians than their family members. Perhaps the longevity, understanding of family history and combined relationships made that connection stronger.

Nancy (a middle aged adult with ASD/ID) mentioned she sees her father’s physician (her father is now deceased). As her father passed away five years ago, Nancy has seen this PCP for some time. This line of dialogue was chosen as it took several questions for Nancy to share her thoughts. This was Nancy’s response to being asked about her physician:

Researcher: Nancy, do you have a family doctor?

Nancy: Yes, I do, I have been going to him for a long time. He was my dad's doctor. I don't know his name.

Caseworker: Dr. XX

Nancy: His office is on XXXX and he lives in XXXX. I know everyone in the office. Researcher: Do you always see (your physician)?

Nancy: Most of the time. Sometimes I see other doctors if he isn't there. Researcher: How do you feel going there?

Nancy: I feel very happy and welcome there.

Nancy's caseworker also confirmed the relationship Nancy has with her physician and his office staff:

Researcher: Is Nancy interested in her health? Does she pay attention to her health?

Nancy's caseworker: Yes, she does pay attention. She likes to know exactly when all of her appointments are. She wants them on her activity calendar. She likes to ask questions of the nurses, about their families. And the doctor, she knows all of the personal information for the doctor.

This is Nancy's guardian's perspective on how he expects the PCP to serve as a coordinator of Nancy's care:

Nancy's guardian: The plan is that (Nancy's physician) is the gate keeper for all of the other doctors, since there are so many. We did have an outside psychiatrist who was a lady that my dad had found and communication between her and me was terrible and I finally fired her. We got a community support person.... he handles her case and Nancy really seems to like him so he seems to be working out better.

This vignette of Nancy's experience indicates the importance of not only the PCP in coordinating her care among a variety of specialists, but it also points to the important relationship among her supported living caseworker, her guardian and her physicians. When the relationship is well coordinated and roles are clearly identified, the adult with ASD/ID benefits from well-planned healthcare delivery. Nancy is comfortable with her PCP and, in fact enjoys going on her physician visits.

Mrs. F explained the very special relationship her son has with his PCP. Her son transitioned to her (and her husband's) physician at the age of adult transition. This physician has cared for members of the family for twenty-eight years. Their physician was instrumental in helping her son recover from malnutrition which happened in his mid-twenties while in the care of a group home where he was physically and emotionally abused. This PCP facilitated all referrals to any specialty needed, including neurology, psychology, neuro-psychology, GI and dentistry. Mrs. F described this strong bond her son and his physician share:

Mrs. F: (Her son has seen his physician) since he was 22 or 21. Like if I write down (her doctor's name), (her son) will whisper "that is my best friend".... He was so desperately sick for about a year and he saw (his doctor) all the time and he knew that (he) was helping him and saving him and he was worried about himself. He adores (him)....

This quote indicates the bond of trust which exists between their PCP and Mrs. F's family, in particular for her son with ASD/ID. Mrs. F feels strongly their PCP saved her son's life when he got very ill from this traumatic experience.

Mrs. J also has a long-term relationship with her physician. Her son began to see her physician when the local adult PCP who sees developmentally delayed individuals was not working out for him. As mentioned previously, the waiting room environment and long waits were difficult for her son to handle. This PCP works with both Mrs. J and her son exclusively; she mentions the value of her physician understanding both of their histories:

Mrs. J: Yes (she is in a group practice). She is right now but we don't ever see anyone but her. (Our doctor) coordinates with other specialists, like the dentist and inoculations when he needs to be sedated. She attempts to schedule needs and coordinates when he is sedated. Also, (she) is careful on weight management....The other thing, when she was prescribing the blood pressure meds for (her son) she said that she "knows this one works for me, so I feel more comfortable giving that to him because it works for you."

Given the multiple examples of sharing the same PCP, there appears to be great value in this arrangement as it seems to enhance the understanding of the family medical history, while sharing a social connection. As well, due to the closer relationship, there appears to be improved coordination with other providers of services. It seems this model appears to emulate some of the same structures as patient-centered medical homes (PCMH).

PCP Serving as Coordinator of Care/Services: Less Positive Experiences

Mr. L, the parent of a 25 year old son, earlier mentioned the continued use of a pediatric specialist for the management of his son's psychotropic medicine. His son sees an adult PCP, who would normally coordinate his prescription medications, however, Mr. L, did not seem concerned about the lack of coordination between the pediatric specialist and the Adult PCP:

Mr. L: I have no idea how they coordinate (his care). In fact I had to tell (his son's adult PCP) that his medications were going to be coordinated by (a pediatric ASD specialist) and I felt a bit awkward telling him.

Mr. L presents a potentially challenging situation in terms of coordination of care and symptom monitoring. As many of the psychotropic medications may cause physical side effects, such as weight gain, gastric distress, elevated cholesterol and blood pressure levels and more, effective information sharing is critical. In many cases, it is up to the parent of guardian to be the conduit between and among medical professionals. Alex (a late middle aged adult with ASD/ID) and his father agreed the communication between Alex's primary care physician and his psychiatrist is virtually non-existent, requiring his aging father to intervene when needed (once again, dialogue is needed for the adult with ASD/ID to tell his story):

Alex's dad: Which of your doctors share

information? Alex: I don't really know.

Researcher: So your psychiatrist doesn't work with your medical

doctor? Alex: No

Alex's dad: No not at all. In fact, I am supposed to call her once per month. Alex, why do I call her?

Alex: To see how I'm doing at home and

everything. Alex's dad: What is her name?

Alex: xxxx, she is through xxxx.

Alex's dad: She would accept whatever he said because he was doing pretty good, but twice he was rated ineligible because he was so healthy. So I was going to his meeting with him and we go in and review the things that he needed help with. He would rather not get into anything difficult. Is that about right?

Alex: Yes that is right.

This story explains the needed role of an advocate when health practitioners do not coordinate care for their clients. In Alex's case, who was a high functioning adult with ASD/ID, he was capable of going to physician visits on his own. However, like many people, unsure how to navigate the communication among all of his physicians, as well as his social support system. This speaks, once again, to the importance of family members serving as advocates for their loved ones, in this case in assisting with coordination of services.

Role of Family Members in the Coordination of Care

Typically, families must be actively involved in coordinating healthcare for their family members. Although a PCP can serve as a "gatekeeper" of referrals to specialists and oversee general health, the family must be actively engaged in advocating for their loved one in the medical environment.

Jack is a higher functioning adult with ASD/ID and sees many specialty physicians, as well, has a long term relationship with his internist. Jack and his sister share their internist, and are generally pleased with her care:

Jack's sister: I just love (our doctor). I started seeing her when I moved back here. It's been about 18 years now.

Jack: So I came down with a cold and she gave me some medicine and told me to stay off for a while. I called (my sister) one time and told her I don't feel very good and we called her (their doctor) and she took care of me left and right. She made sure I took this one medicine and she had me off for a while (from work)I do everything they have me do, the doctors.

However, Jack's sister is really the coordinator of a vast network of orthopaedic surgeons who care for her brother's issues, which has ranged from club feet, a broken femur, broken ankle, Achilles heel repair and fluid on the knee. Jack's sister maintains a meticulous notebook with her brother's medical history, and she serves as his medical historian and care coordinator.

Sister: Yes, I have Jack on "My Chart" now.

Researcher: (speaking to Jack) Yes and you can look at your records too. (To Jack's sister) Are you going to keep your book?

Sister: Yes, I will keep it.

Researcher: Yes, because you have copious notes before My Chart became available.

Sister: Yes, we have folders and folders on him.

Jack: Yes, folders and folders.

Sister: I know I have a chronological file where everything is dated and accidents, a timeline. Given the complexity of Jack's orthopaedic history, his sister is wise to maintain this important information and to continue to advocate for his needs. Jack is accompanied by his sister or his mother to every doctor's visit. She feels strongly advocacy is a necessary part of maintain her brother's active life.

Finally, Mrs. M is the mother and guardian for her adult son. She is also a medical professional and works closely on a professional basis with her son's physician who is a functional medicine specialist. Mrs. M also sees the same physician. Functional medicine is an integrative, science-based healthcare approach where practitioners look "upstream" to consider the complexity of interactions in the patient's history, physiology and lifestyle that can lead to illness. The unique genetic constitution of each patient is considered, along with both internal (mind, body, and spirit) and external (physical and social environment) factors that affect total functioning (Center for Functional Medicine, n.d.). Mrs. M mentioned her son is on a very long list of nutritional supplements, has a very defined diet and practices gut health; and the only prescription drugs he is now on is for his epilepsy. Her physician, along with her watchful monitoring, has reduced all other psychotropic and GI related medications. She is very pleased about her son's overall improvement and happiness:

Mrs. M: ...So my son had classical manic symptoms and when I came back here and started with Dr. (xxxx) and now you would barely see his bi-polar and he sleeps and he doesn't beat on windows any more. He still bites himself and hits himself when he can't tell you what's going on. But he is so different and he is on a list of supplements like this (gesturing the length of her arm)...Dr. XX is the only person that he (her son) sees because nobody else has helped his seizures or helped anything with (her son)...

As Mrs. M is a healthcare professional, she is educated on the latest literature related to functional medicine and serves as a partner with her son's PCP. They share a mutual philosophy to his treatment, and at this point, her son is no longer taking psychotropic medications. Strong partnerships among family and healthcare practitioners are key to ensuring a good medical plan and ongoing health. Family members who are not always available to attend physician visits need caseworkers and other residential support to be involved in communications between the guardians and the physician.

Reliance on Caseworkers in Coordination of Care

For those aging adults with ASD/ID, many have failing or deceased parents who can no longer serve as their guardian. At this point in life, it is often a sibling who takes on that responsibility. Several sibling guardians participated in the study, and shared their reliance on group home caseworkers to assist in coordinating their medical care and visits. Nancy's guardian lives approximately two hundred and fifty miles away from Nancy and counts on both her case coordinator and Nancy's primary care physician to keep him informed of Nancy's health status and healthcare management:

Nancy's Guardian: Well, (the caseworker) is our eyes and ears. She is our advocate (there) because she is very devoted to (Nancy) and she is very professional. So the two combined, we asked her to be our eyes and ears and our advocate there so any time there needs to be a decision made we always involve her and we always copy her on everything because she spends a lot more time with Nancy than we can.... (Her primary care physician) keeps records on all of the medications. (Her doctor) is supposed to be the one making sure she isn't having any issues with her medicines.

As mentioned previously, Nancy's guardian worked diligently to improve communications among all of the physicians Nancy sees for her chronic illnesses. Her caseworker is integral to the success of this coordination, and her guardian has "let his guard down" on worrying about coordination issues now that her casework is so capable of managing Nancy's care.

Mrs. S is well into her 80's and has physical disabilities. At this point in her life, it is difficult to attend any medical appointments for her son. She counts on the group home staff to manage her son's office visits and medical needs:

Mrs. S: Basically, usually it is the manager of the house (who makes the doctor's appointments); he is very good with everything. Yes, he will call the office to book the appointment and explain exactly the way it is. And they have been very good about it and sometimes he reminds the nurse that you got to explain, because he is not going to like it...

Mrs. S was grateful her son's medical care was now being more actively managed by the manager of his group home. This manager has been with the facility for over 25 years, the entire time her son was a resident. She trusts the manager implicitly to ensure her son's concerns are handled proactively. As he enjoys relatively good health, she has piece of mind knowing her son will be well taken care of when she is no longer able care for him.

Often, if a group home resident is hospitalized, a home worker accompanies the adult and serves as a “sitter” in order to make their hospitalization as smooth as possible. Mrs. K’s son was hospitalized and recuperating from a surgery, when a complication developed. Tragically, her son passed away due to the complication. Mrs. K is left with many questions from her son’s death; on concern she shared was the reliance on group home workers in the inpatient setting:

Mrs. K:Well, our provider at the time (group home) had someone there with him the whole time. So here is my question; did they rely on them more than they should have? I mean they are not medical professionals. It wasn’t that they didn’t see signs of his deterioration, I think he was throwing up blood or something.

As we learn from these examples, residential and supported living caseworker play an integral role in coordinating care and ongoing home treatments for adults with ASD/ID. Their role in conveying information is counted on by guardians and healthcare professionals. This last story brings concerns about their roles in the inpatient environment, as hospital employees seem to consider caseworkers to be “sitters” and may rely on them in ways which they are not properly trained to fulfill.

Coordination of Care Challenges: Emergency Rooms

Several informants mentioned the difficulty in using emergency room services where communication with the patient’s PCPs is not a common practice. In both of these stories, adults with ASD/ID were referred to a pediatric emergency rooms, as their PCPs thought they would find more “understanding” care for their loved one.

Mrs. J: One area where we did have some difficulties when he was sick last year. He was very sick to his stomach with acute pain. She (his PCP) did not know where to send us for care. She suggested we go to a children’s hospital! I said, I cannot take an adult man to a children’s hospital! It concerns me that we did not know where to send him and if got very sick again, I am not sure what we should do. Other than that situation, we are very pleased with (their primary care physician).

Emergency rooms can be a daunting experience for any person, but especially those with significant ASD/ID sensory challenges. Some emergency departments are now designing designated spaces for geriatric patients, and this kind of environment, which has much less sensory stimulus may be a better care environment for aging adults with ASD. Many of the participants noted their fear of taking their loved ones to emergency rooms, as few emergency departments know how to accommodate adults with ASD/ID.

Coordination of Care Challenges: Preventive Health Services

Preventive health services are important to protecting, promoting and maintaining health and well-being and to prevent disease, disability and potentially, death. For an adult visiting a PCP, common preventive health services include vaccinations, screening for several chronic concerns including blood pressure, hepatitis B and C, cholesterol, diabetes, obesity, colorectal cancer, depression and diet counseling. For women, other preventive screening includes mammography, osteoporosis screening, and cervical cancer screening. As mentioned in the literature review, adults with ASD/ID may have difficulty in handling some of the more invasive testing and minor procedures. Some of the informants shared these challenges in receiving preventive care:

In section one, we heard the story about Mrs. K's daughter, who had a significant complication from the Depo Provera shot. Her daughter never received a GYN exam, as they assumed she would have to be sedated to undergo that type of examination. The other woman in the study, Nancy, did not receive GYN exams either, even though she received the same Depo shot to reduce her menstrual cycle.

Nancy's Caregiver: No, she does not (have GYN exams). (Her brother) asked me about that too. She hasn't had any problems with that. I told (her brother) that if (the doctor) ever asked for it that I would take her, but I'm just not sure how she would do. I don't see that ending very well.

Mrs. S mentioned her son has high blood pressure, and his PCP ordered an EKG in order to monitor his heart function. Unfortunately, her son would not comply with the screening:

Mrs. S: He has had a few primary care doctors throughout the years. I don't think he stayed too long, you know. There were certain things that he would not let them do, one of them is to have an EKG...I'm not sure what it was, but he was absolutely hysterical.

Mrs. J mentioned the challenge of offering a yearly flu shot for her adult son. Her son works in a sheltered environment, so receiving a flu shot would be a very good idea. However, he usually refuses, even with a much loved nurse:

Mrs. J: He responds very well to (his nurse) In fact, he tried to let her give him a flu shot last year but he is just so afraid.

Preventative health services are essential in the management of chronic illness, and needed as adults age. Unfortunately, for many people with ASD/ID the invasive nature of some procedures, even things like blood draws and immunizations, can be quite traumatic. For many, they must be fully sedated to undergo most simple medical procedures. As mentioned by several

interviewees, including Mrs. J, there is a need to develop innovative ways to find less invasive ways to screen people for disease. As medical technology evolves to find less invasive testing, adults with ASD/ID will benefit from these innovations.

Specific Aim 3:

To discover what other barriers (e.g. access to available health services, policy concerns, such as health insurance and residency location, advocacy, aging guardians and others) can potentially influence the health for ASD adults.

As indicated in the literature review, there are other potential barriers to providing optimal care which may impact healthcare outcomes and influence the determinants of health in the adult ASD/ID population. First, access to healthcare and the quality of health services impact health outcomes, especially in an acute episode. Access to care is challenging for ASD/ID adults and their caregivers, as so few providers are trained to serve people with special needs. In particular, since many of the adults interviewed were covered by Medicaid as an insurance payor, this can provide a first layer of access limitations for this population. Policymakers can make decisions that impact access to care, as well as influence other social service supports which ultimately impact determinants of health, including policy related to residential support.

Residential living can also present challenges for many residents, as other residents may present physical aggression and caregivers may not live up to their responsibilities. Finally, the support received from aging parents and guardians, and their continued ability to advocate for their loved ones influence access to care and potentially healthcare outcomes.

Barriers to Health: Access to Available Services

For many, it is very challenging to find a primary care physician (PCP) who is focused on the needs of those with ASD or ID, in addition to caring for a broader population of patients in their general practice. One informant discussed the only adult internist who devoted his practice to people with intellectual disabilities in this mid-western city.

Mrs. M: I'm not sure he had control over the environment and there were so many people trying to get into see him...he was just slammed all the time. ...I heard he had cut back (on appointments) and that is why he was going out to (a residential center) for a half day per month but I don't know. I know people are going to be really upset when he retires because there is no one else.

Another informant in this study, who was from one of the largest cities in the United States, mentioned there was only one adult psychiatric unit in the city that would admit people on the autism spectrum:

Mrs. F: The neurologist was at the only hospital in (the city) that would take an autistic person. It was the only psych ward (in the entire city that would take a person on the ASD spectrum).

Mrs. M echoed the concern regarding the lack of access to specialty care devoted to adults with ASD/ID:

Mrs. M: We talked about this when I was on (a community leadership group for professionals serving the ASD population). I mean how do you train or get a doctor that is interested in developmental disabilities? Because once they leave (pediatric services) and age out of there, I mean the (local pediatric ASD center) has taken back a few adults, but that is not full medical care...I have a patient ...(who) is mentally disabled and (he is going into) a medical home. And I said, awesome, perfect. Because if it is designed that way, then maybe that will work...

Every informant interviewed shared concerns about access to physicians. Some were concerned about the lack of access as a Medicaid patient (and some practices do not see Medicaid patients), some just found obstacles to care, as we saw in particular with Mrs. F, who had one choice for a psychiatric facility in one of the largest cities in the United States. Very few adult PCPs have expertise in developmental disabilities and no participant was enrolled in a medical home.

Barriers to Health: Medicaid Coverage

Certainly, a major component of this access issue is the kind of health insurance coverage the individual possesses. Since the vast majority of those with ASD and ID are not gainfully employed with healthcare benefits, most are reliant on public support (Medicaid) once parental insurance is no longer available (now extended to the age of 26, based on the Accountable Care Act provisions). Two participants did have gainful employment in the past, with healthcare benefits. Alex, who was injured on his way home from work when he encountered ice on his bike ride, was especially challenged with Medicaid. He tells two stories here, the first related to dentistry (Medicaid only pays one visit per year) and the next with losing all benefits through no fault of his own:

Dad: You can tell her how you would go to dentists and they wouldn't work on you and stuff?

Alex: Yes I had one that had an office in xxxx and xxxx and for some reason they kept re- scheduling my appointment and I would ride the bus only to find out my appointment was cancelled and I had a meltdown right in the lobby.

Researcher: What would be their reason for cancelling

you? Alex: They would say my insurance wasn't working.

Dad: From a perfect state he lost continuity.

This story speaks to the insurance problems in finding a dental practitioner who would accept Medicaid, but also speaks to the lack of communication, and in turn, respect for the patient (Alex took 3 different buses, totaling over two hours of travel to get to this dental office). Alex also experienced significant problems when he was disenrolled in Medicaid, for no apparent reason. This resulted in Alex being unable to visit a doctor for nearly a year while the applications were updated for his membership:

Alex: I have only seen him (his physician) one time because we had to change last year because I had a little problem. I got everything through Job and Family Services and we had a little debate with them. They took away my Medicaid for a few months and we finally got that straightened out. They said I forgot to renew one time and me and my case manager had to go through and get everything straightened out. So we just went through my schedule so I can get my dentist and doctor's appointments all caught up... I haven't seen anyone in over a year.

Alex's Dad: Even the caseworker said we did nothing wrong.

Insurance coverage is a significant concern for all Americans, and for this population, public programs are often utilized. For two of the youngest participants, who were in their 20s, they still utilized parent's health insurance coverage through the parent's employment benefits. Both parents were fearful of what the future would hold in terms of their benefits when they converted to strictly Medicaid:

Researcher: How long can he keep (coverage through your plan)?

Mr. L: I don't really know. I mean this year I dropped the other kids, but not (my son with ASD/ID), not knowing if there would be a consequence, but just to make sure. I wasn't sure if some of the medication would still be covered and some of these medications are phenomenally expensive.

Given the concern regarding the lack of access due to Medicaid, it speaks to the larger issue regarding public policy for adults with developmental disabilities. Several informants shared their concern that public policy decision makers do not "get it":

Mrs. J: I want them to appreciate what it is like to be him in this world that causes sensory challenges and these sensory challenges can sometime cause physical pain. I hope their staff will be willing to help. Medicaid does not fully support all of the needs of this special population, and that is scary to think about as we age.

Mrs. F: Well the concern is he will never see a dentist. We have had quite an adventure at the dentist. He has to be sedated to sit in the chair....In (their state) you can only see a dentist once a year and if anything is wrong. You can only have anesthetic if you break your jaw.... We live in a very primitive world over here. It cost me \$1400 to get anesthetic for him to get his teeth cleaned. Out of pocket.

These stories illustrate the frustration in insurance coverage for basic medical, dental and psychiatric issues for this population. It is truly the “stroke of a pen” that can mean access to care for this special needs population.

Barriers to Health: Group and Supported Residential Living

Public policy matters go beyond health coverage issues and access to medical services, as it also includes issues related to residential funding. Mrs. F told the story how a good placement for her son became a very dangerous situation due to a significant decrease in funding:

Mrs. F: The funding was never strong. It was a small group home and we helped to found it....They were short funded here in (my state)... now they are 10 to 15 people short staffed so the agency moved in 3 super low-functioning violent people to get extra funding so (my son) and his friend started getting hurt... the staff became very lazy, they just wanted to sit around and watch Netflix and drug up the kids...So all of these kids would just sit in their rooms and be sad and (her son) was getting severely hurt, I mean really bad injuries and they would say “oh he must have fallen out of bed”... So he stopped eating because he was scared to eat with them. And the staff didn’t do anything about it. He lost 65 pounds in two months.

Mrs. M also worried about her son’s treatment in his group home, as staff was sometimes shorthanded and turnover is high, due to low wages. Also, some of the staff was not as committed as they could be to the residents of the home, as described below by Mrs. M. She also shared concern for the behavior challenges from other residents, who may be may be lacking appropriate supervision:

Mrs. M: That is what we worry about for the future...that is why we wanted (name) as our provider, because they get it. But they have got to train their staff because they have high turnover and they don’t pay well... Well, I walked in and the staff was asleep last week. I mean they were really asleep. They didn’t hear me come in twice. ... Yes, he (her son) could have been behind a locked door, and a seizure happens, so I reported her but, I hated to....Group homes are wonderful and terrible because you know, there are roommates....When you put people with autism together, you have a bunch of people with autism.

Mrs. M’s son was in a previous group home where gaps in care were very evident, actually harming her son’s health:

Mrs. M: He has head injuries from the seizures and falls and had to get stitches in his head. But that’s because they were not giving him his medicine in (his group home) He had to be

hospitalized (there) and when I arrived there he was having seizures and come to find out his blood level was zero for his seizure meds. So the doctor looked at me and said “I think there is only one answer for what’s going on here”. Somebody was stealing his medicine. That is when I brought him back (home).

Several participants shared these alarming stories about their adult’s residential placement, while others had very positive stories. From these stories, we can sense the link between physical and emotional well-being and residential placement.

Advocacy: Influence on Ability to Serve

Many family participants talked about their continued advocacy for their loved ones, as they attempted to remove barriers to treatment and care. Even those parents who were at advanced ages continued this effort, such as Mrs. S:

Mrs. S: Well you know, no one taught us anything hardly. You know in the 50’s they had nothing. We went through a lot. Fortunately or unfortunately we knew politicians. I think today it is the same way. It’s not what you know, it’s who you know. That will never end. When (my son) was growing up we were very close to a couple of local politicians and they did a lot to help us. To find places and whatever, you know. We were lucky in that respect.

As his brother’s guardian Mr. Z is very involved in advocating for his brother, but also for other’s with ASD, through volunteer work with the national advocacy organization, Autism Speaks. Here he talks about his appreciation of his mother’s dedication to his brother, as well as his new role of guardian to his brother:

Mr. Z: Yes it is a real mess but I’m lucky because my mother did all of the heavy lifting. I just have to do all of the bureaucratic follow through and it is substantial. You have to become a guardian and a representative payee and all of those other things that is involved in taking over the life of someone who is disabled. But I’m glad that I am doing it to face the bureaucratic entity.

Alex, who does not have a guardian, is continuing to build his self-advocacy skills, however it has been difficult to navigate the process at times (he did lose benefits for a significant period), as well as must serve as his own healthcare advocate. He mentioned during the interview the challenge of keeping track of his extensive medical history, which includes spinal surgery, ongoing spinal issues and a long list of psychotropic medicine which he has used over the years (once again, dialogue is needed to understand the story of Alex, and adult with ASD/ID):

Researcher: So when you have had to transition from all of these different doctors, do they get your records and send them over for you?

Alex: Yes

Alex's Dad: How do you know?

Alex: Hmmm

Researcher: Does dad help you with that?

Alex: He used to.

Alex's Dad: Yeah, but I have been in the real craziness for about 9 or 10 months here or even beyond. I just couldn't keep track of anything including myself. So I have moved all of his paperwork to him. I was always the keeper of history and he was pitcher of history. So he has got boxes of the stuff. (Alex's dad was caregiving for his wife who was in the late stages of Alzheimer's disease; she recently passed away)

Alex's father continues to develop Alex's advocacy skills, speaking to the need for adults with ASD/ID needing to continue to work on coping skills for their entire lives. For several aging parental guardians, they mentioned their concern about serving in this advocacy role as they age and have their own health concerns:

Mrs. S: (related to challenging behaviors) Sure you have to put your foot down. I mean now that I'm old aged he tries it and I will threaten him, maybe I shouldn't do that- but. I tell him do you want to go or do you want to stay home? He will say ok and I will say then knock it off with the whining. I'm really too old to take it like I used to you know. It's harder for us now to do it, you know. (Mrs. S is in her 80s)

Finally, Mrs. M, who advocates for group and farm living environments, discussed the challenge of finding the right residential and living situation for people with ASD/ID. She describes the complexity of serving the ASD/ID population, which results in many misunderstandings of their needs and capabilities by policy makers and higher functioning adults with ASD. The Center for Medicare and Medicaid services recently discussed eliminating funding for farm residential environments, and Mrs. M discussed her concern that advocacy groups many not appreciate the unique needs of those with ASD who also have ID:

Mrs. M: ...we have high functioning advocates for Autism who are rigid and they don't see and they are saying we speak for autism. And I'm like, you are not speaking for me. Because one of them was in the Obama administration driving this CMS stuff until he left. I think people finally saw that he was so rigid and he is the one that said everyone has to be out in the community, everyone has to live downtown on a bus line and everybody's got to have a job and I'm like hold on, wait a minute. And he is going around now, his group, which is a bunch of online guys that probably have high functioning autistics and they are challenging states that are not doing the right plan for CMS and I mean they are just really out there.

Advocacy for disabled adult children is something that all the parents discussed as a priority in their lives, even as their own health began to fail. Aging parents experienced long histories of working with educational, social, medical and mental health services to ensure they children had access to services and ensuring their safety and good health. This mother reflected on the group of autistics who represent the Neurodiversity style of thinking, which may not necessarily help those with ASD/ID, as they are not as functionally capable to manage their behavioral, social and cognitive challenges as higher functioning autistics can in society. She had serious concerns that this population of autistic adults would be forgotten about, as their only voice of advocacy comes from aging parents.

CHAPTER 5: DISCUSSION

The goal of this exploratory study was to describe the experiences of adults with ASD/ID and their caregivers in navigating the healthcare system, bringing to light the successes, challenges, thoughts and perspectives of the informants. Since limited research exists on the life events of these adults, it was unclear what would be learned about their lives, especially related to their health. The intention of this discussion is to sensitize readers to the experiences described by these adults, their family and their caregivers and to consider how to improve the lives of this growing population. Some of the adults interviewed encountered negative health outcomes and suboptimal relationships with healthcare providers; others seemed to have very positive relationships, with good preventive care and monitoring of health. Clinical and communications accommodations were absolutely necessary to make healthcare provision more comfortable for this population. Coordination of care was seen as an imperative, with most family members taking on this responsibility, with support from residential caregivers and some primary care physicians. Several barriers to accessing healthcare services included finding appropriate services, managing sensory concerns, lack of healthcare professional training and insurance limitations. The informants offered insights and suggestions to enhance clinical and patient care experiences, communication and coordination improvements and advocacy strategies that could make a positive difference in their lives. The key to each adult's success will be to balance customization of their individual care needs with a broader system, designed to meet their emotional, sensory, social, behavioral and coordination of care requirements. Creating partnerships with families, residential care providers and healthcare professionals may offer opportunities to better serve and understand the health needs of these vulnerable adults. This study supports the critical need for more healthcare professionals to dedicate their practice to this expanding population, and for many healthcare providers to gain training in working with adults with ASD, as well as ID. Of course, health policy must support these strategies; especially promoting training of physicians and other healthcare professionals and further expansion of medical homes through the Medicaid program. Perhaps some of the lessons learned in this study can offer novel ideas on how healthcare delivery systems, research organizations and public policy administrators might be more responsive to the needs of aging adults with ASD/ID.

Several key elements learned from this study deserve more in-depth discussion, including utilizing a life course perspective in studying aging adults with ASD/ID, issues related to access to care, utilization of family physicians, the residential location and its impact on health, the impact of communication challenges and access to preventive healthcare services.

Autism as Viewed Through a Life Course Perspective

This study and the data analysis were undertaken from a life course perspective. The life course perspective provided a framework for examining the intersection of aging, ASD and ID. As noted in the range of ages who participated in this study, we observed the interplay of life stages and transitions in relation to life outcomes (Coyle, et al., 2014). Transitions from previous states to future states, such as the transition from pediatric to adult medical care, are integral events that influence life-course trajectories. For the older individuals (age 35+) who participated in the study, they did not have the opportunity to work with specialty medical professionals such as developmental pediatricians, speech therapists, occupational therapists and other clinicians as a child. As far as education, very few of the adults had high school diplomas, and did not have the benefit of mandated education in the “least restricted environments” as afforded to the younger participants. As ASD was identified as a disability in the late 1940’s, many of the older participants were diagnosed with ASD at a later point in life, then they would today. As these individuals reach ages where chronic illnesses may impact their life course, the impact of long-term psychotropic medication usage, as well as sedentary and socially isolated lifestyles may have a detrimental effect on longevity and quality of life. Many of the older individuals were sent out of state to residential facilities that were designed to warehouse individuals with intellectual disabilities, practicing educational and “treatment” techniques that were not necessarily evidenced-based.

The “linked lives”, another concept central to the life-course paradigm, highlights the fact that events experienced by one member of a family may have implications for the life course of another family member (Hogan, 2012). Parents and caregivers have many details and experiences to share from their own perspectives on how the primary care providers and their offices serve and how they represent those whom they care for. Guardians, especially parents, spend an adult lifetime advocating for their children and monitoring their needs. There is a growing body of literature on how the stress of caring for their children over a lifetime impacts

their health and well-being. As these parents age and may need to serve as caregivers to spouses, or for other adult children and family members, their attention to the adult with ASD/ID may be lessened with the added stress in serving as caregivers. According to the literature review, the years of high stress experienced by families, also takes a toll on the physical and social well-being of parents. For the older parent participants, the worry about their child's future was mentioned by nearly all. For those parents who already passed, siblings noted the careful planning their parents took to ensure their family member was in a safe and comfortable living environment, with appropriate financial supports. As noted in the literature review, the significance of these parental and sibling relationships is often overlooked in policy, practice and research. Determining adequate support for families over a life course is something needing more attention and thought.

According to Ferraro and Kelley-Moore (2003), early risk factors shape trajectories not only in short-term outcomes, but in long-term outcomes as well. These adults have lived with their disabilities and associated co-morbidities throughout their lives; their caregivers have often taken a lead in the management of these challenges. As a result, the pair (adult and caregiver) continue to navigate through systems not well designed for either person or their myriad of complex needs. Through stories shared in the previous chapter, the effort to remove barriers in order to receive healthcare services over the life course were highlighted. In particular, the management of psychotropic medications brings out a particular long-term consequence to other health concerns. This will be explored further below.

Challenges to Access to Care

In this study, nearly all participants (some self-reported, some reported by guardians) characterized the health of the person with ASD/ID as being in relatively good health, yet all reported at least three chronic concerns, most often psychiatric/behavioral, gastric and weight/dietary issues. Other significant reported diseases included epilepsy, vertebral and other orthopedic challenges, sleep disorders, diabetes, dental problems and hyperlipidemia. Nearly all individuals in the study were hospitalized at least once in their lives, if not more than once. Many reported how difficult it was to find healthcare providers who were willing to see people with developmental disorders and how challenging the clinical environments were for their loved ones. Given these needs, access to care is vitally important. All reported a relationship with a

primary care provider, although all had some difficulties in maintaining these relationships at times due to challenges with finding physicians who will accept Medicaid patients. Very few held a high school diploma, and as a result, few had sustainable employment. Thus, public insurance through Medicaid serves as the primary payor of health services. Some reported difficulty in maintaining Medicaid and other social service support at times, when they were removed from the Medicaid program (in one case, with no explanation). Public policy support for continuity in healthcare coverage and social services is absolutely essential for all of these adults with ASD/ID. Further, enhanced coordination with residential services may improve living and health circumstances for many individuals. As Mrs. F shared, her son's health took a precipitous turn when he lost a significant amount of weight when he was frightened to eat community meals in his residential facility. Perhaps if there was a more formalized relationship between his healthcare provider and the group home, his change in health status could have been communicated to his physician and serious health concerns could have been averted. In several circumstances, improved coordination among the residential facility, the family and the physician could have identified several individuals' serious illnesses.

Importance of the Family Physician

What was striking in these interviews was the positive relationships found when an adult with ASD/ID had the same physician as another family member. These relationships were often long-term and deeply rooted in trust. Although these "family physicians" were often internists or sometimes family practitioners, they were not physicians who were exclusively focused on serving people with special needs. Often the family physician relied on psychiatrists to prescribe psychotropic medications and in some instances, to manage behavior through therapy. Also, the family physician would make appropriate referrals to specialists for management of ailments such as epilepsy, diabetes and orthopaedic injuries. These patient/physician relationships were quite collegial and positive, and were often spoken about in very warm terms. For those informants who did not see a family physician, the relationships with providers did not strike the same chord of trust and understanding. Often the adult with ASD/ID did not see providers for long periods of time. This was for several reasons, most notably due to having Medicaid for their insurance coverage. Finding providers who accept Medicaid is a challenge for many people, but most certainly for people with intellectual disabilities and ASD.

Specialist physician visits were also challenging at times for some individuals, as indicated by Mrs. K's experience when her daughter was asked to leave the office due to her behavior. In fact, some participants noted certain specialty physicians refused to see any special needs adults. PCPs received limited training for special needs patients; specialist physicians receive little if no training.

ASD group homes often had "preferred providers" whom they referred to for office visits. As mentioned above, these preferred providers could possibly develop stronger relationships with their group homes in order to train group home staff on health monitoring and health promotion. For several of the group home participants, they had the advantage of a physician who would conduct home visits, thereby avoiding the clinical setting and ensuring the environmental comfort of the residents in a familiar environment. Perhaps this could be a clinical care delivery model which other group homes could utilize to enhance comfort. Also, residential facilities often worked with local First Responders to train them on suggested approaches to working with their clients.

Independent Living vs. Group Living: Does it Make a Difference for Health?

The participants in the study lived in a variety of environments. One participant lived independently, three lived independently with support, one lived with family and seven lived in group settings. As discussed in the literature review, living arrangements and environment play a vital role in maintaining health, and recent literature recognizes that differences in health status vary with the nature of the caregiving arrangement for people with ID. In Western countries, the trend has been for people with ID moving out of the family home to live in the community in individual or smaller group homes, not in large congregate care facilities, as once was the norm. Healthcare providers have raised concerns about compromised healthcare quality for individuals living in the community, without constant family supervision. Smaller home situations may lack access to healthcare in these homes and finding clinicians who are knowledgeable about the person and their condition can be challenging, resulting in inadequate recognition of potentially life-altering conditions (Krahn, Hammond, and Turner, 2006). Mrs. M shared with us her son's experience where his epilepsy medication was not being administered, and as a result, his seizures were uncontrolled. Others told impressive stories how their children or siblings were well supported, loved and cared for in group home environments. In the study conducted by

Lewis, et al. (2002), persons living in community-based group homes were more likely to have a personal dentist or physician, more likely to have a normal body mass index and less likely to be obese. In group homes, social activities and daily programs often keep people more active, which is certainly a positive. In a study from Israel, Lifshitz and Merrick (2003) found the community residence adults displayed more medical problems and individuals living at home exhibited more dental problems. This study found similar results. Alex, the participant who did live independently had significant dental issues, and had difficulty accessing a dentist who would see him in the outpatient setting as a Medicaid patient. The group home residents also had limitations in receiving dental services, but perhaps had more supervision on daily dental care. Clearly, more analysis needs to be conducted to better understand how residence locations impacts health and oral status. The challenge in understanding health outcomes based on residence has been the availability of large sample sizes and great variability in settings to evaluate the health of adults. Based on the literature and this study, socialization, access to safe living environments and availability of resources will have an impact on health outcomes.

Implications of Communication Challenges

As indicated in the literature review, people with ASD are often underdiagnosed with chronic illnesses because of the impediments they face with respect to identifying and communicating symptoms of ill health (Mouridsen, Rich and Isager, 2016). This study illuminated several situations where this was certainly the case, potentially resulting in life threatening situations. Even in the highly monitored environment of the hospital inpatient setting, the ability for healthcare providers and caregivers to identify medical concerns is sometimes extremely compromised as the ASD/ID adult may not be able to communicate their symptoms and pain. In the case of the son of Mrs. J, his abdominal pain eventually resolved itself while in the hospital, with truly no explanation of what caused the discomfort. For the son of Mrs. K, his post-operative complications were not identified until it was too late for his survival. How can the healthcare delivery system do a better job of understanding the needs of this population, who face life with limited communication abilities? Visual techniques are often effective for this population, or perhaps interactive videos may help to convey their pains and discomfort. Certainly, research for new and innovative ways to assist the adult ASD/ID population in conveying their health concerns to their caregivers and their healthcare providers is needed.

Access to Preventive Health Screenings

Related to communication concerns is the ability of adults with ASD/ID to tolerate preventive healthcare procedures and screenings. Many chronic conditions could be better managed and perhaps prevented through more effective screening and prevention services provided by primary care providers. As mentioned by several participants, this is very challenging for many. For example, none of the over 50 age participants have had a colonoscopy. The two women in the study did not have internal examinations or pap smears (and were not at the age yet for mammograms). Even flu shots were difficult for some.

As mentioned in the literature review, biology has a major influence on health. There is evidence that people with intellectual disabilities have poorer health than their peers due to the interplay of the determinants of health, including biology, lower health literacy levels, inability to identify poor health, limited problem solving abilities and weak communication skills (Krahn, et al., 2006, Emerson, et. al., 2001). As a result, this often leads to missed or late diagnosis and lost opportunities for timely treatment (Croen, et al., 2015). Preventive health screenings and health education individually tailored to the abilities of the patient, while supplemented with training for family and caregivers, may provide an important improvement in health promotion. As proposed by several families, there can be creative ways to work with adults with ASD/ID, such as utilizing numbing cream for blood draws, immunizations and other punctures, creating calm environments by removing stressful features and by communicating through calm, respectful and appropriate ways. Also, small incentives for successful visits and treatment can also be quite helpful.

Limitations

This study was intended to work as closely with people with ASD/ID as possible, as suggested by the critical disabilities studies discipline. However, only four adults participated as active informants in the study. Parents and guardians were very interested in participating in the study, but the eight other participants indicated their adult children/siblings were unable to actively participate in an interview (two were deceased, but the other six declined the interview). The interview questions for adults with ASD/ID were shared in advance so that guardians could make informed decisions regarding their participation. This was disappointing, as the goal was to have their direct perspectives and voices heard. However, this is understandable, given the

potential communications challenges between the researcher and the adults with ASD/ID. As mentioned in Chapter 3, the methods section, good qualitative research demands we build on the strengths of people with disabilities, while understanding their (and our own) limitations (McCarthy, 1998). People with intellectual disability who are recruited as informants may be considered vulnerable if their ability to provide assent is compromised (Robert and Roberts, 1999). Thus, the number of adult participants was limited.

A further limitation was the challenge in finding adults above the age of 40. The original design of this project was to find adults who were considered approaching the “older ages” of ASD. Initially, it was difficult to find this population, as many people in that age cohort were never given the diagnosis of ASD. In fact, several people expressed an interest in the project, but did not have the official diagnosis (although family and caregivers noted their assumption of the adult being on the autism spectrum). Also, once the study was announced, many of the family members of younger participants asked to have their voices heard. Since many of these individuals had other co-morbidities and extensive experience in the healthcare environment, it was determined they should be included in the project.

The characteristics of the study informants may result in some limitations to a broad understanding of healthcare experiences. Interestingly, the guardians/family members in this study were all well-educated people, with both parents and guardians possessing at least a Bachelor’s degree, and many who earned advanced or terminal degrees. It is unknown if the healthcare experiences for those whose family have less education is different from this more highly educated set of informants. Also, socio-economic status of the parent/guardian was not considered as part of this inquiry, thus we are limited in knowing if family socio-economic factors impact access to care or the ability to communicate, advocate for needs or coordinate healthcare services. Finally, the study evaluated two women as part of the study. According to the emerging literature on women with ASD/ID, females seem to have more frequent incidence of chronic illnesses and have shorter life spans than men. It would also be interesting to do a more focused study on women as a single group, separate from men.

Conclusions and Future Work

According to the most recent literature on adults with a combined ASD/ID diagnosis, there is a lack of a coordinated response to ensure the best possible health and social care is

provided to this special population in later life (Lin, Lin Hsu, 2016). This study confirms there seems to be no coordinated planning, including the integration of residential, healthcare and occupational services for this growing population. The opportunity for better understanding, planning and intervention is upon us and must be pursued. Public policy is important to building this integration of services which impact well-being. Further research should guide and enhance public policy changes to create improved coordinated planning programs.

This study presents many opportunities for further research. Several areas warranting additional research include better understanding the healthcare provider relationship (from the provider perspective) with the ASD/ID adults; sharing and spreading best clinical and environmental practices; assessing alternative care settings to prevent injury and reduce emergency room use; exploring expanded use of the medical home concept for adults which has been reasonably successful in pediatrics; conducting longitudinal studies of the impact in using psychotropic medications; and deepening our understanding of how the life course perspective and the neurodiversity movement may apply to the adult ASD/ID population.

The Provider Perspective and Sharing Best Practices

It would be very interesting to learn about the healthcare provider side of this relationship. The studies on healthcare providers thus far report a lack of self-perceived competency by PCPs in treating and diagnosing adults with ASD (Bruder, et al. 2012; Golnik, et al. 2009). There is very limited literature on best practices for optimal compliance and enhanced comfort in the clinical setting for adults with ASD/ID. Some individual physicians are becoming more creative on preventive medical procedures for this population; for example, Mrs. J noted using finger sticks as an effective method for traditional blood draws. Sharing these kinds of approaches would be very helpful to adult medicine practitioners. As more evidenced-based data emerge on “best practices,” finding effective ways to create a dialogue on the treatment of adults with ASD/ID to share these practices will be very helpful in starting this movement to enable improved patient care.

Alternative Care Settings To Prevent Injury and Reduce Emergency Room Use

Also, hospital settings must be better prepared for these adults, especially in the emergency room (ER) and in the operating room (OR). A recent study by Miller (2015)

examined the extent of ASD knowledge among nurses working in an ER and found that about two-thirds of ER nurses surveyed reported having accurate knowledge, correctly identified causes of visit and comorbidities, and chose appropriate interventions for ASD cases. However, nurses still reported having limited knowledge and resources available to them and felt a need for ASD education early on in their training. In addition, adults with ASD are using the ER at higher rates, presumably as they are now entering older age and may have limited access to primary and preventive care. In a very recent study by Vohra, Madhavan and Sambamoorthi (2016), they found the rate of ER visits in the United States more than doubled from 2006 to 2011 (2,549–6,087 per 100,000 admissions). Adults with ASD (all types) visited the ER most often for the following reasons: primary psychiatric disorder, primary non-psychiatric disorder and injury. The study also found the mean total ER charges for adults with ASD were 2.3 times higher than for adults without ASD. As the majority (80 %) of adults with ASD were covered by public health insurance, as compared to one-quarter (25 %) adults without ASD, this finding reflects public payors account for the vast majority of adults with special needs. These special, stressful environments deserve more scrutiny to identify how to optimize treatment and enhance patient care experience. The high costs of the ER environment, plus the high rate of hospitalization after many ER visits, results in expensive healthcare encounters. Could these encounters be better managed in the outpatient environment by enhancing the relationship through medical homes? Also, can injury prevention programs help to reduce these ER visits?

Exploring the Medical Home Concept for Adults with ASD/ID

This study had no participants who were members of a medical home. As mentioned in the literature review, pediatric patient-centered medical homes (PCMH), originally organized to serve special needs children, are now considered the standard of care for all children. Providers who serve as a medical home have demonstrated more comprehensive and coordinated care and greater success at meeting needs when compared to the broader cohort of children and youth with special needs (Volkmar, Paul, Rogers and Pelphrey, 2014). It is surprising, as more Medicaid programs look for ways to reduce cost and improve care that medical homes are not becoming more of a standard model for serving adults with intellectual disabilities. This points to another intersection of opportunity for public policy and research to work together to improve healthcare delivery and potential healthcare outcomes for adults with ASD/ID.

Understanding the Long-Term Impact of Using Psychotropic Medications

The pervasive use of psychotropic medication in the adults under study, and the concern conveyed by all of their caregivers is certainly an area of research which needs more attention. As we learned from our informants, many different drugs are utilized to manage anxiety, depression and behavior for people with ASD/ID. Many participants utilized these medications for nearly their entire life, with very mixed results of improvement in symptoms. Today, the only medications which are approved for children with ASD by the U.S. Food and Drug Administration (FDA) for reducing agitation and irritability are risperidone (brand name Risperdal) and aripiprazole (Abilify). However, both drugs commonly produce significant weight gain, as do many of the other medications our informants mentioned utilizing over time. What are the long-term effects of these medications (most never approved by the FDA for the treatment of ASD symptoms) over the decades? Funding is needed to conduct longitudinal studies to better understand the health impact of psychotropic medications.

Potential Application of Life Course Perspective and the Neurodiversity Movement on Adults with ASD/ID

The life course perspective was fundamental to the design of this project. The stories shared by all of our informants pointed out how life experiences and health evolves across the lifespan for people on the autism spectrum. There is no doubt that a better coordinated and aligned healthcare delivery system is essential to ensuring positive health outcomes. This study noted some positive and negative ways the healthcare delivery system impacted each individual under study. However, the broader perspective of how to positively impact determinants of health should be considered to find ways to improve quality of life experiences. There is some exciting work being led by Dr. Paul Shattuck at the Life Course Outcomes Research Program, part of the A.J. Drexel Autism Institute, the first research organization built around a public health science approach to understanding and addressing the challenges of autism spectrum disorders. As the number of adults with ASD/ID increase exponentially in the next decade, they and their guardians and caregivers will demand improved and expanded choices for all aspects of life, including residential choices, occupational opportunities, healthcare access and community inclusion and acceptance. The neurodiversity movement will also influence these expectations, as many will be advocating for self-determination of their life choices. Public policy makers and

private funding sources need evidence to understand the needs of the ASD/ID population in order to allocate resources and measure the impact of these initiatives. There is an urgent need to explore all of these research areas for the growing number of aging adults with ASD/ID.

Critical disability studies: More and better research

How might researchers answer the call to explore and improve the lives of this growing population? A critical disability studies perspective is absolutely necessary, employing a multidisciplinary and interdisciplinary approach to potentially integrate research efforts to augment our understanding of the lives of the ASD/ID adults. Critical disability studies recognizes that disability is part of the human condition, and that the study of disability has important political, social and economic implications for society as a whole. Through more interdisciplinary research, scholars and advocates may potentially augment the understanding of the lived experience of the combined diagnosis of ASD/ID, as well as recognize ways to remove barriers to good health, thereby reducing illness and suffering. The disciplines of gerontology, medicine, health services research, public health and public policy are just a few of the fields that could collaborate to promote greater awareness of the determinants of health and to advocate for social, political and economic change. As mentioned, the Society for Disability Studies implores professionals to “interrogate the connections between medical practice and stigmatizing disability”, therefore taking on a new paradigm of thinking, employing neurodiversity concepts like self-determination and recognizing the role of key advocates in improving the health and well-being of those with ASD/ID.

REFERENCES

- Ananthanarayan, C., Sigal, M., and Godlewski, W. (1998). General anesthesia for the provision of dental treatment to adults with developmental disability. *Anesthesia Progress*, 45(1), 12.
- Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D. and Charman, T. (2006), Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the special needs and autism project (SNAP), *Lancet*, 368, 210-5.
- Baker, D. L. (2006). Neurodiversity, neurological disability and the public sector: notes on the autism spectrum. *Disability and Society*, 21(1), 15-29.
- Bartlo, P., and Klein, P. J. (2011). Physical activity benefits and needs in adults with intellectual disabilities: systematic review of the literature. *American Journal on Intellectual and Developmental Disabilities*, 116(3), 220-232.
- Bauman, M. L. (2010). Medical comorbidities in autism: challenges to diagnosis and treatment. *Neurotherapeutics*, 7(3), 320-327.
- Bennett, M. (2016). “What is Life Like in the Twilight Years?” A Letter About the Scant Amount of Literature on the Elderly with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 46(5), 1883-1884.
- Berry, J.G, Agrawal, R.K Cohen, E. and Kuo, D.Z. (2013). The landscape of medical care for children with medical complexity. *Overland Park: Children’s Hospital Association*.
- Bishop-Fitzpatrick, L., Minshew, N. J., and Eack, S. M. (2014). A systematic review of psychosocial interventions for adults with autism spectrum disorders. In *Adolescents and Adults with Autism Spectrum Disorders* (pp. 315-327). New York: Springer.
- Blum, R. W., Garell, D., Hodgman, C. H., Jorissen, T. W., Okinow, N. A., Orr, D. P., and Slap, G. B. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions: a position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*, 14(7), 570-576.
- Bruder, M. B., Kerins, G., Mazzeella, C., Sims, J., and Stein, N. (2012). Brief report: The medical care of adults with autism spectrum disorders: Identifying the needs. *Journal of Autism and Developmental Disorders*, 42(11), 2498-2504.
- Caldwell, K. (2014). Dyadic interviewing: a technique valuing interdependence in interviews with individuals with intellectual disabilities. *Qualitative Research*, 14(4), 488–507.
- Capron, A. M. (1999). Ethical and human-rights issues in research on mental disorders that may affect decision-making capacity. *The New England Journal of Medicine*, 340(18), 1430-1434.

- Carbone, P. S., Behl, D. D., Azor, V., and Murphy, N. A. (2010). The medical home for children with autism spectrum disorders: Parent and pediatrician perspectives. *Journal of Autism and Developmental Disorders*, 40(3), 317-324.
- Centers for Disease Control and Prevention. CDC Wonder. <http://wonder.cdc.gov/>. March 2015.
- Chamak, B., Bonniau, B., Jaunay, E., and Cohen, D. (2008). What can we learn about autism from autistic persons? *Psychotherapy and Psychosomatics*, 77(5), 271-279.
- Cheak-Zamora, N. C., and Teti, M. (2014). "You think it's hard now... It gets much harder for our children": Youth with autism and their caregiver's perspectives of healthcare transition Services. *Autism*, 1362361314558279.
- Clark, T. (2010). On 'being researched': why do people engage with qualitative research? *Qualitative Research*, 10(4), 399-419.
- Clarke, P. (2009). Understanding the experience of stroke: a mixed-method research agenda. *The Gerontologist*, gnp047.
- Coppus, A. M. W. (2013). People with intellectual disability: What do we know about adulthood and life expectancy? *Developmental Disabilities Research Reviews*, 18(1), 6-16.
- Coury, D. L., Swedo, S. E., Thurm, A. E., Miller, D. T., Veenstra-VanderWeele, J. M., Carbone, P. S. and Taylor, J. L. (2014). Treating the whole person with autism: The proceedings of the autism speaks national autism conference. *Current Problems in Pediatric and Adolescent Healthcare*, 44(2), 26-47.
- Coyle, C. E., Kramer, J., and Mutchler, J. E. (2014). Aging together: sibling carers of adults with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 11(4), 302-312.
- Creswell, J. W. (2013). *Qualitative inquiry and research design: choosing among five approaches* (3rd Ed.). Los Angeles, CA: Sage Publications.
- Crabtree, B. F., and Miller, W. L. (Eds.). (1999). *Doing qualitative research*. Los Angeles, CA: Sage Publications.
- Croen, L. A., Zerbo, O., Qian, Y., Massolo, M. L., Rich, S., Sidney, S., and Kripke, C. (2015). The health status of adults on the autism spectrum. *Autism*, 19(7), 814-823.
- Davidson, J. (2008). Autistic culture online: virtual communication and cultural expression on the spectrum. *Social and Cultural Geography*, 9(7), 791-806.
- Dresser, R. (1996). Mentally disabled research subjects: The enduring policy issues. *JAMA*, 276(1), 67-72.
- Egan, A. M., Dreyer, M. L., Odar, C. C., Beckwith, M., and Garrison, C. B. (2013). Obesity in young children with autism spectrum disorders: Prevalence and associated factors. *Childhood Obesity*, 9(2), 125-131.

- Elder, G., Jr. (1995). The life course paradigm: Social change and individual development. In G. Moen, G. Elder, and K. Luscher (Eds.), *Examining lives in context* (pp. 101–139). Washington, DC: American Psychological Association.
- Emerson, E., and Hatton, C. (2011). Estimating future need for social care among adults with learning disabilities in England: an update. *Durham: Improving Health and Lives Learning Disability Observatory*.
- Emerson, E., Hatton, C., Hastings, R., Felce, D., McCulloch, A., and Swift, P. (2011). The health of people with autistic spectrum disorders. *Tizard Learning Disability Review*, 16(4), 36-44.
- Erlandson, D.A., Harris, E.L., Skipper, B.L., and Allen, S.D. (1993). Quality criteria for a naturalistic study. In *Doing naturalistic inquiry: A guide to methods* (pp.131-161). Newbury Park, CA: Sage Publications.
- Evenhuis, H., Schoufour, J., and Echteld, M. (2013). Frailty and intellectual disability: A different operationalization? *Developmental Disabilities Research Reviews*, 18(1), 17-21.
- Farley, M. A., McMahon, W. M., Fombonne, E., Jenson, W. R., Miller, J., Gardner, M., ... and Coon, H. (2009). Twenty-year outcome for individuals with autism and average or near-average cognitive abilities. *Autism Research*, 2(2), 109-118.
- Fereday, J., and Muir-Cochrane, E. (2008). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, 5(1), 80-92.
- Ferraro, K. F., and Kelley-Moore, J. A. (2003). Cumulative disadvantage and health: Long-term consequences of obesity. *American Sociological Review*, 68(5), 707.
- Fernhall, B., and Pitetti, K. H. (2001). Limitations to physical work capacity in individuals with mental retardation. *Clinical Exercise Physiology*, 3, 176-185.
- Finlay, W. M., and Lyons, E. (2001). Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychological Assessment*, 13(3), 319.
- Friedlander, A. H., Yagiela, J. A., Paterno, V. I., and Mahler, M. E. (2006). The neuropathology, medical management and dental implications of autism. *The Journal of the American Dental Association*, 137(11), 1517-1527.
- Fujiura, G. T., and Parish, S. L. (2007). Emerging policy challenges in intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 13(2), 188-194.
- Garland-Thomson, R. Feminist Disability Studies, *Signs* 30.2 Winter (2005): 1557-1587.
- George, L. (1993). Sociological perspectives on life transitions. *Annual Review of Sociology*, 19, 353–373.

- Gerhardt, P. F., and Lainer, I. (2011). Addressing the needs of adolescents and adults with autism: A crisis on the horizon. *Journal of Contemporary Psychotherapy*, 41(1), 37-45.
- Ghaziuddin, M., Tsai, L., and Ghaziuddin, N. (1992). Comorbidity of autistic disorder in children and adolescents. *European Child and Adolescent Psychiatry*, 1, 209-213.
- Ghaziuddin, M., Ghaziuddin, N., and Greden, J. (2002). Depression in persons with autism: Implications for research and clinical care. *Journal of Autism and Developmental Disorders*, 32(4), 299-306.
- Goffman, E. (1964) *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs: Prentice Hall.
- Gray, D. E. (2002). 'Everybody just freezes. Everybody is just embarrassed': Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health and Illness*, 24(6), 734-749.
- Grondhuis, S. N. and Aman, M. G. (2014), Overweight and obesity in youth with developmental disabilities: A call to action. *Journal of Intellectual Disability Research*, 58, 787-799.
- Guest, G., Bunce, A., and Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 18(1), 59-82.
- Guh, D. P., Zhang, W., Bansback, N., Amarsi, Z., Birmingham, C. L., and Anis, A. H. (2009). The incidence of co-morbidities related to obesity and overweight: A systematic review and meta-analysis. *BMC Public Health*, 9(1), 1.
- Haas, K., Costley, D., Falkmer, M., Richdale, A., Sofronoff, K., and Falkmer, T. (2016). Factors influencing the research participation of adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 46(5), 1793-1805.
- Happé, F., and Charlton, R. A. (2011). Aging in autism spectrum disorders: A mini-review. *Gerontology*, 58(1), 70-78.
- Hassiotis, A., and Turk, J. (2012). Mental health needs in adolescents with intellectual disabilities: Cross-sectional survey of a service sample. *Journal of Applied Research in Intellectual Disabilities*, 25(3), 252-261.
- Hastings, R. P. (2002). Parental stress and behavior problems of children with developmental disability. *Journal of Intellectual and Developmental Disability*, 27(3), 149-160.
- Haveman, M., Heller, T., Lee, L., Maaskant, M., Shooshtari, S. and Strydom, A. (2010), Major health risks in aging persons with intellectual disabilities: An overview of recent studies. *Journal of Policy and Practice in Intellectual Disabilities*, 7, 59-69.
- Havercamp, Scandlin, and Roth (July-August, 2004), Health disparities of adults with developmental disabilities, adults with other disabilities and those not reporting disability in North Carolina, *Public Health Reports*, 19, 418-426.

- Healthy People 2020 [Internet]. Washington, DC: U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion [Accessed: July 22, 2016]. Available from: [<https://www.healthypeople.gov/2020/about/foundation-health-measures/Determinants-of-Health>].
- Heller, T., and Sorensen, A.. (2013) Promoting healthy aging in adults with developmental disabilities. *Developmental Disabilities Research Reviews* 18(1), 22-30.
- Hertz-Picciotto, I., and Delwiche, L. (2009). The rise in autism and the role of age at diagnosis. *Epidemiology*, 20(1), 84.
- Heslop, P., Blair, P. S., Fleming, P., Hoghton, M., Marriott, A., and Russ, L. (2014). The confidential inquiry into premature deaths of people with intellectual disabilities in the UK: A population-based study. *The Lancet*, 383(9920), 889-895.
- Hillier, S. L., Nugent, R. P., Eschenbach, D. A., Krohn, M. A., Gibbs, R. S., Martin, D. H., ... and McNellis, D. (1995). Association between bacterial vaginosis and preterm delivery of a low-birth-weight infant. *New England Journal of Medicine*, 333(26), 1737-1742.
- Hogan, D. P. (2012). *Family consequences of children's disabilities*. Los Angeles: Russell Sage Foundation.
- Homer, C. J., Klatka, K., Romm, D., Kuhlthau, K., Bloom, S., Newacheck, P., ... and Perrin, J. M. (2008). A review of the evidence for the medical home for children with special healthcare needs. *Pediatrics*, 122(4), e922-e937.
- Howlin, P., Goode, S., Hutton J. and Rutter, S.. (2004) Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*, 45(2), 212-229.
- Hsieh, H. F., and Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277-1288.
- Iacono, T., and Murray, V. (2003). Issues of informed consent in conducting medical research involving people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 16(1), 41-51.
- Johnson, J. (2001). In-depth interviewing. In J.F. Gubrium and J.A. Holstein (Eds.) *Handbook of Interview Research: Context and Method*. London: Sage Publications.
- Kelly, T. B., and Kropf, N. P. (1995). Stigmatized and perpetual parents: Older parents caring for adult children with life-long disabilities. *Journal of Gerontological Social Work*, 24(1-2), 3-16.
- Kleinert, A. and Sheppard-Jones, K., (2014). *Health Matters: From Research to Practice*. The University of Kentucky.
- Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M., and van Dyck, P. C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005–2006. *Pediatrics*, 122(6), e1149-e1158.

- Krahn, G.L., Hammond, L. and Turner, A. (2006), A cascade of disparities: health and healthcare access for people with intellectual disabilities, *Mental Retardation and Developmental Disabilities Research Reviews*, 12, 70-82.
- Lambert, V. A., and Lambert, C. E. (2013). Qualitative descriptive research: An acceptable design. *Pacific Rim International Journal of Nursing Research*, 16(4), 255-256.
- Lewis, M. A., Lewis, C. E., Leake, B., King, B. H., and Lindemann, R. (2002). The quality of health care for adults with developmental disabilities. *Public Health Reports*, 117(2), 174.
- Lifshitz, H., and Merrick, J. (2003). Ageing and intellectual disability in Israel: A study to compare community residence with living at home. *Health and Social Care in the Community*, 11(4), 364-371.
- Lin, J. D., Lin, L. P., and Hsu, S. W. (2016). Aging People with Intellectual Disabilities: Current Challenges and Effective Interventions. *Review Journal of Autism and Developmental Disorders*, 1-7.
- Löe H. Periodontal disease—the sixth complication of diabetes mellitus. (1993) *Diabetes Care*, 16(1), 329-334.
- Lofland, J., and Lofland, L. H. (2006). *Analyzing social settings*. Belmont, CA: Wadsworth Publishing Company.
- Mactavish, J. B., Mahon, M. J., and Lutfiyya, Z. M. (2000). “I can speak for myself”: Involving individuals with intellectual disabilities as research participants. *Mental Retardation*, 38(3), 216-227.
- Magiati, I., Tay, X. W., and Howlin, P. (2014). Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: a systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review*, 34(1), 73-86.
- Mandell, D. S. (2013). Adults with autism—A new minority. *Journal of General Internal Medicine*, 28(6), 751.
- Marks, B., Sisirak, J., and Heller, T. (2010). *Health Matters: The Exercise and Nutrition Health Education Curriculum for People with Developmental Disabilities*. Baltimore: Brookes Publishing Company.
- Matson, J. and Shoemaker, L. (2009). Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities*, 30(6), 1107-1114.
- Mazzone, L., Ruta, L., and Reale, L. (2012). Psychiatric comorbidities in asperger syndrome and high functioning autism: diagnostic challenges. *Annals of General Psychiatry*, 11(1), 1.
- McCarthy, M. (1998). Interviewing people with learning disabilities about sensitive topics: A discussion of ethical issues. *British Journal of Learning Disabilities*, 26(4), 140-145.
- McGhee, A., and Dorsett, P. (2011). Ageing of people with an intellectual disability: Effective training for frontline workers. *Journal of Social Inclusion*, 2(1), 65-82.

- McGrew, K. B., Groger, L., Kunkel, S., and Center, S. G. (2003). *The Costs of Triple Jeopardy: Aging, Developmental Disabilities, and Ohio's Impending Care Shift*. Scripps Gerontology Center, Miami University.
- Medical Home Initiatives for Children with Special Needs Project Advisory Committee. (2002). The medical home. *Pediatrics*, 110(1), 184-186.
- Meekosha, H., & Shuttleworth, R. (2009). What's so 'critical' about critical disability studies?. *Australian Journal of Human Rights*, 15(1), 47-66.
- Melville, C.A. et al. (2008) The prevalence and incidence of mental ill-health in adults with autism and intellectual disabilities. *Journal of Autism and Developmental Disorders*, 38(9), 1676-1688.
- Miller, S. M. (2015). *Nurses caring for adults with autism in an emergency department: A survey of knowledge*. Doctoral Projects. Paper 7. http://scholarworks.sjsu.edu/etd_doctoral/7.
- Miller, W.L., and Crabtree, B.F. (1992). Primary care research: A multimethod typology and qualitative road map. In B.F. Crabtree and W.L. Miller (Eds.), *Doing qualitative research*. Newbury Park, CA: Sage Publications.
- Morse, J. M. (2003). Principles of mixed methods and multimethod research design. In A.M. Tashakkori and C.B Teddlie (EDS.), *Handbook of Mixed Methods in Social and Behavioral Research* (189-208). Thousand Oaks, CA: Sage Publications.
- Mouridsen, S. E. (2013). Mortality and factors associated with death in autism spectrum disorders-A review. *American Journal of Autism*, 1, 17-25.
- Mouridsen, S. E., Brønnum-Hansen, H., Rich, B., and Isager, T. (2008). Mortality and causes of death in autism spectrum disorders an update. *Autism*, 12(4), 403-414.
- Mouridsen, S. E., Rich, B., and Isager, T. (2016). Injury patterns among individuals diagnosed with infantile autism during childhood: A case-control study. *Scandinavian Journal of Child and Adolescent Psychiatry and Psychology*, 4(2), 88-95.
- Mouridsen, S. E., Rich, B., and Isager, T. (2016). Risk of cancer in adult people diagnosed with infantile autism in childhood: A longitudinal case control study based on hospital discharge diagnoses. *Research in Autism Spectrum Disorders*, 23, 203-209.
- Mouridsen, S. E., Rich, B., and Isager, T. (2016). Diseases of the circulatory system among adult people diagnosed with infantile autism as children: A longitudinal case control study. *Research in Developmental Disabilities*, 57, 193-200.
- Mukaetova-Ladinska, E. B., Perry, E., Baron, M., and Povey, C. (2012). Ageing in people with autistic spectrum disorder. *International Journal of Geriatric Psychiatry*, 27(2), 109-118.
- Mukaetova-Ladinska, E. B., and Stuart-Hamilton, I. (2015). Adults with autism spectrum disorder (ASD): Service user perspective on ageing transition (s). *Journal of Autism*, 2(1), 1-11.

- Myers, S. M., and Johnson, C. P. (2007). Management of children with autism spectrum disorders. *Pediatrics*, 120(5), 1162-1182.
- Nebel-Schwalm, M., and Worley, J. (2014). Other Disorders Frequently Comorbid with Autism. In Thompson E. Davies, III, Susan B. White, and Thomas Ollendick (Eds.), *Handbook of Autism and Anxiety* (pp. 47-60). New York: Springer International Publishing.
- Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Boisclair, W. C., Ashkenazy, E., and Baggs, A. (2013). Comparison of healthcare experiences in autistic and non-autistic adults: A cross-sectional online survey facilitated by an academic-community partnership. *Journal of General Internal Medicine*, 28(6), 761-769.
- Noy, C. (2008). Sampling knowledge: The hermeneutics of snowball sampling in qualitative research. *International Journal of Social Research Methodology*, 11(4), 327-344.
- Olivie, H., 2012. The medical care of children with autism. *European Journal of Pediatrics*, 171, 741-749.
- Orsmond, G. I., and Seltzer, M. M. (2007). Siblings of individuals with autism spectrum disorders across the life course. *Mental Retardation and Developmental Disabilities Research Reviews*, 13(4), 313-320.
- Ortega, F. (2009). The cerebral subject and the challenge of neurodiversity. *BioSocieties*, 4(4), 425-445.
- Pan, C., and Frey, G.(2006). Physical activity patterns in youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 36(5), 597-606.
- Park, S. Y., Cervesi, C., Galling, B., Molteni, S., Walyzada, F., Ameis, S. H., ... and Correll, C. U. (2016). Antipsychotic Use Trends in Youth With Autism Spectrum Disorder and/or Intellectual Disability: A Meta-Analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*, 55(6), 456-468.
- Patel, Dilip R., et al. Developmental disabilities across the lifespan. *Disease-a-Month* 56.6 (2010): 05-397.7. Protection of Human Subjects.
- Patton, M. Q. (2002). Fieldwork strategies and observation methods. In Michael Q. Patton (Ed.), *Qualitative research and evaluation methods* (pp. 259-338). Thousand Oaks, CA: Sage Publications.
- Perkins, E. A., and Berkman, K. A. (2012). Into the unknown: Aging with autism spectrum disorders. *American Journal on Intellectual and Developmental Disabilities*, 117(6), 478-496.
- Perkins, E. A., and Moran, J. A. (2010). Aging adults with intellectual disabilities. *JAMA*, 304(1), 91-92.
- Perry, J. (2004). Interviewing people with intellectual disabilities. In E. Emerson, C. Hatton, T. Thompson and T. Parmenter (Eds.), *The international handbook of applied research in intellectual disabilities*, (115-132). Chichester, England: John Wiley and Sons.

- Pessah, I.N., Seegal, R.F., Lein, P.J., LaSalle, J., Yee, B.K., van de Water, J. and Berman, R.F. (2008), Immunologic and neurodevelopmental susceptibilities of autism, *Neuro toxicology*, 29, 532-45.
- Pies, C., and Kotelchuck, M. (2014). Bringing the MCH life course perspective to life. *Maternal and Child Health Journal*, 18(2), 335.
- Piven, J., and Rabins, P. (2011). Autism spectrum disorders in older adults: toward defining a research agenda. *Journal of the American Geriatrics Society*, 59(11), 2151-2155.
- Richards, L., and Morse, J. M. (2012). *Read me first for a user's guide to qualitative methods*. London: Sage Publications.
- Roberts, L. W., and Roberts, B. (1999). Psychiatric research ethics: an overview of evolving guidelines and current ethical dilemmas in the study of mental illness. *Biological psychiatry*, 46(8), 1025-1038.
- Robertson, J., Emerson, E., Gregory, N., Hatton, C., Turner, S., Kessissoglou, S., and Hallam, A. (2000). Lifestyle related risk factors for poor health in residential settings for people with intellectual disabilities. *Research in developmental disabilities*, 21(6), 469-486.
- Roulston, K. (2010). Asking questions and individual interviews. In *Reflective Interviewing: A Guide to Theory and Practice*, (pp. 9-32). London: Sage Publishing. Retrieved from http://www.sagepub.com/upm-data/32446_02_Roulston_Ch_01.pdf
- Scully, C. (2000). Oral Health in America: A Report of the Surgeon General (Executive Summary). (n.d.). Retrieved August 22, 2016, from <http://nidcr.nih.gov/DataStatistics/SurgeonGeneral/Report/ExecutiveSummary.htm>
- Seltzer, M., Greenberg, J., Floyd, F., Pettee, Y. and Hong, J. (2001). Life course impacts of parenting a child with a disability. *American Journal on Mental Retardation*, 106(3).
- Seltzer M., Greenberg J and Hong J. (2010). Maternal cortisol levels and child behavior problems in families of adolescents and adults with ASD. *Journal of Autism Developmental Disorders*. 40, 457–469.
- Seltzer, M., Greenberg, J., Orsmond, G. and Lounds, J. (2005). Life course studies of siblings of individuals with developmental disabilities. *Mental Retardation*, 43(5), 354-359.
- Shabani, D. B., and Fisher, W. W. (2006). Stimulus fading and differential reinforcement for the treatment of needle phobia in a youth with autism. *Journal of Applied Behavior Analysis*, 39, 449–452.
- Shavelle, R., Strauss, D., and Pickett, J. (2001). Causes of death in autism. *Journal of Autism and Developmental Disorders*, 31(6), 569-576.
- Shattuck P.T., Narendorf, S.C., Cooper, B., et al. (2012). Postsecondary education and employment among young with an autism spectrum disorder. *Pediatrics*. 129, 1042–1049.

- Shields, P. and Tajalli, H. (2006). Intermediate theory: The missing link in successful student scholarship. *Journal of Public Affairs Education*, 12(3), 313-334.
- Silverman, C. (2008). Fieldwork on another planet: social science perspectives on the autism spectrum. *BioSocieties*, 3(3), 325-341.
- Silverman, W., Zigman, W., Kim, H., Krinsky-McHale, S., and Wisniewski, H. (1998). Aging and dementia among adults with mental retardation and down syndrome. *Topics in Geriatric Rehabilitation*, 13(3), 49-64.
- Sinclair, J. (1993). Don't mourn for us. First published in the Autism Network International newsletter, Our Voice, 1. URL (accessed May 2015): http://ani.autistics.org/dont_mourn.html.
- Singh, J., Illes, J., Lazzeroni, L., and Hallmayer, J. (2009). Trends in US autism research funding. *Journal of Autism and Developmental Disorders*, 39(5), 788-795.
- Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., and Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry*, 47(8), 921-929.
- Smith, L., Greenberg, J., and Mailick, M. (2012). Adults with autism: Outcomes, family effects, and the multi-family group psychoeducation model. *Current Psychiatry Reports*, 14(6), 732-738.
- Spence, S., and Schneider, M. (2009). The role of epilepsy and epileptiform EEGs in autism spectrum disorders. *Pediatric Research*, 65(6), 599-606.
- Stevenson, J., Harp, B., and Gernsbacher, M. (2011). Infantilizing autism. *Disability Studies Quarterly*, 31(3).
- Sullivan, W., Heng, J., Cameron, D., Lunskey, Y., Cheetham, T., Hennen, B., ... and Swift, I. (2006). Consensus guidelines for primary healthcare of adults with developmental disabilities. *Canadian Family Physician*, 52(11), 1410-1418.
- Swift, P. (2008). Morbidity and Mortality in Autism: A Research Development Paper. *Foundation for People with Learning Disabilities, London*.
- Taylor, S. J., and Bogdan, R. (1998). In-depth interviewing. *Introduction to Qualitative Research Methods*, 3, 87-116.
- Taylor, J. L., and Seltzer, M. M. (2011). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders*, 41(5), 566-574.
- The American Association of Family Practitioners, (October 15, 2014). Primary Care. Retrieved from <http://www.aafp.org/about/policies/all/primary-care.html>.
- Tregnago, M., and Cheak-Zamora, N. (2012). Systematic review of disparities in healthcare for *Spectrum Disorders*, 6(3), 1023-1031.

- Trost, J.E. (1986). Statistically non-representative stratified sampling: A sampling technique or qualitative studies. *Qualitative Sociology*, 9, 54-57.
- Tyler, C., Schramm, S., Karafa, M., Tang, A., and Jain, A. (2011). Chronic disease risks in young adults with autism spectrum disorder: Forewarned is forearmed. *American Journal on Intellectual and Developmental Disabilities*, 116(5), 371-380.
- Tsakanikos, E., Costello, H., Holt, G., Sturmey, P., and Bouras, N. (2007). Behaviour management problems as predictors of psychotropic medication and use of psychiatric services in adults with autism. *Journal of Autism and Dev. Disorders*, 37(6), 1080-1085.
- U.S. Department of Health and Human Services. Office of Disease Prevention and Health Promotion. Healthy People 2020. Washington, DC. Available at [<http://www.healthypeople.gov/2020/about/foundation-health-measures/General-Health-status>]. Accessed [May 22, 2015].
- Vohra, R., Madhavan, S., and Sambamoorthi, U. (2016). Emergency department use among adults with autism spectrum disorders (ASD). *Journal of Autism and Developmental Disorders*, 46(4), 1441-1454.
- Volkmar, F. R., Paul, R., Rogers, S. J., and Pelphrey, K. A. (Eds.). (2014). *Handbook of autism and pervasive developmental disorders, : Diagnosis, development, and brain mechanisms* (Vol. I). Hoboken, New Jersey: John Wiley and Sons.
- van Engeland, H. and Buitelaar, J.K. (2008), “Autistic spectrum disorders”, in Rutter, M., Bishop, D., Pine, D., Scott, S., Stevenson, J., Taylor, E. and Thapar, A. (Eds.), *Rutter’s Child and Adolescent Psychiatry*, Blackwell, Oxford.
- What are Disability Studies? (2016). Retrieved November 22, 2016, from <http://disstudies.org/index.php/about-sds/what-is-disability-studies/>
- White, S. W., and Roberson-Nay, R. (2009). Anxiety, social deficits, and loneliness in youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 39(7), 1006-1013.
- Woolfenden, S., Sarkozy, V., Ridley, G., Coory, M., and Williams, K. (2012). A systematic review of two outcomes in autism spectrum disorder—epilepsy and mortality. *Developmental Medicine and Child Neurology*, 54(4), 306-312.
- Wu, T., Trevisan, M., Genco, R. J., Dorn, J. P., Falkner, K. L., and Sempos, C. T. (2000). Periodontal disease and risk of cerebrovascular disease: the first national health and nutrition examination survey and its follow-up study. *Archives of Internal Medicine*, 160(18), 2749-2755.

Appendix A: INFORMED CONSENT (Guardian who will participate in Interview)

Project: AUTISM SPECTRUM DISORDERS AND THE HEALTHCARE EXPERIENCES OF OLDER ADULTS

The goal of this research study is to describe the experiences of adults with Autism Spectrum Disorders (ASD) and their caregivers in navigating the healthcare system to receive primary healthcare services. We hope that an understanding of these experiences will lead to more responsive interactions for people with ASD in the healthcare system and improved healthcare coordination between primary care physicians and specialists.

Investigator: The research project is being conducted by Karen Kent, a Graduate student in the Social Gerontology PhD Program, at Miami University of Ohio under the supervision of Dr. Suzanne Kunkel and Dr. Kate de Medeiros. Karen was a healthcare administrator prior to teaching full-time at Xavier University in the Department of Health Services Administration. Karen is also the mother of a 17-year-old son who is diagnosed with ASD and Intellectual Disabilities.

Description of Participation: As a volunteer, you will first be asked to fill out a short demographic form which will provide basic information about you and the person you care for. This information will be helpful to guide our interview. You will also be asked to provide some information regarding adaptive abilities using the Vineland II test. Next, you will be interviewed for approximately one hour by the researcher, Karen Kent. The interviews will be audio-recorded by the researcher and later transcribed for the purpose of data analysis. The interviews will be conducted at a place that is convenient for you. Also, the information generated during the study will remain confidential and will solely be used for the purpose of the study. To protect privacy and identity, we will not use real names when reporting the findings of the study. Any information you share with me will be treated as confidential information, stored in a secure location for the duration of the project, accessed only by myself, and destroyed after the data has been analyzed.

Length of Participation: The time to fill out the forms will take about 45 minutes. The interview will last for approximately one hour, depending on how much information you would like to share. It may be necessary to have more than one interview session if you decide to stop and finish at another time. For the adult with Autism, the interview will be shorter, and will last approximately fifteen minutes. You will be present for that interview.

Risks and Benefits of Participation: There are no benefits to participating, although some people enjoy the opportunity to share and discuss their experiences. There are no real risks from participation in the study, but you may feel uncomfortable recalling stories or sensitive issues related to family or experiences. Each participant will receive a \$25 gift card or cash for your time in participating in the interview(s).

Volunteer Statement: You are a volunteer. The decision to participate in this project is completely up to you. If you decide to be in the study, you may stop at any time. You will not be treated any differently if you decide not to participate or if you stop once you have started. You do not need to answer questions that bother you.

Fair Treatment and Respect: Miami University wants to make sure that you are treated in a fair and respectful manner. Contact the University's Institutional Review Board (IRB) at humansubjects@miamiOH.edu or 1-513-529-3600, if you have any questions about how you are treated as a study participant. If you have any questions about the project, please contact *Karen Kent*, (513) 319-7939 or by email at kentke@miamiOH.edu., or *Dr. Suzanne Kunkel* (513) 529-2914, or by email at kunkels@miamiOH.edu.

Participant Consent:

Participant Name (PRINT)

Date

Participant Signature

Date

Investigator Signature

Date

I authorize the audiotape of this interview ☐ Yes ☐ No

Original form to: Research File

Copy to participant and caregiver

Miami IRB approval 01075r

Appendix B: INFORMED CONSENT (Legal Guardian who will not participate in Interview, but must provide consent for participation)

Project: AUTISM SPECTRUM DISORDERS AND THE HEALTHCARE EXPERIENCES OF OLDER ADULTS

The goal of this research study is to describe the experiences of adults with Autism Spectrum Disorders (ASD) and their caregivers in navigating the healthcare system to receive primary healthcare services. We hope that an understanding of these experiences will lead to more responsive interactions for people with ASD in the healthcare system and improved healthcare coordination between primary care physicians and specialists.

Investigator: The research project is being conducted by Karen Kent, a Graduate student in the Social Gerontology PhD Program, at Miami University of Ohio under the supervision of Dr. Suzanne Kunkel and Dr. Kate de Medeiros. Karen was a healthcare administrator prior to teaching full-time at Xavier University in the Department of Health Services Administration. Karen is also the mother of a 17-year-old son who is diagnosed with ASD and Intellectual Disabilities.

Description of Participation: As a guardian, you are asked to provide consent for the adult with autism to participate in this study. Although you are not participating in the interview, you are authorizing via this consent to allow the adult you are responsible for to participate. The person who accompanies the adult to their physician's visit will also be asked for consent for their participation and will be asked to provide data for the Vineland II test for adaptive behaviors. The information generated during the study will remain confidential and will solely be used for the purpose of the study. To protect privacy and identity, we will not use real names when reporting the findings of the study. The demographic form and interview information will be treated as confidential information, stored in a secure location for the duration of the project, accessed only by myself, and destroyed after the data has been analyzed.

Length of Participation: The interview with the adult with diagnosis of ASD will last for approximately fifteen minutes, depending on how much information they would like to share. The caregiver interview will last approximately one hour, with extra time needed to fill out a demographic form and Vineland II test. It may be necessary to have more than one interview session if the caregiver decides to stop and finish at another time.

Risks and Benefits of Participation: There are no benefits to participating, although some people enjoy the opportunity to share and discuss their experiences. There are no real risks from participation in the study, but the interviewee may feel uncomfortable recalling stories or sensitive issues related to family or experiences. Each participant will receive a \$25 gift card or cash for their time in participating in the interview(s).

Volunteer Statement: Participations are volunteers in this study. The decision to authorize participation in this project must be made by you, in order for the adult to participate. If anyone decides to be in the study, they may stop at any time.

Fair Treatment and Respect: Miami University wants to make sure participants are treated in a fair and respectful manner. Contact the University's Institutional Review Board (IRB) at humansubjects@miamiOH.edu or 1-513-529-3600, if you have any questions about how you are treated as a study participant. If you have any questions about the project, please contact

Karen Kent, (513) 319-7939 or by email at kentke@miamiOH.edu., or *Dr. Suzanne Kunkel* (513) 529-2914, or by email at kunkels@miamiOH.edu.

Participant Consent:

Participant Name (PRINT)

Date

Participant Signature

Date

Investigator Signature

Date

I authorize the audiotape of this interview ☐ Yes ☐ No

Original form to: Research File

Copy to participant and caregiver

Miami IRB approval 01075r

Appendix C: INFORMED CONSENT (Caregivers who are not Legal Guardians)

Project: AUTISM SPECTRUM DISORDERS AND THE HEALTHCARE EXPERIENCES OF OLDER ADULTS

The goal of this research study is to describe the experiences of adults with Autism Spectrum Disorders (ASD) and their caregivers in navigating the healthcare system to receive primary healthcare services. We hope that an understanding of these experiences will lead to more responsive interactions for people with ASD in the healthcare system and improved healthcare coordination between primary care physicians and specialists.

Investigator: The research project is being conducted by Karen Kent, a Graduate student in the Social Gerontology PhD Program, at Miami University of Ohio under the supervision of Dr. Suzanne Kunkel and Dr. Kate de Medeiros. Karen was a healthcare administrator prior to teaching full-time at Xavier University in the Department of Health Services Administration. Karen is also the mother of a 17-year-old son who is diagnosed with ASD and Intellectual Disabilities.

Description of Participation: As a volunteer, you will first be asked to fill out a short demographic form which will provide basic information about you and the person you care for. You will also be asked to provide some information regarding adaptive abilities using the Vineland II test. Next, you will be interviewed for approximately one hour by the researcher, Karen Kent. The interviews will be audio-recorded by the researcher and later transcribed for the purpose of data analysis. The interviews will be conducted at a place that is convenient for you. Also, the information generated during the study will remain confidential and will solely be used for the purpose of the study. To protect privacy and identity, we will not use real names when reporting the findings of the study. The demographic form and interview information will be treated as confidential information, stored in a secure location for the duration of the project, accessed only by myself, and destroyed after the data has been analyzed.

Length of Participation: The time to fill out the forms will take about 45 minutes. The interview will last for approximately one hour, depending on how much information you would like to share. It may be necessary to have more than one interview session if you decide to stop and finish at another time. For the adult with Autism, the interview will be shorter, and will last approximately fifteen minutes. You will be present for that interview.

Risks and Benefits of Participation: There are no benefits to participating, although some people enjoy the opportunity to share and discuss their experiences. There are no real risks from participation in the study, but you may feel uncomfortable recalling stories or sensitive issues related to family or experiences. Each participant will receive a \$25 gift card or cash for your time in participating in the interview(s).

Volunteer Statement: You are a volunteer. The decision to participate in this project is completely up to you. If you decide to be in the study, you may stop at any time. You will not be treated any differently if you decide not to participate or if you stop once you have started. You do not need to answer questions that bother you.

Fair Treatment and Respect: Miami University wants to make sure that you are treated in a fair and respectful manner. Contact the University's Institutional Review Board (IRB) at

humansubjects@miamiOH.edu or 1-513-529-3600, if you have any questions about how you are treated as a study participant. If you have any questions about the project, please contact *Karen Kent*, (513) 319-7939 or by email at kentke@miamiOH.edu., or *Dr. Suzanne Kunkel* (513) 529-2914, or by email at kunkels@miamiOH.edu.

Participant Consent:

Participant Name (PRINT)

Date

Participant Signature

Date

Investigator Signature

Date

I authorize the audiotape of this interview ☐ Yes ☐ No

Original form to: Research File

Copy to participant and caregiver

Miami IRB approval 01075r

Appendix D: INFORMED ASSENT

Project: AUTISM SPECTRUM DISORDERS AND THE HEALTHCARE EXPERIENCES OF OLDER ADULTS

What is a research study?

Research studies help us learn new things. We can test new ideas. First, we ask a question. Then we try to find the answer.

This paper talks about our research and the choice that you have to take part in it. We want you to ask us any questions that you have. You can ask questions any time.

Important things to know...

- You get to decide if you want to take part by speaking to the researcher, Karen Kent.
- You can say 'No' or you can say 'Yes'.
- No one will be upset if you say 'No'.
- If you say 'Yes', you can always say 'No' later.
- You can say 'No' at any time.

Why are we doing this research?

We are doing this research to find out more about what it is like when you go to your doctor as a person with autism.

What would happen if I join this research?

If you decide to be in the research, we would ask you to do the following:

- Speak to Karen Kent about your experiences at the primary doctor's office (your family physician)
- Allow your family member/parent to speak to me about your experience at the doctor's office.

Could bad things happen if I join this research?

Some of the questions might make you uncomfortable or the questions might be hard to answer. We will try to make sure that you are comfortable.

Could the research help me?

This research will not help you at the doctor's office. We do hope to learn something from this research though that will help other people when they visit the doctor's office.

What else should I know about this research?

If you don't want to be in the study, you don't have to be.

It is also OK to say yes and change your mind later. You can stop being in the research at any time. If you want to stop, please tell Karen Kent, and she will stop the interview.

To thank you for being in the study, we will give you a \$25 gift card or \$25 in cash. You can choose if you want a gift card from a store, a restaurant or from Amazon.

You can ask questions any time. If you would like to talk to my supervisor, I can put you in touch with her.

Is there anything else?

If you want to be in the research after we talk, please write your name below. I will sign my name as well. This shows we talked about the research and that you want to take part.

Participant Assent: (mandatory - to be recorded verbally)

Optional Participant Assent signature:

Participant Name (PRINT)

Date

Participant Signature

Date

Investigator Signature

Date

Miami University wants to make sure that you are treated in a fair and respectful manner. Contact the University's Institutional Review Board (IRB) at humansubjects@miamioh.edu or 1-513-529-3600, if you have any questions about how you are treated as a study participant.

If you have any questions about the project, please contact Karen Kent, (513) 319-7939 or by email at kentke@miamioh.edu, or Dr. Suzanne Kunkel (513) 529-2914, or by email at kunkels@miamoh.edu.

Original form to: Research File

Copy to participant and caregiver

Miami IRB approval 01075r

Appendix E: RECRUITMENT ANNOUNCEMENT: KAREN KENT

AUTISM SPECTRUM DISORDERS (ASD) AND THE HEALTHCARE EXPERIENCES OF AGING ADULTS

- **What** ◇ This dissertation research project is being conducted by Karen Kent, a doctoral student in Social Gerontology at Miami University and mother of a 17-year-old son with autism. This research is about the experiences of middle age and older adults with Autism Spectrum Disorders (ASD) and their caregivers in navigating the healthcare system to receive primary care services. Very little research is known about what it is like for our loved ones with ASD to go to the doctor.
- **Who** ◇ Adults with a combined diagnosis of ASD and Intellectual disabilities who are at least age 40, along with their caregivers who (participate/live/etc.) at _____ (name of organization/group). The caregiver is the person who coordinates and supervises their loved one's healthcare. You will be asked to fill out a form and participate in an interview. You will be compensated \$25 in cash or a gift card for your time (the adult with ASD and the caregiver, each).
- **Where** ◇ Karen will be happy to meet with you at your home or any familiar or convenient location for you and your loved one.
- **When** ◇ Adults and caregivers will be interviewed as part of this study. Adults will have a short interview (15 minutes) and caregivers will have a one hour interview. These interviews will be conducted at your convenience.

For more information: Please contact Karen Kent at 513-319-7939 or kentke@miamioh.edu. Miami University wants to make sure that you are treated in a fair and respectful manner. Contact the University's Institutional Review Board (IRB) at humansubjects@miamiOH.edu or 1-513-529-3600, if you have any questions about how you are treated as a study participant.

Appendix F: IRB APPROVAL

OFFICE FOR THE ADVANCEMENT OF
RESEARCH AND SCHOLARSHIP (OARS)
Institutional Review Board for
Human Subjects Research
102 Roubush Hall
Oxford, OH 45056
513-529-3600

Date: October 15, 2015

To: Ms. Karen E. Kent, Dr. Susan Kunkel

From: Dr. L. James Smart, Jr., Chair
Institutional Review Board for Human Subjects Research

RE: *Visual Cognition and Event Related Potentials*

Thank you for submitting the application referenced above to the Institutional Review Board (IRB).

The board has reviewed and approved your proposal through the regulatory Expedited Review procedure.

Your protocol approval number is: 01075r

Approval of this project is in effect until: October 14, 2016

If you complete your project before the date listed above, please send an email message indicating so to humansubjects@miamiOH.edu and we will close your file.

Regulations require periodic review of all ongoing human subjects research projects. If your project will continue beyond the approval date shown above, you will need to submit an Application for Continuing Review and status update for review before the expiration date.

Please submit your next application for continuing review by: September 14, 2016

Should you wish to change your procedures relating to the use of human subjects or personnel having access to the data, you must obtain approval from the IRB prior to instituting any changes.

On behalf of the committee and the University, I thank you for your efforts to conduct your research in compliance with the federal regulations that have been established for the protection of human subjects. Thank you for your attention to this matter, and best wishes for the success of your project.

Appendix G: DRAFT INTERVIEW GUIDE FOR Caregivers

Project: AUTISM SPECTRUM DISORDERS AND THE HEALTHCARE EXPERIENCES OF OLDER ADULTS

Specific Aim #1

1. How did you find your primary care physician (PCP)? Who did you ask to provide you with recommendations? Has (your loved one) always seen this doctor or have there been other primary care doctors?
2. When you think about healthcare, who among your healthcare providers – doctors, nurses, other staff members – “gets” your (loved one) the most. In other words, who seems to really know what they need when you come for a visit. Can you give me an example?
3. Tell me about your (loved one’s) last doctor’s office visit. How did you make the appointment? How did you prepare to go? How did they feel prior to the appointment? What was it like when you first came to the appointment? What was the experience like in the waiting room and waiting for the doctor in the exam room? How did their doctor greet you?continue questions/prompt throughout the course of a typical appointment
4. Give me an example/story how their doctor seems to understand autism. Give me an example/story how your doctor does not understand autism.
5. How do you explain autism to your PCP? How do you as the caregiver explain autism or interpret the needs of the adults to the PCP and office staff?
6. How does the office staff at your physician’s office work with you on meeting your (loved one’s) needs? Tell me about some of those experiences in the waiting room; in making appointments; in renewing prescriptions; in seeking specialty referrals?
7. Tell me about a time when things went well in your appointment.
8. Tell me about a time when things did not go well in your appointment.

Specific Aim #2

9. How does your doctor help explain your medical needs to other referring doctors or healthcare professionals (i.e. therapists, mental health professionals, etc.)? Does your doctor explain your autism needs to other healthcare workers?
10. How does your doctor help to coordinate your healthcare information with other specialists? How do you feel about sharing information about autism/special needs with new healthcare providers?

11. Have you ever experienced any breakdowns or contradictions in medical advice among your healthcare providers? Tell me about one of those experiences.
12. What was your experience in transition from the pediatric provider to the adult provider? What did the pediatric office do to make you comfortable in the office environment?

Specific Aim #3

13. Are there things in the doctor's office environment that irritate your loved one or make them feel uncomfortable such as sounds, smells, textures, equipment, and lighting?
14. Do you (the caregiver) do anything in advance of the doctor's appointment to prepare (the adult) for the visit? Do you use any motivators to get them through the visit (behavioral supports)? Does the physician offer any supports or motivators?

Other potential questions:

15. Have you ever felt like you were treated differently because of your age, good or bad? How so?
16. Have you ever felt like you were treated differently because of your autism, good or bad? How so?
17. Do you get to see your physician as often as you might like?
18. Preventive healthcare: How does your doctor talk about preventive healthcare, like exercise, diet and other kinds of prevention with you (define this based on gender)? Do you think these are important to your health?

Appendix H: DRAFT INTERVIEW GUIDE FOR ADULTS

Project: AUTISM SPECTRUM DISORDERS AND THE HEALTHCARE EXPERIENCES OF OLDER ADULTS

Specific Aim #1

1. What do you like about going to the doctor's office?
2. What do you not like about going to the doctor's office?
3. Tell me about a time when things went well at the doctor's office
4. Tell me about when things did not go well at the doctor's office.
5. What do you do first to prepare to go to the doctor the day of our visit? What happens next (and so on)?

Specific Aim #2

6. Tell me about what it is like when your doctor sends you to another doctor for a certain health issue.

Specific Aim #3

7. Are there things in the doctor's office environment that irritate you or make you feel uncomfortable such as sounds, smells, textures, equipment, and lighting?
8. Are there things that you look forward to when you visit the doctor?

Appendix I: DEMOGRAPHIC FORM

Project: AUTISM SPECTRUM DISORDERS AND THE HEALTHCARE EXPERIENCES OF OLDER ADULTS

Please note: You may skip any questions on this form if you do not want to share this information

Personal Data

1. Date of Consent (MM/DD/YY): _____
2. Subject Number identifier: _____
3. Caregiver Number identifier: _____
4. Subject Location of Residence
City: _____ State: _____ Zip Code: _____
5. Location of Interview: _____
6. Interview Date (MM/DD/YY): _____
7. **Caregiver:** Date of Birth (MM/DD/YY): _____
Sex: Male (code=0) Female (code=1)
Race: White (=1) Black or African American (=2) Asian (=3)
Native American/Alaska Native (=4) Hispanic (=5) Other (=6)

8. Relationship with Adult: Parent (=1) Sibling (=2) Spouse (=3)
Other Family Relation (=4) Friend (=5) Appointed Guardian (=6)

Questions 9-21 are focused on ASD Adult:

9. **ASD Adult:** Date of Birth (MM/DD/YY): _____
Sex: Male (code=0) Female (code=1)
Race: White (=1) Black or African American (=2) Asian (=3)
Native American/Alaska Native (=4) Hispanic (=5) Other (=6)

10. Age of Diagnosis of Autism: Early Childhood (age 1-3) Preschool (3-5) Primary (5-10)
Middle School (10-14) High School (14-18) Adult (18+) Unsure
11. Does the adult with ASD also have an intellectual disability? Yes/No
Please rate the level of intellectual disability:
☐ Low ☐ Medium ☐ Severe ☐ Profound

12. Please indicate all other health concerns:

- ☐ Asthma ☐ Blood Pressure ☐ Cholesterol ☐ Diabetes ☐ Epilepsy
☐ Dietary Restrictions ☐ GI Issues ☐ Mental Health ☐ Sleep Issues ☐ Dental
☐ Other _____

13. Financial status:

- ☐ More than enough resources ☐ Just enough ☐ Barely Getting By ☐ Financial Emergency

14. Health Insurance Type (Check all that apply)

- ☐ Medicare ☐ Medicaid ☐ Commercial (employer) ☐ other ☐ Don't know

15. Do you have a dedicated Primary Care Provider (i.e. Do you see the same doctor on each visit?)

- ☐ Dedicated Primary Care Physician ☐ No ☐ Don't know

16. Please check all the specialists that you see on a regular basis:

- ☐ Cardiology ☐ Developmental Disabilities ☐ Allergy ☐ Neurology ☐ Rheumatology
☐ Sleep Problems ☐ Pulmonology ☐ ENT/Hearing ☐ Ophthalmology ☐ Urology
☐ Dermatology ☐ Psychology ☐ Surgery ☐ OB/GYN ☐ Endocrinology ☐ Other

Therapies _____

17. Have you ever been hospitalized? ☐ Yes ☐ No ☐ Do not recall

18. What is your highest level of education? ☐ No HS Diploma ☐ HS Diploma ☐ Some College
☐ College graduate

19. ASD Adult: How would you rate your current health status? ☐ Good ☐ Fair ☐ Poor ☐ Don't know

20. Have you had the following preventive screenings? ☐ Cholesterol ☐ Blood Pressure ☐
Urinalysis ☐ BMI ☐ Pap Smear/Pelvic ☐ Prostate ☐ Mammogram ☐ Colon Cancer

21. Where do you currently live on a usual basis? ☐ at family home ☐ Live independently ☐ Live independently with support ☐ Group Home ☐ Nursing Home/Assisted Living ☐ Other arrangement

Questions 22-23 are focused on the caregiver

22. Caregiver: What is your highest level of education? ☐ No HS Diploma ☐ HS Diploma ☐ Some College ☐ College graduate ☐ Graduate School Education

23. Caregiver: How would you rate your current health status? ☐ Good ☐ Fair ☐ Poor ☐ Don't know

24. Do you use the same primary care physician? ☐ Yes ☐ No

25. Do you provide any caregiving support for others? ☐ Yes ☐ No

26. If yes to question 25, indicated those that you support ☐ Spouse ☐ Child ☐ Sibling ☐ Parent
☐ Friend