EVALUATION OF COUNTY SERVICES FOR CAREGIVERS OF ADULTS WITH DEVELOPMENTAL DISABILITIES

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ABSTRACT

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The population of adults with developmental disabilities (DD) that are living within their families’ homes has been on the rise in recent years. With more than 75% of these adults living with their parents, the caregiving time span is increasing into the later adult lives for these parents (Braddock, 1999). As caregivers age, many will experience health declines and declines in their ability to perform daily tasks. Many of these parents also face financial hardships in order to provide the necessary care that their adult children require (Heller, Caldwell, & Factor, 2007). It is important to understand the issues faced by caregivers in order to better assist them with their daily needs.

County services are currently available to help caregiving parents whose children have developmental disabilities. Despite the availability of these programs, there are many barriers to accessing them. Future care planning has become one of the most commonly sought after services in recent years. According to Heller and Factor (1993) future planning includes plans such as financial, legal, living arrangements, and supports. Lack of knowledge and limited resources prevent many caregivers from making future plans for their adult children (Heller, Caldwell, & Factor, 2007).

The purpose of this study was to determine whether county services for individuals with DD in Wood County Ohio are being utilized by the caregivers that they intend to assist and how frequently services are being used. This was accomplished by sending a survey to caregivers whose adult children are using services provided by Wood Lane. The responses were categorized based on frequency of responses. Caregivers were primarily mothers and sisters were one of the most frequently chosen to take over care responsibilities. Overall, caregivers have made some
future care plans and feel at least somewhat prepared to deal with the future. Caregivers also need more assistance with education, training, respite, and family support services. In conclusion, there are areas where the county and providers can make improvements to better serve the individuals within the community.
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CHAPTER I. INTRODUCTION

Parents of children with Developmental Disabilities (DD) face unique challenges that parents of children without disabilities often do not face. For example, the caring time span for a parent of a child without disabilities is often around eighteen years. For parents of developmentally disabled children, the time span is much longer. The lifespan with for those with DD has been steadily increasing due to medical advancements and this in turn has required additional time for families to be involved in providing care (Sterns & Ansello, 2008). Today, many people with developmental disabilities can expect to outlive their parents. The possibility of their children outliving them and the associated fear can create stress for many caregivers (Dillenburger & McKerr, 2010). In addition to longer lifespan, the living situation for individuals with disabilities has changed over the past decades. Children with DD were previously institutionalized and thus their parents did not participate in their direct care (Pollack, 2011).

Currently, the vast majority of individuals with developmental disabilities are living at home or in care settings where their parents are responsible for their care decisions (Braddock, Hemp, & Rizzolo, 2008). This additional responsibility on family members can cause difficulties when they are providing direct care along with managing their day-to-day lives.

Many counties and states have publicly funded agencies to provide individuals with disabilities and their families the required services that would assist in their daily needs. It can be argued that the family members of those with DD are among the most important people in their lives in a variety of ways. For this reason it is important to make sure that both the individual with DD and his/her parents receive the assistance they need. County agencies are available to provide help to families by offering services such as family support, respite, financial aid, transportation, and other family services. For the developmentally disabled individual, there are employment opportunities both within the community and within the service provider agency.
There are also socialization opportunities, physical or recreational activities, and day habilitation programs. Each of these are offered to the individual with DD, but these services often are a help to families as well. Many parents carry an enormous amount of burden and responsibility in their caregiving experience and find that these services are not always available or that changes are needed to make them more effective (Vinton, 2010). However, when the services are available and are utilized by these parents, they can have positive effects on the well-being and quality of life for the parents.

The Health Care Service Utilization Model by Andersen and Newman (1973) demonstrates the factors that lead to the use of health care services. This model was used to determine whether caregivers would use services available to them. It is what led to the creation of questions such as whether they are aware of services, whether they use them, and what they need assistance with.

There are three factors that encompass this model (i.e., predisposing, enabling, and need) and these factors were examined for their role in individual’s decision to use health services. Predisposing factors include the characteristics possessed by the individuals prior to the illness or other health concerns (umanitoba.ca). These characteristics range from education and occupation to beliefs, gender, and age (umanitoba.ca). Predisposing factors also include knowledge and beliefs people have toward the health care system and how that knowledge and beliefs will impact the utilization of health services (umanitoba.ca). This research specifically examined whether caregivers were aware of services and whether their needs were being met. Using the premise of predisposing factors, caregivers may not possess the knowledge to gain access to and/or utilize services or they may question whether services will benefit their children or
themselves. It is also unlikely for a caregiver who has used services in the past and was unsatisfied to use services again.

The next factor in the service utilization model is enabling factors. Enabling factors either aid or hinder the individual’s ability to seek care (umanitoba.ca). Factors such as income, health insurance, availability of services, and waiting time all play a role in whether someone will seek care. For example, if a caregiver does not have transportation then they will most likely not be using services as regularly as they need (umanitoba.ca). Many caregivers do not have the financial means or the appropriate insurance to obtain the services they require. There are also waiting lists for many services. All of these can hinder caregivers’ ability to obtain services for either themselves or their children. Family support is another enabling factor is individual’s motivation to seek services. Encouragement and support can help a caregiver decide to look for services, but without the support it can be even more difficult to seek them. Many caregivers have support systems in place but others do not. Single mother households are on the rise and single mothers can have difficulties in finding the time, money, and support difficult.

The final factor in the service utilization model is need. Need is the most immediate precipitator of health care use (umanitoba.ca) and it can be either perceived need or evaluated need. How individuals view their own health and then determine when and how to seek care is perceived need. Evaluated need represents a professional opinion about the health status of an individual and their need to seek medical attention. When caregivers are caring for themselves and an adult child with developmental disabilities, many may put their own needs aside to deal with their children’s needs. Research has indicated that when asked to describe their health, many will state they are in great health despite actually having multiple health concerns (Dillenberger & McKerr, 2010). Caregivers may be more willing to seek services for those they
care than themselves because of their care recipients’ need for health care, coupled with the judgment of professionals. This may play a role in which service caregivers use the most. Within caregiving environment there are many arenas in which caregivers could require assistance. The most desired and used services may represent the greatest perceived and actual need.

**Purpose of Study**

The purpose of this research was to determine service usage by caregivers of individuals with Developmental Disabilities (DD) in Wood County Ohio. The survey looked at whether caregivers were aware of services and how frequently they used the services. This research also focused on whether participants believed that their needs were being adequately met and where they would like more assistance with their needs. Future care planning involves making legal decisions, getting finances in order, and designating someone to provide care (Heller, Caldwell, and Factor, 2007) It is important for caregivers to engage in future care planning for the safety and security of their children in the future. This research investigated whether caregivers have made future care plans, designated someone to take over care, and felt prepared to deal with the future. Because it is important to consider the possible rewards associated caregiving, participants were asked to describe what some of these rewards have been. An investigation of the rewards of caregiving can provide insight into why parents continue to be caregivers one their children become adults.

**Goals of Research**

There were five main goals associated with this research. The first was to determine how many participants in the study were aware of, and used services available for their use. The second was to determine which services were the most commonly used and whether caregivers receive adequate assistance when seeking them. The next goal was to determine if caregivers
were prepared to deal with the future of caregiving and if they have made future care plans. It was also the goal of this research to investigate who would be most likely to be the primary care provider and the person designated to take over care. Research has shown that mother of individuals with DD are most often care provider and siblings are usually designated to take over care responsibilities. The final goal was to determine the rewards participants in this study believed that they have experienced through caregiving.

**Research Questions**

This research was designed to answer the following research questions:

1. Are individuals who provide care to adults with DD aware of services available in Wood County, Ohio?
2. Are family support, financial, and legal services the most commonly used services by caregivers of adults with DD, but also services where additional assistance is desired?
3. Will individuals who provide care to adults with DD have made future care plans or are they unprepared to deal with the future?
4. Will mothers of adults with DD be the primary caregiver with sisters being the most commonly chose individual to take over care in the future?
5. Do caregivers of adults with DD experience rewards within their caregiving experience?

**Definition of Terms**

The following terms are commonly used when discussing adults with developmental disabilities:

*Activities of Daily Living (ADLs)*: basic self-care tasks, akin to the kinds of skills that people usually learn in early childhood such as bathing, grooming, and toileting. (Caring.com)

*Americans with Disabilities Act*: prohibits discrimination and ensures equal opportunity
for persons with disabilities in employment, state and local government services, public accommodations, commercial facilities, and transportation. (ADA.gov)

*Bridges to Transition:* a model to successfully assist youth in the transition from school to the world of work. (Wood Lane)

*Burden:* a source of great worry or stress. (Merriam-Webster online)

*Caregiver:* person who provides unpaid care to a relative or friend 18 years or older to help them take care of themselves. (National Alliance for Caregiving)

*Community Employment Service/ Employment First:* employment in the general workforce should be the first and preferred option for individuals with disabilities receiving assistance from publicly funded services. (Wood Lane)

*Day Habilitation:* assistance with acquisition, retention, or improvement of self-help, socialization, and adaptive skills which takes place in a non residential setting. (ddsn.sc.gov)

*Developmental Disabilities (DD):* group of conditions due to impairment in physical, learning, language, or behavior areas. (CDC.gov)

*Down’s Syndrome:* genetic disorder caused by abnormal cell division resulting in extra genetic material from cell 21. (ndss.org)

*Quality of Life:* the individual’s unique perspective of their position in life, in relation to culture and value structures, aspirations and expectations. (WHOQOL; Yoong and Koritas)

*Intellectual Disability (ID):* below average cognitive ability meeting three characteristics; IQ between 70-75 or below, significant limitations in adaptive behaviors, and the onset of the disability occurs before the age of 18. (aaidd.org)
Medicaid: social health care program for families with limited incomes and resources.  
(Medicaid.gov)

Normalization: the utilization of means which are as normative as possible to establish or maintain personal behaviors and characteristics; process to minimize the perceived differences in those with disabilities. (thetqrp.com)

Rehabilitation Act of 1973: forbids organizations and employers from excluding or denying individuals with disabilities an equal opportunity to receive program benefits and services. It defines the rights of individuals with disabilities to participate in, and have access to, program benefits and services. (hhs.gov)

Respite care: a temporary break from caregiving while the person whom they care for is still receiving care. (alz.org)

Social Security Disability: Social Security benefits provided to an individual who has an inability to work in the same manner as they previously did. It has been determined that the individual cannot adjust to other work because of medical conditions, or his/her disability is expected to last for at least one year or result in death. (ssa.gov)

Stress: physical response to events that make you feel threatened or upset your balance in some way. (helpguide.org)

Supplemental Security Income (SSI): federal income supplement program funded by general tax revenue. (ssa.gov)
CHAPTER II. REVIEW OF LITERATURE

Developmental Disabilities

Individuals with (DD) have faced hardship and discrimination for years. Prior to legislation, (e.g., Americans with Disabilities Act & the Rehabilitation Act of 1973) children with DD were usually institutionalized and had few rights. The shame and stigma associated with DD led many parents to choose institutionalization and to hide their children from society (Pollack, 2011). In the 1950’s, institutions began closing due to changes in public opinion which focused on providing more rights to those with disabilities, and people with DD started having more involvement in the community. In the 1960’s the idea of normalization was introduced. Normalization called for individuals with disabilities to receive a quality education and receive residential services to assist them in living their lives as closely to an acceptable standard as possible (Baer & Daviso, 2007; Kyung Kim & Dymond, 2012).

According to Braddock, Hemp, & Rizzolo (2008) and Fujiura and Park (2003) approximately 75% of adults with disabilities are living with their families. Over 25% of those family caregivers are age 60 and older (Heller & Arnold, 2010). The lifespan of adults with developmental disabilities is also on the rise, with many living into their older adult years (Botsford, & Rule, 2004). As explained by Janicki and Ansello (2000), individuals with DD face differences in their aging experiences than individuals without DD. For example, their residential status often involves living with a family member throughout their adult lives, they are less mainstreamed than the average adult, and they are often not in charge of their own federal benefits (Sterns & Ansello, 2008). In addition to their own aging process, those caring for them are aging as well. As the lifespan of adults with DD rises, the time span for caregiving lengthens.
Many of the issues faced by adults with DD on a daily basis are now exacerbated with the effects of the caregiver’s aging process.

Parents of Adults with Developmental Disabilities

For parents of an adult child with DD, it is a daunting task to continue to provide care when both the child and the parent are facing declines in functioning. As stated by Shearn and Todd (1997) parents are not only responsible for the care of their developmentally disabled children, but as they age, caring for themselves can become more difficult as well (Yoong & Koritas). Parental caregivers play many roles in the care of their children, each having a potential impact on parents. In 2011, Rowbotham, Carroll, and Cuskelly discussed the different roles of mothers and fathers who are caring for an adult child with DD. Mothers spend an average of 12.5 hours per day caring for their adult child while fathers spend approximately 7.25 hours each day. Mothers are more likely to experience caregiver stress because of the increased number of roles and tasks mothers perform each day (Rowbatham, Carroll, & Cuskelly, 2011). The quality of life for these mothers is not only impacted by their roles but by the numerous responsibilities and burdens associated with care and completing other roles. These burdens or responsibilities include performing tasks for their children, making sure they arrange and keep appointments, and the amount of time they spend caring for someone else (Rowabatham, Carroll, & Cuskelly, 2011).

Experiences of Parental Caregivers

Family Support Services and Social Support

Both formal and informal supports are important when providing care. Informal supports include support received from family, friends, and others. Formal supports are provided by organizations or agencies to assist people with a variety of needs. Support includes emotional,
instrumental, informational, and appraisal (e.g., constructive feedback, affirmation and social comparison) and as described by Thoits (1995) can be used as a coping mechanism to build resilience (Perkins & LaMartin, 2012). As discussed by Dunst et al., (1993) family support services, formal support, are available for caregivers to use and are designed to strengthen family’s ability to care for their relative with DD. Their goal is also to improve the well-being of caregivers (Heller, Miller, & Hsieh, 1999). Family support programs are also designed to assist caregivers with coping and reducing the burden of caregiving (Heller, Miller, & Hsieh, 1999). Additionally, Heller and Factor (1993) discuss how family support systems are there to help keep the individual with DD in the family home by decreasing burden experienced by caregivers (Heller, Miller, & Hsieh, 1999). Most caregivers reported having adequate social support but using at least two support services to help them care for their children (Dillenburger & McKerr, 2010). The most common support that caregivers seek is social and recreational (Minnes, Woodford, & Passey, 2007).

Fiori, Antonucci, & Cortina (2006) found that for many older caregivers it is often difficult to find support due to reduced social networks, lower attendance at social gatherings and reduced participation in religious or other activities as a result of advancing age (Perkins & LaMartin, 2012). Caregivers in the Yoong and Koritas (2012) study reported that friendships were restricted due to caregiving demands. They also reported missing out on family events or other social activities because of their child’s needs. For married caregivers, caregiving had an impact on their marriages. Time spent together was for caregiving rather than quality time (Yoong & Koritas, 2012).

Caregivers also find supports within the adult children they are caring for. Caregiver’s adult children provide one of the longest lasting and most constant forms of support. Yoong and
Koritas’ (2012) investigated quality of life for mothers of adults with DD. One aspect of quality of life in their study was the social support these mothers received. Many mothers acknowledged they were in support groups and had made friends with other caregiving mothers as a form of support. One of the constant forms of support however was with the adult child they were caring for. The children provided a companion for them, and were there to help them during difficult times. Since their child lived with them there was a constant form of support rather than periodic supports from outside sources (Yoong & Koritas, 2012).

**Stressors of Caregiving**

Every caregiver has a unique experience when it comes to caring for their child. However, there are common factors that many of these caregivers share, such as the stress of caregiving, health impacts, financial problems, and concerns about the future.

**Stress and Burden**

Stress is defined as the body’s reaction to life events creating a feeling of unbalance or a threatening sense in your life (helpguide.org). Similarly, burden is a source of great worry or something that is emotionally difficult to bear. Stress and burden are unique to the individual, what is viewed as stressful to one may not be to another. Individuals also respond to stress and burden in their own way.

Many caregivers will experience some level of stress or burden during their caregiving trajectory (Krauss & Seltzer, 1998; Minnes, Woodford, & Passey, 2007). Many factors have been shown to increase the level of caregiver burden and the ability to cope with stress. Minnes, Woodford, and Passey (2007) found that despite having good levels of social support and reporting high overall well-being, there were eight identified stressors that emerged during their interviews. These stressors, while possibly not impacting quality of life, create burden and worry
on the part of the caregiver. Rising levels of burden can have a negative impact on the psychological well-being of older adults. Creating long term housing plans, finding emotional and social support, getting their child involved in social activities, meeting their own needs, making accommodations within their home or the community, separation from family and friends, creating a will and/or guardianship, and finally dealing with medical professional, all are major areas of concern for many caregivers (Minnes, Woodford, & Passey, 2007). Many of these findings match what others studies have shown in terms of caregiver burden (Minnes, Woodford, & Passey, 2007). Dillenberger and McKerr (2010) also found that one of the biggest concerns caregivers face is the needs of their children. Medical needs, keeping them occupied, dealing with behavioral issues, and worrying about the future are what many caregivers deal with on a daily basis (Dillenburger & McKerr, 2010).

Hayden and Goldman (1996) investigated stressors and compared them among different groups of caregivers. Stressors and other forms of burden can have an impact on the well-being of the caregiver. Marital status has been shown to have an impact on the level of stress of many women. Single mothers scored significantly higher on stress tests than married mothers (Hayden & Goldman, 1996). Single mothers are taking on many jobs by themselves, are less likely to have support, and are in more desperate financial situations. The level of the disability and the amount of maladaptive behaviors on the part of the child with DD also impacted mothers stress levels. Families of children who have severe or profound DD scored significantly higher on stress measures than those caring for children with moderate to mild disabilities (Hayden & Goldman, 1996). Caregivers whose children needed extensive amounts of care or required three or more outside services also scored higher on stress measures (Hayden & Goldman, 1996).
Greenberg, Seltzer, Krauss, and Hea-Won (1997) compared mothers of adults with DD to mothers of those with mental illness. Mothers of those with DD scored significantly higher on stress measures than other mothers. These mothers also reported doing more daily life tasks for their children and providing more amounts of care than mothers of those with mental illness. The number of behavior problems also increased the amount of stress mothers experienced. Many mothers showed a lessened ability to cope with the stress. Pessimistic attitudes about the future were also examined; there were no significant differences between the two groups, but mothers who were more pessimistic were more likely to experience depressive symptoms. Social support also showed to have no effect on the amount of stress. Mothers caring for someone with DD were more likely to say a family member was a form of support, while the other group mentioned friends whose children experienced the same problems. Despite having these social supports the amount of burden was not reduced for them (Greenberg, Seltzer, Krauss, & Hea-Won, 1997).

Physical and Mental Health

Studies on the health concerns of caregivers for adults with DD have been mixed. Many caregivers reported their health as being good or even excellent when in reality they had many health problems (Carr, 2005). Parent caregivers focused on the needs of their children rather than their own. One of the biggest problems caregivers face is depression. Heller, Miller, and Factor (1997) and Black et al. (1985) found the ability to cope with the burdens and stress they faced contributed to the prevalence of depression. The diagnosis and severity of the developmental disability also contributed to the ability to cope with the situation (Williams & Perkins, 2014). Finally, cultural variables were found to contribute to mental health status. Blanchester and
McIntyre (2006) showed Latina mothers were found to report more depressive symptoms than other mothers and less ability to cope (Williamson & Perkins, 2014).

Participants in the Dillenburger and McKerr (2010) study reported good levels of health despite their various health concerns. Some of the participants stated that they suffered from ill health and were on a variety of medications. Their study also found that older caregivers were twice as likely to experience psychological illness when compared to the general population (Dillenburger & McKerr, 2010). Carr (2005) explored the health of caregivers whose children had Down’s syndrome and compared them to mothers in the general population. This study found that mothers whose children had Down’s syndrome scored significantly higher on stress tests and saw their family less often than they would like. Mothers who were on the younger end of the spectrum were more likely to have negative health consequences as a result of this stress. Younger mothers saw their families less often, had more restricted social lives, and reported feelings of being run down or depressed (Carr, 2005). Caregivers for the DD population are also more prone to chronic conditions and have greater levels of heart disease, high blood pressure, and a poorer overall immune system (Heller, Caldwell, & Factor, 2007). Mothers as the primary caregivers were more likely to have arthritis and limitations in their activities of daily living when compared to non caregiving mothers (Williamson & Perkins, 2014).

Financial Concerns

Financial concerns are faced by many caregivers due to the demands that caregiving places on their time and work schedule. Parish, Rose, and Swaine (2010) found there were financial concerns for many parents who have a child with DD. Younger parent caregivers face higher poverty rates and are increasingly in single parent households. Older parents are also showing higher rates of poverty in that they are less likely to be employed or they have fewer
jobs than younger parents (Parish, Rose, & Swaine, 2010). Lower income levels are also associated with lower educational levels for many caregivers (Parish, Rose, & Swaine, 2010). Heller, Caldwell, and Factor (2007) also found that caregivers of children with DD were more likely to be working multiple jobs and living below the poverty level (Heller, Caldwell, & Factor, 2007). Fujiura & Yamaki (2000) found 28% of children with DD were living below the federal poverty line (Emerson, 2007). Many adult caregivers were found to have no savings and twice as likely to be in debt as those not in a caregiving position. Many worried about their financial situations on a daily basis. Fujiura et al. (1994) found there were considerable amounts of out of pocket costs associated with caregiving as well (Heller, Caldwell, & Factor, 2007). The majority of these caregivers turned to service providers as a way to reduce their out of pocket expenses (Emerson, 2007). Some service providers are able to provide a yearly stipend to families caring for those with DD and for those who meet financial eligibility requirements.

**Satisfaction and Quality of Life**

As discussed, caregivers face a great deal during their caregiving career. Despite this, many caregivers expressed the positive aspects of their situation. Many studies have focused on the influence of caregiving on quality of life measures. While there are situations that may have had a negative influence, quality of life is in the eyes of the beholder. Many of these caregivers perceived their experience as being positive.

**Quality of Life and General Well-being**

Quality of life has been conceptualized in many ways in the literature. In 1991, the World Health Organization (WHO) created the Quality of Life Project to develop an international and cross cultural definition of quality of life. As shown in the article by Yoong and Koritas (2012), the WHO defined quality of life as “the individual’s unique perspective of their position in life,
in relation to their culture and value structures, aspirations and expectations (WHOQOL, 1994; Yoong & Koritas, 2012). Yoong and Koritas discussed how quality of life takes into account physical, emotional, and psychological health in addition to well-being. There are two types of quality of life measures, objective and subjective. Objective measures are independent of an individual view and look at cultural context of quality based on observed criteria. Subjective measures of quality of life, meaning it is what the caregivers view as having an impact on their lives, will be the focus in this study (Yoong & Koritas, 2012).

Over the years studies have been conducted to assess overall well-being and quality of life for parents of adults with DD. In one study, mothers who had their children with DD living with them were compared to mothers whose children with DD lived out of the home. They examined well-being, quality of life, and life satisfaction. Older mothers whose adult child lived in the home had higher scores on all three of the measures (Rimmerman & Muraver, 2001). Minnes, Woodford, and Passey (2007) looked at the well-being of caregivers of adults with DD. They looked at stressors, depression, and quality of life to determine how the overall well-being of caregivers was impacted. Within the stressors category they looked at both maladaptive behaviors on the part of the adult child and caregiver health. Maladaptive behaviors that showed to have an impact on caregivers were low concentration levels and inability to stay focused. Overly dependent behaviors were also seen to have an impact. These maladaptive behaviors, as well as others, have been shown to increase the level of caregiver burden. When the researchers looked at caregiver health, however, most reported their health as being good or even excellent and they reported positive quality of life (Minnes, Woodford, & Passey, 2007). Many caregivers were able to deal with the stress and not be impacted by the amount of burden because of the love and satisfaction they got from caring for their child.
Evaluation of Caregiving

Many caregivers do not view everyday stressors in the same way as others do. The care they provide is a great deal of work but they consider it to be a part of who they are. Most caregivers agree that their greatest joy is those who they provide care for (Dillenburger & McKerr, 2010). Being able to provide care and spend time with their adult child with DD brings a sense of fulfillment to caregivers; this is especially true in older mothers, age 60 and up (Dillenburger & McKerr, 2010). In general, caregivers described their relationship with their children as being positive and filled with love (Dillenburger & McKerr, 2010). Mothers in the Rowbotham, Carroll, and Cuskelly (2011) study found that despite an overwhelming number of tasks and time spent on caregiving, their satisfaction with their experience was extremely high. Over the years of caring for their children, they had learned how to deal with the needs of their children and anticipate problems before they became an issue. The more time they spent in the caregiving role the higher the life satisfaction measures (Rowbatham, Carroll, & Cuskelly, 2011). Rimmerman and Muraver (2001) discussed how mothers in their study caring for their children with DD in the home had fewer undesired life events than mothers whose DD children lived out of the home. Life events were areas such as finances, health and illness, social life, home life, and others that could be impacted by caregiving. Mothers in their study had learned to adapt and spend most of their time with their children, possibly contributing to this lower number of undesired events (Rimmerman & Muraver, 2001).

Future Care Plans

Future care plans include financial, medical, living arrangements, legal decisions, and designating someone to take over care (Heller, Caldwell, & Factor, 2007). When assigning
someone who will take over care for their adult children, many caregivers will choose a sibling of the child with DD to provide care (Krauss, 1990). White (2001) found siblings often provide the longest lasting relationship for the adult with DD (Heller & Arnold, 2010). Siblings of those with DD play many roles in their lives and those roles have been increasing over the years due to the longer life span and their parents aging (Heller & Arnold, 2010). In a study done by Seltzer, et al. (1997) sisters were found to have more direct involvement in the lives of their siblings with DD (Seltzer, et al, 1997). Sisters have been found to provide more emotional support than brothers and provided more caregiving companionship (Greenberg, et al, 1999; Orsmond & Seltzer, 2000).

In addition to designating someone to provide care, many other decisions must be made for the future of their adult children. While many caregivers are aware that these plans need to be made, they are unsure of how to make them. Dillenburger and McKerr (2010) examined caregiver’s ability to make future care plans. The majority of people in their study (72%) had not made future care plans but acknowledged their awareness of the importance of making future plans. For those who had made plans, they were usually not complete, and areas of decisions were often unclear. Caregivers in their study worried about the future of their children with DD as well as their own health and well-being. Many were concerned about how much longer they would be able to provide care. Some caregivers reported feeling desperate about the future decisions for their children. One caregiver expressed her hopes for her child to pass before she did so that her son would not have to be placed in a home (Dillenburger & McKerr, 2010).

Having the feeling of being unprepared and the uncertainty about your child’s future creates anxiety for many caregivers. Many caregivers who do seek help are left unsatisfied with their case managers and felt more overwhelmed by the process (Hewitt et al, 2010).
To assist caregivers in making future care plans, programs have been created and tested with parents. Hewitt et al. (2010) conducted research that investigated caregivers’ desires for a lifetime assistance program. Mothers were between the ages of 41 and 50. They evaluated caregivers’ ideas about future care planning in terms of what they most wanted out of it and specifically what is needed. The Lifetime Assistance Pilot which combined future life planning with ongoing life planning and caregiver support was the program they chose to study. Their research was based on the idea that with increasing longevity and the increase in the number of individuals with DD living with family members it would lead to more people desiring the future care planning assistance. Their findings were centered around four main ideas that came to light after the focus groups had met, adequacy of current services and supports for future planning, person selected for quality of life monitoring after the death of the caregiver, services and supports families currently use and those they are willing to pay for in the future, and the desire for a lifetime assistance program. During the focus groups, caregivers expressed an overall low level of satisfaction with their county case management service. This dissatisfaction was highest in the areas of financial planning and monitoring of quality of life. The majority of respondents had made plans in terms of selecting someone to care for their child; caregivers who were over the age of fifty were most likely to select a sibling of their child while younger caregivers chose their parents. When asked about the desire for a future planning program, 81% responded that they would like assistance in financial planning and others wanted help in legal planning (Hewitt, et al, 2010). Based on their findings there is a general lack of satisfaction in the help caregivers are receiving with future care planning and a desire for assistance with these plans. Caregivers in this study had made plans for guardianship in the future, one very important part of
care planning, but there are many other components that need to be addressed and many caregivers need help with doing this.

In a 2004 study by Botsford and Rule, they evaluated the before and after thoughts about professionally led psycho-educational groups targeting permanency planning. They studied mothers who had not made plans prior to the group about the future of their adult child with DD. When the educational groups were completed, the researchers looked at whether there was an increase in knowledge and awareness of resources, their sense of confidence to make plans, and their advance planning process. On all of these measures, there was an increase in the satisfaction levels, and caregivers felt more confident to make the necessary plans. Similar style programs have also shown to have the same positive benefits for other groups of caregivers (Botsford & Rule, 2004). Not only are the psycho-educational groups beneficial for caregivers but they are helpful to service providers as well. These types of programs are cost efficient and can reach a large number of people at one time. These programs also allow for development and change while they are going on, depending on what the caregivers would like to know more about (Botsford & Rule, 2004).

**Community Service Providers**

*Background*

Many communities throughout the country have some models of service offered to those with DD and their families. Person- centered services are common in many agencies and imply that individuals can choose their own service providers and play a more active role in their life decisions. However, person-centered care can create more hardships for the families. For example, the system became more difficult to navigate and the responsibility to choose the providers and services now fell solely on the family (Dyke et al., 2013). There is also a general
consensus among caregivers that the resources available to them are less than satisfactory. Many resources available do not provide adequate help in areas where help is needed the most (Heller, Miller, & Hsieh, 1999).

Dyke et al. (2013) noted that responsibility falls on the parents to ensure their children are getting the proper services, a daunting task for many older caregivers (Dyke et al., 2013). Mothers played a strong advocacy role and were the primary organizers for service options (Dyke et al., 2013). Mothers who were interviewed in Saaltink and Ouellette-Kuntz’s (2014) article discussed the many roles they have taken on to ensure their children are receiving everything they can. The mothers took on administrative tasks such as completing applications, filling out needs assessments, and keeping records of diagnoses for eligibility purposes. Parents also engaged in information gathering; determining which services exist, whether the service will meet their children's needs, and how to ensure eligibility. It was also important for the mothers to engage in relationship building with either formal or informal services or supports. Finally, they acted as advocates for their children, pushing for forward movement within the system and for more services to better meet their child's specific needs (Saaltink & Oullette-Kuntz, 2014).

**Alternatives to the Current System**

As seen with future care planning, alternative programs exist and have shown to be beneficial to caregivers. Low satisfaction levels with the current system has led to the development and testing of new programs. Hewitt et al., (2010) looked at caregivers desires for a lifetime assistance program. They found overall low levels of satisfaction with the county service providers. Of those interviewed, 34.7% were dissatisfied or very dissatisfied with their case managers, 32% were dissatisfied with quality of life monitoring, 18% were dissatisfied with financial planning services, and 81% said they would like the assistance program to be
implemented (Hewitt et al, 2010). Vinton (2010) looked at caregiver’s perceptions of services before and after the implementation of the Home and Community Based Services model. They looked at satisfaction of coordination, people running the services, how funds were distributed, and what services were provided. While participants revealed that they were satisfied in being able to ask their coordinator questions and get good responses, they were displeased overall. When they completed the post test measures (i.e., after the evaluation of the program), each of the items addressed had increased in satisfaction rankings (Vinton, 2010). Many caregivers also faced issues of waiting lists and services providers who had a difficult time determining who had the highest level of need. Services offered were often not individualized. The researchers concluded that there needs to be more effort in creating care based on needs and situations, but financial and other barriers prevent them from doing so (Hayden & Goldman, 1996).

The programs that have been developed over the years have been shown to have success on numerous measures. These programs are geared more towards the consumer and allowing the families to make decisions. Some of the programs that have been tested allowed the families complete access to information and services so that they could choose which worked best for them (Heller, Miller, & Hsieh, 1999). Other programs have allowed a similar amount of access, but provided a service facilitator who made a plan. The plan was based on what the consumer’s specific needs and wants were. These types of programs not only gave the adults and their families the freedom of choice but they instilled confidence within the caregivers (Vinton, 2010). Vinton’s study compared satisfaction levels of services before and after implementing the program. Many of the caregivers who were involved in the study reported an increase in trust in the system and were more satisfied with what was offered. Many also expressed that they felt
more confident in their own caregiving abilities and were more likely to use services in the future (Vinton, 2010).

**Barriers to Access**

Despite the success of many of these programs and caregivers’ desire for their permanent implementation, there are barriers to accessing them or providing them on a long term basis. Chou, et al. (2008) discussed how families of those with DD/ID often have difficulties in obtaining services and programs due to gaps in the availability and other barriers to utilization (Hewitt et al., 2013). Samuel, Hobden, LeRoy, and Lacey (2011) also examined some of the biggest barriers to accessing services and found that family members lacked awareness of services or how to obtain these services, waiting lists, financial issues, and transportation to be among the biggest barriers to services (Hewitt et al, 2013).

Some of these programs are expensive and hard to turn into a system wide program. Many county or private service providers do not have the resources to make the necessary changes (Hewitt et al., 2010). Hewitt et al., (2010) found that startup funds for these programs were usually very large and not something many providers can afford. Programs also require hiring new staff or training current staff on the new program. Finally, making changes system wide takes time and requires policy changes that are difficult to make (Hewitt et al., 2010). Making programs available to families of children with DD from all socio-economic levels can be difficult as well. The cost of hiring new staff members and starting up the programs will increase fees, exceeding what many caregivers can pay. For agencies who do not charge for services, securing financial resources to pay for these programs can be even more difficult (Hewitt et al., 2010).
Time can be another barrier faced by caregivers and service providers. There are many caregivers who do not have sufficient time or the resources to break away from their child to attend these programs. In the Botsford and Rule (2004) study, they found that older caregivers were reluctant to try new programs or did not have the means (e.g., financial, time, or mobility) to attend them (Botsford & Rule, 2004). Questions were also raised about the extent to which the satisfactory results could be sustained and concerns about policy. Many caregivers in their groups expressed feeling confident in understanding the plans that need to be made but were unsure about whether the resources to help them would be available. The inadequacy of the current support system left many caregivers frightened (Botsford & Rule, 2004). Money, policy, and burdens of caregivers were making these programs difficult to implement everywhere. Making the current staff and programs aware of what could be done based on these studies may help change the ways of thinking and working towards a change.

The current reality is that no one agency can provide all the services that a caregiver could possibly desire. That being said, there are definitely areas where improvements can be made. It is important for case managers to acknowledge family stress and create a collaborative environment between the parent and the agency to ensure that the adult child with DD is getting the best care. Parents will need to play the instrumental role, because no one knows their child better than them and there will be no better advocate than the parent. A healthy balance between the parents’ roles and the services providers’ roles should be the goal.
CHAPTER III. METHODOLOGY

Researchers Lens

When entering the gerontology program at Bowling Green State University I only had a few ideas on where I would like to take this program in terms of my future. I had an interest in Alzheimer's disease from my undergraduate classes, but the excitement that should have been there was not. In the very first class of graduate school, the professor had everyone go around and say the field they were interested in working in. One student talked about her work at Wood Lane and the gratification she had from her job. The light bulb went off at that moment. In junior high and high school, I worked in the multiple handicaps classroom with my partner Jessica who had Down’s syndrome. When I got into college and went into Speech Therapy, I continued to work with children who had developmental disabilities. However, in my undergraduate program I decided that my target population was with older adults and that is why I had made the transition. It had not previously occurred to me that I could work with those who have developmental disabilities when they became adults.

Throughout graduate school, I took classes focused on policies and other issues that older adults face in getting their needs met. Most often, money was the biggest prohibiting factor. Going with this idea, I wanted to translate that into how caregivers of adults with developmental disabilities perceive their needs as getting met. The original goal was to explore the experiences of parents of adults with DD who were in their later lives, ideally the parents would be in their 70’s and 80’s and the adult children would be in their 40’s and up. However, with such a small population to work with, I decided to focus on any parents whose children were now an adult, for this study ages 22 and older. It proved to be just as beneficial because younger parents have their
own concerns just as older parents would and these parents are thinking about the future when their adult children may need care from others.

Based on what I had read in the literature, there seems to be a great need for services in the community of caregivers. For a variety of reasons, there is a lack of services. Alternate types of service delivery models have been studied and have had success. but there are numerous barriers to making them a reality. Caregivers in the literature also experience a great amount of stress and burden associated with their roles as caregivers. This stress and burden impact their need for services. The goal with this research was to determine if Wood County Ohio was one of the areas where caregivers had an overall dissatisfaction with their service providers or if this county was able to effectively overcome the hardships of providing services. I also wanted to look at the most used services and how often they were used by individuals to help manage their stress. I believed that if caregivers had a heavy workload and were stressed, they would frequently use services designed to help with their workload. For this research, it is not only the caregivers utilizing services; it is also their adult children as well. Many individuals with DD and Intellectual Disabilities (ID) depend on agencies such as Wood Lane to find employment, get help with life skills, and for other basic needs. While this may be a service for the individual, it is directly helping their caregivers as well.

Once I had an idea of the direction I wanted to go with the research, I was set up with the director of adult services at Wood Lane in Bowling Green, Ohio. We discussed the people who utilized the services and who would be the best target population at Wood Lane. Once I had created the survey, the director and I discussed it to ensure that questions were appropriate based on what services people received from Wood Lane. I also had the opportunity to attend a board meeting. Not only was this the way in which the county approved the research but a way to see
how the board operates in making decisions and how they function within the community. In addition to receiving approval from the Wood Lane Board of Directors, this research was approved by the Bowling Green State University’s Institutional Review Board.

Participants

Participants in this study were residents of Wood County Ohio who have one or more adult children with DD/ID. Participants were recruited with assistance from Wood Lane. Caregivers taking this survey have either used Wood Lane services themselves, their adult children use services at Wood Lane, or they in some way have their information registered with the county board of DD. This survey was anonymous to the researcher. Surveys were sent out to 266 parents who met the qualifications of having adult children with DD and were registered with Wood Lanes services. For the purposes of this survey, parents whose adult children were of age 22 or older. This meant that the adult child could no longer be enrolled in a school and would need other services during the school time period. Recruitment letters, instructions, and surveys were mailed to each eligible participant. Surveys were sent to all 266 qualified caregiver to ensure the highest response rate. Participants were asked to complete the survey and return it in a pre-addressed stamped envelope and to not place any identifying information on the survey or envelope. By returning the survey, participants provided their consent to use their responses for this research. Surveys were returned to Wood Lane addressed to me, and I was the only person who opened the envelope to ensure that the staff at Wood Lane could not identify who had completed a survey.

Of the 266 surveys sent out, 62 were returned, a 23% return rate. There were 48 mothers, three fathers, four sisters, one stepparent, and one grandparent to the individual with DD. In addition to family members, one respondent was a court appointed legal guardian. Additionally,
there were three surveys where both a combination of the mother and father completed the survey. Finally, one survey respondent chose not to answer the question that asked for information about their relationship to the adult with DD/ID.

**Instrument**

Participants were sent a 12 question survey regarding their experiences as a caregiver to individuals with DD/ID. The survey is provided in Appendix A. They were also mailed a recruitment letter and consent form (see Appendix B and Appendix C). The survey contained multiple choice, open-ended questions, and questions where they were asked to rank their thoughts or feelings. Categories were created based on the frequency of answers provided by participants. Answers that did not fall into one of the categories were placed into a category labeled “other”.

In addition to multiple choice questions, participants were given three open-ended questions. The first question asked participants to name services they were aware of in the county. The second asked participants which services they would like more assistance with. Answers for both questions were scored similarly to the multiple choice questions. Responses were broken down into categories based on the frequency of answers. The final open-ended question asked participants to describe the rewards they have experienced as a caregiver of an individual with DD/ID.

**Procedures**

The goal of this survey was to determine how many of the respondents were aware of services and utilized services available to them. Further, the goal was to determine which services were the most commonly used and which caregivers desired more assistance. While Wood Lane was the vehicle through which to gain access to participants, the survey was not an
evaluation of Wood Lane specifically. There are other agencies within Wood County that caregivers can utilize. Participants were sent a 12 question survey asking about where they learned of services, which services they used, how often they used them, and which services they would like more help with. In addition to services used, they were asked to describe some of the rewards of being a caregiver. This question was added as a way to explore why people provide care despite its hardships but also as a way to end the survey on a positive note. Asking caregivers to think about the potential lapses in unfulfilled needs may bring about negative emotions. Asking them about the good times hopefully took away those feelings.

The first question participants were asked about was their relationship to the person whom they provided care for. The literature shows that the majority of direct caregivers are the child’s mother, and that sisters are the next most likely to take over care or be involved when the parents can no longer provide care. For this reason I wanted to ask the gender of the caregivers. In addition to what caregiver was taking the survey, participants were asked who they would likely assign to take over caregiving responsibilities to see how their responses compared to what has been reported in the literature. Participants were asked to circle all the categories of services they used as caregivers or their child used at Wood Lane. They were also asked about frequency of use and where they would like more assistance. These questions were asked to determine whether those using the services were taking advantage of the opportunities available to them and whether the services were helpful. They were also asked about areas where they believed that they were receiving adequate services. Participants were then asked to rate their feelings on how prepared they were to deal with future issues that may arise. Future care planning is something the literature has shown to be a major concern for many caregivers because of the inability to make these plans. For this reason caregivers were asked to make this rating and asked
whether they had made these plans. Caregivers often carry a heavy burden of responsibility and accessing services may not always be the easiest.

Analysis of Data

Surveys were collected over a period of two months to allow time for participants to respond. Once all surveys were collected they were removed from their return envelopes in case any identifiers had inadvertently been placed on the envelopes. Surveys were then examined for frequency of responses. For questions where participants were able to write in their own answers, categories were created based on themes that emerged from their written answers.
CHAPTER IV. RESULTS

In Andersen and Newman’s 1973 Model of Service Utilization, the factors that lead to individuals seeking care or assistance are delineated. If individuals are unable to access services, face barriers such as transportation and finances, or do not perceive their own need as being great enough, their ability/willingness to seek services will be impacted (umanitoba.ca). Based on that premise, caregivers were asked about their service usage and areas where they would like more assistance. If caregivers were satisfied with the services or have the means to access them, service usage would probably increase.

To begin the survey, participants were asked to identify their relationship to the individual with DD/ID who they provide care for. Figure 1 shows the results. The majority of respondents (n=48 or 77%) were mothers followed by the sisters of the individuals. Three surveys were completed by a combination of the mothers and fathers. One participant who selected “other” stated she was a court appointed legal guardian to the individual. No male siblings participated in the survey and one participant chose not to answer their relationship to the individual.
Participants were then asked to identify any services that they were aware of within the county. Services could be provided by Wood Lane, Wood County Committee on Aging, or any other agency they were aware of within the county. Categories were then created based on the most common answers provided by the participants. Categories include General County Agency, Transportation, Financial, Employment, Respite/Day Habilitation/Residential, Support Services, Recreational/Social, and “Other”. Many participants named a county agency rather than specific services they offered leading to the creation of the first category, General Agency. The next category created was Transportation and it provided for answers such as taxi and shuttle services. The Financial category was created for those who wrote waivers, insurance, and Medicaid/Medicare assistance as a service they were aware of. Many participants stated employment services or job coaching as a service, and therefore, the Employment category was created. Respite/Day Habilitation/Residential was designed to encompass any response dealing with in home care, day programs, and housing services and that provides a break to those in a caregiving position. Case managers, life skills training, and support groups were mentioned by a number of participants and became the Support Services category. Finally, a category to accommodate all recreational and social responses was created. Any responses not relevant to the research were placed in the “other” category. Examples of these responses were Easter Seals and the Probate Court.

Of those taking the survey, 58 (94%) were able to answer with one or more services that they were aware of. Two participants did not know of any services and there were 2 no responses. Results of this question are shown in Figure 2.
In order to determine how often services are being used, participants were asked about their frequency of utilization by ranking their use as never, rarely, often, and frequently. There were 58 (94%) participants who responded their frequency of use. Two participants did not answer the question and 2 were excluded based on their answers. Results are shown in Figure 3. As predicted, the majority of participants in the previous question were able to name one or more services or providers in Wood County. The majority of participants were also using the services available to them.
Participants were also asked where they learned of services that are available for their use. Options were TV, Radio, Newspaper, Advertisement/Brochure, Internet, Other, and not aware of services. Participants could choose more than one option. There were 59 (95%) respondents to this question and 3 no responses. Three participants selected they were not aware of services. Radio and TV were two options that no participants named as their source for learning of services. Although participants who selected “other” were not required to name their source, many provided one. Most common answers were word of mouth, educational settings, and through Wood Lane or other county agencies. Results to this question are show in Figure 4.

![Figure 4](chart.png)

**Figure 4**  How Caregivers Learned of Services

To determine which services are most commonly used in Wood County, participants were asked to select all the services they use the most from a list including respite, transportation, financial, legal, medical, family support services, none, and other. There were 60 (97%) participants who chose to respond to this question, 1 no response, and 1 answer was excluded. Results are shown in Figure 5.
The following two questions focused on areas where caregivers would like more assistance with caregiving. They were given the same options as prior questions, respite, transportation, financial, legal, medical, family support services, none, and other. Participants who selected “other” were then asked in the following question to explain which services they would like more assistance with. Additional participants took the opportunity to explain what they would like as well. There were 55 (89%) participants who responded to the first question regarding services they would like more assistance with. Twenty participants (32%) answered the following question regarding “other” services they would like assistance with. Based on answers provided by participants, categories were created to accommodate these responses, Respite/Housing, Medical/Daily Care, Education/Training, Insurance/Finances, and “other”. Similar to prior questions, those answering in or out of home care were classified as Respite/Housing. Medical or Daily Care was based on the need for assistance with activities of daily living or finding physicians that were appropriate for their adult children’s needs. Training and education seminars were requested by numerous participants as where they would like more
assistance. Finally, Insurance and Finance assistance for those requesting help with waivers, managing finances, and determining eligibility for Medicaid. “Other” was created for all answers where two or less participants mentioned a need for the service, such as socialization opportunities. Results for the first question regarding services are shown in Figure 6 and results for those who selected “other” are shown in Figure 7.

Family support services, legal, and financial services were thought to be the most commonly used due to their importance in the future care planning process and towards the health of the caregivers. It was also thought that these services would be areas caregivers would need more assistance with. For this research question, Family Support, Transportation, and “Other” were the most commonly used services Transportation and Family Support Services were also areas of adequate assistance for the majority of caregivers (Shown in Figure 11). Respite and transportation were areas where additional assistance was desired.

![Figure 6 Services Where More Assistance is Desired](image-url)
One important aspect of caregiving is the creation of future care plans to provide for the individual with DD once the caregiver can no longer do so. Participants were asked whether they had made future care plans and who will likely take over care responsibilities once they were unable to care. Participants were asked to select from the options yes, no, I plan to, not sure, and other to determine if they made plans. Many caregivers who answered this question wrote side notes explaining plans that they had made were either incomplete or they were unsure how to continue beyond the plans they had made. Fifty-nine participants (95%) answered this question, there were 2 no responses, and 1 answer was excluded. Results from this question are shown in Figure 8.

The following question asked participants who would most likely take over care when they could no longer do it themselves. Options participants could chose from included female sibling, male sibling, family friend, other family member, residential care facility, and other. Fifty-eight participants (94%) selected who would take over care, there were 2 non responses, and 2 answers were excluded. No participant selected family friend as an option and 12 (19%) participants selected a combination of options for their adult children. The most common
The combination selected was residential care facility with a female sibling. Results from this question are shown in Figure 9.

**Figure 8** Have Caregivers Made Future Care Plans

- Yes
- No
- Not Sure
- I Plan To
- Other

**Figure 9** Designated to Provide Care

- Sister
- Brother
- Other Family
- Residential Care
- Combo
- Other
Continuing the topic of future care planning, the next question had participants rate their preparedness in dealing with the future of caregiving. Participants were given a scale of 1 to 5 where 1 was unprepared, 3 was somewhat prepared, and 5 was prepared. Fifty-nine (95%) participants responded on their level of preparedness while there were 2 non responses, and 1 exclusion. Results are shown in Figure 10.

The research question set out to determine whether caregivers have made future care plans. In this research, the majority of caregivers selected that yes they had made future care plans, but they also wrote that plans were incomplete. Caregivers also selected that they only felt somewhat prepared to deal with the future, followed by feelings of being prepared. Overall, many caregivers in this research felt at least partially prepared to deal with the future.

Before moving onto the final question, participants were asked to choose which services they feel they are receiving adequate assistance with. Service options to choose from were the same as prior questions including respite, transportation, financial, legal, medical, family support services, none, and other. Fifty-six participants (90%) chose to respond to the question and there
were 6 no responses. There were 11 participants (17%) who selected “none”; they do not receive adequate assistance with any of the listed services. Results are shown in Figure 11.

![Figure 11 Areas of Adequate Assistance](chart.png)

The final question was open ended and asked participants to describe the rewards they have found within their caregiving experience. There were 48 respondents (77%) to this question. Results on this question were mixed. Answers were classified as being positive, mixed, and negative. Thirty-four (55%) caregivers had positive comments about their adult children and the experiences they have had. However, some parents (.06%) had concerns or issues that they used this question to express. Answers that were classified as mixed (16%) were for parents who had both a positive and negative comment. For example, many mothers made comments about their children being a blessing, they love seeing the joy on their children’s faces when they accomplished something new, and the unconditional love they received from their children.
Other participants talked about how their children resented them for interfering, how the job is exhausting, and there is a feeling of isolation.

One participant said: “Our son brings joy and laughter, we enjoy watching him enjoy life, enjoy him being a caring brother to his sisters, pursuing his own interests and seeing his skills abilities and achievements grow little by little.” Another participant shared the following - “Feeling of isolation. There are waiting lists for all services because he falls between assistance.” Another mother shared “Our daughter resents us for interfering, but I feel better knowing she is at home being cared for so I would consider that a reward”.

The following are additional quotes from parents in regards to rewards they have found in providing care to children with DD or comments on their experience with caregiving:

“Love and safety for my child. It’s difficult to trust others so most of the burden falls on me. I’m not sure if I could let others help me”.

“Just knowing my child is safe and not being mistreated or taken advantage of. I would like to have him eventually move in with a roommate or a group home but these services are out of reach and poorly staffed. Staff for these services need better training, pay, and education in order to be better held to higher standards of care”.

“Helping my daughter have a better life”.

“My child has changed my life in many ways. He keeps me real. We have met wonderful people we would have probably never crossed paths with. He has taught me to slow down and enjoy every moment”.

“Watching her bring joy to those around her with her smile, willingness to work hard and her love for people”.
“It strengthens your character and faith, it strengthened our family”.

“Our daughter took a good family and made us a great family- she impacts everyone she meets and brings out the best in that person- she works her hardest always and has the correct focus on what is important in her life which is a lesson to us everyday”.

“We are rewarded for caring for a man who brings joy and laughter to his parents. We enjoy watching him enjoy life. We observe him being a good caring brother to his sisters. We enjoy him pursuing his own interests and seeing his skills, abilities, and achievements grow little by little”.

The research question set out to determine if caregivers would find rewards in their experience. More caregivers discussed the positives they have found in their experience than those who discussed negative. Even parents with answers classified as “mixed” had some aspects they considered a reward. Many parents viewed caregiving as their job and also who they had become.
CHAPTER V. DISCUSSION

Based on Andersen and Newman’s Health Care Service Utilization Model (1973) it was the goal of this research to examine the service usage and areas where caregivers feel their needs are adequately met. It was also the goal to determine which services caregivers would like more assistance with and whether they had made future care plans, a service that has recently become more popular with providers. Finally, the goal was to determine if caregivers in this study were able to find rewards in their caregiving experience.

Caregivers face a variety of issues while caring for someone with DD/ID. Some of the issues that were discussed in the literature and were focused on were supports caregivers receive, stress and burden they may be facing, caregiver health, financial concerns, future care planning, and the experiences caregivers have had. It was also determined that services do exist to assist caregivers and that over the years new programs have been developed to build on the effectiveness of those services.

Family support services and supports from other sources are important for caregivers to have. Caregivers in the literature reported using at least two forms of formal supports to help meet their needs (Dillenberger & McKerr, 2010). Many caregivers reported feeling isolated or missing out on social events to tend to their caregiving responsibilities (Yoong & Koritas, 2012). Because of these feelings and the stress that can come with caregiving, support services were developed. Caregivers in this research selected family support services as being one of the most used services and one of the top for areas they would like more assistance with.

If you examine stress and burden caregivers may face, it is important to remember that each caregiver has their own unique experience. However, there are common stressors that many caregivers will face. The creation of long term housing plans, finding support systems, getting
involved, isolation from friends and family, getting their own needs met, and creating a will and other legal decisions are just some of the common issues shared by caregivers (Minnes, Woodford, & Passey, 2007). An additional area of burden that some caregiver may face is financial impacts. Caregivers, especially older caregivers, have fewer jobs, less savings, and are more likely to be in debt. Out of pocket costs will cause many caregivers to turn to county services to assist in their need (Emerson, 2007; Heller, Caldwell, & Factor, 2007). Future care planning services have become more popular in recent years. The stress they cause for many caregivers can be overwhelming. Many caregivers do not make future care plans because they do not have access to the appropriate information or they are unsure of what these plans involve (Dillenberer & McKerr, 2010). Because of these issues faced by caregivers, services such as financial, legal, family support services, and others were chosen as categories on the survey. It was predicated that legal, support, and financial services would be among the highest used services because of the burden associated with them and their involvement in making future plans. While support services scored in the top three for most questions, financial and legal were rarely used and ranked low on the list for services caregivers would like more assistance with.

The final goal of this study was to look at the rewards caregivers have found within their experience. With so many burdens and stressor being dealt with on a daily basis it is important to look at the positives family members find. The literature examined the satisfaction and rewards many caregivers have found in their experience. Despite the overwhelming demands, the various duties they preformed, and the amount of time spent in their role, caregiver satisfaction and quality of life was extremely high (Rowbatham, Carrol, & Cuskelley, 2011). Overall, caregivers in this study found joy and happiness in their caregiving experience as well. Similar to Dillenburger and McKerr, caregivers expressed great joy in seeing their children achieve their
goals and receiving unconditional love. Many caregivers expressed the feeling of becoming a better person and not taking the small things in life for granted. Being a caregiver for someone with DD gives you a new perspective on life and what is important. However, similar to Yoong and Koritas’s findings, there were caregivers who felt isolated from friends and family and restricted in their own lives. Each caregiver has a unique experience and views that experience in their own way. What may have been a burden for one caregiver was seen as a blessing by another.

Many caregivers will use services for a variety of reasons. Whether it is to obtain family support, gain access to medical professionals, or to seek assistance with finding their children a job or day habilitation, providers can be an important tool for families. However, many caregivers lacked the knowledge to obtain services, dealt with long waiting lists, or do not have transportation or financial means to use services (Hewitt, et al., 2013). It was discovered in this study though that the majority of caregivers use services often or frequently and more caregivers than not were aware of services they could use. Caregivers were also asked about areas where they would like more assistance. One participant took this opportunity to write that list waiting lists are an issue he/she deals with. Transportation was among the highest utilized and desire services. Many caregivers rely on transportation for their son or daughter to get to the county provider or their jobs, which were obtained through the county.

Limitations

Several limitations with this research should be noted. The sample for this study was very small. The response rate was 62 out of 266 surveys mailed to caregivers (23% response rate). With so few participants in comparison to the number of individuals that use services offered by Wood Lane, it was difficult to get an accurate picture of people’s feelings and attitudes.
Participants were also recruited through Wood Lane and those receiving services through the Wood Lane Board of Developmental Disabilities, rather than all individuals registered with the Wood County Board of Developmental Disabilities. This limited the number of participants with DD that could be receiving care from family members in Wood County but not receiving services from Wood Lane. Participants registered with Wood Lane are more likely to be using services than caregivers of adult children with DD who are not.

Other limitations that should be noted are in the responses provided by participants. Many questions had a number of participants choosing not to respond. There were also a number of questions where responses had to be excluded due to incorrect response types, such as selecting two answers when only one should have been chosen or writing in their own answers.

Finally, this research did not look at the specific information of the caregivers or their children. Information such as they age of the caregiver, the type of developmental or intellectual disability, and the severity of the disability were not required for participants to provide.

Future Research

Despite the small sample size you can see where improvements can be made for Wood County. Future research should focus more on obtaining a larger sample size. Moving into more than one county in Ohio and other states would also allow for a more accurate picture of the unmet needs in the developmental disabilities caregivers’ arena. Future studies should also focus on the exact hardships caregivers face. This is something that if I were to replicate the survey and start over I would include. Based on some of the responses I received on the final question I believe caregivers would be willing to talk about some of these hardships. Finally, future research should acquire information regarding the age of the caregivers and the type and severity of the developmental or intellectual disability. This information would be helpful in gaining
insight into the burdens and stress of caregiving as well as the types of services caregivers might desire.

Conclusions

Caregivers in Wood County have an overall understanding of the services that are available to them and are taking advantage of those services. However, there were many areas of unmet need. Future care planning, respite, and transportation were all service aspects where caregivers had concerns or needed more assistance. There are also many caregivers who do not feel they receive adequate assistance with any service provided. Making sure that each area of concern is addressed will help better meet the needs of those caring for individuals with developmental or intellectual disabilities. As discussed previously, it will take cooperation from both caregivers and service providers to create the best possible system. With limited resources and a growing need for services, meeting all the demands is difficult. Understanding where the unmet needs are and how caregivers are feeling can help create a better source of balance within the system.

Recommendations

The results of this research provide recommendations for services in Wood County and for Wood Lane specifically. While many participants in the survey were satisfied with services they commonly use and had positive comments about their experience with the county, others reported that there were areas where improvements would be beneficial. Individuals’ perceptions of services and providers showed that areas such as respite, family support services, and transportation were very important and therefore used often. These services were also areas where many would like more assistance. Participants also requested information and education about the services, how to access them, how to apply for more services, and various other
information regarding access. Therefore, a primary recommendation is to provide more information to caregivers of individuals with DD, specifically on how to access services.

Participants also indicated that educational programs were needed; especially education on sexuality for their children with DD. Another area of education that must be focused on for caregivers of children with DD is financial assistance programs. A common expressed need by numerous participants was receiving aid with insurance and waiver assistance. Many caregivers found themselves unsure of what they qualified for and needing assistance with application. One participant stated her daughter had been without insurance for four years because she does not know how to apply for insurance or what she would be eligible for. Providing more assistance in this area could help many caregivers better meet their needs and their children’s needs.
REFERENCES

Activities of Daily Living: What Are ADLs and IADLs?


Wood Lane. (n.d.). http://www.woodlane.us/

APPENDIX A

Caregiver of Adults with Developmental Disabilities Survey

Instructions: Please fill out the survey choosing the answer that most represents your opinion on the topic. The survey will take approximately 10 minutes to complete and you may choose to skip questions you do not wish to answer. When you are finished please return the survey at your earliest convenience in the preaddressed envelope. Please do not place any identification markers on the survey. Thank you.

1. How are you related to the person whom you provide care for?
   - Mother
   - Father
   - Male Sibling
   - Female Sibling
   - Grandparent
   - Aunt/Uncle
   - Family Friend
   - Other

2. What types of Wood County services are you aware of that can provide you with assistance? (For example, services can come from Wood Lane, Wood County Committee on Aging, or other agencies)

3. As a caregiver, how frequently do you utilize county services that are available to you? Circle one.
Never  Rarely  Often  Frequently

4. How did you find out about the county services available? Circle all that apply.

Television  Advertisement/ Brochure  Internet
Radio  Internet
Newspaper  Other

5. Which category of county services do you most utilize? Circle all that apply.

Respite Services  Legal Services  Other
Transportation  Medical  None
Financial  Family Support Services

6. As a caregiver what types of services would you like more assistance with?

Respite Services  Legal  Other
Transportation  Medical  None
Financial  Family Support Services

7. If you chose other, please explain what area of caregiving and the service you would like more assistance in?
8. Have you made plans for the future of the adult you care for if/when you are unable to provide care? Future plans include financial, legal, medical, and housing decisions.

Yes  No  Not Sure  I plan to  Other

9. Who will likely take over care responsibilities when you no longer have the ability to do so? Example: Selecting female sibling means your child’s sister will provide care.

Female Sibling  Other family member  Residential care facility
Male Sibling  Family friend  Other

10. Do you feel as though you are adequately prepared to deal with the challenges of caregiving in the years to come?

1  2  3  4  5
Unprepared  Somewhat  Prepared

11. What aspect of caregiving do you feel you receive adequate assistance with?

Respite Services  Legal  Other
Transportation  Medical Planning  None
12. What are some of the biggest rewards you have experienced throughout caregiving? Please explain why.
APPENDIX B

To Whom It May Concern,

My name is Annalee McGowan and I am a graduate student at Bowling Green State University. I am currently researching the unmet needs and the benefits of caring for an adult with developmental disabilities. The focus of this research will be on those providing care and the areas of services they utilize to assist them. You are being asked to participate in this research because you or the person you care for are using services at Wood Lane. While the research is not evaluating Wood Lane’s services specifically, it is the means in which I am finding caregivers. This letter was sent by staff at Wood Lane and your personal information was not released to me.

The research will consist of an anonymous survey asking about areas where you as a caregiver would like more assistance, how you learned of services available for your use, the future of caregiving, and the rewarding aspects of providing care. I will be looking at possible services you receive from both Wood County and Wood Lane. The answers you provide will in no way affect your services. The goal is to achieve an understanding of whether services are being used and if caregivers feel they are prepared to deal with the challenges of caregiving.

With this letter you have received a survey and letter of consent. If you would like to participate in the research, please fill out the survey and return it at your earliest convenience. You will be provided a preaddressed and stamped envelope in which to return it in. As the primary researcher in this study I will be the only one to review the returned surveys. Again, this survey is anonymous so no personal information will be required. If you have questions about this research feel free to contact either myself or my advisor.

Thank you for your time,
Annalee McGowan
amcgowa@bgsu.edu
(513) 678-6726
Or
Dr. Nancy Orel
norel@bgsu.edu
(419) 372-7768
Informed Consent for Caregivers of Adults with Developmental Disabilities

Caregiver Needs

Introduction: Hello my name is Annalee McGowan and I am a graduate student at Bowling Green State University. I am pursuing a graduate degree in Gerontology and my area of focus is on adults with developmental disabilities. My advisor is Dr. Nancy Orel, Director of the Gerontology program. My research topic is focused on finding the unmet needs of caregivers who provide care for adults with developmental disabilities. I am also seeking to determine which aspects of caregiving are being met. As a caregiver of an adult making use of the services offered by Wood Lane I invite you to participate in this study. This survey is not an evaluation of the services offered through Wood Lane, but rather it is a means to discover what types of services are needed for caregivers.

Purpose: The purpose of this research is to determine if caregivers of adults with developmental disabilities are receiving the support they need. The goal is to determine what areas caregivers would benefit from assistance in caring for the adult with disabilities, and identify areas in which they believe they are receiving adequate assistance. The benefits of this survey will assist in policy and program development.
Procedure: Included with this letter, you have received a survey which includes questions regarding different aspects of caregiving. Each question will provide a scale to rank answers or space in which to mark answers in. For each of the questions choose the option that most resembles your thoughts about the topic. Should you choose to participate in the survey, it should take you approximately 10 minutes to complete. When you have finished please place the survey in the preaddressed envelope and return it to Wood Lane.

Voluntary Nature: Your participation in this survey is completely voluntary. You do not have to complete the survey. If you do begin the survey you may choose to withdraw at any time. Your decision to participate or not participate will in no way affect the services you or your adult child receives from Wood Lane or your relationship with Bowling Green State University.

Anonymity Protection: All data collected will be anonymous and will not be linked to you. You have received a preaddressed and stamped envelope to return the survey in. Please do not put any identification marks on the envelope or the enclosed survey. For example, do not write your name or the name of the person being cared for on the survey and do not place a return address on the envelope. This will help to ensure that the responses remain anonymous. Returning the survey will be your acknowledgement of consent. The surveys will be kept in a locked office at Wood Lane and only reviewed by the researcher. Any data collected will be kept on a password protected computer at the researcher’s residence to ensure your information is kept private.

Risks: The risks of participation are no greater than that experienced in daily life. However, if you need to speak with someone please contact the staff at Wood Lane.
Contact Information: If you have any questions about my research or your participation please contact me or my advisor: Annalee McGowan, Principle Investigator, amcgowa@bgsu.edu or (513) 678-6726 or Dr. Nancy Orel, Advisor, norel@bgsu.edu or (419) 372-7768. Participants may also contact the Chair of the Human Subjects Research Board at 419-372-7716 or hsrb@bgsu.edu if participants have any questions about their rights as a participant in research. Thank you for your time.
DATE: May 1, 2014
TO: Annalee McGowan
FROM: Bowling Green State University Human Subjects Review Board
PROJECT TITLE: [580218-2] Evaluation of County Services for Caregivers of Adults with Developmental Disabilities
SUBMISSION TYPE: Revision
ACTION: DETERMINATION OF EXEMPT STATUS
DECISION DATE: April 30, 2014
REVIEW CATEGORY: Exemption category # 2

Thank you for your submission of Revision materials for this project. The Bowling Green State University Human Subjects Review Board has determined this project is exempt from IRB review according to federal regulations AND that the proposed research has met the principles outlined in the Belmont Report. You may now begin the research activities.

Note that an amendment may not be made to exempt research because of the possibility that proposed changes may change the research in such a way that it is no longer meets the criteria for exemption. A new application must be submitted and reviewed prior to modifying the research activity, unless the researcher believes that the change must be made to prevent harm to participants. In these cases, the Office of Research Compliance must be notified as soon as practicable.

We will retain a copy of this correspondence within our records.

If you have any questions, please contact Kristin Hagemyer at 419-372-7718 or khagemy@bgsu.edu. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within Bowling Green State University Human Subjects Review Board's records.