

FUTURE PLANNING FOR ADULT CHILDREN WITH DISABILITIES:
THE IMPACT OF LONG-TERM SUPPORTS AND SERVICES AND
CAREGIVER PSYCHOLOGICAL WELL-BEING

A DISSERTATION

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BY

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DEDICATION

I dedicate this endeavor to my parents for encouraging me to be self-sufficient and to pursue my dreams.

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ABSTRACT

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Research shows that as of 2015 in the United States, an estimated 71% of individuals with a developmental disability or mental illness live with a family caregiver (Heller, 2017). The problem addressed in this study is that many of those caregivers are 60+ years of age and are facing end-of-life decisions about their adult family member without adequate long-term supports and services. It is important to look at this population from an ecological framework. The purpose of this dissertation is to (1) evaluate the relationship of the aging caregiver's psychological well-being to his/her future planning for adult children with a developmental disability and/or mental illness; and to (2) evaluate the relationship of the adult child's receipt of or need for long-term supports and services to the aging caregiver's motivation to plan for the adult child's future after the caregiver is no longer able to provide care. A subsample of graduates and siblings for this study was drawn from the original Wisconsin Longitudinal Study that studied randomly selected graduates from all Wisconsin high schools in 1957 over their lifetime until 2011. Even though the results of the analysis were not statistically significant, this study provides justification for using an ecological framework from

which to study implications for public policy, practice and research into future planning strategies for individuals with DD/MI.

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CHAPTER I

INTRODUCTION

A Study on Future Planning for Adult Children with Disabilities

Future planning for aging caregivers of adults with developmental disabilities and/or severe mental illness is affected by any number of factors that occur within the individual's bio-ecological context. According to the 2011 U.S. Census Bureau, there are an estimated 11 million individuals with non-normative conditions (defined in this study as a developmental disability and/or mental illness), aged 18 or older living independently or with family members in the United States (Saxena, 2015). With today's advances in the quality of health care, individuals with a developmental disability (DD) or mental illness (MI) are living longer and requiring an extended period of care-giving services, which puts a strain on families and public resources. Along with this factor is a greater demand for federal, state, and local support services that are already experiencing long waiting lists, closing facilities, and a shortage of allocated funds (Braddock et al., 2017). Therefore, aging adults who care for an adult child with a DD/MI face difficult decisions about the future care of that child. The need for long-term supports and services (LTSS) is projected to double by 26 million by 2050 (Grossman & Magana, 2016). Those LTSS may be more problematic for families of children with a serious mental illness than with just a developmental disability.

With the mounting state and national fiscal debt and the increasing numbers of older caregivers in the United States, the lack of adequate social policies and programs

affects more and more caregivers and care recipients, resulting in stressful decisions, especially at the end of life. In addition, the mental health system in the United States is fragmented and unable to serve those who need those services (Ghosh, Greenberg, & Seltzer, 2012). Many states do not have waiting lists (Texas is one), so the estimates of families waiting nationally for residential services is grossly underestimated (Heller, Caldwell, & Factor, 2007).

Public policy for caregivers of DD/MI is underfunded or non-existent. There are only two federally funded programs specifically designed to provide support for caregivers of adults with disabilities. The National Family Caregiver Support Program, enacted under Title III-E of the Older Americans Act Amendment of 2000, provides funds to states to help caregivers of adults over age 60 (Arnold, Heller, & Kramer, 2012). The Lifespan Respite Care Act, enacted in 2006 but not funded until 2009, provides in-home and out-of-home respite services for caregivers of children and adults with special needs. Funding of these two policies is problematic and competitive (Arnold et al., 2012).

The demand for support services is outweighing the availability of needed long-term care, placements and interventions. Thus, the stress of worrying about the future care of one's family member with DD/MI can affect the caregiver as well as the care recipient. Professionals in the LTSS areas must be proactive in advocating for caregivers in this population to help them find the necessary services. In Texas, for example, the number of LTSS recipients with DD or MI almost doubled from 2005 to 2016 (25,251 to 44,632; Larson et al., 2018). Unmet support and service needs include respite services,

case management, transportation, recreational services, housing options, financial planning, and guardianship procedures (Heller et al., 2007).

Statement of Problem

Research shows that as of 2015, in the United States, an estimated 71% of individuals with a developmental disability or mental illness live with a family caregiver (Heller, 2017). The problem addressed in this study is that many of those caregivers are 60+ years of age and are facing end-of-life decisions about their adult family member without adequate LTSS. Many aging parents of adults with DD/MI are ill-equipped or do not know where to turn to make decisions or plans that protect the rights of their loved ones without putting them in danger of losing benefits or of being placed inappropriately. Of the total national expenditures in 2015 for family support in the United States, only 15% of families caring for a family member with a disability received financial support (Larson et al., 2018).

With LTSS already strained, decisions are even more tenuous for caregivers struggling to find the proper supports after they are gone. The waiting list for residential out-of-home services is daunting. As of 2014, in the United States, there were 100,000 individuals waiting for residential out-of-home services; and there were twice as many waiting for any type of long-term support (Larson et al., 2018). The health needs that characterize this growing population also add new challenges on existing service networks (Heller, Scott, Janicki, & Pre-Summit, 2017). Therefore, it is important for researchers to investigate what supports (or lack of), such as increased technology

services, psycho-educational initiatives and family support policies, might improve the circumstances of the caregiver as well as the individual with a DD/MI in the later stages of life. It is also important to be proactive in assisting families in this population to plan for the future care of their family members with DD/MI.

Researchers agree that there is a dearth of research on how the caregivers of family members with DD/MI are impacted in old age (Hodapp, Sanderson, Meskis, & Casale, 2017). Looking at the relationship that exists with a caregiver's psychological well-being, his/her receipt of or need for LTSS for the DD/MI child, and his/her anxiety about the future of that adult child through the lens of an ecological framework may help to answer questions about why aging caregivers are worried about the future care of their DD/MI care recipients and to suggest possible steps for improving the availability of the services they need. Using an ecological framework is justified because of the current complex changes within the public service sector that may affect the family context.

Purpose of the Study

The purpose of this dissertation is (1) to evaluate the relationship of aging caregiver's psychological well-being to his/her future planning for adult children with a developmental disability and/or mental illness and (2) to evaluate the relationship of the adult child's receipt of or need for long-term supports and services to the aging caregiver's motivation to plan for the adult child's future after the caregiver is no longer able to provide care. This study may have implications for public policy, practice, and research into future planning strategies for individuals with DD/MI.

This study used data from the Wisconsin Longitudinal Study, a population-based study in Wisconsin that uses data that extends from the high school graduates through their life span from 1957 through 2011 and siblings from 1977 through 2011 (Seltzer, Greenberg, Floyd, & Hong, 2004), to study the relationship of future planning to psychological well-being and the relationship of future planning to the receipt of or the need for LTSS utilizing an ecological framework. This view is especially applicable because of the ongoing dynamics within the family system and its ecological environment.

Research Questions

More research needs to be conducted into what influences a caregiver's likelihood to plan for the future care of a family member who has DD/MI. The need for further research into this area leads to the following research questions, which guided this study:

RQ1. To what extent does the receipt of long-term supports and services influence the adult caregiver's likelihood to plan for the future of a family member with DD/MI?

RQ2. To what extent does the need for long-term supports and services influence the adult caregiver's likelihood to plan for the future of a family member with DD/MI?

RQ3. To what extent does the adult caregiver's level of psychological well-being influence the likelihood to plan for the future of a family member with DD/MI?

Significance of the Study

This study is significant because it may provide insight into barriers to how aging caregivers' plan for the future care of the family members with DD/MI. This study may also be able to suggest weaknesses in current family support policy. Individuals and families with DD/MI are in danger of being victims of poorly thought out and ineffective public policies, in situations where public expenditures are being cut (Disability Policy Consortium, 2013).

Having a child or other family member diagnosed with an intellectual and/or developmental disability is a traumatic event to a family. The diagnosis affects the whole family system: parents, siblings, and extended family subsystems, especially in old age. In some cases, families who already face problematic situations and have poor communication and problem-solving skills and poor health are even more challenged psychologically, physiologically, and behaviorally when faced with the future of the family member after the caregiver's death. Future research that incorporates the entire family system will benefit the support processes needed by primary caregivers (Canary, 2008).

Understanding the caregiver's ability to manage his or her environment, as it relates to having a child with a disability, may provide some insight into possible barriers to planning for the future care of the child. Secondly, understanding the caregiver's goals and sense of direction, within the context of having a child with a disability, may provide insight into having a more positive outlook for the future. Finally, understanding the

relationship between the need for long-term supports and services and planning for the future may help service providers promote more structured end-of-life planning for the caregiver and the care recipient.

Terminology and Definitions

The following definitions of terms were used to define concepts related to this study:

Non-normative Conditions: Any diagnosable developmental disability or long-term, serious mental health problem (User's Guide, 2011).

Developmental Disability: Identified by Wisconsin Longitudinal Study as sons or daughters with the following conditions: mental retardation, Down syndrome, cerebral palsy, autism spectrum disorder, brain injury before age 22, fragile X, fetal alcohol syndrome, and several other very rare conditions (User's Guide, 2011).

Mental Illness: Identified by Wisconsin Longitudinal Study as sons or daughters with the following conditions: bipolar disorder, schizophrenia, and psychotic episodes (User's Guide, 2011).

Wisconsin Longitudinal Study: A population-based study in Wisconsin that uses data that extends from the high school graduates and siblings through their life span from 1957 through 2011 (Seltzer et al., 2004).

Long-Term Supports and Services: Include a range of paid and unpaid medical and personal care assistance for people who experience difficulty as a result of aging, chronic illness, or disability (Reaves & Musumeci, 2015).

Psychological Well-Being: A multi-dimensional concept of wellness that includes a positive image of one's self and one's life, feelings of personal growth, a belief that there is purpose and meaning in one's life, the ability to effectively manage one's life and environment, a positive relationship with others, and a sense of control and the ability to make rational decisions (Ryff, 1995).

Future Planning: Planning and executing the necessary set of activities that will provide best-choice supports available for individuals with DD/MI and their families in the future (Burke, Arnold, & Owen, 2018).

Limitations

One of the limitations for this study is that the Wisconsin Longitudinal Study (WLS) is not nationally representative, since the original cohort is made up of graduates and siblings of Wisconsin high schools who graduated in the late 1950s and early 1960s. Most of the sample is Caucasian, with only a few African American, Hispanic, or Asian ethnic groups. The age range of the graduates is homogeneous, since they all graduated in 1957. Approximately 2,000 siblings of the graduates were empaneled in 1977, most of whom are 6 to 8 years younger than the graduates (Herd, Carr, & Roan, 2014).

Delimitation

The delimitation for this study is in my selection of questions taken from the WLS data to address the research questions. Only select questions from the Non-Normative Screener Modules in the 2003-2005 (R5) Wave for graduates and the 2004-2007 (R5) Wave for siblings were pulled to represent the variables in this study.

Assumptions

It is assumed that all WLS data, samples and variables within the study have been drawn honestly and with the highest confidentiality.

CHAPTER II

LITERATURE REVIEW

Future Planning for Adult Children with Disabilities: The Impact of Long-Term Supports and Services and Caregiver Psychological Well-Being

This chapter presents a review of the literature regarding the importance of receiving the LTSS needed to care for an adult child with a DD and/or MI. It also discusses whether the caregiver's motivation to future plan for an adult child with a DD/MI is influenced by the receipt of LTSS or the level of need for LTSS and the caregiver's psychological well-being. Looking at the relationship that exists with a caregiver's psychological well-being, the receipt of or the need for LTSS, and the level of future planning from an ecological framework may lead to social policies and programs for improving the availability of the services these caregivers need.

Over the life span, each of us experiences many challenges that shape our character and determine how we will handle various situations. Psychologists have studied human behavior and human reaction to different circumstances in an attempt to explain what influences and impacts human behavior. Changes in society, in the environment and in political policies can influence human behavior, resulting in stressful relationships. In addition to an increase in the number of aging LTSS recipients, there is also an increase in minority and diverse populations in the US, prompting a greater need for more cultural and language-specific services. Family support policy is not a national

priority in the US (Heller et al., 2007), which also adds to the difficulty that these caregivers face.

According to Talley and Crews (2007), the future of care giving will depend upon the complex relationships among care partners worldwide: care receivers, family caregivers, professional service providers, and societal/political/scientific forces across a variety of cultures. Little is known about how caregivers' context influences long-term supports, psychological well-being, or future planning. Policy makers must consider the changing global community as well as the family context in formulating policies for those who have special needs, making this issue especially important to study in an ecological framework. Understanding these changing needs is paramount to the success of formal supports and services for U.S. disability populations (Williamson & Perkins, 2014).

Ecological Framework

A bioecological model of human development (Bronfenbrenner & Morris, 2006) within a family context of environmental interaction offers a good framework around which to study the relationship between long-term supports and services, psychological well-being, and future planning involving aging family caregivers of adults with DD/MI. This theoretical framework can illuminate how intertwined these factors are with the decisions made in different state and federal policy sectors and the decisions made by families of caregivers and care recipients. How well an individual fits within his/her environment may be dependent upon how well connected and engaged he/she is within a

supportive network. The amount of support needed versus the amount of support available may have a direct effect on family context. Current policy strategies, along with the shortage of adequate long-term supports and services, seriously threaten the well-being of caregivers of family members with DD/MI (Eckenwiler, 2007). The ecological framework focuses on the individual who can affect his/her own environment and context (Saxena & Adamsons, 2013). The bioecological model of today encompasses all of the economic and social changes that present potentially greater disruptive scenarios for 21st century families. It is important for disability research to understand the importance of how the social context influences families with a child with DD or MI (Stoneman, 2005).

Urie Bronfenbrenner (Friedman & Allen, 2010) adapted Ludwig von Bertalanffy's general systems theory to include a bioecological perspective, the whole being more than the summation of its parts (i.e., parents, siblings, extended family, relationships, environment, etc.). Whereas von Bertalanffy viewed the reinforcing interactions that occur within a social system as a simple cause and effect relationship; Bronfenbrenner, on the other hand, believed that these relationships were much more complex and were involved with external forces. Bronfenbrenner was concerned with how the individual interacted with his environment, and he referred to these interactions as the ecological environment (Friedman & Allen, 2010). Bronfenbrenner likened this ecological concept to a set of nested Russian dolls, with the focal individual being at the core; the outer layers representing additional environments or settings that affect the developing person (Bronfenbrenner, 1986).

In his bioecological model, Bronfenbrenner defined *development* as a continuous change in the biological and psychological characteristics of human beings (Bronfenbrenner & Morris, 2006). The ecological theory evolved from a major focus on environment to a focus on the process of understanding development in terms of the person interacting with his immediate and remote contextual environments over time.

According to Bronfenbrenner and Morris (2006), there are four defining properties of the bioecological model, which they referred to as the *process-person-context-time* model. The person is the focus of the developmental process that takes place in various contexts across time.

The person embodies the unique genetic, biological, and psychological characteristics of the individual within an immediate external environment (Bronfenbrenner & Morris, 2006). These personal characteristics do not just happen, how they manifest depends upon the individual's interactions and interpretations of their experiences at different levels within that environment (Saxena & Adamsons, 2013). Bronfenbrenner identified person characteristics into three categories: demand, resource and force characteristics. Demand characteristics include age, gender, race, disability, and physical appearance. Resource characteristics are not immediately recognizable and include mental, emotional, and socio-economic/support resources. Force characteristics are the individual's unique motivations, perceptions, and resilience in the face of hardships (Saxena & Adamsons, 2013).

Within the context component, Bronfenbrenner identified five interrelated systems: microsystem, mesosystem, exosystem, macrosystem, and chronosystem (Ravindran & Myers, 2012). The microsystem is made up of the person, the family, the school and other environments within his/her immediate surroundings, with which the person interacts. Besides family and school, the person may interact with support groups, church groups, and social groups, which may have positive psychological influences on the person's well-being. A positive psychological well-being leads to enhanced mastery, resilience, and effective coping (Saxena & Adamsons, 2013).

The availability of socio-economic and long-term supports and services can reinforce a positive psychological well-being. The direct interaction of the person with his/her support network is an example of the microsystem interacting with the mesosystem. Resources outside the immediate family, such as the community and long-term support services, and financial difficulties are part of the person's exosystem because they indirectly affect the person. The public and social policies and sociocultural beliefs that may limit or enhance long-term supports and services are part of the macrosystem, which affects elements in the exosystem and microsystem. For example, Section 504 of the Rehabilitation Act in 1973 provided long-term supports and services for individuals with disabilities and their families (Saxena & Adamsons, 2013), thus providing them a better quality of life. Since the 1970s, changes have been made in social policy, cultural values, and laws that have led to a better understanding of disability and

how it affects the family system. Thus, the chronosystem interacts with the other systems of Bronfenbrenner’s bioecological model.

The purpose of this dissertation is (1) to evaluate the relationship of aging caregiver’s psychological well-being to his/her future planning for adult children with a developmental disability and/or mental illness and (2) to evaluate the relationship of the adult child’s receipt of or need for long-term supports and services to the aging caregiver’s motivation to plan for the adult child’s future after the caregiver is no longer able to provide care. Table 1 illustrates how the variables for this study fit within an ecological framework.

Table 1

Variables in Ecological Framework

Variable	Microsystem Individual/Interpersonal	Exosystem Organizations/Community	Macrosystem Public Policies
Psychological Well-Being	X		
Future Planning	X	X	
Need for LTSS		X	X

Modified from Williamson & Perkins, 2014

From an ecological framework, the need for long-term supports and services should be studied from the exosystem layer and the macrosystem layer, since public policy may affect the exosystem. Psychological well-being is within the individual and can best be studied as part of the microsystem. Factors that affect future planning usually involve the family at the microsystem level but can involve local resources, such as lawyers, within the exosystem. Although not a variable in this study, the macrosystem will be discussed as far as it involves the sociocultural environment that indirectly affects the individual by affecting elements in the exosystem and microsystems. Changes at the macrosystem affect the life situations of the person and in turn his/her sense of psychological well-being (Ryff, 1989).

Long-Term Supports and Services

Historically, long-term supports and services for adults aging with DD/MI have ranged from the sheltered workshops and state institutions of the 1970s and 1980s, to age-appropriate settings such as nursing homes in the 1990s, to person-centered planning focusing on the self-determination of adults with disabilities within their family and community contexts. Currently, the focus is on the human rights of those with disabilities, giving them the right to full inclusion in the community, to a universal design of learning, and to supported decision making for the future (Heller et al., 2017). The delivery of long-term supports and services are embedded within Bronfenbrenner's macrosystem layer. Bronfenbrenner conceived this level to be a larger society that is

made up of cultural variations, public policies, and laws that have a challenging influence on the individual and family with disabilities (Algood, Harris, & Hong, 2013).

Caregivers who do not have a network of strong long-term supports and services may suffer elevated levels of physical and or mental health symptoms (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001), which puts the care recipient at risk of misplacement or worse. Aging caregivers need to be educated on the ever-changing avenues to care options for their child with DD/MI. Taggart, Truesdale-Kennedy, Ryan, & McConkey (2012) proposed that governments and policy makers provide the means for caregivers to be proactive in providing the support necessary for the future of relatives with intellectual disabilities. It may also be the responsibility of support service providers who work with this population to get the information out to caregivers. This may involve special training, new intervention techniques, and advocacy groups (Parish & Lutwick, 2005).

Suggestions for broader, more inclusive policies include consumer-directed supports, support initiatives, and supportive legislation. Consumer-directed supports (a Medicaid-based program in some states) provide families with cash subsidies or vouchers, such as the Consumer Directed Services (CDS) program in Texas under the Texas Department of Aging and Disabilities Services ([DADS], 2015). Federal family support initiatives should collaborate across the aging and developmental disabilities service systems to bring about a network of services that work in parallel to one another. For example, the National Family Caregiver Support Program, established in 2000,

provides grants to states and territories to fund supports for caregivers of family members with disabilities (National Family Caregiver Support Program, 2019). Other legislation could include giving caregiver tax credits, enhancement of Family and Medical Leave Act, and the Lifespan Respite Care Act, which authorizes state funding to coordinate respite services (Heller et al., 2007).

On the local level, services such as case management, income support, medical assistance, crisis intervention, psychological services and respite are important to the well-being of the family context where DD/MI are present. If the caregiver family or the individual with a DD/MI is not eligible for Medicaid or Medicare, getting these services may become problematic. Even if eligibility requirements are met, services vary broadly by state and/or region.

Local support groups may provide an avenue for caregivers to access emotional and informational support. Neely-Barnes, Graff, Marcenko, & Weber (2008), found that consumer-directed support programs and family involvement predicted an increase in caregiving satisfaction with services and greater access to services for the care recipient. Anxiety was higher for caregivers of DD children when social supports were lower and when stressful events occurred (Barker et al., 2011).

Understanding the needs of families who care for aging special needs persons is vital if policy makers are to provide effective formal resources and services (Williamson & Perking, 2014). Several studies call for increased assessment tools to better understand the diverse challenges, supports and resources that caregivers need to adapt to the ever-

changing circumstances within their family context (Kelly, Wolfe, Gibson, & Feinberg, 2013; Park, Hoffman, Marquis, Turnbull, Poston, Mannan, & Nelson, 2003; Samuel, Hobden, LeRoy, & Lacey, 2012). The Pre-Summit Workgroup on Caregiving and Intellectual and Developmental Disabilities suggests that research in the aging field and research in the DD/MI fields be integrated to better understand the impact of caregiving on families as they adapt to caring for a family member with DD/MI (Heller et al., 2017), especially in old age. Even though advances have been made to improve opportunities for persons with DD/MI and their family caregivers, progress is slow. The question is whether the progress has a positive or a negative impact on the psychological well-being of families in this population.

The amount of perceived level of LTSS may impact the caregiver's physical and mental well-being (Grey, Totsika, & Hastings, 2018). Caregivers with higher support needs were associated with higher levels of stress, especially in light of changes in policy and family context.

Psychological Well-Being

At the microsystem level of the ecological framework, which may have the greatest impact on the individual, the stress of worrying about the future care of one's family member with DD/MI can affect the caregiver's psychological well-being as well as the health of the care recipient. How one makes sense of life experiences, especially in the context of caring for a child with DD/MI, affects one's psychological well-being.

Higher psychological well-being correlates with satisfaction of psychological needs (Milyavskaya, Philippe, & Koestner, 2012).

Ryff's (1995) psychological well-being is an inter-related, multi-dimensional concept of wellness that embodies a positive evaluation of one's self and one's life, feelings of personal growth and improvement, a belief that one's life has purpose and meaning, the capacity to master one's life and environment effectively, a positive relationship with others, and a sense of purpose and ability to make decisions. Ryff's model of well-being is consistent with a eudaimonic perspective on Aristotle's formulation of human good, which has evolved into the concept of self-realization (Ryff, 2014). Ryff's Psychological Well-Being scales have withstood extensive testing and scrutiny and have been translated into 30 different languages (Ryff, 2014). The scales have been used extensively in research. For example, Springer, Pudrovskaya, and Hauser (2011), examined Ryff's scales of psychological well-being to determine if age and maturation influenced the results of the survey. Springer et al. found that age and maturity explained only 1% of the variance in psychological well-being dimensional scores. Psychological well-being, as envisioned by Carol Ryff (1995), includes six dimensions: autonomy, environmental mastery, personal growth, positive relations, purpose in life, and self-acceptance (see Table 2). This conceptual framework of wellness was used by the WLS to survey the well-being of graduates from Wisconsin high schools in 1992-1993 and 2003-2005.

Table 2

Ryff's Dimensions of Well-Being

Autonomy	Having the strength to follow personal convictions, even if they go against conventional wisdom
Environmental Mastery	Being able to manage the demands of everyday life
Personal Growth	Feeling that personal talents and potential are being realized over time
Pos. Relation with Others	Having close, valued connection with significant others
Purpose in Life	Having goals and objectives that give life meaning and direction
Self-Acceptance	The capacity to see and accept one's strengths and weaknesses

Ryff, 1989

Autonomy. A person who exhibits autonomy is one who has the inner strength and motivation to control one's own behavior and has a desire to be self-sufficient. A person who scores high on Ryff's (1989) psychological well-being scale is self-determined and independent, has personal insight, and is able to resist social pressures to think and act in certain ways. Autonomy is within the individual and is therefore part of

the microsystem. Parents who exhibit autonomy are more supportive, more personally effective, and better able to relate to the needs of the child with DD/MI (Dieleman et al., 2019). Transitioning to a new environment, as relates to future planning for out-of-home placement, requires autonomy in order to determine best choices for all involved. Parents who are self-determined, problem-focused, and willing to resist social pressures are better advocates for their children with DD/MI.

Dieleman et al. (2019) examined the relationship between parental autonomy and child behavior on a given day and found that there was an indirect effect on the parent's level of autonomy and the behavior of the child on that particular day. Dieleman et al. imply that a parent's need-related psychological functioning may be determined by the day-to-day variations in the child's behavior. Deci and Ryan (2000) considered how need determines behavior. Deci and Ryan posit that need is essential to autonomy, relatedness, and competence, which ensure positive well-being. Ahrens and Ryff (2006) found that well-educated women who played multiple caregiver roles tended to have higher levels of autonomy. Parents of children with DD/MI, who also care for other family members, have greater role involvement. Receiving the appropriate supports and services often leads to greater autonomy and environmental mastery for both caregivers of DD and/or MI (Grossman & Magana, 2016).

Environmental mastery. A person exhibiting environmental mastery is defined by Ryff (2014) as someone who is competently optimistic in controlling his/her environment, is able to adjust to external challenges, takes advantage of surrounding

opportunities, and is able to make choices about suitable needs and values. A mature individual is able to adapt to diverse situations and demands. Aging caregivers of adults with DD/MI who feel in control of their microsystem and are able to understand their situational environments will be able to plan for the future of their loved ones when they are no longer able to care for them. Differences between the stressors experienced by parents of children with a severe mental illness and the stressors experienced by parents of children with a developmental disability may determine the level of adjustment to the environment.

Seltzer et al. (2004) studied accommodative coping in terms of positive well-being outcomes on environmental mastery. Accommodative coping was defined as the ability to modify one's goals to fit the circumstances or environment in which they find themselves. Seltzer et al. found that parents of children with severe mental illness had lower levels of environmental mastery as opposed to higher levels of environmental mastery and self-acceptance for parents of children with developmental disabilities. Parents who have children with only a developmental disability were better able to adjust to new roles and gain expertise of the disability challenges (Ryff, 2014). A positive psychological well-being leads to enhanced mastery, resilience, and effective coping (Saxena & Adamsons, 2013).

Personal growth. Higher well-being has been linked to personal growth. To achieve psychological well-being one must continue to grow in ones thinking and problem-solving skills. Personal growth is the ability to continually develop, to set goals,

to be open to learning and new experiences, and to change in ways that reflect an expanding sense of self-actualization (Ryff & Keyes, 1995). Aging caregivers who have an elevated level of personal growth are more likely to be open to diverse challenges and to set goals, especially as related to planning for end-of-life events. Bauer and McAdams (2000) found that older people set long-term life goals that are based on intrinsic concerns, such as caring for a child. Family caregivers in Texas reported increased intimacy, personal growth, and comfort after attending structured educational sessions (Mastel-Smith & Stanley-Hermanns, 2012).

Positive relations with others. Having positive relationships with others leads to improved networks of communication, a concern for the welfare of others, and empowerment (Ryff, 1989). Aging caregivers who have positive relations with others are more likely to search for ways to meet the needs of their loved ones with DD/MI. Caregivers can access more information regarding the disability, make more social connections, and receive more emotional support if they are members of a local support group (Grossman & Webb, 2016).

Purpose in life. Springer, Pudrovskaya, and Hauser (2011) found that purpose in life and personal growth tend to decline with age. A person whose purpose in life is well-defined is someone who proactively has a direction and goal for living and for the future, values the meaning of present and past life experiences, and whose beliefs make life meaningful (Ryff, 2014). Research has shown that those with high levels of purpose in life exhibited better cognitive functioning (Boyle, Buchman, Wilson, Yu, Schneider, &

Bennett, 2012), optimism about the environment (Ferguson & Goodwin, 2010), and reduced rates of mortality (Boyle, Barnes, Buchman, & Bennett, 2009). Planning for the future will be successful if goals have been set and followed, especially for those caregivers of adult children with DD/MI.

Self-acceptance. Healthy levels of self-acceptance lead to a positive self-image, better coping strategies, and a positive outlook on life circumstances (Ryff, 1989). Self-acceptance is the ability to accept one's strengths and weaknesses in the past and in the present; it is a focus of self-actualization and is important in maintaining a direction for the future (Ryff, 2014). Salmon, Kwak, Acquaviva, Brandt, & Egan (2005) studied caregiving at the end of life, using self-acceptance as a mediator. Salmon et al. found that if caregivers were able to navigate the challenges in caring for a loved one without compromising self-acceptance, they experienced lower levels of caregiver burden and satisfaction with how they gave care.

Future Planning

According to Burke et al., (2018), future planning is defined as any planning and executing of the necessary set of activities that will provide best-choice supports available for individuals with DD/MI in the future. Having a clear plan for the future entails being satisfied with what is happening at the microsystem (individual and interpersonal), exosystem (organizational and community), and macrosystem (public policy) levels of the ecological framework (Williamson & Perkins, 2014). Changes need

to be made on all three levels in order to address the needs of individuals with disabilities and their families (Grossman & Magana, 2016).

Taggart et al. (2012) found that aging caregivers of individuals with DD/MI received little useful information to help them with their preferences for end-of-life planning and/or the support systems that they needed to succeed in those plans. Suggestions by caregivers themselves include providing accessible information in a timely manner, offering one-to-one support and guidance, and preparing individual future plans early, before a crisis occurs. Carr and Khodyakov (2007) found that higher education may influence how people plan for end of life planning.

Although some progress has been made, the greatest barrier to future planning for adult caregivers of individuals with DD/MI continues to be the lack of needed supports and services (Burke et al., 2018). Other possible barriers to future planning by the aging adult caregiver include avoidance because of the painful emotions involved with leaving their loved ones, lack of practical support and knowledgeable advice about the best options, lack of suitable housing options or residential facilities, and difficulty in affording knowledgeable attorneys to ensure correct legal processes (Heller & Caldwell, 2006). Therefore, it is incumbent on service providers and governments to explore and to make system/global changes that will improve ways that caregivers get their information. Caregivers need to be encouraged to plan ahead (The Arc of the United States, 2017).

Inter-Relatedness

Psychological well-being, receipt of or need for LTSS, and planning for the future may be inter-related when experienced by families who have loved ones with DD/MI. This relationship may explain how external events in the exosystem and macrosystem take on internal psychological significance at the microsystem level and why this interrelationship is important. Utilizing Bronfenbrenner's concepts of process, person, context, and time may also explain how relationships on multiple levels across time may affect decisions, made or not made, by aging caregivers of adults with DD/MI. The purpose of this study is (1) to evaluate the relationship of aging caregiver's psychological well-being to his/her future planning for adult children with a developmental disability and/or mental illness and (2) to evaluate the relationship of the adult child's receipt of or need for long-term supports and services to the aging caregiver's motivation to plan for the adult child's future after the caregiver is no longer able to provide care. This study may have implications for public policy, practice, and research into future planning strategies for individuals with DD/MI.

Receipt of or need for LTSS and psychological well-being. Psychological well-being in aging caregivers of adults with DD/MI could be influenced (either positively or negatively) by the level of their need for long-term supports and services for their loved ones. Caregivers who receive the long-term supports and services that they need for their loved ones, may exhibit high levels of autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance. Conversely, if

they are not receiving the LTSS that are needed, they may exhibit low levels on all dimensions of the psychological well-being assessment.

Ferguson and Goodwin (2010) studied optimism in older adults as related to perceived social support and perception of control. Ferguson and Goodwin found that optimism was a major contributor to well-being in older adults and that positive perception of support and expectations played a role as well. Sharifian and Gruhn (2018) studied the differential impact of social participation and social support on psychological well-being across the life-span. Sharifian and Gruhn (2018) found that social support did not act as a buffer for age-related decline in psychological well-being, but that higher social participation resulted in higher psychological well-being. Sharifian and Gruhn suggested that higher social participation opens avenues to accessing other needed resources and maximizing psychological well-being. Thus, the more socially involved aging parents of an adult child with DD/MI, the more likely they are to find valuable resources that they may need for their child. The more connected to others (i.e., support groups) an aging caregiver is increases his/her sense of meaning and purpose in life leading to a sense of mastery in the role obligations as a caregiver (Gilmour, 2012). Participation in support groups may be associated with lower levels of caregiver burden.

Aging adult caregivers may hesitate to ask for help due to implications to their self-esteem (Nadler & Fisher, 1986) and sense of control over their environment. Kawachi and Berkman (2001) found that the need for help due to a decline in physical ability may lead to feelings of dependency and inferiority. Caregivers' inclination to ask

for help may also be negatively influenced by cultural differences, the severity of the recipient's disability diagnosis, the perceived level of support needed or available (Grey et al., 2018), and remoteness to sources of support, among others. Older caregivers are more likely to not ask for additional support needs than younger caregivers (Hayden & Heller, 1997). The type of disability of the care recipient may also be an influential factor in determining the predictors of psychological well-being (Seltzer & Heller, 1997).

Receipt of or need for LTSS and future planning. Planning for the future of an adult child when the caregiver is no longer able to do so may be influenced by the level of their need for long-term supports and services. However, many parents do not discuss future planning with other family members (Heller & Factor, 1994). Even when they do pursue future residential placement, they are put on long waiting lists (Heller, 2000). Barriers to the planning process need to be understood, and steps need to be taken to counteract those barriers. When barriers hamper the success of future planning, the care recipient may be in danger of misplacement or worse.

Planning for the future of loved ones with DD/MI may be a source of great anxiety for aging caregivers (Smith, Hatfield, & Miller, 2000). According to Burke et al. (2018), the greatest barrier to future planning is the lack of available services and/or the lack of knowledge about how to access those services. Therefore, if families of DD/MI members are given opportunities to learn about available long-term supports and services, they are more likely to be less anxious about conducting future planning. If they are aware of and satisfied with the level of support being given at the exosystem level, they

will be more willing to plan for and execute the necessary set of activities that will provide best-choice supports for the future.

Psychological well-being and future planning. Helping aging caregivers make concrete plans for the future of their loved ones with DD/MI likely reduces caregiver burden and increases caregiver well-being (Heller & Factor, 1991). Heller and Caldwell (2006) found that peer support groups involving other aging caregivers who are working on plans for the future of adult children with DD/MI led to reduced caregiver burden and increased psychological well-being. The emotional support provided by peer groups who have similar caregiver experiences was found to increase purpose in life and personal growth (Hong, Seltzer, & Krauss, 2001), two dimensions of psychological well-being. High levels of purpose in life lead to being open to the future (Ryff, 1989).

Differences between DD and MI

Parents of children with a severe MI tend to have greater challenges and are more stressed than those of children with only a DD (Seltzer et al., 2004). The unpredictability of their day-to-day experiences makes them more likely to have lower levels of psychological well-being as opposed to those parents of children with a DD. Ghosh et al., (2012), found that parents of children with a MI had higher levels of depression, especially if the child lived with them (Piazza, Floyd, Mailick, & Greenberg, 2014), than those without MI. Over time parents of mentally ill children reported poorer overall health. Late life caregivers of those with MI or DD were less likely to attend to their own health care needs and have experienced more financial barriers in accessing their own

medication and mental health services (Magana & Smith, 2008). If the aging caregiver's spouse developed a disability and their MI or DD child lived with them, the healthier caregiver was more likely to initiate a future planning process (Grossman & Webb, 2016).

Conclusion

With mounting state and national fiscal debt and the increasing numbers of older caregivers of individuals with DD/MI in the United States, the demand for support services is outweighing the availability of needed long-term care, placements, and interventions. Researchers agree that there is a dearth of research on how the caregivers of family members with DD/MI are impacted in old age (Hodapp et al., 2017). The problem addressed in this study is that many of those caregivers are 60+ years of age and are facing end-of-life decisions about their adult family member without adequate long-term supports and services. The waiting list for residential out-of-home services is daunting, and the need for long-term supports and services is projected to double by 2050 (Grossman & Magana, 2016).

The current study adds to the literature by examining the impact of the need for long-term supports and services on the adult caregiver's psychological well-being and the predicted level of future planning for the adult care recipient. The following research questions were explored, using hierarchical multiple regression.

RQ1. To what extent does the receipt of long-term supports and services influence

the adult caregiver's likelihood to plan for the future of a family member with DD/MI?

RQ2. To what extent does the need for long-term supports and services influence the adult caregiver's likelihood to plan for the future of a family member with DD/MI?

RQ2. To what extent does the adult caregiver's level of psychological well-being influence the likelihood to plan for the future of a family member with DD/MI?

Chapter Summary

This chapter presented a review of the literature regarding the importance of receiving the LTSS needed to care for an adult child with a DD and/or MI. It also discussed whether the caregiver's motivation to future plan for an adult child with a DD/MI is influenced by the receipt of LTSS or level of need for LTSS and the caregiver's psychological well-being. Looking at the inter-relationship that exists with a caregiver's psychological well-being, the receipt of or need for LTSS, and the level of future planning from an ecological framework may lead to social policies and programs for improving the availability of the services that these caregivers need.

CHAPTER III
METHODOLOGY

Chapter Overview

This chapter gives a summary of the WLS database and its sample, the subsample and measures used in this study, and the preliminary analysis used to study the relationship that exists with a caregiver's psychological well-being, the receipt of and need for long-term supports and services, and the level of future planning for an adult child with a DD/MI.

Database Summary

This study used data from the WLS, a population-based study in Wisconsin that uses data that extends from the high school graduates through their life span from 1957 through 2011. Following the original study with the graduates from Wisconsin high schools in 1957 (a random sample of 10,317 men and women), follow-ups were conducted in 1964, 1975, 1993, 2004-2007, and 2010-2011 (Herd et al., 2014). In the follow-up surveys, not only the graduates, but also their siblings and spouses were interviewed.

The WLS is recognized as one of the longest running, most-comprehensive cohort studies available (Herd et al., 2014). Researchers have used the WLS to study numerous areas, including family background, social support, psychological well-being, and end-of-life planning. The WLS data collection is funded by the United States' National Institute on Aging. Documentation and some data can be downloaded freely from

<http://www.ssc.wisc.edu/wlsresearch/>. Nonpublic data that is protected may be requested by qualified researchers. If approved, the researcher will receive access to the data via email.

The WLS original cohort was a random 1/3 sample of nearly every student in their senior year of high school across Wisconsin in 1957. Most of the sample was Caucasian, with only a few African American, Hispanic, or Asian participants (Herd et al., 2014). The age range of the graduates is homogeneous, since the sample graduated from high school in 1957; however, the sibling sample is more heterogeneous, ranging from 6 to 8 years younger than the graduate. Related to education, approximately 55% of the graduates and siblings had more than a high school education.

Study Subsample

The subsample ($N = 189$) used in this study was restricted to those graduates ($N = 127$) and siblings ($N = 62$), in the R5 non-Normative Wave of the WLS, who answered yes to *Do any children have a DD or MI?* (see Table 3). The non-normative child was first identified during the 1992-93 Wave of the WLS, when they were approximately 20 years of age. They would have been diagnosed for at least 12 years by the time the 2004-2007 Waves, used in this study, were conducted, making them approximately 40 years of age. The WLS identified the DD group as those sons or daughters with mental retardation, Down syndrome, cerebral palsy, autism spectrum disorder, brain injury before age 22, fragile X, fetal alcohol syndrome, and other rare conditions (User's Guide,

2011). Those sons or daughters in the MI group included those with bipolar disorder, schizophrenia, and psychotic episodes.

Table 3

Subsample Descriptives

Characteristic	Graduate (<i>N</i> = 127)	Sibling (<i>N</i> = 62)	Total (<i>N</i> = 189)
Child with DD	57 (45%)	34 (55%)	91
Child with MI	59 (46%)	24 (39%)	83
Child lives with Resp.	34 (27%)	20 (32%)	54
Child does not live w/Resp.	81 (64%)	41 (66%)	122
Resp. Education Level			
HS only	54 (43%)	30 (48%)	84
13 years or more	73 (57%)	32 (52%)	105
Resp. Financial Success			
Somewhat Successful	75 (59%)	43 (73%)	118
Very Successful	48 (38%)	15 (24%)	63
Resp. is Member of Support Group	18 (14%)	5 (8%)	23

Of the 127 graduates, 45% had a child with a developmental disability and 46% had a child with a long-term mental illness. However, there may be some incidents of dual diagnosis. As pertains to education, 57% of the graduates had 13 or more years of education as opposed to 43% who had only a high school education. Some graduates (38%) considered themselves very successful financially, whereas 59% rated themselves as somewhat successful.

Of the 62 sibling participants, 55% had a child with a developmental disability and 39% had a child with a long-term MI. Again, there may have been incidents of dual diagnosis. Educationally, 52% of the siblings had 13 or more years of education as opposed to 48% with only a high school education. Some of the siblings (24%) considered themselves very successful financially, whereas 73% rated themselves as somewhat successful.

The sample in this study was further limited to those graduates and siblings who answered selected questions on the Psychological Well-Being (PWB) Survey for graduates in the 2003-2004 (R5) Wave, and the Non-Normative Screener Modules in the 2003-2005 (R5) Wave for graduates and the 2004-2007 (R5) Wave for siblings. The non-normative questions dealt with the need for LTSS and about future planning.

Measures

The measures used in this study were taken from questions on Ryff's PWB Survey and from WLS Non-Normative Screener Modules from 2003 to 2007.

Need for Long-term Supports and Services

LTSS included 12 questions, taken from the R5 Waves of the WLS that dealt with the receipt of or need for services for the child with DD/MI. That need included case management, income support, medical assistance, crisis intervention, psychological services, and respite services. Questions required a yes or no answer to whether the child received or needed LTSS. (If the child already received services, the respondents were

asked only if they needed LTSS.) Table 4 contains the percentage of respondents (graduate or sibling) who answered yes to either question.

Table 4

Percentage of LTSS

	Receive	Need
Case Mgmt.	75%	18%
Income Support	87%	21%
Medical Assist.	83%	26%
Crisis Interv.	15%	18%
Psychological Serv.	80%	29%
Respite Services	4%	10%

Psychological Well-Being

Ryff's (1995) Psychological Well-Being has six dimensions: autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance. The survey is originally made up of 42 questions; however, the WLS survey used only 18 questions that are answered on a Likert scale, ranging from 1 to 6 (1 = *Agree Strongly*, 2 = *Agree Moderately*, 3 = *Agree Slightly*, 4 = *Disagree Slightly*, 5 = *Disagree Moderately*, 6 = *Disagree Strongly*). Negatively phrased items were recoded.

Autonomy. Only three questions in the WLS survey measured autonomy. The questions asked how much the respondent agreed that he/she “tends to be influenced by people with strong opinions,” to what extent the respondent agrees that “I judge myself

by what I think is important, not by the values of what others think,” and that “I have confidence in my opinions, even if they are contrary to the general consensus.”

Environmental mastery. Only three questions in the WLS survey measured environmental mastery. The questions asked how much the respondent agreed that he/she was “in charge of the situation” in which he/she lived; how much everyday life “often gets me down;” and how much respondent was “good at managing the many responsibilities of my daily life.”

Personal growth. Only three questions in the WLS survey measured personal growth. The questions asked how much the respondent agreed that he/she views life as “a continuous process of learning, changing and growing;” whether he/she “gave up trying to make big improvements/changes” in his/her life; and whether it is “important to have new experiences” that challenge “how you see yourself and the world.”

Positive relations with others. Only three questions in the WLS survey measured positive relations with others. The questions asked how much the respondent agreed that “maintaining close relationships has been difficult,” whether he/she has not “experienced many warm and trusting relationships,” and whether others describe him/her as “a giving person, willing to share my time.”

Purpose in life. Only three questions in the WLS survey measured purpose in life. The questions asked how much the respondent agreed that he/she lives life “one day at a time” and doesn’t think about the future; that some people wander aimlessly through

life, “but I am not one of them;” and that “I sometimes feel as if I’ve done all there is to do in life.”

Self-acceptance. Only three questions in the WLS survey measured self-acceptance. The questions asked to what degree the respondent agreed that he/she is “pleased with how things have turned out” in his/her life, whether he/she likes “most aspects of my personality,” and if he/she feels “disappointed about my achievements in life.”

Figure 1 contains the percentages of graduate and sibling respondents who scored high on the survey. My determination of what was a high score was based on averaging the top 33% of the scores, since Ryff’s survey does not establish a cutoff score. Figure 1 shows that both graduates and siblings scored lower on autonomy and higher on purpose in life as compared to the other 5 dimensions.

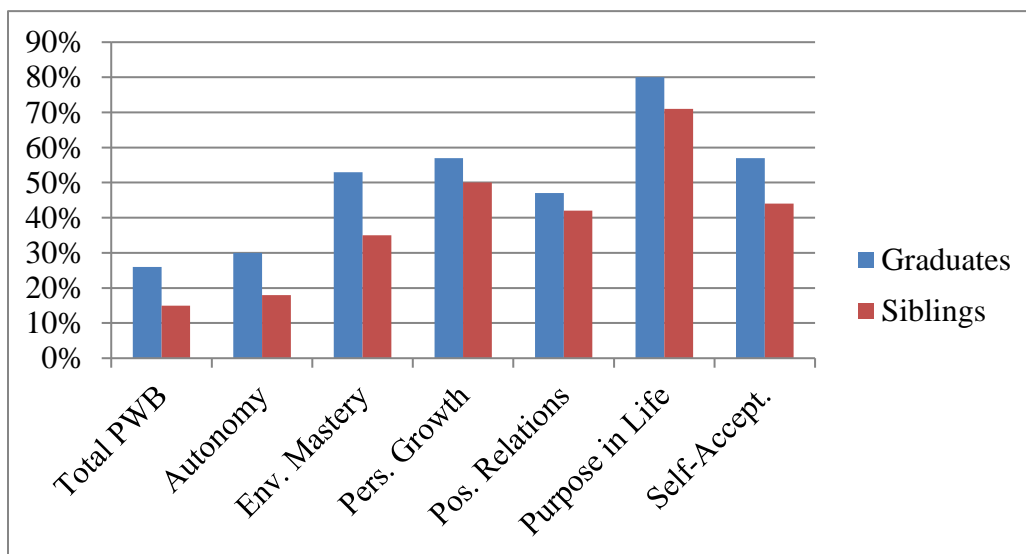


Figure 1. PWB Percentage of High Scores (Graduate & Sibling)

Future Planning

To measure future planning (dependent variable), two questions were taken from the R5 Wave of the WLS data. Those questions, requiring a yes or no answer, included if the respondent had made any preparations for the end of life and if someone would help the child in the future. Table 5 presents the number of graduates and siblings who answered both questions. Fifty-eight percent of graduates and 60% of siblings had made preparations for end of life. Sixty percent of graduates and 68% of siblings had appointed someone else to help for their child in the future when they are no longer able to do so.

Table 5

	Graduates				Siblings			
	<i>N</i>	Yes	No	Inap.	<i>N</i>	Yes	No	Inap.
Made preparations for end of life?	127	74	14	39	62	37	3	22
Will someone help child in the future?	127	76	30	21	62	42	13	7

Note: Inap. = Inappropriate or not answered in this Module.

Analysis

The WLS data of interest was checked for missing values and recoded when necessary. Questions with negative responses were reverse coded to be consistent with other positive answers. Other questions were combined and computed to represent the dependent and independent variables. To measure the receipt of or need for LTSS, 12 questions, that required a yes or no answer, were separated into the two LTSS independent variables. Psychological well-being was measured by first reverse recoding

negatively phrased questions and then summing the mean of the three questions related to each of the six dimensions. Then the mean for each of the six dimensions were combined to represent the third independent variable. To measure the dependent variable of future planning, two questions were summed together.

Hierarchical multiple regression was used to study the relationship that exists with a caregiver's psychological well-being, the receipt of or the need for long-term supports and services, and the level of future planning for an adult child with a DD/MI. My research questions were as follows:

RQ1. To what extent does the receipt of long-term supports and services influence the adult caregiver's likelihood to plan for the future of a family member with DD/MI?

RQ2. To what extent does the need for long-term supports and services influence the adult caregiver's likelihood to plan for the future of a family member with DD/MI?

RQ3. To what extent does the adult caregiver's level of psychological well-being influence the likelihood to plan for the future of a family member with DD/MI?

Chapter Summary

This section presented a summary of the WLS database and its sample, as well as the subsample and the measures used in this study. It also presented steps in the preliminary analysis used to study the relationship that exists with a caregiver's

psychological well-being, the receipt of or need for long-term supports and services, and the likelihood to plan for the future of an adult child with a DD/MI.

CHAPTER IV

RESULTS

Chapter Overview

This chapter outlines the results of the hierarchical multiple regression, including the steps in the preliminary analysis for this study, the assumptions of multiple regression, and the main analyses of the regression models.

Preliminary Analysis

To examine the research questions in this study, a hierarchical multiple regression was conducted to assess to what extent the receipt of or need for LTSS, psychological well-being (independent variables) influenced the future planning (dependent variable) for the adult child with DD/MI. Multiple regression analysis is a statistical technique that assumes a linear (not causal) relationship of several independent variables on a single continuous dependent variable and is popular in numerous fields of study (Tabachnick & Fidell, 2007). Multiple regression analysis can help to understand how much the dependent variable will change for every one point change in the independent variables.

There are three major multiple regression techniques (standard, stepwise, and hierarchical) that differ depending on the order of entry of the independent variables into the equation model (Tabachnick & Fidell, 2007). For standard multiple regression, all independent variables are entered at once, according to the statistical program being used. The disadvantage to using the standard multiple regression is that each independent variable is assessed for the amount of variance it contributes to the dependent variable. If

the contribution is small, there could still be a strong relationship (Ho, 2014). Stepwise regression may also be problematic since the predictor variables are entered by an automatic computed statistical criteria (Ho, 2014). A hierarchical regression allows the independent variables to be entered one at a time or in blocks, based on researcher choice, whereby the researcher can compare each step to the previous steps using *F*-tests. Each independent variable is assessed at its own point as to the explanatory power it contributes (Ho, 2014). I chose the hierarchical technique to assess to what extent the receipt of or the need for LTSS, psychological well-being (independent variables) influenced the future planning (dependent variable) for the adult child with DD/MI.

Prior to running a hierarchical multiple regression, it is necessary to first test the assumptions for the regression analysis. For multiple linear regression models to be reliable, variables must meet the assumptions of normality, independence, linearity, homoscedasticity, and collinearity (Tabachnick & Fidell, 2007). Analysis was performed using SPSS 25 Regression.

Regression analyses must meet the assumption of normality. Normality is usually assessed by examining the skewness, kurtosis and scatterplots to determine if the independent variables are normally distributed around the dependent variable. When the distribution is normal, the values of skewness and kurtosis are ideally zero. However, skewness and kurtosis vary with sample size (Tabachnick & Fidell, 2007). For example, when the sample size is large, the standard errors for skewness and kurtosis are closer to zero; but when sample size is small, skewness and kurtosis values may appear

significantly different from a normal distribution. Field (2013) suggested using the following criteria for small sample sizes to determine skewness and kurtosis, especially when interpreting SPSS outputs, rather than 0. Field suggested that an absolute value of 1.96 is significant at $p < .05$, that an absolute value above 2.58 is significant at $p < .01$, and that an absolute value above 3.29 is significant at $p < .001$. Field (2013) also suggested that skewness and kurtosis are not reliable for large samples. For this study, the Q-Q-Plot displayed a wide distribution, and skewness values varied from -2.64 to .11; therefore, the assumption of normality was met (see Table 6).

Table 6

Descriptive Statistics (N = 189)

Variable	Min.	Max.	Mean	SD.	Skew	Kurt.
DV (Future Plan)	-1	1.75	.37	.57165	.114	-.275
IV (Receives LTSS)	-.50	.33	.10	.30618	-1.21	-.301
IV (Needs LTSS)	-.50	.33	-.004	.25800	-.58	-.707
IV (Psych. W. B.)	-.33	5.08	4.01	.72194	-2.64	12.81

Another assumption of regression is that the residuals of the prediction are not correlated or related to one another. Independence of errors is assessed by examining the plot of residuals or by examining the Durbin-Watson Statistic, which can vary between 0 and 4 (Field, 2013). Since the Durbin-Watson Statistic ($d = 1.76$) is between 0 and 4, the assumption of independence has not been violated; that is, the errors of prediction are

independent of one another. The histogram of standardized residuals indicated that the data points were close to the line.

The relationship between the predicted dependent variable and the independent variables must be linear otherwise the analysis is much weaker and may lead to a Type I error (Tabachnick & Fidell, 2007). The assumption of linearity is tested by examining the scatterplot of standardized predicted values and comparing the standardized residuals to the predicted values. Since there was no curvature in the plot pattern, this assumption was met for future planning and the predictor variables.

Homoscedasticity is the assumption that the standard deviation of errors is approximately the same for all variables, or the points on the scatterplot should be about equal across the regression line (Tabachnick & Fidell, 2007). The assumption of homoscedasticity was met, as assessed by visual inspection of the plot of standardized residuals versus unstandardized predicted values. Points on the scatterplot were approximately equal around the regression line.

If multicollinearity is present, it means that the independent variables are highly correlated with one another and will jeopardize the statistical significance of the variables (Tabachnick & Fidell, 2007). If the variance inflation factors are higher than 5, multicollinearity will be present. No evidence of multicollinearity was found, as assessed by collinearity statistics of tolerance and VIF values (Receives LTSS, Tolerance = .78, $VIF = 1.28$; Needs LTSS, Tolerance = .78, $VIF = 1.28$; Psych. Well-Being, Tolerance = .99, $VIF = 1.00$).

Main Analysis

The main analysis was to look at the receipt of or the need for long-term supports and services and caregiver psychological well-being as they relate to the likelihood of the caregiver to make plans for the future care of an adult child with a DD/MI.

A multiple hierarchical regression analysis was performed to understand the effects on future planning (dependent variable) based on the receipt of LTSS, the need for LTSS and psychological well-being (independent variables). The first step of assessing a hierarchical multiple regression is to examine goodness of fit. This is assessed by examining the sums of squares (F -ratio), R , and R^2 . Goodness of fit is defined by Field (2013) as an index that measures how much the actual data model corresponds to how well the data would be correlated in a normal population distribution model. For the model to be a good fit, the F -ratio should be greater than 1 (Field, 2013). The F -ratio measures how variation is explained by the model as opposed to how much is unexplained. The F -ratio is found in the analysis of variance (ANOVA) table produced in the multiple regression analysis in SPSS. The correlation coefficient (R) measures the strength of the relationship between predictor variables and the outcome variable (Field, 2013), and is found in the model summary table produced by SPSS. The coefficient of determination (R^2) is the measure of the amount of variability in one variable shared by another variable, as explained by the model. R^2 increases when new variables are added to the model (Field, 2013).

A three-step hierarchical multiple regression was conducted with *Future Planning* as the dependent variable. Previous research shows that the lack of planning for the future seems to impact the caregiver's psychological well-being (Taggart et al., 2012); therefore, *Psychological Well-Being* was entered first as a predictor variable in Step 1 of the regression. *Receives LTSS* was entered as a second predictor variable in Step 2 of the regression. *Needs LTSS* was entered as a third predictor variable into Step 3 of the regression.

A hierarchical regression analysis produces a comparison table that explains a significant amount of variance in the dependent variable after accounting for each independent variable. To test if the variance is statistically significant, researchers use a Pearson significance level of .05 for p (Tabachnick & Fidell, 2007). However, there are some researchers who believe that a p value of .05 is too arbitrary. Pritschet, Powell, and Horne (2016) conducted a review of the literature on "marginally" significant results. Pritschet et al. found that in 2010, the majority (54%) of social psychology articles that they looked at used marginal p -values somewhere between .07 and .10. However, Pritschet et al. noted that some studies may be underpowered and unable to be replicated because of Type I or Type II errors. Gelman and Carlin (2017) stated that p -values may or may not provide strong evidence against or for a null hypothesis. Gelman and Carlin preferred avoiding hypothesis testing and to use hierarchical modeling to look at variations, thus accepting statistical conclusions with uncertainty. Based on the findings of Pritschet et al. (2016) and Gelman and Carlin (2017), I chose to use a hierarchical

regression to compare the results based on both a significance level of .05 and a significance level of .10. The results of the model comparisons are shown in Table 7.

The results of the hierarchical regression model, based on an alpha of .05, revealed that the *F*-test for Model 1 was not significant, $F(1, 187) = 0.08, p = .773, \Delta R^2 = 0.00$. This model indicates that adding *Psychological Well-Being* did not account for a significant amount of additional variation in *Future Planning*. The *F*-test for Model 2 was not significant, $F(1, 186) = 1.35, p = .247, \Delta R^2 = 0.01$. This model indicates that adding *Receives LTSS* did not account for a significant amount of additional variation in *Future Planning*. The *F*-test for Model 3 was not significant, $F(1, 185) = 3.15, p = .078, \Delta R^2 = 0.02$. This model indicates that adding *Needs LTSS* did not account for a significant amount of additional variation in *Future Planning*. However, if alpha is .10, the *F*-test for Model 3 was marginally significant, indicating that adding *Needs LTSS* explained an additional 2% of the variation in *Future Planning*.

Table 7

Goodness of Fit for Variables Predicting Future Planning^a

Model	R^2	df_{mod}	df_{res}	<i>F</i>	<i>p</i>	ΔR^2
1	0.00	1	187	0.08	.773 ^b	0.00
2	0.01	1	186	1.35	.247 ^c	0.01
3	0.02	1	185	3.15	.078 ^d	0.02

a. Dependent Variable: Future Planning

b. Predictors: (Constant), Psychological Well-Being

c. Predictors: (Constant), Psychological Well-Being, Receives LTSS

d. Predictors: (Constant), Psychological Well-Being, Receives LTSS, Needs LTSS

The results for each regression are shown in Table 8. Psychological well-being did not significantly influence future planning, $\beta = -0.02$, $t(185) = -0.31$, $p = .757$. Based on this sample, a one-unit increase in psychological well-being does not have a significant effect on future planning at either the .05 or .10 significance level. At the .05 significance level, the receipt of LTSS did not significantly influence future planning; but it did at the .10 significance level, $\beta = -0.15$, $t(185) = -1.86$, $p = .065$. This indicates that at level .10, on average, a one-unit increase in the receipt of LTSS will decrease future planning by 0.29 units. At the .05 level, the need for LTSS did not significantly influence future planning; but it did influence future planning at .10 significance level, $\beta = 0.15$, $t(185) = 1.77$, $p = .078$. This indicates that at level .10, on average, a one-unit increase in the need for LTSS will increase future planning by 0.32 units.

Table 8

Summary of Hierarchical Regression Analysis for Variables Predicting Future Planning

Variable	<i>B</i>	<i>SE</i>	β	<i>t</i>	<i>p</i>
Model 1					
Psych. Well-Being	-0.02	0.06	-0.02	-0.29	.773
Model 2					
Psych. Well-Being	-0.02	0.06	-0.02	-0.33	.741
Receives LTSS	-0.16	0.14	-0.08	-1.16	.247
Model 3					
Psych. Well-Being	-0.02	0.06	-0.02	-0.31	.757
Receives LTSS	-0.29	0.15	-0.15	-1.86	.065*
Needs LTSS	0.32	0.18	0.15	1.77	.078*

* $p < .10$

Chapter Summary

This chapter presented the results as related to the research questions. This chapter also outlined the results of the hierarchical multiple regression, including the steps in the preliminary analysis for this study, the assumptions of multiple regression, and the main analyses of the regression models.

CHAPTER V

DISCUSSION

Summary

This chapter provides a summary of the present study and a discussion of the results as they relate to planning for the future of an adult child with DD/MI. Strengths and limitations of the study and recommendations for future research will be presented.

Aging adult parents of an adult child with a DD/MI face difficult decisions about the future care of that child, especially at the end of life. The difficulty in accessing state and national programs, which are already financially stressed, affect more and more caregivers and care recipients, which in turn may affect the likelihood to plan for the future (Larson et al., 2018). The demand for support services is outweighing the availability of needed long-term care, placements, and interventions. Future planning is defined as planning and executing the necessary set of activities that will provide best-choice supports available for individuals with DD/MI and their families in the future (Burke et al., 2018). The greatest barrier to future planning is the lack of available services and/or the lack of knowledge about how to access those services.

The significance of this quantitative study was to provide insight into some of the barriers of future planning by examined whether the receipt of or the need for LTSS might influence the adult caregiver's likelihood to plan for the future of a family member with DD/MI, and whether the adult caregiver's level of psychological well-being might influence the likelihood to plan for the future of a family member with DD/MI.

The current study found that psychological well-being scores did not significantly influence future planning; however, there was a marginally significant influence on future planning by both the receipt of LTSS and the need for LTSS. The results indicate that if the receipt of LTSS goes up, future planning will go down. Cautiously, this may be explained by looking at the percentage of those participants in the study who were already receiving LTSS, especially for case management (75%), income support (87%), and medical assistance (83%), since these services may be more likely to reduce caregiver stress than others in this study. Even though planning for the future is important, perhaps the participants were not concerned at this particular time period because of the satisfaction with receiving the LTSS they need. This may support the view of Heller and Caldwell (2006) who found that people are reluctant to plan for the future because it is too painful to think about leaving their loved ones. Study participants may have already completed plans for the future. Over 50% of all participants had made end-of-life plans or indicated that someone would help the child in the future. Only 11% of graduates and 5% of siblings in the study had not made preparations for end of life. As noted in Table 3, most care recipients were not living at home – thus future planning may have already been carried out. Future planning may also go down if the care recipient is considered to be more self-sufficient due to having received the services they need.

Results also indicate that if the need for LTSS goes up, future planning will also go up. Cautiously, this may imply that if need is not met or is out of their control, the caregiver may be more motivated or encouraged to go ahead and pursue future plans,

which may be more in their control, especially if future planning consists only of asking another family member, such as a sibling, to take over. Prenda and Lachman (2001) found that older adults will continue to plan, even though they face temporary obstacles, if they have an overall sense of control and positive well-being.

Aging caregivers, whose spouses developed a disability, were more likely to initiate a future planning process if the adult child with IDD was living with them (Grossman & Webb, 2016). Getting help from support groups may encourage future planning, even though only 22% of the participants in this study were members of a support group. Heller and Caldwell (2006) examined “family-led training” and found that when older, more experienced caregivers were trained to provide information and assistance to less experienced families with IDD and/or MI children, the trainees were more likely to plan for the future by establishing special needs trusts and to start a residential process. In the current study, 65% of the participants’ children did not live with them. On average, 30% of the adult children lived with the respondent. Seltzer et al. (2011) reported that co-residing was associated with lower income levels and more psychological problems.

In this study, psychological well-being did not significantly influence future planning. However, when examining the six dimensions of Ryff’s model, I noted a marginally negative correlation between autonomy and the receipt of LTSS. This may imply that the more services that are needed, the less self-sufficient the caregiver may feel. This negative correlation may also confirm the indirect affect between a caregiver’s

autonomy and the child's behavior, as found by Dieleman et al. (2019). Autonomy scores were lowest of the six dimensions of Ryff's PWB Survey for the participants in this study, as illustrated in Figure 1 earlier. Aging caregivers of adult children with severe mental illness as opposed to only developmental disabilities tend to have lower levels of well-being (Ghosh et al., 2012), especially if they used emotional coping as opposed to problem-solving strategies (Kim, Greenberg, Seltzer, & Krauss, 2003), and greater service use (Lunsky, Tint, Robinson, Gordeyko, & Ouellette-Kuntz, 2014).

Seltzer et. al. (2001) found that caregivers tend to have a more positive perception of their well-being due to life-style changes in adapting to their caregiver roles, especially dealing with a loved one with a DD versus one with a MI. Of the sample in this study, 45% of the graduates and 55% of the siblings had a child with a developmental disability and 46% of graduates and 39% of siblings had a child with mental illness. Therefore, since the sample is close to evenly split between DD and MI children, it is hard to distinguish the differences between DD and MI.

Other factors that may have influenced the outcome of this study include the residential status of the DD/MI child, the educational level and financial success of the caregiver, and whether the caregiver had already made plans for the future. On average, 65% of the DD/MI children did not reside with the caregiver, which implies that there would be less caregiver stress. Over 50% of the graduate and sibling caregivers had some higher education and were somewhat to very successful financially. It is possible that

only those with higher levels of education, financial success and lower stress levels completed the surveys for the 2004-2007 WLS.

Implications

This study may have implications for public policy, practice and research into future planning strategies for individuals with DD/MI. An ecological approach to future planning can provide a more meaningful framework to inform caregiver research, policy and practice to improve quality of life for caregiver families. This study also underscores the importance of exploratory studies into what precipitates or hinders caregivers to make end-of-life plans leading to new practices and updated policies that better benefit the caregiver and the care recipient. For example, Arnold, Heller, and Kramer (2012) suggested that caregiver advocates need to push for policies and funding that provide the LTSS that the DD/MI community need, such as the National Family Caregiver Support Program and the Lifespan Respite Care Act. Practitioners and LTSS providers need to take a proactive approach to communicate with caregivers and to identify and address any reluctance and/or fears about future plans that caregivers may be experiencing before a crisis situation arises. Assessing caregiver needs and psychological well-being can help increase trust in the support system and encourage planning for the future (Mahon, Pappas, Randhawa, Tilley, & Vseteckova, 2019).

Strengths

The strength of this study is in the use of an ecological perspective to draw attention to a unique aging caregiver population, trying to plan for the future of an adult

child with DD or MI, while taking into consideration the caregiver's psychological well-being and the availability of or lack of LTSS for the adult child. Having a child or other family member diagnosed with an intellectual and/or developmental disability is a traumatic event to a family. The diagnosis affects the whole family system: individuals, parents, siblings, and extended family subsystems, especially in old age.

Examining psychological well-being, LTSS, and future planning through an ecological framework helps to focus on the interaction between the individual and his/her environment in order to target different contextual areas that need to be changed, such as individual interventions, community level programs, or state and national policies (Grossman & Magana, 2016). The psychological well-being of the individual caregiver impacts the well-being of the care recipient. Therefore, it is important to understand the dynamics that increase or decrease the caregiver's well-being, within an ecological context.

Research indicates that the caregiver's relationship (microsystem) with the LTSS systems is associated with caregiver mental health (Williamson & Perkins, 2014), reinforcing a correlation within different levels of the family's ecological context. If caregivers are more involved in the LTSS process (exosystem), they are more likely to receive more services and be more satisfied with provider competence (Neely-Barnes et al., 2008). In this study, for example, 57% of the care recipients were already receiving LTSS, and 62% of caregivers had already made end-of-life plans.

Formal support service utilization may vary by caregiver income (McConkey, Kelly, Mannan, & Craig, 2011), geographic location (Harrington & Kang, 2016), and racial/ethnic minority (Magana, Seltzer, & Krauss, 2002). Heller and Caldwell (2006) noted that caregivers on waiting lists (macrosystem) had greater caregiver burden and lower mental health. Grey, Totsiki, and Hastings (2018) found that caregivers who had higher support needs displayed higher stress levels. Grey et al. also found that aging caregivers with higher socio-economic status had better psychological outcomes and that support need was not associated with psychological distress. In this study, psychological well-being was not associated with the need for support; and caregivers had higher incomes, lived in and around Wisconsin, and were mostly Caucasian.

Caregivers who are more socially involved or who participate in support groups are more likely to plan for the future. Sharifian and Gruhn (2018) found that having positive relations with others and being socially engaged acted as a buffer to declines in psychological well-being in aging caregivers. Parents who participate in training and support activities and who attend some college or who graduate from college are more likely to engage in future planning activities (Burke et al., 2018). Of the participants in this study, 55% had 13 or more years of education and 62% had made future plans.

Older caregivers of adult children with DD/MI face many challenges within their ecological environment when they begin to plan for the future care of their children. The greatest concerns seem to be about how to navigate the process to find acceptable, appropriate placement facilities and how to pay for them (Lunsky et al., 2014). Families

who have been helped by advocates, support groups and practitioners to navigate the LTSS system are better able to understand their rights and how to access necessary services (Harrington & Kang, 2016).

Changes in local resources and public policies at the exosystem and macrosystem indirectly affect the lives of aging caregivers and care recipients. Caregivers may be affected by the lack of reliable information on how to negotiate the future planning process. They need to be provided opportunities for one-to-one support and guidance. Practitioners must take into account the caregiver's and care recipient's preferences in residential accommodations (Taggart et al., 2012).

Limitations

I acknowledge that there are several limitations related to the robustness of this study, including generalizability, representativeness, and sample size. First, the WLS is not nationally generalizable, since the original cohort is made up only of graduates and siblings of Wisconsin high schools who graduated in the late 1950s and early 1960s. Most of the sample is Caucasian, with only a few African American, Hispanic, or Asian ethnic groups. The age range of the graduates is homogeneous, since they all graduated in 1957. Approximately 2,000 siblings of the graduates were empaneled in 1977, most of whom are 6 to 8 years younger than the graduates (Herd et al., 2014). Additionally, the subsample ($N = 189$) consisted of only 127 graduate and 62 sibling older caregivers of adult children with DD and/or MI, who answered the future planning and LTSS questions and the psychological well-being survey questions used in this study. Although the WLS

is a longitudinal dataset, the measures from this study were taken at only one time period (2003-2005 for graduates and 2004-2007 for siblings), making it cross-sectional. Cause and effect relationships could not be identified due to the cross-sectional nature of the data. Therefore, this study is not generalizable.

A second limitation for this study is in the selection of questions taken from the WLS data to address the research questions. An exhaustive search was conducted to find available questions that seemed relevant to represent the variables in this study. Questions were taken from the Non-Normative Screener Modules in the 2003-2005 (R5) Wave for graduates and the 2004-2007 (R5) Wave for siblings. However, since the questions were not specifically designed to capture the purpose of this analysis, there was a weak correlation among the future planning, LTSS and psychological well-being variables.

Finally, due to the small sample size ($N = 189$) used in this study, Type 2 error is much more likely. Consequently, it would be important to interpret the results with caution as $p < .10$ was used to determine significance. Replication with larger samples would be necessary to really know if these results are accurate or whether rejecting the null hypothesis would be accurate.

Future Direction

Future research that is robust, generalizable, and replicable and that incorporates the entire family system will benefit the support processes needed by primary caregivers. Research shows that family caregivers gain valuable skills and knowledge over a lifetime

of caring for a family member with a disability (Canary, 2008). Therefore, there is a need for more longitudinal, population-based research to compare disability related variables across time (Grey, Totsika, & Hastings, 2018). Policymakers and practitioners should explore ways to utilize this lifetime knowledge base to improve policy and practices that better fit the needs of the caregivers and care recipients.

Even though this study was limited to examining a small sample of non-normative caregivers at one time period, there is a need for large sample studies that focus on the successes and failures of existing LTSS policies over time and the impact that those services have on families who care for children with DD/MI. Policymakers and practitioners need to consider caregiver perspective, psychological well-being and ability to advocate in an ecological context. Future studies should collect and compare robust data at all levels of the ecological environment to examine different variables that influence the likelihood of aging parents to plan for the future of adults with DD/MI and that are generalizable to other circumstances. Increasingly more diverse caregiver and care recipient populations demand that federal, state, and local governments find innovative ways to coordinate and finance deliverable person-centered LTSS that promote well-being and maximize funding (Reaves & Musumeci, 2015).

Heller, Scott, Janicki and the Pre-Summit Workgroup on Caregiving and Intellectual and Developmental Disabilities (2017), recommend that future initiatives need to work to better integrate already existing community education, outreach programs and research so as to promote stronger, more inclusive practices. Heller et al.

(2017) also recommend that future initiatives need to increase training for clinicians and funding for more research on best practices. Future studies also need to explore ways to make systemic changes in the service delivery system to include future planning activities for adult children with DD/MI (Burke et al., 2018).

Additionally, there is currently a dearth of research on types of disabilities as they relate to aging family caregivers and LTSS (Grossman & Webb, 2016). This study did not include a comparison group, nor did it account for the differences between the stressors involved with having an adult child with DD versus MI. Therefore, it would be interesting to address the diversity of caregiving based on types of disability, caregiver experiences across the lifespan, and problematic innovations and policies that relate to caregiving for adult children with DD and or MI. Research should examine community-based interventions that target quality of time and social activities of caregivers (Ghosh et al., 2012) to determine the impact on psychological well-being and future planning.

Summary

Even though the results of this study showed only a marginally statistically significant relationship with psychological well-being, LTSS, and future planning, research shows that future planning for loved ones with DD/MI may be a source of great anxiety for aging caregivers (Smith et al., 2000). As of 2015, in the United States, an estimated 71% of individuals with a developmental disability or mental illness live with a family caregiver (Heller, 2017). The problem is that many of those caregivers are 60+ years of age and are facing end-of-life decisions about their adult family member without

adequate LTSS. Additionally, planning for end-of-life arrangements and access to formal support services for adult children with DD and/or MI are influenced by various issues at the individual, family, community, and cultural/social policy levels. The need to understand future planning and formal support services will change as cultural and environmental circumstances and demographics change. Therefore, it is important for researchers to investigate what supports (or lack of), such as increased technology services, psycho-educational initiatives, and family support policies, might improve the circumstances of the caregiver as well as the individual with a DD/MI in the later stages of life.

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