

“Hopes, Dreams, but No Plans”: Aging Parents of Individuals with Intellectual and Developmental Disabilities

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ABSTRACT

Individuals living with an intellectual or developmental disability (IDD) are often reliant on others for most of their lives. As a result, the parents of individuals with IDD are positioned in a unique caretaking role as they age alongside their dependent children. Drawing from in-depth interviews with 14 older parents of individuals with IDD, the present study discusses the ways in which these aging parents attempt to make future plans for both themselves and their children within the neoliberal framework of the United States. This paper argues that because parents of individuals with IDD are reliant on an inherently unpredictable system of public services for support, the capability to plan for their old age is limited.

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“Most parents of special needs will tell you that they hope they live one day longer than their kid. Isn’t that a strange thought? You know, for a parent, you never want to see a parent lose a child. Ever. That’s not supposed to happen. The parents go first and then their kids live on, but for parents that have a kid with special needs...it’s kinda strange, but...if you really stop and think about it, you’re worried about them. And you’re [always] gonna be worried about them. What’s gonna happen to them after I’m gone? But if they go, then I want to go one day after that.”

-Wendy

INTRODUCTION

The experience of parenthood tends to follow a predictable timeline. After welcoming a newborn baby into the family, parents spend the next two decades raising the child at home until they are finally ready to move out and live as an independent adult. Once empty nesters, parents can expect the occasional phone call, birthday card, or visit from their child; as the years pass by, roles eventually reverse and grown children care for their parents as they reach old age (Macmillan and Copher 2005, Umberson et al. 2010). This chronology of parenthood is continually reinforced as the norm in American society through movies, books, and casual conversation. However, not all parents lead lives that match this status quo. Particularly, parents of children with an intellectual or developmental disability (IDD) face countless challenges that the vast majority of parents do not experience. IDD describes a broad category of disabilities that originate before the age of 18 and are characterized by significant limitations in both intellectual functioning and adaptive behavior, such as everyday practical and social skills (American Association on Intellectual and Developmental Disabilities). Common examples of IDD include autism spectrum disorders, Down syndrome, cerebral palsy, and many other disorders that make daily functioning a challenge.

For parents of children with IDD, there is no assurance that their children will ever have the capacity to live independently or care for themselves, let alone provide care for their aging

parents; as a result, parents of children with IDD cannot necessarily hold onto the same expectations that many other parents take for granted over the course of their lives. In order to understand the sociological significance of these parents and their aging chronologies, we also need to understand their daily realities. This project explores the lives of older parents of individuals with IDD, their experiences, and the ways in which they plan for the future. Over the next several pages, I will use relevant scholarly literature to contextualize the topic of aging parents of individuals with IDD. Next, I will discuss my proposed research questions and methods. Finally, I will present my results and make conclusions on the findings of my research.

LITERATURE REVIEW

Understanding and Philosophizing Intellectual Disability

What does it mean for an individual to be disabled? Legally, an individual with a disability is a person who has a “physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such impairment, or a person who is perceived by others as having such an impairment” (Americans with Disabilities Act: 1990). Historically, however, societal perceptions of disability as a concept have shifted dramatically. Until recently, disability was seen primarily as a form of illness (LoBianco and Sheppard-Jones 2008). Under this view, known as the “medical model,” disability is thought to be caused by disease, injury, or damage to bodily functions (Haegele and Hodge 2016). As a result, proponents of the medical model argue that similar to sick individuals, those with a disability must be medically cured to function within society (Brandon and Pritchard 2011). This notion has historically resulted in disabled individuals being institutionalized, forcibly sterilized, or even euthanized (Carlson and Diedrich 2009: 5).

Now known as “the old paradigm,” the medical model of disability has largely been abandoned in favor of a newer school of thought (Haegele and Hodge 2016: 197). This new paradigm, called the “social model” of disability, separates impairment from disability; in the context of the social model, an impairment is an abnormality of the body while disability is considered the “disadvantage or restriction of activity caused by a social organization that does not take into account people who have impairments” (Haegele and Hodge 2016: 197). In other words, individuals with impairments are disabled only by existing in disabling physical and social environments. For example, an individual who is unable to walk has an impairment that becomes a disability in an environment without any wheelchair ramps. Disability can also be imposed on individuals with impairments through isolating, exclusionary social environments such as segregated vocational opportunities. Advocates of the social model emphasize that the responsibility of finding solutions for disability rests on society rather than on the individual. Proponents of this model, along with disability rights activists, have been successful in creating social change— notable examples include the passages of the Americans with Disabilities Act (ADA) in 1990 and the Individuals with Disabilities Education Act in 2004. These acts ban discrimination of people living with impairments in employment, education, and public services (Kittay 2015).

While legislation like the ADA marked undoubted progress for individuals with physical impairments, the social model of disability does not necessarily apply to individuals with intellectual or cognitive challenges. Even with environmental modifications like a wheelchair ramp, individuals with severe IDD often still struggle to function in society. As a result, we need to look beyond the traditional disability studies models when studying IDD. Most of the current scholarly work on intellectual disability is rooted in theoretical moral philosophy.

Traditionally, the classically liberal theories of philosophers like Kant, Plato, and Foucault rendered individuals with IDD as irrelevant or unworthy of personhood status. Classical liberalism depends on “the conception of the person as independent, rational, and capable of self-sufficiency” (Kittay 2001: 559). For example, Kant believed that the ability to have autonomy and moral, rational thought is the distinguishing feature between humans and nonhuman animals (Kittay and Carlson 2010: 4). Similarly, John Locke defines a person as a “thinking intelligent being, that has reason and reflection, and can consider itself as itself, the same thinking thing, in different times and places” (Locke in Kittay 2001: 563). John Rawls, an American liberal philosopher, theorizes that only those who are capable of fully cooperating in society are considered equal citizens and deserving of justice; in order to be considered a citizen, an individual must have the moral power to be rational in “recognizing and pursuing their own conception of the good” and reasonable in recognizing “the fairness of others also pursuing their own ends” (Rawls 1980: 526). These definitions of personhood effectively place individuals with IDD, whose moral or intellectual reasoning are often impaired, as distinctly nonhuman and not deserving of justice.

Meanwhile, several other moral philosophers are challenging the notion that personhood lies in the ability to have rational thought. Most notably, according to Kittay, “being a person has little to do with rationality and everything to do with *relationships*—to our world and to those in it” (Kittay 2001: 568). The mother of a young woman with severe IDD, Kittay proposes a theory that roots personhood in the capacity of an individual to participate in relationships with other people and to shape the world around them (Kittay 2001). By heavily emphasizing the deep parent-child relationship she is able to create, Kittay claims her daughter as unarguably human. Because many children with IDD rely heavily on their parents for care even into adulthood, the

relationship between these children and their parents allows individuals with IDD not only access to daily necessities, but also personhood status. Therefore, while studying individuals with intellectual disability, we must also study their parents.

Caretaking, Dependency, and Stigma

The act of caregiving forms a multifaceted relationship between those who provide care and those who receive it. Because individuals with IDD generally require high levels of guidance, parents of children with IDD play a unique caretaking role. In many ways, care and kinship are closely linked—caring for a family member can be a practice of “complementing and confirming biological and juridical understandings of kinship” (Alber and Drotbohm 2015: 7). In the case of parents caring for their child, the act itself of providing care makes them “good parents” in the eyes of society, thus reinforcing their parenthood (Alber and Drotbohm 2015: 7). Similarly, parents who refuse or are unable to care for their children face condemnation from the greater society (Gray 2002).

However, by equivocating parenting with caretaking, parents of children with IDD are placed in a unique, challenging position. For parents of children with IDD, managing their child’s disability generally requires a level of caretaking far beyond what is expected of parents whose children are typically-developing. Unlike individuals with certain physical disabilities that can be alleviated by altering their surroundings, individuals with IDD often suffer from impairments that remain profound regardless of the environment (Kittay 2001). As a result, many individuals with IDD rely heavily on care and supervision from other people, including their parents.

When an individual requires such intense, constant care, they are inevitably dependent on those around them to function in society. While it is part of the human condition to be dependent on others to some degree, individuals with severe IDD are often highly dependent on caregivers over the course of their whole lives, even for simple tasks such as eating or bathing. As a result, caregiving can also be referred to as “dependency work” with caregivers and the beneficiaries of care participating in “dependency relations” (Kittay 1998: 128). In these dependency relations, the act of caring for the dependent places the dependency worker (in many cases, the parents of an individual with IDD) in need of support “wherever and whenever caring for the dependents is incompatible with producing the material support needed to sustain those in the relationship” (Kittay 1998: 128). In other words, caring for a dependent generally means that without additional support, it is challenging to simultaneously provide “the *means* to take care of them and do the caring for them.” (Kittay 1998: 129).

For example, caring for individuals with IDD is often carried out by family members at a “great cost to themselves, financially, medically, and professionally” (Kittay 2001; Carlson and Kittay 2010: 10). When a family member acts as an unpaid caretaker for their disabled loved one, the high demands of caretaking often make it difficult for the caretaker to sustain consistent employment and earn a reasonable income. However, caring for individuals with IDD is also an incredibly expensive endeavor; studies estimate that the total lifetime cost of raising an individual with IDD is over \$2 million (Buescher et. al 2014). These expenses come from a wide variety of sources including therapies, medical bills, and day programs. When the high cost of supporting an individual with IDD combines with the reduced ability of caretakers to earn a stable income, it becomes nearly impossible to care for a highly dependent person without requiring additional support. As a result, caregiving parents are often subjected to the conditions

of “derived dependency” (Kittay 1998: 130). This means that by supporting their dependent children with IDD, parents themselves become dependent on others to support them in return.

Empirical evidence suggests that caring for individuals with IDD has concrete effects on the wellbeing of those who provide the care. Parents of children with IDD are likely to experience higher levels of parenting stress, poorer psychological health, and more physical health challenges than parents of children without an IDD (Ha et al. 2008, Hassall et al. 2005, Herring et al. 2006, Hatton and Emerson 2003). This increased stress is often attributed to the unique burdens that IDD places on parents, such as managing their child’s behavioral difficulties, covering additional financial costs from services and treatment, and navigating the emotionally burdensome stigma of disability (Ha et al. 2008). Given that intellectual disability is heavily stigmatized in the United States, familial caretakers also tend to experience a phenomenon known as “courtesy stigma” (Goffman 1961). Coined by Goffman in the early 1960s, courtesy stigma refers to how members of families impacted by IDD “experience stigmatization because of their affiliation with the stigmatized individual rather than through any characteristic of their own” (Gray 1993: 104). Parents of children with IDD can be stigmatized by their biological relationship with their child and their “‘known-about’ identity as the parent of a child with a disability” (Gray 2002: 737). Just as stigma can impact individuals with IDD themselves, courtesy stigmatization often leads to social stress and isolation for parents of children with IDD (Voysey 1972).

Additional circumstances that impact parental stress include the severity of the child’s disability, co-occurring diagnoses, and duration of disability. Demographic characteristics of the parents, such as socioeconomic status, race, and gender, likely also play a large role in the experiences of parenting a disabled child. However, given that the majority of existing studies

have examined primarily white, upper-middle class families (Benson and Karlof 2009; Piazza et. al 2014; Hassall et. al 2005), these effects are relatively unknown. Scholars also debate the role of gender on the stress levels of parents of children with IDD. Some studies show that mothers experience greater depression, lower wellbeing, and worse physical health outcomes than fathers (Herring et al. 2006, Emerson et al. 2010). Additionally, mothers generally feel more stigmatized as a result of their child's disability than fathers (Gray 1993). However, other studies have found that mothers do not differ in their wellbeing compared to fathers (Ha et al. 2008). While these mixed messages in the literature make it challenging to make nuanced statements about parents of children, it is very clear that parenting a disabled child is a uniquely challenging endeavor.

Shifting Dependencies and the Life Course

In general, intellectual and developmental disabilities are chronic conditions—they do not necessarily improve over the course of time. As a result, children with IDD carry their disabilities with them as they age and often continue to rely on their parents and families for care throughout adulthood. However, the care dependencies and needs of individuals with IDD and their parents change over time. Life course theory can provide a useful framework for examining the shifting relationships and caretaking dependencies of parents of individuals with IDD as they age.

Developed by Glen H. Elder, Jr, life course theory focuses primarily on the principle that an individual's successional life transitions are embedded within and shaped by the historical times and places they experience over their lifetime. Because “all life choices are contingent on the opportunities and constraints of social structure and culture,” historical forces that shape overarching social trajectories also influence the behavior and development of individuals (Elder

1998: 2). For example, Elder argues that during the Great Depression, fathers tended to become more irritable and explosive due to economic hardship. Subsequently, fathers' increased irritability tended to negatively impact the quality of marriage, parenthood, and family life as a whole (Elder 1998: 4). Also inherent to life course theory is the concept of "**linked lives**," which posits that lives are lived interdependently and "social and historical influences are expressed through this network of shared relationships" (Elder 1998: 4).

Very few lives are lived more interdependently than those of parents and their children. In a parent-child relationship, the duty to provide care and the need to be cared for are "closely linked to age-specific requirements and are situated in specific life phases," (Alber and Drotbohm 2015: 10); as a result, a child's life course transition often results in a complementary transition for their parent, or vice versa. In the case of most parents, the changing "rights and duties of care" become most obvious as their child transitions into adulthood and grows more independent (Drotbohm and Alber 2015: 10). For example, if a child leaves home after high school to go to college, the child's parents may also experience a life transition: becoming empty-nesters. Similarly, when parents transition into advanced old age, their child generally returns to care for the aging parent.

However, in the case of individuals with IDD, age-related markers of specific life phases tend to be non-normative. Thus, individuals with IDD do not necessarily follow the same succession of life transitions that usually apply to typically-developing individuals, such as moving away from home or getting married. When individuals with IDD age and diverge from a normative life course timeline, the temporal cadence of their parents' lives also diverges.

Despite the exceptional social characteristics of these families as they age, there is limited empirical sociological research on the linked aging experiences of parents of adults with IDD.

This is likely due to the fact that, historically, short life expectancies meant that children with IDD used to pre-decease their parents or face institutionalization (Hewitt et al. 2010). As a result, these parents generally did not witness their children with IDD enter adulthood.

However, recent technological and medical advances mean that the current average lifespan of a person with IDD in the United States is now approaching 70 years of age (Hewitt et al. 2010).

Currently, over 600,000 adults with IDD currently live in the United States; given that the overall prevalence of IDD in the United States is also increasing¹, that number is likely to double by 2030 (Hewitt et al. 2010; Ouellette-Kuntz et al. 2015). This sizeable population of older people with IDD means that many parents of these individuals are now experiencing the process of aging alongside their children.

As the population of adults with IDD continues to rise, the subjective experiences of older parents of these individuals remain understudied. While some quantitative studies have been conducted, these studies are generally split between two competing theories of stress and aging: the cumulative stress model and the adaptation model (Ha et al. 2008). Proponents of the cumulative stress model use survey data to argue that by early old age, parents of individuals with IDD have poorer mental and physical health than both parents of typically developing children and middle-aged parents of individuals with IDD (Seltzer et al. 2012). Scholars attribute these adverse health outcomes in part to the cumulative result of years of acute parenting stress. Meanwhile, the adaptation model posits that older parents of children with IDD are better able to cope with stress than younger parents of children with IDD. Multiple studies have found results that support this theory of adaptation over the cumulative stress theory, also

¹ Scholars attribute the increasing population of individuals with IDD to a variety of epidemiological factors. Examples include changing diagnostic criteria for IDD, shifts in exposure to IDD risk factors (such as alcohol during pregnancy and contaminated drinking water), increased awareness of IDD, increased average parental age, and overall changes in population characteristics (McKenzie et al. 2016; Lai et al. 2013).

using survey data (Ha et al. 2008, Kono and Mearns 2013). While it is difficult to determine which theory better reflects reality, it is easy to say that quantitative methods such as surveys cannot completely capture the lived experiences of these parents as they age.

Out of the handful of known qualitative studies on aging parents of children with IDD, most were conducted in the United Kingdom. For example, Pryce et al. (2017) interviewed 9 older British parents (between the ages of 65 and 85) who have at least one child with an IDD and created a thematic framework for how families with IDD tolerated uncertainty about the future, including themes such as accepting the parenting role, facing challenges, and positive meaning making. According to Pryce et al., these aging parents experience profound anxiety over future thinking and distrust of professional care services. The majority of parents deal with the anxiety via avoidance, or lack of explicit planning. Other researchers in the United Kingdom have echoed these results, finding that older caregivers of adults with IDD generally report obstacles such as lack of guidance, absence of appropriate residential options, and emotional struggle as barriers to future planning for their children (Taggart et al. 2012). Based on these UK studies, it is clear that even just thinking about the future—let alone making concrete plans—is a source of anxiety for the aging parents of children with IDD.

Negotiating IDD in the United States

Over the course of their lives, parents of children with IDD encounter a variety of unique stresses and experiences that parents of neuro-typical children do not always face. Yet, to fully understand the realities of life for parents of children with IDD we must remember that these parents are caring for their children within a particular social context; in the present study, that social context is a small city in rural Minnesota. Using a life course theoretical framework, the

ability of humans to make decisions and form relationships depends on the “opportunities and constraints of social structure and culture” (Elder 1998: 2). In the United States, a specific mode of governance known as neoliberalism has greatly impacted public life, and particularly, the options available to parents as they navigate raising children with IDD.

Coming to rise in the late 1970s through the influence of world leaders such as Ronald Reagan, Margaret Thatcher, and Deng Xiaoping, neoliberalism is a post-Cold War school of thought that “promotes individual freedom, self-determination, and choice through an emphasis on minimal government involvement, free trade, the free market, and promotion of the private sector rather than the public sector” (Oxford Dictionary of Gender Studies). Neoliberal thought revolves around the assumption that “individual freedoms are guaranteed by freedom of the market and of trade” (Harvey 2005: 7); as a result, because neoliberal rationality posits that the wellbeing of a nation and its citizens depends on the success of the free market, neoliberalism frames all elements of life in terms of economics and “configures human beings exhaustively as market actors, always, only, and everywhere” (Brown 2015: 31). While the United States and the United Kingdom are particularly associated with neoliberalism, neoliberal theory has had a wide-reaching impact and “almost all states, from those newly minted after the collapse of the Soviet Union to old-style social democracies and welfare states such as New Zealand and Sweden, have embraced...some version of neoliberal theory and adjusted at least some practices accordingly” (Harvey 2005: 3).

Under neoliberal rationality, the state is responsible only for creating an institutional framework within which the free market can function. Practically, such an emphasis on the free market often has a wide range of economic policy consequences including “deregulation of industries and capital flows; radical reduction in welfare state provisions and protections for the

vulnerable; privatized and outsourced public goods, ranging from education, parks, postal services, roads, and social welfare to prisons and militaries...[and] the conversion of every human need or desire into a profitable enterprise” (Brown 2015: 28). One well-known example of neoliberal thought is the idea of “trickle-down” economics, in which tax cuts for the wealthy are expected to bolster the free market economy and eventually benefit the society as whole (Aghion and Bolton 1997: 151). Similarly, within a neoliberal framework, reduction of public services, such as welfare for the vulnerable, is necessary in order to allow growth of the free market. Like classical liberalism, neoliberalism places high value on individual qualities like independence, self-sufficiency, and rationality. So, just as the free market theoretically benefits from minimal government intervention, citizens themselves are also expected to thrive with little public support.

Neoliberalism has been heavily critiqued in practice. Because citizens of a neoliberal state are “required to procure individually what was once provisioned in common,” neoliberal policies are often criticized for intensifying socioeconomic inequality and division of wealth (Brown 2015: 42). Instead of leading to a trickle-down of benefits, tax cuts for corporations and the wealthy often mean that poorer citizens must pay more to access public resources and maintain the tax pool. Combined with the reduction of public services such as health care, public education, and welfare provision, neoliberal tax policies leave “larger and larger segments of the population exposed to impoverishment,” as citizens are expected to support themselves without substantial government assistance (Harvey 2005: 76). Quantitative studies support the notion that as neoliberal economic policies grow, wealth inequality also intensifies. For example, Pickety (2014) found that in 1970, the top percentile of American society received about 8% of the national income (Pickety 2014: 316). However, after the rise of neoliberalism in the late

1970s and early 1980s, this number jumped to 13% by 1990—and by 2010, over 18% of national income went to the richest 1% of the United States (Picketty 2014: 316). Such large disparities in wealth distribution and income mean that for everybody except the very rich, making ends meet is getting harder and harder.

Under a neoliberal agenda, public supports and welfare services decrease in conjunction with an increase in wealth inequality. This combination has the potential to put strain on vulnerable groups of citizens—including individuals with IDD and their families. The process of deinstitutionalization serves as an example of neoliberalism's impact on the IDD community. Historically, instead of living at home, individuals with IDD have been forced to live in large public institutions with deplorable material and social conditions. Ever since disability advocates articulated deinstitutionalization as a policy goal in the late 1960s and early 1970s, many public institutions have been replaced by community-based services for individuals with IDD, such as group homes with three to eight residents and in-home support staff (Mansell 2006: 67).

Living in the community rather than an institution has been shown to concretely benefit the wellbeing of individuals with IDD; however, those benefits are oftentimes limited by the fact that neoliberal societies like the United States, where welfare services are not easily accessible and the remaining public services are underdeveloped, often do not provide the support or resources necessary for individuals with IDD to thrive in a community setting and receive high-quality care (Mansell 2006: 72). In 2015, it was estimated that 60% of adults with IDD in the United States reside at home, making families the single largest provider of care to this population (Heller et al. 2015). Even though living in a family member's home technically

counts as living in the community, this kind of residential arrangement often results in a shift of caretaking responsibility from the government to the families.

As the population of adults with IDD in the United States continues to grow, families and the services meant to support them are subjected to an increasing amount of strain. Many families impacted by IDD in the US rely on a variety of federal and state services and funds, such as Medicaid and the HCBS Waiver program, for financial and emotional support; however, the service system is struggling to rely on limited funding and infrastructure to keep up with the growing demand of care (Parish and Lutwick 2005). For example, in 36 states, there are waiting lists of nearly 60,000 people with IDD in need of long term care. Meanwhile, in 2000, the budget for family support services in 2000 was \$1 billion, compared to the \$29 billion spent in total for entire developmental disabilities services system (Parish and Lutwick 2005).

Despite an increase in need, parents of individuals with IDD are often left with few places to turn. Quantitative studies have shown that in general, parents feel that the current system of support for their disabled children is not adequate for planning for their child's future, nor sufficient for monitoring quality of life in the future (Hewitt et al. 2010). They also report low levels of satisfaction with county case management services, quality of life monitoring, and financial planning services (Hewitt et al. 2010). Since many families rely on services to provide care for their disabled children, it is important to consider that these parents are working within a specific set of support structures that limit or mold their choices. The scarcity of aid options for families and individuals impacted by IDD in the United States undoubtedly affects how parents navigate their children's future care.

In conclusion, older parents of children with IDD are situated at the intersection of several sociological arenas, such as aging, disability, family, welfare, and caretaking. Given the

unique challenges and limitations such an intersection creates, how do parents of children with IDD navigate their aging experiences along with their children? In a neoliberal context, how do these parents think about and plan for the future, both for themselves and for their children? How do parents relate to the support services available to them over various phases of their lives? To answer these questions, I investigate the lived experiences of older parent of children with IDD living in a small rural city in Minnesota.

METHODS

Why Qualitative Research?

Over the summer and early fall of 2017, I conducted a series of semi-structured interviews with parents of individuals living with IDD. I chose this method for several reasons. First, the use of in-depth interviews allowed me to fill a substantial gap in the current literature on this topic. The vast majority of existing research on parents of children with IDD is based on quantitative survey data (e.g. Kono and Mearns 2013, Piazza et al. 2014, Seltzer et al. 2012, Yamaki et al. 2009). While survey research can illuminate broad trends or patterns in the lives of these parents, it cannot capture the depth of specific experiences. Second, it was only through in-depth interviews that I could adequately address my research questions and capture the complexity of my research participants' lived experiences. Because this project is an attempt to understand how older parents create unique perceptions of growing older, only qualitative methods can satisfactorily address such a goal. The process of interviewing gave me an invaluable opportunity to meet these parents, hear their stories, and try to make sense of their parenting experiences.

Semi-structured interviews were the most applicable format for my research question because participants were relatively free to direct flow of conversation. While I made sure to cover all of the key topics in the interview guide and “intervene when appropriate,” having the room to explore within a loose structure allowed participants to open up and share aspects of their stories that I might not have anticipated (Morris 2015: 10). As a result, in addition to the raw data, I was also able to learn which topics and experiences the interviewees themselves found most important.

Recruitment and Sample Characteristics

I focused specifically on families living in Northfield, Minnesota. Located about one hour south of the Minneapolis-St. Paul metropolitan area, Northfield is a rural college city with a population of approximately 20,000 residents (U.S. Census Bureau). Northfield is unique in that it is home to Laura Baker Services Association (LBSA), an organization that provides residential, occupational, and in-home services to adults with special needs. LBSA also hosts family support gatherings and respite care events (Laura Baker Services Association, 2017). Through LBSA, I sent out a recruitment email to all parents with children who are associated with the organization in some way, either residentially or through the use of other services. Parents who were interested in participating reached out to me via email.

I conducted a total of 12 interviews with 14 parents of individuals with IDD. For the purposes of this project, I define IDD using the following criteria developed by the American Association on Intellectual and Developmental Disabilities (AAIDD): the individual suffers from significant limitations in intellectual functioning (IQ is between 70-75 or below), the individual suffers from significant limitations in adaptive behaviors, and the onset of the disability occurred

before age 18. The most common forms of IDD include autism spectrum disorders (ASD), Down syndrome, cerebral palsy, Fragile X, epilepsy, and Fetal Alcohol Spectrum Disorder (FASD) (American Association on Intellectual and Developmental Disabilities 2017). While I will not include specific diagnoses in my results for the sake of confidentiality, about half of the parents in this study have children who require intensive care and supervision at all times. The remaining parents have children who can live or function independently for brief periods of time, but still need long-term care.

Several of the parents I interviewed had multiple children with special needs. In this regard, this study includes experiences based on a sample of 15 individuals with IDD. The parents I interviewed ranged in age from 46 to 78, with an average age of around 58 years. Their children ranged in age from 11-49 years old, with an average age of around 23 years. While I had originally hoped to interview only parents whose child with IDD was over 18, I included a few slightly younger families to ensure a workable sample size (See Table 1. Research Participants).

There is a notable lack of racial and socioeconomic diversity in my sample. All of the participants identified as white. At 88%, the city of Northfield itself is predominantly white—much higher than the national average of 72% (United States Census Bureau: 2010). As a result, creating a representative, racially-diverse sample would have been challenging in this context. Most interviewees described themselves as upper-middle class, with no participants identifying as below middle class. Providing support for individuals with IDD is often a costly endeavor; this means that my participants' relative financial security almost certainly shapes ways in which they think about caring for their children (Kittay 2001). Overall, the homogeneity of my

research sample means that this study's findings are limited in their generalizability and should be considered specifically in the context of Northfield, Minnesota.

Table 1. Research Participants			
<i>Name of Parent²</i>	<i>Age of Parent</i>	<i>Age of Child/Children</i>	<i>Child's Residential Status</i>
Steve	61	28	LBSA
John	60	23	Home with parents
Cynthia	60	25	Home with parents
Irene & Bill	62 & 64	27	Home with parents
Ed	55	23 & 21	1 at LBSA, 1 at home with parents
Jane	58	17	Home with parents
Helen & Kirk	57 & 54	26	Home with parents
Stacy	46	21 & 17	1 in an independent living option, 1 at home with parents
Ann	49	15	Home with parents
Wendy	60	26	LBSA
Bruce	47	15 & 11	Both at home with father
William	79	49	LBSA

The Interview Experience

Throughout the interview process, I was surprised by the richness and honesty of the stories that my participants chose to share with me. Because my interview guide addressed potentially overwhelming or emotional topics, I originally anticipated that parents would be hesitant to talk about such personal information with me. However, many interviewees were forthcoming and eager to share details of their lives (See Appendix A: Interview Guide).

² All names used for parents and children are pseudonyms

Interviews generally lasted around an hour and a half, ranging from 45 minutes to 2 hours. I took care to find an interview location in which both the interviewee and I felt comfortable. Seven of the interviews took place in the student center at Carleton College, four of the interviews took place at the participants' homes, and one interview took place at a public coffee shop. I recorded the dialogue of each interview and then transcribed the recordings to create a data set of 12 interview transcripts.

As a researcher, I must acknowledge how my own social location may have impacted data collection. While interviewing, it was clear to me that my unique mix of identities and experiences granted me both privileges and disadvantages in the field. For example, in addition to the privileges I gain from being a young, white, cisgender, able-bodied woman, I also have a longtime affiliation with LBSA. I have volunteered with LBSA clients for the past three years and continue to visit LBSA weekly. While my recruitment materials and consent form made it clear that I have a connection to LBSA, I sought to minimize any potential power dynamics and therefore did not explicitly discuss my volunteer role serving LBSA clients. If an interviewee asked me about the motivation behind my project, I did disclose my experiences volunteering with LBSA; however, such questions generally came up only at the end of the interview. Despite my efforts to remain distant from LBSA while interviewing, three of my participants were individuals whom I had met prior to our interviews through LBSA programs and events. In general, these participants seemed especially comfortable with my presence and frequently commented on my own dedication to individuals with IDD. However, it is also possible that my familiarity with these interviewees may have led them to be wary of openly commenting on their experiences with LBSA.

While I do not aim to simply list all of my identities and their associated effects, there is one more social location of mine that likely impacted research conduction: my role as a student at Carleton College, an elite liberal arts institution. Many parents dream that their children will be able to go to college someday, let alone attend a school of Carleton's caliber. In the majority of my interviews, it quickly became clear that I was talking to parents of children who did not or likely could not ever attend college. I fully informed all of my interviewees that I was conducting research for my senior thesis in sociology at Carleton (see Appendix B: Consent Form). As a result, many participants referred to my life at Carleton throughout the interview, sometimes in comparison to their own children. For example, one father, Steve, specifically referred to me while describing challenges in his life:

I also know by having Cal, my life has changed differently than what it would've been had he been a normal kid, if he were attending Carleton College and gonna be a senior. My life would've been different.

In many ways, my status as a young person and a student generally makes it easier for older people to share their thoughts and experiences with me. However, I am aware that being a Carleton student also puts me in a position of intellectual power; for parents of individuals with IDD (many of whom were close to my age), it might have felt vulnerable to open up to a young researcher in such a position. Because many of my interlocutors were highly educated themselves, this was a dynamic I had not anticipated. It was only through the process of interviewing that I was forced to position myself in relation to my interviewees, their children, and their experiences.

Data analysis

I used a highly inductive method while analyzing my interview transcripts. In an effort to not subtly shape my results based on preconceived notions, I transcribed the entirety of each interview. While analyzing the transcript data, I primarily used a “categorizing strategy,” which involved coding and thematic analysis with a focus on relationships of similarity among responses and allowed me to identify important common threads and themes among my participants’ narratives as I read and re-read each interview (Maxwell 2013: 105). Using an iterative process, I then based my coding categories around the data itself, not predefined assumptions that may wrongfully influence my data analysis.

While categorizing analysis was my project’s primary analysis strategy, I also integrated Maxwell’s “connecting strategy” with this coding and thematic analysis (2013: 105). This involves “seeing actual connections between things, not just similarities and differences” (Maxwell 2013: 106). In other words, connecting analysis focuses on relationships of contiguity within an actual context, which nicely compliments the lack of context incorporated into categorizing strategies. While my research question is meant primarily to address commonalities between specific elements of participants’ experiences, presenting a holistic view of these parents and their stories is also necessary. Every participant’s experiences are situated within a larger context that is shaped by that interviewee’s unique journey as a parent of a child with IDD. As I discuss the results of my research, it is important to keep in mind this balance between categorization and contextualization.

RESULTS

Lifelong Dependency and Parenting: “You’re never gonna just fly the coop”

“If a person is single and you go through life being single, you can think of just yourself...But all of a sudden if you have a kid, whether it’s one, two, or three who have a disability...well if you have kids *without* a disability, you expect them to go off and move on, and they’ll be in your life but they won’t be dependent forever. But that other one, now, all of a sudden, you’ve got that disabled person [and] they’re with you for the rest of your life. The big kicker is, you’d like to see when it’s your turn to have that off your plate.”

-Kirk

On a sunny day in mid-July, I stood on the doorstep of an idyllic suburban house belonging to Kirk and Helen, a couple in their mid-50s. They had invited me to their home for an interview, and even though I was nearing the end of my research, my nerves still hadn’t quite worn off. I gathered my courage and rang the doorbell; moments later, the door swung open and I was standing face-to-face with somebody who was neither Helen nor Kirk but their 26-year-old daughter, Sarah. Out of the 15 individuals with IDD in my sample, Sarah is one of the ten “co-residers” who live at home with their parents. Throughout the course of my two-hour interview with Helen and Kirk, Sarah made her presence known; occasionally she’d call out to her parents for help and Helen or Kirk would excuse themselves to offer her assistance. While Helen describes Sarah as “pretty high functioning,” Helen and Kirk acknowledge that Sarah struggles to navigate the world independently:

[Sarah] doesn’t understand...time management, she doesn’t understand a sequence of events. It’s really hard for her to figure out what to do during the day...If we just backed off, she would just be in front of the computer or the TV all day, and she wouldn’t eat. She’s pretty high functioning, but she needs cueing; she needs to be cued for everything.

Even though Sarah is 26 years old, Helen and Kirk remain involved in every aspect of her life. Sarah relies on them to help her find a job and drive her to and from that job. For things like grocery shopping and budgeting, Helen and Kirk help Sarah stay organized. Helen and Kirk

remind her to brush her teeth and her hair every day. Like Helen and Kirk, many other parents of co-residers reported similarly high involvement in their kids' lives well past the typical life course expectations. Co-residers remain primarily dependent on their parents for daily care and often cannot be left alone for extended periods of time; for parents of co-residers, caring for their adult children often results in limited opportunities for personal time, difficulty working full time, and a highly rigid home life.

According to my interviewees, having such heavy caregiving duties often comes at a cost. As Ed, a 55-year-old father of two adult daughters with IDD (one a co-resider and one a non-co-resider), puts it, "we can't just go on a vacation and leave the kids at home, even though they're in their 20s...and we can't just go out to dinner and leave them because you can't just hire a 13-year-old from down the road to come to watch my kids." Because finding professional caregivers for older individuals with IDD is difficult, activities like going out with friends or having a date night are hardly ever spontaneous events. Stacy talked directly about the challenges of maintaining a social life while caring for her two children with IDD: "Do I spend time with friends? No. Do I go out for dinner with people? No. If I need to go out to dinner with my husband, does it take a lot of coordination? Yup." Even when parents of co-residers are able to take a break from caregiving, their freedom is often interrupted if their children have any needs that arise. For example, Kirk and Helen described how every Monday afternoon for three hours, a Personal Care Assistant (PCA) comes to care for Sarah. These "sacred" Monday afternoons give Helen and Kirk their only chance for respite each week; yet, Kirk also spoke eagerly about how he wanted to buy a new pair of earbuds so that if Sarah called him while they were out biking on Mondays, he could assist her over the phone.

For many parents of co-residers, their daily realities stand in stark contrast to their perception of the typical timeline of parenthood. Several parents of co-residers talked about their daily lives in relation to those of other older parents who have entered the empty-nester stage of life. According to Cynthia, age 60, her bi-monthly respite time is bittersweet because she knows that “all of the things that other people our age can do, we get to do twice a month.” However, for parents of co-residers whose kids remain reliant on them for many of the basic necessities of life (such as being fed, entertained, or socially connected), it is simply not an option to “leave them hanging” without support—even though this means that the parents remain heavily involved in the daily care of their child for an unusually extended period of time.

Yet, even for my interviewees who *had* moved into the empty-nester stage of life, their child’s change in residential status did not drastically shift the overall dependency relationship. About half of my interviewees have children who have moved away from home and live at LBSA or in another residential community. Many parents of these “non-co-residers” stay surprisingly engaged in their child’s daily life. When I asked Wendy, whose 26-year old son, Michael, is a resident at LBSA, what she does with her free time, she replied, “Being really involved with Michael is a big part of it!” Wendy’s response seemed to hold true for many of my non-co-resider interviewees, as most of them live within easy driving distance of their child’s residence and see them multiple times a week.

Despite the constant presence of paid caretakers watching over their child’s residence, parents of non-co-residers generally prefer to participate in things like managing their child’s budgets, taking them to appointments, and frequently socializing with their child. Additionally, most parents of non-co-residers do not anticipate this dynamic shifting significantly in the future.

For instance, Stacy, the mother of two young adults with IDD, talked directly about her involvement in her 21-year-old son's life:

Interviewer: "Do you think that having Daniel living away from home makes things any easier on you?"

Stacy: "No, because I have to coordinate with [Daniel's caretakers], I have to remind them, 'Oh here's the appointment.' Because I still go to [the appointments]. They're not going to be in charge of his medical. I'm going to always participate."

My interviewees tend to view the overall level of their direct parental role as ultimately stagnant, even over time or with changes in their child's residential status. While their child's specific needs may change over time, the overall dependency relationship does not—for example, Helen doesn't see her caretaking responsibilities dissipating anytime soon because now, instead of helping her daughter with things like school or behavioral issues, "it's more getting her a job, getting her involved and plugged in and transportation...It's just different."

For parents of co-residers and non-co-residers alike, it's easy to attribute this sustained involvement in their child's life to the notion that being directly responsible for the wellbeing of their disabled children is central to their identities as parents. As Cynthia explained to me, "When you're *that* involved in the care of someone every minute of every day, it tends to become your identity." Being engaged in a direct parenting role that extends far beyond the average timeline, parents of children with IDD often "can't imagine ever not attending" their child's copious appointments or seeing their child regularly. So, even though parents of non-co-residers acknowledge and appreciate the benefits of the newfound sleep, free time, and stability that come with placing their child in a separate residential option, I also heard parents of non-co-residers describe the process of their child leaving home as "the most painful thing we ever had to do." Not only are my interviewees' life-courses linked to that of their child, but their identities are linked as well.

Even as my interviewees may internalize their children's sustained dependency in positive ways, the fact remains they are ultimately responsible for ensuring their children's safety, wellbeing, and many other basic necessities of life. Parents of children with IDD remain in an involved dependency relationship with their child for an abnormally extended period of time. According to Kittay, such "dependency relations require support from additional sources to be sustainable" (Kittay 1998: 129). What are the additional sources of support available to aging parents of individuals with IDD in the United States? Even with these supports, how do the sustained dependency relationships between parents and children impact the parents' transition into old age? I argue that while there is a system of public and private services meant to aid parents, the parents view this support structure as unreliable, unpredictable, and ultimately unsuccessful in helping them care for their children and themselves as they age.

Caretaking within a Broken System: "Going Out the Back Door"

Transitioning to Adulthood: "The Drop Off"

"As soon as they're done with school, it's all up to us. I can't imagine families where both of them are working, because...[before the drop off] you've got this 40 hours a week that they're in school where it's somebody else's responsibility for them and taking care of them. And you can get things done, you can work...[but] now all of a sudden, you've gotta supervise your children, you've gotta be the one who's gotta get them to this and get them to this and get them to this...I'm the one who has to go and help them find a different way to fill their time instead of just sitting in front of the TV. It's all up to the families at that point."

-Ed

For parents like Ed, their child's high school graduation is not necessarily a celebratory occasion. As their children with IDD age and enter adulthood, parents of these children are often left with little support from the structures they had previously relied on for much of their child's lives. A notable example of this lack of public support for families occurs when an individual

with IDD turns 21 years of age. According to the 1990 Individuals with Disabilities Education Act (IDEA), all children with special needs are federally entitled, up until age 21, to a “free, appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.” (IDEA). This gives kids with special needs not only education, but social engagement and a place to be during the day, five days a week. During summer vacation, additional Extended School Year (ESY) services are available under IDEA to students as determined on an individual basis with no cost to parents (Minnesota Disability Law Center).

However, after individuals with IDD turn 21, that entitlement ends and parents become responsible for keeping their kids occupied and engaged during the day. This transition at age 21 is often so severe that four of my interviewees referred specifically to the newfound absence of support from the public-school system as “falling off the cliff” or “the drop off.” To my interviewees, the very notion of the drop off seems arbitrary and illogical. As Kirk emphasized, “it’s not like all of a sudden, your disability is gone”—when their child turns 21, the severity of their child’s impairments and their overall state of dependency remain the same. For parents, the net result of hitting the drop off is that instead of gaining freedom after their kid finishes high school, the weight of their child’s dependency shifts even more heavily back onto their shoulders.

If the shock of the drop off itself is harsh, the new reality of life for parents and their grown children after the falling off the cliff is even harsher. For Stacy, whose 21-year-old son is entering his first year out of school, hitting the drop off is a draining experience: “There’s no services, no nothing, no connections...he’ll never have the day filled for 6 hours like he did when he was in school. And so maybe just because my memory is poor, but this feels like the

most stressful thing we've ever encountered." For many of my interviewees, finding a daily occupation for their grown children with IDD is a particularly stressful post-drop off challenge—and the responsibility falls mainly on their shoulders. One dad, John, is not alone in feeling this burden:

Interviewer: "When Brian transitioned out of school when he turned 21, was that tough for you?"

John: "Well yeah, because it put everything on me. Because you know what they have for Brian, out here? Nothing. Nothing."

Like John, half of my interviewees articulated the difficulty that comes with trying to keep their kids busy and engaged during the day. For most adults, having a meaningful occupation is a central part of life and a gateway to independence. However, for adults with IDD, finding employment of any kind is incredibly challenging—let alone employment that is rewarding to the employee. Nationwide, only 16% of adults with IDD are employed in a paid job that is integrated into the community (as opposed to being segregated from non-disabled employees), compared to the 73% of adults without disabilities who have paid jobs (Hiersteiner et al. 2016). The State of Minnesota has publicly expressed a desire to help people with disabilities have "choices for competitive, meaningful, and sustained employment in the most integrated setting" (Minnesota's Olmstead Plan). Yet, at the same time, the percentage of adults with IDD in Minnesota who have integrated employment is lower than the national average at only 9% (Winsor et. al 2016: 9). Of these adults with IDD who have found employment, the average employee only works 13 hours a week (Hiersteiner et al. 2016).

This high rate of unemployment for individuals with IDD puts their parents in a difficult position. While services do exist that are meant to help individuals with IDD who are seeking employment, such as Epic Enterprises in Dundas, Minnesota, my interviewees described feeling ultimately responsible for finding jobs for their kids. For a mom like Helen, whose daughter

Sarah is currently searching for work, services like Epic are not necessarily helpful—as Helen describes it, “[Sarah] works with Epic. But they have not found the jobs for her.” In a small town like Northfield, the reality is that there are very few jobs available for individuals with IDD. As a result, places like Epic must stretch to create opportunities despite having limited tasks—too often, parents like Kirk feel frustration from the fact that employers are “spread very thin trying to help a number of other people. So instead of giving one person 6 hours a day, they give 3 people 2 hours, and they’re all disabled. Are [they] doing many people favors? Not necessarily.” For parents, having their child work for only a few hours a week does little to alleviate the stress of keeping their child busy during the day.

Oftentimes, parents must also balance the desire for their child to have a paying job with the reality that many of the jobs available to individuals with IDD are far from optimal. Like Ed, most of my interviewees placed a high value on finding an occupation for their child “that makes them feel somewhat accomplished and fulfilled.” However, not only is there shortage of jobs available to individuals with IDD in Northfield, but many parents like John view the jobs that *do* exist as “incredibly menial.” To ensure that their child has a rewarding daily occupation, some parents like Steve end up funding day opportunities for their child on their own:

One of Cal’s occupations today is delivering Meals on Wheels. [He] absolutely loves it, and if we said to him, ‘You no longer can do meals on wheels,’ he would adjust to it but...his life would be less enjoyable...We’d much rather find ways for him to do like delivering Meals on Wheels or having connections with the community, connections with people, and fulfilling something than sitting at Epic Enterprises and putting labels on bags of parts...So, to do Meals on Wheels, he has to have a 1-on-1 person with him. How does that get funding? So, we’re looking into whether we can self-fund some of that stuff, to give him that opportunity.

Steve, who identified himself as upper-class, is willing to make a financial sacrifice so that his son can participate in a meaningful, fulfilling occupation. Given that all of my interviewees

described their socioeconomic status as middle-class or above, many of them have the ability to invest time and money in securing satisfying daily activities for their children. Even if it may be a financial stretch, parents are often willing to bear the cost; however, my interviewees recognize that having the ability to fund such endeavors is rare. Sometimes, parents even go so far as to create organizations to occupy their children—John, who runs an artistic organization at which his son works, acknowledges that “not everybody has the option of time or resources...everything we do, we don’t have any funding for. Everything we do is, you know, we pay for.” Navigating the job search is a key example of how after the drop off, parents are left primarily responsible for their child’s wellbeing at a time in life when other parents are stepping back from the burdens of parenthood. The outside supports are not in place to help parents find daily engagement for their child, and as a result, parents must do it on their own.

Navigating Complex Services: “None of This Comes with a Manual”

Unfortunately, the struggle to find a satisfying occupation is just one of the many roadblocks that parents encounter as they seek opportunities for their child and resources for themselves. Adults with IDD are eligible for a variety of publicly-funded services meant to financially assist them and their families with several key aspects of care, such as healthcare, housing, and daily assistance; notable examples include Medicaid and Social Security disability programs (Social Security Office of Retirement and Disability Policy). However, to my interviewees, attempting to navigate and benefit from these services is an illogical, overwhelming, and draining process. Parents repeatedly painted a picture of a system riddled with frustrating complexities that make it challenging for even the highly-educated to benefit. Helen described this phenomenon in the following manner:

[After the drop off], parents are really left with having to navigate [public services] without any kind of preparation or warning. And there's waiting lists and there's government rules and there's funding streams that people are confused about...honest to God, you need a Master's Degree to figure out that whole piece. And nobody's really educating folks on what they're supposed to be doing.

Trying to navigate through the intricacies of state and county programs and gather information about services without prior knowledge is “just overwhelming, period.” Even for Ann, who works in social services herself, searching for information and resources for her son is emotionally exhausting because “first, you get this huge diagnosis that's weighing on you, but then all of a sudden, you're in this confusing world of, you know, what do I do, what are services, what's available, how do I get them, who do I talk to?” Several of my interviewees or their family members work in social services and, like Steve, they simply “can't imagine a family that is unfamiliar with the human resources, navigating that world.” Parents feel that even just the first step of getting information about available services for their child is a struggle.

To my interviewees, educating themselves about the human services system is not only incredibly confusing, but is made worse by the fact that they feel as if they're in it alone. Through their county, parents have access to a professional caseworker, generally a social worker, who is tasked with helping individuals with IDD and their families access resources and providing them with information and guidance. Even though this system is designed with the intention of providing support to parents, similar to the job search, many of my interviewees seemed to view professional services workers as somewhere between inconsequential and actively *unhelpful*. Parents feel that they are the ones who wind up taking the initiative to get support for their kids: as Stacy, age 46, put it, “you need to let your social worker know and you've got to start this email chain and just be telling them, you know, you can't live like this.” One dad even hypothesized that the Minnesota Department of Human Services (DHS)

intentionally adds to the complexity of the service system in order to deter parents, because if they “make it hard to access, make it really complex, make it really difficult” then they can “weed out three-quarters of the people” who are seeking services and funding for their children.

The most positive comment on social workers came from Ed, who reported his success: “We’ve talked to people after years and their social worker never mentioned to them that their kid might be eligible for greater services... We’ve been lucky that we’ve had social workers who have been pretty good and given us the information we needed.” Occasionally, independent groups like LBSA will provide workshops and informational sessions to parents about the changes in services that occur when their child transitions into adulthood. Yet, for parents, this information oftentimes comes too late—as Helen, who recently went to a group informational session, told me, “[The session leaders] were talking about...transitioning into adulthood and these adult services. And we’re all like, why didn’t somebody tell us sooner?” For my interviewees, the sheer complexity of the human services world combined with a perceived lack of professional support creates a stressful, omnipresent burden.

Even for parents who have the educational background and experiences necessary to navigate the available social services, gathering relevant information about the options available to help their child is just the first step. The process of actually *receiving* the benefits that services theoretically provide is a separate frustration. For example, many parents described the challenges of securing a Home & Community-Based Services (HCBS) Waiver for their child. Funded through Medicaid, the HCBS Waiver provides a combination of medical and non-medical services for individuals with IDD in a non-institutionalized setting. Examples of the services an HCBS Waiver can support include case management, a home health aide, adult day health services, and respite care for parents (Medicaid.gov). The goal for the HCBS waiver is to

allow for “service delivery in integrated, community-based settings” as opposed to in segregated institutions (U.S. Department of Health and Human Services, 2000).

My interviewees consistently mentioned the HCBS Waiver as crucial in providing benefits for their child along with financial and emotional relief for the parents; without a waiver, Richard explained that paying for services such as a Personal Care Assistant (PCA) can be “prohibitively expensive” for parents. However, because the HCBS Waiver program is funded 60% by the federal government and 40% by each individual state, there is a limited number of Waivers available to grant (Medicaid.gov). Minnesota has among the longest waitlists in the nation; at any given time, approximately 4,000 applicants are stuck on county waiting lists for an HCBS Waiver (Serres 2016). As a result, parents who are trying to secure a Waiver for their child generally apply while their child is young and then must wait for years before actually reaping the benefits. Helen and Kirk described the stress of waiting nine years for a Waiver for their daughter, Sarah—they applied when Sarah was 13 and did not receive Waiver services until she was 22. While the HCBS Waiver does provide many benefits for families, its restricted availability means that the very process of getting one is a challenge.

Many of my interviewees also described the process of securing stable housing for their child as a particularly stressful, urgent task. For the parents of co-residers in my sample, the possibility of dying before finding a stable residential situation for their child is an omnipresent fear. However, like HCBS Waiver benefits, residential options for adults with IDD in group homes or independent living options are hard to access.

Even though the State of Minnesota’s vision statement expresses the goal that “supports and services will allow sufficient flexibility to support individuals’ choices on where they live and how they engage in their communities,” the reality is that parents like Steve feel as if “there

aren't choices" at all (Minnesota Olmstead Subcabinet 2017: 47). In a small city like Northfield, appropriate residential options for adults with IDD are already hard to come by. For my interviewees whose children live at home, a major obstacle to finding suitable housing stems from the fact that the State of Minnesota is cutting back on publicly-run residential options for dependent adults. In 2009, hoping to reign in Medicaid spending, the State of Minnesota authorized a moratorium on the growth of licensed corporate foster care (group homes) and community residential settings (Minnesota Department of Human Services 2009). In 2015, the Minnesota DHS expanded on the existing moratorium by announcing the impending closure of 48 of the 120 remaining public group homes, a move meant to shrink the \$19 million deficit in the State of Minnesota's budget for vulnerable population (Serres 2015). While there are 4,700 privately-run group homes in Minnesota, the inability to create public facilities combined with the rising population of adults with IDD means it is increasingly difficult to find a group home bed (Serres 2015).

Even though the Minnesota DHS and some activists promote the 2009 moratorium as a positive step away from the institutionalized model of care for people with IDD while simultaneously reducing public spending, my interviewees have a more hostile attitude towards the legislation. In their eyes, the moratorium and the subsequent shortage of group home beds in Minnesota make it difficult to plan for their child's residential future. For parents who are trying to eventually to move their child into a group home, finding an available, desirable option is essentially a waiting game. Cynthia, age 60, told me that she and her daughter have been waiting for a spot at LBSA for over 10 years; even though she attributes part of this delay to the fact that they live in a different county than LBSA, the county line is certainly not the only factor. As Ed,

age 55, describes it, “quite honestly, the reality right now is you get into a group home when somebody dies...there just aren’t any openings anywhere.”

For parents like Helen and Kirk, who are in their mid-50s, the moratorium not only adds stress to their lives but also fails to serve its advertised purpose. While the Minnesota DHS argues that the moratorium is a crucial step in re-integrating individuals with IDD into the community, Helen feels that the end result for her daughter, Sarah, is further isolation:

The options aren’t there so what are you supposed to do? When your only option—and what the law says and the homestead says—is that people are supposed to be living in the community. And living in your parents’ basement is considered living in the community. But Sarah and these folks are more isolated than they’ve ever been because they don’t have transportation, they don’t have regular jobs, they don’t have the opportunity to get together unless the parents direct that or somebody else organizes that.

According to Helen, there is a disconnect between the State’s move to integrate young adults with IDD and its practical impact on these individuals and their families. In a neoliberal context, the State’s withdrawal of support from services like group homes makes economic sense; however, without the appropriate private services in place to support the growing population of individuals like Sarah, the end result is that many of my interviewees are entering old age without having the security of a stable housing situation for their child.

For parents, attempting to navigate such limited residential and service options is complicated by the fact that the service system is inherently political. As a result, like all politics, the system is also unpredictable. Many of the support programs parents rely on are publicly funded. Additionally, laws that impact individuals with IDD are influenced by the federal and state governments and their budgets. To parents, depending on lawmakers and politicians to support their child’s care means that their world, both present and future, is filled with uncertainty.

I conducted my interviews during the summer of 2017, approximately six months after the election of President Donald Trump Jr. and right in the middle of renewed debates by lawmakers over the fate of the Affordable Care Act (and subsequently, the Medicaid funding that supports many of my interviewees' children). In many of my interviews, the tension was palpable; Ann confessed that "it's been terrifying to see the senate debate health care, and you know, trying to conceptualize what it would look like if that [Medicaid] went away for people with disabilities. I mean I just, I could barely, I just didn't even listen." Other parents like Jane were more direct in their concerns: "Well they're looking at Medicaid and they keep saying that it won't hurt the disabled, but you can't cut that much and not hurt the disabled. And they don't have enough as it is!" To my interviewees, the idea that their child's health and safety depend on an ever-changing group of lawmakers in Washington D.C. is almost too much to bear. As Carl put it bluntly, "if the Republicans continue to try to take this [Medicaid] away from people, it would absolutely destroy a place like Laura Baker and the people who live in there."

The unpredictability of politics makes planning beyond the short term for healthcare, housing, and occupational services a daunting task for families who rely on public programs. One dad, Richard, describes how thinking about the future for his kids is emotionally draining:

I think the medical situation's all up in the air, you know, if it's going to radically shift every eight years of presidents... every time I would talk to [the director of LBSA], you know, there would be new waiver things going and new arrangements of Medicare and...I kinda want to sit there and think about that stuff, but if I internalize it right now and it changes radically in two years...I just don't want to put the mental energy into something that's not going to be there two years from now.

For Richard and parents like him, trying to make long term plans in a constantly-changing political landscape is a like trying to hit a moving target: nearly impossible. However, the unfortunate reality is that given their child's indefinite dependency, parents of children with IDD

must look beyond the short term and think about a future when they are no longer alive or able to care for their child.

Planning through Unpredictability: “What’s Gonna Happen to Brian?”

“Well yeah, it’s stressful! You don’t know what’s gonna happen. And you don’t know what’s gonna happen with any kid, but you know...at least my [neurotypical child] will hopefully have a job...he’ll be able to take care of himself. And we do worry about the way the world is changing and how fast it’s changing...so you kind of wonder, what are they gonna do?”

-Jane

Preparing for Old Age: “Things Could Change Dramatically”

For most people, planning for the future is a complex, overwhelming task. As I’m reaching a transitional phase in my own life, I’ve begun to realize that planning precisely how I want my future to look in five, ten, or even 20 years is made difficult by the fact that life is naturally unpredictable; there are earthquakes, car accidents, medical emergencies, and lottery jackpots that nobody could have ever anticipated. Parents of children with IDD face an additional challenge in that they must not only try to plan for their own futures, but also the future of their children. Because very few of my interviewee’s children have the capacity to make independent decisions about major aspects of their life, like financial security, daily care, and stable housing, parents are left feeling that as they age, they must also create plans so that their child will be supported once parents die.

In addition to the natural unpredictability of life, parents are already operating within an ever-changing political system that makes short term planning, let alone long-term planning, a particularly challenging endeavor. Irene expressed frustration over these challenges: “Well, I always think it’s about, will there be enough financial means to support Ian without being a burden to his sister in the future. And some of that has to do with politics, as we’ve talked about,

you know, what will that world look like? We don't know.” Like Irene, many of my interviewees expressed an intense desire to set up their child for a future with financial, occupational, and residential stability; yet at the same time, creating concrete plans for their child feels impossible.

Along with the political uncertainty, planning is further complicated by additional factors such as their child's changing needs and the fact that plans often rely on the complicated lives of other people. For example, one important arrangement that parents will ideally facilitate at some point before their death is the transition of their child's guardianship from themselves to another responsible party (generally another child, niece or nephew, or other family member). However, finding the appropriate person to take over the guardianship role means planning around somebody else and that person's own unpredictable life; as Alice puts it, planning guardianship for her son, Michael, is challenging because she needs to “come up with contingency plans and who would be in line to fill these roles. Right now, we have a plan, but 10 years from now that plan could look really different if somebody passes away or whatever.” Ed echoes the difficulty of trying to plan the guardianship transition; even though he has to be looking for other family members who might be suitable to take over care of his two children, “everybody else is getting older too and passing on... Whether or not any of them are in a type of situation [in which] I feel like I could trust them enough to turn that care over... that's going to be determined by those people and their situations in life too.”

As parents of children with IDD begin to age, the broad uncertainty surrounding ever-changing politics and unpredictable family members combines with realities of old age to create a double bind for parents. On one hand, for these parents, entering old age raises the stakes—if they haven't already managed to set up reliable situations for their child, it feels like time is

running out. Ed, age 55, describes this feeling of urgency: “That’s one of the biggest issues with Emily...without knowing what her future is in terms of a place to live, you know, we don’t want to be aging with her living in the home because then what happens when...we die...and then she’s forced out of the home she’s lived in all her life.” For parents like Steve, who is in his 60s, the idea of aging while trying to set his son, Cal, up for the future is an omnipresent stressor:

Tomorrow we’re going up to our cabin... [Cal will] have the biggest smile on his face, and I’ll know ‘Wow, not only am I gonna have a good time, he’s gonna have a great time.’ But it’s also a challenge knowing that as we get older, as [my ex-wife] and I get older, um, we’re the ones doing this with him. We wish there were others that were doing it, we wish [his sister] was a little bit more active and that it wasn’t just on our shoulders. That’s probably the thing that keeps you up at night the most...psychologically, that’s what gets to me.

To Steve, his own aging is a constant reminder of the knowledge that his son may soon have to manage in a world without him. Preparing for that future becomes an even more pressing matter. However, at the same time, the inherent unpredictability of the physical and mental changes that beset parents as they age make planning and caring for their child increasingly challenging. Sometimes, parents find themselves in a position where they too need care; for example, even though William, feels as if he can still manage some of his normal responsibilities at 79 years of age, he also admits that, “certainly a lot of the burdens of just daily life that I’ve always taken care of are suddenly seeming like a reach.” He goes on to describe how caring for his son, James, is getting harder and harder: “Sometimes I don’t think I have enough strength left at the end of the day to have James home that night.”

Several other married parents described how, in addition to losing the physical mobility or mental capacity to care for their child, they fear the possibility of becoming dependent on their spouse for care (or vice versa). Ed expressed to me this concern, saying: “you know, say I become physically disabled due to a stroke or something, or [my wife] develops

Alzheimer's...now I'm aging and I'm responsible for my two adult children and my wife and that's what I'm doing." Ultimately, as parents age, attempting to plan for their child's future simultaneously feels increasingly necessary and increasingly complicated by the very process of aging itself.

Futures on the Backburner: "Everything is on Hold"

"Future goals for myself? No. I got nothing. But you know what? Brian will be all I have to take me to the end. I will go down taking care of Brian, because who's gonna do it? There's nobody out here to do it. He's my only son. You know, so what am I gonna do?"

-John

Even though parents talked to me about a wide range of stories, experiences, and opinions, I closed each conversation by asking my interlocutor if they have any future goals—first for their child, and then for themselves. Without fail, my interviewees had no trouble articulating visions for their child's ideal future. Most responses were similar in that they focused on the desire for their child to be safe, happy, healthy, and involved in a community. Steve sums up the general sentiment well by stressing his desire for his son, Cal, to "live as good a life that he can live." However, the ease with which my interviewees described goals and plans for their children disappeared as soon as I pushed them to talk about their own goals. When I asked Cynthia about how she sees her future, she said that like John, she isn't thinking about herself: "First of all, I want to have Maya in a place where she can be safe and thrive. And then I can look forward to what I want to do." When I asked if she has any future goal for herself, Cynthia continued to describe how the unpredictability of planning for Maya creates unpredictability in planning for herself:

Cynthia: No, I can't think that far ahead right now. It's hard to do. Even for the short term, you know, it's difficult to plan anything...So, everything is on hold, everything is waiting, to make sure that she is cared for.

Interviewer: Sounds like a state of limbo.

Cynthia: Yeah, one day at a time.

Interviewer: That's a good motto! I try to use that as well, but it's hard.

Cynthia: Yeah, it's hard! Especially when people ask what your plans are and you have none, it's like "oh I should have plans!" (Laughs)

Here, Cynthia articulates a crucial point: even as she is getting older and slowly approaching the end of her life, she only thinks about herself and her future in relation to her daughter. Her plans revolve around Maya's plans—however, because Maya's plans are so unpredictable, so are Cynthia's.

Many other parents expressed a similar sentiment. For example, when I asked Kirk and Helen if they had made any plans for retirement, they both looked incredulous. Helen pointed out that for them, "it's not gonna be like our friends who are making plans. We're not making plans." Kirk jumped in to add that "for many of our friends, when they retire it's about them. And for us, I don't see it as it's about us...it's about *all* of us," including their daughter, Sarah. Like Helen and Kirk, Ann talked to me about how her own future is "just a huge question mark." For Ann, whose son, Matt, has complex medical challenges and lives at home, the many unknowns surrounding Matt's situation makes it challenging for Ann to plan for herself:

You know, with Matt's diagnosis, he could be in the hospital any day...I try to plan, I try to think ahead, but I just kind of live for today. Um, do I hope to retire? Yes. Do I know where Matt's going to be living? No. Do I know if he's going to be living with me? He might. So, I don't know... I just don't know what my future is.

Similarly, when I asked Stacy what she thinks retirement might look like for her down the road, she told me, "I don't even think of that. I think of, what is the housing for Daniel and Kate gonna look like. And that's really where my thoughts are at." Even for parents like Steve, who are already retired, looking forward always occurs after thinking of their child first: "I don't

see myself today in retirement just moving away and walking away from Cal. I just don't see myself doing that...Now I have to go okay, if I want to spend time during the wintertime in Arizona, what does that look like? Do I think I'm able to be away for two months at a time? I need to answer those questions.”

Again, and again, I heard narratives like Stacy's and Steve's—stories of how, even as my interviewees approach old age, their primary concern is planning for their child before they plan for themselves. Because planning for their child's future is riddled with challenges, stressors, and unpredictability, the end result is that these parents are living in a state of limbo; my interviewees simply can't be certain that their child will be well cared-for after they die. As a result, their own plans remain indefinitely on the backburner.

How do my interviewees live with such omnipresent uncertainty? Pryce et. al (2015) found that aging parent caregivers of adults with IDD in the UK tolerate the fears and anxieties associated with future thinking by finding positive meaning in their caretaking, relying on outside support networks, and living “one day at a time” (Pryce et. al 2015: 87). While all of my interviewees described utilizing at least one of these coping strategies, I propose an additional method for withstanding the uncertainty associated with parenting an individual with IDD: becoming a parent-advocate.

My interviewees have been to the White House on behalf of their children. They've testified in front lawmakers, appealed to school boards, called state and county representatives relentlessly, and created their own programs for adults with IDD. They've become activists for their children and the IDD community as a whole. As William, age 79, puts it, “when there are people there who are voting against your child or...who think that a line item in the state budget

is more important than the life of your child,” fighting for the IDD community becomes increasingly important.

My interviewees also used advocacy language to describe how they make decisions for their children on an everyday basis. Especially for parents who are entering old age, the need to arrange various elements of their child’s life becomes increasingly salient because parents often feel that their children cannot make decisions in their own self-interest. Parents like Steve, age 61, told me that he and his co-parent have “always been strong advocates, but I think we’ve become stronger advocates [by] being able to articulate to others, ‘This is what we believe will be best for Cal.’ Setting up the trust for him and saying, ‘Here’s how we think this money should be used to enrich his life.’”

At the end of each interview, I asked my participants what they would say if they could give advice to younger parents who have a child with IDD. Kirk’s response in particular stood out:

If you have to, be an ass! Really! When it comes to authority, whether it’s school or the county or the state, you stand up and do every damn thing you can for your kid. Because, to be quite blunt, they’re not gonna give a damn. You kid is just another kid among all of them...They’re not gonna go, ‘boy...I think we could do some more for your kid!’ They’re not gonna do that...So, if you gotta stand up and be an ass to them, then that’s what you’ve gotta do! You gotta do any doggoned thing...you can for them.

As systems of support for individuals with IDD are stretched thin by limited funding and increased demand, parents like Kirk use advocacy to fight for their children and gain control over the vast uncertainty of parenting. While admirable, such constant advocacy often comes with a cost. I have used my findings to demonstrate how attempting to plan for their children’s future often means that my interviewees struggle to advocate for themselves and their own needs as they enter old age. In order for parents of individuals with IDD to live the best life possible,

there must also be structures in place to support these parent-advocates throughout all stages of life.

CONCLUSION

As the IDD community grows in size, supports for individuals with IDD and their families are dwindling. This is due to the unique socio-historical context that parents of children with IDD must navigate as they care for their children—in the United States, neoliberal policies and an emphasis on personal independence lead to limited public assistance for individuals and families living with IDD. How do these parents navigate their own aging experience while caring for children who remain dependent into adulthood? In the context of the United States, how do parents think about and plan for the future, both for themselves and for their children?

To address these questions, I conducted in-depth interviews with 14 parents of individuals with IDD in a small Minnesotan city. My interviewees ranged in age from 46 to 79 years and their children ranged in age from 11 to 49 years. The children of about half of my interviewees live at home with their parents, while the other half live in alternative residential situations such as a LBSA or another group home. Independent of whether their children reside at home or elsewhere, all of my interviewees remain heavily engaged in a dependency relationship with their offspring. In line with the concept of linked lives, the unique timing of life course transitions for individuals with IDD means that their parents' lives also follow a nontraditional course (Elder 2004). For older parents of individuals with IDD, their child's transition to adulthood is not synonymous with the development of full independence; as a result, at the time in life when many parents can step back and watch their children grow into independent adults, my interviewees step forward instead.

For my interviewees, stepping forward to care for their grown children feels like falling off a cliff. In dependency relationships, caregivers themselves become derivatively dependent on outside sources for support (Kittay 1998); yet, in the United States, the drop off of public resources available for adults with IDD after age 21 means that my interviewees are left without assistance as they navigate their child's transition into adulthood and their own transition into old age. Additionally, my interviewees feel that the services that *are* available to them are difficult to access, overwhelmingly complex, and ever-changing. For parents who already face a unique caretaking burden, this struggle for support only adds to the existing physical, emotional, and social impacts of raising a child with IDD (Gray 2002; Ha et. al 2008; Kono and Mearns 2013; Seltzer et. al 2011).

The experiences of my interviewees reveal a harsh disconnect between public policies and the IDD community they are meant to serve. For example, the State of Minnesota portrays the moratorium on new group homes as a favorable opportunity to combine public savings and re-integration of individuals with IDD into the community. However, to my interviewees, the shortage of residential options exacerbated by the group home moratorium further isolates individuals with IDD and leaves their parents in a stressful and precariously uncertain situation.

In the unpredictable political environment of the United States, my interviewees must accept that the question of "What's going to happen to Brian?" will likely remain unanswered or ambiguous at best. However, as these parents get older and the threat of their own mortality looms on the horizon, everything from placing their child in an appropriate residential situation to allocating money for their child's clothing and shampoo becomes a priority. In trying to prepare for their child's future needs, my interviewees often place their own future goals and plans on the backburner.

As we continue sociological conversations about parents of children with IDD, it is important to remember that my interviewees are among the privileged. The parents in my research sample are all white, of middle-to-upper socioeconomic class, and highly educated—yet, even *they* find it challenging to secure resources for themselves and their children. For a parent who might not have the monetary privilege, intellectual ability, or social support required to navigate raising a child with IDD, such disadvantages only bring more unique challenges to parenthood. I encourage sociologists to pay attention to the members of this largely understudied group who are at an even greater risk of slipping through the cracks than my interviewees. Not all parents can go to the White House on behalf of their children; as a result, in order for sociologists to drive change on behalf of all parents of children with IDD, there must be a push for qualitative research on parents who are not in a position to advocate for themselves or their children.

In this paper, I use the case of older parents of children with IDD to demonstrate how public supports in place for the IDD community fail to reflect the community's experiences and needs. As the population of adults with IDD in the United States continues to grow, and as their parents continue to age, we need to listen to parents like Jane, Ed, and Stacy and use their stories—not those of lawmakers in Washington D.C.—to drive political change. It may be impossible to predict the future for these parents and their children, just like it is impossible to predict the future for anybody. However, it is possible to say that without increased public resources for individuals with IDD, family support services, and public awareness of IDD, the outlook will not drastically improve for my interviewees and other parents like them. At some point in their lives, every person is dependent on others—so, just like Irene puts it, I hope that

the United States is “a kinder nation than what we appear to be right now” and can step up to help a community that is currently in need of compassion.

APPENDICES

Appendix A: Interview Guide

Child information

Tell me a little about your child.

1. What's their name?
2. How old are they/when were they born?
3. What's your child's gender?
4. If your child is a resident of Laura Baker, how long have they been there?
5. If your child isn't a resident of Laura Baker, where do they reside?
6. How does the medical community classify your child's IDD?
7. In what ways do you notice your child is challenged?
8. What kinds of services does your child receive (e.g. Medicaid, HCBS Waiver, nonprofit)?

Sibling information

1. Do you have other children?
2. How old are they?
3. What are their names?

4. What are their genders?
5. Do your other children currently play a role in caregiving for this sibling?
6. Are you hoping or planning that the sibling will take over the parent role when you are deceased?

Parent information

Tell me a bit about yourself now.

1. In what year were you born?
2. Where are you from?
3. Which city do you live in? How long have you lived in Minnesota?
4. What is your educational background?
5. How do you identify your socioeconomic class? Working class, middle class, upper-middle class, etc?
6. How did your child's diagnosis impact your family's financial situation?
7. What is your occupation? Are you still working? Are you retired?
8. If working, is working a choice for you?

9. If working, do you plan on retiring anytime soon?

10. If working, what do you think retirement might look like for you in the future? Do you have any goals/expectations of retirement?

11. If retired, how are you spending your retirement years? How does your fixed income influence the options you're able to offer your child?

12. Are you married?

13. If so, for how long?

14. If not, how would you describe your relationship status?

15. How has the experience of parenting your child with IDD affected your marriage/romantic life/intimate relationships?

16. How do you identify politically?

17. Is your political identity a response to your child's needs? For example, health care politics

Life arc

“Now tell me a little bit about the arc of your life, starting when your child with IDD was born (remind them to be brief)”

1. How old were you when your child with IDD was born?

2. Did you have other children at the time?

3. When your child was recognized as having an IDD, did it affect your family planning going forward? (decide to stop having kids, etc)
4. Did you ever serve as the primary caretaker for your child? If so, what was that experience like?
5. Have you ever hired professional care providers for your child?
6. If so, what have those experiences been like? Have you been satisfied with the quality of care your child receives?
7. Did your child go to school? How did your life change when your child transitioned out of school?
8. As you encounter age-related health issues, how does having a child with IDD impact your ability to respond to your own needs?
9. Given your limited amount of time, does your child's care impact your efforts to care for yourself?
10. If your child is part of a residential community, why did you decide to move your child there?
11. How often do you visit or see your child?

12. How has living apart from your child changed your life?

13. If living with child, why did you decide to care for your child yourself/within the family?

14. How do you make decisions related to your child and your child's future? Do you involve your child in decision-making processes (i.e. person-centered planning)?

Reflections

1. As you get older, has your role as a parent changed? If so, how?

2. As you get older, do you have any concerns or fears for your child? How do you handle these concerns?

3. If you have any future goals for your child, would you like to share some of those with me?

4. If you have any future goals for yourself, would you like to share some of them with me?

5. What unique burdens do you think having a child with IDD has had on you? What life goals have you abandoned?

6. What are your friends doing at this stage in your life that is not available to you (financial, time commitment, health, emotional well-being)?

7. What have you gained over the course of your life as a result of having a child with IDD?

8. What have you gained at this particular stage in your life as a result of having a child with IDD?

9. What advice would you give to a younger couple with a child who has IDD? For themselves and for their child.

10. What question didn't I ask you today that I should have? What's the answer to that question?

Final questions

When I was in the very beginning stages of planning this project, my original research question was this: how do the older parents of grown children with intellectual and developmental disabilities (IDD) experience aging and think about planning for the future?

1. Is there anything more about this question you'd like to add that you haven't already said?

2. Do you have any questions for me?

Appendix B: Consent Form

Consent Form

Who am I? My name is Rachel Gallagher. I am a student at Carleton College.

What is this research about? This research is about parents of adults with intellectual or developmental disabilities (IDD) and how these parents experience aging. You were selected as a possible participant due to you and your child's relationship to Laura Baker Services Association.

Why is this research being conducted? I am conducting this research for my senior thesis in the Sociology/Anthropology department at Carleton College.

What will you be asked to do? I am asking to conduct a one-on-one interview with you. The interview will last about an hour. If you are comfortable being recorded and choose to consent, I will make an audio recording of the interview. I will ask you questions about your experiences parenting a child with IDD, getting older, and planning for the future.

Is your participation in this research voluntary? Yes. You may choose not to respond to any or all questions. You may also stop the interview at any time if you change your mind about participating.

Are there any benefits or risks to you? My research is not designed to provide any direct benefits or risks to you. However, if you would like to read my final paper and are willing to provide your address, I'd be happy to send you a copy.

How will your identity be protected? Your identity will be confidential and a pseudonym will be used when referring to you. All facts about you will be kept private. We will keep your records private to the extent allowed by the law, and all records of your name and identity will be destroyed when the data analysis has been completed.

Is there any compensation for your time? No, you will not receive compensation for your participation.

Who should I contact with questions? Please contact me with your questions, concerns, or comments at gallagherr@carleton.edu. If you would like to discuss this project with my thesis advisor, Annette Nierobisz, please contact her at (507) 222-4114 or at anierobisz@carleton.edu. If you have questions or concerns and would like to speak with somebody besides the researcher and her advisor, If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher or her advisor, contact the Institutional Review Board for Research with Human Subjects at Carleton College, c/o Office of the Associate Dean of the College, Carleton College, One North college Street, Northfield MN, 55057; telephone (507) 222-4301.

Statement of Consent: I have read this document and understand the information. I consent to participate in this study.

I agree to allow the researcher to create an audio recording of this interview

Signature of interviewee: _____ Date:

Signature of researcher: _____ Date:

Address (if interested in receiving a final copy of the paper):

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