The Correlates and Predictors of Residential Living for Adults with Intellectual and Developmental Disabilities

By

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To my mother and father for always challenging me to do my best.

To my sisters for their immeasurable support.

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TABLE OF CONTENTS

Page

Chapter

Appendix

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1

INTRODUCTION

A defining moment of any adult's life is establishing their own household, deciding where and how they will live independent of their parents (Arnett, 2000). For adults with an intellectual and developmental disability (IDD), their residential status and residential transitions may look very different from a typical adult. By conducting and reviewing research on residential settings of adults with IDD, we can begin to understand where they reside and why they live there. Residential status/placement is important to consider for adults with IDD for two reasons. First and foremost – given the appalling history of institutionalization in the United States– adults with IDD need a safe place to live with a good quality of life within the community. Second, because of the shift away from institutional living, it is imperative that families and adults with IDD obtain appropriate long-term supports and services, which includes residential living.

In order to understand the progress that has been made in regards to residential living, I will first discuss the historical context of institutions and the subsequent deinstitutionalization that led to the current housing philosophy. Second, I will discuss different types of residential placements, how they are defined and the national prevalence rates for each placement. Third, I will review the potential correlates of living in different residential settings based on the current literature. Next, I will focus on two specific issues- independent living and ASD. Finally, I will present the current study and research questions.

Historical Context

The first institutions in the United States began in the early 1800s, with the opening of the American School for the Deaf in 1817 and the Perkins Institute for the Blind in 1829. By the mid-1800s, training schools for youth with intellectual disabilities (ID) became the dominant system of care for persons with disabilities. These training schools were locations where people with disabilities lived while participating in educational programs intended to help them eventually live as independently as possible within society (Trent, 1994). However, as the popularity and even early success of these training schools grew, so too did the number of people who attended them. Eventually, institutions came to have massive overcrowding and low-quality services. At its peak in the mid-1960s, institutions across the US housed over 175,000 residents with IDD (Ticha, Hewitt, Nord, & Larson, 2013). Institutions could no longer fulfill what they had set out to do as training schools. Consequently, institutions became holding grounds for persons with IDD. Thus, adults with IDD remained closed off from society in these institutions, never returning to their communities.

Moreover, at the beginning of the 20th century, the eugenics movement, which wanted to limit the reproduction of those with "undesirable traits," including individuals with disabilities, gained popularity (Thomson, 1998). These factors together led to the maltreatment, abuse, neglect, and unsafe experiments (e.g., sterilizations, lobotomies, etc.) in institutions. Individuals with IDD living in institutions endured appalling conditions, often for decades (Trent, 1994). As eugenics and institutions fell out of favor and people began to advocate for adults with IDD to live in the community, a change to the living conditions of adults with IDD was imminent and necessary.

Several key events and policy changes eventually led to the deinstitutionalization movement in the later decades of the 20th century (Forrester-Jones et al., 2010; Kozma et al., 2009). In the 1950s, the Association for Retarded Children (presently known as The Arc), a parent advocacy group, began to raise awareness of the conditions of people with disabilities in the United States. President John F. Kennedy inaugurated the President's Panel on Mental Retardation that supported the deinstitutionalization movement and funded research to improve conditions for those with disabilities. Later, in 1966, President Johnson established the President's Committee for People with Intellectual Disability (PCPID). More importantly, costs of keeping large institutions open were increasing. Large institutions became financially burdensome for state governments, which opted to cut costs by shifting services to community residences (Finch, 1985).

Policy changes also helped change the landscape for adults with IDD. Legislation that supported the inclusion of students with disabilities in public school, the Education for All Handicapped Children Act (EAHCA), was passed in 1975. EAHCA, now known as the Individuals with Disabilities Act (IDEA), mandated that all students with disabilities receive a free appropriate public education (FAPE) in their community school (Wright & Wright, 2007). This change in school policy meant that children with disabilities could attend public schools in their communities instead of being educated in institutions removed from their communities.

Current policies have promoted a move to community settings. These policy changes have helped shift the view of people with disabilities in society. One such policy change came from the Americans with Disabilities Act (ADA) and the Olmstead decision. The ADA states, "…the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals" (ADA, 1990). In 1999, the Olmstead decision further elaborated on the ADA by finding that it was discriminatory to segregate and isolate individuals with disabilities in institutions (ADA About Olmstead, 2017; Milne, 2012). Instead of large institutions, the current Home and Community Based Services (HCBS) policies support individuals with disabilities receiving long term support services in their own home and community settings (Medicaid HCBS, 2018). Approximately half of the spending for the HCBS waiver across all states goes into residential habilitation, which is defined as supports that help the adult live in the community (Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013).

Due to these recent changes, the prevalence of living in an institution now is low. According to the Residential Information Systems Project (RISP) report of trends through 2014, over half of the large institutions in the United States have closed and most that were not closed have fewer than 16 residents. Since 1998, there has been an increase in smaller residences (less than 15 people) and a decrease in facilities with more than 16 or more residents (Larson et al., 2017). While institutions continue to exist on a small scale, the trend is that all large facilities will eventually close. So where do adults with IDD live now, if not in institutions?

Definitions of Residential Settings

Before discussing prevalence rates of different residential settings, it is important to define the various available residential settings for adults with IDD. One problem in examining residential settings is the lack of consistency across research and practice. In one review, Ticha et al. (2013) examined published studies using National Core Indicators (NCI) data. The NCI records performance and outcome data collected on adults with developmental disabilities (DD) across 39 states in the United States. Adults with IDD in the NCI data set have to be receiving at least one paid service from the state to be included (NCI, 2018). Even within studies using NCI data alone, there were conceptual differences in the types of settings included in the studies and how they were defined (Ticha et al., 2013). For example, some studies grouped all supervised living together, while others separated supervised living by residence size rather than location.

As a result, residential settings are most often aggregated into bigger residential categories (e.g., living in supervised settings). Research conducted by various organizations or using different datasets prioritize specific types of residential settings, which in turn determines the categories used for analyses. For example, independent living is a core indicator of successful transition to adulthood according to National Longitudinal Transition Study-2 (NLTS-2) and IDEA 2004 (Anderson, Shattuck, Cooper, Roux, & Wagner, 2014; Arnett, 2000). Thus, some studies prioritize independent living by examining factors related to living independently versus living dependently (Bouck, 2014; Gray et al., 2014; Wehmeyer & Garner, 2003). Other studies focus on family outcomes and categorize individuals as living at home or away from the family home (Seltzer, Greenberg, Krauss, & Hong, 1997). The residential categories that appear in the literature most frequently are (1) living with parents/relatives; (2) supervised living; and (3) independent living.

There are some conceptual differences on how living in the family home is defined. For example, some studies only consider living with parents as living in the family home, while others also consider living with legal guardians and foster parents as living in the family home (Anderson et al., 2014; Seltzer et al., 1997). However, in most studies living in the family home is defined by living with parents, siblings, and other relatives (Anderson et al., 2014; Hewitt et al., 2017; Woodman, Mailick, Anderson, & Esbensen 2014). For this study, I will define living in the family home in a similar fashion, as living with parents, siblings, and other relatives.

The second main category involves supervised living settings. There exists a wide range of dependent residential settings, such as group homes, large residential communities, nursing homes/hospital, institutions, foster care (Anderson et al., 2014; Bouck, 2012; Seltzer et al., 1997). Some studies do distinguish between these different types of dependent living settings (Hewitt et al., 2017; Woodman et al., 2014; Woolf, Woolf, & Oakland, 2010), but usually these settings are aggregated into one category, often called supervised/dependent living (Anderson et al., 2014; Bouck, 2012; Bouck & Joshi, 2012; Bouck, 2014; Seltzer et al., 1997; Stancliffe et al., 2012). Most dependent living settings are also defined by their size. The main categories for residence size were 1-3 people (small), 4-6 people (small-medium), 7-15 people (medium), and 16 or more was a large residential facility (Larson et al., 2017).

Living independently is often defined by the location, by whom the adult is living with, and by the amount of supervision the adult with IDD requires. Independent living can be defined as in his/her own apartment with a roommate or spouse with no supervision or a little supervision (e.g., 10% of the time; Woodman et al., 2014; Woolf et al., 2010). Semi-independent living (living independently with supports) was described as living in their own apartment but with less than 100% supervision or agency owned apartment with case manager supervision (Hewitt et al., 2017; Seltzer et al., 1997; Woodman et al., 2014).

Prevalence Rates of Persons in Various Residential Settings

To better understand the current prevalence of adults with IDD living at home, living in dependent/supervised settings, and living independently, we examined percentages of adults with IDD living in different residential settings from national reports and studies that looked at correlates for living arrangements. Studies were not consistent in reporting for all residential settings, thus, prevalence data were reported on the main residential categories. There were a few discrepancies in some cases between the prevalence rates within each category. These differences may be attributed to methods of participant recruitment or the data source itself (i.e., NCI data, NLTS-2 data, or Wisconsin longitudinal study, etc.). Regardless of discrepancies, we will report main percentages found across studies and data sources.

Living in family home. Most adults with IDD are living in the family home. Rate of living in the family home ranged from 10% to 97%, with a median of 69.8%. The rate of living in the family home differed by data source. The RISP report suggests that 57% of people with IDD reside in the family home (Larson et al., 2017). Larson, Doljanac, & Lakin (2005) reports a 78% prevalence rate of living at home for adults with IDD. For independent studies (i.e., unique data source), rates were 10% to 73.9%, with a median of 45.5%. Two NLTS-2 studies reported very high rates of living in the family home for participants with IDD at 97% and, depending on the disability, between 78% (ID) and 87.1% (autism spectrum disorder, ASD; Anderson et al., 2014; Bouck, 2012). Based on two studies that used the longitudinal data from Wisconsin, prevalence rates of living at home ranged from 69.8% to 89.8% (Essex, Seltzer, & Krauss, 1997; Seltzer et al., 1997; Woodman et al., 2014). Esbensen, Bishop, Seltzer, Greenberg, and Taylor (2010) reported prevalence by disability, and the rates were 29% (ASD) to 78% (Down syndrome; DS). Since the Wisconsin study was a longitudinal study, the changes in percentage of adults living at home most likely changed due to time. Adults were younger at the beginning of the study and thus were more likely to live in the family home.

Two studies using NCI data found the prevalence of living at home was lower and ranged from 27.6% to 45.8%, with a median of 39.8% (Hewitt et al., 2017; Stancliffe et al., 2012). Based on the NCI data the prevalence of living at home was 27% (Ross, Marcell, Williams, College, & Carlson, 2013). Although reasons remain unclear for these low home living percentages, most likely differences exist because the NCI data is based only on adults who are receiving state services, whereas the NLTS-2 is data collected from a young population with an average age of 23. Only 13% of families who provide in-home care to adults with IDD are supported by state-based waiver services; thus, the studies based on NCI data may not be representative of the whole population (Hewitt, Agosta, Heller, Williams, & Reinke, 2013). Moreover, for those who do receive state funding, half of most states' budgets for adult services are spent on residential habilitation, thus it is likely that most adults in the NCI data would be receiving residential supports (Rizzolo et al., 2013). Despite some variation, most studies reported high rates of living in the family home, with most reporting 50% to 70% or more living in the family home.

Living in supervised settings. Again, prevalence rates vary widely between settings and studies. Following living with family, group homes are the next most prevalent living setting for adults with IDD. For group home, prevalence rates ranged from 6% to 57%, with a median of 28%. According to the RISP report the prevalence of living in a group home is 6% (small) and 23% (large; Larson et al., 2017). Rates for living in group homes ranged from 23.3% to 30.7% for studies using NCI data (Hewitt et al., 2017; Stancliffe et al., 2012; Ross et al., 2013). None of the studies using NLTS-2 data report directly about group homes, but Anderson et al. (2014) reported data on supervised living, with rates between 6.1% (ID only) and 11.8% (ASD). The prevalence rate for groups homes based on Wisconsin longitudinal data ranged from 14% (DS) to 57% (ASD); for those with IDD it was 55.2% (Esbensen et al., 2010). A moderate number of people—approximately 25%—are living in group homes.

The prevalence rates of people in institutions and nursing facilities were relatively low. Rates of living in institution ranged from 0% to 32.4%, with a median of 4% (Blacher, Kraemer,

& Howell, 2010; Esbensen et al., 2010; Hewitt et al., 2017; Stancliffe et al., 2012; Wehmeyer & Garner, 2003; Woodman et al., 2014; Woolf et al., 2010). The high rate of institutional living for one study (Woolf et al., 2010) was due to the method of recruiting participants, with the authors recruiting participants through residential centers. The studies using NCI data reported rates of living in an institution from 4.1% to 17.6% and for living in nursing facility from 0.1% to 1.2% (Hewitt et al., 2017; Stancliffe et al., 2012). The prevalence rates for institutions for studies using Wisconsin longitudinal data ranged from 1% to 10.4%, and for nursing homes the prevalence rate was 11.9% (Esbensen et al., 2010; Essex et al., 1997; Woodman et al., 2014). Lastly, prevalence rates for living in foster care for adults with IDD ranged from 6.4% to 10.3%, with a median of 7.5% (Essex et al., 1997; Hewitt et al., 2017; Seltzer et al., 1997; Stancliffe et al., 2012).

Another setting that was not examined in any of the studies is intentional communities, such as Camphill communities, L'Arche, or Friendship House. There are over 40 intentional communities across the United States that provide residential services for adults with IDD. These settings are rarely researched or considered in research. Taken together, however, living in such "other" settings seems relatively rare, probably encompassing less than 5% of all individuals with IDD.

Living independently. Large-scale national studies report rates of independent living for adults with IDD to be between 11% and 16.2% (Bouck & Joshi, 2012; Larson et al., 2017; Newman, Wagner, Cameto, & Knokey, 2009; Newman, Wagner, Cameto, Knokey, & Shaver, 2010; Ross et al., 2013). In published research studies, prevalence rates for living independently ranged from 0% to 60%, with a median of 7.1% in published research studies. Again, there was some variation based on data source. Based on the NLTS-2 data, independent living ranged from

3% to 33.8%, with a median of 18.5%. Based on NCI data, rates of independent living ranged from 7.1% to 14.7%. The Wisconsin and Massachusetts studies had lower rates of independent living, ranging from 0% to 12.0%, with a median of 1.0%. Across the independent studies, independent living rates ranged from 0% to 60%, with a median of 2%. The study that had a 60% rate (Wehmeyer & Garner, 2003) is the only one with such a high level of independent living, which may be due to a bias in that participants were recruited through advocacy organizations. Semi-independent living, which included agency apartments and is inconsistently defined across studies, had a low prevalence rate between 3.0% and 11.9%, with a median of 6%. Overall, independent living appears to occur in less than 10% of individuals with IDD.

Across all studies, adults with IDD are mostly living in their family home, then in group homes, followed by living independently, and then spread throughout other residential settings. Depending on how studies recruited participants, however, there may be a bias or variation on the rates of living arrangements. Although it is straightforward to report the rates of living in different settings, determining how the characteristics of adults with IDD and their caregivers impact residential status can be complex.

Correlates of Residential Settings

By examining the correlates of residential settings, we can begin to examine why adults with IDD may live where they live. Differences that may impact residential placement relate to personal characteristics of the adult with IDD and of the parents and family. Although findings are mixed, the variables noted below either predicted a specific living arrangement or were associated with a specific living arrangement.

Characteristics of adults with IDD. In trying to determine the predictors of living at home or the predictors of living away in other settings, we came across complex issues related to residential status, principally associated with the categories that various studies used for analyses. The task of separating the correlates and their relation to living at home or living away from home was difficult. In this section, we will try to examine and determine the adult characteristics that predict living in the family home and living away from the family home. To simplify the complexities, living away from the family home was considered only living in more supervised living settings (e.g., group home, nursing home, etc.). We will discuss the predictors living independently separately, since living independently may differ from more supervised settings.

Older age was the only strong predictor of living away from the family home and younger age was a predictor of living at home. Two studies found that younger adults with ASD and DS were more likely to live in the family home (Hewitt et al., 2017; Stancliffe et al., 2012), with living away increasingly more likely when adults with IDD were in their 40s and 50s (Hodapp, Burke, Finley, & Urbano, 2016). Older adults with IDD were less likely to live in the family home (Anderson et al., 2014; Essex et al., 1997; Hewitt et al., 2017; Stancliffe et al., 2012; Woodman et al., 2014). Studies that did not find age differences often examined much younger adults, with a mean age of 23 to 24 years (Bouck, 2012; Bouck & Joshi, 2012; Bouck, 2014). In contrast, the studies that did find that older adults were more likely to live away from home were those in which participants had mean ages of 33.6 to 43.94 years (Hodapp et al., 2016). Thus, it is possible that the likelihood of a residential placement or transition only occurs at a much older age, as Woodman et al. (2014) suggests, since older adults with IDD are more likely to live away from home. Residential transitions at older ages for adults with IDD may be due to older ages of caregivers and inability to continue to provide care rather than the age of the adult with IDD, the interplay between these two variables needs to be explored more in depth.

Most studies found better adaptive behavior or functional skills predicted living independently (Anderson et al., 2014; Esbensen et al., 2010; Wehmeyer & Garner, 2003; Woodman et al., 2014; Woolf et al., 2010). Adults with less adaptive skills were more likely to live in supervised care (Gray et al., 2014). Level of ID (or IQ) also plays an important role in predicting residential placement. Adults with more severe levels of ID were 2.51 and 10.47 times more likely to live in a supervised setting (Gray et al., 2014; Hewitt et al., 2017). Also, those with more challenging behavior were 1.34 times more likely to live in more supervised settings and half as likely to live in the family home than those without challenging behavior (Hewitt et al., 2017). Woodman et al. (2014) found that adults with IDD with lower health quality were more likely to move away from the family home. Disability type may predict where adults with IDD live, in particular ASD and DS. When compared to ID only, adults with DS were more likely to live in family home and less likely to be in other settings, especially when younger. In addition, those with DS were more likely to move out of the family home at an older age than those with ID only (Stancliffe et al., 2012).

Adults with ASD were 1.29 times more likely to live in the family home than those with ID only and more likely to have never lived outside of the family home (Anderson et al., 2014; Hewitt et al., 2017). Conversely, some studies found that adults with ASD were more likely to live away from the family and more likely to live in supervised settings than those with DS, ID only, and CP (Blacher et al., 2010; Esbensen et al., 2010; Hewitt et al., 2017). These differences in disability may be attributed to IQ level rather than ASD itself. In both Esbensen et al. (2010) and Hewitt et al. (2017), the participants with ASD had lower levels of ID than the DS group and the ID only group. No data on the level of ID was collected for Blacher et al. (2010), except for adaptive behavior and the adults with DS had higher adaptive scores than those with ASD.

Family characteristics. We also examined the literature for family-related correlates. Family factors are important to explore in relation to residential settings because we know that adults with IDD continue to live in the family home until they are older. Continuing to live in the family home comes with its own potential issues, such as continued parent stress, depression, and caregiver burden (Krauss, Seltzer, & Jacobson, 2005; Seltzer et al., 1997). To be able to best support parents and caregivers either with residential transitions or in their residences, it is pertinent to find out why adults with IDD stay in or leave the family home.

Adults with IDD were more likely to experience residential transitions out of the family home when mothers were older and their health declined (Essex et al., 1997; Woodman et al., 2014). However, Essex et al. (1997) and Woodman et al. (2014) are based on the same or very similar group of participants. Other studies suggest that families would continue to provide care and only one-third of families thought about residential placement (Krauss & Seltzer, 1993). When thinking about future caregiving, parents with more social supports suggest they will care until they are no longer able to care (Chou, Lee, Lin, Kroger, & Chang, 2009). In regards to family predictors of residential living few have been researched and even these potential family predictors came from the same group of participants. Not only were there few family predictors but those family predictors came from the same data set published approximately 20 or more years ago. Furthermore, since there are few family related studies, it is also unknown whether certain predictors/characteristics, either of the mother or of the adult with IDD (which are related), are most important for predicting living away from one's family home.

Other Issues in Residential Living

Although this study will mostly focus on prevalence rates of various residential settings and offspring vs. parent-family correlates of home vs. away living, other issues are also important. One of the main issues in residential living is the idea of living independently. Given the complexities of residential placements and living, controversies exist in regards to what successful residential placements entail for adults with IDD (Mandell, 2017; Ticha et al. 2013). Currently, there is an emphasis in policy and practice on both community living and independent living. Some organizations promote and value independent living, others promote partially-supervised community living, and other organizations see the benefit of settings that provide constant supervision for those adults with more severe and profound disabilities (Mandell, 2017). While the prevalence of adults with IDD living independently is relatively low (e.g., approximately 11%), it is still considered important philosophically and theoretically for adults with IDD to strive for independent living.

In some regards, living away from the family home and on your own is a normative transition for typical adults (Arnett, 2000). As seen in the correlates of living away from home, some characteristics of adults with IDD appear to predict living independently over living at home or living away from home in more dependent settings. Those characteristics were higher adaptive skills, mild ID, and less challenging behaviors (Gray et al., 2014; Hewitt et al., 2017; Wehmeyer & Garner, 2003). It is likely that adults with IDD with less severe disabilities have more skills to live independently, which in turn means they may require less supervision from caregivers.

It is also important to examine more closely living status of individuals with several types of disabilities. Disability type may play an important role in residential living status. There is mixed information on where adults with ASD are more likely to live. In some studies, adults with ASD were more likely to live in the family home than living independently (Anderson et al., 2014; Hewitt et al., 2017). In other studies adults with ASD are more likely to live in supervised settings than at home or independently (Blacher et al., 2010; Esbensen et al., 2010). Adults with DS were more likely to live in the family home (Hodapp et al., 2016; Stancliffe et al., 2012). What characteristics specific to ASD or DS may be contributing to these differences from their peers with ID only? Reasons for accessing different residential settings can be quite complex and there is probably an interaction between many characteristics and variables that determine residential placement.

Current Study

The current study focuses on family and adult issues related to residential placements. This study aims to identify the variables that predict different living arrangements for both family and adult characteristics. Family dynamics seem to be the most important in regards to residential status of the adult with IDD (Krauss & Seltzer, 1993). However, few current studies have examined these family characteristics, instead focusing solely on the adult or family demographics. This study will examine those family aspects from older studies to see if there has been a change in the past 20 years for why adults move away from the family home, particularly given the emphasis on community living by the ADA and prominent disability organizations. Furthermore, this study includes various perspectives not just that of the parent of the adult – thus we can gather information on the adult with IDD and their family, even if the parent is deceased. By examining these predictors, we may help service providers assist families and young adults with IDD in accessing more residential placements that fit their needs or teach skills that help place students in their desired residential setting.

The following research questions guide this study: (1) What percentage of individuals with intellectual and developmental disabilities live in different types of residential settings?; (2) What are the adult characteristics and family-related correlates associated with living in the family home versus living in other settings? (3) What do exploratory analyses tell us about those participants who are living independently or who have autism? In examining the results of this national, web-based survey, this study will offer an understanding of the rates of living in different residential placements and the factors associated with living in the family home versus living in other settings. This study will let us examine why adults with IDD live where they live.

CHAPTER II

METHOD

Participants

There were 518 respondents in this study. Respondents of the survey were mostly White, well-educated, married mothers with a mean age above 60 years (see Table 1). Other respondents included fathers, siblings, and legal guardians/caregivers. Since this was a national survey, respondents reside in 46 of the 50 states and Washington DC (missing North Dakota, South Dakota, Hawaii, and Nevada). There was no difference in respondent demographics for race, ethnicity, gender, income, marital status, and number of hours worked between those who lived at home and those who lived away.

Most adults with IDD were males (65.9%) had an intellectual disability (76.4%) and/or autism (46.2%; see Table 2 for all other disabilities represented in the study). The adults with IDD had an average age of 33, and a moderate level of functioning with less support needs, good health, and few to no behavior problems. Most adults with IDD graduated with a special education certificate and only slightly over 30% had a part-time or full-time job in the community (See Table 2).

Procedures

Survey development. To answer the proposed research questions, we developed a survey instrument. Along with my doctoral advisor and a research assistant (a Master's student in Special Education), I developed the survey based on the literature review of residential services. After several iterations, the survey draft was completed. We sent the survey for review

Table 1

Respondent Demographics

Variables	Total % (N) Or Mean (sd)
Respondent Role	
Mother	63.5% (329)
Father	7.7% (40)
Sibling	11.2% (58)
Legal Guardian/Other	17.6% (91)
Gender	
Female	88.8% (443)
Race	
White	90.4% (463)
Black/African-American	5.7% (29)
Other	4.0% (20)
Ethnicity	
Latino/Hispanic	6.9% (36)
Respondent Income	
<$40,000	15.0% (73)
$40,001 - $60,000	15.6% (76)
$60,001 - $80,000	17.4% (85)
80,001- $100,000	16.4% (80)
>$100,000	35.7% (174)
Marital Status	
Single	10.1% (52)
Married/Long term relationship	70.9% (366)
Divorced/Widowed	19% (98)
Respondent Education	
High School/ Some College	31.5% (163)
College Graduate	32.0% (166)
Graduate/Professional Degree	36.5% (189)
Respondent Employment Hours	
Retired	35.4% (183)
≤ 20 hours	17.0% (88)
≥ 21 hours	47.6% (246)
Legal Guardian/Conservator	
Mother	66.8% (346)
Father	43.2% (224)
Individual/Sibling/Other	39.7% (206)
Primary Caregiver	
Yes	71.3% (368)
Mother Alive	
Yes	84.7% (439)
Father Alive	
Yes	8.0% (33)

Variables	Total % (N) Or Mean (sd)
Mother Work Hours	
Retired	28.2% (118)
≤ 20 hours	31.3% (130)
≥ 21 hours	40.5% (169)
Father Work Hours	
Retired	58.9% (203)
≤ 20 hours	13.7% (24)
≥ 21 hours	27.4% (48)
Mother Education	
High School/ Some College	40.8% (199)
College Graduate	30.7% (150)
Graduate/Professional Degree	28.5% (139)
Father Education	
High School/ Some College	41.1% (193)
College Graduate	25.7% (121)
Graduate/Professional	33.2% (156)
Mother and Father Income	
<$40,000	18.5% (86)
$40,001 - $60,000	15.5% (72)
$60,001 - $80,000	16.4% (76)
$80,001- $100,000	15.9% (74)
>$100,000	33.6% (156)
Age	
Respondent Age	58.47 (9.85)
Mom Age	60.84 (8.51)
Dad Age	62.29 (8.73)
Health	
Respondent Health	3.44 (.95)
Mom Health	3.29 (1.02)
Dad Health	3.26 (1.03)
Parent Variables	
Ability to Care	3.40 (1.49)
Parent Connected to the Community	30.20 (10.6)
Respondents Connected to Community	29.97 (10.43)
Number of Siblings	1.74 (1.45)

Table 2

Demographics of Adults with IDD

	Total % (N) or Mean (sd)
Adult Age	32.70 (12.32)
Gender	65.3% (193)
High School Degree	
Did not graduate	8.4% (43)
Regular Ed Diploma/GED	16.6% (85)
Special Ed Diploma & Occupational	75.0% (385)
Maladaptive Behavior	108.26 (11.22)
Normal	68.3% (352)
Marginal to Moderate	27.0% (139)
Serious to Very Serious	4.7% (24)
Adult Mental Health	2.93 (.99)
Poor/Fair Health	34.8% (179)
Moderate to Excellent Health	65.2% (335)
Adult Health	3.25 (.96)
Poor/Fair Health	20.4% (105)
Moderate to Excellent Health	79.6% (409)
ADL	16.30 (8.52)
Less Support Needs	53.2% (272)
More Support Needs	46.8% (239)
Level of Functioning	2.43 (.89)
Mild/Moderate	48.2% (249)
Severe/Profound	51.8% (268)
Jobs in the Community	34.8% (175)
Types of Disabilities	
Intellectual Disability	77.4% (401)
Autism Spectrum Disorder	44.0% (228)
Speech- Language Disorder	36.1% (187)
Learning Disability	29.3% (152)
Epilepsy	22.4% (116)
Behavioral Disorder	23.2% (120)
Down Syndrome	18.0% (93)
Cerebral Palsy	16.0% (83)
Other Health Impairment	15.6% (81)
Visual Impairment	13.3% (69)
Emotional Disturbance	12.4% (64)
Hearing Impairment	6.6% (34)

and feedback to the doctoral committee, adult service experts, family members (parents and siblings), researchers, practitioners, and advocates. We incorporated their feedback into the final draft of the survey.

We then placed the survey online for data collection on REDCap (Research Electronic Data Capture), a secure, password-protected survey platform, where responses and data can only be accessed by study personnel (Harris, Taylor, Payne, Gonzalez, & Conde, 2009). We reviewed the web-based survey for any typos or errors. After the review, the final survey was submitted to the Vanderbilt University Institutional Review Board (IRB**)**. The IRB approved the survey for dissemination, along with the email scripts and flyer to be sent to organizations and individuals to recruit participants.

Once the survey editing was complete and the survey was approved by the IRB, the survey was placed into production for dissemination. The survey took approximately 30 minutes to complete. The survey was open for four months, from January 2018 to April 30, 2018. The survey was anonymous, confidential, and optional. Respondents could refuse to answer any question at any time. A personalized link was created for the survey (link: https://is.gd/residential_respite_survey).

The survey had three sections: (1) Respondent characteristics, (2) Characteristics of the adult with a disability, and (3) Residential information. The primary method of responding to the survey was online. Respondents were eligible to participate in the web-based survey if they were above the age of 18 years and were family members or caregivers of an adult with a disability who is also older than 18 years. Respondents could reply about a family member with any disability type. Respondents were initially asked to state if they were older than 18 (yes or no) and if they have a family member who is 18 years or older and has a disability (yes or no). If they responded no to either or both of those questions, they were not eligible to take the survey. If they responded yes to both of these initial questions, they were directed to the initial survey page to begin the survey. If the respondent had more than one family member with a disability, we asked that they respond only about the oldest adult with a disability. To provide access to the survey to any interested individuals, a paper version of the survey was also created in case participants could not respond online. Individuals who responded to the paper version were provided with returned stamped envelopes to return the survey by mail. To request a paper survey, participants needed to email or call in a request. Only one care provider requested paper surveys for their families but none were returned.

Within the REDCap survey, we used branching logic. Branching logic is the ability to show or hide a data collection field (e.g., another question on the survey) based on previously entered values (Branching Logic Guide, 2017). Thus, some questions were only asked if the respondent had replied in a specific manner to the previous question. We used branching logic so that only applicable questions would appear on the survey based on previous responses. For example, if the mother noted that she was the respondent of the survey, then she would not see such subsequent questions such as "Is the mother alive?" REDCap has a function and coding box to easily code branching logic.

Incentive. At the end of the survey, respondents were provided the opportunity to enter a raffle for a $25 gift card to a store of their choice. Besides the randomized raffle, there were no other financial benefits for the respondents. Respondents were also provided the opportunity to enter to receive a report of the survey results. When they completed the survey, respondents were directed to a separate screen with a different REDCap survey to enter the raffle and to enter their email for the report. In this way, their email could not be linked to their individual survey responses. Their responses remained confidential. At the close of the survey, ten participants were randomly selected from the database to receive a gift card. Participants were contacted and asked to confirm their email and gift cards were sent electronically via email.

Survey dissemination. After the survey was placed into production on REDCap, the survey link was disseminated nationally. A flyer was created to disseminate the information about the survey with the survey link (see Appendix A). An email was sent to relevant disability organizations across the United States (see Appendix B for email script). We contacted over 800 disability organizations using A to Z disability yellow pages (http://www.yellowpagesforkids.com/), Tennessee Disability Pathfinder (https://vkc.mc.vanderbilt.edu/vkc/pathfinder/), and other disability organization referral websites. Emails were also sent individually to leaders in the field and potential participants (see Appendix C for email script to participants). The flyer was attached to each email that was sent. Upon request, a letter with IRB approval information was also sent.

We also contacted approximately over 50 Councils on Developmental Disabilities (DD Councils), 67 University Centers for Excellence in Developmental Disabilities (UCEDDs), over 400 Centers for Independent Living (CILs), 730 Arc chapters, over 70 Down syndrome Affiliates, Autism organizations (e.g., Autism Speaks), the Volunteer Advocacy Project (VAP) participants, residential communities, respite care providers, Postsecondary education (PSE) programs, and other types of organizations that provide adult services.

Organizations were asked to disseminate the flyer to the families of adults aged 18 years or older who receive services through their organization, to post the flyer to social media or their websites, or to disseminate the flyer through communication systems, such as newsletters. For example, the Sibling Leadership Network (SLN) posted the information for the survey on their website and some Arc chapters posted the flyer in their newsletters.

Survey Measures

In addition to answering questions about themselves, respondents answered demographic questions about either both parents (if they were the sibling) or the parent who was not respondent (e.g., the mother answered questions about the father). Demographic questions about the parents included if they were deceased or alive, income, marital status, education, and health.

Part I: Family & respondent characteristics. Section one of the survey asked for demographic information in regards to the respondent and the family. The first question was the role of the respondent. Roles could be mother, father, sibling, legal guardian/caregiver, and other (write in box provided). We asked basic demographic questions about the respondents: age (drop down options 18-90 years), gender (male, female, other with write in), race (White, Asian/Pacific Islander, Black/African American, Native American, other with write in), ethnicity (Are you Hispanic/Latino- yes or no), income (less than \$20,000; \$20,001-\$40,000; \$40,001-\$60,000; \$60,001-\$80,000; \$80,001-\$100,000; and more than \$100,001), level of education (some high school, high school graduate, some college or associates, college graduate, graduate/professional degree, other with write in), marital status (single, long term partnership, married or civil union, divorced or separated, widowed), number of hours of work per week (retired, unemployed, less than 5, 5-10, 11-20, 21-34, 35+), and state they currently reside in (drop down list of 50 states and territories).

Health. To measure the health of the respondent, we asked respondents to rate their current physical health on a 5-point scale. Respondents could select: (1) poor; (2) fair; (3) good; (4) very good; and (5) excellent. This single question has been used in previous research as a good indicator and rating of one’s health (Esbensen, Seltzer, & Greenberg, 2007; Idler &

Benyamini, 1997). The variable specific to the mother's health only had 422 respondents because 78 of the mothers in the data set were deceased. Thus, we created a new variable that combined mother's health and deceased. If the mother was deceased she would receive a score of 0 for the variable mother health and alive and all other health ratings remained the same.

Caregiving roles and conservatorship. We asked the ability of the parent to care for the adult with a disability. They could respond from (0) both parents deceased; (1) poor; (2) fair; (3) good; (4) very good; and (5) excellent. We asked how many siblings the adult with a disability has. Responses were between 1 to 10 and more than 10. We asked the respondents if they were the primary caregiver who oversaw the everyday care for the adult with a disability. They could respond yes, no, or that they have never been the primary caregiver for the adult with a disability. We asked who had legal responsibility for the adult with a disability (this might differ from who is the primary everyday caregiver). The responses included the individual, mother, father, sibling, and other.

Involvement in disability community. To measure the level of involvement in the disability community, we asked a set of ten questions related to the respondent's experience in the disability community. The respondents could rate each question on a 5-point scale: (1) not at all; (2) slightly; (3) to some extent; (4) quite a bit; and (5) very much so. We asked these sets of questions to the parents, but if the siblings were respondents they responded about themselves and they also responded the same set of questions about their parent's connection to the disability community. The Cronbach's alpha for respondent disability connectedness is .924. The Cronbach's alpha for disability connectedness of the parents rated by the siblings is .948. Both alphas are high, thus we summed the ratings of each ten question to create one variable, "disability community connectedness." Since some respondents did not respond to all ten questions, we summed the scores and divided by the total number of questions answered to get a mean item score for each participant (92.9% of participants answered all ten questions). The maximum score is 50, meaning the respondent is highly involved in the disability community. The minimum score is ten, which means the respondent is not at all involved in the disability community.

Part II: Characteristics of the adult with IDD. The second section was in regards to the characteristics of the adult with a disability. First, we asked the age of the adult with a disability with a drop-down menu between ages 18 to 90 years. We also asked the respondent to check all the applicable disabilities of the adult. There were 24 possible responses, these included the 12 possible disabilities from IDEA (e.g., intellectual disability, autism spectrum disorder, speech-language, etc.), specific genetic syndromes (e.g., Down syndrome, Williams syndrome, Fragile X syndrome, etc.), unknown if the disability is unknown, and other with a write in option.

Level of functioning. Respondents rated the level of functioning of the adult with a disability on a 5-point scale. They could rate from (1) profound (extensive support needs in all areas of life), (2) severe (many support needs in most areas of life); (3) moderate (some support needs); (4) mild (minimum support needs); and (5) independent (no support needs).

Activities of daily living. To get a precise measure of level of functioning, we used the Waisman Activities of Daily Living Scale (ADL; Maenner et al., 2013). The ADL has 17 activities: making his/her own bed, household tasks, running errands, home repairs, laundry, washing/bathing, grooming, dressing and undressing, toileting, preparing simple foods, mixing and cooking simple foods, preparing a complete meal, setting and clearing a table, drinking from a cup, eating from a plate, washing dishes, and banking/managing finances. Each activity is rated on a 3-point scale, (0) does not do at all; (1) does with help, and (2) independent or does on own. Scores for each activity are added together to compute a total ADL score. Since only 88.8% of participants answered all 17 activities we took the mean item score by diving the total by the number of items answered (if the participants responded to eight or more items on the scale). Only three participants responded to less than 15 items on the scale.

The minimum score is 0 (requires full assistance) and the maximum score is 34 (completely independent). The ADL has been used in previous research to measure the level of independence of the adult with a disability (Sanderson, Burke, Urbano, Arnold, & Hodapp, 2017). The 17-item ADL have been shown to have internal consistency (e.g, alpha = .94; Sanderson et al., 2017). For this survey, the ADL scale had a high Cronbach's alpha of .95.

Scales of Independent Behavior—Revised. To measure maladaptive behavior, we used the Scales of Independent Behavior—Revised (SIB-R). SIB-R is an 8-item scale which provides a General Maladaptive Index (GMI), with higher scores inferring more serious maladaptive behaviors (Bruininks et al., 1996). Behaviors included externalizing, internalizing, and asocial behaviors. The summed score reflects both frequency and severity of the behaviors. For frequency, we asked "How often does this occur?" Responses included: less than a month, 1-3 times a month, 1-6 times per week, 1-10 times per day, and 1 or more times an hour. For severity, we asked "how serious is this behavior?" and responses included: not, slightly, moderately, very, and extremely. The SIB-R has been used in previous studies with families of adults with disabilities with great reliability (e.g., alpha = .82; Sanderson et al., 2017). For this survey, the SIB-R had a Cronbach's alpha of .83.

Health. We asked the respondent to rate both physical and mental health of the adult with a disability. Similar to the previous health question, respondents could rate the physical and mental health of the adult as (1) poor; (2) fair; (3) good; (4) very good; and (5) excellent.

Employment. To determine level of employment, we asked if the adult with a disability participated in five different job types (modified from Blustein, Carter, & McMillan, 2016): (1) part time in the community, (2) full time in community, (3) part-time sheltered, (4) full-time sheltered, or (5) volunteer in the community. Respondents could check yes with supports, yes without supports, or no for each job type. For this study, we aggregated full-time and part-time in the community as a measure of employment in the community. Thus, responses were either (0) did not work in the community or (1) worked part-time or full-time in the community.

Part III: Residential characteristics. The last section of the survey asked the respondents questions about the residential experiences of the adult with a disability.

Current living setting. We asked where the adult with a disability currently lives. The respondent could check from 13 different settings modified from the definitions in the literature review. The 13 different settings were: family home with the parents, living with siblings, lives with other relatives (e.g., grandparents, etc.), small group home (4 or less in a home), large group home (4 or more in a home), independently (lives alone or with roommates) with supports/supervision, independently (lives alone or with roommates) without supports or supervision, residential community (a cluster group of houses for people with disabilities; not a group home), nursing home, foster care, intentional community (L’Arche, Camphill, Friendship House, etc.), institution or intermediate care facility (ICF), and other (with the opportunity to write in). The settings were adapted from settings in a literature review.

Residential characteristics. Beyond the type of setting we asked about different aspects and characteristics of the residential setting. We asked how long the adult lived in their current residence with possible responses being between less than a year to 10 or more years. We asked how many other people lived in the adult's current household (excluding the adult), where respondents could provide a specific number (write in).

Analysis Plan

Rate of living in residential settings. First, we examined the different rates of living across the 13 identified residential categories. We provided the percent of living in each residential category as listed in the survey. Any settings listed under the other write-in category were manually coded for one of the residential settings. For example, one respondent wrote in "living with mother and brother", which was coded as living with parents.

Predictors of living at home or away from home. In order to conduct the analyses, we aggregated the 13 residential categories into two groups. The two categories for the main set of analyses were living in the family home and living away from the family home. Living in the family home included living with parents, siblings, and other relatives. Every other residential category was placed in living away from the family home (e.g., group home, living independently, nursing home, foster care, etc.).

For the univariate analyses, we conducted t-test and chi-squares analyses with two residential categories as the independent variable. We examined differences by residential type in respondent and family characteristics (race, income, age, ability to provide care, rurality, disability connectedness, etc.) and adult characteristics (level of functioning, maladaptive behavior, age, etc.). We corrected for multiple significance testing in relevant analysis using the Benjamini-Hochberg correction (BH Correction; Benjamini & Hochberg, 1995). We then conducted a logistic regression to determine the predictors of living at home versus living away from home. The independent variables in the regression were determined by the univariate analyses. Additionally, if variables were highly correlated, only one variable was used in the regression.

We conducted a logistic regression instead of a multinomial logistic regression (MLR) because there were not enough participants in the independent living category. An efficient way to determine whether or not to use MLR, is to check if the sample size is appropriate. An appropriate sample size is if the sample size is greater than the number of predictors times ten. There also can be no empty cells between the independent variable and dependent variable for an MLR. For example, there are only three respondents for the category mother health category poor under living independently. Thus, we could not conduct a MLR because there were empty cells and the sample size was not large enough for the independent living group (Multinomial Logistic Regression, 2018).

Exploratory analyses. Although we could not use independent living as an outcome for the regression, this residential living setting remains important for both theoretical and policy reasons. To explore the category of independent living, we aggregated the residential categories into three groups, living independently, living with family, and living in in other settings. Living in the family home includes living with parent, siblings, and other relatives. Living independently includes living independently with and without supports. Living in other settings included all other settings not included in the family home or living independently.

We conducted one-way analysis of variance (ANOVA) between three residential categories to determine if there were differences related to living independently for family (i.e., ability to care and involvement in disability community) and adult characteristics (i.e., ADL, level of functioning, age, and maladaptive behavior). If we found mean differences between groups, we conducted the Scheffe post hoc test. We used the Scheffe post hoc test because it accounts of differences in sample sizes. If there were no significant effects, no post hoc analyses were conducted.

We also explored issues related to DS and ASD. First, we examined if there were difference in residential status for the three residential settings groups. If we found differences, we then further examined the differences in adult and family related characteristics for having that specific disability DS or ASD versus not having DS or ASD.

CHAPTER III

RESULTS

Preliminary Analyses

Figure 1 presents a flow chart showing how we arrived at the final respondents. After data collection was closed, we had 1,046 respondents. We removed any respondents who did not respond to the residential question (n = 412), which left 634 respondents. We believe the 412 respondents removed were people who accessed the survey to look at it but not to respond or who partially responded to the survey but did not complete it. Since we collected data on all types of disabilities, we then removed any participants who did not have IDD (n = 57), which left 577 respondents. We kept the following disabilities: ID, ASD, Down Syndrome, Prader-willi syndrome, Williams syndrome, Fragile X, Angelman syndrome, and Rett Syndrome. We also reviewed the "other" category to make sure that all participant with IDD were in the data set. For example, two participants checked other and wrote in "Mental Retardation," which is considered ID, therefore we included them in the data set. Finally, we removed any respondents whose child was still in high school because they most likely live at home (n = 56), leaving 518 total respondents for analyses.

Rate of Living in Different Residential Settings

These adults with IDD were mainly living in the family home with parents (57.5%), followed by living in small (11.2%) and large (8.3%) group homes. Third, adults with IDD were living independently with supports (8.7%). Each of the other settings had less than 2% of the adults with IDD (See Table 3). For the two residential groups, 62.7% of adults with IDD were living with the family and 37.3% of adults with IDD were living out of the family home.

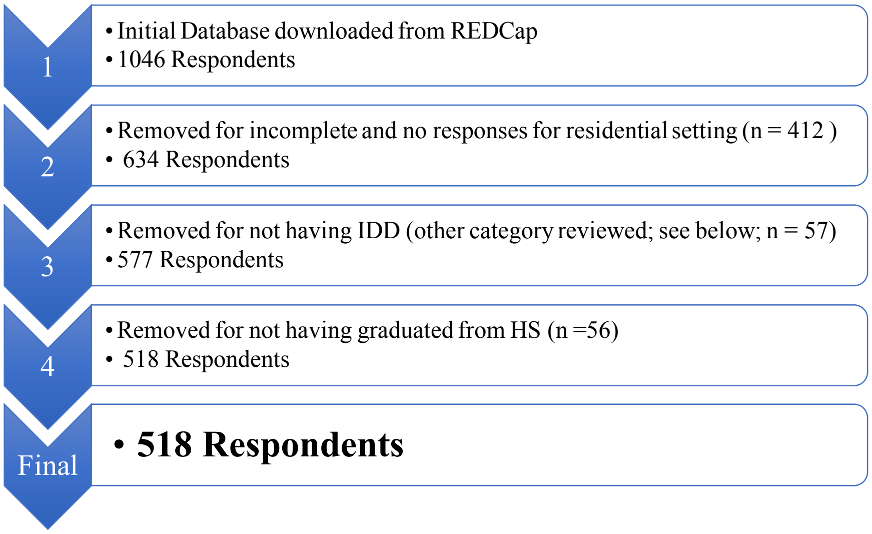

Figure 1. Flow chart for obtaining the current data set.

Table 3

Residential Settings for Adults with IDD and Characteristics of Residential Settings

	Total % (N) or Mean (sd)
Residential Settings	
Family home with parents	57.5% (298)
Family home with siblings	3.9% (20)
Family home with relatives	0.8% (4)
Independently with supports	8.7% (45)
Independently without supports	1.4% (7)
Small group home	11.2% (58)
Large group home	8.3% (43)
Intermediate Care Facility	1.0% (5)
Foster Care	.8% (4)
Nursing Home	.2% (1)
Intentional Community	1.0% (5)
Residential Community	1.2% (6)
Other	4.2% (22)
Type of Settings Split into Two Categories	
Living with family	62.7% (325)
Living out of family home	37.3% (193)
Characteristics of Residential Setting	Mean (sd)
Length in Current Residence	8.62 (3.44)
Number of Residents	2.42 (1.55)

Correlates and Predictors of Living at Home or Away from Home

Family and respondent characteristics. We first conducted chi-square and t-test analyses for respondent characteristics variables by the two residential categories, living at home and living away from the family home. When the adult was living in the family home, a greater percentage of respondents were mothers, whereas a higher proportion of respondents were legal guardians/caregivers when the adult with IDD lived away from the family home, $\chi^2(1, N = 518) = 43.38$, $p < .0001$, $ES = .29$. Mostly parents were conservators for the adult with IDD when they lived at home, while the sibling or individual was the legal guardian/conservator when the adult lived away from home, $\chi^2(1, N = 518) = 19.21$, $p < .0001$, $ES = .39$. Similarly, as compared to when the adult lived away, the respondent was most likely the primary caregiver when the adult lived in the family home, $\chi^2(1, N = 518) = 204.01$, $p < .0001$, $ES = 1,61$. In addition, 78.1% (236) of those primary caregivers in the family home were mothers, compared to 60.6% (40) of primary caregivers were mothers when the adult lived away from home. See Table 4 for an overview of the results.

Mothers and fathers were more often alive and younger when the adult was living in the family home than away from home (see Table 4). When the adult was living in the family home the mother was most likely alive and in better health than mothers of adults with IDD who lived in other settings, $t(516) = 3.72$, $p < .0001$, $ES = .34$. Lastly, parents' ability to care was much higher when the adult with IDD lived in the family home than adults with IDD who lived away from the family home, $t(515) = 8.73$, $p < .0001$, $ES = .79$. After the BH Correction for multiple significance testing, all other variables were not significant (see Table 4). Thus, adults with IDD were more likely to live at home when the parents were present (alive, respondent, caregiver, and guardian) and active (younger, better health, and able to care).

Table 4

Analyses of Family and Respondent Characteristics by Two Residential Categories

	Living with the Family % (N) or Mean (sd)	Living Away from Family Home % (N) or Mean (sd)	X^2 *or t*	*p*	*Effect Size (r/Cohen's d)*
Respondent Role					
Mother	73.5% (239)	46.6% (90)	43.38	***p* < .0001***	.29
Father	7.4% (24)	8.3% (16)			
Sibling	8.3% (27)	16.1% (31)			
Legal Guardian/Other	10.8% (35)	29.0% (56)			
Income					
<$40,000	15.1% (47)	14.8% (26)	1.65	.800	.008
$40,001 - $60,000	16.7% (52)	13.6% (24)			
$60,001 - $80,000	16.0% (50)	19.9% (35)			
$80,001- $100,000	16.3% (51)	16.5% (29)			
>$100,000	35.9% (112)	35.2% (62)			
Respondent Education					
High School/ Some College	34.8% (113)	25.9% (50)	6.69	.035	.11
College Graduate	32.6% (106)	31.1% (60)			
Graduate/Professional	32.6% (106)	43.0% (83)			
Legal Guardian					
Parent	79.4% (258)	61.7% (119)	19.21	***p* < .0001***	.39
Individual, Sibling, or Other	20.6% (67)	38.3% (74)			
Primary Caregiver	93.2% (302)	34.4% (66)	204.01	***p* < .0001***	1.61
Mother Alive	92.0% (299)	73.1% (141)	33.97	***p* < .0001***	.53
Father Alive	95.7% (266)	84.4% (114)	15.61	***p* < .0001***	
Mother Work					.35
Retired	21.1% (60)	43.6% (58)	23.38	***p* < .0001***	-.18

	Living with the Family % (N) or Mean (sd)	Living Away from Family Home % (N) or Mean (sd)	*X^2 or t*	*p*	*Effect Size (r/Cohen's d)*
≤ 20 hours	35.6% (101)	21.8% (29)			
≥ 21 hours	43.3% (123)	34.6% (46)			
Father Work					
Retired	57.1% (60)	61.4% (43)	1.36	.507	-.01
≤ 20 hours	16.2% (17)	10.0% (7)			
≥ 21 hours	26.7% (28)	28.6% (20)			
Mother Education					
High School/ Some College	39.4% (123)	43.2% (76)	2.10	.349	-.007
College Graduate	33.0% (103)	26.7% (47)			
Graduate/Professional Degree	27.6% (86)	30.1% (53)			
Age					
Respondent Age	57.28 (8.34)	60.44 (11.08)	-3.32	.001	-.33
Mother Age	58.93 (7.95)	64.74 (8.31)	-6.95	**$p < .0001$***	-.72
Father Age	60.56 (8.62)	66.54 (7.48)	-6.19	**$p < .0001$***	-.73
Health					
Respondent Health	3.34 (.943)	3.62 (.930)	-3.27	.001	-.30
Mother Health	3.24 (.957)	3.39 (1.14)	-1.47	.143	-.15
Father Health	3.23 (1.00)	3.34 (1.09)	-.919	.358	-.11
Mother Health and Alive	2.98 (1.27)	2.48 (1.79)	3.72	**$p < .0001$***	.34
Family Characteristics					
Ability to Care	3.81 (1.19)	2.71 (1.68)	8.73	**$p < .0001$***	.79
Parent Connected to Community	29.16 (10.46)	32.40 (10.70)	-2.96	.003	-.31
Respondents Connected to Community	29.17 (10.40)	31.32 (10.37)	-2.27	.024	-.21
Number of Siblings	1.69 (1.40)	1.83 (1.53)	-1.10	.273	.17

*Significant after BH Correction at .05 level.

In order to show these findings concretely we created two graphs. Figure 2 illustrates the percentage of parents of adults with IDD who lived in the family home who were either deceased, not able to provide care (i.e., rating poor or fair), and able to provide care (i.e., rating of good/excellent ability to provide care). There is a greater percentage of parents of adults with IDD who are able to provide care when the adult is living in the family home, compare to when adults with IDD were living away from home. There is a decrease in number of parents who are able to provide care for those adults with IDD living away from home. Furthermore, there is an increase in number of parents deceased (both parents) when the adult was living away from the family. Figure 3 illustrates the percentage of parents deceased, in poor health, and in good health living in the family home and living away from home. In regards to this variable, it seems that the parent being alive was the biggest difference between those who lived at home and those who lived away.

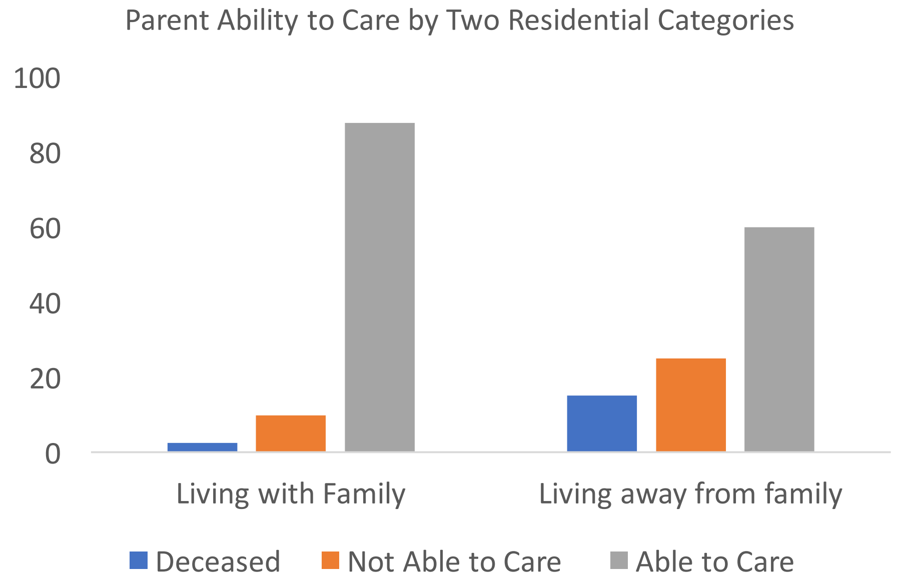

Figure 2. The percentage of parents of adults with IDD who are deceased (blue), not able to care (orange), and who are able to care (gray) by living in the family home and living away from the family.

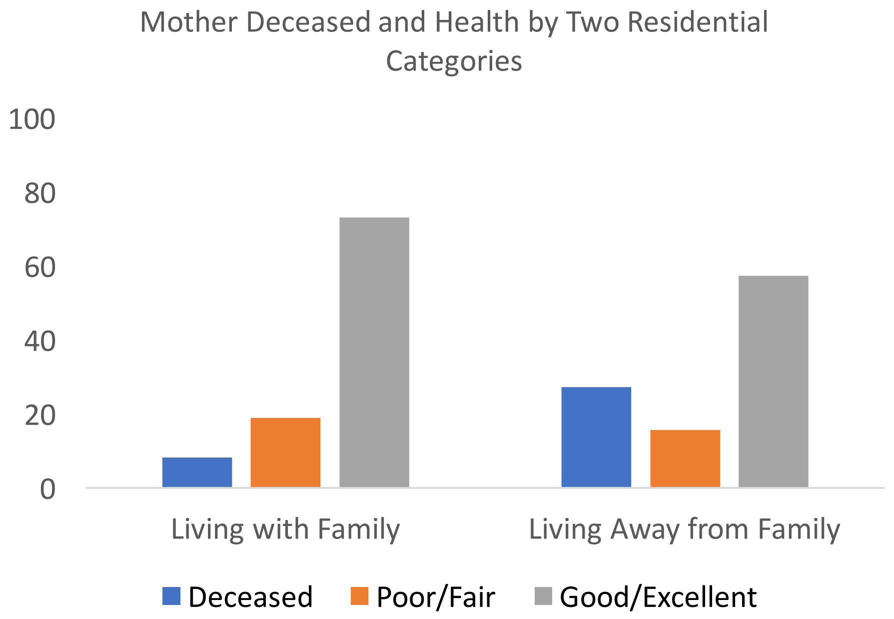

Figure 3. The percentage of parents deceased (blue), in poor health (orange), and in good health (gray) living in the family home and living away from home.

Characteristics of adult with IDD. When living away from the family home, adults with IDD were older, *t(*518) = -8.91, *p* < .0001, *ES* = -.81*,* had a lower level of functioning (with more severe and profound IDD), *t(*518) = 4.09, *p* < .0001, *ES* = .37*,* and had proportionally more adults who had ASD, χ^2(1, *N* = 518) = 9.63, *p* = .002, *ES* = .28*.* There was also no difference for adults with DS (68.8%) than those without DS (61.4%) in living at home, χ^2(1, *N* = 518) = 1.79, *NS.* All other variables were not significantly different between living at home and living away from home after BH Correction for multiple significance testing (see Table 5).

To show more how different age groups impact residential status for adults with IDD we created a graph. Figure 4 shows the percentage of adults with IDD in each age decade living in the family home and living away from home. A greater percentage of adults with IDD in their 20s were living in the family home. There is a decrease in living in the family home in their 30s,

Table 5

Analyses of Characteristics of Adults with IDD by Two Residential Categories

Variable	Living with Family % (N) or Mean (*sd*)	Living Away from the Family home % (N) or Mean (sd)	*t or* X^2	*p*	*Effect size (Cohen's d)*
Age	28.93 (9.60)	38.76 (13.41)	-8.91	***p* < .0001***	***-.81***
ADL	16.48 (8.49)	14.22 (8.09)	.585	.559	.05
Less Support Needs	53.0% (170)	53.7% (102)			
More Support Needs	47.0% (151)	46.3% (88)			
Level of Functioning	2.55 (.88)	2.23 (.86)	4.09	***p* < .0001***	***.37***
Mild/Moderate	54.3% (176)	37.8% (73)			
Severe/Profound	45.7% (148)	62.2% (120)			
Maladaptive Behavior	108.37 (11.12)	108.04 (11.32)	.319	.750	.03
Normal	68.2% (214)	66.3% (124)			
Marginal to Serious	31.8% (100)	33.7% (63)			
Adult Health	3.29 (.96)	3.17 (96)	1.37	.172	.13
Poor/Fair	19.6% (63)	21.9% (42)			
Good/Excellent	80.4% (259)	78.1% (150)			
Adult Mental Health	2.98 (.99)	2.84 (.98)	1.50	.133	.14
Poor/Fair	32.8% (106)	38.2% (73)			
Good/Excellent	67.2% (217)	61.8% (118)			
ASD	49.2% (160)	35.2% (68)	9.63	**.002***	**.28**
Down Syndrome	19.7% (64)	15.0% (29)	1.79	.181	.12
Jobs in the Community	35.0% (111)	34.4% (64)	.19	.890	.04

*Significant after BH Correction at .05 level.

followed again by greater percentage of adults with IDD living in the family home during their 40s. Then finally in 50s and above category, a greater percentage of adults with IDD were living away from home.

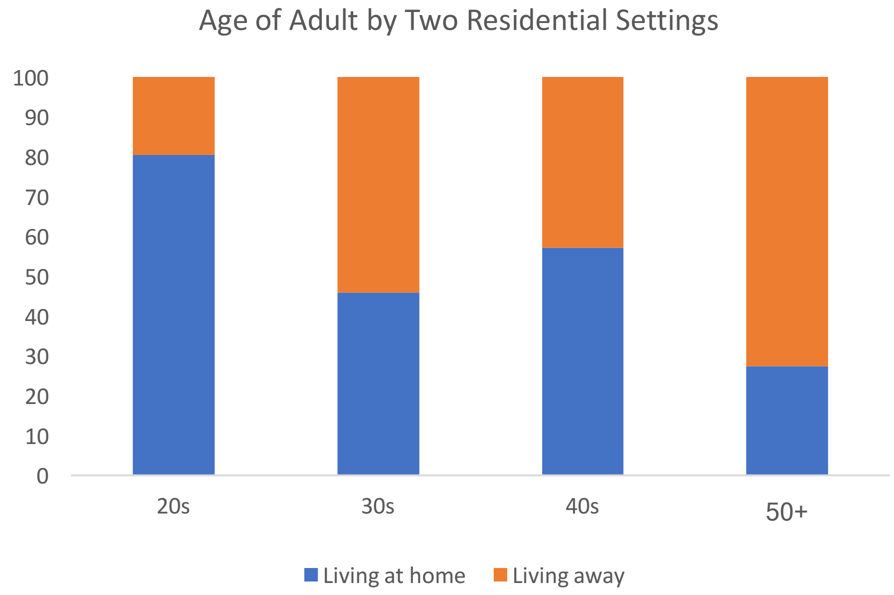

Figure 4. The percentage of adults in each age decade, 20s, 30s, 40s, and above 50 years living in the family home (blue) and living away from home (orange).

To determine each predictor's independent contribution to whether the adult lived at home versus lived away from home, we conducted a logistic regression of living in the family home on adult age, adult maladaptive behavior, adult's daily living skills, if the adult had autism, parent's ability to care, and mother's health/alive. We did not use level of functioning because it was highly correlated to ADL score ($r = .752$).

Both characteristics of the adult with IDD and of the parent emerged as significant, independent predictors. Older adults with IDD were more likely to live away from the family home than in the family home. Adults with IDD were more likely to live away from home when their parents were less able to care for them. Adults with IDD were more likely to live away from home when the mother was in poorer health and/or deceased. While ASD was a significant predictor in the univariate analysis, it did not predict living at home when controlling for other factors. The regression was significant, $\chi^2(6) = 105.55$, $p < .0001$. See Table 6 for overview of the results.

Table 6

Logistic Regression of Predictors of Living Away from Home vs. Living at Home

	B	SE	Wald X^2	Odds Ratio	Lower 95% CI	Upper 95% CI	*p*
Parent's Ability to Care	-.49	.11	-4.52	.61	.49	0.76	**$p < .0001$***
Mother Health and Alive	.60	.20	3.00	1.82	1.23	2.72	**.0027***
Adult Age	.81	.15	5.47	2.25	1.68	3.02	**$p < .0001$***
Maladaptive Behavior	.05	.14	.39	1.06	.80	1.39	.698
ADL	.11	.17	.65	1.12	.80	1.55	.515
Autism	-.31	.24	-1.31	.73	.46	1.17	.190

*Significant at .01 level.

Exploratory Results

Living independently. Within the three residential categories, most adults with IDD were living with family (62.7%), followed by living in other dependent settings (26.6%) and only 10.6% of adults with IDD were living independently (with or without supports).

We were able to examine some correlates comparing three residential categories, living at home, living independently, and living in other dependent settings. If we found mean differences between groups, we conducted Scheffe post hoc analyses to determine which means differed. In the post hoc analyses we found differences in the mean were significant for the adult and parent related variables. Overall, when adults with IDD lived at home parents had the greatest ability to care for them, followed by living independently, and then living in other settings, *F*(2, 514) = 42.80, *p* < .0001, *ES* = .80. When the adult was living independently or in other settings the parent indicated being more involved in the disability community than parents of adults with IDD who lived at home, *F*(2, 419) = 5.81, *p* = .003, *ES* = -.27. Mother health and alive were similar between those living in the family home and living independently, however, mothers of adults with IDD who lived in other settings had a poorer health or were deceased compared to mothers living at home but not living independently, *F*(2, 419) = 9.24, *p* < .0001, *ES* = .34.

Adults with IDD living at home were also significantly younger than the adults with IDD living independently, with adults with IDD living in other settings older than the other two groups, *F*(2, 482) = 49.96, *p* < .0001, *ES* = -.88. Adults with IDD were living independently were much higher functioning than those living in other settings but were similarly functioning to those living at home, *F*(2, 514) = 19.99, *p* < .0001, *ES* = .38. However in terms of daily living skills, adults with IDD living independently had more daily living skills than those in the family home and those living in other settings, *F*(2, 512) = 11.20, p < .0001, *ES* = .34. Adults with IDD living in other settings were the lowest functioning. There were no difference in maladaptive behavior for adults with IDD between the three residential settings, *F*(2, 512) = .633, *NS.* Thus, adults with IDD who lived independently were higher functioning and had less support needs. See Table 7 for an overview of the results.

Down syndrome. There was no difference in residential placements for adults with DS versus those without DS for both two categories or three categories. Since there were no differences in residential settings between those with and without DS, we did not explore differences in characteristics.

ASD. While having ASD was not significant in the logistic regression as a predictor of residential status, it was a significant predictor of staying at home in the univariate analysis. Thus, we explored ASD further by examining the differences between the three residential categories. A greater percentage of adults with ASD are living at home versus living independently or in supervised settings. For adults with ASD, 70.2% (160) were living at home, 8.8% (20) were living independently, and 21.1% (48) were living in more supervised settings. For adults without ASD, 56.9% (165) were living at home, 12.1% (35) were living independently, and 31.0% (90) were living in more supervised settings, $\chi^2(2, N = 518) = 9.67$, $p = .008$.

In examining the characteristics of adults with and without ASD, the main differences were in maladaptive behavior, mental health rating, and age. Adults with ASD were younger, $t(518) = 5.56$, $p < .0001$, *ES =.50,* had more severe challenging behavior, $t(518) = -8.40$, $p < .0001$, *ES* =.75 and lower mental health ratings, $t(518) = 4.75$, $p < .0001$, *ES* =.42, than those without ASD. There were no differences in family characteristics (see Table 8).

We further examined age and maladaptive behavior of just the adults with ASD in relation to their residential settings. No difference emerged in maladaptive behavior across residential settings, $F(2, 226) = .791$, $p =.445$. Then we examined age by residential category for only the adults with ASD. Adults with ASD in the family home were significantly younger (*M* = 27.05, *SD* = 8.60) than those living independently (*M* = 29.53, *SD* = 7.19) and adults living in other settings (*M* = 36.49, *SD* = 13.80), $F(2, 211) = 16.30$, $p < .0001$. In contrast, those without ASD were older across all residential categories, adults without ASD in the family home had a mean age of 30.62 (*SD* = 10.15), adults without ASD living independently had mean age of 38.88 (*SD* = 14.40) and adults without ASD living in other settings had a mean age of 42.61 (*SD* = 13.33).

Table 7

Exploratory Analyses of Adult and Family Variables by Three Residential Categories

	Mean Living with Family (*SD*)	Mean Living Independently (*SD*)	Mean Living in Other Settings (*SD*)	*F*	*p*	*Cohen's d*
Family Characteristics						
Parent Ability to Care	3.81 (1.19)	3.16 (1.60)	2.53 (1.69)	42.80	***p* < .0001***	.80
Parent Involvement in Disability Community	29.16 (10.46)	34.63 (10.95)	31.37 (10.48)	5.81	***.003****	-.27
Mother Health and Alive	2.98 (1.27)	2.84 (1.78)	2.33 (1.78)	9.24	***p* < .0001***	.34
Adult Characteristics						
Adult Age	28.87 (9.57)	35.46 (13.00)	40.41 (13.76)	49.96	***p* < .0001***	-.88
ADL	16.48 (8.49)	20.47 (8.20)	14.22 (8.09)	11.20	***p* < .0001***	.34
Level of Functioning	2.55 (.88)	2.69 (.86)	2.04 (.89)	19.99	***p* < .0001***	.38
Maladaptive Behavior	108.38 (11.16)	106.67 (12.35)	108.61 (10.92)	.633	*.531*	.03

*Significant after BH Correction at .05 level.

Table 8

Exploratory Analyses Characteristics of Adults with ASD

Variable	ASD % (N) or Mean (*sd*)	No ASD % (N) or Mean (sd)	*t or* X^2	*p*	*Effect Size*
Age	29.34 (10.39)	35.15 (12.79)	5.56	$p < .0001$*	-.50
Maladaptive Behavior	112.68 (11.20)	104.76 (9.89)	-8.40	$p < .0001$*	.76
Normal	49.3% (112)	82.5% (226)			
Marginal to Serious	50.7% (115)	17.5% (48)			
Level of Functioning	2.47 (.82)	2.40 (.93)	-9.23	.356	.08
Mild/Moderate	47.1% (107)	49.0% (142)			
Severe/Profound	52.9% (120)	51.0% (148)			
ADL	1.00 (.44)	.94 (.55)	-1.453	.147	.12
Less Support Needs	54.9% (123)	51.9% (149)			
More Support Needs	45.1% (101)	48.1% (138)			
Adult Health	3.32 (.98)	3.19 (.95)	-1.59	.113	.14
Poor/Fair	19.5% (44)	21.2% (61)			
Good/Excellent	80.5% (182)	78.8% (227)			
Adult Mental Health	2.70 (.96)	3.11 (.98)	4.75	$p < .0001$*	-.42
Poor/Fair	43.4% (98)	28.1% (81)			
Good/Excellent	56.6% (128)	71.9% (207)			
Family Characteristics					
Parent Ability to Care	3.32 (1.59)	3.50 (1.35)	-1.38	.169	-.12
Parent Involvement in Disability Community	29.44 (10.43)	30.84 (10.77)	1.36	.176	-.13
Mother Health and Alive	2.90 (1.37)	2.70 (1.61)	-1.48	.139	.13
Number of Siblings	1.46 (1.19)	1.96 (1.60)	3.95	$p < .0001$*	-.35

*Significant after BH Correction at .05 level.

CHAPTER IV

DISCUSSION

This study examined the percentage of people living in different residential settings, the family and adult related factors associated with living in vs. apart from the family home, and factors associated with living independently and autism. Few studies so far attempt to look at family-related factors in predicting residential placement. This study produced three main findings.

Our first main finding related to the percentage of adults with IDD living in 13 residential settings. Consistent with national prevalence rates and also other studies, we found that adults with IDD were most often living in their family home, followed by group homes, and lastly in an independent living arrangement either with and without supports (Anderson et al., 2014; Hewitt et al., 2017; Larson et al., 2017). Similar to other studies, there were very low rates of adults with IDD living in institutions, nursing homes, host homes, residential communities, and intentional communities (Esbensen et al., 2010; Essex et al., 1997; Hewitt et al., 2017; Seltzer et al., 1997). Overall, residential living rates were similar to other studies.

Our second finding related to the adult and family-level predictors. The only adult-related factor that impacted residential status was the age of the individual with IDD. Specifically, adults with IDD in their 20s were most frequently living in the family home, whereas, adults with IDD in their 50s were more likely outside of the family home. This is similar to studies that look at age by decades (Hewitt et al., 2017; Hodapp et al., 2016; Stancliffe et al., 2012). Age, thus, was an important predictor of adults with IDD living within versus. away from the family home.

These findings add to a small body of research that also show that adults with IDD who are older are more likely to live away from home and younger adults are more likely to live within the home (Anderson et al., 2014; Essex et al., 1997; Stancliffe et al., 2012; Woodman et al., 2014). However, this finding differs from a few studies that did not find age differences (Bouck, 2012; Bouck & Joshi, 2012; Bouck, 2014). These differing studies included participants who averaged 23 years of age, which is much younger than the average age in this current study.

While previous studies suggested that several other adult-related predictors impacted residential status, we found a slightly different set of adult-related predictors for whether the adult lived at home. For example, some studies have found that adults with better daily living skills, higher IQs, and less challenging behaviors were more likely to live away from home than in their own home (Gray et al., 2014; Hewitt et al., 2017; Wehmeyer & Garner, 2003). Conversely, adults with more severe disabilities were more likely to live at home or in other supervised settings (Woolf et al., 2010). We did not find any impact of these adult characteristics. Differences between our findings and existing studies may be due to our dichotomization of those individuals within home vs. away from home. Different studies looked at specific types of residential arrangements outside the family home.

Important family-level factors were related mainly to the mother being present and active in a caregiving role. This finding roughly equates to parents being better able to care for the adult and the mother is alive and in good health. We found a greater percentage of parents who had a better ability to care when the adult lived at home than when they lived in other settings. Similar to our study, some studies noted that adults were more likely to live away from home when the mother's health declined as they got older (Essex et al., 1997; Woodman et al., 2014). While being in good health contributes to the ability to care for the offspring with IDD, we found that it was more important just that the mother was simply alive rather than health alone. Even more important was the parent's ability to care. While Seltzer et al. (1997) found that the amount of care given by the mother was not a predictor of living at home or away, we found evidence supporting the opposite. Thus, the issue of living at home and away from home, while related to both adult and family, seems more related to family issues. Living away from home was related to a potential overall decline over time in the ability to care of the parents. Some other findings in this study also confirm this—respondent role, primary caregiving, and conservatorship all differed when the adult lived at home from when they lived in other settings. When the adult lived at home, a greater percentage of parents were the primary caregiver, the respondent, and the conservator.

Our third main finding related to the exploratory analyses of both independent living and adults with ASD. Independent living is often considered separately from other settings because it requires less supervision, which means that those living independently have less severe disabilities as previous studies suggest. In those studies, adults with IDD who were living independently had higher adaptive skills, high IQ, and less challenging behavior (Gray et al., 2014; Hewitt et al., 2017; Wehmeyer & Garner, 2003). In this study, we found that adults with IDD living independently also had higher levels of daily living skills than adults living in family homes or in more supervised settings. There were also age differences in relation to independent living, as those in the family home were younger, those living independently were next oldest, and those in supervised settings were the oldest. This pattern of age supports the change in residential transition happening at an older age for adults with IDD. However, we found no differences in regards to maladaptive behavior.

There were some family-related differences, but they did not differ substantially than those we found when comparing living at home and away. Adults with IDD living independently also had parents who were more able to care, alive, and in better health. The only family-related variable that was influenced by independent living concerned involvement in the disability community. Adults with IDD who lived independently had parents who were more involved in the disability community than those adults who lived at home or in other supervised settings. Thus, it is possible that having more knowledge and involvement in the disability field might influence the amount of support and access to services parents receive.

Lastly, we explored issues in ASD in relation to residential status. While we found that adults with ASD were more likely to live in the family home, when we controlled for other variables in the regression, this was not the case. In exploring differences between those with ASD and without ASD, we found that those with ASD had more maladaptive behaviors and were younger. When examining these two characteristics in relation to residential settings there were no difference across residential settings in regards to maladaptive behavior but there were age differences. Adults with ASD were much younger than adults without ASD, which may be why they were more likely to live in the family home. While some studies did find that adults with ASD were more likely to live at home, others found that those differences disappeared when controlling for other related factors (Anderson et al., 2014).

Taken together, these results suggest the importance of providing supports and services to family caregivers. Nationally, only 13% of families receive support in the family home through state funding (Hewitt et al., 2013), an especially low rate considering that adults continue to live in the family home until they are older and parents are no longer able to care. These results suggest that we must support parents who are long-term caregivers in two ways: 1) providing supports and services in the home for long-term caregiving; and 2) by determining the best community living supports for when the parent is deceased or no longer able to care for the adult with IDD.

Given that parents will be long-term caregivers for their adults with IDD, these study findings suggest that families should be provided with more services in the family home. Studies suggest that long-term caregiving, while there are some positive aspects, can have adverse effects on parents, such as increased levels of depression, stress, social isolation, and increased caregiver burden (Krauss et al., 2005; Llewellyn, McConnell, Gething, Cant, & Kendig, 2010; McDermott, Valentine, Anderson, Gallup, & Thompson, 1997; Seltzer et al., 1997). Thus, in both practice and policy, we need to shift to supporting parents in the family home but also try to find innovative ways to support adults moving into the community.

In more normative transitions to adulthood, a typical adult is most likely to leave the family home in their late 20s/early 30s (Arnett, 2000). Thus, when the parent's health declines or they pass away, they are likely not taking care of their adult child. In regards to policy and practice, then, we have to support parents and meet caregiving needs outside the family home before the mother's health declines or she dies. In a crisis situation, siblings or family members would be dually burdened with not only dealing with the death of a parent (for example), but also trying to find supports and services for the adult child with IDD. In essence, two stressful transitions are occurring simultaneously, a situation that may increase stress and cause stress for all involved. It is imperative, thus, to find community living alternatives to the family home well before the reduction in the mother's own health and ability to care.

One obvious alternative is to engage siblings in future caregiving. However, Burke, Taylor, Urbano, & Hodapp (2012) found that siblings who had parents who were less able to care noted themselves as less likely to assume caregiving for their siblings. If so, then it is doubly important, in practice, to work with families to determine future caregiving before the decline of the parent's caregiving abilities. Siblings may also need supports in navigating the disability field. Further, they may not be aware of their role as a future caregiver or involved in the planning process (Arnold, Heller, & Kramer, 2012; Heller & Kramer, 2009). In practice, we must equip families and siblings with the possible supports and services that they can access for the adult with IDD. While the number of adults supported by state funding is increasing, it still does not meet the needs of adults with IDD (Hewitt et al., 2013). In regards to policy and funding, we must move beyond supporting community living and residential supports with state funding only when families are no longer capable of caring (e.g., having to be on a waitlist until crisis). Practitioners and policy makers also need to start finding innovative ways to provide residential supports and services that do not rely solely upon state funding but also meets the family's needs (Hewitt et al., 2013).

Our findings also support the idea that adults with IDD who live independently look different from their peers who live in community settings in regards to adaptive skills. Equipping adults with IDD with more adaptive skills may impact the expectations and attitudes of caregivers. Better daily living skills may lead caregivers to feel encouraged that adults with IDD are more capable of living independently but with supports. In terms of practice, teachers and other practitioners might focus on teaching young adults with IDD independent living skills that would support living as independently as possible, if this is indeed a goal for which they are striving. However, these results also support the idea that residential status is about the fit to the living environment for the adult with IDD based on their needs (Henninger & Taylor, 2014).

Thus, a person with more adaptive skills may be more apt to be in less restrictive or less supervised living arrangements.

Future Research

One of the main concerns across past studies and this study is the lack of diversity in the participants/respondents. One major issue to consider in future research in housing is variance based on cultural differences. For example, Magana and Smith (2006) suggest that, compared to White (non-Hispanic) mothers, Latina mothers were more satisfied with their child with ASD co-residing in their household. Leaving the family home and living independently or separate from the parents might be a normative transition only for White families. Thus, cultural differences might add to the complexities of determining appropriate residential settings for adults. However, very little research yet exists on housing, residential status, and cultural differences for adults with IDD. This area needs to be further examined.

It would also be beneficial to examine philosophical and attitude-related differences towards housing that may impact the residential status of adults with IDD (i.e., how attitudes and expectations impact future living status). Also, future research should examine what constitutes a successful residence by looking at outcomes across all settings.

Lastly, while many studies suggest that parents and siblings need supports, future research must address what successful supports for families entail and how practice can best address those family and adult supports for residential settings. In looking at the barriers to residential settings, we can begin to examine where families may need supports for residential services. Also, because states vary in the amount of supports they provide, future research should look at differences between states in terms of residential status. Furthermore, future research should examine systemic issues and the impact of policy on residential services and access to residential supports (Ticha et al., 2013).

Limitations

There are a few limitations to this study. First, this survey was a web-based survey. Web-based surveys are advantageous because data can be collected quickly and efficiently. However, a limitation of web-based surveys is that people without internet access may not be able to respond, and non-responders may be predominantly low-income families or families in rural areas. Another limitation is the lack of diversity in this study, which had mostly White mothers as respondents. Cultural differences and attitudes can impact housing and so this study may only reflect the experiences of the specific demographic. Because we were limited in sample size, we were also not able to conduct regression analyses with independent living as a separate living category. All limitations should be addressed in future research.

Conclusion

This study, then, provides a basic understanding of where adults with IDD are more likely to live and reasons why adults move out of the family home. Overall, adults with IDD are mostly living in the family home. Adults were most likely to leave their family home if they were older and the parents lost their ability to care, were deceased, or in poor health. In identifying these factors, we can begin to understand the landscape underlying access to residential services and what predicts leaving the family home. This understanding can help service providers know how to assist adults and their families in accessing more normative residential transitions rather than solely when the family stops being able to care. Research still needs to address how policy, attitudes/philosophies, culture, and housing affordability have shaped the outcomes for accessing different residential placements for adults with IDD.

Appendix A

Recruitment Flyer

VANDERBILT KENNEDY CENTER

Residential and Respite Care Services Study

A study for family members of adults with Intellectual & Developmental Disabilities.

Anonymously share your experience with Residential Care Services and Respite Care Services.

10 Randomly selected participants will receive a $25 gift card to the store of their choice.

To participate in this survey, please click the link below.

May copy and paste link into Internet browser

https://is.gd/residential_respite_survey

*Please note, the survey will take less than 30 minutes to complete. Please allow yourself ample time to complete the survey

Email:
Maria.p.mello@
Vanderbilt.edu

Call:
(615) 669 - 2581

Appendix B

Recruitment Email Script to Disability Organization

Dear [INSERT Organization name here],

We are conducting a survey of families of adults with disabilities to explore the factors associated with different types of residential placements and respite care services for adults with disabilities.

We are contacting you because you are an organization that works with families and persons with disabilities. We would like to request your assistance to help us disseminate the survey flyer and link to your families of adults with disabilities. If you could send the flyer (attached) and the email below to your families, we would greatly appreciate it. If you have a newsletter or bulletin board, feel free to post the information. Thank you for your support in advance.

The survey will take less than 30 minutes to complete. The survey is anonymous and voluntary and the responses are confidential. The responses will be helpful in determining issues and supports related to residential and respite care services. We will raffle ten $25 gift cards at the close of the survey for participants who complete the survey.

If you would like to complete the survey please follow the link:
https://is.gd/residential_respite_survey

If you have any questions or concerns pertaining to the survey, please contact Maria P. Mello, M.Ed., BCBA at maria.p.mello@vanderbilt.edu or at (615) 669-2581.

Best,
Maria P. Mello
Department of Special Education
Vanderbilt Kennedy Center
Vanderbilt University

Appendix C

Recruitment Email Script to Participants

Dear [Participant],

We are conducting a survey of families of adults with disabilities to explore the factors associated with different types of residential placements and respite care services for adults with disabilities. We are contacting you because you are a family member of an adult with a disability.

The survey will take less than 30 minutes to complete. The survey is anonymous and voluntary and the responses are confidential. Your responses will be helpful in determining issues and supports related to residential and respite care services. We will raffle ten $25 gift cards to a store of the participant's choice at the close of the survey for participants who complete the survey.

If you would like to complete the survey please follow the link:
https://is.gd/residential_respite_survey

If you have any questions or concerns pertaining to the survey, please contact Maria P. Mello, M.Ed., BCBA at maria.p.mello@vanderbilt.edu or at (615) 669-2581.

Best,
Maria P. Mello
Department of Special Education
Vanderbilt Kennedy Center
Vanderbilt University

REFERENCES

ADA (1990). *Information and Technical Assistance on the Americans with Disabilities Act*. Retrieved from: https://www.ada.gov/ada_intro.htm

ADA About Olmstead (2017). Olmstead: Community integration for everyone. Retrieved from: https://www.ada.gov/olmstead/olmstead_about.htm

Anderson, K. A., Shattuck, P. T., Cooper, B. P., Roux, A. M., & Wagner, M. (2014). Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder. *Autism, 18*(5), 562-570.

Arnett, J. J. (2000). Emerging Adulthood: A theory of development from the late teens through the twenties. *American Psychologist, 55*(5), 469-480.

Arnold, C. K., Heller, T., & Kramer, J. (2012). Support needs of siblings of people with developmental disabilities. *Intellectual and Developmental Disabilities, 50*(5), 373–382.

Benjamini, Y., & Hochberg, Y. (1995). Controlling the false discovery rate: a practical and powerful approach to multiple testing. *Journal of Royal Statistical Society, Series B (Methodological)*, 57(1), 289-300.

Blacher, J., Kraemer, B. R., & Howell, E. J. (2010). Family expectations and transition experiences for young adults with severe disabilities: does syndrome matter? *Advances in Mental Health and Learning Disabilities, 4*, 1-16.

Bouck, E. C. (2012). Secondary students with moderate/severe intellectual disability: considerations of curriculum and post-school outcomes from the National Longitudinal Transition Study-2. *Journal of Intellectual Disability Research, 56*(12), 1175-1186.

Bouck, E. C. & Joshi, G. (2012). Functional curriculum and students with mild intellectual disability: Exploring post-school outcomes through NLTS-2. *Education and Training in Autism and Developmental Disabilities, 47*(2), 139-153.

Bouck, E. C. (2014). The post-school outcomes of students with mild intellectual disability: does it get better with time? *Journal of Intellectual Disability Research, 58*(6), 534-548.

Blustein, C. L., Carter, E. W., McMillan, E. D. (2016). The voices of parents: Post-high school expectations, priorities, and concerns for children with intellectual and developmental disabilities. *The Journal of Special Education, 50*(3), 164-177.

Branching Logic Guide (2017). Branching Logic in REDCap – How to Guide. Retrieved from: https://www.ctsi.ufl.edu/files/2017/06/Branching-Logic-in-REDCap-%E2%80%93-How.pdf

Bruininks, R. H., Woodcock, R. W., Weatherman, R. F. & Hill, B. K. (1996). *Scales of Independent Behavior Revised (SIB-R)*. Chicago, IL: Riverside.

Burke, M. M., Taylor, J. L., Urbano, R., & Hodapp, R. M. (2012). Predictors of future caregiving by adult siblings of individuals with intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities, 117*, 33-47.

Chou, Y., Lee, Y., Lin, L., Kroger, T., & Chang, A. (2009). Older and younger family caregivers of adults with intellectual disability: Factors associated with future plans. *Intellectual and Developmental Disabilities, 47*(4), 282-294.

Esbensen, A. J., Seltzer, M. M., Greenberg, J. S. (2007). Factors predicting mortality in midlife adults with and without Down syndrome living with family. *Journal of Intellectual Disability Research, 51*, 1039-1050.

Esbensen, A. J., Bishop, S. L., Seltzer, M. M., Greenberg, J. S., & Taylor, J. L. (2010). Comparisons between individuals with Autism Spectrum Disorders and Individuals with

Down syndrome in adulthood. *American Journal on Intellectual and Developmental Disabilities, 115*(4), 277-290.

Essex, E. L., Seltzer, M. M., & Krauss, M. W. (1997). Residential transitions of adults with mental retardation: predictors of waiting list use and placement. *American Journal on Mental Retardation, 101*(6), 613-629.

Finch, E. S. (1985). Deinstitutionalization: Mental health and mental retardation services. *Pyschosocial Rehabilitation Journal, 8*(3), 36-48.

Forrester-Jones, R., Carpenter, J., Cambridge, P., Tate, A., Hallam, A., Knapp, M., & Beecham, J. (2014). The quality of life of people 12 years after resettlement from long stay hospitals: Users' views on their living environment, daily activities and future aspirations. *Disability & Society, 17*(7), 741-758.

Gray, K. M., Keating, C. M., Taffe, J. R., Brereton, A. V., Einfeld, S. L., Reardon, T. C., & Tonge, B. J. (2014). Adult outcomes in autism: Community inclusion and living skills. *Journal of Autism and Developmental Disorders, 44*, 3006-3015.

Harris, P. A., Taylor, R., Thielke, R., Payne, J. Gonzalez, N., Conde, J. G. (2009). Research electronic data capture (REDCap) – A metadata-drive methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics, 42*(2), 377-381.

Heller, T., & Kramer, J. (2009). Involvement of adult siblings of people with developmental disabilities in future planning. *Intellectual and Developmental Disabilities, 47*(3), 208–219.

Henninger, N. A. & Taylor, J. L. (2014). Family perspectives on successful transition to adulthood for individuals with disabilities. *Intellectual and Developmental Disabilities*, 52(2), 98-111.

Hewitt, A. S., Stancliffe, R. J., Hall-Lande, J., Nord, D., Pettingell, S. L., Hamre, K. & Hallas-Muchow, L. (2017). Characteristics of adults with autism spectrum disorder who use residential services and supports through adult developmental disability services in the United States. *Research in Autism Spectrum Disorders, 34*, 1-9.

Hewitt, A. S., Agosta, J., Heller, T., Williams, A. C., & Reinke, J. (2013). Families of individuals with intellectual and developmental disabilities: Policy, funding, services, and experiences. *Intellectual and Developmental Disabilities, 51* (5), 349-359.

Hodapp, R. M., Burke, M. M., Finley, C. I., & Urbano, R. C. (2016). Family caregiving of aging adults with Down syndrome. *Journal of Policy and Practice in Intellectual Disabilities, 13*(2), 181-189.

Idler E. L., Benyamini Y. (1997). Self-rated health and mortality: A review of twenty-seven community studies. *Journal of Health and Social Behavior, 38*, 21–37.

Individuals with Disabilities Education Improvement Act (IDEA) of 2004, 20 U.S.C. ξ 1440 (2004).

Kozma, A., Mansell, J., & Beadle-Brown, J. (2009). Outcomes in different residential settings for people with intellectual disability: A systematic review. *American Journal of Intellectual and Developmental Disabilities, 114* (3), 193-222.

Krauss, M. W., & Seltzer, M. M. (1993). Current well-being and future plans of older caregiving mothers. *The Irish Journal of Psychology, 14*(1), 48-63.

Krauss, M.W., Seltzer, M. M., & Jacobson, H. T. (2005). Adults with autism living at home or in non-family settings: positive and negative aspects of residential status. *Journal of Intellectual Disability Research, 49*(2), 111-124.

Larson, S. A., Doljanac, R., & Lakin, K. C. (2005). United States living arrangements of people with intellectual and/or developmental disabilities in 1995. *Journal of Intellectual and Developmental Disability, 30*(4), 236-239.

Larson, S., Eschenbacher, H., Anderson, L., Pettingell, S., Hewiit, A., Sowers, M., Fay, M. L., Taylor, B., Agosta, J. (2017). In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2014. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. Access at https://risp.umn.edu/publications

Llewellyn, G., McConnell, D., Gething, L., Cant, R., & Kendig, H. (2010). Health status and coping strategies among older parent-carers of adults with intellectual disabilities in an Australian sample. *Research in Developmental Disabilities, 31*, 1176-1186.

Maenner, M. J., Smith, L. E., Hong, J., Makunch, R., Greenberg, J., Mailick, M. R. (2013). An evaluation of an activities of daily living scale for adolescents and adults with developmental disabilities. *Disability and Health Journal, 6*(1), 8-17.

Magana, S. & Smith, M. J. (2012). Psychological distress and well-being of Latina and non-Latina white mothers of youth and adults with an autism spectrum disorder: Cultural attitudes towards coresidence status. *American Journal of Orthopsychiatry, 76*(3), 346-357.

Mandell, D. S. (2017). A house is not a home: The great residential divide in autism care. *Autism, 21*(7), 810-811.

McDermott, S., Valentine, D., Anderson, D., Gallup, D., & Thompson, S. (1997). Parents of adults with mental retardation living in-home and out-of-home: Caregiving burdens and gratifications. *American Journal of Orthopsychiatry, 67*(2), 323-329.

Medicaid HCBS (2018). Home and community based services. Retrieved from: https://www.medicaid.gov/medicaid/hcbs/index.html

Multinomial Logistic Regression (MLR; 2018). Conduct and interpret a multinomial logistic regression. Retrieved from: http://www.statisticssolutions.com/mlr/

National Core Indicators (2018). About the National Core Indicators (NCI). Retrieved from: https://www.nationalcoreindicators.org/about/

Newman, L., Wagner, M., Cameto, R., & Knokey, A. M. (2009). The post-high school outcomes of youth with disabilities up to 4 Years after high school. *A Report from the National Longitudinal Transition Study-2.* Menlo Park, CA: SRI International.

Newman, L., Wagner, M., Cameto, R., & Knokey, A. M., and Shaver, D. (2010). Comparisons across time of the outcomes of youth with disabilities up to 4 Years after high school. *A Report of Findings from the National Longitudinal Transition Study (NLTS) and the National Longitudinal Transition Study-2 (NLTS2).* Menlo Park, CA: SRI International.

Rizzolo, M. C., Friedman, C., Lulinski-Norris, A., & Braddock, D. (2013). Home and community based services (HCBS) waivers: A nationwide study of the states. *Intellectual and Developmental Disabilities, 51* (1), 1-21.

Ross, J., Marcell, J., Williams, P., & Carlson, D. (2013). Postsecondary education employment and independent living outcomes of persons with autism and intellectual disability. *Journal of Postsecondary Education and Disability, 26*(4), 337-351.

Sanderson, K. A., Burke, M. M., Urbano, R. C., & Hodapp, R. M. (2017). Who helps? Characteristics and correlates of informal supporters to adults with disabilities. *American Journal on Intellectual and Developmental Disabilities, 122*(6), 492-510.

Seltzer, M. M., Greenberg, J. S., Krauss, M. W., & Hong, J. (1997). Predictors and outcomes of the end of co-resident caregiving in aging families of adults with mental retardation or mental illness. *Family Relations, 46,* 13-22.

Stancliffe, R. J., Lakin, C., Larson, S. A., Engler, J., Taub, S., Fortune, J., & Bershadsky, J. (2012). Demographic characteristics, health, conditions, and residential service use in adults with Down syndrome in 25 U.S. states. *Intellectual and Developmental Disabilities, 50*, 92-108.

Thomson, M. (1998). *The Problem of Mental Deficiency: Eugenics, Democracy, and Social Policy in Britain* c. *1870-1959.* New York: Oxford University Press.

Ticha, R., Hewitt, A., Nord, D., & Larson, S. (2013). System and individual outcomes and their predictors in services and supports for people with IDD. *Intellectual and Developmental Disabilities, 51*(5), 298-315.

Trent, J.W. (1994). Inventing the feeble mind: A history of mental retardation in the United States. Berkeley, CA: University of California Press.

Wehmeyer, M. L. & Garner, N. (2003). The impact of personal characteristics of people intellectual and developmental disability on self-determination and autonomous functioning. *Journal of Applied Research in Intellectual Disabilities, 16,* 255-265.

Woodman, A. C., Mailick, M. R., Anderson, K. A., & Esbensen, A. J. (2014). Residential transitions among adults with intellectual and disability across 20 years. *American Journal on Intellectual Developmental Disabilities, 119*, 496-515.

Woolf, S., Woolf, C. M., & Oakland, T. (2010). Adaptive behavior among adults with intellectual disabilities and its relationship to community independence. *Intellectual and Developmental Disabilities, 48*(3), 209-215.

Wright, P. W. D & Wright, P. D. (2006). *Special Education Law*. Hartfield, VA: Harbor House Law Press.