

Parental Attitudes toward Involvement in the Lives of Adults with Intellectual and
Developmental Disabilities Following Residential Transition.

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ABSTRACT

This study attempted to examine parental experiences leading up to, and following the transition of their son or daughter with intellectual and developmental disabilities (IDD) to a community-based residential placement. This is a field of study that has not been sufficiently researched, despite the increasing number of adults with IDD who have moved out of their parental home and into community-based residences in recent years. For the purposes of this study, the researcher performed semi-structured interviews with six parents of adults who had been diagnosed with IDD and had been subsequently transitioned into community-based residences. Through the use of an Interpretive Phenomenological Analysis (IPA) research design, the researcher identified several phenomena, which arose across the participants that warrant further study and examination. Specifically, the researcher found that the participants' descriptions could be clustered around three main superordinate themes: balancing independence and protection, the redefinition of the parent's identity, and the practical and emotional preparation and response to the transition itself. As these phenomena are further researched in the transition process from parental home to community-based residence, it is proposed that better outcomes for all involved will be experienced.

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Introduction

Historical Perspectives

The research in the field of intellectual disabilities and developmental disabilities (IDD) is fairly comprehensive across numerous topics. However, the majority of the work done in the early half of the twentieth century was performed on the diagnosis of disabilities and special education for children with developmental disabilities (Scheerenberger, 1983). Even in regard to adults with IDD, a great amount of the available research has addressed the function and efficient delivery of post-secondary education. The role that adults with IDD play in the community, outside of the classroom or workshop, on the other hand, is a much newer and sparser field of study (Scheerenberger, 1983). Throughout the first half of the twentieth century, the majority of American parents of individuals with IDD were presented with two disparate options. If a family could afford to care for the needs of their family members, they had the option to keep their son or daughter in their home. Meanwhile, until the mid-1950's, families in lower socio-economic brackets faced great financial pressure to place their offspring with disabilities into large residential institutions (Scheerenberger, 1983). In the United States, the number of these institutions, and the population admitted into these facilities, skyrocketed until the 1970's. Often, following admission, these individuals had little to no contact with their families. (Scheerenberger, 1983). Recently conducted research continues to suggest that parents of individuals placed in larger institutional residences

have lower levels of contact with the individuals than families of individuals who were placed in community-based settings (Spreat and Conroy, 2002).

Thus, for decades, families were presented with a dilemma of extremes when it came to the role they took in their sons' or daughters' lives. They could assume near-complete responsibility of their children's care and life choices by keeping their son or daughter at home, or they could seek an institutional placement. In these placements, it was often observed that the professionals in charge of care disregarded or even disdained parents' wishes and advice about the care of their sons or daughters (Roos, 1976). Even recently conducted with parents of individuals placed in larger residential facilities continues to suggest that parents express experiencing low levels of participation in decision making or operations of the facilities. These results remain true even for parents who report a high level of visitation and contact with their son or daughter (Schwartz and Tsumi, 2003). This suggests that for decades, parents could either opt to maintain all, or nearly all, of the parenting roles they fulfilled throughout their son's or daughter's lives, or cede the majority of the decision making role to professionals who frequently viewed parental input as irrelevant to their work in caring for the adults (Roos, 1976).

A Third Option: Community-Based Housing

Starting in the 1950's, pressure began to build, through legislative and political means, for a return to a more community-focused approach to housing. This movement first saw success during a great wave of deinstitutionalization that occurred under the Richard Nixon administration. One result of the deinstitutionalization movement was a new residential option for adults with disabilities: community-based housing. Wolf Wolfensberger described this option and its benefits in 1971: "I can see no reason why

small specialized living units (mostly hostels) cannot accommodate all of the persons now in institutions,” (Wolfensberger, 1971). The Rehabilitation Act of 1973, and the later development of the American’s with Disabilities Act, signed by President George H.W Bush, served to advance a number of options besides institutionalization, including community-based group housing.

This new option for families served as a middle road. There was now a possible choice between life-long responsibility of caring for a son or daughter who lived in the home - often until their parents passed away or were otherwise incapacitated - and placement in large institutions where parents would have little say over decisions made in their child’s life. Additionally, community-based homes were more often located nearer to the individual’s family. This allowed for parents and family to potentially maintain more frequent connection with their sons or daughters than with institutionalized individuals (Spreat and Conroy, 2002). As common sense would dictate, a shorter distance from the residential location was found to strongly correlate with higher rates of parental visitation (Baker, Blacher, & Pfeiffer, 1996).

The largest shift towards community-based residential placements was yet to come. In 1999, the US Supreme Court decided in the case of *Olmstead v. L.C.* that the state of Georgia was required by the Americans with Disabilities Act to allow for adults with disabilities to receive funding for services delivered in community housing, rather than just in the large institutions set up for adult housing in the state (Milne, 2012). Specifically, Justice Ruth Bader Ginsberg, in writing the majority opinion of the court, stated:

“...proscription of discrimination may require placement of persons with mental disabilities in community settings rather than in institutions... Such action is in order when the State’s treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.” (*Olmstead v. L.C.*, 1999)

The decision law led to a movement by the IDD population, their families, and service providers to push for community group housing as a major option around the United States, and resulted in a significant increase in the development of community housing options. As of 2011, twenty-seven states had established Olmstead plans that hewed to the courts findings that in-home or community-based residential services be provided funding by the state. Eighteen other states have established their own versions of plans in response to the ruling (Milne, 2012).

While the percentage of adults residing in larger residential facilities was decreasing even before the Olmstead ruling (Larson, Doljanac & Lakin, 2005), since Olmstead, this pattern has accelerated. Subsequently, the number of adults living in institutional facilities decreased from 207,356 in 1977 to 67,066 in 2004 (Lakin & Stancliffe, 2007). While the number of persons residing in larger institutions has decreased, it has not coincided with an increased number of adults with IDD living at home. That number has remained high, and has been quoted as a majority of adults with IDD (Larson, et al., 2005), but the overall percentage of individuals with IDD living in a small (defined as six or fewer residents) non-familial homes increased more than ten-fold between 1977 and 2005 (Lakin, Prouty, & Coucouvanis, 2006). Lakin and Stancliffe’s 2007 review of Center for Disease Control and Prevention statistics found that, despite the previously alluded to decreases in population in larger institutional facilities, the

overall percentage of individuals with IDD of all ages living in the parental home had decreased by sixty-six percent in that time. Remarkably, this number likely underrepresents the percentage of *adults* with IDD living out of the family home - the same study found that the percentage of *children* (identified as individuals under the age of eighteen) with IDD living out of the home had actually decreased over the same time by seventy-one percent (Lakin and Stancliffe, 2007).

The use of smaller, community-based housing is only likely to increase. All parties with a stake in the process of residential placement have been found to be trending towards this third residential option. It was found that over forty percent of youth with IDD, autism spectrum disorder, or multiple disabilities expect to live away from home following their exit from the school system (Riesen, 2010). Parents, meanwhile, have reported higher levels satisfaction when their adult offspring were placed in smaller, community-based placements than when their son or daughter was placed in a larger institution (Schwartz, 2005). Finally, group housing is increasingly seen as a more cost-effective per-resident option for states and service providers to fund (Riesen, 2010).

Meanwhile, studies indicated that there are many benefits to group housing or other community-based residential care facilities. Living in community-based housing has shown to have a positive effect on choice-making, adaptive, social and daily living skills, and improved quality of life for adults with IDD (Cummins & Lau, 2003; Stancliffe & Lakin, 2007). Other studies have found parents and family of the individual also benefitted following the residential transition (Werner, Edwards, & Baum, 2009). One study found that “virtually all parents reported family life to be better following placement, especially in recreation, social life, and relationships with their other children”

(Blacher, Baker, & Feinfield, 1999: p 452). Research has also discovered that three to five years post-placement, maternal self-report level of worry regarding the care and well-being of their children had significantly decreased (Seltzer, Krauss, Hong, & Ormond, 2001). This suggests that not only can out-of-home placement benefit the adult themselves, but the parent can feel relieved of aspects of caregiving-related burden and stress, and that the positive benefits can extend to other relationships in the parent's life.

However, the research does not unequivocally support positive results. One study found that while adults with IDD living in group homes reported significantly less loneliness, adults who were still living with their parents were more likely to report feelings of happiness. Results of parents and caregivers in that study closely mirrored the opinions of the adults themselves (Rourke, Grey, Fuller, & McClean, 2004), though they differed in respect to views of appropriateness of placement, with parents expressing less desire to change living arrangements than the adults (regardless of whether the adult was currently living at home or had been residentially relocated). In regard to the parents specifically, the effects of the out-of-home placement on life satisfaction has found to be mediated somewhat by the parent's own situation, dependent on whether a mother is part of a one or two-parent family (Rimmerman & Muraver, 2001). They found that single mothers were less likely to view an out of home placement positively. That same study suggested that all mothers of adults who lived out of home experienced more undesirable life events. It is important to note that Rimmerman and Muraver were not able to show that such a move served a causal role in the increase, and one can imagine how it is possible that a mother who has experienced more undesirable life events may be more likely to look for or require their son or daughter to be placed out of the home as a result.

One qualitative study described a parent who labeled the day her daughter moved out as the “most awful time of our lives,” and who went on to recount continuing negative effects of her daughter’s placement (Lindsay, 2008: p15).

Resulting satisfaction to residential placement likely correlates with the quality of residential services. Studies have shown that a successful out-of-home placement is hardly guaranteed, and that several individual characteristics of the adults, including intellectual and adaptive functioning, diagnosis, gender, and ethnicity may affect success of residential placement (Gregory, Robertson, Kessissoglou, Emerson, & Hatton, 2001). Others have noted how environmental factors, such as staff’s level of emergency-response training, or location within the community can contribute to a breakdown of residential placement (Allen, 1999). This being said, the research on the effects of community placement is largely beneficial, and strongly supports increasing access to, and use of, smaller, less restrictive out-of-home living options (Riesen, 2010).

As mentioned, research suggests that one of the benefits of community placement is that parents may more frequently contact their offspring (Baker, et al., 1996), and that in doing so, may take a more active role in the decision making and care-taking processes than if their son or daughter had been placed in a large institution (Schwartz, 2005). However, the results regarding levels of contact between institutional and community-based housing have been mixed. One study viewed the rates of contact parents had with their offspring before and after transition from an institutional placement to a community placement. While the increase seen in the amount of contact families had with the individuals after they had been deinstitutionalized was statistically significant, the increase was also small (DHHS, 1985). Later studies continued to find mixed reports.

Some suggested that parental visit rates to institutional settings were similar to those when the son or daughter lived in the community setting (Grimes & Vitello, 1990), while others found higher rates of contact within community settings (Spreat & Conroy, 2002).

Furthermore, while the research suggests that increased family involvement and contact as a result of community placement can be beneficial, even these results have been mixed. For instance, a study was performed following up with families of individuals who were deinstitutionalized during the progressive closing of the Pennhurst State School and Hospital from 1977 to 1987. In the study, the US Department of Health and Human Services included the following case example, which they found to be descriptive of many of the families undergoing the same process:

“While Susan was at Pennhurst, she had little or no contact with her family. When she moved to the community, however, family visits increased dramatically. She has been visiting with her family in South Carolina at least three to four times a year over the past ten years... It seems that, to alleviate their own guilt [from years of no contact], they have become a doting family.” (United State Department of Health and Human Services, 1985: p 95)

Susan’s case suggests both increased quantity of contact and improved quality of the parent-daughter relationship. However, a further exploration of this case study highlights a major concern the authors discovered regarding the effects of deinstitutionalization and community living. For those families that did increase their contact following deinstitutionalization, their increased role sometimes intruded upon the perceived independence of their loved ones. Consider the continuation of the Pennhurst case study of Susan:

“In fact, they are perpetuating the myth of the sick, helpless, eternal child in Susan. Over the past few years gifts to Susan have been gifts that encourage dependence rather than foster independence... Staff and the provider agency have been unsuccessful in discouraging such gifts.

“While increased family contact is certainly a desired outcome, it should never occur at the expense of the individuals who are struggling so hard, in many cases, to achieve their independence. Certainly, in this case, Susan is getting mixed messages from her family and from staff and others around her.” (US DHHS, 1985: p 95)

Whether this case study is specifically reflective of parents whose offspring are deinstitutionalized, or whether it is applicable to all parents of adults with IDD who are placed in a community-based residence, is unclear. However, the idea of parental over-involvement throughout the lifecycle of the individual with IDD has been studied across the general population of parents of individuals with IDD. Parental over-involvement in the lives of adult sons or daughters with disabilities has been found to impact negatively upon the parents’ view of their children’s abilities, as well as upon rapport between parents and residential staff (van Ingen, et al., 2008; van Ingen & Moore, 2010). This raises several questions about the costs and benefits of community-based living arrangement enabling high levels of parental involvement. Does it universally benefit the son or daughter to have their parents continue to maintain higher levels of control and contact in their lives and decision making post-placement? To what extent do parents expect to stay involved with their children after the transition to community-based housing? How does real-life parental involvement compare to their expectations from before the transition? And finally, how does their level of involvement impact upon the functioning of their sons or daughters, or their own lives?

Self-Determination

Concurrent to the push for deinstitutionalization and community housing, a parallel process arose regarding treatment and goal-setting for the IDD population. Starting in the mid 1970’s many states in the US began to advocate for self-determination as a main focus of care and education for adults (and children) with severe mental illness

and disabilities (Kennedy, 1993). Self-determination has been defined as “acting as the primary causal agent in one’s life and making choices and decisions regarding one’s life free from undue external influence or interference” (Wehmeyer, Kelchner, & Richards, 1996). It grew out of the disability rights movement of the 1960’s and 1970’s (the same one that saw the push for deinstitutionalization) and the self-advocacy movement of the 1980’s (Wehmeyer and Schwartz, 1998). Whereas the initial definition of self-determination applied to international policy and nation-building, it was ably adapted to apply to individuals, especially those with disabilities. Self-determination has grown over the past two decades into a major focus of state government treatment of the IDD population, and a cause for funding from the US Department of Education (Ward, 1996). Self-determination is also included as a major tenet of the American Association for Intellectual and Developmental Disabilities (AAIDD; formerly the American Association of Mental Retardation) and other national interests groups (National Gateway to Self-Determination, 2011). Additionally, there has been increased federal emphasis applied through the development of the US Administration on Intellectual and Developmental Disabilities, which lists self-determination as one of its primary goals. Several state-based governmental organizations have similarly listed self-determination as a requisite for funding (DHHS, 2012). The literature would suggest that this push is warranted: it has been demonstrated that self-determination is highly correlated with quality of life for individuals with IDD (Wehmeyer and Schwartz, 1998).

Following the assumption that self-determination is a positive target outcome, the question arises: how can living arrangements affect self-determination in adults with IDD? The research has suggested environmental factors, including residential factors,

have great impact upon the level of self-determination that an individual may experience. One study suggests that smaller sized residential options had a positive effect on several of the component elements of self-determination, especially choice-making (Stancliffe & Abery, 1997). Specifically, studies have suggested that community-based residential options (as well as community-based work options) support and enhance self-determination in relation to restrictive, institutionalized settings (Wehmeyer & Bolding, 2001). However, Wehmeyer & Bolding caution that the within-subject design of their study prevented them from ascribing a causal relationship to the difference in setting. Additionally, they did not address whether there was any significant difference between levels of self-determination felt or observed in the lives of those adults with IDD who lived at home with family, and those who lived in smaller, community-based residences. Some research has been found that addresses this specific comparison with mixed results. Duvdevany, Ben-Zur, & Ambar (2002) compared levels of self-determination and lifestyle satisfaction in adults with IDD who lived in community-based group homes, and those who lived with their parents. The results showed that the adults who lived in group homes actually experienced significantly lower levels of self-determination than did individuals who lived at home. However, the adults who lived in community group homes scored higher in regard to self-reported levels of lifestyle satisfaction (Duvdevany, et al., 2002). This may hint at a disconnect between self-determination as a specific construct, and quality of life as a practical matter, or at least may suggest that self-determination as a goal may not be wholly sufficient to guarantee positive outcomes across all measures of life satisfaction.

Regardless of the whether it is appropriate to include self-determination as a major goal, the fact remains that several state and federal agencies include it as a major factor in regard to funding of available resources. Thus it is imperative to identify the best manner in which to define, measure, and support self-determination. While studies have been performed and measures developed to assess a parent's rating of their son or daughter's level of self-determination (Wehmeyer et al., 1996) it is unclear as to how these parents view their own role in their child's self-determination. Using the definition of self-determination mentioned above, which lists "one individual" as the target of self-determination, questions arise: *do* parents view themselves as part of the "one" who deserves to be free of "undue external influence and interference" or as part of that external structure that can serve to influence their child's independence? If they do not consider themselves a part of the target construct identified by that definition, how, if at all, does it affect their participation in the ongoing life of their son or daughter? And, for the purposes of increasing self-determination, how *should* they view their part of that definition in order to increase the likelihood of beneficial outcomes for all parties involved?

While there is little relevant research that addresses parents' views of their inclusion or exclusion from the definition of self-determination as it applies to their offspring, service providers, as well as state and national governments in several countries, do apply the definition primarily to consider the adult with IDD individually, rather than the family as a unit (Pilnick, Clegg, Murphy, & Almack, 2010). This clarity in definition does not fully address all the concerns that arise regarding self-determination as it applies to the population of adults with IDD. When one considers the views of

parents or service providers, not all parties involved agree that society should rigidly pursue the goal of self-determination for adults with disabilities in practicality. Many parents and service providers equivocate when considering how to respond to the realities of IDD and its effects on the decision-making capabilities of the adults in question. Thus, while self-determination has been a major cause of state and national organizations, it is unclear as to whether families of IDD individuals, or the professionals who work with these adults, whole-heartedly embrace the goal in the same manner. In fact, studies have shown that families and service providers both frequently espouse verbal support for the theoretical ideal of self-determination. These same families will then equivocate once real-life situations are discussed or experienced (Pilnick, et.al.2010). The literature questions whether this equivocation, which is technically opposed to a great deal of local, state, and national legislation, may be warranted. For instance, the qualitative study performed by Pilnick, et al., (2010), observed hours of interactions between adults with IDD and their parents, staff, or other caregivers. They found that, while self-determination was frequently endorsed as primary goal for their work with the individuals, the caregivers or aides would often use their questioning styles to undermine independent choices made by the adults with IDD when they judged the choices to be faulty. This contradicts the very definition of self-determination, albeit with the intention to protect the individual in questions. One particularly enlightening example involved a discussion between an adult and a service provider regarding their transition out of the school system. In this example, the adult with IDD expressed a desire to become a police officer, which was met with logical, oppositional questioning (gentle as it may have

been), until the adult agreed that alternative occupational opportunities should be pursued (Pilnick, et al., 2011).

Additionally, following an analysis of these conversations between adults and their support system, the researchers found that even when the reported intent of parents or service providers was to allow for as much self-determination as possible, the parents or service providers would often subtly or unconsciously undermine self-determination through the selection of the agenda of the discussion. For instance, the authors noted that the parents and service providers would ensure that these planning sessions would emphasize discussion of housing choice, employment, and recreation, often without consulting the adult for whom the planning session was being conducted. Thus, even if the adult with IDD developed or helped to develop plans across areas of their life, issues viewed by the adults as more personally important, but by their parents as less relevant, may have been deemphasized, theoretically undermining self-determination in the name of advocacy and quality of life. And it is important to note, that the authors did not use their pulpit to argue that this was harmful. In fact, in their conclusion section the authors noted that a rule-based approach only allowing for self-determination to be the guide served most frequently to provide moral clarity for the professionals, but could have negative practical effects for the individuals themselves and may “paradoxically result in undermining user choice and control” (Pilnick, et al., 2010: p 415).

Murphy, Clegg, and Almack also addressed this issue. They studied interviews conducted between young adults with IDD, their parents, and transition staff, to identify typical styles of discourse, in regard to the emphasis placed on self-determination. The study suggested that there were two common forms of discourse: one that highlighted

self-determination as an unequivocal yardstick for all aspects of the transitions; and one that qualified the individuals' status as "adults" and equivocated regarding their claims to self-determination (Murphy, et al., 2011). The authors used their results to advocate for a less rigid approach in which all "stakeholders" would be involved to discern the correct course of action. This again, does not agree precisely with the definition of self-determination as it is posited with many governmental agencies.

The research also demonstrated that regardless of how individuals with IDD may be influenced during the decision making process, it was often the caregivers and service providers themselves who wielded the power necessary to either enable or discount the decisions of the adults with IDD (Pilnick, et al., 2011). This research was conducted in United Kingdom, where legislation has pushed as strongly for the cause of self-determination as in the US. There, the UK government outlined a policy which determined that "all people with learning disabilities and their families will have greater choice and control over their lives and have support to develop person-centered plans" (Pilnick, et al., 2011; p 319). Yet the authors astutely pointed out that the reference to "all people with learning disabilities and their families," is lacking, as frequently the views of those two populations ("people with learning disabilities" and "their families") do not necessarily coincide. To advocate for greater choice and control for the adult may result in less choice and control for the families, and vice versa. Thus, they argue that to advocate rigidly for self-determination in its purest definition is not only potentially harmful, but extremely difficult in a practical sense. Following this conclusion they acknowledge that this leaves the door open for answers of how to best navigate the dilemma (Pilnick, et al., 2011).

The conclusions raised by these studies question the benefit of a rigid adherence to the belief that self-determination should be a target outcome above all. This questioning stance is supportable when one considers research that suggests that groups of adults with IDD living with their parents may express higher levels of self-determination, while simultaneously reporting lower levels of lifestyle satisfaction than those adults living in group homes (Duvdevany, et al., 2002).

This paper does not attempt to define self-determination, or to or to argue how strictly the rules regarding self-determination should be applied, either practically, or via legislative efforts. If self-determination of the adult with IDD was an overriding, primary goal towards which all planning and work should be targeted, parental expectations following out-of-home placement, or throughout the life-span could theoretically be clearer. Rather, the research demonstrates that while self-determination is nearly universally viewed as a positive general goal, questions remain about if and when an adult with IDD's right to self-determination should be qualified due to the reality of IDD. At the very least it suggests that other considerations, such as quality-of-life, could or should be considered alongside self-determination.

The continued existence of these questions further signifies that there is no set format for parents to follow in regard managing this transition to residential services. Considering this uncertainty, an exploration of the current reality of parental involvement is warranted. This includes whether or not parents actively consider self-determination (or similar constructs), or their role in supporting self-determination, when assessing their own level of involvement in the lives of their adult child. Knowing this may shed light on how parents have attempted to balance the goal for their son or daughter to be self-

determined with the goals of realistically supporting their sons or daughters through a successful transition.

The Separation/Launching Stage

The transition stage to adulthood with typically developing individuals is still a difficult time for young adults and their parents. This stage, frequently labeled, the “launching stage,” (Carter & McGoldrick, 2005) has been defined as the period of life when children move out of the parental home and establish a life independent from their family. It has been noted that even with parents of typically developing adults, this is a period of great disequilibrium, as it often precipitates enormous changes in the relationships between parents and their children, as well as in regard to other relationships in their lives. Specifically, some research has suggested that the loss of the parenting role can be a great difficulty (Carter & McGoldrick, 2005). On the other hand other research has suggested the launching of children into adulthood, and the subsequent decreases in parental responsibilities, is a largely positive experience (Blacker, 2005; Neugarten, 1991; Rubin, 1979). Blacker (2005) explored the launching phase and its effects on parents of adults with typically developing children. She described that launching stage as a very individualized experience, for both mothers and fathers. She suggested that immediately following the last child’s move from the home, the adjustment can be difficult for some parents. However, her research suggests that after a short time the experience is more universally positive for parents, in that they frequently experience feeling “relieved” or “revitalized” (Blacker, 2005; p 291). Frequently, the research suggests that for parents to successfully navigate the launching stage, they need

to be able to discover new interests and ideals, separate from their previous experiences which were largely tied to their self-as-parent (Anderson, 2005; Blacker, 2005).

This being said, the launching phase is significantly better defined for parents of typically developing children, both in the age in which it occurs, and in the roles expected of all parties during and after the moving out. The research regarding a parent's (re)discovery of their identity separate from their children was performed exclusively with parents of typically developing children. Whether or not parents of offspring with IDD find this redefinition to be as generally positive or successful as the do the parents studied by Anderson (2005) and Blacker (2005), is unclear. Whether or not this redefinition occurs at all has not been thoroughly researched.

Parents of adults with IDD will often hope to remain a major source of support and advice in their son or daughter's life, and to continue to stay in contact. However, few parents (and fewer young adults) anticipate that they will have direct control over many aspects of their son or daughter's ongoing life, hence the disequilibrium associated with the ceding of the "paternal role". While they may hope to offer advice, and to influence their child's decisions, few parents expect to directly decide their son or daughter's major life choices, such as job placement, where they live, aspects of their romantic lives, what they do for fun, etc. While there are exceptions to this, most parents view their child's move toward independence and self-reliance as a major target of parenting, and this stage is associated with success and celebration.

The research suggests that parents of children with IDD struggle more over the course of their child's life in discovering what their role will be as a parent (Miller,

1994). However, “letting go,” or “separating,” consistently serves as one of the most problematic processes for parents of children with IDD. The “separation stage” of parenting for this population is defined by Nancy Miller as both an emotional, and a physical process, one that starts at birth, increases greatly during puberty, and reaches a crescendo at variable times in the life of a child with IDD (Miller, 1994). It is acknowledged that this process can occur much earlier, later, less predictably, and over longer periods of time for individuals with IDD than for the typically developing population. She acknowledges that parental confusion over whether to pull back or to step in and protect their son or daughter, can be one of the major obstacles to an individual’s move towards independence (Miller, 1994). The literature shows that a failure to anticipate and plan for the eventual separation of parent and child may impede the child’s progress toward whatever self-sufficiency is attainable for them (Turnbull & Turnbull, 1997). The literature also suggests that parents of individuals with IDD and other handicaps often fail to acknowledge a need to “let go” and continue to view their son or daughter as a child (Turnbull & Turnbull, 1997).

This confusion is often confounded by a separate but simultaneous transition: it is acknowledged that the period of transition out of the public school system is one of great stress and confusion for individuals and their parents (Neece, Kraemer, & Blacher, 2009). Parents and adults with IDD are often confronted with an abrupt loss of services following graduation from the public school system (McDonnell & Nelson, 2010). Following this loss, the burden falls squarely on the individual and their family to acquaint themselves with the workings of a separate system of resources and supports than that they were familiar with from the individuals’ adolescence (McDonnell &

Nelson, 2010). As a result, parents of individuals with IDD experience increased levels of insecurity (Blacher, Kraemer, & Howell, 2010), parental stress (Jordan & Dunlap, 2000), and depression (Lounds, Seltzer, Greenberg, & Shattuck, 2007).

Following the transition out of the school system, and during their son or daughter's entry into community life, parents are often met with similarly confusing expectations and mixed messages. Service providers increasingly encourage the parents to consider out-of-home placement for their children (Blacher, et al., 1999). The research and service providers exhort them to place their trust in professionals who are to care for their children (van Ingen & Moore, 2010). During and following the same transition in which they are advised to relinquish large parts of the parental role, they are often expected or advised to maintain high levels of advocacy, contact, and specific goal setting in order to ensure both their access adequate resources in the transitional years (Rehm, Fisher, Fuentes-Afflick, & Chesla, 2013; van Ingen & Moore, 2010). This defines an extremely thin line upon which parents are expected to walk.

While Miller and others have outlined their theories on how best to walk this line, there is little consensus on the topic. Truly, it is often accepted that the transition process should be more idiographic and variable than nomothetic and rigid (Blacher 2001; Miller, 1994). And many that have studied this process have suggested that this transition period's importance far outweighs the amount of research that has been conducted on the topic (Blacher, 2001, Seltzer et al. 2001), suggesting that parents are largely left to fend for themselves.

Thus, further research is necessary. This is especially important as options available for out-of-home placement have increased, and as the research and service providers alike support such a placement (Riesen, 2010). There has been an increase in the number of adults with IDD living outside of the home (Lakin & Stancliffe, 2007). Despite this, the majority of parents of adults with IDD still expect, and wish, to care for their son or daughter as long as possible (Bigby, 1997). The research suggests that parents continue to have grave concerns regarding the future care of their offspring following a residential transition. These concerns include the very plausible idea that staff will not love and care for their sons or daughters in the way that they had. They also remain concerned that bad things would happen to the adults without the care and oversight that they could provide at home (Hubert, 2010). As such, a majority of parents do not make formalized residential plans until it is absolutely necessary, and often not even then (Freedman, Griffiths, Krauss, & Seltzer, 1997). When residential planning *is* undertaken, much of the time it involves planning that the child will stay in the home as long as possible, followed by expectations that a sibling of the adult, or another family member, will assume care-taking responsibilities once the parents' health no longer allows them to perform that role (Seltzer, Begun, Magan & Luchterland, 1993). Indeed, research has suggested that the most common predictors of residential placement are poor parental health, and higher age of the adult with IDD (Essex, Seltzer, & Krauss, 1997). However, it is notable that this tendency may be changing: an increasingly greater percentage of adults with IDD and their parents are taking advantage of out-of-home, community-based placement options (Lakin & Stancliffe, 2007).

Prior Research on Post-Placement Parental Involvement

While some research has been conducted regarding parental expectations of their level of involvement and contact with their family member following residential transition. (Seltzer et al., 2001), it is still a sparsely covered topic. Research in the field at this early stage remains conflicting and minimally applicable in clinical settings. Those that have studied it have found that the process is highly variable between families, for many idiographic reasons. Levels of intellectual, cognitive, and adaptive functioning among adult with IDD obviously varies a great deal from individual to individual. Number and type of available placements or resources vary greatly between states or often, between county or parish. The research suggests that diagnosis, or parental views on level of functioning greatly impacts upon the parental view of the transition to adulthood, as well as residential transitions (Blacher, et al., 2010). Additionally, some studies have shown that parental expectations regarding their role in caregiving, and level of satisfaction in their child's placement all remain highly volatile years after the transition (Baker & Blacher, 2002), while some studies suggest that role and expectations remain largely fixed, and suggest that early development of patterns of involvement is key (Baker, et al., 1996).

However, the research has identified several clear concerns about the process. First, parents' actual level and form of involvement after having a son or daughter move out of the home does not often match up with parental expectations at the start of the transition (Clegg, Sheard, & Cahill, 2001). This is concerning as it suggests that parents may not be as prepared for the transition out of the home as possible. Secondly, there are significant differences in how the parents view their role in the transition process and

how service providers view the parental role. These differences are also present in how the parents and the service providers view the role of the service providers in the transitions (Clegg, et al, 2001). This is important as these differences in the expectations held by the two parties may serve to hinder parent/staff rapport, especially early in the process.

Schwartz and Tsumi's 2003 study measured a number of important components of parental involvement, including level of contact with their son or daughter, the level of contact the parents had with the staff, and the level of participation that parents had in the overall decision making process in the residential setting. They discovered that parents maintained high level of in person and phone contact with both their children and with staff. However, these same parents expressed low levels of participation when it came to decision making and operation of the residence. These results corroborated early research performed by Baker, Blacher, & Pfeiffer (1996), which found that parents in their study averaged slightly more frequent than monthly contact with their sons or daughters, despite having little involvement in the residential program development itself (Baker, et.al, 1996). This is important data to have, and is applicable to parental expectations for the residential transition in general. However, Schwartz and Tsumi's participants were parents of children placed in larger institutions of fifty to 180 people, while the participants of the Baker, et al., study were parents of adults placed in larger Devereaux facilities in Florida. This may serve to explain the lower levels of participation in decisions making, and leaves unanswered how much of a role parents whose sons or daughters are moving into smaller groups home should expect to play in the decision making process. Certainly, the research on the differences between parental involvement

with institutionalized and deinstitutionalized offspring (Spreat & Conroy, 2002; Stancliffe & Abery, 1997) suggests that Schwartz and Tsumi's findings have limits to their application to parents of children in community-based residences.

Seltzer, Krauss, Hong, & Ormond (2001) performed a quantitative study on maternal and sibling involvement in the lives of the adults with IDD following their "launching" from the home. Their results discovered several important concepts to the pattern of maternal involvement following this transition. First, they discovered that maternal involvement during the transitions was an extremely strong indicator of maternal involvement during the first three years following the move. This supports the idea that the early expectations of parents and early levels of involvement, whether or not they are maintained at the same rates throughout the years, are key to the parents' ongoing level of contact. They found that mothers increasingly felt satisfied with their level of contact, and that their concerns regarding the residential staff's ability to care for their son or daughter diminished over the years. They found that the number of direct caretaking tasks the mothers participated in, as well as the level of contact they had with staff, decreased over time.

This data was largely quantitative, and while it is incredibly informative, it is lacking in description of the specific events and changes that caused these evolutions in maternal role. Also due to sampling concerns the study included only mothers and siblings, but was unable to examine fathers' experiences in this time (Seltzer, et al., 2001).

The above research does demonstrate that our understanding of the experiences of parents whose children have been placed in community-based housing is lacking.

Considering that increasingly more parents are entering this process, this is a concern for service providers who would like to help parents to prepare for the transition. The closest research to providing a blueprint for what parents, or at least mothers, could expect, is the Seltzer, et al., article (2001). The study lays out which care giving tasks, and how many tasks a parent can expect to be involved in, and how satisfied parents are with the placement three to five years following the transition of moving out. But again, it is important to note that the Seltzer, et al., article (2001) measures involvement as the number of caretaking activities engaged in by the parents. It does not provide data regarding parent's level of participation in regard to decision-making in their son or daughters lives. Simply measuring the number of care taking tasks or rate of contact per month does not fully describe what it means to be a parent. Additionally, what these articles lack in their description of the changes in level of contact is the process behind the changes; the events that can trigger or assist with the launching of the individual and the separation of the parent. It does not address who, if anyone, assisted the parent in redefining their role. All of this information would be helpful for parents who enter this time of transition understandably wary of what to expect.

Purpose of the Study

Since the Olmstead ruling, states have continued to push for the development and emphasis on community-based housing as a viable option for adults with IDD (Blacher, et al., 1999; Milne, 2012; Riesen, 2010). It is evident that community-based options have increased in popularity over the past decade and are likely to continue to do so.

Additionally, the number of adults who are relocating as a result of parental or personal preference, rather than as a result of parental illness or incapacitation of, is also increasing, allowing for significantly higher levels of potential contact and involvement by the families post-placement (Seltzer, et al., 2001). As such, the number of parents who will confront the issue of determining how to adapt their role continues to increase. Concurrently, state and national organizations, and governmental bodies continue to advocate for the highest level of self-determination available to each individual adult with IDD (NGSD, 2011; DHHS, 2012). This occurs despite the fact that there is conflicting evidence regarding whether self-determination in as it is literally defined is pursued by parents or services providers (Pilnick, et al., 2009) and how beneficial it would be if it is pursued outright (Murphy et al., 2011). As such, an increasing number of parents are going through this uncertain transition, with a son or daughter for whom they have, on average, played a more involved and protective role than the average parent (Miller, 1994). Parents in this era are on average more capable to remain protective and involved than prior generations of parents who primarily sought residential relocation of their offspring only due to health concerns or other incapacitation. Yet despite continued ability to continue to care for and protect their offspring, the majority of legislation and social science advises parents to separate from their sons or daughters in order to allow for increased levels of independence.

Despite the fact that the number of parents entering into this transition is increasing, and likely to continue increasing, it remains clear that the transition period to adulthood is understudied in the development of individuals with IDD. This is especially concerning in light of literature which suggests the transition out of the home is

particularly stressful, not only for the individual themselves, but for their parents and families (Lounds, et. al, 2007; Miller, 1994). It is important to explore what major themes and issues arise for parents as they struggle to define and discover what their role will be now that their child has moved out, and what major occurrences eventually help them elucidate their new role. Many studies have assessed what themes and concerns arise for the individuals themselves, and the general benefits and drawbacks of living apart from their parents (Wehmeyer & Bolding, 2001; Young, 2006). Other studies have identified the effects this transition has on parental quality of life (Werner, et al, 2009). However, few have addressed the intricacies of the parents' experience, and how parents perceive this process (Seltzer et al., 2001).

Gaining an understanding of the parental experience during this transition could help identify areas of future study, and could lead to identifying concerns in need of intervention. It may serve to help parents get a better sense of what previous parents have experienced during the transition, or what events occurred that helped to redefine or evolve the parental role following residential placement. Considering the research that shows that such a move is fraught with worry and concern (Hubert, 2010; Seltzer, et al., 2001), a better understanding of the process may help parents to decide if residential placement is right for their son or daughter. It may also help to prepare parents who have already decided to pursue a community-based residential placement for their son or daughter for this momentous change in their lives. Finally, gaining an understanding of parents' expectations may serve as a resource for service providers to prepare for interactions with parents during this time.

Statement of Intent

This study attempts to examine in greater detail parental expectations of their own involvement, and subsequent experiences in this regard, as it addresses the transition of their son or daughter with IDD to a community-based residential placement. By addressing this issue with parents who are currently undergoing this transition, and with those who have had time to experience the reality of life following residential transition, the researcher hopes to identify major themes regarding parental involvement that are important and impactful during this time.

Methods

Research Perspective

As asserted in the statement of purpose, and demonstrated by the review of the literature, there are critical shortages in the level of support available for parents of adults with IDD as they plan for and enter the process of transitioning their son or daughter out of the home. Because variables and relationships in these areas have not been treated extensively in the literature, a qualitative research methodology is more appropriate for research at this stage (Richards & Morse, 2013).

It has been suggested that there are multiple benefits to a qualitative approach in exploring a research question. First, it has been stated that qualitative approaches in research are appropriate when a topic lacks research or theory (Morse, 1991). In this regard, qualitative research is used to reveal possible variables that may be used in future research involving more quantitative studies. Often conceptualization of these variables is not well developed, and thus not available to be studied quantitatively. Appropriate qualitative research can help to discover and define these conceptualizations.

Secondly, qualitative research may help to provide context for previously researched concepts. In their 1985 text, Lincoln and Guba argued that if a field of research is dominated by quantitative studies, the understanding of that field may be flawed. They argued for a “naturalistic” paradigm, based upon the search for qualitative description that helps to add an understanding of reality as seen through the lives of research participants, which allows for a more accurate study of the phenomena. It has

been noted that such a paradigm, and its allowance for a “properly contextualized understanding” of the data, would be of enormous benefit to the fields of health and clinical psychology (Lyons, 2007). It has been posited that it is through the careful selection of an appropriate qualitative research design that this context and naturalistic understanding can be more thoroughly achieved.

Finally, one aspect of qualitative research design that has argued to be a benefit over some types of quantitative research is a minimization of the “speaking position.” Lyons in 2007 defines this as “the interpretive framework which shaped [the researcher’s] research questions and informed his or her analysis – and that they will reflect upon this process.” In other words, there is a concern that in quantitative psychological research, the researcher may apply context to life variables based on his or her prior views on the topic at hand. This context may either be inaccurate, or simply beside the point. In quantitative research, simply by choosing the questions that are asked, and often by limiting the possible answers to those questions as well, the researcher limits the scope of the data, and the context that may be critically valuable to the information he or she acquires. Qualitative research can help to mediate and lessen some of the effects of this. It has been suggested that it can do this in one of two ways. The first is that qualitative research, with its common dependence on semi-structured interviews, allows for the conceptualization of the research to be a more social process, and one that allows for the research participants to act as “co-researchers” who can “actively shape the research product.” (Heron, 1996). In other words, qualitative research has many ways to limit the restrictions that a researcher can place upon the information the participants provide. This ideally allows for more context in which to couch the target

constructs, and possibly even discovery of constructs not intended or expected to be found by the researcher at the start.

It is important to note that qualitative research does not wholly eliminate researcher bias through the taking a speaking position. It has been noted that the dynamic created by any research between the accounts offered by the participants and the interpretive framework of the researchers is inescapable (Lyons, 2007). It is important to note that only through acknowledgement of the researcher's own perspective, and subsequent strategies to address this identified dynamic that such a bias may be reduced. What qualitative research allows for, especially in the field of psychology, is a forum for a researcher to address his or her own possible biases. Researchers should, in many forms of qualitative research, work in discussions regarding the reservations and concerns they may have regarding his or her perspectives on the data. Frequently, this will include an open written discussion by the researcher regarding his or her own positions and experiences before one begins a discussion of the results (Rubin & Rubin, 1995). However, it is not limited to one section of a research summary. Often it is important with key variables to remind the reader of possible specific instances of biases, something that is possible within the format of qualitative data analysis. Thus, this research summary will include brief discussions of the primary investigator's background and possible effects that it may have had upon the aforementioned dynamic between data and the interpreter.

Researcher bias. In this case the researcher has personal experience with the topic at hand, as well as the population that is being studied. As a sibling of an adult with IDD, the researcher witnessed the transition of his sister out of the home. This included

discussions with his parents during the planning, moving, and post-move stages, and personal observations of the way that his parents managed the transition and their own reactions to life as a parent post-transition.

Additionally, the researcher found that a separate experience influenced the early stages of analysis, and thus required that the researcher acknowledge and attempt to account for the biases these experiences may have caused. Specifically, the researcher spent several years as a graduate student working as a behavioral consultant for a group home of adult men. During this time, the researcher worked closely with the group home staff. During the initial data analysis of this study, the researcher found himself viewing negative statements made by participants regarding caregiving staff in a defensive manner, and may have ascribed more negative emotions to such responses.

Thus, it is likely that the researcher entered with pre-determined expectations regarding the participants' responses. This personal involvement with the population, as well the professional involvement with service providers accessed by such a population, caused the researcher to view the participants and their experiences with sympathy. If not accounted for, such sympathy and connection with the population can hinder objective analysis of the data.(Rubin & Rubin, 1995).

However, as noted by Rubin & Rubin (1995), and Lyons (2007), neutrality is likely not a reasonable goal in qualitative research. Primarily, this is because complete neutrality is nearly impossible to attain (Lyons, 2007). Additionally, it has been theorized that due to the interview format inherent in the majority of qualitative research, including the interview format for this study, pure neutrality would likely result in a lack of

empathy which could limit the interviewer's ability to elicit in-depth description and emotional context.

Steps were taken to confront possible bias. This includes strict adherence to the standards of Interpretive Phenomenological Analysis (see below) as outlined by Smith and Osborn (2008) and Smith and Eatough (2007). Furthermore, if the researcher's experience particularly conflicts or agrees with specific interpretations of the data, it has been noted. Finally, the dissertation committee is aware of this potential bias and worked to ensure the highest standard of quality in regard to possibly objectivity of the research.

Interpretive Phenomenological Analysis. As discussed in the literature review, any young adult's transition out of the home is a highly emotional period for parents, especially for parents of adults with disabilities. Prior studies of this period have examined certain aspects of parental involvement and parental responses regarding their level of contact with their son or daughter (Seltzer, et al., 2001). Little research, however, has specifically explored the parental role and parental reactions to their role within the context of their family lives and broader social circumstances. Thus, the researcher chose to use Interpretive Phenomenological Analysis (IPA) as the specific qualitative method for exploring what parents thought and felt before, during, and after the transition. A phenomenological approach is most appropriate due to the fact that research using IPA tends to deal with significant, emotionally laden, and transformative events in a person's experience (Smith & Osborn, 2008). IPA has been demonstrated to be particularly well-suited to the fields of health, social, and clinical psychology, because in these fields it is paramount to discern the ways that people perceive and understand significant events in their lives in order to properly understand the data (Giorgi & Giorgi, 2008). Additionally,

due to the fact that IPA allows for highly descriptive accounts of an individual's experiences - ones that are ideally grounded in the perspectives of the individual rather than guided by quantitative measures - IPA is particularly helpful in the exploration of under-researched fields. The format of IPA is also designed to recognize and, where possible, minimize the researcher's bias in interpreting the data from the interviews. IPA studies also typically involve smaller sample sizes in studies, often from samples of six to twelve participants (Smith, 2004). However, it is important to note that proponents of IPA have argued that the research design is as appropriate, if not more so, with even smaller sample sizes, including single case studies (Smith, 2004). All in all, a smaller sample size allows for more detailed interpretive accounts of all the participants' responses, and for specific comparisons to be drawn from analyses of the separated cases (Smith & Osborn, 2003). Additionally, IPA was chosen for this study due to its record of successful use in addressing topics with parents of adults with intellectual disabilities (Pownall, Jahoda, Hastings, & Kerr, 2011; Reilly, Huws, Hastings, & Vaughn, 2008).

Participants

Recruitment procedures. For the purpose of this study, the principal investigator recruited parents or parental dyads whose adult children were both diagnosed with IDD, and had moved from the home to community group housing within the past ten years of the initial contact date. The researcher recruited parents through several means. Primarily, the researcher used referrals from mental health organizations that served the identified population. This included mental health organizations that operated adult community group homes, organizations that ran adult day programs, parental advocacy groups, and IDD advocacy groups. The organizations were asked to send information regarding the

study through the use of flyers, word of mouth, and e-mails that contained a contact number and e-mail of the researcher. Further recruitment was performed through the use of flyers and notices posted on internet listservs that served the IDD population. Network recruitment using the snowball technique was also performed - participants were asked to pass on information regarding the study to people they knew who might qualify. All recruitment documents and procedures were approved by the Rutgers University Institutional Review Board.

As discussed previously, the sample size in qualitative studies is frequently small. Thus it is expected that the researcher shall be able to select a purposeful sample of participants, ones who have intensely experienced the particular phenomena at hand, and who will be able to best answer the research questions (Creswell, 1994). To be included in the study, parents had to be: a) under the age of seventy, b) able to speak or write English proficiently, c) willing to provide informed consent, d) have a son or daughter who has moved from the home into group housing or similar community-based residential facilities for adults with IDD within ten years of the initial contact date, e) the aforementioned son or daughter must have a diagnosis of mild or moderate cognitive disability as defined by the AAIDD (AAIDD, 2010).

The researcher and committee chose to limit the study to parents whose son or daughter had moved from the home in the past ten years, because it was determined that these parents would still be able to recall factual information about the transition and their role following the move, as well as the emotional responses they experienced during this time.

The researcher and committee opted to limit the participants to parents of adults assessed to have a mild to moderate level disability. This is not to say that the exploration of a parental role for parents of severely intellectually or developmentally disabled children is not a valuable field of study. However, studies have demonstrated the more severe the disability, the higher that a parent's level of stress is likely to be, and that residential placement is more likely to have been sought for based on emergency need (McClintock, 1996). Additionally, it has been suggested that parents of more severely disabled children are more reluctant to search for residential placement, and hold more negative attitudes towards residential institutions (Hubert, 2011), which supports the concern that a representative sample of these parents would yield mostly participants who had placed their children due to emergency concerns. As discussed in the introduction, parents who sought placement specifically due to emergency reasons were not the target population of this study.

Participant demographics: Four mothers and two fathers were recruited for the study. The sample includes participants from two northeastern states. Each of the participants met all of the inclusion criteria.

The ages of the parents in the present sample ranged from fifty to sixty-eight years old ($M=62.0$, $SD=6.32$). All participants were biological parents of the offspring with IDD. Five of the six parents were currently married and living with their spouse at the time of their interview. One parent was divorced from the biological father of the son in question, had remarried since, and was living with her second husband at the time of the interview. It is important to note that this sample included two heterosexual parental dyads. All six participants identified as Caucasian. One of the participants identified her

religious affiliation as Catholic, two others as Jewish, two as Protestant, and one participant did not choose to identify her religious affiliation. All six participants reported being born in the United States (US), as were all of their sons and daughters discussed for the purposes of this study. This suggests that acculturation to life in the US, and to the level of social services available in the US was not a factor in their understanding of available resources.

There were five adult children discussed by the participants of the study, including four sons and one daughter (one of the parental dyads discussed both a son and a daughter with the same diagnosis, both of which had transitioned from their home to community-based residential facilities). The ages of the offspring discussed in this study ranged from twenty-two to forty years of age ($M=32.2$, $SD=6.61$). The number of months since the offspring had transitioned from the home ranged from seven to 118 ($M=55.4$, $SD= 56.1$). The primary diagnosis of one of the offspring was Down syndrome, two were primarily diagnosed with Developmental Disability, Not Otherwise Specified, and two were diagnosed with Static Encephalopathy of Unknown Origin. Three of the five adults with IDD were reported to have been diagnosed with moderate intellectual disability, and two were diagnosed with mild intellectual disability. No assessments were performed by this researcher to ensure the accuracy or validity of the reported severity of the disability of the adults discussed, as no contact was made with these adults, only with their parents. The participants reported that two of the adults discussed were currently placed in semi-independent living situations within the community (defined as living alone, or with a spouse, with assistance from non-parent caregiving staff), while three of the adults were

reported to be residing in community-based group homes (defined as living in a shared home with three or more other residents with similar diagnoses of IDD).

Measures

Semi-structured interview. The semi-structured, open-ended interview schedule (See Appendix A1) for this study was created by the researcher with input from committee members - all of whom have extensive history of work with families of individuals with IDD - professionals from other organizations that provide services for families of individuals with IDD, and the literature on this topic (Blacher, 2001; Cuskeley & Bryde, 2004; Seltzer, et al., 2001).

A series of non-intrusive prompts were not included in the protocol, but were designed to allow for participant elaboration on topics. This is in accordance with long-interview-based qualitative data (McCracken, 1988) and IPA guidelines (Smith & Eatough, 2007). These include verbal and non-verbal prompts for elaboration and/or direct repetition of key words or phrases used by the participants in order to encourage clarification and expansion of a topic.

Vineland-II Scale of Adaptive Behavior, Parent/Caregiver Rating Form.

Participants were mailed a Vineland-II, Parent/Caregiver Rating Form. The Vineland-II scales are the most widely used rating scale available for measurement of adaptive behavior and functioning in individuals with IDD (Sparrow, Cicchetti, & Balla, 2005). The Parent/Caregiver Rating Form includes all of the items included in the Vineland Survey Interview Form, but is adapted for use by parents and care-givers, through the use of more readily-accessible language. The results of the Vineland-II were used in order to

collect demographics regarding the adult offspring of the participants. With regard to the purposes of this study, the results of the Vineland-II were not included as an independent variable to be studied, but rather to provide the researcher with a more detailed understanding of the participants' views of the adaptive functioning of their sons or daughters.

No copy of the Vineland-II was included in the appendices of this paper, as it is copy-written material.

Parental Attitudes Toward Involvement Questionnaire: Participants were also mailed a questionnaire (See Appendix A2) that briefly touched on the topics that were expanded upon in the open-ended interview. This questionnaire was created by the researcher, with input from committee members, all of whom have extensive history of work with families of individuals with IDD; professionals from organizations dedicated to the service of individuals and families with IDD; and the literature on this topic (Schwartz & Tsumi, 2003; Cuskeley & Bryde, 2004; Seltzer, 2001). As with the Vineland-II, this questionnaire was used by the researcher to inform the open-ended interview, and as a touchstone for potential discussion topics within the interview. The measure did not serve as a stand-alone measurement with which to analyze data, nor did the results from this measure serve as any form of independent or dependent variable for the purposes of this study.

Procedures

In order to protect confidentiality, all initial contacts were made by the participants to the researcher. While some of the participants were initially referred by

third-parties, the researcher did not collect information on these potential participants. In an effort to protect confidentiality of the participants, the researcher required that if parents were interested in participating, they should contact the researcher first.

Upon initial contact the researcher completed a brief phone screen (Appendix B1), which lasted approximately ten minutes. This phone screen included a thorough explanation of the study and a brief series of questions designed to gather demographic information, and to determine if the eligibility requirements were met. At the end of the telephone screen verbal assent for further contact was acquired. This included the collection of a mailing address to which a pre-interview packet could be mailed.

During the initial phone screen each participant was given an assigned identification number, so that no written responses or data would include any identifying information. Demographic information by the primary investigator and the key for deciphering the identification numbers was, and will be, kept on a password protected database on a password locked laptop. No identifying information other than the identification numbers was written on any interview materials, either regarding the phone screen, questionnaires or full interview, and all materials will kept in a locked cabinet in a secure room. For descriptive clarity, any and all references to individual participants within the body of this document will be performed through the use of pseudonyms.

If eligibility requirements were met, and the participants agreed to continue, they were mailed a packet containing the Vineland-II Parent-Caregiver form, the Attitudes Toward Parental Involvement (see Appendix A2) questionnaire, an informed consent document (see Appendix B2), which included an addendum to the consent procuring

consent to audio-record the semi-structured interview component, and a pre-addressed, stamped, envelope for return. Subjects had the option to use the pre-addressed envelope to return the questionnaires and consent form, or to request that the information be picked up in person by the principle investigator. All six participants, and one other person who opted not to participate in the semi-structured interview, opted to return the packet by mail.

Upon return of the mailed packet, participants were telephoned in order to schedule a formal telephone interview. All interviews were conducted while the researcher was in a private room in order to protect confidentiality of the participants.

In order to encourage participation, all participants who complete the mailed packets were offered a ten dollar gift certificate to Target or Starbucks, regardless of whether they agree to complete a full interview. Additionally, all participants who complete the full interview were entered into a drawing for a thirty dollar gift certificate that was provided at the end of the data collection period

If the participants agreed to complete the phone interview, the primary investigator scheduled and completed the semi-structured, open-ended interview regarding the parental expectations of their level of involvement that was partially guided by their individual survey responses. Starting from after the first interview, responses from prior interviews were utilized to inform upon idiosyncratic domains of inquiry for use in questioning in subsequent interviews.

All interviews were audio recorded by permission of each participant for the purposes of ensuring accuracy of transcription. The audio recordings are only identified

by the participant's unique identification codes to ensure confidentiality. During transcription the researcher removed all identifying information through the use of a pseudonym. All hard copies of the transcripts, audiotapes, survey results and any other data collected was, and will be, securely maintained in a locked location, separate from the location of the identification coding system. All paper data, including survey responses, was stored in a locked cabinet separate from the identification key and demographic information, which were kept as electronic data on a password locked laptop computer. All paper and electronic data will be stored for three years following the completion of the study, and then destroyed.

Data collection. It has been noted in the literature on the use of IPA that, with some small exceptions, the vast majority of studies that use this form of qualitative research methodology rely upon the semi-structured interview for the method of data collection (Smith, 2004; Smith & Eatough, 2007). This is by design. The advantages of semi-structured interview are many, and often produce the type of data most valuable for an appropriate IPA data analysis. Generally, while the investigator will decide in advance what questions can and should be asked, and will develop a loose schedule (Smith & Osborn, 2008) for the interviews, this schedule is seen more as a guide, rather than a strict set of questions to which the course of the interview must be held (Smith & Eatough, 2007). Often the order of specific questions, or whether some of the questions are asked, is fluid, as the researcher may allow the participant to guide flow and focus of the interview at any given point (McCracken, 1988, Smith & Eatough, 2007). In its drive for reliability across participants, a fully structured interview significantly limits the use of probes and questions not previously identified and agreed upon by the researcher.

Conversely, a semi-structured interview, if the schedule is created well enough, allows the interviewer to freely probe interesting areas that arise, and to follow along with the participants' interests in the topic at hand (Smith & Eatough, 2007). This helps to provide the depth of information required for an adequate phenomenological analysis. Additionally, as previously described, the purpose of IPA is often to elicit and expand upon new phenomena, unanticipated by the interviewer. A properly constructed semi-structured interview allows the interviewer to adapt the order and possible exclusion of pre-identified areas of inquiry, and to accept and encourage discussion into areas not previously expected to be explored.

For the purposes of this study, an interview schedule was developed that included broad, overarching questions that allowed for significant flexibility for participants to discuss topics as they saw fit. The interview schedule, as recommended by IPA guidelines (Smith, 2004) and general long-form semi-structured interview guidelines (McCracken, 1988), included a series of recommended prompts that were available for use, if necessary, in order to elicit further depth from participants regarding information already provided. Thus, by design, the interviewer started from the most general possible questions, in the hopes that the participant would find them sufficient to talk about the subject at length. However, the interviewer was prepared for whenever a participant provided a short or tangential reply, or did not understand a question, with more specific prompts. Additionally, the interviewer was prepared to probe into areas of discussion raised by the participant that were not included in the interview schedule. Examples of the overarching and "grand-tour" (McCracken, 1988) questions can be read in the written interview schedule (Appendix A1).

Specific areas of inquiry were identified by the primary investigator through discussion and input from committee members and other professionals familiar with the population in question, as well as from the recent literature on the topic (Blacher, 2001; Cuskeley & Bryde, 2004; Kim & Turnbull, 2004; Seltzer, 2001). These areas were also raised in the Parental Involvement Questionnaire provided in the pre-interview packet (Appendix A2). These anticipated areas of inquiry included:

Transition-related inquiries. Questions in this section regarded: the parents' level of involvement in the planning of the transition; the services accessed during the transition period; parental expectations regarding the transition; and emotional reaction to this period of time.

Resources and support: Questions regarded: any possible sources of support and advice, including those that may have helped the parents prepare for and define their role as a parent following the transition; services that were accessed in order to assist the son or daughter in adapting to the process; and services that were accessed in order to help the parents process their own reaction to the transition.

Changes in role or level of involvement: Questions regarded: any specific differences in the parental role or level of involvement from the pre-transition period; and parental reactions to their change in role/level of involvement.

Future expectations: Questions regarded: parental expectations for their role and level of involvement over the next five to ten years.

Parental level of involvement in specific life areas: Questions regarded specific areas of their sons' or daughters' life in which parents found that they had particularly

changed their role/level of involvement; maintained the role/level of involvement; or were otherwise notable for their role/level of involvement. These specific life areas included: romantic/sexual relations, residential and occupational concerns, financial concerns, health and psychological concerns, and hygiene, self-care, and personal appearance.

It is important to note that for the purposes of an IPA style research study, these areas of inquiry were not intended to guide or describe any themes or phenomena to be identified or discussed within the data analysis. As described below, those themes and phenomena were grounded in the responses of the participants, and at most, guided by the expectations of the primary investigator or any prior theory in this area (Storey, 2007).

Data analysis

The analysis followed the steps set out by Smith and Osborn (2008) and Storey (2007). Following the interviews, the audio recordings were transcribed as best as possible, including non-word vocalizations (e.g. laughing, hesitations, etc.), though prosodic elements of the participants' speech were not recorded. Smith and Eatough (2007) advise that, unlike with a conversation analysis, noting and transcribing prosodic components are not necessary for an IPA data analysis. The transcriptions (see Appendices C1-6), as is advised by all guides of the performance of an IPA, included all of the speech of the interviewer as well as the participants. As noted by Smith and Eatough, audio recording and accurate transcription is paramount to an IPA study.

The first step of analysis occurred during the transcription in which the researcher kept a record of initial thoughts and potential points of interest and significance that were

noted during this initial review of the material. This is a frequently recommended step based on the belief that it may be useful to return to these initial reactions to check against later interpretations that develop following reading and rereading and the subsequent immersion in the material. (Smith & Eatough, 2007). During this process, the notes often included a written description of the researcher's emotional or cognitive response to the material provided by the participants. These notes were deemed to be of import and will be referred to during the description of the results. This was done in order to alert the researcher in acknowledging his own interpretive framework that he would bring to bear during the analysis. This was advised so that the researcher could compensate during the analysis, or at least acknowledge in the writing how his response may have affected the interpretation of the data. This ideally allows for transparency in which a reader may be able to follow and review the researcher's interpretations of the text (Storey, 2007).

The first stage of analysis involved several close readings of each transcript to gain familiarity with the interview content. Following these readings, the interviewer then re-read each transcribed interview line by line and noted individual points of interest and perceived significance. The notes taken during this time were not expected or required by the IPA data analysis to be completed in any particular form, and may refer to content of interest or may involve comments on the participants' use of language or clarifications regarding the meaning of participants responses, even when this may be unclear at upon the first review. These latter notes were often checked against the audible material in order to ensure that the written form of the response is not changing in interpretation when stripped of the emotional valence of the participants' actual speech.

The next stage of analysis involved returning to the transcript, along with the initial notes, in order to transform the notes into more specific themes or phrases. It has been noted by several sources (Smith & Eatough, 2007; Smith & Osborn, 2008) that caution must be used at this point of the analysis to ensure that the researcher's interpretation of the material retains a clear connection to the content of the participants' actual words.

Additionally, during this stage the researcher was liberal regarding the inclusion or identification of possible thematic ideas within the text that could have relevance to the final analysis, given that review and exclusion of irrelevant or incorrectly conceptualized themes would occur later in the process.

The next stage in the analytic process involved a reduction of the data. This is defined by an amalgamation of the themes, and by the establishment of connections between separate but related themes. Researchers performing an IPA are advised to imagine this phase as "a magnet with some of the themes pulling others in, and helping to make sense of them" (Smith, 2004: p 71). It was during this phase that not only did a clustering or connecting of the themes occur, but that a selection of themes also occurred.

This selection of themes is a necessary step in order to omit themes that were previously thought to be grounded within the data. It is a natural occurrence that themes may seem to arise in earlier readings that do not stand up to more rigorous readings of the data. Repeated readings of the interview transcriptions are thus not performed solely for the discovery of themes that were missed upon the initial readings, but also to allow the researcher to check his previous interpretations against the hard data to assess their

validity. During these later readings themes may be omitted either because they do not fit the larger structure that emerges or because the researcher failed to find sufficient evidence in the text to support their validity and, subsequently, their inclusion.

It was through this process of clustering, ordering, and connecting that a discovery and identification of superordinate themes occurred, along with an organizing of the subthemes which help to comprise each of the more overarching ones. These separate theme clusters were given a descriptive theme title (Smith & Eatough, 2007), which serves to convey the purpose and relevance of the subordinate themes included. This organization resulted in a Table of Themes (Smith & Eatough, 2007), in which each subordinate theme was included with a specific phrase or line of text from an interview to serve as an example. It is this Table that served as the ostensible product of the process that involved the constant checking of the text throughout each analytic step in order to preserve the integrity of the actual spoken material in the abstracted themes.

It was only during the organizational process that the researcher began to incorporate prior psychological research and theory to analyze and interpret the data. This was performed as a way of honoring IPA's phenomenological commitment to the data. Researchers have written about the dilemma faced by IPA studies as to when and how much one should apply prior psychological theory to new data. Some researchers (Smith & Eatough, 2007; Storey, 2007) acknowledge that relying too much on prior theory during the development of the themes and data risks shoe-horning the content into theoretical boxes in which it does not naturally fit, and may violate the attempt to describe the data as ideographically as possible. If prior theory was used as a lens through

which the data was understood this was repeatedly checked against the hard data in order to answer the question “where does it say that in the actual transcript?” (Storey, 2007).

Smith and Osborn (2008) recommended two possible routes of inquiry when analyzing more than one interview for a study. One possible strategy that has been found appropriate for an IPA is that the process occurs separately for each of the participants’ interviews, and only following the final development of each individual Table of Themes from each participant that a cross case analysis is performed. The other strategy involves allowing prior analyses to inform upon the analysis of subsequent interviews. What is similar across strategies is that before moving on from one interview to the next an individual Table of Themes for that interview needs be completed (see Appendices D1-6). The researcher in this instance chose to perform the latter style of analysis. By remaining aware of what previous participants had stated, it was possible to identify both what information existed that supported previously discovered themes, and what information was new, different, and possibly contradictory. This allowed the researcher to apply a check to theoretical themes as they were developed, as themes that had been suspected to be generalizable may not have been so in actuality. While the former style of cross case analysis is often performed in order to preserve the idiographic nature of the analytic content, the second still protects much of the idiographic content while also allowing for a consistent and ongoing system of checks and balances for a process in which subjectivity needs be checked often.

Following the final individual analysis, the researcher performed a cross case analysis of the themes. This process included a paring of themes, including omissions of themes that were more individual, rather than generalized across parents. This did not

require identical experiences or reactions to have arisen, but at least that several or all of the participants expressed some information pertinent to that theme. From this analysis, the researcher developed a Table of Superordinate Themes (Appendix D), which was used to guide the final write-up.

Presentation

The proponents of IPA suggest that the final write-up of the data begins immediately following the development of the individual and Table of Superordinate Themes. The literature on the presentation of IPA suggests that the write-up actually serves as the final step of data analysis, in which the themes are further fleshed out and the discussion of each is continually checked against the hard data to ensure validity. (Smith & Eatough, 2007; Storey, 2007).

Additionally, it has been suggested that the data may be presented in one of two ways. The first is that the researcher of the IPA may present the results and the discussion of the results separately. In this format the author writes the results by discussing all of the themes as they arose from the responses of the participants. It is following this full elucidation of the themes that the researcher may then begin to discuss how the results fit into the larger context of the current literature.

The second format suggests that the researcher may elect to write the sections together, allowing for the description of the themes discovered by the current study to be simultaneously compared to the current literature and theory on the topic. The proponents of IPA do not recommend one format more than the other the other. They merely state that either format is appropriate for the final write-up (Smith & Osborn, 2008).

For the purposes of this study, the researcher has presented the results and discussion as one section. This decision was made due to the large amount of data to be presented. This format of presenting the results and discussion simultaneously ideally prevents the need for the reader to repeatedly check between sections to recall specifics of the theme being discussed. Instead, details of the current theme will remain fresh in the memory of the reader as they explore how the theme fits into the context of the current literature.

Results

As noted in the methods section, and in the literature on the topic (Smith & Eatough, 2007; Smith & Osborn, 2008), IPA's format is ideal for several types of research inquiries. First, the style preserves and presents the idiographic experiences of the participants, while allowing the analyst to distill the spoken data into recognizable themes. With this aim, if the analyst can clearly present the connection of themes to the hard data, the IPA may help to identify themes of which the participant may not have been wholly cognizant (Smith & Osborn, 2008). Preserving the idiographic experience is one of the main benefits to qualitative analysis, and a particular aim of IPA research.

Secondly, as noted by the proponents of qualitative psychological research in general (Richards & Morse, 2013), and IPA specifically (Smith, 2004), this type of research is often used in circumstances in which the literature remains sparse, or where theory remains underdeveloped. To this end, the use of IPA requires generalization of themes across participants, insofar as the limited sample size allows. This is assuming that there are themes which can be drawn empirically from the data.

With these dual aims in mind, this section will present the superordinate themes that were found to be relevant across participants. This will include direct quotation of the transcripts so as to allow the reader to assess the validity of the connections between the themes and the hard data. This style of write-up results in a translation of the themes into a narrative account. It is by this process that the themes can be explained, illustrated, and nuanced.

Before the presentation of the themes, the researcher has included a section introducing and describing the participants individually, or as a parental dyad. This will include components of their accounts that help to describe each participant's larger experiences related to the transition period, as well as information regarding their personal characteristics and family situation. This is included in order for the reader to have an understanding of the personal context within which the participants' responses are embedded.

Finally, the results and discussion section will conclude with a brief review of the limitations to this study, as well as possible implications to this field of research.

Participant Descriptions

The researcher has assigned pseudonyms to each of the participants in order to protect their confidentiality. The participants are presented in no specific order, and information that might serve to identify them has been omitted.

Additionally, for the purposes of brevity, some of the excerpts from the transcriptions have been edited. These edits were entirely limited to either omission of certain vocal hesitations (e.g. instances in which the participant said "um," or "uh," and/or ellipses denoting pauses in all speech) or omission of parts of an answer that do not pertain in any way to the topic at hand. The latter edits will be denoted in the text of the results section as ellipses. The transcriptions in their entirety are presented in Appendices C1 - C6.

Anna. Anna is a fifty-year-old mother of Adam, a twenty-two-year old man. Adam is diagnosed with cerebral palsy, visual and physical impairments, and mild

intellectual disability. Anna is also mother to one other typically developing adult daughter who lives independently. Anna was also mother to a third typically developing child who passed away nine years prior to the interview. Anna is divorced from Adam's father and has since remarried. She discussed that although Adam's biological father has contact with him, he has played a minimal role in Adam's life during and after Adam's transition to the residential placement.

Among the participants, Anna was the parent who most recently experienced her son's transition from her home. Adam moved into his group home after graduating from his school in 2013. This comes with a caveat: Adam had previously been enrolled in a residential school four years prior, when he was seventeen. Over those years, he spent five nights a week at his school. That placement was due to his visual impairment and the fact that the school was the best equipped in the state to accommodate students with such impairments. Anna reported that another reason that she sought the initial residential school placement was so that Adam would rise to the "crisis" criteria that would be required for a housing placement following his exit from the school system at age twenty-one. This suggests that she had been planning to find Adam a permanent residential placement for several years prior to his eventual full time move from the home:

Anna: Well my son moved out when he was seventeen. He moved out to be a residential student at the [specialized school]. So that was kind of like a, beginning of him transitioning from where he was, at a regular self-contained special need school, and he qualified, being visually impaired, for the [specialized school], and they had a residential program. I knew that would put him one step closer to receiving the highest level of need when he turned twenty-one.

Anna's overall experience of the process of transitioning her son will be covered in greater detail, as will other parents' experiences, in the section on the subordinate themes, and cross case analyses. However, it should be noted that while she identified

above that the first move was the “beginning of him transitioning,” she noted that the latter transition when he moved out full time was different in many ways, including her own emotional response:

Anna: Yeah, so when he moved to the [specialized school], it was, it was great for him, and it was a release for me. But then with the school, it was just as if I still was fully responsible for him. So if he was sick, I had to go and pick him up. If he had a doctor's appointment I would be the one who had to schedule it and take him. So in that whole sense, I'm still the mom. I'm the one selecting his diet, I'm the one to take him to the dentist appointment or who take him to emergency room, if they need to call 911. It was my full responsibility as a parent, um, even though he was there. Now that he's moved out, it's totally different. All of that is gone now.

This quote also helps to illuminate Anna's general view of the transition from her home. Anna expressed several positive experiences, both in her views of his placement and in how his status makes her feel, but also in how the move has affected other areas of her life. At one point when asked to give an overview of his placement, Anna describes, “hitting the jackpot.” Additionally, Anna expressed a great deal of trust in the staff working with Adam since the move, though she acknowledged that the initial turmoil of change was hard. One can hear aspects of both the initial difficulties and the more relaxed feelings that she has felt since:

Anna: Oh yeah, things have settled down. It was now that he has his-. It's just like throwing three kids, even they knew each other, if you put people who don't know everything about each other, and they're supposed to take care of them. It's chaotic, and the kids don't know what to do and they're unsure. But as the time has gone on and they know the staff now, they know the routine, Adam's routine, of getting up and going to his work, and the van picks him up, then he gets to work he gets a sandwich lunch, and when he comes home, he lays down. So they know Adam when he walks in the door it's "Hey, Adam! Come on let's do this!" And so I don't hear from him. [Laughs]. I'll get a call like "Mom don't come up I'm going to a dance" and I'm like "Ok." So it's just like, he is, he's happy. And so he doesn't need- he's happy without mom being involved as much. And, so I step back and let him go.

Possible reasons for Anna having a largely positive reaction to the transition, while other parents have not, will be addressed in full. However, one insight into her experience may be to recall that she lost a daughter some years before Adam's transition. She discussed that this loss may have lent perspective during Adam's transition, and helped her to feel less anxiety entering the process:

Anna: A little bit of my history so you can understand the way I think is: I had another daughter, Adam's sister, who passed away nine years ago, suddenly. And I have another daughter, and then I have Adam. So, I learned that I had to let go years ago, and that let me know that. You know, you gotta let your kid let go sometime. Mine was an ultimate type of letting go. But it was easier for me to let Adam go because I knew he was there, and I knew he wasn't dead. So, for me it wasn't hard, because it was like, he's still here. It's not like he's gone. And with so many other parents they put them into a group home and they're like, "Oh my god, they're gone." And they're not. You know? They're just not. You can see your child any time you want, but I think that's how a lot of parents react. Because they're so involved in their children's lives that it's just not that way anymore.

Bonnie and Brian. Bonnie and Brian are a married couple that both agreed to participate in the study. Bonnie, sixty-six, and Brian, sixty-eight, are the parents of two adults that are both diagnosed with intellectual disabilities. Their son Bill, is forty and moved out of the house ten years prior to the interview. Their daughter Bridget, thirty-five, moved out just over seven months prior to their interviews. Both children were diagnosed with static encephalopathy of unknown origin, though Bill has also been diagnosed with Autism Spectrum Disorder as a result of the DSM-V changes in diagnostic criteria. The parents viewed their children's functioning as the lowest of any other participants in the study, and their responses on the Vineland corroborated their descriptions of this from their interviews. Both parents discussed how both adults spent years on the waiting list for residential placements despite their children earning their

state's "highest level of need" in regard to placement. Eventually, the family had to take matters into their own hands to push the process along:

Brian: Fourteen years ago they set up group homes. He's in there for almost ten. This [winter month] he's in there for ten years. [Date], he moved in. They opened up the homes in, you might say, stepping stones. They opened up a first and then a second and then a third. He was in the fourth one that was established. Which, my wife and I purchased the house, and donated half of it to the school. The [non-profit] school. And they get money from the [state] from the [state Department of Developmental Disabilities], under contract, under a static contract with the state, to provide services for him and three other young men in that home. It's a four person house. They all have their own bedroom. Bill happens to have the master bedroom, so he has his own bath, if you will. We had purchased the home, renovated it, and then sold half of it to the- or we sold it to them at a fifty percent off of market value.

Brian, who worked in accounting and who previously owned his own business, estimated that in the purchasing and retrofitting of the house, he had spent nearly \$250,000 of his own money, even after factoring in the sale to the non-profit organization. However, following this expenditure on their own behalf, both parents have described a great deal of frustration with the placement in general, and their own level of control specifically. As a result, Brian and Bonnie opted for a separate route for their daughter's placement. They purchased an apartment for their daughter, where she lives with no roommates, and they have served as the de facto "house managers," as Bonnie described it. They have controlled the hiring and firing of staff (which was a major rationale for this alternate residential option), but as they have remained selective in their hiring, are still covering several of the day and night shifts at Bridget's home themselves.

Bonnie and Brian's experiences may be harder to generalize to other parents, including that they have not one, but two children with disabilities, and in that they financed much of the creation of both community-based residential placements. Still, their experiences are noteworthy. First, they are the parents in this study who expressed

the least satisfaction with group-home management and staff. This excerpt from Bonnie's interview captures a great deal of the general tone that colors both participants' responses:

Bonnie: But, I think the fact that they are...in settings that they're accepting means that it was the right decision, for me to make. I'm getting old. I would like a little bit more of a life for myself. Although, I'm not seeing that I'm getting it. I'm not seeing that either situation is giving me the support that I'm comfortable walking away from. Even the group home situation. I mean, I suppose, I could close my eyes to the negative things. I certainly see other parents that do that. It's not my nature. So, I'm not able to do that. I see other parents who must have similar situations that they're dealing with, and have- are just so happy that they don't have the responsibility full time, that they seem to be able to accept it. I have less ability to do that.

Why specifically, Bonnie and Brian view the results of the transition negatively, and why they have not managed to separate themselves from the day-to-day management of their children is not entirely clear. There are simply too many individual factors to attempt to identify one causal factor for this. However, one issue may be that they rated Bill and Bridget as the lowest functioning of the five adults discussed on the Vineland scale. This is important to keep in mind when considering many of their responses as it likely contributes to their reaction. This may be especially true in regard to questions of decision making and locus of control. While it is easy to suggest Bonnie and Brian were more pessimistic than the other parents regarding the capabilities of their adult children, it is likely that they are reacting practically to their son and daughter's lower levels of adaptive and cognitive functioning.

Clara. Clara, sixty-one, is the mother of a son, Charlie, who moved out of Clara's home just less than ten years from the date of the interview. Charlie, now thirty-two years old, is diagnosed with a seizure disorder, intellectual disability, and visual impairments. Clara's interview topics often surrounded an interesting, and impactful change in

Charlie's life since he moved from her home: Charlie's marriage to a woman with Down syndrome, Carrie.

Charlie met Carrie soon after he had moved out of his parents' home the first time. They had met at their job placement. Clara described their rather unique courtship:

Clara: There are people in the field that really try to encourage loving romantic relationships with individuals with disabilities, because it's difficult for them to initiate themselves. So people that support them, a lot times, will help to, if they see a spark between a man and a woman, they will, you know, try to help them get together socially, outside of the workplace. Let them have outlets for romance. And for love. In this community- it was the ARC [City] that I'm talking about. And so, his job coach was saying to him "You and Carrie, you really make a cute couple" And so he literally went up to her one day and said "So do you wanna try the boyfriend/girlfriend thing?" [Laughs], so we thought that was really cute. Several of our single friends have said "I gotta use that line," they say. Isn't that great? So he said "Do you want to try the girlfriend/boyfriend thing" and she said "sure" And Charlie was interested in other women, through the years, but this was different. This he just wanted to be with her. He wanted to spend time with her. It was not just silly stuff. It was- they just became very, very close friends.

Shortly after Charlie began his relationship with Carrie, his first residential placement ended abruptly. There was a house fire in the group home that he shared with two other young adult men with IDD. Following the fire, he moved back to his mother's home, but when Charlie, Clara, and Charlie's father began to search for a new residential placement, Charlie's parents raised the idea of having him move in with Carrie. After prolonged discussions with Carrie's parents, this came to pass. As such, Charlie and Carrie share an apartment in a split level house. Their main residential aide lives in the other apartment within the house, with her own family.

It is important to note that, like Anna, Clara also suffered the death of a daughter prior to transitioning her son out of the home. However, this occurred much more proximally to Charlie's transition than to Adam's. This appeared to have caused

significantly differences in how these deaths impacted each parent's experiences during the transition. For Anna, whose daughter passed away nearly a decade prior to Charlie's move, the tragedy provided perspective during the transition and may have helped her to adjust more easily. This was not the case for Clara. Clara describes that she was still in the grips of grief, and in the process of mourning when her son Charlie requested to move to his own apartment. As a result, she played a significantly smaller role during the transition that she may have otherwise:

Clara: Well, I wasn't, I wasn't mentally ready for him to move out. We had just lost a child to a car accident. She was just sixteen. So I wasn't really ready for him to move out. So I took a pretty backseat. My husband was the one who, who met with the people from the ARC [City], to put together his, his proposal for funding, for his own home. [Governor] was the governor at the time, and he had set aside some monies for transitioning use, and, and for, you know, individuals moving into their own places, their own homes. And so it was a five year chunk of money. And my husband saw that if Charlie was in a mindset where he would be able to easily start living on his own, mentally, that we should move on it. So that's what we did. So my husband was the one who really met with the people from The ARC [City], he was more proactive in it than I was. I just wasn't, I wasn't able to be very involved emotionally.

Despite this early setback, Clara described that she increased her role soon after, and that it has evolved positively since that time. Throughout her interview, Clara presented with largely positive reactions to Charlie's living arrangement. She expressed that her experiences in her own life, and in Charlie's life have been satisfying to her and that she enjoys a positive relationship with Charlie's current staff. She reported high levels of trust in the live-in staff's ability to appropriately assist Charlie and his wife. A prime example of the generally positive view she espoused throughout the interview was demonstrated in her final response of the interview:

Int: Is there anything else that I haven't asked about that you think is important for me or for other parents to know?

Clara: Just that I do think that if you can get it done, it's the thing to do. I have no regrets. No regrets, over any of it. In fact, Carrie's parents were very, very, opposed to the marriage. And we just went to her mother's eightieth birthday party, where she announced to everyone in the room that they didn't want the marriage, and now it's been the best thing that ever happened to her. It's just, you know, I don't have any regrets over any of it.

Clara's interview is an interesting study in contrast to Bonnie and Brian, as both sets of parents have had nearly a decade of experiences since they have had a son move out of the home. Clara's experiences and emotional responses have remained largely positive, while Bonnie and Brian have not been completely satisfied with Bill's placement. Though, as discussed previously, Clara presented Charlie as significantly higher functioning than Bill and Bridget.

Dan and Denise. Dan, sixty-four, and Denise, sixty-two, are the parents of Dylan, a thirty-three-year-old man diagnosed with Down Syndrome, and mild intellectual disability. Dylan moved out of his parents' home a little more than thirty months prior to the interview process. He lives in an apartment with two other adult men with intellectual disabilities, while the other side of the building is occupied by three women with intellectual disabilities, one of whom is Dylan's long-time girlfriend - a relationship which preceded the development of the home itself. The housing apartment is run by a private non-profit organization, and while each resident receives state funding, the house is not state run.

Both Dan and Denise describe an initial difficult few weeks, followed by primarily positive experiences over the following two years. They both expressed feeling satisfied over their decision to pursue a residential placement:

Dan: I think it's a very personal decision, and you know we know parents who would never think of having their disabled child leave the home until it was absolutely

necessary. But as far as anybody sitting down with us, and talking about how our life would be different, how his would be different, or what to expect, no, I don't know of anybody that we actually sat down with. We just knew that it was the right thing for him, and the right thing for us. And thankfully this opportunity came up, which is, you know, not a state funded facility. Cause if we had to wait for a state placement, we'd be waiting years and years and years.

As will be discussed later, both Dan and Denise identified that they have experienced a great deal of personal freedom and relief resulting from seeing their son transition from the home. They identified this freedom as a major motivation for searching for a placement to begin with.

Superordinate Themes

It was noted that across the participants, three major superordinate themes were addressed, some with more variability across participants than others. These themes were titled: balancing independence and protection; the redefinition of the parent's identity; and the practical and emotional preparation and response to the transition itself. These titles were chosen because they most aptly and succinctly describe the information clustered within the superordinate theme. Each theme is broken down into smaller subthemes, each of which are then defined and illuminated further.

Balancing independence and protection. All of the participants described or alluded to, the appropriate post transition balance between protecting their sons or daughters versus allowing for independence. This larger theme of the balance between the two was seen to be broken down among several subthemes, each of which make up the large picture of where parents perceived the balance of decision making power to lie. These subthemes include the decision to search for a residential placement, post-

transition locus of control, and the ways conflicts between parents, adult, and/or service providers were addressed by the parents.

The literature largely advocates for self-determination to be one of the major goals of service providers in working with any individuals with IDD, and especially so with adults. However, as mentioned previously, parental views on self-determination for these adults remains mixed, or largely negative. Pilnick, et al, (2010), discussed how both parents and service providers often verbally support the idea of self-determination for these adults when discussed theoretically, yet equivocate on how strongly to apply it when real-life situations are discussed. The research does not often compare the service providers' view of self-determination and its benefits directly to the views of parents themselves. However, what is not up for debate is that state and federal agencies frequently support or require the use of self-determination in planning the provision of services and decision making in the lives of adults with IDD (NGSD, 2011; DHHS, 2012).

It is interesting that each of the participants at least partially discussed the idea of self-determination for their son or daughter, and their opinions on how it applied in their case. Some discussed the issue directly by name, and some addressed it through the expectations or language they used in regard to the trust that the parents held, following the transition out of the home, in the decision making capacities of their sons or daughters, and, the in case that their level of trust was low, who they expected would take part in the decision making in the lives of their sons or daughters.

Decisions regarding placement. The first decision to be discussed was the actual decision to search out, or to accept placement. The question of who, specifically determined that a move should and would occur was discussed by all. For Anna, Bonnie, and Brian, the decision mostly seems to have been determined by the parents, sometimes at the advice of service providers, sometimes not. Here is Anna, discussing both the decision to place her son in the group home when he turned twenty-one, after his transition out of his residential school (she also mentions, prior to this excerpt, that the choice of school was “purely my decision”).

Anna: For the transitioning into the group home, again, that is up to the parent. You have to first decide what you want for your child. Do you want your child to be at home and get services, or do you want your child to go to a group home for independent living? So a lot of that depends on your feeling as to how you want your child's life to go. You have some input, you know, from teachers, up to where different level of children can go... So it's basically it's driven by the parent. So it's the school will kind of help you as much as they can, you have DDA assisting you and giving you information, and services, and where some are available, but basically it's just pounding the pavement as a parent.

Of particular note is that Anna strongly asserted that this was entirely her decision...as opposed to the school, or the state's decision. She acknowledges that the DDA and other state resources, or school resources, assisted her in collecting information which helped her to make the decision. She presents the situation as if there were two parties who could have possibly been involved in the decision: her, and the service providers. Anna does not, at any point in her interview, discuss the idea that her son may have been involved in the decision. It is not that she answered the question, “should Adam have been consulted in deciding where and how to live” in the negative. His potential involvement in this particular decision did not even arise. This is not to say that she should have involved Adam's opinions in the decision. It is simply an observation that she did not.

Bonnie, and Brian used similar language in discussing this initial decision. Note the language that Brian used to describe the transitions of Bridget:

Brian: I'm more concerned with the trauma to her, in that, when Mom and Dad are dead, I don't want her to have to be relocated at that point in time. So we've relocated her now, while we can still be participants in her life.

And when he refers to Bill's transition:

Brian: Bill, we put in a group home because he needed the socialization. He always did well with other people around, so we tried to encourage the [company] group to put higher functioning folks in the house, which they did, they put two folks in who were higher functioning than he.

The "we" to which Brian refers is he and Bonnie. Note that in each case, the adult offspring are discussed completely in the passive voice, in that they have had the transition "done to them". Nowhere in the interview does he discuss Bill or Bridget being brought in as participants of the discussion, or even their preferences for consideration.

Interestingly, Bonnie, while she uses similar language to talk about the initial decisions to place her son and her daughter, does describe an anecdote in which it becomes clear that she and Brian took Bill's initial reaction to the group home decision regarding *when* to transition him:

Bonnie: I mean we thought he was going to need to transition in a couple of weekends, and then gradually move in. And that was what we were planning on doing. In Bill's case, he spent one weekend, and he was reluctant to come home. He seemed like, "you know, I'm ok here" So we made the decision to move him. He started transitioning the week before Thanksgiving. We were planning on transitioning him over the next four weeks or so. He did so well, right after Thanksgiving we moved him back in on a permanent basis.

However, even in this instance, the language used by Bonnie is one in which her son took a passive role.

Denise, on the other hand, reveals a more even balance between the aspirations of herself and Dan, and the desires of her son, Dylan:

Denise: So, I think because we were so involved from day one, we had a pretty good idea what the vision [for the group home] was going to be, and it matched with what we wanted for Dylan, and what he wanted. He wanted his own place, next to his girlfriend, and I don't know, he was going to take care of himself. And that's what we wanted for him, so it kind of all came together, and we trusted that it would be the right setting.

This is the closest that Denise comes to directly addressing the questions of how the decision to search for placement was made, and by whom. It remains to be seen how she and Dan would have managed the situation if Dylan had been openly against the move and they had been for it, or vice versa.

It is almost exactly this sort of divide that arises for Clara. While Clara mentions that she and her husband had ensured that Charlie was placed on the state list for potential residential placement as early as age twelve or thirteen, for her this was a more theoretical step. In this passage she describes exactly how this theoretical notion of a transition out of the home, became a reality:

Clara: I mean, I mean, my scenario in my head was that he'd be in his late thirties, mid to late thirties, and I'd be going to him like, "Well, it's time for you to move out." I will always embrace that, that he needed to have his own home. But, and then I said to- I thought that he would say to me "what do you mean? This is my home, what do you mean I have to move out?" and then his heart would be broken, and my heart would be broken. Little did I know that he would ever come to me at twenty-one-years of age and say to me and say, "I want to get my own place."

These four separate experiences suggest that the process of deciding to transition out can be fairly idiographic. With Anna, Bonnie, and Brian, the parents hardly raise the idea that their children might have participated in the initial decision to move out. With Denise, she describes that the placement was ideal as it represented what both she and her husband wanted, as well, as what Dylan wanted. However, since there were no contradictory aims between parent and son in this instance, it is hard to delineate the roles each side took in identifying the need for a placement. Then, you have the example of

Clara, in which her son's wishes were the driving force for the transition to occur, though she and her husband had at least considered the idea previously.

It is important to note that Dylan and Charlie's parents reported that they had the highest level of functioning on the Vineland questionnaire. This may have factored into the level of involvement the adults played in the decision on where they would live. However, self-determination as a legislative aim does not necessarily suggest that lower levels of functioning would warrant less involvement in this major decision. And it is interesting that none of Anna, Bonnie, or Brian discussed acquiring input from their children in even the most informal of manners.

This serves to illuminate applicable examples of both the work described in Murphy et al., (2001) and Pilnick et al., (2011). The experiences of Anna, Bonnie and Brian, mirror the descriptions presented in the two articles where the parents and services providers made many of the impactful decisions in the lives of their adult sons and daughters with little input from the adults in question. This was seen even in cases of parents who identified self-determination as a positive outcome for their offspring. However, at least to some extent this balance of power was less accurate in regard to Clara, Dan, and Denise. This may suggest that Pilnick et al., (2011) and Murphy, et al., (2011) may be less representative of the population at large, and that further study into the nuances between families is warranted.

It has also been noted by Riesen (2010), that teenagers and young adults with intellectual disabilities increasingly expect and aspire to living independently from their parents when they leave the school system. Inclusion as an aim of school placement, and

the subsequent modeling of their fellow students, may be a reason that this increase is occurring. But whatever the reason, it is likely that more young adults may place their parents in precisely the same situation which arose between Charlie and Clara. It is interesting to note that in this instance, Clara and her husband actively changed their transition plans they had made for their son to accommodate his wishes. In this sample size of one, Clara's positive reactions to her son's continued successful residence may serve as an example of a successful inclusion of the adult's wants into decisions about his future.

Establishing the locus of control. Once the transition out of the home occurs, the issue for parents is to find where the balance the decision making process resides. The son or daughter has moved out; how, if at all, does the balance between parent and offspring change? Is the adult with IDD expected to take an increased, and increasingly independent role in the decisions in their lives? Or do the parents maintain the role they had while their son or daughter lived in the parental home?

Interestingly, the change in the balance seems less to resemble a two-ended spectrum on which the balance shifts from one side (parental control) to the other (adult control), but rather that a third party (service providers) arrives to at least partially replace the parent on their end of the spectrum.

With minimal prompting, several of the parents gave their views on the cognitive and planning limitations of their son or daughter. For instance, Dan discussed this issue following a comparison he drew between Dylan and his other son, who was typically developing. Dan addressed concerns that due to Dylan's functioning level and the

subsequent level of expectations placed upon Dylan, he would continue to require support throughout his life, even in regard to smaller, less consequential decisions:

Dan: Dylan is always going to need support, and it's just a question of how much and who provides it.

Int: I like how you put that, and if you don't mind I'd like to expand on it. Can you give me an example of how Dylan is "always going to need support"?

Dan: Well, you know, he mentally is, I guess like a thirteen year old. So he's gonna make immature decisions, you know, on a regular basis. He, you know, sometimes deciding to take a day off from work because someone else at the apartment isn't working that day. Or, you know, spending money foolishly, or whatever. It's just gonna be that way.

This is a clear example of a parent, who, as will be shown later, can espouse great respect and pride in his son's level of independence, and report that increased independence is a major goal he holds for his son. Yet, separately, Dan brought up his son's level of functioning and lack of decision making ability to support the need for staff to oversee even small, day-to-day decisions such as "deciding to take a day off from work." This dynamic between theoretical support of self-determination and the belief in the necessity of intervention in real-life, practical matters, mirrors the research in Pilnick, et al., (2010). Several parents demonstrated similar contradictory belief structures. Take the case of Anna, who expressed feeling pride in the great strides her son had made in increasing his own independence while in the residence. Yet earlier in the interview she had, in effect, expressed disagreement and annoyance with the staff being unwilling to overrule her son even regarding issues as small as a haircut:

Anna: Oh yeah, absolutely. I mean I am his legal guardian, so basically, bottom line, I do have say over everything, you know, because basically my son's at the level where if someone says "I need to give you a flu shot" he might say "No", you know? No. and you have the people who are obligated, um, The ARC of [city] is, like, obligated because he is eighteen, over eighteen and he's an adult that he does have his say, with everything like "do you wanna get a haircut?" You know,

"No." "Do you need to get this?" And he'll say no. I'm like, "You what?" And they're like, "we can't, you know, go against his wishes", and I'm like, you know, "give him to me, I'll take him home, and take him to the barbershop to get his hair cut." So, um, you know. My thought is that I have- basically, I will make all the decisions for him, for his life.

As discussed in Pilnick et al., (2010), some of the parents in the study expressed the need for their continued decision making to take the place in their children's lives. In the interviews where this is not the case, they present a desire for the staff to take part of that decision making role. Another example of this is seen in Bonnie's interview. She discussed how she wished for the staff to take more of a controlling role over her son in the new environment.

Bonnie: ...now that in his case, he needs that structure, to contain him and that everybody's got to be on board with it as far as the staff is concerned, because he doesn't have limits if you don't create limits for him. But basically the group home concept is that they're adults living in their own home, and as long as they're not going to harm somebody, they kind of have a lot of leeway, even when it's inappropriate behavior. OK? And in his case the noise, the fact that he repeats so much is part of the inappropriate behavior. He's not physically harming anybody, so it's ok for that. But-

Int: How do you feel about how that's been managed in the group home?

Bonnie: I feel that it's hasn't been managed in the group home. That they've given him more leeway than what I gave him at home. But they say that they have restrictions on [the staff]. As far as how much control they can place on him. We would very simply say to him "if you can't calm down..." He's a big television watcher, he gets very excited for the action packed stuff, and he gets so into it he's yelling and screaming and so forth. At home we would just say to him, "if that's the way you're going to react, we're going to have to shut it off until you calm down." they tell me that that's taking away his right to watch TV. And, I don't agree with that. I guess it could be, but in his case, he needs that control over him. Because he can't do that on his own.

It is important to remember that it is not this study's purpose to take a stand on whether a more restrictive or a more independent environment is more appropriate.

Pilnick et al., (2010) covered the concerns that in many cases service providers and parents agreed that there were realistic concerns regarding the cognitive and decision

making capacities of the adults with IDD. It is simply interesting to note that despite a range in functioning level (Dylan's parents described him as functioning like "a teenager," or, "a thirteen-year-old," while Bonnie and Brian described both of their children as "operating on a preschool level"), nearly all of the parents outlined some areas in which they expected the staff to take on the decision making capacities, rather than their children.

In regard to the balance between the parent's experienced level of control and that of the staff/administration's level of control, the literature has suggested it has been largely one sided. It was discussed in the literature review, that in the past, when large institutional residences were the preeminent option for adults with IDD, that parents frequently experienced their opinions and suggestions as being ignored, often felt patronized (Roos, 1976). Recently conducted research suggests that while parents of individuals who received placement in larger institutions may have felt more respected than in the past, they still experienced a lack of participation in the decisions made in their children's lives or in the running of the institution (Scwartz & Tsumi, 2003). However, both of these sources exclusively discussed larger institutional housing. The questions remain as to the level of participation that parents felt when their son or daughter was placed in smaller, community-based group homes.

Several of the participants in this study addressed this balance between themselves and the staff. Brian spoke about his frustration and concerns regarding the obstacles he faced in participating in the running of the group home:

Brian: Because of our experience with the group home, and, I suspect, we'll get to it later, but I'm not totally pleased with it, because I have no say in the hiring and

firing of staff. If I observe something that's incorrect, I'm expected to go to the manager, and to the assistant director, and then director to get things rectified. And it's typical, I hate to say it, but it's typical not-for-profit bureaucracy.

This example helps to elucidate Brian's distaste in his level of control over the group home staff. This negative reaction to the functioning of the group home staff helped to lead Bonnie and Brian to find and develop Bridget's independent residence when she transitioned out of the home.

Other parents also discussed shock and surprise when they were overruled, or when they were informed that a role they once had played was now under the purview of staff. Anna elaborated on a particularly enlightening example of this:

Anna: Like, I had the nurse call me and the doctor's office called me because of Adam. They hadn't changed his information, and you know, they wanted to set up and appointment, so I set up an appointment. And the house manager called me and scolded me for making an appointment because that was his job. And I was like, "well wait." That was kind of like, I can understand it but, that was kind of a slap in the face, that it kind of might be, that that part of my role was taken away. You're the parent. I could pull him out if I wanted to. I know I have that ultimate decision for my son. But just kind of letting go in that sense of, "OK, all right, I'll not step on your toes with my son, ok." But that was kind of a shock...

Here, Anna discusses feeling shocked, and possibly hurt by the concept that there were things that she was not allowed to do for her son without the oversight of the house manager. It is a part of her role that she finds herself ceding to another party, and not necessarily in a willing manner. However, it is important that she identifies a caveat that this dynamic between her and the house staff is only in place as long as she permits her son to live there. In addition, note that there is a complete omission of her son as participant in such a potential decision as removing him from the group home. Still, even given the idea that Anna believes that she would have final say in the matter of a decision to keep him in or out of the home, it is a frequent theme in the participant's responses that

they find themselves slowly ceding control to staff members, and needing to process their reactions to it.

It is interesting to note that in Schwartz & Tsumi (2003), the authors do not describe a significant emotional reaction, either positive or negative, across participants to the fact that they do not feel as involved in the decision making process anymore. They simply find that participants, regardless of level and frequency of contact with their offspring, report a decreased role. Neither was there a consensus emotional reaction among the participants in this study. As noted, Bonnie and Brian described frequent negative reactions to feeling less involved in the decision making, while Anna found such revelations “shocking.” However, some of the parents reported expecting to have relinquished certain responsibilities in the life of their son or daughter. These parents described a positive reaction to their decreased role, not necessarily due to increased independence of their son or daughter, but rather, to the fact that their son or daughter would come to rely upon and draw practical support in their daily life from the staff. Take the reports of Dan and Denise, for example:

Int: So you said you found yourself, relying more on staff to assist him with some things.

Denise: Well, I mean, they’re getting paid to be there for him, so you know, it was part of their job to offer support services for, so, you know, we wanted him to rely more on them, than calling us every time some little thing came up. And that’s what happened, so, I mean, now we know everything that’s going on, but he does go to staff first for certain things.

Here is Dan discussing the concept:

Int: So it sounds as if, you guys have allowed for the idea that a lot of external supports, or, you know, other services will be able to help him with some of those decisions.

Dan: Yeah in fact, we have found that it's really necessary, because, as parents there are times where, whatever we say to him he just shuts down. No different than a teenager, with a parent constantly telling him this is the right way to do this. So we've found we need other people to, you know, teach him the proper way to do things and etiquette and so forth, so that we're not always harping on it, because then he shuts down.

Int: Ok. And how do you feel about, or rather, you said it's been necessary to allow for others to help him through some of those decisions. How do you feel about that idea?

Dan: I feel good about it, because it works. Whatever works is good.

Int: So the other are helping, you feel that the other people have been helping him efficiently.

Dan: Sure. Between you know, the staff at [Dylan's employment organization] and the staff at the apartment house, he gets a lot of good decisions, and they keep him focused on the right things, and when he does something he shouldn't be doing they stop it right away and it doesn't become an issue, and you know, parents can only go so far, especially parents that aren't there. So, it's very necessary for handicapped child to get that sort of support. Especially for someone like Dylan, you know, who is a high functioning Downs adult. But he's still immature, and will always be immature.

Given that the parents noted a shift in responsibility and decision making control, along with other aspects of their parental role to the staff, it was interesting to hear about the general expectations placed on the staff. It has been acknowledged that practical decision making matters and other responsibilities previously belonging to the parents, are now viewed as the responsibilities of staff. What was interesting to note is what other expectations parents held of the staff, especially in regard to the relations that they had with the adults with IDD. Obviously a parent has a more involved relationship with their children beyond simple caretaking. A parental relationship involves emotional connections. How, if at all, this part of the parental relationship would shift to the staff was an issue that several of the parents discussed. Initial expectations were often that the staff would become "part of the family." These expectations were frequently amended, with mixed emotional reactions on the part of the parents. Take the example of Clara.

Clara discussed her evolving expectations of the relationship between her son and his wife, and the staff at the apartment:

Clara: ...everybody that's been with Charlie for all these years, we've had people, found people that will live. And it's really, it's really interesting because we, both sets of parents, initially wanted it to be like a big family. And it's been found that the individuals that do this work, really they're, they're good. They're respectful of Charlie and Carrie, but they don't want to look at it as a family, they want to do their job. They look at it as an important job, and it is. But, like, they never, we have not found one person, and there have been several that have been there at the house, that like sit down and have dinner together. They, they fix Charlie's and Carrie's dinner, and Charlie and Carrie have dinner and then they kind of do their own thing. So it's, it's different than what I've anticipated. I thought that we'd have a family atmosphere, and we haven't. They're there to support them, and, you know, to do things to help them, and organize them, and keep them safe. But we have not found anybody who looks at it like a family.

As is apparent from a close reading of this particular excerpt, it seems that Clara was slightly disappointed in the lack of familiar relations between her son and the care staff. She, and other parents in the study, discussed that they partially expected staff to almost take the role of surrogate parent in their absence. However, this view, in every parent that brought it up, was frequently tempered by a realization that staff are not expected to be parental. The parents who most frequently espoused positive views of staff are the ones that acknowledged that the staff will not do things as the parents did them, nor will they attempt to have the same type of relationship that the parents had with their children. Immediately after the previous excerpt, Clara expanded upon her experience of the staff's relationship with her son and daughter-in-law. In doing this, she noted that not only does she feel comfortable with the actual level of interactions the staff member has with her son, but that she processed the experience, and has developed a rationale for why such a professional relationship is preferable to expecting a surrogate parent figure:

Clara: But we have not found anybody who looks at it like a family. And that's probably better, because there is a turnover, and it's in every home, everybody that has

their kid, that have their young adults in homes, everybody experiences this. And if, if your son or daughter gets too close, too emotionally close to the person, that's really hard. Change is hard. Change is hard for everybody, but it's really hard for people with special needs. So, this has been more, they have adapted to, they've adapted nicely to... Well she's a nice person, but it's not like the first lady. The first couple of ladies, they [Charlie and Carrie] would call "my [name of aide]," "my girl". They would try to personalize it. And then they just set themselves up for disappointment. So to see that growth in them is really good too.

In this excerpt, one can view the evolution of Clara's views on what she hopes for in a successful relationship between the staff and her son. Other parents from the study were less direct in their expectations of the staff to replace them in a parenting role, but they do expand upon the idea that parents entering into the transition cannot expect staff to do things or help their children in the exact same ways that they did them.

Some parents expected a more professional relationship from the outset. Dan for instance described his expectations when he gave some advice to future parents entering the transition process:

Dan: Yeah, I would say, where your disabled child goes, there will be staff. Ninety-nine point nine percent of the time the staff will be caring, and will do what's best for your child, but you have to recognize, staff is staff, they're not parents, they won't treat your child, and look after your child like a parent would, and the place they go to is not your home, and it's not going to be run like you ran your home. Things will be different.

Int: And, because I would love to follow up a little bit on that, specifically how would you say that's different?

Dan: The reason I made that statement is we know a lot of other parents who have children at this apartment assisted living apartment house, as well as people that have their children in group homes and they're always complaining. "They're not doing this for my child, they're not doing that. This is different. Why aren't they doing this?" And it's mostly, just small stuff and it's because their child isn't cared for like they cared for their child when they were home. So unless you're willing to let go, and understand it's going to be different, you know, you'll have trouble with it.

Some parents, however, were not as positive about the valence of the relationship experienced between staff and their son or daughter, and openly wished for more. One parent, Bonnie, was struggling in processing the fact that staff members may not be tied in as emotionally as she was:

Bonnie: I still know Bill better than anyone else knows him. And I wish I didn't. I wish they knew him better. He's ten years in the group home. I wish they truly knew him better. They don't.

Int: So it sounds as if you were expecting that your role would be lesser than it is right now. What do you think if anything, if you had to guess, has prevented that, or has led you to continue to be the person who knows Bill best?

Bonnie: I think the turnover that they have in home, has a lot to do with it. I think the turnover is a huge problem. I, I think that the individuals, that they hire, that stay, for the most part, that are well-trained, and -thinking people, maybe. It's not just education. It's heart. I don't know how else to explain it. It's not just level of education. It's the personality of the individual, who is dealing with them, as to whether they actually care about the people. So it's a combination of their skill level, and their caring.

It is important to note that turnover has been quoted by both Bonnie and Clara regarding their experiences of staff, and as a critique they have had regarding the ability to create lasting relationships with their son or daughter. However, it is interesting to note that both parents have brought up the fact that they expected the relationship between staff and adult to be stronger than it eventually was in reality. One parent attempted to view the actuality of the relationship as a positive, and the other viewed it as an ongoing negative. What is clear, is that expectations of a more than professional relationship between staff and adult is at the very least optimistic, and often, could possibly be detrimental to the satisfaction experienced by the parent regarding the placement.

However, regarding the larger superordinate theme of “balance between independence and protection,” the only evidence presented so far has been in regard to

how parents expect ongoing protection to occur, between how they themselves will continue to step in to protect. However, a pattern that arose with several, but not all of the parents, addressed the unexpected level of growth that they witnessed in their son or daughter in regard to their level of self-care, activities of daily living (ADLs) or general levels of independence. As discussed in the literature review, the most common reason that parents begin to contemplate and search for placement of their adult sons or daughters is concern over their own health and their capacity to care for their children (Essex, et.al, 1997; Seltzer, et al., 1993). Other reasons for transition were discussed by the parents in this study, and will be addressed later, including accommodating the wishes of the adult themselves, and the parents wishing to reach the post-parenting stage of freedom typically associated with retirement and the moving out of offspring. The growth and level of independence that their son or daughter experienced as a result of the transition, mostly came as a surprise to the parents. None of the parents highlighted that as even a partial reason for seeking placement were to allow for the continued maturation of the adult and their skills:

Clara: He's become more and more independent. When he moved out of our home...he was very much a mama's boy. I had, I had very much...um...uh...nurtured to...over-nurtured, as far as his daily living skills. I didn't bathe him, I mean he was independent in his bathing, as I put down on the survey. Um...he's been independent in bathing, but...um...things like eating, um...he had never prepared, and he still doesn't though, prepared his own food. But he, with the cerebral palsy he doesn't...he can't even cut his own food. So...things had to be done for...you know, cutting up had to be done for him. Um...and I continued to give him everything in bowls, because...he doesn't really use a fork. He uses a spoon for almost everything. He doesn't really manipulate a fork correctly, or didn't. And then he moved out, and others didn't follow up on that stuff, and he had to learn to adapt. I mean, so, he still doesn't cut his own food, but he uses a fork, and he doesn't everything given to him in bowls. He's just...He's just much more, uh, developed, than he was with me. Um... and I think emotionally also, I definitely think emotionally developed. Because he's had to process, I mean he's had to figure things out. He's been left without the...the immediate support that I gave him.

Later, when asked how this increase in independence might have come about, Clara elaborates on the change from living with his mother, to living in an independent apartment:

Clara: I mean, I mean he does stuff that I, that I didn't think he would do, but when asked, because people didn't hold back...and they just, they didn't realize his limitations, or didn't want to realize his limitations? Or I was creating limitations that really weren't there? And so he's doing, so my reaction to this is reflective of how proud he is of himself. Getting the mail! That's the other thing. We get all this snow; he goes out in the middle of the snow. I mean he could have broken a bone, when he goes out to get the mail. No matter what the weather's like, no matter what the pavement is like, he has his job so he's got to get the mail. He's just, it's neat, it's really neat.

Int: Well would you say that, so I guess I'm hearing a couple of notes of this, but would you say you're surprised? Or it's unexpected how independent he would be?

Clara: Yes. Absolutely. Absolutely unexpected. It's a very nice surprise. Nice for him. I concentrated on... I think I concentrated on what he couldn't do.

While traveling out to get the mail may not seem like a major event in defining the independence of an adult, with context, the feat becomes more impressive. Charlie is legally blind, though he has a small amount of vision. Clara discussed at other points in the interview how he often rebels against the supports others expect him to use in order to travel. Walking out to the mailbox, in the snow, no less, is not only a demonstration of a practical independent skill, but an example of Charlie's independent will that he refuses to be dissuaded from completing his household job: collecting the mail. Nor is Clara the only parent to discuss her surprise at the level of independence her son experienced:

Dan: We knew Dylan mentally was a young teenager, and, he would always be a young teenager, and we would have those type of issues going forward

Int: And that view has stayed the same in the two years...

Dan: Well, if anything I'd say it's improved, to the sense that he has really settled in and calmed down and, he's doing better than I expected.

Int: Ok, so it sounds as if there are areas in which he's more independent now in making decisions, and we talked about the small decisions...

Dan: Yeah, and I think he's matured a little bit too.

Int: Are there areas in which you expected more independence, and you find yourself playing a bigger role than expected?

Dan: No I don't think so not at all.

While one would anticipate parents feeling primarily positive emotions in reaction to this growth in skills and independence, it was not exclusively so. While every parent who acknowledged that their offspring had "matured" or increased the level of independence espoused positive reactions, with at least two of the parents, there were also some conflicting negative emotions, specifically, doubt and guilt. Take Anna's response to noticing her son was increasing not only his skills, but his number of interests that he held independent of her:

Anna: But some of the things that were like, well, when we had his meeting after a couple of months, I was like "He likes this, he likes this" and they were like, "well now, he's doing this, and likes this", and I was like "oh really?" So it was kind of like he was, he didn't, just like any child, he's different with other people than he is with you. So he was exploring interests that with me, he would never want to explore. No, no, no. But with other peers, he would become extremely interested in that. And I was kind of like "wait a minute, you didn't want to do it with me?" But then you have to go back and realize: he just didn't. It's just like my daughter: she would do things without me at a certain age. He's the same way. He's at an age where he wants independence, he wants to be with his friends; he doesn't want to be with his parents. That's a hard thing to come up to accept when, he's been your basically your baby for your whole life. So even, more so than your kid going off to college and that kind of stuff. Because he's so dependent on you, I guess that's what I mean. Normal children aren't totally dependent; they can go off and start their own stuff. And you have someone who's so dependent on you. And then they're off for a month, and you see them doing things he never had with you. That's kind of like "Wow was I holding him back?" Kind of a guilt trip. It's a good thing, but it's like, wow I feel bad because he wasn't doing this with me.

Int: One of the phrases you said, "that was really hard." I think you did a good job explaining some of the details. I am very interested not just how you envisioned yourself, but how you've reacted, what you've felt about what's happened. When you said it was "Hard to see that" can you elaborate a little bit?

Anna: Well, It's a parent's- It's like you're starting to feel failure. That you didn't do enough. I think it's a normal reaction. Like with a lot of things it's like "How could I have missed that? How could I have not worked that with him when he was with me? How did I miss that?" And it's the whole as a parent, just this child needs so much from me, and I didn't have enough to give him because I missed that. That was a lot. And that's where he seems to me that, you know, I got a call from his aide the other night, and from his house manager, and she said, "I bought him a pair of shoes, his shoes didn't have ties." and I'm like "Oh god what did you do that for? He's not going to tie his shoes, I tried for years and years and years". And I said "There's no way he'll go for those things" and she's like "You know what, he's tying the first loop." And I'm like "You've gotta be kidding me." So you're like, you feel you weren't adequate as a parent. It's just basically a lot of what I've felt. What did I miss? Why didn't I do more? Why couldn't I figure it out? That's kind of how I've felt with him with that."

There is quite a bit of emotional content apparent in this section. Anna describes feeling guilt, and doubting herself as a mother. She wonders if she was "holding him back," or that she wasn't able to figure out how to teach him things that others were better able to teach. She explains how, considering that Adam was even more dependent on her than a typically developing child, she feels particularly responsible for previous limitations or failures to develop skills. If one returns to Clara's paragraph, those possible feelings of guilt and doubt are equally present in the concerns that she, as a mother, by concentrating on what he couldn't do, "created limitations that really weren't there."

Additionally, there are possible undertones of jealousy or regret in the first response regarding his interest in activities completely separate from her. Anna does point out, probably correctly, that this is a reaction that many parents experience with their child when they start to pull away from their parents. However, what is particularly notable about that passage is the eloquence with which Anna describes how these feelings are likely magnified by the connections inherent in the relationship between a parent and a son with IDD. She had experienced this with her typically developing daughter as well, and she used that experience with her daughter to help gain perspective

on the changes in her son, after the fact. However, it does appear that despite the previous experience with her typically developing daughter, that the experience was more startling and surprising when it happened with Adam.

How and when to step in. The final subtheme that was discovered to make up the larger superordinate theme of balancing independence with protection, specifically addresses how the parents of the adults with IDD identified that they would intervene if and when decisions were made that they disagreed with, or if they felt their son or daughter needed to be protected. Murphy et al., (2011) found that often, even when parents spoke highly of allowing self-determination, there were specifically defined areas in which the parents qualified these beliefs and would overrule certain decisions. With this in mind, two questions arise that were each discussed by the participants: First: how would one overrule the independent decisions of their son or daughter? Second: when?

Some of the parents directly addressed the question of how they would go about managing a situation in which they disagreed with, or were concerned about the decision or action taken by their son or daughter. It is particularly noteworthy of how divergent their ways of doing this would be. Here is Clara:

Clara: I guess it's mostly when I would intervene, would be if I felt that something wasn't safe for him, or something like that. But for judgment calls, or relationships, well, yeah, I would intervene if he was getting into a relationship that was unsafe. There's one, there was one man that they bowl with. And, we sat Charlie down and asked him to "please, don't..." We didn't take him out of bowling, we didn't take him out of that environment. But this guy is known to get really upset and punch people. So I guess my involvement would be to talk to Charlie, and to help him reason through it. We sat down with Charlie and his friend, they're both big guys. They're both very, very gently souls and, we said "just stay away from [other man]. Just stay back. Even though he uses inappropriate language, don't correct him. It's not your role, you know? He could hit you." And I started, I said to Charlie "you wouldn't see it coming, would you?

Would you see a fist coming at you?" "Well, no." And I said, "well, think about that." So, I guess we had to sit down and reason with him.

Here, Clara is sure to point out that she did not step in to remove Charlie from a situation in which he could be harmed, (though her language suggests that she could if she felt it was so necessary). Instead, she “reasoned” with Charlie. It is interesting to compare this to Pilnick et al., (2010) in which the authors describe an interesting dynamic in which parents or staff would frequently use leading questioning styles to assert their ideas and values upon the decisions made by adults with intellectual disabilities. This seems to be an example of that. Still, it is significantly less forceful of an assertion of parental control than the ones Bonnie described with her daughter:

Bonnie: For instance, this morning, Bridget's caregiver called and said that Bridget had urinated on herself, and that she had told her that she needed to go in the bathroom and take a bath, and take a shower and change her clothes, and Bridget was absolutely refusing to participate in it. And she had done her best to motivate her, and then called us to let us know what the situation was, because she said "I don't want to leave her the way she is, because I don't want her, being diabetic to wind up with skin problems". So she called us and Brian immediately went over there to get Bridget to go into the bathtub. Because he will say "Get your butt into the bathtub." Ok? He will override her.

Here is another anecdote that Bonnie recounted shortly after this prior example:

Bonnie: That's one of the things that Bridget does is she [has a compulsive behavior]. She [does the compulsive behavior]... now her [behavior] has progressed ... I won't permit her to do that. I want [items] taken away from her, because it's an inappropriate thing to do. So, my instructions are, "you take that away from her." Her closet is now locked so that you can't do the OCD, kind of behaviors, kind of thing, and we, we're not going to go there if we can avoid it.

In these two examples we hear that Bonnie and Brian still interact with their daughter as a parent might with a young child. While one can see the legitimate need for Bridget to take a shower in the first example, Bonnie’s description of Brian demanding that she “get her butt in the shower,” is stark in contrast to Clara’s questioning of Charlie. It is important to acknowledge the clear differences between Charlie spending time with

another man who has a history of aggressive behaviors, and the immediate medical concerns involved with Bridget urinating on herself. However, in Bonnie's second example, the need for intervention appears less urgent, yet she maintains a similar level of overriding her daughter. She states that she "won't permit" Bridget to engage in her compulsive behavior within her own home. Bonnie's description of the behavior (which was redacted in order to protect the confidentiality of the participant) suggests that it is an obsessive-compulsive, or otherwise inappropriate ritualistic behavior. One would hardly imagine a mother stepping in with such force to prevent a similar behavior in a typically developing adult with OCD or a similar psychological concerns.

Dan was asked about how he would manage a situation in which he or Denise disagreed with something in Dylan's life. Here is an anecdote in which he and Denise involved themselves in a situation regarding Dylan's occupational placement:

Dan: I wouldn't make our own decision, but maybe overrule. Part of the discussion was that he talked about wanting to do office work. He can't do that, he can't type, he couldn't take messages off a phone. He could file, he could sort mail, he could deliver mail, but how much of that is there today? So we got involved to say, you know this really isn't something that's gonna work out, and we convinced him that it wasn't going to work out.

Shortly thereafter, Dan expressed exactly how far he and Denise might go if they continued to feel dissatisfied with Dylan's choices regarding his own level of care:

Dan: Well, you know, if he was being [unintelligible] in the apartment, and not keeping the place clean, or, not eating appropriately, and the staff couldn't work it out with him, they would come to us and we would do what was necessary to get it back on track.

Int: Ok, I was just wondering, because if you would be able to describe, because this is exactly what I'm looking to find. But what would you expect would be an example of "do what is necessary" in some of those instances.

Dan: Well it could be, just sitting and talking, and coming to an agreement with him, that what he was doing wasn't going to work out going forward and he had to change. Or it would be, sitting and saying, "You're not going to be able to stay here if you keep going". And it depended on the situation, what he did.

In this excerpt, Dan discussed the fact that if Dylan continued to disregard their views of what is acceptable, that they would use the final option of removing him entirely from the group home, or at least threaten to do so. It is this example from Dan that perhaps serves to complete the bridge between Clara's almost Socratic questioning style of Charlie, and the complete override performed by Bonnie and Brian. While all parents find their own ways to step in and alter or override their son or daughter's actions, the way that each parent chooses to do so remains idiographic and individualized. Whether one style or tack is more successful or appropriate remains to be seen, but what is clear is that there does not seem to be any one set format of interjecting a parent's control into individual's decisions in their son or daughter's life.

After one discovers how the participants would override their son or daughter, the question remains of when they would choose to do so. The parents in this study outlined certain areas of their child's life in which they felt most strongly that they would step in to protect their child, either from what they felt was poor decision making or caretaking on the part of staff, or to protect their sons or daughters from their own decisions. While these areas of their child's life in which they would overrule were often loosely defined; the parents frequently found that the choice to intervene or step in was difficult to define clearly, and often resulted in a judgment call based on intuition. Some of these areas have already been discussed. Clara gave an example of interceding in regard to a relationship between her son and another man. Bonnie expressed overriding her daughter on situations as divergent as a possibly urgent medical concerns, and a ritualistic habit. Dan

on the other hand described that he and Denise had interceded in his son's occupational placement, and that they would consider doing so again if their son's personal hygiene and homecare grew lax.

However, one area of the adults' lives was routinely discussed by the participants as requiring their ongoing involvement. Dan explained here:

Int: So it sounds that one thing that you've described is that you do trust other people a great deal to help assist him with some things, but I'm interested in this idea that there are some decisions or some areas where you expect that you need to play a role in.

Dan: That's right.

Int: So they seem to be, I think your phrase was "issues of his well-being"?

Dan: Yeah because no one has his well-being more at the top of their list of concerns than his parents.

Int: And so, mostly because I'm trying to get your sense of it, because well-being can be a big thing, I'm interested in knowing how you define well-being.

Dan: His general health. The work he does and how he performs it. If there's a problem we need to get involved in that. You know, if he's going to switch jobs, we want to be part of that to make sure it's being done for the right reasons.

What is hard to tell from the transcript is that Dan takes several seconds between the final question and final response, and then needs time to identify and outline what defines "well-being." While he had used the phrase initially almost off-handedly, and with an air of assurance as if it explained itself, he seemed taken aback by being asked to define "well-being."

What does arise from Dan's response is that he expects that issues of "general health" are an area in which he feels he and Denise should overrule or intervene. It is the

general area of “well-being,” with specific regard to physical health that the participants most universally described a need to intervene.

Anna, for instance, was generally happy with her decreased role and level of contact with Adam. But when asked how her role could possibly change in the future, she opined that the one area in which she might have reason to increase her role, would be medical:

Int: So just a couple more questions. How do you foresee your level in his life changing if at all, in the next five or ten years?

Anna: I think it's going to be about the same. About the same. I think I'll always be involved to the level I am right now, as long as I'm capable of it. I wouldn't be any less. But if he might have to have surgery, then I will be at the hospital staying with him. So then my level of involvement goes right back to “The Mom” [emphasis from participant]. I'd be staying with him every night, and that would not be responsive of... That's when I would take over, that's not- I'm not going to let somebody else do that with my son. So if something like that happens, my level of involvement would increase.

Clara also discussed this topic. As discussed in the participant introductions, Clara generally expressed trust in staff, and respect for her son's independence. She frequently reported taking his views into consideration regarding decisions in his own life. She explains here, however, that even ten years after he has moved out, she is still the person accompanying her son to doctor's appointments, rather than allowing staff to accompany him.

Clara: I'm still involved with Charlie's doctor quite often. My background is nursing, so, I take him to his doctors' appointments, so there are those kinds of things too, that we have to talk to the staff about. And that's just my own preference. She would, she would, in any other home, be doing those appointments but, that's just my own... With the seizures, Charlie still has ongoing seizures, so I... It's not just the neurology though. He has nerve, nerve problems in the eyes that causes the blindness. Causes him to be legally blind, and this particular problem can lead to more, more issues. More blindness. He could lose more and more vision as he

gets older. So far he's been stable and he's thirty-four, and that's awesome. But those kinds of his medical issues like that I like to stay on top of.

Bonnie and Brian, on the other hand, reported not accompanying their son to medical visits. They did not address the concern in regard to their daughter, but given the level of control they have exerted over her placement, it is likely that they still participate in this area of her life.

Bonnie and Brian did discuss that one major area in regard to Bill's physical health that they find themselves speaking up and making staff aware of their concerns, is in the area of their son's diet. In Bonnie's interview, she mentioned that she wanted the staff to step in to take more control in regard to Bill's food selection:

Bonnie: It's like I was talking to his substitute house manager yesterday, about, Bill. You can't allow him to have too much of certain foods, because he'll overeat them, and then you'll have a problem with him having diarrhea which will also become a problem for Bill. So Bill doesn't understand that, so you have to understand that, and control the situation. So yes, we will override, he, he can't have three apples, he can only have one or a half of one, or whatever works best for his system. So, in that regard, if we have a manager that is willing to have conversations with us about it, we will do the same thing.

Bonnie discusses how Bill's diet may cause her to "override" him here. But this override seems to be defined as having a conversation with the house manager in order to affect change. Here is Brian, discussing his similar disappointment in his level of control over his son's diet, and how that compares to his daughter:

Brian: I believe that he's secure. He's reasonably well fed. Although we have conversations over diet all the time. Dietary needs. You know? It's kind of an ongoing battle, as to what they, expect and what I expect. They win, because they control it.

However, this quote does more than reveal Brian's concern for his son's diet. It is a window into the way he views his relationship with the housing staff and management.

He throws his hands up at the idea that the management “win” because they control that aspect of his son’s life.

But even in the domain of medical care, the parents’ responses were not completely identical. Two parents discussed possible decreases in their role in the medical area of their offspring’s life: Anna and Clara. Earlier in the interview, Clara discussed how she preferred to stay on top of Charlie’s medical appointments. However, as she discussed Charlie’s growth since leaving her home she equivocated. Here, she recalled an incident in which her son asserted his independence, interjecting himself into a conversation between Clara and Charlie’s doctor.

Clara: This doctor would turn to me and say "how has his year been?" And, finally Charlie said, I turned to Charlie and said "Charlie, would you like to tell Dr. Blah-Blah how your year has been?" And I'd redirect, I'd do it with all of his doctors. But this time, he did it again, he spoke to me, but Charlie leaned in front of me and said "My year has been ok," and then he started this whole conversation, and I thought "that's awesome [laughs], he just took it over! He just did it."

Later in the interview, Clara stated that she might “need to pull away...and have other people take him” to doctor’s appointments. This appears to have been a speculative idea rather than a premeditated plan, and it from her responses it seemed she may have developed this notion during the interview.

Meanwhile, it was Anna, the parent to most recently transition her son out of the home (Bridget had transitioned out more recently, but this had been Bonnie and Brian’s second child to do so), who seemed most apt to relinquish her control over this area of her son’s life. While she acknowledged that only a medical crisis could cause her to increase her level of involvement and control over her son’s care, she also was the only

parent who noted that she allowed for others to schedule and attend her son's medical appointments:

Anna: Now that he's moved out, it's totally different. All of that is gone now. I can not [choose not to] make doctor's appointments. I do not have to go, you know? If he's sick, he would not come home, he would stay there, and an aide will take care of him. So it's like totally my parenting in the nurturing is there, but with taking him to the doctor, that's all, you know, what they do for him.

In Anna's relinquishing of her direct involvement in the medical concerns of Adam's life (she did state that she would expect to be "kept abreast" of all medical issues), one can see the main question addressed by the parents in regard to this theme: wherein lies the locus of control over aspects of the adult's life? Anna does not expect that Adam will begin to schedule and attend his own doctor's appointments. Rather, she expects that others will assume the role that she once filled in this regard. Bonnie and Brian describe, unhappily so, that staff and the group home management make decisions in their son's life that they do not agree with, not that he is making such decisions himself. More positively, the fact that their son relies more on staff than his parents comes as a relief to both Denise and Dan. It is what they expected and desired when they entered the process. Even Anna, whose son, Adam, had been residing in his group home for less than a year at the time of the interview acknowledged that for as long as he is under their roof, she must play by their rules. She did, in her earlier excerpt, acknowledge that ultimately, she would be the one to decide whether her son would stay under that roof. However, this only goes to further demonstrate that the balance between independence and protection, in the experiences of these four parents, has not changed as much as likely would be the case with a typically developing child. Several of the parents discussed how, their child grew more independent once they moved from the parental

home. However, the major shift in the dynamic seems to be described as a handing off of the ongoing protective role to staff and management, rather than a transition of a child into their adult, independent life.

Redefinition of the parent's identity. In addressing how the parents have seen their identity change following the transition, three main subthemes arose. The first addresses what remains of the relationship between parent and child following the shift in practical responsibilities to staff and management. In the second, the parents addressed how their own life changed as they separated from their child; how they established their personal identity during and following what Carter and McGoldrick (1997) labeled "the launching stage." Finally, the third subtheme addresses how often, and in what forms the parents contact their son or daughter.

Before delving into the information provided by the participants, it is important to delineate between this second superordinate theme from the first, in which there was a great deal of discussion of the day-to-day responsibilities of the participants. In discussing who would take their son or daughter to the doctor, the parents focused mainly on the outcomes for their adult child, rather than themselves. In discussing the state of their relationship with their child, the parents spoke more to their own status. This focus on the parent, rather than the offspring is what delineates most strongly the line between the first superordinate theme and the second.

The ongoing parental relationship. Perhaps the most eloquent description of what is meant by the first subtheme of the shift in the relationship was provided by Denise:

Int: That's fine. Can you describe how you personally reacted, emotionally, if possible, to the transition period itself.

Denise: Well, I didn't find it terrible, I was really happy, I go back to a promise that someone made to me, years, and years ago. They had the older child, the more medically involved child than we did, and she said, we were talking one time, and she said one time, "I just want to be mom, and not mommy anymore," and I looked at her, and I knew exactly what she meant. When the, the child still needs you for a lot of day-to-day things, you're the mommy, and it's not until they start getting older, and start becoming more independent that you become the mom. Do you understand what I'm saying?

Denise continues later to explain that she had looked forward to "not being mommy," anymore, but becoming "mom". Later, after discussing how she intends to still attend Dylan's doctor's appointments, she uses the phrase "I'm still his mother," which she was asked to expand upon:

Denise: You know, well, if I go over to his apartment, and I see that it's not as tidy as it should be, I'll say something. You know, if I see that his toenails need clipping, I will say something, about that. You know, it's kind of funny, because I never say that stuff to my other son but I do to Dylan. So the other guy can take care of it by himself, but Dylan, he still needs reminders, so, you know, you're still, you're still the mother, just making sure everything is being done the right way, you know? I talk to staff, and make sure everything is OK from their perspective. I mean, you, you know, my mother once told me "it doesn't matter how old you are I'm still gonna be your mother" He's still, he can be fifty years old, and you're still the mother. So, you know, you want things to be right for them, you want them to be somewhat easy for them, and if you can make it easier, or make things better, then you do it, you know.

The final sentence here is particularly valuable. First it helps to encapsulate the delineation of this subtheme from the prior superordinate theme. It entails more of an emotionality of response than simply explaining how one would expect a decision to be made, and whilst addressing the topic of protection and independence, it does specifically address Denise's maternally protective instinct towards Dylan; her personal urges and desires to protect, not how she goes about protecting. Interestingly, Denise echoes, nearly exactly, a sentiment that Miller describes as making the separation stage difficult, especially for parents of individuals with IDD: "With a child who is challenged in any

way, there is a greater tendency for parents to hang on and to protect. You know the world is going to give her some hard knocks, and you want to postpone her frustrations as long as possible (Miller, 1994; p 83).

Additionally, Miller covered the topic in her description of what occurs “after separating.” She states “separating from your adult child does not finish your parenting... Depending on the extent of her independent living skills, and the community resources available, you may have to continue to be involved and responsible for finding or providing for some of her care,” (Miller, 1994; p 90). Miller also goes on to describe the separation stage thusly: “letting go is a sense of freedom from parenting (Miller, 1994; p 90).” Miller’s ideas about the ongoing, yet changing roles regarding parenting are what is explored in this subordinate theme. While parenting continued to occur for each participant, how did the socio-emotional charge of parenting change, if at all?

Whether the other participants felt a similar change in their relationship to their child is of relevance to this paper. Miller’s book describes an ongoing but changing role as a parent, which is echoed by Denise in her interview. Is this an experience that is felt across parents, with sons or daughters with significantly differing levels of functioning?

Brian did not give as much of a title to the role he now inhabits, but he did go so far as describing his type and level of interactions he continues to hold with his son and daughter:

Brian: To be very honest with you, I always expected to be involved, to be honest with you, to some level. Even if it was taking Bill, picking him up once a month and taking him for a haircut. I always expected to do, to do that. There are some parents that, you might say, dump and run. I mean there's parents of kids in the group homes that I know of that have left the state, because, to quote, "I don't

want to pay taxes in NJ." And I say, "Well, who the hell do you think is going to support your kid for the rest of his life?"

This is about as emotional as Brian grew during the entirety of his interview. He frequently expressed incredulity and exasperation at the affairs of the state he lived in and what he perceived as the state failing the population of adults with IDD. He expressed similar frustration with his son's group home specifically. But through comparison of his feelings towards other parents, we perhaps can see a small glimpse into how he views his ongoing relationship with his son. His emotional tone in this response towards "dump and run" parents, can be described as disgust. Brian cannot imagine abandoning his son to a similar situation. Later, he goes on to label his current relationship with his son as "social" while establishing that he ideally will see a similar level of relationship with Bridget as he is able to develop her apartment and her staff.

Clara didn't go so far as to entitle the how her relationship had changed either. However, she did draw comparisons between her relationship with Charlie, and her relationship with her other daughter. Here, Clara addresses how much she was involved in helping Charlie get through the difficulties he faced during the first few years of his marriage to Carrie:

Clara: And so, you are involved as a parent much more than you would ever be with a person without disabilities, just because of the nature of the beast. Like my daughter has been married for fifteen years, and, I know that she and my son-in-law disagree and have issues...but I will know when things aren't great, if they're having difficulties, but I know none of the details, absolutely none. Because I, I had the freedom in the beginning to say "I don't want to know details about it, because I will harbor resentment, and you will get over it, and you will go on, but I will harbor resentment towards him, so I do not want to know. Unless you're in an unsafe situation, then I want to know." So I have the freedom allow her to resolve things. Whereas with Charlie and Carrie, and her parents know so much more than they ever wanted to know to. But they talk to us about absolutely everything. And they need help processing what's going on too. So yeah, the first couple of years, they were tough for all us.

Clara describes how, as a parent of a son with disabilities, she continues to provide a great deal of emotional support to Charlie to assist him in managing his romantic relationship, more so than she would with her daughter for instance. Specifically, Clara explained in this interview, that she and her husband scheduled weekly dinners at their house for Charlie to be able to come over and discuss his marital concerns away from Carrie. They described that these dinners were initially intended to last only a short time so that Charlie could “process” his difficulties in the marriage. However, they allowed Charlie to decide when and if he would like to cease the dinners, and he hasn’t to date. The relevance of this passage suggests that Clara and her husband played a more emotionally supportive role than they have with their other child, a role which encroached upon areas of Charlie’s life that Clara suggests she wouldn’t have discussed with her daughter.

Before moving on to other examples of how parents redefined their relationship to their adult children, it should be noted that Clara was not the only parent to draw comparisons to their other children. All of the participants who had at least one other, typically developing child, raised some form of comparison. As with Clara, all the participants pointed out that while some small similarities occurred, the differences far outweighed the commonalities. Dan was the parent who most staunchly denied the idea that experiences with other children could be helpfully compared to this transition:

Dan: Our level of involvement, with his brother is a lot less, but you know, he's much more capable and responsible.

Int: Can you give me an example of how, an area in which it's less for his brother than for Dylan?

Dan: There's no comparison. It's like comparing the young teenager with the adult.

Int: So I know it's going to be difficult, but I'd like to try to expand it. Can you think of one example of a decision or a part, of [Dylan's brother's] life where your level of involvement is completely different or a little different, or anything?

Dan: Every level. He doesn't call every day; he doesn't call and say, "[staff] is having a membership meeting, should I go?" He doesn't call and say "I got paid today, here's what I got." He doesn't call and ask about what to wear to this affair. I mean it's totally different.

Denise, for her part, echoed Dan in how her relationship with Dylan differs from the one she has with her other son.

Denise: That's definably a good question, because in [Dylan's brother]'s case, especially now that he's married I will never tell them how to do something, but if they ask for my opinion, which they occasionally do, I will give it to them. With Dylan I don't wait to be asked, I just tell him what my opinion is. Because, yeah I still feel that, he needs guidance, he needs to be pointed in the right direction, whereas with [Dylan's brother], if he's coming to us with a question, you know, it's a little more heavy, it's a little deeper. I mean he's living in [European city] now, so he was going to [European city] whether or not we agreed with it or not, but he did ask us, "what do you think about us going to [European city]", and I mean my husband started, with "Well the job experiences that you're going to get are wonderful" and I said "well you know, you're going to a different country, so you have to think how your life is going to be different over there." So generally it's an, if I'm asked, I'll offer some of what I feel with him, but with, you know, with Dylan, we are always still giving it, whether or not he wants to hear what we're giving to him.

Anna, for her part, equivocates. She brought up the idea of having a child go off to college as a touchstone several times. Often she used it as a comparison as to how such a transition is different from the one she experienced with Adam. On one occasion however, she used the experience of seeing a child off to college as a metaphor for her experiences of having Adam occasionally return home, and her response when he does.

Anna: Yeah, I mean, it's good to see your child bloom. It's good, you know, when you have a child who goes away. And after their first semester of college and being away from home, they come home a little bit different, a little bit more mature. First they fall back in to the role, they can't do their laundry, they can't cook their own food. But you see a difference in them, and that's extremely satisfying because it makes me feel I did the right thing for Adam. That's, that's a good feeling when you feel you really done something right for your child, and really feel that this was the best thing for him. And that makes you feel good. That I got it right.

Thus, it seems that while several parents did not feel that there were relevant connections between the launching of a typically developing child and a child with IDD, some parents may find useful similarities. Bonnie and Brian were the only parents who did not also have typically developing offspring. But Brian did compare his own launching from his parents' home with the transitions of his children, and reported that he felt they were "comparable, or parallel". However, in the same response, he explains that Bonnie still purchases his son's clothing, and has not yet removed himself from his daughter's care. While there are exceptions, the majority of responses suggested that the transition period for a typically developing child, and a child with IDD were very different. This is information that could be valuable to other parents approaching the transition. It may help them to avoid making inaccurate assumptions based on experiences with their other children. At the very least, it would suggest that the parents should draw these assumptions carefully.

Returning to the question of just how the participants viewed their relationship with their child as changed, two parents, Bonnie and Anna, expressed not only how the relationship changed, but how they felt about the change they experienced. Here, Bonnie recounts that she has noticed stark differences since her son and daughter have moved out, though unfortunately her emotional reaction is not entirely positive:

Bonnie: Well, both of my children, the fact that they have moved out has distanced me from them. In that they are not as warm and loving towards me. And, I try to be with them, but they are really, their perceptions, Bridget's are that I'm still Mom. I'm more of the caregiver that moved on, because I'm not the direct care person anymore. If that makes any sense. That was difficult for me. But, I think the fact that they are in settings that they're accepting means that it was the right decision, for me to make.

It is interesting that Bonnie, who earlier expressed negative feelings toward the fact she still knows her son better than any staff at his house does, also describes that a more distant relationship with her children is difficult for her. As contradictory as this may sound, theory on the transition suggests that it is understandable. The separation stage, is fraught with several conflicting emotions. As Miller (1994) pointed out, letting go can be freeing and positive for parents, while at the same time apprehension towards the change can be frightening. Bonnie's responses illuminate a similar conflicting emotional state. One that highlights that the relationship, while remaining parental in many respects, changes in emotional valence.

In an earlier excerpt, Anna described that "my parenting in the nurturing is there, but with taking him to the doctor, that's all, you know, what they do for him." Later, she goes further into how and why her relationship with her son has changed:

Anna: So that was difficult in that he had gained such independence when he was living in school with friends, and then he had to come home with mom. And although he loved Mom, he wasn't happy. So having him now at his group home all the time, I don't have to deal with him not wanting to be here. And that when he does come, he wants to spend time with Mom, and he knows he's going back to his friends. So for me, it's a really good thing, because I feel that it makes him, he's happier when he's more independent. And the happier he is the happier I am, so it's been good for him and it's been good for me because I have my life back, basically. After twenty-one years you really devote to your child, and everything revolves around them. I mean everything revolves around your children, but a special needs child who really has no other, he can't do it on his own.

Contrast this response to that of Bonnie's. Here, Anna described a similar decrease in the role. She described that her son "knows he's going back to his friends," and though he spends less time with her, he seems to enjoy this time more, and by extension, so does she. While Bonnie mentioned that her daughter and son have "distanced themselves" from her, did not elaborate on how they seem to feel about this,

only that such a change has been difficult for her. Most important is that despite a shared experience - a decrease in emotional connection, one that seems to be initiated by their children – the parents react very differently. This suggests that while parents entering this process could expect a similar change in their relationship with their son or daughter, from this sample there does not appear to be cross-case agreement in how positive or negative this experience might be.

Life apart from their child. Anna's response also helps to illuminate part of the second subtheme to be discussed in this section: the participant's redefinition of themselves apart from their adult children. Anna describes here that after twenty-one years, she "has her life back." She expands upon it later in the interview:

Anna: My whole where I went and what I did was tied to Adam, and that's not it anymore. So I have this tremendous freedom of being able just to be myself again. And I do thing I haven't been able to, because of raising Adam.

Here she begins to define what it is like to be "Anna" post-transition. These sentiments of freedom, and parents getting back to "themselves" were actually quite common.

As presented in the introduction, there has been research performed on parental reactions to their life with "empty nest" or as is defined in Carter & McGoldrick (2005), during the "launching phase". This research has suggested the launching of children into adulthood, and the subsequent decreases in parental responsibilities, is a largely positive experience (Blacker, 2005; Neugarten, 1991; Rubin, 1979). Blacker (2005), specifically suggested that one of the main components of this positive experience was the parents' ability to discover an identity apart from their children. However, there is little research

to assess how much this may apply to parents of offspring with IDD. This is the question that was addressed by the participants in this subtheme.

In this case the prior research on the launching stage was still very accurate: the results were largely positive. As with Anna, who described the relief of “getting her life back,” all of the parents who felt that they had been able to adequately decrease their level of day-to-day involvement regarded this as positive. Frequently this included an increase in personally pleasurable activities, the most common of which was travel. Each of the participants mentioned that they had engaged, or planned to engage in travel that they would not have been able to do whilst their son or daughter was still in the home. Dan and Denise completed their interviews after returning from a three week long European vacation, which they identified as the second vacation of such length in the two-plus years that Dylan had been out of the home. While Clara acknowledged that she and her husband did engage in frequent travel while Charlie still lived with them, she described how the experience had been different following his move out of the home:

Clara: Well, we've been able to travel. Which we've absolutely loved. It's been really a wonderful thing for us. We really enjoy traveling, because, we feel so comfortable with, the security that he, with the quality of people that are in his [Dylan's] life. And he when we would travel, in the past, would really have a hard time. He'd be, he doesn't act out. He's not a hyper kind of guy at all, but he'd be depressed. He'd just basically be depressed and he wouldn't eat well, and he'd really have a tough time. But that's been great for us, for our marriage, to be able to do some traveling. It's been really nice. We were never able to do that.

Anna, for her part expressed that since Adam had moved out the home, she had been able to spend significantly more time at a vacation home she had on the coast. In doing so, she also explained how travel, additional leisure time, and relief from Adam's

in-home behavioral concerns were also positively affecting other relationships in her life, especially with her second husband.

Anna: I enjoyed it. It was the level of stress in my life tremendously decreased. I mean, because when, it was almost like fringing that, um, what was I going to do with him [Adam] this weekend? What was the deal now? What was I going to do to keep him happy? I mean he's up at six and he doesn't want to go to bed until ten...

Int: That's OK, you just said how you had to act when he was still living at home about being up at six, and wouldn't-

Anna: Oh yeah, so it's stressful. And then my husband, who was very good with him, but it was like, he had a different threshold level, than me with my son, because that's all I knew. He didn't have a special needs child, so I was stressed about his reaction, when he was actually fine, yet I was stressed about making him happy, making Adam happy, because Adam wants "Mom." He, you know, wanted full one hundred percent attention. And, you know, when you do that, when you work full time, it's exhausting. It's just totally, totally exhausting. so, it was a relief, and less stress because you're not having to deal with, you know, that anymore. That was great. That was to me, it was a major independence.

Anna suggested that the independence she felt after the transition positively affected other relationships in their lives, including her marriage. Clara echoed this sentiment in her prior excerpt.

Meanwhile, consider the current research, which holds that parents of children with IDD experience less positive marital adjustment, more marital discord, and higher rates of divorce than do parents of typically developing children. A meta-analytic study performed in 2004 suggested that while these effects were less powerful than had previously assumed, but that they did exist (Risdal & Singer, 2004).

In this study, there were no direct references, besides the one expressed by Anna in the prior excerpt, by any of the participants as to any negative effects on marital-satisfaction from raising their children. Furthermore, out of the six participants, all except

Anna were still married to their first spouse, who was the biological parent of their child. Additionally, while Anna did report that Adam's biological father was only "semi-involved" in Adam's life, she made no allusions as to Adam's upbringing affecting her first marriage. Obviously, as with any conclusions drawn from this study, the sample size limits the ability to directly refute the results of other, larger, quantitative analyses. This was a small sample size, and it is possible that the participants would have felt reluctant to discuss marital discord in the course of the interview.

On the other hand, parents were willing, without being directed to do so, to address their marital satisfaction. As can be seen with Anna and Clara, the parents in this study did report positive marital satisfaction following the transition. While Denise did not directly address a change in marital satisfaction, she did mention how it was "nice to just be two adults in the house again, like it was thirty-five years ago." She also suggested that marital satisfaction could possibly be tested in the wake of an adult child leaving the home:

Denise: So, you know, a lot of people I've seen after their kids go off to college, they sit there and they look at each other like, "what are we going to do?" And I don't think that's different whether you have a normal child or a disabled child. Hopefully you have a good marriage and you enjoy being with your husband again, hah, and doing things together and also doing things separately.

This quote gets to the heart of another matter as well: how the parent chose to fill their time apart from the child. Dan and Denise both discussed how much open time they had since the transition. They largely described this as "freedom" from having to transport Dylan to his activities on a daily basis. To give you an example of how large of a change that Denise felt this "freedom" was, consider this the following: at the end of each interview, the participant was asked an open ended question regarding what would

be the most valuable advice they could give to another parent entering this transition period. While Denise addressed several other concerns in her response she opened with the following:

Denise: Well the biggest thing that I would say to any parent is after your children leave the home, you have to have your own interests. You have to have hobbies or activities or volunteer work, or something you enjoy doing to fill your days. Because once the kids are gone, your schedule totally changes, I mean, gone are the days of, you know, baseball games and soccer games, plays and everything else.

This discovery, or rediscovery, of alternate interests is often described as one of the key changes for parents of any child, during the launching stage (Anderson, 2005; Blacker, 2005). Denise clearly concurs. As discussed above, nearly every participant expressed that they had either chosen to travel more, or planned to travel more. Other experiences were notable. For example, Brian explained that he had increased, and planned to increase further, his participation in parental support groups, and political advocacy efforts in support of adult disability services:

Int: What would you say is the biggest change in your life since they've moved out? Or how has, not necessarily the biggest, but how has your life changed since they moved out?

Brian: I have more time to, to do things that are more important to me, than child care. I mean, I guess I say I spend more time, in community involvement, in the disabled community involvement. I can go to more meetings. I mean, I'm not divorced from it because I don't ever expect to get away from it, as long as I have a big mouth and I think I can change things. I'm now putting together a strategy to call on the politicians to try and educate them. Because the bureaucrats don't seem to go anywhere. They just totally ignore you and do what they want to do. So, it, it's, I think it's going to have to come from the legislature telling them what to do. I also have an opportunity to play golf. That I enjoy. I started taking art lessons after Bill moved out, so I have time to do that. I have more time to do what I want to do.

As was noted in the participant introductions, Brian and Bonnie expressed more frustrated and otherwise negative emotions regarding the services they have received for

their son and daughter, not just in the transition out of their home, but since the time that their children aged out of the school system. Despite this frustration, Brian expressed an actual increase in his level of effort in pushing for legislative change and systemic overhaul since his son and daughter moved out. Brian spent several long passages of the interview discussing the flaws as he sees them in the system, and instead of throwing up his hands, he seems to have used large parts of the free time he gained since Bill moved out to stay engaged in advocacy for disability rights. At the very end of the interview, he describes that doing so makes allows him to not feel like a passive participant in the larger picture.

Levels and types of contact. However the parents spend their free time, all of them were quick to note how they have not removed themselves entirely from their child's life. Each parent discussed to some extent how frequently they actually contacted their son or daughter. In the Schwartz & Tsumi article (2003), the authors discovered that the parents reported consistent level of contact across time, and found that the parents had direct contact with their son or daughter (defined as visitations, either parents visiting offspring, or vice versa), a little more than once a month on average. This study's sample size limits its ability to refute or support such claims made by quantitative studies. However, this study addresses a population that is different from that of Schwartz & Tsumi (2003), which only studied parents of adults placed in larger institutions. Thus, a qualitative analysis of the level of contact need not defend or refute their claims, but only to discuss possible trends or phenomena in the rate of contact among adults living in community-based housing.

Each of the participants addressed the specific level and type of contact that they had with their son or daughter. Anna reported that she had already, in the short time since Adam had moved out, decreased her overall level of direct contact with him:

Anna: So for me, I'm not going out there as much. I talk to him on the phone whenever, so I'll call, he'll call me. He likes to get letters. I mean I'm not up there twice a week anymore, I'm up there once every two weeks.

At the time of their interviews, Bonnie and Brian still served as “staff” or direct caretakers for Bridget in her home several days a week, though they stated they were continuously looking for staff to take over all of the shifts over the following months so that they could fade themselves out of the direct care role entirely. In regard to their contact with Bill, Brian noted in an early excerpt that he has reduced his contact with Bill to twice a month for what he views as largely social visits. Bonnie for her part described her level of contact thusly:

Bonnie: I see Bill maybe once a month, if that. He really, since he's moved out, seems very happy with that type of an arrangement. He usually comes home on the holidays. I find the half of an hour a little bit more than I like it to be. It becomes a challenge, because it's really an hour, each way. The ten minutes with Bridget work much better. I see her, in my case, probably four times [days] out of seven in a week. And it's partly that's because of transitioning too. We're filling in shifts. Ok? I don't anticipate that when she's fully staffed that we will have that much contact. But personally, it's not just seeing Bridget. I think it makes a difference for us to see the staff.

While the information that Bonnie provides about seeing her son perhaps once a month, and her daughter, several times a week is valuable, there is another point of interest in this excerpt. Bonnie expresses that she sees the thirty minute trip to see Bill as almost too much to manage in-person contact more than once a month. One of the issues that the researcher hoped to explore in entering this study was to find out if the parents found they were more likely to visit the home of their son or daughter based on the fact that they were located in the community, thus, likely closer than if the son or daughter

had been transitioned to a larger institution, further from home. To some extent, the participants did discuss distance from their son or daughter, or how long it took to drive to the residence, and occasionally noted it as a reason for their rate of contacts. Denise discussed how the physical closeness affected their level of contact immediately following Dylan's move:

Denise: You know, again, we're only three miles away, so if there was something, we could be over there in five minutes, and take care of what needed to be taken care of.

Int: There were some things that you needed to take care of?

Denise: Yeah, Like a light bulb burned out and he didn't know how to change the bulb, you know, for the first time we go over there, you show him how to do it, and he calls the next time you're like "well can you get someone from staff to take care of this, because, you know, we hate to keep running over there to change a bulb." But I think in the beginning we were there for all those little things that came up, but now less so, two years later.

However, Denise and Dan both discussed how their level of direct contact with Dylan has decreased dramatically since the time he initially moved into the home, from receiving phone calls from Dylan several times a day, to the current state of contact which Dan reports as "we talk to him [on the phone or by e-mail] every day, and see him every week." Both parents described that this decrease was largely due to Dylan's increased level of comfort with his situation:

Int: One thing that you said earlier also, was that he called you more when he first moved out, but that he's become more independent since then?

Dan: Oh yeah, at first he was calling, it seemed like every hour, it wasn't but it seemed that way. With every little thing that came up, you know, and as time has gone on, he's more confident making a lot more of the smaller decisions

Compare their rate of contact with Dylan, to Clara's rate of contact with Charlie. She reported a very different rate of contact than the other families, one that is especially remarkable given that her son moved from the home nearly a decade prior to the

interview. As discussed before, Charlie visits his parents' home for dinner on a weekly basis, a visit that Clara mentioned only continues because Charlie wishes it to. But it is her description of her contact by telephone that is the most different from the other participants:

Clara: Well, I'm the one that does all the, or most of the interacting with the people who serve, and support [son] in his home. He has a, well I won't get into that right now. I'm more involved, basically on a daily basis, with the people that live in his home.

Int: On a daily basis.

Clara: Definitely. I'm not there physically. But I'm at least on the telephone with people

Int: Ok, what, what, tends to happen on a daily basis?

Clara: It's mostly Charlie and his wife, now. He's been married for nine years. They pick up the phone and call their parents, not with complaints, just conversationally, probably four times a day. [Laughs]. Four or Five times a day. We laugh about it all the time. If something that occurs to them that they would like to say to us, they just pick up the phone and call us. So we talk a lot. Yeah.

While this rate is much higher than the other participants, this seems to be largely initiated by Charlie, rather than Clara. This is similar to Dan and Denise, who saw their rate of contact with Dylan decline when he began to grow more comfortable in his own home and he reached out to them less. Other than for Bonnie and Brian, who are still in the process of running and finding staffing for Bridget's home, each parent discussed, to some extent, how their adult child often seemed to determine, more than any other aspect post-transition, the literal rate of contact between parent and offspring. Anna noted how Adam will often decide whether or not he is going to see his mother on any given week.

Anna: And so I don't hear from him. I'll get a call like "Mom don't come up, I'm going to a dance," and I'm like, "OK." So it's just like, he is he's happy. And so he doesn't need-, he's happy without Mom being involved as much. And, so I step back and let him go.

This particular information highlights the value of the qualitative study. The researcher entered the process of this study with an informal hypothesis that physical closeness due to community placement might cause the rate of contact between parent and offspring to increase in comparison to large institutions. If the researcher had limited the study to the independent variable of distance from the home, and the dependent variable of rate of contact, it may have been that a small effect size would have been discovered - each and every participant identified that they saw their child more frequently than the 'once a month' rate from cited for larger institutions (Schwartz & Tsumi, 2003).

However, by allowing the parents latitude in how they discussed rate of contact with their son or daughter, it is possible that a more relevant predictor was uncovered. Across at least four of the five adult children discussed in the study, it seems that variations in rate of contact seemed to be determined by the adult, rather than the parent. While each of the parents discussed making regular trips to the group homes, the rate of these trips was similar. Variations in contact, including via telephone, or actual visitations, seemed highly dependent on the adult, whereas, as seen in the discussion of the first superordinate theme, many other aspects of the adult's life were determined primarily by their parents or by their home based staff.

Managing the transition. The final superordinate theme that arose from the interviews regarded experiences that specifically addressed the transition itself. This can be broken down into two main subthemes. The first regarded preparation in advance of the transition, in which the participants discussed how they prepared, who helped them to

prepare, and what lead them to begin seeking the transition in the first place. In the second, the parents discussed the experiences that followed the move out the home, and their reactions to these experiences.

How parents prepared for the transition. If the reports of the participants were in accord on any issue it was that some form of preparation for a son or daughter moving out of the home began years ahead of the actual move out date. This section will demonstrate that the parents, nearly across the board began preparing for such a move in two ways. The first stage of preparation seemed to be the hypothetical consideration of a residential placement, and a search for a specific location. The second stage commonly began for parents after the point at which a location was found, or at least, the idea of moving out of the home became more realistic and viable. This realistic stage consisted of the parents preparing their children to become more independent, or to receive care and guidance from sources other than their parents.

Hypothetical planning stage. To begin this section, take Anna's example. As discussed during the participant interviews, Anna sought and received a five-day-a-week residential placement for a then seventeen-year-old Adam in the state school for the blind, not just because of the services that he would be able receive educationally, but as it would, in her words "put him one step closer to receiving the highest level of need when he turns twenty-one", and that it served as "stepping stones to the full transition to a group home". This suggests she began planning for a residential placement at least four years prior to the age at which he would become an adult, and would age out of educational services.

Additionally, Anna discussed the fact that finding Adam a placement required a great deal of personal effort and insight on her part. In the following excerpt, Anna discussed what kind of support she received in attempting to work out the details of a full-time residential placement for her son.

Anna: So it's basically it's driven by the parent. So it's the school will kind of help you as much as they can, you have DDA assisting you and giving you information about services, and where some are available, but basically it's just pounding the pavement as a parent.

Int: That's very helpful, a fantastic answer. When you say "Giving you information" it sounded like the school staff. Can you be specific as which school staff, and what information?

Anna: ...And then the staff at the school for the blind, there was a transition specialist, Kelly, who helped. But I gotta tell you, she made-, kind of, basically what they do is hand you a packet of information, and like "here you go," [laughs] and you have to, like I said, do all the work. They give you a package and you have your, [State Disability Service Administration], your services coordinator for the [State Disability Service Administration], and mine was excellent and she would also help me in, you know, giving me, you know, "here's a bunch of agencies, you can try that." And then she helped me contact them, and offered to come with me, um kind of thing. So they were helpful too.

Here, Anna addressed the fact that while her school had "transition specialist," she felt that the services they provided amounted to handing her information and expecting her to do the rest. She did report feeling positively supported from her state service coordinator. However, the lack of support from the school system is a trend that could be seen across the participants' experiences.

Anna began the process of transitioning Adam out of the house more than four years before the actual move to a full-time residential placement. Bonnie and Brian discussed how early they began the process of acquainting themselves with the resources and residences available. In their experience this started later in their children's lives than it had for Anna, but required a great deal more time between actual placement and

finding a location. Recall, from the participant introductions, that Bill, who is five years older than his sister was placed at age thirty, and Bridget at age thirty-five. Here is Brian discussing just how far ahead of their placements he and his wife began searching, and how they began to do so.

Int: So that sounds as if that's in the mid to late nineties. Was that the first time you began planning for either Bill or Bridget to find a residential placement?

Brian: Yes. We really hadn't given it a lot of thought, because, like I said Bridget was about nineteen and Bill was twenty-four or some place around twenty-five. And I could be off a few years in my memory. Yeah, that's when we kind of got involved. I had sat on the ARC of [county]'s board, because we were living in [city] at the time, and that's in that county. So I was a member of the ARC board, and went to board meetings because I wanted to know what they did, how they did it, or how well or poorly they did it. 'Cause, I mean, we had always had, somewhere in the back of our mind, the thought that at some point the kids are going to move out, either, willingly, at our urging, or when we're dead they'll be relocated.

This suggests two things. First Bonnie and Brian “always had” considered the idea that their children would eventually be placed out of their home. Second, they began acquainting themselves with the search process five to six years prior to actually placing Bill, and some fifteen to sixteen years prior to Bridget’s placement. Brian expresses here that to begin the search, he involved himself on the board of the local county ARC. The ARC is a national non-profit organization that provides services for adults and children with disabilities and their families. This includes organizing and running community-based group homes across several states. Brian involved himself in their board so as to acquaint himself with the options the ARC provides. While neither Bill nor Bridget ended up being placed in a ARC run group home, here it seems that Brian was using his involvement in the ARC to gauge the level of services offered in general in the field of adult residential care.

When Brian addressed the level of support available to himself and other parents, he described even less satisfaction in the resources he encountered than did Anna.

Brian: No. [Bill's school] has what they call a transition program, but it's all geared to the kids. They're one of the few schools that back, years ago established a transition class, or transition program where at age eighteen, they move the kids into the work center, which is a separate building. They move them in there for maybe one day a week, for the first quarter, and then the second quarter of the year they put them up to two days a week. They talk to them about jobs and employment, how to write a resume. So they have a transition for the, for the children, or for the kids. But truly, no one has a program for the parents, other than, going to, if the parents become somewhat active and they go to different meetings, the [separate non-profit organization] runs meetings about the transition and what to expect. And they also run programs on registration with SSI, and SSDI, and that sort of thing. So there are programs, but most of them, I'm hesitating because I want to say all of them. But boy, if it's not all, it's ninety-five percent of them, take place during the day. So unless you're, you might say, of an executive level, because today most men, most households, mom and dad both work. Assuming that they're both together, because I guess fifty percent of the households are single parent homes. So, assuming that there's a mom and a dad in the house. So for them to go to a program at say ten in the morning or one in the afternoon, just doesn't, kind of like, fly. There are some programs that run on weekends, but they usually start on Fridays. [Non-profit organization] runs a kind of deal where I think it starts on Thursday or Friday, or maybe runs on a Saturday as well, but never on a Sunday. So, they're not really convenient for working, working breadwinners, you might say, in the family, to get educated.

Brian and Bonnie reported having enough monetary flexibility to be able to attend these sorts of meetings. So it is remarkable that it struck Brian that these meetings, which he cited as the primary means of a parent being able to "educate" his or herself on the residential options available, were so inaccessible to the average married couple, let alone a single parent.

Dan and Denise help to clarify what seemed to be a process of planning that for many of the parents evolved from the initial hypothetical stage of planning and the realistic stage. Often the parents describe, as Brian did, the hypothetical stage as occurring "in the back of their mind" or in the form of "always expecting" their son or

daughter to move out at some point. Denise express that this stage included signing Dylan up for the waiting list in the state. Often, it was not until a legitimate option arose that the families began “realistically” plan for the transition. Here is Denise:

Int: First off, when did you begin planning for your son to find a residential placement, do you remember?

Denise: Hopefully or realistically? I mean, hopefully, probably from the time that he turned twenty-one, because we did register him with DDD, which is what everyone told us to do.

Int: You registered him at twenty-one?

Denise: Maybe it was eighteen? No, I think it was eighteen. We did the guardianship and all that, all at the same time. So we were hope, hoping that something would change within the state, that when he turned older there would be a place for him. Realistically speaking, with the waiting list the way it is in [the state], it didn't seem to become a realistic option after a while, and then, when the [name of residence] presented itself, probably as a gem of an idea, um, I would say it was probably ten years ago, that's when we started thinking there might be a place for him to move to when the time came.

Clara's experience was slightly different than the others, in that Charlie came to his parents at age twenty-one and requested to move out the home into an apartment with his best friend. Still, it has been noted that Clara and her husband had been considering the concept, hypothetically, for some years: in prior excerpts, Clara discussed how she envisioned that Charlie would move out of her home when he was in his thirties. Since he actually moved out at twenty-one, her reports suggest that she had been hypothetically considering the move nearly two decades before she intended to undergo the realistic process of actually moving her son out.

This division in planning stages appears to be a phenomena that occurs for each participant. As discussed by Denise, the initial “hypothetical” stage of planning seems

mostly to involve passive ideation of when a transition would ideally occur, and what it would look like. The hypothetical stage seems to occur for a parent as early as when their son or daughter is an adolescent (Anna and Clara), or as late as when their children begin to transition out of the school system (as with Dan, Denise, Bonnie, and Brian). While ideation and idealization seems to dominate the “planning” during this stage, some specific steps would be taken, such as Dan and Denise signing up for the state’s waiting list, while Anna, Brian, and Clara all involved themselves in local non-profit organizations, including the city or county ARC (Brian and Clara), and/or parental support groups (Brian and Anna).

The hypothetical stage of planning, as described by these participants, seems to mostly terminate with a separate experience which clarified either availability of a potentially viable placement, or that clarified the need to find such a placement. Frequently, it would include the discovery of a realistic housing location. However, several parents quoted another experiences as motivation for the transition: realization of their own mortality.

For Dan and Denise, the “realistic planning stage” began with the identification of a legitimately possible group home placement. Specifically, the couple became involved in the development of an independent group home project. For the other parents, they were pressed into searching out a legitimate placement due some experience in which the parents began to consider how their children would be cared for following their incapacitation or death.

Considerations of mortality as impetus for transition. Prior research suggests that for many years, the two main rationales for searching for a placement were the incapacitation of the parents (e.g. illness, debilitation, or death of a parent/caregiver), or behavioral issues which were beyond the abilities to be controlled within the home. (Essex, et al., 1997; Seltzer, et al., 1993). Past research has also suggested that even amongst parents who abstractly planned for a residential transition, the parents largely desired and expected to care for their son or daughter as long as their health or economic situation would allow (Bigby, et al., 1997; Seltzer, et al., 1993). Recently conducted research, however, has suggested that there is a larger trend towards parents planning searching for a residential placement prior to the point at which they can no longer realistically care for their son or daughter (Lakin & Stancliffe, 2007). The participants in this study, largely seem to fall into the latter group. Each expressed a desire to see their child move out of the home while they, the parents, were still physically healthy and relatively capable as caretakers. Some of the parents actually provided anecdotes about knowing families who had waited until the last possible moment to transition their child, situations similar to those described by the Bigby, et al., (1997) or Selter, et al., (1993) articles. Interestingly, it was from observing these other families that some of the participants determined to find transitional placements ahead of time. Bonnie and Brian both labeled this as a rationale for searching out placements for both of their children:

Brian: [Bridget]'s medically compromised, she's behaviorally compromised, and very low functioning, but at the same time, I realize I'm going to die and pass on, and I have to have a program in place which at least somebody can administer, and, I'm more concerned with the trauma to her, in that, when Mom and Dad are dead, I don't want her to have to be relocated at that point in time. So we've relocated her now, while we can still be participants in her life. Same thing with Bill, that's the only thing to relocating the children outside of the home.

Bonnie meanwhile, used the examples of one of Bill's roommates to express why waiting until one or more parent passes away might be not as successful. She cited this anecdote as one of the reasons why she began to push for a placement for Bridget, despite not feeling emotionally prepared to do so:

Bonnie: I still 'til today, would want my kids to be able to be at home. But, my experience was that I watched Bill in his house and I watched the two young men, particularly the first one who only had a dad when he moved into the house. His mom had died like two or three years before, and his dad was not in good health, and his dad died about six or eight months after he moved into the house, and I watched how he handled it so much better because he had his own space. He didn't have to go through, the transition of, moving because he no longer had parents. And, I think that the direction that the state is going in, right now, where they're not placing people until it's an emergency placement for most community-based people is horrible. I think there's an age when, as adults, and you've aged, that they need to move on with their life. That's it's not really a benefit for them to be home, and that's the only reason that Bridget has moved. That's the main reason, and that everybody's got to reconcile that in their own mind. I mean I cried a lot of tears for my kids leaving, and I've been very happy that they have happiness in their lives, by being somewhere else than here.

Additionally, Clara described how witnessing the difficulties faced by a neighboring woman with disabilities had caused her to increase her level of planning for Charlie's eventual transition.

Int: So one thing that you said in there was that you really expected that people really weren't going to get [son] like you did, or they weren't going to do the things for him, that you could do, or that you did. Yet you always sort of envisioned that he would be moving out? I mean so those seem like two conflicting ideas to me.

Clara: Right, well that was because of our exposure to the disability community, and the number of older adults that I saw having to adjust to this lifestyle because it, there was a girl, the woman that lived across the street from us. And her father had died while they were all young. And her mother and her sister slept in the same bed as her mother. Her sister had Down syndrome. Slept in the same bed as her mother. And she was in her forties when her mother got cancer and passed very quickly, so never did anything. I mean there were other sisters but none of them were willing to take her into their home. So she was left having to adjust to her own place, you know? Sleeping by herself for the first time in her life, and in her own place, *and* the loss of her mother. And she had a terrible, terrible time. The emotional adjustment was just... I mean she's doing great now, but initially it was just awful. And I thought that's never going to happen to Charlie. And that's,

actually, when I met [woman with Down syndrome] is when I started to pull back from Charlie a little bit. So I'm painting this picture that I did so much for him up until the day he walked out of the house, that's not true. He was probably in his teens, early teens when I met [woman]. And I started encouraging him to do x, y and z. It, it opened my eyes. So even though I didn't think he was going to move out until his early thirties or something, I started helping him to be a little more independent.

Clara also described in her interview that a major benefit of finding a placement for Charlie when she did was that she remains healthy enough to perform "quality assurance checks" at his apartment on a semi-regular basis. She highlighted this in her recommendations for other parents.

Anna, for her part, described how her own health scare caused her to realize that she needed to search for a placement for Adam before she would be unable to care for him.

Anna: Another thing about me, I had a brain tumor, three years ago, and it scared the hell out of me. It's fine, I'm fine, I had it removed. It was benign. But I went into seizures. And I was very lucky that Adam had been at the school already and my husband was there. It scared the hell out of me. It was a rude awakening of "what happens if something happens to me?" And, I'm like, you know, it scared the hell out of me. And that was another reason I was so insistent he got into residential because, again, he has his sister. He has his father, who's semi-involved, but I didn't want the burden to fall onto his sister. So I was insistent, and dedicated to making sure that he was set for life, and to live a life happily, without Mom. And, so, he's moving in that direction, and that's exactly what I wanted.

It may seem that this example demonstrates that a participant did wait until after they started to have difficulties caring for their son or daughter. However, Anna was approximately only forty-seven or forty-eight years old when she had the tumor, suggesting that this was not a slow deterioration and that she waited until the last second to consider residential placement. Instead, she had already found Adam a residential school placement, one that was partially designed to make getting a permanent adult residential placement easier when he graduated from college.

Again, the fact that the study consisted of only six participants cannot suggest that there is a sweeping trend towards parents searching for residential placements earlier than previously demonstrated. However, several parents discussed their current health as a positive in regard to helping their adult child transition, as well as a factor allowing them to ensure that they felt confident in their son or daughter's care.

Realistic planning stage. This stage seems to be defined by the parents planning specifically how to make their son or daughter prepared for such a transition. This frequently included focusing on increasing independent skills, such as activities-of-daily-living (ADLs) and/or relying on the care of others.

Often this involved activities that could be compared those completed by typically developing adolescents and teens. For instance, Bonnie and Brian described "weaning" their children off of their care by finding them an adult summer camp. Clara searched for and found a part time job that would result in her being away from home when Charlie arrived from school:

Clara: And the first thing I did was I went back to work. And that was interesting. He would have to get off the bus, and we had a great big long driveway, 350-foot-long driveway. He would have to come down the panhandle hill and down the long driveway and let himself in with his own key. And, now it took him almost a year to figure out how to do the key correctly. And that, so that year I was looking for a job but I didn't go back to work until I knew he could do the key. And I had neighbors who were checking. I mean I had all kinds of backup, so it was a safe environment for him, but that was *huge* for me emotionally, to, to be working. I really enjoyed working and I mean that was, it was really great for him. He'd get in the house and he'd me call right away so I knew he was ok. And he hated it, initially. He'd call and he'd be crying. And it was breaking my heart. But it really, that was huge.

The parents described beginning this specific preparation of their children sometimes years in advance. As the transition grew closer, the parents would increase the

specificity of the skills taught. Denise, for example, described that once the group home project was underway, but before the home was completed, she and Dan proceeded to require Dylan to do his own laundry, cook some of his own meals, and complete other household tasks.

It remains to be seen how representative that this sample was of typical parents of adults with disabilities. It is possible that the “hypothetical” stage does not occur for most parents. Each of the parents discussed that they had “always” considered the likelihood of their son or daughter moving out at some point in their adult hood. As such, they were more apt to begin the process of searching for specific locations earlier, and had begun to prepare their children earlier. Nearly universally, the parents recommended that this “weaning” of their children should occur as early as possible. However, if the prior research completed by Bigby, et al., (1997) and Seltzer et al., (1993) remains accurate in describing the population at large, it may be difficult for parents to make use of these recommendations. Many parents may not have determined that a residential placement will ever be right for their child. In this study, the participants agreed that preparing a son or daughter for independence (or for having caregivers besides their parents) is a goal that should begin to be addressed significantly in advance of the actual transition. For parents who have considered the prospect of a residential placement for their son or daughter, this preparation seems to be one of aspects the parents in this study found most important to success.

Experiences following the transition. In the second subtheme associated with the transition itself, the participants discussed their experiences following the transition. In

this section the participants addressed their experiences following the transition, and their own reactions to these experiences.

Among the participants responses, in regard to their experience post-transition, there were two particularly clearest phenomena that arose across participants. First: the increased need, often surprisingly so, for the parents to involve themselves in what were termed “little things” or “day-to-day things”, but that parental involvement decreased considerably after a short amount of time. Secondly: the main obstacle to parents reducing their role further than they already had was early dissatisfaction with staff, and they discussed whether or not they were able to overcome this dissatisfaction.

Involvement in the “little things.” Nearly across the board, parents reported that immediately following the transition they were heavily involved in day-to-day matters. They found that their son or daughter required some weeks to accustom themselves to searching out staff assistance for matters such as replacing a broken lightbulb, or deciding what activities to get involved with. In this excerpt Dan explains how he experienced this process with Dylan:

Dan: Oh yeah, at first he was calling, it seemed like every hour, it wasn't but it seemed that way. With every little thing that came up, you know and as time has gone on, he's more confident making a lot more of the smaller decisions

Int: Smaller decisions?

Dan: Yeah.

Int: Can you give me an example of what the smaller decisions that he's been making by himself now?

Dan: Like, what to buy at the grocery store.

Int: So he used to call you and ask you that?

Dan: Yeah, he used to call for all kinds of stuff, that just, everyday stuff.

Int: And so, at what point did you first notice, or was it clear that he was relying on you less for those small decisions?

Dan: Oh, I would say after a few weeks.

Int: So fairly quickly.

Dan: Yeah. Yeah, I think at first he just wanted to know we were, you know, still easily reached. You know, that we were there to support him.

Int: So you felt that he was, making that you were there more to...

Dan: Yeah, he was a little, you know, nervous about it or anxious, or whatever you want to call it. He got more comfortable very quickly.

Int: And how about you, sir?

Dan: I would say we were anxious about how it would all work out, and as time when on we got more comfortable too.

The time frame that Dan reported of two to three weeks before his son “settled in” seems to be consistent for several of the other parents. It is interesting that Dan notes that he believes part of the reason that Dylan maintained the higher level of contact earlier was not that he did not trust the staff, or could not manage aspects of his life, but that he wanted to ensure that his parents were still close by and would support him. Considering that Dan and Denise lived merely five miles from Dylan’s house, it appears they did take advantage of their physical closeness to provide him with extra support early in the process:

Denise: Well we knew that, we’d still be getting the daily phone calls, um. In the beginning, I think it was more still with every little thing that, you know, he needed, or had a question about, we got the first phone call. So he wasn’t really going to the staff in the beginning, and he is now. But that’s typical Dylan, I mean, we went away for the four weeks down in Carolina, and the first week he was constantly calling us in the day. And so I finally told him, I said “Dylan, we’re on vacation here, so you know, jot down what you want to tell us and make it one phone call, you know.” So then he dropped down the number of calls, and

by the third week, he wasn't calling anymore, so you know, that tends to be the pattern. When things are new and tend to be a little different, he calls more often, or he, you know, sends and email more often, and then when he gets into that pattern where, you know, we're not there all the time, he settles down and figures things out for himself sometimes.

Int: So it sounds like from his past, you were prepared for that level of him contacting you at the start.

Denise: I think so. You know, again, we're only three miles away, so if there was something, we could be over there in five minutes, and take care of what needed to be taken care of.

Anna experienced a similar phenomenon with her son:

Anna: There's been an adjusting of dynamics of the staff in the group home, and it was a little different, there was a lot of, he didn't have steadiness in his aides at first. So they didn't have the aides lined up, and when he would have temporary aides, temporary aides, more temporary aides. At school he had the same aides for years. And so what I had to get involved in was, every time I would go over there, they didn't know what to do because it was somebody new who didn't know him, so there would be something I had to fix because you know, they had moved, they had folded his clothes and it was in the wrong drawers, and he was upset and I was like, "because his underwear is in the wrong drawers! What happened to Tim [an aide]?" Well he's not there, so I had to be very involved in small functions and help the house manager come up with an routine, just because I knew so much and had, like, a list so that the temporary aides could go through it and have a cheat sheet until he got his regular aides that he's had for a few months. So that was difficult. And then it was also that he was always calling to be like "Mom, mom, mom" and he wasn't happy because, you know, they didn't give him his chocolate milk. So it was the little things that his, his routine, I had to help them establish when we had actually gone over all of that in detail time, and time, and time again. Before he went to the residential, you have to go over ever little detail, like his diet and his medicine, you know? His routine, because for these children routine is key. For them not to have milk out, or for to have their brains go off wire because something's not right and they worry about it and worry about their routine. So I was up there a lot in the beginning trying to help them try to establish his routine, and that was something that was kind of unexpected.

Anna did go on to explain that the house manager, with Anna's help, had since developed a new routine for Adam's life in the residence. Since then, Anna has been able to decrease her role in day-to-day goings-on significantly.

Difficulties with staff. Another oft-quoted obstacle quoted by the participants for reaching a steady routine or equilibrium was noted. Anna's previous excerpt touches on this. She discusses how change in aides early caused more difficulties settling in, and that once the home got its "regular aides" that Adam was more able to settle in. Staff turnover and/or general miscommunication with staff seem to be the biggest post-transition concern that most of the participants had. Early in the transition, the families mostly struggled with the "mistakes" that they felt they had seen the staff make. Some of the parents were able to come to terms with the staff and how the staff would manage things in the home. Some struggled. Two parents, Dan and Brian, discussed this experience in nearly identical vocabulary, while experiencing markedly different levels of acceptance and satisfaction in its wake.

Dan: Yeah, I would say, where your disabled child goes, there will be staff. Ninety-nine-point-nine percent of the time the staff will be caring, and will do what's best for your child. But you have to recognize, staff is staff, they're not parents, they won't treat your child, and look after your child like a parent would, and the place they go to is not your home, and it's not going to be run like you ran your home. Things will be different.

Int: And, because I would love to follow up a little bit on that. Specifically how would you say that's different?

Dan: The reason I made that statement is, we know a lot of other parents who have children at this apartment assisted living apartment house, as well as people that have their children in group homes and they're always complaining. "They're not doing this for my child, they're not doing that, this is different, why aren't they doing this", and it's mostly, just small stuff and it's because their child isn't cared for like they cared for their child when they were home. So unless you're willing to let go, and understand it's going to be different, you know, you'll have trouble with it.

Int: Did you find that it was hard for you to let go in that way?

Dan: No not at all, because I had thought about that and I was aware of it and had accepted it, and knew that Dylan very much wanted to be as independent as he could.

In this excerpt Dan advised that other parents entering the transition process need to be aware that less than one hundred percent of the details will be correct, or at least, that staff will not go about caring for their children like the parents did previously. In anticipating this and being “willing to let go” it seems that Dan acquired a certain amount of satisfaction with his son’s placement. In contrast, here is Brian’s response:

Brian: Well, [residential non-profit] just opened up a fifth group home, and two of the parents approached me and said "gee my son is moving in. What's your experience been?" I said, "well, your expectations should be set at the level of seventy to eighty percent. Whatever you think they should be doing, should happen, seventy to eighty percent of it is gonna be done right, but it's the twenty to thirty percent that's gonna kind of like drive you nuts. And so don't have this expectation that it's, “gee, he's in great hands, and I can walk away from this situation, because they're gonna read everything that I wrote about my child, his needs, his wants, his desires, his shortcomings, and they're gonna understand it, and do it correctly” and by correctly I mean, as a reasonable person would do it. Because again it goes back to the staffing. I hate to use the word, but the intellectual capacity of the staff, just does not exist, at that price point. And, so what your expectations should be is at an average of seventy-five percent. Because that's been my observation. Because it's the little crap that just drives you crazy.

Brian and Dan both expressed that parents should be prepared for the fact that staff will not engage in caretaking tasks in a similar manner, and that this may be shocking in the days and weeks after the transition. However, one parent expressed that he was able to accept and come to terms with this process, while the other parent expressed more difficulty. There are too many individual variables, between Dan and Brian to surmise that any particular aspect of their personality, their offspring’s personality, or the staff of the group homes caused or affected the difference in their level of acceptance. What does matter for the purposes of this study is that the parents overtly noted that staff often had a differing style of caretaking than they did. Other parents experienced the same level of initial frustration, and had their own individualized response. Anna also warned parents of this initial reaction:

Anna: And those people don't know your child. And, you know, you're going to be expecting things to go "Why isn't he working yet? Why isn't he this yet?" They don't know your child. They need to find out for themselves, even though you've written a book for them on everything your child likes, how he does things, they don't read the book. They find out for themselves, at their own pace. And that can be a little bit frustrating but that's just the way that it is. So that's something that I would warn parents about: to expect that. And expect that everything that was promised, you might get a letter saying, he didn't get it. Things that you thought were all taken care of, you might get someone giving a phone call saying it wasn't taken care of. So even though you thought that you had everything, and had copied everybody and done it ten times over, something's not going to be done. And that was frustrating.

Anna describes her frustration that despite all that she had prepared and written for the staff to assist them in getting to know Adam, and to work with Adam the way that she had, the staff required their own amount of time to develop their own routine with her son. It is important to note that, in discussing this issue each participant has posed their response as advice from which future parents would benefit. That in itself suggests that it is an aspect of the transition that the participants were not entirely prepared for when entering the process. Both Anna and Brian discussed writing a great deal of information in order to prepare staff, but that they felt that this process affected neither the speed at which staff grew accustomed to their son or daughter, nor how the staff provided support for their son or daughter.

Clara touches on the value of remaining patient, with staff and with her son, throughout the time since he moved into his apartment. In the following excerpt she expressed her belief that the parents need to hold back on intervening with their child. While it is difficult and scary at first, patience has served her well and imagined it would serve for others.

Clara: The other thing I would say is, as frightening as it is, when you let them try, they will. I think people with intellectual disabilities get it. They can get it. They just need more time. They, if they are given time, they can get it, they can

accomplish. It's just that we, in our fast paced, in our society, we have these expectations. We have these immediate expectations. And if you keep the expectations, don't ratchet it down, but wait. And they will get it.

With Clara, this advice seems to arise from experience. In previous excerpts she mentioned that patience and trust in staff or in Charlie was not her first instinct. She described witnessing her son grow more independent since moving out from her direct care. She credited this independence, and much of his success, to staff. Specifically, she credited the fact that staff may have asked more of Charlie than she did in her home; protecting him less and expecting more of him. In those excerpts she wonders if she had been “creating limitations” that didn’t exist for him. It was through this process of being patient with staff’s ability to manage her son that she was able to gain new perspective on what her son was able to accomplish.

In regard to interactions with staff, and the parental reaction to it, at least three parents expressed their belief in the need to accept and “let go” in the face of this frustration. These parents opined that this process not only helped them to grow in satisfaction with their son or daughter’s placement, but that this acceptance may have served to assist their son or daughter in being more successful in their placement. One can already see how Dan expressed this belief in his previous excerpt in which he advised that those parents who are not “willing to let go” are going “to have trouble with it [the transition].” Denise took the opportunity in her interview to recount a request that was made of her and Dan immediately following the transition:

Int: Ok. To discuss the actual transition itself, did it work out the way you expected? Were there any surprising moments?

Denise: Well, it actually was much better than we expected. Well, let me tell you a little story. The executive director, had realized that the parents were going to be very

involved, especially one of the parents, so what he said was, “alright, the first week, when you’re moving everybody in, that’s OK, because you’re getting everybody settled.” But it was his suggestion that after the first week or two, that the parents kind of stay way a little bit. You know, come over take them out to dinner, but stay out of the apartment, and let them get used to the place being their own. Well we thought it was a great idea, I mean, what better way to adjust, you know, but having staff there, and take care of things, and settling into a new routine. We talked to Dylan every day, so that was not, so I mean it wasn’t like we were totally disconnected. Well, there were a couple of other parents who were like, “you can’t tell me not to come, I’m going to go over there as often as I want.” So, looking back I think the parents that were, were a little too involved, after that first or second week, their kids had more problems. Whereas we took a little back seat, and I think the adjustment went smoother in the long run, because he found out he could take care of things himself.

Anna recounted a similar belief. She noted that the parents who have maintained more of a “hovering” relationship in the short time that her son and his roommates have been in the group home have caused difficulties for themselves, and surprisingly, the other children and parents connected with the home:

Anna: Yeah, oh yeah. I've stepped back incredibly

Int: Can you describe that? I'm just interested in what that means when you've "stepped back"

Anna: Well I mean, I'm letting him live his life. There's another mother in the group, and she's caused problems, and that's another issue that you have to deal with in group homes, is the dynamics of the parents of the children. She's a hoverer, she is there, she's there all the time. I mean, if the kids go to the ballgame, she has the van meet her. And she's not letting go. And it's become a problem because she complains, and the children's schedule was starting to have to revolve around what she wanted, and myself and the other mother were like, "wait a minute, if you want to take your child out that's ok, but when our children are involved, we trust the staff and let them go."

Thus, a phenomenon that seemed to exist across parents was that immediately following the transition, dissatisfaction with staff’s caretaking was particularly salient across parents. Some parents were able to distance themselves from this through a process of “letting go,” or acceptance of a new equilibrium between staff and offspring.

Some parents, specifically Bonnie and Brian, were not able to reach this same stage of acceptance. As discussed in the participant introduction, their level of dissatisfaction with their son's staff was so salient and impactful that they highlighted it as a major motivation for why they chose to pursue an independent housing placement for their daughter.

Given that the responses of the parents to their initial dissatisfaction were divergent, and given the sample size, no specific conclusions can be drawn as to the reasons why some parents felt it prudent to accept what they initially saw to be flawed. Neither can conclusions be drawn explaining if such acceptance generally correlates with either positive or negative outcomes for the parents, or for adults with IDD. However, it is relevant that the parents who raised this issue all raised it in the form of a warning for future parents. They expressed feeling unprepared for such a reaction, despite great preparation ahead of time, and wished that other parents could avoid such a shock in the future.

Discussion

Limitations of the Study

There are several limitations to this study that must be acknowledged. The proponents of qualitative research, and IPA specifically, note that while there are several important benefits to this style of research, there are drawbacks. Generalizability is one of those potential failings. One cannot assume from the anecdotes of six participants that any apparent trend or phenomena will occur with any probability for other parents entering into this transitional stage. These participants all possessed qualities that were unique to their situation, and any number of pre-existing personal, environmental, or other aspects of their situation may have affected the experiences that they had, and the emotional reactions to their experiences. These idiographic qualities may present obstacles in the generalizing of these participants' accounts to other parents of this population.

Specifically, this population was relatively homogenous as compared to the overall population of parents of adults with IDD. All six participants identified as Caucasian, and all six reported relative economic stability. Meanwhile, Gregory, et al., (2001), suggested that several personal, racial, ethnic, and gender-specific factors of the parents and individuals with IDD can contribute to the success or failure of a residential placement. Thus, the participants' homogeneity may have affected the overall level of success of the residential placements. Additionally, the vast majority of public resources for adults with IDD and their families in the US are state-based, and these six participants were recruited from only two states, both of those in the Northeastern United States.

Suggesting that similar options or levels of services to what these parents received would remain constant across the regions or states would be a mistake. This is especially true given that prior research has suggested that environmentally specific factors, such as level of staff training and location of the residence, can greatly affect whether or not a placement is successful (Allen, 1999).

The literature that does exist suggests that the transitional process is, and should remain, as idiographic and personalized as possible (Blacher, 2001; Miller, 1994). Indeed, there are clear distinctions between each participant, even between the two halves of parental dyads included in this study. Even when the participants discussed similarly experienced phenomena, they frequently reacted in very differing manners. However, this is often the case across several fields of study, and especially within the field of psychology. To allow this as an excuse to fail to fully identify possible phenomena or to prepare parents for at least a probability of experiences during this tremendously eventful and impactful transition would be remiss. The results of this study suggest that there are some aspects of previously researched phenomena that can be more fully described, as well as possible new phenomena whose exploration could benefit the increasing number of parents entering this transition.

Conclusions and Potential Implications

As described, the purpose of the IPA study can be twofold. One, it can provide context and qualitative data regarding previously identified, but unsatisfactorily defined phenomena. Two, it may help to identify and define possible new phenomena. In this study, both aims were successful. New phenomena, were identified and described, and

ideally could be studied further. For instance, the participants' responses suggested that their son or daughter served to drive the rate and type of contact that they maintained with their parents. Other participant responses, such as how mortality factors into planning for placement, did not identify new phenomena, but rather, added context to previously defined constructs (Essex et al., 1997; Seltzer, et al., 1993).

The participants discussed several phenomena that cross three major superordinate themes: balancing independence and protection; redefining the parent's identity; and managing the transition itself.

In regard to the first theme, the larger consensus of the parents seemed to be that the process of ceding control over their son or daughter's life did not emulate the typical dynamic of parent ceding to independent young adult. Instead, the parents viewed this transition of control as from parent to staff or management. This seems to corroborate and define in detail the results of research performed by Murphy et al., (2011) and Pilnick, et al., (2010). These prior studies suggested that while parents may espouse verbal support for independence and self-determination, they (and some service providers) still equivocate and limit this self-determination as it applies to real-life scenarios. This is valuable information. Self-determination is currently a major goal of legislatures and advocacy groups for the adult population with IDD. Research exists that suggests that community-based housing supports self-determination, and it is presumed that this research is used to support what is an increasing trend of adults finding community-based placements. However, it does not appear that this process of idealizing self-determination and independence from outside caretaking is a goal of parents during

this process. Rather, the main goal for parents in this sample was a successful handing off of the responsibilities to a new source of support. In this, service providers and parents may be at odds. This tension was seen in excerpts in which participants expressed disdain or frustration with staff or management in the instances that they allowed for more independence or self-determination of the adult with IDD than the parents would have allowed in their home.

While continuing to address their experiences in regard to the locus of control, an interesting phenomenon arose for several parents. Where independence was seen, it often resulted in the expected proud and positive emotions from the parents. However, often these positive emotions were accompanied by conflicting emotions of guilt or jealousy. Anna and Clara both discussed how seeing their sons grow more independent and capable caused them to feel concerned as to whether they had been holding their child back, or wondering why their child was so successful under the care of others and not their mothers. While these more negative emotions did not seem to greatly impact the parents who recounted such experiences, such conflicting emotional reactions to this transition may warrant future study.

As to how parents viewed their own reactions to the transition and the effect it had on their lives, a few important phenomena arose that may help to add to the research currently available. Prior research on the launching stage in general suggests that parents adjust well to the so-called empty nest. However, much of this research (Anderson, 2005; Blacker, 2005), was performed with parents of typically developing children. It was unclear as to whether this research would apply to parents of adults with IDD. In fact, the

parents in this study corroborated the prior results, insofar as the parents who have been able to separate further from their children have been largely satisfied. Anna, Clara, Dan, and Denise all describe positive effects on their own lives and other relationships as a result of the transition. Anna actually suggested that the transition improved the relationship and happiness that she experienced between herself and her son. Bonnie and Brian, however, did not express that they had shared in this positive response to the transition. This may have had much to do with the fact that they were still far from separated from their daughter, who had moved out of the home less than a year prior. At the time of their interviews, they were still serving as primary caretakers at their daughter's apartment several days a week. However, even Bonnie and Brian discussed that since their son had moved out, their daughter had become easier to manage, and they retained aspirations of freedom that the other parents experienced, pending the more complete development of their daughter's residence.

Interestingly, none of the parents described the guilt or increase in negative experiences surrounding the transition that had previously been identified as a common experience (Rimmerman & Muraver, 2001; Seltzer, et al., 2001). While Clara expressed some guilt immediately following the transition, when one examines more closely, it does not corroborate the guilt described in Seltzer, et.al (2001). That paper specifically addressed parental guilt in response to placing a son or daughter in a residence out of the home. Clara's guilt may be more accurately ascribed to allowing her husband to take more of the responsibilities during the transition than she would have otherwise allowed. This decreased involvement seemed to be more of the result of her grief following the death of her daughter, rather than specific to the residential placement. These results may

suggest that while the past research in this area continues to hold value in regard to many aspects of this period in a parent's life, some of the findings may be outdated. Obviously, a six person sample is not enough to determine that a more quantitative study's findings are invalid. However, as demonstrated in the literature review, the process of transitioning an adult child with IDD out of the home is becoming more and more commonplace (Lakin & Stancliffe, 2007). It may be that as this process becomes more normative, parents will cease to feel as much guilt for opting to find a residential placement for their child. Again, while there is not enough evidence presented here to directly refute Seltzer et al., (2001), there may be enough to suggest a duplication of the study with today's population of parents.

From the results of this study, it also seems that while parents held to a general consensus of two to three in-person visits a month, it was interesting to note that nearly all of the parents discussed that the level of overall contact between themselves and their son or daughter was driven by the offspring. The parents who expressed relatively high levels of contact by phone (e.g. Clara, Dan, and Denise) suggested that the majority of this contact was initiated by the adult with IDD. The parents who expressed relatively lower levels of contact (e.g. Anna; Bonnie and Brian, with regards to Bill), suggested that their child either requested less contact, or initiated contact infrequently. Due to the nature of the study, these findings of a possible correlation are hardly conclusive. However, further research on the specific level of contact between parents their offspring, with an eye towards which party initiated contact, may be valuable.

Finally, the respondents alluded to phenomena regarding the transition itself that certainly could warrant further study. There is little specific research into what parents can expect prior to, during, and following a transition, and the participants in this study suggested that there were few resources to help them create expectations. However, some similarities in responses from these participants may suggest that there are shared experiences that future parents can be made aware of before entering into this important transitional period. This includes that the parents seemed to experience two planning stages, one hypothetical, and one more specific and realistic. The parents each described the first stages of planning beginning years prior to the move, and reported preparing their son or daughter to be independent from their parents significantly ahead of time as well. Further research could be tasked to look into the average time frame at which parents began to plan for the move, and at which points certain aspects of preparation were undergone. The results of such a study would possibly help service providers, group home staff, and others to provide parents with guidelines that may be empirically supported in their validity.

The parents also addressed how specific incidences in their lives often served as an impetus to begin specific planning. For Dan and Denise, this impetus was the development of a specific housing project. However, each of the other parents cited concerns regarding their own mortality as a cause for specific planning. These responses agree partially with research that suggests that a main motivation for finding residential placement is parent's mortality or incapacitation (Essex, et al., 1997; Seltzer, et al., 1993). The response of these parents provided context that may have helped to define this

factor further. Or the fact that the parents cited the *future* potential for incapacitation, may represent that the prior research, performed two decades ago, may require updating.

Additionally, the parents reported that they were initially disappointed in the manner in which the staff would care for their children. Several of the parents discussed a percentage of things that parents could expect to be incorrect, or at least different from when their son or daughter was at home. Some parents accepted these changes in their lives and in the lives of their sons or daughters. However, some parents were either unable or unwilling to accept this as a part of their lives and spent significant energies in trying to amend certain aspects of the staff's manner or the way that they cared for the adults with IDD. Whatever the response, across participants there existed a shared experience of a shock or initial dissatisfaction. If this phenomenon were to be tested across a larger sample, and found to be relevant for more than just this study, one would assume that service providers or researchers would be able to prepare parents for the days immediately following the move itself. Or, if parents had in their possession an awareness that despite significant levels of preparation in advance of the move, they would likely still face feelings of disappointment or confusion in regard to the care their children, it may move some parents to consider other residential options.

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Appendix A1

Semi-Structured Interview Schedule

Introduction: Hello, my name is David Cernikovsky. For my doctoral dissertation I am interesting in finding out more information about the experiences of parents of adults with Intellectual or Developmental Disabilities after their son or daughter has moved out of the home. I am interested in finding out what level of involvement you expect to have in the continuing lives of your son or daughter now that they have moved out of the home. I am also interested in finding out how your experiences to date have lined up with your expectations, and your reactions to this. In order to do this I have asked you to participate in a one-on-one interview to speak about these issues. The interview will last about one to one and a half hours and your participation is completely voluntary. Participants may withdraw from the study at any time, or may elect not to answer any individual question or questions. As a reminder, we plan to audiotape this interview for the purposes of accurate transcriptions. Written transcripts of all interviews will be made, and excerpts may be used to provide examples for our research, but you will never be identified in the transcripts or any published materials. We hope to use the information you provide in this interview to improve the services offered to parents undergoing this transition, and may serve to assist other parents in preparing for this transition in the future.

INSTRUCTIONS: I am going to ask you a series of open-ended questions. You do not have to answer any questions that you do not want to answer. Please remember that there are no “right” or “wrong” answers.

QUESTIONS:

General open-ended questions:

- When did you begin planning for your son or daughter to find a residential placement?
- Please describe your expectations for your role during the transition process
- What resources/services assisted you in planning for the transition?
- How much thought did you give before the transition as to if it would affect your role as a parent? Please describe your expectations.
- Did anyone else (residential staff, case worker, school staff) describe to you what your role would possibly be following the transition?
- In what ways would you say your role and involvement in your son or daughter’s life changed since they moved from the house.
- In your own words, please describe your current role in your son or daughter’s life.

- Have your expectations of your level of involvement been accurate? If so, in what ways, if not, in what ways?
- What has your reaction been to actual changes (or lack thereof) in your level of involvement?
- What changes, if any, would you want to make in your role or your level of involvement?
- How do you foresee your level of involvement in your son or daughter's life changing in the next five years? Please elaborate.

SPECIFIC AREAS/PROBE QUESTIONS:

- Before this survey interview, you answered a series of questions touching on specific areas in which a parent may or may not be involved in the decisions and everyday occurrences in their son/daughter's life.
- Regarding their romantic relations, you answered _____, please explain.
- Regarding their sexual relations you answered _____, please explain.
- Regarding their residential concerns you answered _____, please explain
- Regarding their occupational concerns you answered _____, please explain.
- Regarding their financial decisions you answered _____, please explain.
- Regarding their health related decisions, you answered _____, please explain.
- Regarding their Hygiene and personal appearance, you answered _____, please explain.
- Regarding other issues you answered _____, please explain.
- Are there any particular areas of your son/daughter's life in which you have been surprised at your level of involvement?
- Are there any particular areas of your son/daughter's life in which you have been pleased at your level of involvement?
- Are there any particular areas of your son/daughter's life in which you have been upset by your level of involvement?
- Are there any other areas in your son/daughter's life in which you have been surprised, pleased or upset at your level of involvement?

Appendix A2

Parental Attitudes toward involvement Questionnaire

Romantic/Sexual Relations						
Please use the following scale for all the following questions. Choose the option that most closely describes your attitudes:						
A) My son/daughter should have complete independent control of this area and may choose to inform me or not. (Complete independent control)						
B) My son/daughter should have independent control, but I should be kept informed. (Independent control/inform parent)						
C) My son/daughter will have control but I should be consulted on all decisions. (Parental consultation)						
D) I should have the ability to overrule my son/daughter if I feel it is prudent. (Parental overrule)						
E) As the parent, I should be in charge in this area of their life. (Parental control)						
N/A) Not applicable to my son/daughter (N/A)						
1. ROMANTIC/SEXUAL RELATIONS						
Regarding the following areas, how much involvement do you anticipate having in your son/daughters life?						
	A) Complete Independent control	B) Independent control/inform parent	C) Parental consultation	D) Parental Overrule	E) Parental Control	N/A
Going on a date	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Engaging in a long-term relationship	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having private, unsupervised time with another person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Engaging in sexual relations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Choosing to get married and to whom	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sexual orientation (e.g. heterosexuality, LGBT, etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking precautions towards safe sexual relations (e.g. condoms, birth control, etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Choosing to have a child of their own	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Issues regarding sterilization (e.g. vasectomy, hysterectomy, IUD, etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Figure A1. Parental Attitudes toward involvement Questionnaire, page 1.

RESIDENTIAL/OCCUPATIONAL CONCERNS						
Please use the following scale for all the following questions. Choose the option that most closely describes your attitudes:						
A) My son/daughter should have complete independent control of this area and may choose to inform me or not. (Complete independent control)						
B) My son/daughter should have independent control, but I should be kept informed. (Independent control/inform parent)						
C) My son/daughter will have control but I should be consulted on all decisions. (Parental consultation)						
D) I should have the ability to overrule my son/daughter if I feel it is prudent. (Parental overrule)						
E) As the parent, I should be in charge in this area of their life. (Parental control)						
N/A) Not applicable to my son/daughter (N/A)						
2. RESIDENTIAL/OCCUPATIONAL CONCERNS						
Regarding the following areas, how much involvement do you anticipate having in your son/daughters life?						
	A) Complete Independent control	B) Independent control/inform parent	C) Parental consultation	D) Parental Overrule	E) Parental Control	N/A
Choice of where they live in the state	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Choosing to change residential locations (for any reason)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alterations to their living environment (e.g. painting room, moving furniture, etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Choosing a job placement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Choosing to quit a job placement (for any reason)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Choice of travel (e.g. private transportation, AccessLink, public transportation, etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Choosing to stay out all night	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Obtaining a driver's license/purchasing a car	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Figure A2. Parental Attitudes toward involvement Questionnaire, page 2

Financial Concerns						
Please use the following scale for all the following questions. Choose the option that most closely describes your attitudes:						
A) My son/daughter should have complete independent control of this are and may choose to inform me or not. (Complete independent control)						
B) My son/daughter should have independent control, but I should be kept informed. (Independent control/inform parent)						
C) My son/daughter will have control but I should be consulted on all decisions. (Parental consultation)						
D) I should have the ability to overrule my son/daughter if I feel it is prudent. (Parental overrule)						
E) As the parent, I should be in charge in this area of their life. (Parental control)						
N/A) Not applicable to my son/daughter (N/A)						
3. FINANCIAL CONCERNS						
Regarding the following areas, how much involvement do you anticipate having in your son/daughters life?						
	A) Complete Independent control	B) Independent control/inform parent	C) Parental consultaton	D) Parental Overrule	E) Parental Control	N/A
Purchases of less than \$10	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Purchases of less than \$50	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Purchases of less than \$200	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Purchases of over \$200	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Signing of legal contracts (e.g. leases, job contracts, etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Option to sign up and use a credit card	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Selection and payment of their choice of vacation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Figure A3. Parental Attitudes toward involvement Questionnaire, page 3

HEALTH CONCERNS						
Please use the following scale for all the following questions. Choose the option that most closely describes your attitudes:						
A) My son/daughter should have complete independent control of this area and may choose to inform me or not. (Complete independent control)						
B) My son/daughter should have independent control, but I should be kept informed. (Independent control/inform parent)						
C) My son/daughter will have control but I should be consulted on all decisions. (Parental consultation)						
D) I should have the ability to overrule my son/daughter if I feel it is prudent. (Parental overrule)						
E) As the parent, I should be in charge in this area of their life. (Parental control)						
N/A) Not applicable to my son/daughter (N/A)						
4. HEALTH CONCERNS						
Regarding the following areas, how much involvement do you anticipate having in your son/daughters life?						
	A) Complete Independent control	B) Independent control/inform parent	C) Parental consultation	D) Parental Overrule	E) Parental Control	N/A
Alcohol use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tobacco use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recreational drug use (with similar consequences as for general population)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gambling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Control over their diet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Control over adherence to any medication regimen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Control over their adherence to any medical recommendations made by their physician (including treatment for diabetes, epilepsy or other chronic medical condition)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Control over their use of any form of psychotherapy, regardless of reason	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Figure A4. Parental Attitudes toward involvement Questionnaire, page 4.

HYGIEGE/PERSONAL APPEARANCE and MICELLANEOUS

Please use the following scale for all the following questions. Choose the option that most closely describes your attitudes:

- A) My son/daughter should have complete independent control of this are and may choose to inform me or not. (Complete independent control)
 B) My son/daughter should have independent control, but I should be kept informed. (Independent control/inform parent)
 C) My son/daughter will have control but I should be consulted on all decisions. (Parental consultation)
 D) I should have the ability to overrule my son/daughter if I feel it is prudent. (Parental overrule)
 E) As the parent, I should be in charge in this area of their life. (Parental control)
 N/A) Not applicable to my son/daughter (N/A)

5. HYGIENE/PERSONAL APPEARANCE

Regarding the following areas, how much involvement do you anticipate having in your son/daughters life?

	A) Complete Independent control	B) Independent control/inform parent	C) Parental consultaton	D) Parental Overrule	E) Parental Control	N/A
Choice of clothing (e.g. style, appropriateness regarding formality or weather)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Choice of haircut	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Opting to get a tattoo	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Level/Frequency of personal hygiene (e.g. brushing teeth, showering, laundry, etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6. MISCELLANEOUS CONCERNS

Regarding the following areas, how much involvement do you anticipate having in your son/daughters life?

	A) Complete Independent control	B) Independent control/inform parent	C) Parental consultaton	D) Parental Overrule	E) Parental Control	N/A
Choosing to vote in public elections, and for whom	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Choice of friends and acquaintances	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recreational activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Refraining from activities (including those scheduled by group home, work site, etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Religious observation (including whether to observe or not, which religion, level/frequency of practice)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Figure A5. Parental Attitudes toward involvement Questionnaire, page 5.

GUARDIANSHIP

7. Have you or do you intend to establish guardianship for your son/daughter

☐ I have applied and/or received guardianship

☐ I intend to apply for guardianship

☐ I do not intend to apply for guardianship

☐ I have not considered this issue

Other (please specify)

8. If you have established or intend to establish guardianship, who is the guardian?

☐ Myself or my spouse/significant other

☐ Sibling of my son/daughter

☐ Other family member

☐ Lawyer

Other (please specify)

9. If you have received or intend to receive guardianship:

What level guardianship have you received or do you intend to receive.

☐ General Guardianship

☐ Limited Guardianship

☐ Not Sure/Don't know

☐ None of the the above

10. What, if any, plans have you made for the care of your son/daughter after your death/incapacitation

Figure A6. Parental Attitudes toward involvement Questionnaire, page 6.

Appendix B1

Phone Screen

The first step in this study is a brief phone screen. Over the next five to ten minutes, I'll be asking some basic demographic questions, such as your name, date of birth, ethnicity and address. I also have some demographic questions regarding your son or daughter, such as their age and level of cognitive functioning. I do not require any identifying information about your son or daughter, nor will I request any identifying information of theirs for the entirety of your participation. All the information you provide will be kept under lock and key, and only viewed by myself. This information will be kept for three years following the completion of the study, at which time it will be destroyed. At the end of the phone screen, if you are eligible to participate, I will give you a 3 digit code. This will be used to link your information to the mailed questionnaires and to your interview responses. Remember that you do not have to answer any question that you do not want to, and you are under no obligation to complete this phone screen or the mailed questionnaires. However, you will receive either a \$10 Target or Starbucks gift card for agreeing to complete and return the mailed questionnaires. You will be provided with a stamped and return addressed envelope for your convenience. Do you agree to participate?

Yes/No Date _____

Name: _____ Sex: _____ Date of Birth: _____

Mailing Address (for questionnaire and gift card): _____

Phone: _____ Cell: _____

Race: _____ Ethnicity: _____

Marital Status: _____ How many children: _____

Age of son/daughter in question: _____

Date of placement in community-based residential facility: _____

What is your son/daughter's specific diagnosis? _____

When was the last time your son or daughter was assessed for their level of Intellectual functioning level (IQ test): _____

What were the results of that assessment (What was their IQ level/diagnosis)?

Appendix B2

Informed Consent, with Appended Assent for Audio-Recording

Parental Attitudes toward involvement in the Lives of Adults with Intellectual or Developmental Disabilities Following Residential Transitions

Informed Consent

In this study, the Principal Investigator (PI) and Dr. Michael Petronko are exploring the expectations and attitudes held by parents towards their level of involvement in the continuing lives of their sons or daughters, after they have moved from the home to a community-based residential facility. This research is part of the PI's doctoral dissertation work. You will be asked to complete two questionnaires which will take you approximately 40-60 minutes. At the end of the questionnaires you may elect to be contacted for a follow-up telephone interview, which will take approximately one hour. The telephone interview will be scheduled according to your convenience. As a token of our appreciation, you will receive a \$10 gift certificate to your choice of Target or Starbucks for completing and returning the questionnaires in the stamped and addressed return envelope, included with the questionnaires. If you choose to participate in the follow-up interview, your identification code will be entered into a drawing for an Amazon.com gift card. All gift cards will be sent to the address given in the initial phone screen in a blank envelope. We are seeking approximately 15 participants for this research.

As you answer the questionnaires, please realize that there are no "right" or "wrong" answers, so respond honestly. Your answers are completely confidential. You have been provided with an identification code that will be used to link your responses to your demographic information obtained by telephone. All material that contains your responses will only include this ID code as a means of identification. All electronic and paper materials that include your responses will be kept in a locked cabinet in a secure office. All demographic information and ID codes will be stored on a password-protected database on a password locked laptop and kept separately from all other materials. All information will be destroyed after the study completion.

The telephone interviews, if you elect to complete it, will be audio-taped. This is solely for the purpose of accurate transcription and coding of the data. All audio-tapes will be kept in a locked cabinet in a secure location, and will be destroyed after the study completion. The principal investigator will conduct all telephone interviews from a private office.

Your participation in this study is voluntary. Your cooperation will help our research, and may help to inform future research regarding how to make this transition easier for parents. It is also possible that your participation in this study will help your own self-reflection and personal growth. At the end of your participation you may be provided with information regarding parental-support groups, individual treatment options or other resources, if you so desire. You may withdraw from the study at any time with no penalty to you or your family members. Some questions may elicit feelings of discomfort. You do not have to answer any particular item if you do not wish. If you become unusually distressed by any part of your participation, you may contact the principal investigator for suggestions as to whom to contact regarding your distress.

Thank you very much for your time. If you have any questions about the study, please contact David Cernikovsky, Psy.M., of the Graduate School of Applied and Professional Psychology (GSAPP) at [REDACTED], or at David Cernikovsky, GSAPP, Rutgers University, 152 Freylinghuysen Road, Piscataway, NJ 08854

If you have any questions about your rights as a research participant, you may contact the IRB administrator at Rutgers University at:

Rutgers University Institutional Review Board for the Protection of Human Participants
Office of Research and Sponsored Programs
3 Rutgers Plaza
New Brunswick, NJ 08901-8559
Tel: [REDACTED]
Email: humanparticipants@orsp.rutgers.edu

Sincerely,

David Cernikovsky, Psy.M.
Principal Investigator
Doctoral Candidate
Graduate School of Applied and Professional Psychology
Rutgers, The State University of New Jersey

Michael R. Petronko, Ph.D., ABPP, FAAIDD
Co-Principal Investigator
Research Professor, Director
Anxiety Disorders Clinic
Center for Applied Psychology
Graduate School of Applied and Professional Psychology
Rutgers, The State University of New Jersey
797 Hoes Lane West
Piscataway, NJ 08854

Name of Participant (Printed): _____

Signature of Participant: _____

Audio-Recording Addendum to Consent Form

You have already agreed to participate in a research study entitled: “Parental Attitudes toward involvement in the Lives of Adults with Intellectual and Developmental Disability Following Residential Transition,” conducted by David Cernikovsky, Psy.M. We are asking for your permission to allow us to audiotape the interview as part of the study.

The recording will be transcribed to ensure authenticity of responses, which is important for data analysis. This analysis includes carefully reviewing the transcripts in order to discover common themes, similarities, and differences across all participants.

The transcription of the recording may include some information about you and your son or daughter, such as your age, ethnicity and gender. It will not include your name, or the name of your son or daughter. Instead, you will be given an identification code and a pseudonym. Only the principal investigator will have access to the code, which will be stored on a password protected database. All recordings and transcripts will be marked only with your ID code and stored in a locked filing cabinet in a secure location. This information will be permanently erased and destroyed three years after the study ends.

Your signature on this form grants the investigator named above permission to record you as described above during participation in the above-referenced study. The investigator will not use the recording for any other reason than that stated in the consent form without your written permission.

Participant Name (Print): _____

Participant Signature: _____ Date: _____

Appendix C1

Transcribed Interview: Anna

[00:01:50] Interviewer: When did you begin planning for your son to find a residential placement?

[00:01:55] Anna: Probably when he was about fifteen, I started to investigate, a best case scenario, in which he would receive the level of...the highest level of need, so that he would be able to receive residential housing, if that makes sense, because children who receive residential housing need to be in crisis level, and I started working, like I said when he was about fourteen, fifteen, in order to rack him up to get that level of involvement.

[00:02:39] I: Ok, so it sounds as if you were trying to establish his level of need fairly early on, several years before he ended up moving out. Is that correct?

[00:02:50] Anna: Correct.

[00:02:51] I: How long ago specifically, did your son move out

[00:02:56] Anna: Well my son moved out when he was seventeen. He moved out to be a residential student at the [State] school for the blind. So that was kind of like a, beginning of him transitioning from where he was, at a regular self-contained special need school, and he qualified, being visually impaired, for the [specialized school], and they had a residential program. I knew that would put him one step closer to receiving the highest level of need when he turned twenty-one.

[00:03:38] I: And so, he moved out of the home first at age seventeen. Is that correct?

[00:03:41] Anna: Correct, but he was at school for five days then he came home on the weekend, and then during the summer time, he had also, he qualified for the extended school year, he would go for the month of July. And there go back to the five days and home on weekends. It was stepping stones to the full transition to a group home.

[00:04:19] I: Ok and so, where, he's living in a group home, as you would call it right now?

[00:04:23] Anna: Mmhmm.

[00:04:25] I: And how long has he been in that group home?

[00:04:27] Anna: He moved in the day after he graduated, so it was probably June of 2013. He moved out of his residential, he went from his residential at school to a

temporary housing, until his house had been fully renovated for him to move into permanently.

[00:04:51] I: So it sounds as if you've gone through two transition periods, one where he spent much of the week out of the home, but lived with you on the weekends, but now he's also moved out full time.

[00:05:04] Anna: Correct

[00:05:06] I: Ok. So, that's interesting. I'll make sure throughout the process to try to establish which of the transitions I'm talking about, during the process, OK? So, would you please just describe your expectations for what your role, what sort of role you would play in the transition process, I guess both, yourself.

[00:05:37] Anna: Well the [specialized school], that was, purely my decision, in the sense that the regular school did not have adequate vision support, and he was eligible, I had to first get the school system to say basically they did not have visual services as needed, and so I had to get the school board to agree that he needed to go somewhere else to receive services, and those services were the [specialized school]. So, that was one transition. You know, working, trying to better his education, and services, and also trying to build up his independent living skills when he would come home. And then with the...So that was all my decision. That wasn't the school, that was my total decision, me totally involved with what was going to happen with that as the next step. For the transitioning into the group home, again, that is up to the parent. There is a... you have to first decide what you want for your child. Do you want your child to be at home and get services, or do you want your child to go to a group home for independent living. So a lot of that depends on your feeling as to how you want your child's life to go. You have some input, you know, from teachers, up to where different level of children can go. You know, some kids are more highly educated, or more mentally capable than my son, who aren't physically impacted, my son's in a wheelchair, so you have children who have Down's syndrome and all. They can live at home and be very happy, and go to a day program, and that's the parent's decision, and my decision was to figure out what would be best for him, whether to have him at home and find a day program for him, or find a residential program. So it's basically it's driven by the parent. So it's the school will kind of help you as much as they can, you have...[state disability department] assisting you and giving you information, about services, and where some are available, but basically it's just pounding the pavement as a parent.

[00:08:24] I: That's very helpful, a fantastic answer. When you say "Giving you information" it sounded like the school staff. Can you be specific as which school staff, and what information?

[00:08:35] Anna: Well with the [specialized school] that was basically, what they were doing was, were coming to [name] County because they did not have visual education, so they had the contract, well they didn't contract, but if they contracted the [specialized school], and they came down once every two months, so they were kind of involved as

how he did. I was thinking this would be a really good place for Adam to be, and get better education, and independent living, because of them knowing and having all the tools visually impaired children need, so for the staff at the school for the blind, while he was in the other school, was key for him getting there. And then the staff at the [specialized school], there was a transition specialist, who helped, but I gotta tell you, she made, kind of basically what they do is hand you a packet of information, and like "here you go" haha, and you have to like I said, do all the work, they give you a package and you have your, um, [state disability department], your services coordinator for the [state disability department], and mine was excellent and she would also help me in, you know, giving me, you know, here's a bunch of agencies, you can try that. And then she helped me contact them, and offered to come with me, um kind of thing. So they were helpful too.

[00:10:23] I: So did you, so it sound as if you took a very hands on role during the transition and people gave you some information and some assistance, but as you said, you pounded the pavement.

[00:10:36] Anna: Yeah, the parent has to be hands on. If the parent, um, I wanted... When my son was... when he went to school, I was the parent advocate, um, for the state. And it helped him, I would put out a newsletter, it was called [name of newsletter], and it was a newsletter of different seminars, different things available to parents. Now it's up to the parent to, find out all this information. You'll get a flier in his backpack saying, there's a workshop on SSI. You don't know how many people get these things, and their children are way past twenty-one, or they're nineteen, twenty, twenty-one and they know nothing about SSI. And I'm like, "your child should have been receiving money since he was eighteen years old!" "What do you mean? I've never heard of this." And you're like "Cause you didn't ask questions." They just relied on everybody else, and there's just these parents who rely on teachers, and other people, when they think that they're gonna do what your child needs. A special needs child, it's just not the way it is. Not in [State].

[00:11:51] I: Ok, So. Did you give any thought before when he moved out to the group home, as to how his moving out would affect your role as a parent?

[00:12:03] Anna: Oh yeah, absolutely. I mean I am his legal guardian, so basically, bottom line, I do have say over everything. You know? Because basically my son's at the level where if someone says "I need to give you a flu shot" he might say "No", you know? No. And you have the people who are obligated, um, The ARC of [city] is, like, obligated because he is eighteen, over eighteen, and he's an adult, that he does have his say, with everything like "do you want to get a haircut" you know? "No". "Do you need to get, um this," and he'll say no. I'm like, you know, and they're like, we can't, you know, go against his wishes. And I'm like, you know, "give him to me, we'll take him home, and take him to the barbershop to get his um, haircut. So um, you know... My thought is that I have, basically, I will make all the decisions for him, for his life. Medical decisions... But they want to be able to take him and become involved in taking to his doctor's appointments, being involved. And I knew that would happen, so basically I still have the power of bottom line say, yes or no.

[00:13:32] I: So, the way you described your role, is, I've think a pretty clear idea. Would you say that that's how, your role is? Or your level of involvement, has it changed at all since he moved from the home?

[00:13:51] Anna: Oh yeah, and it's been a good change. It gives a mom a tremendous break, hahaha. And that's, that, you gotta be honest. Having a special needs kid at the level that my son is, is tough. And it's extremely tough because... and it's even a little bit tougher in the sense that when he would, um... come home from school on the weekend, he was just like a normal college kid, at that age. He didn't want to be home. He wanted to be with his friends, he wanted to be back at school. So you know, instead of the normal teenager going to his room and pouting he's acting like a two year old having a temper tantrum. So that was difficult in that he had gained such independence when he was living in school with friends, and then he had to come home with Mom. And although he loved Mom, he wasn't happy. So having him now at his group home all the time, I don't have to deal with him not wanting to be here. And that when he does come, he wants to spend time with Mom, and he knows he's going back to his friends. So for me, it's a really good thing, because I feel that it makes him... he's happier when he's more independent. And the happier he is the happier I am, so it's been good for him and it's been good for me because I have my life back, basically. After twenty-one years you really devote to your child, and everything revolves around them. I mean everything revolves around your children, but a special needs child who really has no other, um, he can't do it on his own. Like, "oh, get a job, make money, eat macaroni and cheese for a year, and then you'll figure out what to do with your life," he can't do that. You know? So now, he's in a an independent situation with people helping him be independent, but I know he's taken care of, kind of thing.

[00:15:56] I: Ok, so, one thing you mentioned in there was it's, it seems as if both he and you are happier when he comes home now.

[00:16:09] Anna: Yeah, he and...I mean, it's always, people look at you, you get used to having your child and the temper tantrums, and it's just... I'm getting married and to me when my son's over here, when he is home on the weekends, you know, first thing, 6:00 AM he gets up, he turns on the radio full blast, he gets his trucks and I mean the whole house is rocking, because he's ready. To me, I just lay in bed, it's normal to me. It's not normal to my husband. He's just like, "what the hell is that?" And Adam's like "I'M AWAAAAAKE!" But to me it's very normal so I'm the person used to all the different things that he does. So when he comes home to visit, Mom's as happy as can be, and he's just happy, but my husband is like "Oh gosh" and it can be a different kind of situation. So, no, he's happy when he comes home, because he knows, you know, it's going to be a turnaround and he's going to go back to his friends, he's going to go out and get to go to a dance, and gets to go here, or he gets to go there. When he didn't really do that with me, all his social involvement was either through school, or now is through the home.

[00:17:33] I: So it sounds as if, you know, one of the things, if I can go back, you said that you knew part of it was through having legal guardianship, that you knew a bit about, or expected what your role would be. But did anybody specifically discuss with you,

what your role might look like as a parent after he moved out? Or how your role might change? Did anyone prepare you for that?

[00:18:04] Anna: Specifically, no. No. There was no addressing of that specific topic. Um, yeah, no. There was no... And, I know I have a girlfriend who is actually my college roommate, who, her child is autistic, and her daughter moved out, but she did not go through the process that I did with him being twenty-one, and him going away to school, and she was shell-shocked at the difference of when her daughter was away, and she was not prepared that she couldn't just drop by whenever she wanted to. And she could not do this when she wanted to, and it was such a different shell-shock for her, so I know it wasn't discussed with her either. So I was kind of prepared, I kind of gave up a lot of that when he went away to school. And, you know, not always having to be on top of him. And she was not, so really it was cutting of the cord for her. That's just something that was really not discussed, yeah.

[00:19:21] I: You say that you were ready for this transition based on what you'd experienced when he moved out during the weeks to school. Do you think that... Can you compare your, reaction to that point, when he moved to the school for the blind?

[00:19:43] Anna: Yeah so when he moved to the school for the blind, it was, it was great for him, and it was a release for me. But then with the school, it was just as if I still was fully responsible for him. So if he was sick, I had to go and pick him up. If he had a doctor's appointment I would be the one who had to schedule it and take him. So in that whole sense, I'm still the mom. I'm the one selecting his diet, I'm the one to take him to the dentist appointment or who take him to emergency room, if they need to call 911. It was my full responsibility as a parent, um, even though he was there. Now that he's moved out, it's totally different. All of that is gone now. I can not make doctor's appointments, I do not have to go. You know? If he's sick, he would not come home, he would stay there, and an aide will take care of him. So, it's like totally my parenting in the nurturing is there, but with taking him to the doctor, that's all, you know, what they do for him. But, I am informed. So, you know, I'm still in the know. And I don't... a lot of it is, you know, I make myself involved in the house, and I know the house manager very well, and I know aides very well, and it's continuing that communication, that, even though, I don't need to know, or if it was another parent, they wouldn't necessary call them to ask. But for me they do still. So it's kind of my insistence of just being abreast of my son's condition all the time.

[00:21:53] I: Ok. So, would you say that... it sounds as if you were fairly well prepared, and had an idea of what it would look like. Would you say there have been any surprises in your role, or your level of involvement so far?

[00:22:10] Anna: Um... any surprises.... Um, not really. Well, what surprising was, that surprised me, it wasn't a bad thing. It would just kind of me the level of... Like I had the nurse call me and the doctor's office called me because of Adam. They hadn't changed his information, and you know, they wanted to set up an appointment, so I set up an appointment. And the house manager called me and scolded me for making an

appointment because that was his job. And I was like, "well, wait". That was kind of like... I can understand it, but that was kind of a slap in the face, that that kind of might, that that part of my role was taken away. And that you're not allowed to do that anymore. Although, if I pushed it I could, you can do whatever you want. You're the parent. I could pull him out if I wanted to. I know I have that ultimate decision for my son. But just kind of letting go in that sense of "Ok, alright, I'll not step on your toes with my son, ok." But that was kind of a shock, and that, I mean I was really kind of, you know, really prepared and... and yeah, I've been pretty prepared for what I would be going through and um... what it would be like with him gone.

[00:23:47] I: So you just recounted a very nice story about one of the points at which you felt as if you had, to use your words had been "letting go" a bit. Was that the major moment for you? Or were there other moments in which you felt yourself letting go of the responsibility?

[00:24:06] Anna: Well it was, yeah. So they are...um... you know, I've given them, like, for his future work program, you know, the [specialized school], they didn't have a work kind of transition program for children to start doing vocational stuff. They did some work for him in school. So he, like, stocked shelves, and inventoried things. But they never had him go out into the workforce with an aide and kind of transition like other schools do. And I was kind of pushing for that. But some of the things that were like, well... When we had his meeting after a couple of months, I was like "He likes this, he likes this," and they were like, "well now, he's doing this, and likes this." And I was like, "oh really?" So it was kind of like he was, he didn't... Just like any child, he's different with other people than he is with you, so he was exploring interests, that with me, he would never want to explore. No, no, no, but with other peers, he would become extremely interested in that. And I was kind of like, "wait a minute, you didn't want to do it with me." But then you have to go back and realize, he just did. It's just like my daughter she would do things without me at a certain age. He's the same way. He's at an age where he wants independence, he wants to be with his friends, he doesn't want to be with his parents. That's a hard thing to come up to accept when, he's been your basically your baby for your whole life. So even, more so than your kid going off to college and that kind of stuff. Because he's so dependent on you, I guess that's what I mean. Normal children aren't totally dependent, they can go off and start their own stuff. And you have someone who's so dependent on you. And then they're off for a month, and you see them doing things he never had with you. That's kind of like "Wow, was I holding him back?" Kind of a guilt trip. It's a good thing, but it's like, "wow, I feel bad because he wasn't doing this with me."

[00:26:32] I: One of the phrases you said, "that was really hard," I think you did a good job explaining some of the details. I am very interested not just how you envisioned yourself, and how you've reacted. But what you've felt about what's happened. When you said it was "Hard to see that" can you elaborate a little bit?

[00:26:55] Anna: Well... It's a parent's, um... It's like you're starting to feel failure, that you didn't do enough. I think it's a normal reaction. Like with a lot of things it's like,

"how could I have missed that? How could I have not worked that with him when he was with me? How did I miss that?" And it's the whole as a parent, just this child needs so much from me, and I didn't have enough to give him because I missed that. That was a lot. And that's where he seems to me that... You know, I got a call from his aide the other night, and from his house manager, and she said, "I bought him a pair of shoes, his shoes didn't have ties." And I'm like, "oh god, what did you do that for? He's not going to tie his shoes, I tried for years, and years, and years." And I said "There's no way he'll go for those things." And she's like, "you know what? He's tying the first loop." And I'm like, "You've gotta be kidding me." So you're like, you feel... you weren't adequate as a parent. It's just basically a lot of what I've felt. What did I miss? Why didn't I do more? Why couldn't I figure it out? That's kind of how I've felt with him with that.

[00:28:26] I: Ok, I think, first off, that was a very excellent anecdote that you chose. So one of the things that you said in the prior answer was that "it does feel good, but that it also can feel bad..."

[00:28:43] Anna: Well it's... Which part of my feeling good and bad do you want to know about?

[00:28:52] I: Well, so I think you explained very well about some guilt that you felt, but you also mentioned that there were parts that felt good.

[00:29:04] Anna: Yeah, I mean, it's good to see your child bloom. Um... it's good, you know, when you have a child who goes away, and after their first semester of college and being away from home, they come home a little bit different, a little bit more mature. First, they fall back in to the role, they can't do their laundry, they can't cook their own food. But you see a difference in them, and that's extremely satisfying because... it makes me feel I did the right thing for Adam. That's, that's a good feeling when you feel you really done something right for your child, and I really feel that this was the best thing for him. And that makes you feel good. That I got it right.

[00:29:58] I: Ok. Are there any areas of your son's life that you have been more involved in, since he's moved out than you expected to be?

[00:30:11] Anna: A little bit. There's been an adjusting of dynamics of the staff in the group home, and it was a little different in the...his... there was a lot of... he didn't have steadiness in his aides at first, and the reason was because the house that he was in, they weren't ready by the time, I mean they didn't have...they kept getting put off when they were going to move in the two other children who had graduated the year before. They kept getting put off that they were going to, um, move in, so it was kind of like, everything was on delay and Adam's life was the last thing. So, when it got approved they started the housing. So, they didn't have the aides lined up, and when he would have temporary aides, temporary aides, more temporary aides. At school he had the same aides for years. And so what I had to get involved in was, every time I would go over there, they didn't know what to do because it was somebody new who didn't know him. So there would be something I had to fix because, you know, they had moved... they had folded

his clothes, and it was in the wrong drawers, and he was upset, and I was like, "because his underwear is in the wrong drawers! What happened to [aide's name]?" Well, he's not there, so I had to be very involved in small functions and help the house manager come up with an routine, just because I knew so much and had, like, a list so that the temporary aides could go through it and have a cheat sheet until he got his regular aides that he's had for a few months. So that was difficult. And then it was also that he was always calling to be like "Mom, mom, mom" and he wasn't happy because, you know, they didn't give him his chocolate milk. So it was the little things that his... His routine, I had to help them establish, when we had actually gone over all of that in detail time, and time and time again. Before he went to the residential, you have to go over ever little detail, like his diet and his medicine, you know? His routine, because for these children routine is, um... key. For them not to have milk out, or to have their brains go off wire because something's not right and they worry about it and worry about their routine. So I was up there a lot in the beginning trying to help them try to establish his routine, and that was something that was kind of unexpected.

[00:33:08] I: A couple things I heard you say there was you were up there "in the beginning" and you used a lot of past tense with that "I had to be more involved in that." Would you say that things in that respect have changed?

[00:33:23] Anna: Oh, yeah, things have settled down. It was now that he has his... It's just like throwing three kids, even they knew each other, if you put people who don't know everything about each other, and they're supposed to take care of them. It's chaotic, and the kids don't know what to do and they're unsure. But as the time has gone on and they know the help now, they know the routine, Adam's routine of getting up and going to his work. And the van picks him up, then he gets to work, he gets a sandwich lunch, and when he comes home, he lays down. So they know Adam. When he walks in the door it's "Hey, Adam, come on let's do this." And so I don't hear from him. Haha. I'll get a call like "Mom don't come up I'm going to a dance," and I'm like "Ok." So it's just like, he is he's happy. And so he doesn't need... he's happy without mom being involved as much. And, so I step back and let him go.

[00:34:39] I: So you've "stepped back"?

[00:34:40] Anna: Yeah, oh yeah. I've stepped back incredibly.

[00:34:46] I: Can you describe that? I'm just interested in what that means when you've "stepped back."

[00:34:52] I: Well I mean it...I'm letting him live his life. There's another mother in the group, and she's caused problems, and that's another issue that you have to deal with in group homes, is the dynamics of the parents of the children. She's a hoverer, she is there, she's there all the time. I mean, if the kids go to the ballgame, she has the van meet her. And she's not letting go. And it's become a problem because she complains, and the children's schedule was starting to have to revolve around what she wanted, and myself and the other mother were like, "wait a minute, if you want to take your child out that's

ok, but when our children are involved, we trust the staff and let 'em go." So for me, I'm not going out there as much. I talk to him on the phone whenever, so I'll call, he'll call me. He likes to get letters. I mean I'm not up there twice a week anymore. I'm up there once every two weeks. And with that, I have a house up on the shore, so I am able, now that he's not home on the weekends, to go up to the shore, and to enjoy my house up there, and I have this new house for two years, my husband and I. We hadn't been able to go up there and enjoy. I was always on call for Adam he was always at home on the weekend with me, or if he was at school, I had to be ready to go and get him. If they needed me. My whole where I went and what I did was tied to Adam and that's not it anymore. So I have this tremendous freedom of being able just to be myself again. And I do thing I haven't been able to, because of raising Adam.

[00:37:02] I: How have you reacted to having that freedom?

[00:37:04] Anna: Oh I love it. (laughs). Hold on a sec...Sorry my daughter's coming in from [west coast]...His sister. She's out in [west coast] this is as far away as she's been in her life, and she's supposed to be flying home. And that's one of the reasons it's really nice for...I mean... a little bit of my history so you can understand the way I think is...I had another daughter, Adam's sister, who passed away nine years ago, suddenly. And I have another daughter, and then I have Adam. So, I learned that I had to let go years ago, and that let me know that. You know, you gotta let your kid let go sometime. Mine was an ultimate type of letting go. But it was easier for me to let Adam go because I knew he was there, and I knew he wasn't dead. So, for me it wasn't hard, because it was like, he's still here. It's not like he's gone. And with so many other parents and they put them into a group home they're like, "oh my god, they're gone." And they're not. You know? They're just not. You can see your child any time you want, but I think that's how a lot of children react. Because they're so involved in their children's lives that it's just not that way anymore.

[00:39:25] I: So you felt that that helped you with the letting go process.

[00:39:29] Anna: Yes, absolutely. One more second hold on...Ok sorry.

[00:40:07] I: Before we move on. I want to go back to the question I asked in terms of... How have you reacted to the freedom that you described having?

[00:40:23] Anna: Well, I totally, you know, I enjoyed it. It was the level of stress in my life tremendously decreased. I mean, because when, it was almost like fringing that, um, what was I going to do with him this weekend? What was the deal now? What was I going to do to keep him happy? I mean he's up at six and he doesn't want to go to bed until ten. So you're...um... you would have to... I'm sorry what was I saying? My daughter's texting me.

[00:41:14] I: That's ok, you just said how you had to act when he was still living at home about being up at six, and wouldn't...

[00:41:19] Anna: Oh yeah. So it's stressful. And then my husband, who was very good with him, but it was like, he had a different threshold level, than me with my son, because that's all I knew. He didn't have a special needs child, so I was stressed about his reaction, when he was actually fine, yet I was stressed about making him happy, making Adam happy, because Adam wants "Mom"... He, you know, wanted full 100% attention. And, you know, when you do that, when you work full time, it's exhausting. It's just totally, totally exhausting. So, it was a relief, and less stress because you're not having to deal with, you know, that anymore. That was great. That was to me, it was a major independence.

[00:42:26] I: Um... One of the things that you mentioned a couple of times, I think the phrase is "It's not like a child just going away to college." And you've mentioned that another daughter. How old is she?

[00:42:44] Anna: She's twenty-five.

[00:42:47] I: So, are you saying it's not just like having a child go away to college from experience?

[00:42:55] Anna: So, I mean when she went away, to college, it was right after her sister had died, so that was really hard. Because, her sister died in [spring month], and she went to school that September. And it was I kept telling myself that she was still there, she's still there, she's still there. And she would come home because she was worried about me. And so I saw her a lot. And so as I got used to it, and she was feeling more comfortable, and she wouldn't come home as much, it was like she was away but she would come home on the weekends and you'd see a change, and they want to go out with their friends, and don't want to hang. But they still want a full cooked meal and laundry. And that was kind of the same thing with Adam, increasing independence in her, and growth. That's awesome, you see your child do all the things that you have strived for them to do, and you believe you taught them, when they're on their own you start to see those lessons that you taught them come about. You see, you know, her doing things the way that I taught her to do. Or handling a situation the way I taught her to do, or organize things the way I taught her to do. And she uses the tools you taught her, and you don't see that at first when they're home, but when they're away and the parents not doing it, you know, it's tremendously satisfying, and it's the same with Adam he would come home, he would have more tools than...you know, things that I taught him, he would... at school they would say "oh, Adam, you did this, you did that," or he wanted to do it this way, because this is the way Mom did it, so even though it's different levels it was very satisfying to hear that. While away, they're growing on, and moving by the rules that you had taught them.

[00:45:21] I: OK. So one thing if I can just go back a little bit was... Let's skip that. I have a question. Are there... Oh I remember. You mentioned earlier: you feel as if you can visit any time. "He's not gone, I can visit any time I want to". How often do you visit him in person?

[00:45:56] Anna: Now? Probably once every two weeks. He was home for Thanksgiving, for four days, and he couldn't wait to get back. He was ready to go. Other than that, it was like the manager will call me, and this weekend he's booked solid, and there's no time for Mom to come visit. And I'm not offended. If he wants to go out and go to the dance, to go do this, you know, let him go with his friends. He's just that age. I was doing that stuff with my friends. And so, you know, if he calls me and says he wants me to come, I'll come. But that's rare anymore. A phone call is enough.

[00:46:48] I: And how do you feel about that level of contact?

[00:46:50] Anna: I feel ok, actually. Because, I gotta tell you, another thing about me, I had a brain tumor, and... three years ago, and it scared the hell out of me. It's fine, I'm fine, I had it removed. It was benign, but I went into seizures. And I was very lucky that Adam had been at the school already and my husband was there. It scared the hell out of me... it was a rude awakening of "what happens if something happens to me?" And, I'm like, you know? It scared the hell out of me. And that was another reason I was so insistent he got into residential because, again, he has his sister, that's... He has his father, who's semi-involved, but I didn't want the burden to fall onto his sister. So I was insistent, and dedicated to making sure that he was set for life, and to live a life happily, without Mom. And, so, he's moving in that direction, and that's exactly what I wanted.

[00:48:13] I: Now, you said that "that was another reason" why you wanted him to find residential placement...

[00:48:19] Anna: Well... it was because number one, I thought it was the best for him, but another reason... it just confirmed more that I was doing the correct thing.

[00:48:35] I: So you had already decided before then.

[00:48:38] Anna: Oh yeah, he was already in the [specialized school] then, and that was part of the process of getting him residential, and it was more like a confirmation. You know? I didn't want to burden his sister, because already had to deal with him for twenty some years, and she's been my rock. She's been my rock. When work or school would call, she would go out and get him. And, I didn't want her to have to deal with that anymore. I wanted her to be free from all of that. She felt responsible. He's all she has now, her sister is gone, and so she's protective of him and protective of me, and she would do whatever she felt was responsible, and she has responsibility. So it freed her. And that was a just another reason that confirmed that this was the thing for him.

[00:49:39] I: Thank you for answering that. I have a couple questions. If you recall I sent that survey regarding the level of parental involvement that you anticipated having. Just a couple of questions. In regard to romantic or sexual relationships, you put mostly as "not applicable."

[00:50:10] Anna: Yeah. It's just that... Like, he went to the prom. He had about five girls ask him to the prom because he is so incredibly social. And, he, um... So, I wasn't going

to say "No, you can't go to a dance". I mean, it was all supervised and he went with a date. And he got her flowers, and the two of them danced. And so, something like that, that's why I answered "kind of." But he would never ask a girl out and go on a date. He just doesn't understand that. I mean he likes girls, he likes to talk to girls, but he doesn't understand any type of sexual relationship, or... it's like everyone's his girlfriend, his grandma, Ms. [teacher], everyone. He just doesn't understand a one-to-one type of relationship.

[00:51:16] I: So if, another person, or a woman from another group home hypothetically instigated a relationship, how much would you anticipate wanting to be involved in the decision making?

[00:51:32] Anna: First of all, they would call me. I know they just would. That's something that, I guess they have to respond to, but if he wanted to go out with somebody, he has to have somebody with him, so it's never unsupervised. He has a one-on-one, he can't go anywhere without someone. So right there he stays, you know, safe. He's got a great aide, and the only reason I would want to make sure I was involved in anything like that is to make sure if he was in a vulnerable situation. He would never be allowed to go out with somebody who would take advantage of him or something like that. They know that. So, I trust that they know that. I mean they know that. So I trust them on that to make the decision on what he should be able to be doing or not.

[00:52:29] I: So you said "They". When you ...

[00:52:33] Anna: His house manager. His house manager, she worked with him, at the... she was an aide at the [specialized school], so I've known her for years. So, I mean it just all worked out for me, for Adam, really, really well. Some kids move into new houses and they don't know the house manager, I would be much more...it depends on who the person was... you know?... I'm much more trusting with [manager] because I know her and trust her. And, but then again, he's got a one-on-one. Nothing is going to happen to the boy as long as the one-on-one is there.

[00:53:17] I: Alright. Again, one other thing you mentioned, under health concerns, when asked about his possible choice to use alcohol, tobacco, gambling, any of recreational drugs, that was "not applicable" to Adam. Could you explain?

[00:53:36] Anna: Well, it's not applicable because, he doesn't understand what it is. You know? He doesn't... He loves chocolate milk. If you stuck whiskey under his nose he'd probably gag. He's not offered that choice... um. And my guess is that he wouldn't be alone where somebody could offer it to him, for him to take, because his aide wouldn't allow it. So, he doesn't have the choice in the sense that if he wanted to try whiskey and he said "yes," [the aide] would say "no." And that's why it's not applicable. Because he's not going to have a choice in that. Or smoking, or drugs, that's the way that it.

[00:54:23] I: You don't anticipate that he would ever be presented with that? Or choose to involve himself in that?

[00:54:32] Anna: No, no, no, no.

[00:54:36] I: What changes if any, is there anything that you would like to change in your role as a parent now that he's moved out, or in your level of contact or involvement in general?

[00:54:49] Anna: Um...I mean, I think I'm involved at the right level. It's not too much. And it's not... my presence is known. I like where I am right now. I've become very kind of even-keel. I'm not hovering, but they also know that I'm there, and they know that I check in on him, and I check in on any other children. And that's the other thing. They all know that, the other parents, we, look out for the other children. So we're kind of a whole kind of a special little family here. Because we have worked together. Um... you know, as parents who, you know, they had a Thanksgiving dinner, so we all went there. So they know that the parents are involved. They know what's going on. Even if I haven't been there I know [other parent]'s been there. So, you know? And she knows if she can't go to something, I'd be there. So we kind of, I think we're both kind of, you know, in a good spot so, I think my role is good.

[00:56:09] I: So just a couple more questions. How did you foresee your level of in his life changing, if at all, in the next five or ten years?

[00:56:24] Anna: Um...I think it's going to be about the same. About the same. I think I'll always be involved to the level I am right now, as long as I'm capable of it. I wouldn't be any less. But if he might have to have surgery, then I will be at the hospital staying with him. So then my level of involvement goes right back to "The Mom." I'd be staying with him every night, and that would not be responsive of... That's when I would take over. That's not, I'm not going to let somebody else do that with my son. So if something like that happens, my level of involvement would increase. But I think I'm on a good leveled keel right now. And as long as things are going well, which they seem to be, you know? I'm quite happy they are, um, you know, going.

[00:57:27] I: Um... are there any other areas besides if something related to his health were to occur where you would anticipate your level of involvement changing?

[00:57:39] Anna: No, he's basically healthy. I mean his health problems are with his spine. He might have to have spine straightened, so that's a very long, that's a several month process kind of thing. And then like I said, I'd have to become very involved because there would be physical therapy and I'd have to take the helm on that one. But other than that, I mean, you know, he's working. You know, your kids are growing up. He's growing up. You hope for grandchildren, though not from him, but you kind of step back and let your children grow up. You watch 'em and make sure they're not vulnerable. I'll always watch him and make sure he's not vulnerable to any situation but, um, and stay on top of that. But like I said, I think I'm in a really good spot with him, and I don't see anything, for him changing besides for the better.

[00:58:38] I: Was there anything that you wish somebody had prepared you for, that you would, for instance any other parent was going through the same process that you would tell them to prepare for?

[00:58:54] Anna: Oh yes. (Laughs). There's so many headaches. There's so much red tape, and so much... the process is kind of unknown. The steps that need to be taken in order or your child to receive services, there's like no clear cut set of rules. There seems to be a clear set of rules, but there really aren't. Your, you know, you get your services through the [state disability department] and you have your services coordinator, and you start finding out things that, you know, I didn't know. Like he should have been getting his... he was allowed to have the... insurance and medical insurance. I didn't know that. And there's all this paperwork that's out there, nobody says, here's the way. Um... It's hard to say... It would be great if there was somebody who could say, "If you want your child to be in residential, he has to have, a crisis level. If he doesn't have a crisis level he's not going to get residential housing."

[01:00:26] I: Sorry to interrupt, but how about anything that you would wish someone had told to prepare for, or that you would want other parents to prepare for following the move out?

[01:00:41] Anna: Be prepared for a bit of chaos. Be prepared that things are not going to be perfect. That, it's not going to be smooth. No matter how prepared everybody seems and all, it's a totally different situation for these children, it's a totally different situation for the aides, and the manager. And, it's not going to be smooth. There's going to be mistakes made. There's going to be "What are you giving him this for, he doesn't have that", you know, you get that. "He doesn't take that that, he needs his Miralax, but he doesn't need it four times a day." "Who said that?" That kind of stuff, I wasn't, I thought it would be much more smoothly, when he was first in there. So, that's kind of what you need to prepare for, and you also need to prepare for his work program also, when your children are in high school in the school system, and everything's running fine, because they've been in school so long, and everything's fine, and they're getting changed out of that routine into something new, even if they're just going into a day program. And those people don't know your child. And, you know, you're going to be expecting things to go "Why isn't he working yet? Why isn't he this yet?" They don't know your child. They need to find out for themselves, even though you've written a book for them on everything your child likes, how he does things, they don't read the book. They find out for themselves, at their own pace. And that can be a little bit frustrating but that's just the way that it is. So that's something that I would warn parents about. To expect that, and expect that everything that was promised. You might get a letter saying, he didn't get it. Things that you thought were all taken care of, you might get someone giving a phone call saying it wasn't taken care of. So even though you thought that you had everything, and had copied everybody and done it ten times over, something's not going to be done. And that was frustrating.

[01:03:06] I: So the last question, or it might be a couple. I'd like... could you briefly describe specifically Adam's housing situation? That includes the location in relation to

you, the type of house, how many residents, though I think I might understand that. And the type of staff he has provided.

[01:03:34] Anna: Um, so he has an aide at the center and then he has an aide at nighttime, and he has an overnight staff. So Adam is always covered. So are the other children, so we have lots of aides at the house. This house is a rancher. It's in a very nice community in [city]. It is a community that has covenants. So they had to be approved to get the house. And they had some trouble with neighbors, but they got the neighborhood to see it would be a good thing for them. So they were allowed to get the house. It's in a predominantly [religious] neighborhood. Um...the neighbors have welcomed them. Some are rude, but most of the neighbors have been extremely kind and invited them to picnics, to community picnics, and stuff. So it's, um, they had done renovations to the house to make sure that he, that they had room in the hallways, and they did the floor, and that the doors were big enough for wheelchairs to get through. So it's a lovely home. It's on an acre of land, in a wonderful neighborhood. They have their own van, mobility van. And, his aide has gone through training. They each go through three months of training before they're allowed to come on. Just overall working mentality, you know? First aid, certified first aid, and, um... you know, so he's got two... an aide on the weekend who's a tremendous man, and a woman during the week, those are his aides in the evenings. And they've got a gentleman at school, uh, the day program. There are two other children, [describes them]. They both left the [specialized school]. They graduated a year earlier than him, so it was kind of like, I hit the jackpot when they were put in this house together, so it's you know, everything was falling into place with this house for Adam. I live in [town] so it's about a 45 minutes trip to see him.

[01:06:23] I: Alright, that's all I have. Is there anything else that you think I should know, or that you think is particularly important, regarding your role as a parent now that your son has moved out, or the transition process in general?

[01:06:41] Anna: I think that's it. (Laughs). Well, yeah I think I pretty much said, yeah I've covered it.

Appendix C2

Transcribed Interview: Brian

[00:00:22] Interviewer: [Reads intro script]. Could you go over what the diagnosis of your son, and your daughter?

[00:02:06] Brian: Static encephalopathy of unknown origin. Which is a professional shrugging your shoulders, an "I don't know" They say that it's static, they don't anticipate... or expect it to deteriorate, but, um, they don't have a clue as to what's wrong with them, and we've been to many fine institutions across the US looking for an answer.

[00:02:33] I: And so, how old are they now?

[00:02:38] Brian: um Bill is 40, and Bridget is 35. Or [full name] is her legal name.

[00:02:49] I: And how far do you live from them currently.

[00:02:55] Brian: I live about eight miles... or ten miles from Bill, and four miles from Bridget.

[00:03:03] I: Ok, and how often do you see each of them?

[00:03:08] Brian: Uh, I see Bill probably, three times a month, he's in a group home. And Bridget, I have established a home for her and I'm currently hiring staff, so I see her, three times a week at this point. I imagine I'll see her about once a week, probably, on an ongoing basis for the next... year, or more because, I want to keep one of the shifts open to make sure that I'm around to observe the maintenance of the property.

[00:03:50] I: Ok, so that's interesting. That sounds as if that has been two different things your son is in a group home that was previous set up?

[00:03:57] Brian: Yes, he's in a... excuse me (coughs)... he's in a group home that's operated by [company] Adult Services Incorporated, that's a subdivision of the [company] corporation, which started out with the school, where he started attending at age seven, and then they have a work shop program that he graduated to at age twenty-one, and he's in that program, now, for I guess fifteen years. Wow, to think about it.... [laughs]... And then went into housing approximately fourteen years ago, I was sitting on the board at the time, and established a set of group homes...

[00:04:46] I: I'm sorry, you said fourteen years?

[00:04:46] Brian: Fourteen years ago they set up group homes. He's in there for almost ten. This [winter month] he's in there for ten years. [Date] he moved in. They opened up the homes, in you might say stepping stones. They opened up a first and then a second and then a third. He was in the fourth one that was established. Which my wife and I purchased the house, and donated half of it to the school. The [company] school. Um... and they get money from the [state] from the [state disability department], under contract, under a static contract with the state, to provide services for him and three other young men in that home. It's a four person house. They all have their own bedroom. Bill happens to have the master bedroom, so he has his own bath, if you will.

We had purchased the home, renovated it, and then sold half of it to the... or we sold it to them at a 50% off of market value.

[00:06:04] I: I'm going to want to cover that more in a little bit, just quickly to touch base, is your daughter with other, other...?

[00:06:13] Brian: No, Bridget, back then we did it differently. Because of our experience with the group home, and, I suspect, we'll get to it later, but I'm not totally pleased with it, because I have no say in the hiring and firing of staff. If I observe something that's incorrect, I'm expected to go to the manager, and to the assistant director and then director to get things rectified. And it's typical, um... I hate to say it, but it's typical not-for-profit bureaucracy, in that everybody moves kind of like, you know, the old joke the rabbit and the hare? Well the snail could beat their, their... I mean the rabbit and the turtle rather, I mean the snail could beat their turtle. Things move very, very slowly, and frustrated me to the point where, when we had the opportunity to get financing from the [state] for Bridget, we opted into what's called the [public funding] program, or commonly referred to as [public funds program], which allocates a budget for her, based on the, her need, which is evaluated by [public university], on a document called a [document name]. It's a developme...

[00:07:36] I: [Clarifies name of public university]?

[00:07:40] Brian: That's correct. They conduct the interviews, and they, on what is called a [document name] form. It's, I'm guessing it's about a hundred questions. It's a telephone interview, and they ask, Bonnie and I questions about Bridget. And from that, she gets a scoring, and that scoring is then converted into dollars. And based upon the dollars that were awarded to her... not awarded, allocated to her, the up-to-dollar amount, made available to her, we decided to purchase a home, purchase a house with our own capital dollars, and renovate it, and furnish it, because they do not provide any money for capital expenditure. So after, um...I guess putting... a little over a half a million dollars into this project, she's now supported by the state with a budget that consists of a waiver...um housing voucher, at what's called affordable housing rent for the county, so they pay \$888 a month in rent, which helps maintain the property, pay the mortgage and taxes. Um... so unless you've got some, uh, resources, you really can't do this. At least the way that we did this. There are people that go out and rent, or find a rental apartment. But it's extremely difficult, because as... well you're not really from [state] but it's very difficult to find affordable housing in [state].

[00:09:30] I: Well, I've heard tales at least.

[00:09:35] Brian: Yes, well, unless you go into the inner cities, and even they're not cheap, you're not going to find anything for \$888 a month. To my knowledge. So, um, unless the parents have, you might say, some wealth to share, this is not doable, however the state runs around touting it as if it's the best thing since sliced bread. uh... but as you well know, if you're working in the disabled area in [state], they've taken everything, thrown it up in the air, because basically the governor has very quietly told them all he wants them out of the business and he wants everything privatized. I mean that's where they're headed. Kick everything off to provider agencies and let them do the billing directly to Medicare, and be on the hook to any clawbacks, three to five years later when Medicare gets around to auditing. And, um.. there's a big fiasco headed right down... there's a big ball headed in the wrong direction.

[00:10:37] I: It sounds as if even though you did have the resources to set your son and daughter up in a way that I guess, you feel a little more comfortable with, I'm still hearing some notes of frustration and upset with...

[00:10:51] Brian: Oh absolutely! Well, for instance, the budget for Bridget, um... although be it [amount of money, in the hundreds of thousands] is allocated to her by the state, it basically goes for labor, because I have to cover her 24/7. As you saw from her Vineland scoring, etc., she's dependent on folks for everything. She has behavioral issues and she has diabetes. She's medically compromised, she's behaviorally compromised, and low functioning, but at the same time, I realize I'm going to die and pass on, and I have to have a program in place which at least somebody can administer, and, I'm more concerned with the trauma to her, in that, when Mom and Dad are dead, I don't want her to have to be relocated at that point in time. So we've relocated her now, while we can still be participants in her life. Same thing with Bill, that's the only thing to relocating the children outside of the home. Um...we're still very involved, particularly with Bridget, because she's younger and has greater needs. She's not as social as Bill. Bill, we put in a group home because he needed the socialization. Um... he always did well with other people around, so we tried to encourage the, uh, [company] group to put higher functioning folks in the house, which they did. They put two folks in who were higher functioning than he. And he relates more to the higher functioning kids, because he wants... he really is more aware and strives to be normal. Bridget on the other hand... my observation, she is very comfortable being an only child. She's happy or seems to be happy. She's smiling and happy living in her home. She'll tell people "my house". Um... she doesn't seem lonely, she has staff that comes in. Just shift workers, no one resides there, they're all shift workers. They come in and do their shifts. Bonnie and I have hand-picked them. We've hired some people that ultimately did not work out, and so we've terminated them and moved on to hiring other people. And I have two ladies starting on sometime this month or next because, it takes a long time to get them cleared because they have to go through finger printing, background checks, urine analysis for drug use, that sort of thing. So that we don't hire any known weirdos, is what it comes down to.

[00:13:31] I: Well that's very interesting. Hearing that, that, despite, you know, them having the same diagnosis, and... that you guys have... That it's tough enough to go through this process once, that you guys have found two rather different ways to go about...

[00:13:53] Brian: Yes, we chose, you might say, a fork in the road because, as I said, the level of frustration that we enjoy with Bill's house, we didn't want to duplicate it with Bridget. It's why I'm putting up a substantial amount of capital dollars, because the state does not put up any dollars any more, to buy any homes. Unless you're coming out of the institution, part of the Holms... Olmstead federal lawsuit, what, back in the nineties. Yeah, it was a long time ago. They're futzing with it, trying to vacate the institutions... Or [previous state program], which is for kids that were sent out of school... or out of state rather... for educational purposes, for schooling. And then when they turned eighteen or twenty-one, the school district said "ok, we're not paying for them anymore", and the parents said "well, I don't want 'em back, I'm not taking them back." So they left them in place, and they're out of state, and the out of state providers said, "well, this is almost like a free ride." So they're charging anywhere from 200 to 400 thousand dollars a year for the maintenance of these kids, because [state] is stuck in a bind and they have no options. So, they're trying to get all those kids back into the state, or at least into more affordable residential settings, and uh... so they are making capital dollars available there. Not only to purchase homes but to renovate them, to put in sprinkler systems. They bend over backwards for those guys, to fund them. The result being that today, if you have a child living in your home, and you're not, you might say, an activist, as I have become since I retired back in [year]. I had a business I sold,

and I decided I wasn't going back into business again, enough is enough for me, so I became, you might say, a professional volunteer, and I spend probably, um... twenty-five hours a week, on average, at different meetings, and volunteering, and yelling and screaming at people, and trying to convince the politicians and the masses, and whoever will listen in the [state disability department] that what they're doing is broken, the system is broken, but at least it functioned at fifty percent. Now you've got a system that's totally broken, uh... nothing's happening, in this state, because they're allegedly from contract to fee-for-service. Fee-for-service is where the provider bills Medicaid directly, so that if there's any billing errors, which there always are, because the documentation is huge, then the agency is on the hook for the claw-back when the feds come in and say, "well you didn't do this, you didn't do that. Our sample shows that you're off by eight percent." They take the eight percent and they apply it across the last five years you've been in business and send you a bill for \$720,000 and they expect it to be paid in two weeks. So, it's a broken system and it's only going to get worse, because when those audits come through, and I know because I was in the [industry], and I was in on the medical audits. Of course our documentation was stellar and we never received any bills, but, we went through the whole analysis and had to fight every single claim. It's, it's an absolute monster. And the agencies aren't prepared to do it. They're not-for-profits. They don't even have financial people that are truly financial people. They're social workers that balance their checkbooks! So they say "well, you become the comptroller, because you know how to add and subtract!" So, there's a big, big issue that's just been postponed, and nobody wants to listen. They said that they wanted to shift everything to fee-for-service, they announced it like two or three years ago. Now, a normal business, you sit down with your computer people, you put together programs, you put together processes, you put together a plan, a written plan as to how to do this. Not the state! They don't know how to do anything. They still don't have the programs. Here's a perfect example: Bridget goes and is evaluated by a telephone and gets [document name], and gets [amount of money] allocated to her, and I said "OK, here's how I want to spread my line item." It's basically labor, and nursing support. I mean that's really what it comes down to. They don't pay for food, they don't pay for clothing, they don't pay for shelter. The shelter piece comes out of a different department at state. The department of, um... [name of state department]. It's the one that has the best vouchers, the state vouchers. Because HUD is shutdown, you can't get a section eight, or an [name of voucher] voucher from that. So, it's become an absolute circle of incompetence, beyond, um... beyond comprehension, frankly. I mean, I was in business. If I ran my business that way I'd be gone in three weeks. So, she gets this budget and I said "OK, here's how I want to spread it," and they say "OK, that's fine, but we don't have an e-file, an electronic file to put this into, so that when the bills come in, we can match it against the e-file and pay the bills." I said, "What do you mean you don't have it?" They said, "well, that's still under construction." I said, "What? You knew two and a half years ago you wanted to do this program. You're telling me you don't have an.. um.. a simple file set up to receive the data to that each kid that you're touting is going to have a budget to... that the budget is going to be appropriately isolated; one for Bill [last name], one for you know, Joe Blow, et cetera , et cetera, with dollar amounts by categories, they can match and be paid?" They said, "no, we haven't completed that yet."

[00:20:06] I: One thing I have been hearing about your experience, from about having Bill and now Bridget in the house, is that it sounds as if you're heavily involved in the financial, at least... components of it. Is that at a higher level than you guys anticipated going into the process when Bill was moving out?

[00:20:28] Brian: Well, part of it is self-inflicted in that I am a retired [job title], so numbers I'm very comfortable with, I understand the interplay of the real-world with the financial world, and if the financial world is not in place the real-world can't operate. And, and, a lot of people in the not-for-profit world don't even think about it, because they're into rendering services and proving

social services for people, and they expect the financial to fall into place. And, and, um...it's a tender tightrope you might say. So, I get involved with a lot of, um, not-for-profit corps, that, are in need of some financial advice, and I sit on their boards, I sit on the [company] board, I sit on [group], which is a program for managing people's trust funds after the parents are dead, generally after their dead. Special needs trusts. I've sat on the board of [group] which is another provider agency, the ARC of [county], um... I'm a former chairman and current voting member of the [council] which services [counties], which was established by legislation back in 1990... either 1991 or 1993...where parents had a voice in what was happening in the state. However, we're widely ignored by the [state disability department]... the, um... the... [state disability department] staff. And they claim to have parents representing and participating, but in fact they truly don't, so you can participate, but yet, they do whatever they want to do at the eleventh hour, under the guise of "well, we had to get this document in, and nobody was around to review it, so we submitted it before you saw it," and so the errors that exist perpetuate.

[00:22:40] I: One thing I, it seems pretty clear, is that you seem dissatisfied with the resources and services that have been provided for you financially in managing the transitions. How have...how do you view the resources that you've received besides financially, in terms of planning for the transitions before it happened, or that you've received in handling Bill and Bridget lives since the transition?

[00:23:23] Brian: Well on the part of the state, there's no planning. It's.... you're... you're basically, um...you basically find legitimate reasons for getting them approved for community placement. In Bill's case ten years ago... let me back up. Back in the mid 1990's when [former governor] was governor of the [state], that was basically four or five governors ago, she became... she lives out this way. She lives in [county] and she became very aware of the [company] school, which you might say is a local... it's a private school that handles disabled kids, intellectually disabled at the time, they were all intellectually disabled, now they have them both physical and intellectual. Um... to support them in an education process where the local school board said "gee, we really can't provide adequate, thorough and efficient education to these kids locally, so we want to send them to this private school." And the parents bought off on it and sent them, and that's where my kids all... both went. And they're my only children, I don't have any experience in the local public schools, except what I observe and hear now, which is nothing more than a flurry of complaints, but that's a totally different... uh, a different problem. So, when [former governor] was at the helm of the state, she instituted through the [state disability department] the program known as the [initiative name]. And they, the department sent out letters to approximately 1900 people, 1900 families of folks that had been rated a "number one," which meant that you were urgently in need of placement, In [state disability department]'s analysis. When Bridget was registered with [state disability department], the worker who came out to the house and registered her said "my god, how do you handle, Bill, Bridget, and grandma, (who was also living with us)?" And we said, "Well, we just do it. I mean we get up every day and we do what we have to do, and I get ready and go to work, and Bonnie would handle it." And so we got some supports in the house through home health ... program that Bonnie arranged somehow, because she was basically financially indigent, partially why she was living with us, and partially because her mind was wandering, and she needed supports. So she said, "I'm going to put Bridget down as a number one, urgently in need of placement." And we said "well, we're not going to place her. I mean she's only like eighteen years old, there's no way in hell we're gonna place her now." And she said, "Well don't worry about it. You're never going to get called for eight to ten years. At which time you may be wanting to place her, and if not you just tell them 'no we're not ready' and they'll hold you on the list, and every year they'll ask you if you're ready, and when you're ready, you can, you get a group home placement." That was the theory of it. So we said, "Oh, ok, fine." Well, so, they sent a letter to... because Bridget was a number one in their system, they sent a

letter to the house for Bridget. To, to, uh, invite us to hear more about the governor's initiative. We went to the meetings that were established, you might say, regionally, and we went to the one in [town]. And we listened to a fellow named [name], I think his name was [name]. He was the director of [state disability department] at the time, and he talked about all of this program where they wanted to shift the money from contract based, meaning that the agency received the money directly and then provided support for someone in a group home, to allocating the money to the individual, through a fiscal intermediary, so that it didn't screw up their SSI, so that they didn't touch the money, but it's available for support. Which is where they are now. I mean it's twenty years later or thereabouts and we're finally getting it. And therefore, you could then go out purchase the services that you need. I mean supports, or camp, or respite programs. He said, "If you want a pile of sand in your back yard, because your kid enjoys digging in the sand, you'll go buy a pile of sand, if that's what it takes." It was whatever the individual needed to support them in their *current* home, their parent's home. In their... in the current vocation. So Bonnie and I, when we went to the first meeting, we got in the car and we were driving home and she said, "Well, what do you think?" And I said "Well, we have absolutely nothing, at this point. So if they're willing to give us something, we can try it. It's not like they're going to abandon us if it doesn't work." 'Cause, he made a statement of "if it doesn't work, we'll work with you to make sure that it works!" So I said, "I'm going to accept the guy at his word." So we signed up for this [initiative]... Oh, at the meeting he asked for questions, and Bonnie raised her hand and said "I have a question. I happen to have two disabled children very similar in function. One a little higher than the other in certain areas, and lower in others. And I have one child that's a number one, and one's a number three. Which means, you're, you barely exist. You're registered but your file is way at the bottom..."

[00:29:26] I: Bill was rated a three?

[00:29:27] Brian: Bill was a three. Yeah. Um...so he said "Well, just call your case manager and tell him to change Bill from a three to a one, and therefore you'll have both kids," cause he said, "I agree, you can't do this program for one kid and not the other. There's no fairness in that." So she said, "Oh, Ok." And he said, "Well, if the case manager has a problem, give them my name, and I'll have them take care of it." And he said, "Well, what's your name" and she told him our names, and afterwards I think she wrote the names of the kids and everybody down and handed it to him, because you know, things get chaotic and she wanted to be remembered, [laughs].... type of thing. So then, when we came home the next day I called the case manager, [name], and I said "We were just at this meeting," and he didn't know anything about it. Typical [state disability department]. The workers don't know anything about it. It was all done by management. And I said, "He wants to change Bill's classification from a three to a one for housing, so that he can participate in this program." And he said, "Well, I can't do that." "Well, yeah, he said yeah you can do it, and if you have a problem give his office a call, give him a call. They said, uh, that he's prepared to sign off on it." So, lo and behold, Bill got a number one in the mail... we got a letter in the mail. So we took advantage of this program. And as a result of that, I got very involved with different agencies and different committees because I wanted to know and understand more about it. And so I went to meetings and that sort of thing, and got to know a lot of people, not just at the state level, but the local offices, et cetera. So...

[00:31:14] I: So, that sounds as if that's in the mid to late nineties. Was that the first time you began planning for either Bill or Bridget to find a residential placement?

[00:31:26] Brian: Yes. We really hadn't given it a lot of thought, because, like I said, Bridget was about nineteen and Bill was twenty-four or some place around twenty-five. And I could be off a

few years in my memory. Yeah, that's when we kind of got involv... I had sat on the ARC of [county]'s board, because we were living in [city] at the time, and that's in that county. So I was a member of the ARC board, and went to board meetings because I wanted to know what they did, how they did it, or how well or poorly they did it. 'Cause, I mean, we had always had, somewhere in the back of our mind, the thought that at some point the kids are gonna move out, either, willingly, at our urging, or when we're dead they'll be relocated. I mean, they're not gonna stay in the house after we're gone. And we just felt that the trauma of relocating, combined with the trauma of mom or dad, or both of having disappeared would be greater to absorb in these, you know, intellectually challenged minds, as opposed to, kind of doing it in steps. So that was always our plan was ultimately to locate, or relocated them while we were alive.... I guess I always just thought we would have to have more money involved in it, more capital to get it going on my own and support it.

[00:32:54] I: So you were always anticipating that amount of capital that you guys were putting in?

[00:32:58] Brian: Well, I never expected prices to go this high as they did, when... to accomplish the goal... I mean I could have done it less expensively, but I wanted Bill, to uh... traditionally group homes, at least back in the late nineties and early 2000's they were the less desirable properties in the community. They were always either on the highway, or backed into the highway, or railroad tracks, or junk yard, or... um... bus terminals, or something next door. They were the least, the least valuable properties, you might say, in the communities. We moved out here to [county] and... I mean we've always lived a very good life. I got very lucky in my business and made a substantial amount of money, so we lived well, and I didn't want the kids to not live, uh, reasonably well, as we aged and disappeared through death. So, I wanted Bill to be in a decent home in a good location. Uh, I didn't want him on the corner of two intersecting roads with the traffic light in front, because if he went outside, my concern was that he'd get whacked by a car because he didn't have the sense to stay out of the street, that kind of thing. So what we purchased was a four bedroom, [describes house], which basically has two access roads to the circle, um, but it's a rather larger, it's a small development, uh.. I mean the circle's rather large, but it's a development of maybe, I'm gonna guess and say forty houses, all on one acre. So it's not a high traffic street is what I'm trying to say. So, when we went to do Bridget, we found a, uh, small ranch home, because with the diabetes, she really can't...we didn't want to put her in a place where when she aged steps could become a challenge to her, uh... with diabetes, you have problems with the functions of your limbs, particularly your legs and your feet, um. So, we wanted to put her in a, uh, ranch or a condo all on one floor. And we found a place, and it was more expensive than I thought it should be or would be. But we said, well that's the market. We'll do what we have to do. But I could have gone to different towns, and maybe saved, maybe \$100,000 dollars on the project, but it, it, even at that it'd still be close to a half of a million dollars by the time we got done.

[00:35:54] I: So, I have a question. Did anyone prepare you ahead of time? Either time? Before Bill's moving out especially, because you didn't have an idea of what the process would look, about how your role as parent was going to look after he moved out?

[00:36:13] Brian: No. [Company] has what they call a transition program, but it's all geared to the kids. They're one of the few schools that back, years ago, established a transition class, or transition program where at age eighteen, they move the kids into the work center, for... which is a separate building. They move them in there for maybe one day a week, for the first quarter, and then the second quarter of the year they put them up to two days a week. They talk to them about

jobs and employment, how to write a resume. Because some of the kids are higher functioning. Mine don't happen to be able to read or write, or anything like that. But there are kids there that can do that. So they have a transition for the, for the children, or for the kids. But truly, no one has a program for the parents, other than, going to... if the parents become somewhat active and they go to different meetings, the [local disability non-profit] program runs meetings about the transition and what to expect. And they also run programs on registration with SSI, and SSDI, and that sort of thing. So there are programs, but most of them...um... I'm hesitating because I want to say all of them... but boy, if it's not all, it's ninety-five percent of them take place during the day. So unless you're, you might say, of an executive level, um... because today most men, most household, mom and dad both work. Assuming that they're both together, [laughs], cause I guess fifty percent of the households are single parent homes. So, assuming that there's a mom and a dad in the house. So for them to go to a program at say ten in the morning or one in the afternoon, just doesn't, kind of like, fly. There are some programs that run on weekends, but they usually start on Friday's. [Local non-profit] runs a... um.. a kind of deal where I think it starts on Thursday or Friday, or maybe runs on a Saturday as well, but never on a Sunday. So, they're not really convenient for working, uh, working breadwinners, you might say, in the family, to get educated. So a lot of it is just, our regional support council, we meet in the evening, 7:00PM. Once a month, not a big burden. But I mean I send out emails to probably... eighty people. Because I collect e-mails at different public forums, and anything I get that's interesting for anybody, I'll blast out to everybody. Be it about housing, or job opportunities, or education. And, um... I always announce meetings well in advance. I remind people a week before, everyone's welcome. I even tease them: I say, "If you show up, I'll give you five dollars." You know? Whatever it takes. And, and... um... I mean the council meeting, we had one Tuesday night, that was, five people? Six, six people at the meeting? The month before we might have had ten or eleven. But you know, when you consider in the two counties there's almost 2000 students, 2000 people registered. I mean... I don't know. I'd like to see a bigger turn out. But they found over the years, Bonnie and I actually hosted, the, uh, an event at our house, and we invited parent of disabled kids that we knew to advise them about this [initiative] program that [former governor] kicked off, because parents were... their number was being called, so to speak, and they were saying, "No, I don't want to place little Johnny at this point." And we said, "That's fine, we understand that you don't want to give him up, but take the initiative. Even if you take it for \$2000, you'll get in the system and become part of it, understand, become part of the flow of it." And they stalled. "Well, I'm not gonna... you have to sit down and do a budget, you have to submit the paperwork, and I'm not gonna do this." I mean we hosted here in the house, we probably had, um... thirty to thirty-five families, so we had sixty odd parents, because most of them were two family, or two people, two adult households, and tried to explain it to them: "If you're getting nothing now, you get in the system, you can at least send your kid to, um... a weekend respite program. Because if you don't start weaning yourself away from your child when they're young, how in the hell do you expect to wean them away when they're forty-five years old?" I mean, we always sent the kids to camp, we, we would pay out of pocket. Pay up to \$1000 a week to send, for each kid, to send them to camp. Because we always thought it was important, not only for our, um, you might say, our salvation to get away from them, but for theirs, so that they were weaned away from, particularly Mom, cause she was here most of the time. you know? I mean, I was in and out. I had my own business and I worked hard at it, got lucky, and then sold it. And then I started hanging out here, but that's only since, uh... I guess [year]. Years go by.

[00:42:05] I: So, it sounds as if you were looking for opportunities to begin that letting go, or "weaning out process" as you called it, earlier than even the move out.

[00:42:21] Brian: Yeah, Bill was, I'm going to say... Bonnie could give you a better handle on it, but I'm going to guess Bill was, was fifteen or sixteen years old when he first went to camp. I had

heard about a camp here in [state] that's absolutely free, and they do great work, it's through the [community service organization], it's called [name]. It's here in [state], it's run by the [community service organization].. which , I didn't know, and I still don't know what a [community service organization member] does, to be honest with you, hah. But I had a friend who was a [community service organization member], and he said, "We run a camp for kids like yours. Why don't you send them to camp?" And I said, "Well, where is it?" And he said, "Well, it's in [town]." And I said, "Well ok, I don't... can I go visit it?" And he said "Sure!" He, he was a builder, and he said, "I go up and I volunteer, and I do building work and that sort of thing." If they need a door hung or a kitchen cabinet and he said. "I'll volunteer, if they need plumbers, electricians, or all kinds of craftsmen who volunteer their time working on this camp." And I said, "Well, but the next time you're going up, can I go?" And he said, "Sure." He called me one day, and I worked, probably ten minutes from his office, and I worked in an executive capacity, and he said, "Well, can you come on up?" And I said, "Yeah! Let me just clear my schedule." And so we went up and visited. And, um... it was very rural, very rustic, and so I thought, "This is kind of cool." They had a big swimming pool, and a clubhouse, and they did arts and crafts, and um... you know. I didn't see anything, it was wintertime, or, there were no campers there at the time. So anyway... we enrolled him, and then we enrolled Bridget the next year. And they went there until they were, I think they were until... they were supposed to kick them out at age eighteen, but I think that they kept Bill until age twenty.

[00:44:15] I: And how do you feel that that camp helped in the weaning out process?

[00:44:21] Brian: Oh it was magnificent. As I said, it gave us a break, which was important, for us to, you might say, to take a deep breath and take a step back from being a caregiver, you know, 24/7. So, we only had to do it 358 days a year not 365. Um... yeah it was great, and I think for them it was good because it was a sleep-over thing. They went and they stayed overnight. And they became, um...I guess...They gained a level of independence, or dependency on someone else, and a level...I'm sure they had rules that they had to participate and do certain things. And, um... subsequent to that we put them in Camp [name] which was run by the ARC of [county]. Um, and then from there... that didn't work out as well, because the oversight wasn't as great. The kids were getting older, and a lot of these kids, a lot of the intellectually challenged kids, when they're young and they're in school they're fine. It's when they get out of school is when their anxiety levels go up, because their environment changes dramatically. Bill ended up on medications, in his early 20's after he was out of school. He had never been on any anxiety meds prior to that, and ended up on medication, and then we were networking through people that we knew and found a camp up in [separate state], that was, is, excellent. And the kids group every year for two weeks, which the state by the way, paid for, um... all... I had to get a waiver signed by the director of whatever, or assistant director, for them to pay for it. But they paid for it, and I don't know whether they're going to pay for it this year or not. For Bridget, not for Bill. When Bill went into the group home, they dropped the camp program, but we send him for two weeks anyway. And we go up those two weekends in the country. And we drive. We schlep them up. It's nearby [city] up there. Friday nights it's four hours plus to get up there, because of traffic, but we schlep them up, and then we stay in a hotel locally and pick Bridget up on Sunday afternoons. And then Bill goes up New Year's, I guess. The day after Christmas, he goes up, and comes back the day after New Year's Day for a party.

[00:46:56] I: One thing, is that it sounds as if there weren't, and just to go back a bit, you said that there weren't any services or resources that helped you plan for what your life would be like following Bill and Bridget moving out. What did you guys expect your role would be... as a parent, after they had moved out?

[00:47:23] Brian: To be very honest with you, I always expected to be involved to be honest with you, to some level. Even if it was taking Bill, picking him up once a month and taking him for a haircut. Um... I always expected to do, to do that. There are some parents that, you might say, dump and run. I mean there's parents of kids in the group homes that I know of that have left the state, because, to quote, "I don't want to pay taxes in [state]." And I say, "Well, who the hell do you think is going to support your kid for the rest of his life?" But that's where I get into conflict with people that act like asses. But there's nothing you can do about that. You just kind of get through it. But anyway, no, I always expected to be involved with Bill. And as I said earlier on, I expect my involvement with Bridget to be weaned down to ... maybe once a week for a couple of years, and then I'll fill that other slot... and then, hell, I'm getting older, and there's things I want to do. And I can cover that open shift with part timers if I want to go on vacation or whatever. I always expected to be involved with them. I guess it's like how any parent is involved with their, quote, normal kids. Um... I mean when I was a young fellow, my parents would be around maybe, eh, once a month or so I'd see them. Bonnie's mom was a widow so we saw her more often, and then as I said, she came and lived with us for maybe five or six years, because she was having heart problems and surgeries... It was just easier for Bonnie to help rehab her here, than be schlepping into where she lives. Then, we eventually put her into assisted living and then a nursing home, and then she passed.

[00:49:17] I: Well, that's interesting...so that you said that it's comparable to typically developing adults, in some ways. How would you compare your parents' roles and involvement in your life, and Bonnie's mother's role in her and your guys' life, to your ongoing role in your children's lives?

[00:49:39] Brian: In my case...I would say it's, it's, it's parallel. I mean, I don't think... I'm not involved with Bill's day to day care in any way, shape, or form. They take care of him, they order his medications, they feed him. Bonnie buys his clothes, just as she always did when he was a little kid, because there's no money from the state to buy his clothing. There's \$250 dollars per resident in the budget. Today. And when they shift over to Medicaid billing, there's no money for clothing. As a matter of fact, there's no money for food! In there. Because anything that's normal, in normal society, is not a Medicaid allowable expense. So, how they think this program's going to work, it's going to be interesting! [Laughs]. Um, so, I mean, Bonnie....I... from me, I would say it's comparable, or parallel to the way my life was as an adult when I moved out of my parents' home. I, um... with Bill. With Bridget, I'm more involved because... number one I don't have all the shifts filled. 'Cause I'm the guy who does the hiring and firing. And I'm highly selective as to who's going into the house with my daughter. I mean, they have to be competent, and prove that what they claim they can do, they can, in fact, do, or I get rid of them. Um...I put a security system in her residence with cameras. They're aware of it. I said "This is for your protection as well as hers. This way if she falls and ends up with a cut, or a break, or something, we know exactly what happened and there's no accusations, and you don't have to be defensive if you didn't do anything wrong." I think that makes sense. I mean, I'm in a quandary as to why most of these facilities don't have cameras. But... you know, just right to privacy and all that stuff, but... but since I own this property, and lease it to her. And maintain it, and so I do it my way. And... um...

[00:51:57] I: So it sounds as if your level of involvement with Bridget is much higher than with Bill. How would you say you feel about your role in both of their lives? Especially given that you have a bigger role in one of their lives than the other?

[00:52:13] Brian: Well, ... I would expect... for Bridget... when Bridget is out of here for ten years, I would kind of expect my role to be similar for both. That I would visit them to do specific

things with them. Um... you know, go to lunch perhaps, or go for a walk in the park. Or stuff like that. Or have them here for... we have all the kids... we have them back for holidays. The major holidays. We're raised Christian, so we celebrate the Christian holidays. But it, you know, you gotta remember, Bill's out of the house ten years, or a little over. Bridget's only out since um, seven months? Or eight? Let's say [summer month]? So yeah, my role originally with Bill, when he moved out, I saw more of him, because I was less confident that the agency could do what they said they were going to do, so I was not only checking on them but making sure that he was OK. Initially, you know, the... I think where he is a good agency, I just don't think... They hire workers for ten dollars an hour, so you get that ten dollars an hour mentality working for you. Bridget, because I'm directing it, and I'm not charging anything for quote "overhead," I can pay up to fifteen an hour, so I get a different caliber worker. That's part of what drove my decision, is that I didn't want her surrounded by ten dollars an hour people. Not that there's anything wrong with them, but they just don't [exhales]... they don't think the same way. I mean, they can be very kind and gentle, and some people can be very communicative, they don't care how much they're paid. But, you know, having said that, they're working four jobs to cobble together a living in [state], so they're exhausted, they're tired. My people are only cobbling together two or three jobs. So it's different. I would think that ten years down the road, my involvement with Bridget would parallel my involvement with Bill: you know, holidays, or once every two weeks. I mean, Bonnie makes a meal, she takes it down to the house, to Bill's house, and is always welcomed. And, uh...I hope that answers your thought.

[00:54:52] I: It does, I definitely hear... It sounds as if your level of involvement since Bill has moved out has evolved over the years. Would mind describing some of the ways that it's evolved, or some of the times that it evolved, or if you have any stories that illustrate that?

[00:55:09] Brian: Well for instance, when he first went down to the house, not only did we sell him this house to make this kind of the price, but we put all the furniture in the house. We donated all the furniture to the house. Well, he's in there six or seven months, Bonnie goes down, the couch is a disaster: this stuff's all over it. The cushions, quote, "aren't fluffed". Whatever that means, I'm not sure I know, but nevertheless... It's the level of... of control is...is...is awful, because you don't have any. I go in, the place would be dirty. Bonnie and I went down one year when Bill went to camp one year. We physically went down, and cleaned his room and re-painted it. I, just because it was filthy dirty, and... I said, "I don't want him living this way." And I yelled and screamed at management, and they said, "Well we're going to hire a cleaning service to come in." And then the service would come in once, maybe twice and then they would disappear, and I would say, "Well what happened to the cleaning service?" And they would say, "well, we weren't happy with what they were doing." Well, I said, "The work they were doing is better than what the staff is doing," because they expect the night staff to clean the house. Well, I said "How is the night staff gonna run a vacuum? I mean, I don't understand this! If you're not vacuuming up the dirt, the dirt's still there." I would go down and say, "Where's the vacuum?" And they'd say, "Over there in the closet." And I'd go pull it out. Not... nobody would jump up and go pull it out. They'd say, "It's over there in the closet". Again, it's that social interaction that you just don't get, that skill level at that hourly wage. So, I'd pull the vacuum out of the closet, and they had this kind of Dirt Devil thing, that was no bag, it was a canister. Well the canister was so full that the thing wouldn't suck up any dirt. So I said, "Does anybody ever dump this thing or clean it?" And they said, "Well, no. Nobody ever told us to do that." So, I said, "Well, come on I'll show you how to do it." I'd take it outside in the driveway and clean it, and I had to pull the filter, out and I'd pull it out and clean the filter because of course it was all jammed up and I'm surprised it didn't go on fire, to be honest with you. So I said, "Well now it'll work and pick up the dirt." And the girl said, "Well, I was wondering why the thing wouldn't do anything. I would run it around and it just didn't seem to do anything." Go back like six weeks later, canister's full again. I...I just...

different staff because they rotate. You have a thirty to forty percent turnover in the group homes, and they just... Another story, I go down and both of the bathrooms have exhaust fans in 'em. I go down after about a year or so and say, "Does anybody ever clean those things? You know? You take a ladder take the cover off and clean it." "Well, no, I... not that I know of, maybe maintenance does that." So I get a ladder and I go up and take the cover off and it's jammed up. It's all jammed. So I had to take it apart, pull it down, and clean it. So then I went in the other bathroom, the main bath, and did the same thing.

[00:58:23] I: And how long ago was all this?

[00:58:26] Brian: Well I did that. I probably cleaned those things four times. I don't know, probably stopped doing it about five years ago, because I just got frustrated and said, "Well, the hell with it, I'm not doing it any more." Christmas time comes, I'm the only one who puts lights on the house. Management doesn't put any lights on the house. I got to the point where I took the lights off and I bring them home here. Because the first set of lights or the second set disappeared. I said, "Well, where'd they go?" And they said "I guess we threw them out, you only use them once don't you?" I said, "No! You take 'em down, you store them and you put them up the next year." I bought them a Weber grill for \$500. You know, one of these super-duper Weber grills? It caught on, went on fire, they said. I said "OK, but then what did you do with it?" They said, "Well, we used the fire extinguisher on it and then threw it away." I said, "What do you mean you threw it away?" "Well, we threw it out." I said, "Well, you gave the garbage man one hell of a gift." You know? It's just stupid crap like that! To the point where you shake your head and say how can you be that dumb?! But that's what you deal with. And management, uh, acts like they're stressed because they've got four houses to take care of. And that's quoted... this agency, is touted by the state as one of the top agencies in the state. So, I'm, I was on the ARC board. I visited ARC homes. They're awful. There's no carpets on the floor. They had furniture with all wooden arms on them. I said "How come this looks like a barracks?" And they said, "Well, if you put stuffed furniture in here, some of the kids gnaw on it, and you know, they tear it apart. It gets real filthy dirty. This way you can just replace the cushions". It was, you know, like you see in a summer cottage, you know? The wooden frame stuff with some cushions on it. And it...it was awful looking. And, what? That was years back? And other agencies... I was on the Allied board, and I would go look at their homes, now they have like, like 100... I think, when I was on the board, they had like 180 people in residency. So they had a lot of homes, they had a lot of supervised apartments, they had a lot of stuff going on. Some of which were well maintained and cared for, and other's you would say were shabby, and they had a rotation program, where every couple of years, they would go in and replace stuff. But that's a big agency. And they had their own maintenance crew. They had a maintenance crew. The house manager would fill out a maintenance request, an e-mail type thing online, and they would get them and they would prioritize them and they would. They would actually rotate the maintenance because they had enough work to keep these guys busy for going year round. And uh... so, there is some, some benefits to size in that you have the infrastructure, you might say, more correctly. [Company] was stealing maintenance people from the school, so when they weren't busy at school they would send them down "go down to [Street]," that's where Bill lives. And it's fix this, or fix that. When I turned the house over to them, I hired guys to have all the windows washed. I had the whole house power washed, all the windows washed, and I said "I want gutter guards on all, all of the gutters." I put 'em up there. I don't know, it was \$400. I mean it wasn't a fortune, but it was a lot. I go down to the house, it couldn't have been four months later, and because the house was surrounded by trees, a bunch of large oak trees, and I suggested to them that a lot of these large oak trees should come down. But I didn't have any more money left to sink into this project, because I put fencing around it, I did...um...that house cost me all said and done, a best guess is about a half a million dollars. So I made a quarter of a million dollar contribution to them coming

out of the chute, and I figured, well, "You guys should buy into a part of this and do some work around here." Uh... I go down to the house, I'm going to say four months later, all the gutter guards are off the house. So I said, "What happened to the gutter guards?" "Oh, the guy that did that is our maintenance guy. He said they're a pain in the ass, and he can't work with them because all the leaves lay on top of them." I said, "Well it's better than what you have now, because all the leaves are overflowing, all the down spouts are jammed." It's just dumb, dumb stuff. Just, yeah, just petty stuff. Just enough to aggravate the hell out of you. You say "How can you be so stupid!" I mean, what are you thinking about? Take off gutter guards because they're blocking... well. [exasperated laugh]. I mean I don't know about you, but I have gutter guards on my house [laughs] 'cause I'm not going up there to clean the gutters.

[01:03:26] I: So, so, real quick, is there...just in general, are there areas in which... I'm hearing some of the smaller things that you've had to deal with over the years. Are there areas of either Bill's or Bridget's lives in which you've weaned yourself out more?

[01:03:46] Brian: Yes. As I said, in Bill's life I've weaned myself away to where I've visited him maybe twice a month. I do on occasion see him, because he's in the work center, you might say, or a workshop that [company] operates. And I go in there and volunteer on occasion, so I do see him there. Um... but, uh, you know, it's uh... it's social visits and then we talk. You know, that sort of thing. But generally, my involvement is I would say, um... once or twice a month that I see him. And that would be my expectations for Bridget in the future. Maybe a little bit more because families tend to stay closer to their daughters than their sons. I think that's just a natural phenomena in American society, in the circles that I travel.

[01:04:46] I: Are there areas of your children's lives in which you've weaned yourself out less. Where your role as a parent is more similar to what it was when they were still with you?

[01:04:57] Brian: Well, yeah... in Bill's life for instance I don't go to all of his doctor's appointments. I do go to his psychiatrist's appointments because I want to know what's being said and what meds are being scripted for him. But for instance his annual physical, I don't go to. Umm...so I would say I'm less involved there. I do go to his dental visit, because he has to be totally sedated, with a general anesthetic to work on his teeth, and they only do that like once every fourteen or sixteen months. Because that's what Medicaid allows. So I do go to that, 'cause again it's a general sedation and I'm there to give guidance to the staff, although they're not always going to listen. I mean, the medical staff, you know, I tell them take the IV out of his arm while he's unconscious, and they say, "Oh, no, no, we don't do things that way." I said, "Well, when he wakes up he's gonna rip it out of his arm, so you're going to have to deal with it that way." So he wakes up and rips it out of his arm because they won't listen. You know, just typical, "I know better than you" with... I mean I've dealt with him for forty years and they see him once in their lifetimes but they know better. so... But that's you know...I'd say local knowledge. But no, I would say I'm less involved with him. I don't order his meds, I uhh,... I don't prepare meal plans for him, or... Yeah, no. I'm definitely less involved with Bill. My involvement is more social with him.

[01:06:30] I: And how do you feel about that level of involvement with him?

[01:06:33] Brian: Oh I'm fine with it. I drive it basically. I'm the one that determines... he can't use the telephone, so he's not calling looking for somebody. I drive that, that visit. And the length of it as well.

[01:06:52] I: So would you say that you're satisfied with your role in Bill's life?

[01:06:56] Brian: Yeah. Yeah I would say that.

[01:07:03] I: How about in Bridget's life?

[01:07:06] Brian: Well... no, I'm not satisfied with it, in that I'm still very involved with it. I order his meds, Bonnie does her mean plan. I'm the overnight staff on Sunday, Monday, Tuesday at this point in time. I have a lady allegedly starting in the next week if [local community agency] clears her for Monday and Tuesday night. So that would leave me there Sunday night. I'm there Tuesday afternoon, Friday afternoon and all day Sunday, at this point. Because those are open shifts. And I've got another young lady that's supposed to start, probably within the month for Friday afternoon and Sunday afternoon. So that would take me down - If everything goes according to plan - if they all get cleared - I'll be there Tuesday afternoon and Sunday mornings. Saturday and Sunday morning. Weekends are always tough to fill.

[01:08:06] I: What would you say is the biggest change in your life since they've moved out? Or how has... not necessarily the biggest, but how has your life changed since they moved out?

[01:08:16] Brian: um... I have more time to... um...to do things that are more important to me, than child care. I mean...I, uh...I guess I say I spend more time, in community involvement, in the disabled community involvement. I can go to more meetings. I mean I'm not divorced from it because I don't ever expect to get away from it, as long as I have a big mouth and I think I can change things. I'm now putting together a strategy to call on the politicians to try and educate them. Because the bureaucrats don't seem to go anywhere. They just totally ignore you and do what they want to do. So, it, it's, I think it's going to have to come from the legislature telling them what to do. I also have an opportunity to play golf; that, I enjoy. I started taking art lessons after Bill moved out, so I have time to do that. I have more time to do what I wanna do. Because we're so heavily involved with Bridget we haven't had an opportunity to travel, which we would like to do. Now having said that, we did put together a program, and I have people lined up, although I'm paying them overtime for the first week in [Month] so that we can go down to [state] to visit family for a couple of days. We're leaving on a Monday and coming back on a Thursday or Friday. Or something. Five days in total. Which is, um, we've never done that before. This weekend, I think it's this weekend, I have the opportunity to go down to [state] to my sister's house. Again, I got coverage because I shifted people around, to get weekend coverage. You know, on an exception basis, my current staff with flex and cover it. But, you know, now I'm being charged on my budget at twenty-one dollars an hour instead of fourteen, and I have to be careful in that I can't overspend because that's a big, big no-no in government, overspending. [Laughs] You're allowed to piss it away, but you're not allowed to overspend. But anyway, I can shift people around because I can go down to my sisters for my special event. So, I have more freedom to do what I want to do. I'm not sure Bonnie would share that, that she would share my observation, because she feels trapped totally, so... but that's... you'll hear that from her, not me.

[01:10:59] I: just two more questions. First is, is there any... um... is there any advice you would give to other parents? Maybe not so much regarding finances, because I got a great deal of that in the beginning, but is there any advice you would give to other parents regarding what to expect their role to be?

[01:11:25] Brian: Yeah my advice would be to start preparing your child for that transition... um... when they're in their teens. Because if they're not used to Mom and Dad not being around,

that's going to be... um... a real tough transition. That would be my number one advice is to start there. Um, number two, don't have great expectations that the government is going to, um... that they're gonna do it well and do it right. You've got to plan, you might say, just like you planned for a kid to go to college and/or get married and that's going to cost you dollars to do that. Make sure you're setting aside some money to support that child in the future, because they're not going to do it well. Um... get involved. Learn how the system works, understand the system because it's complicated, even people that are committed for years get lost in it, including myself. I mean stuff pops up all the time.

[01:12:35] I: How about what advice you might give for parents following the move out of the home, as to what to expect.?

[01:12:44] Brian: Well, [company] just opened up a fifth group home, and two of the parents approached me and said, "Gee my son is moving in. What's your experience been?" I said "Well, your expectations should be set at the level of seventy to eighty percent. Whatever you think should be done, should happen, seventy to eighty percent of it is gonna be done right, but it's the twenty to thirty percent that's gonna, kind of like, drive you nuts. And so don't have this expectation that it's, 'gee, he's in great hands, and I can walk away from this situation, because they're gonna read everything that I wrote about my child, his needs, his wants, his desires, his shortcomings, and they're gonna understand it, and do it correctly', and correctly I mean, as a reasonable person would do it." Because again it goes back to the staffing, um... the... I hate to use the word, but the intellectual capacity of the staff, just does not exist... um.. at that price point. And... so what. Your expectations should be an average of seventy-five percent. Because that's been my observation. Because it's the little crap that just drives you crazy. Having said that I do believe that he's safe. I believe that he's secure. He's reasonably well fed. Although we have conversations over diet all the time. Dietary needs. Um, you know? It's kind of an ongoing battle, as to what they, expect and what I expect. They win, because they control it. With Bridget it's different. Because I control it, and I'm running it. It's not that I'm a control freak, I would much prefer not to be heavily involved, and that's why I think my hiring people directly, eventually I can become much less involved. I have them call me, because she's diabetic, I have them call me every evening and every morning, to give me her blood sugar numbers, because I will not let them give her an injection without me directing the quantity of insulin that she should get, but again, that time I suspect that will... The one lady that I have on the Wednesday and Thursday night, she's very, very good. And uh... very engaging. I'm feeling more and more comfortable turning her loose. So, it's a process, it's a process, and that's what I would tell parents: it's a process, and it's going to take you, it...uh... my observation it's going to take you two years to get a level of comfort as to um... whether you've made the right decision or not, and ultimately you did make the right decision, because you don't have a choice. You really don't. You're gonna pass, statistically, you'll pass before your child does and therefore you don't have a choice, you gotta get them in the best, safest environment, most stimulating safe environment that you can, you can put together, or cobble together for them.

[01:16:24] I: Is there anything else about... life after your son or daughter has moved out, or um...what it means to be a parent after your son or daughter has moved out that I haven't asked about?

[01:16:43] Brian: No I don't think so. No.

[01:16:50] I: [closing statement].

[01:17:02] Brian: Well, I kind of get up on my soap box too because I'm not too pleased with what the state is doing. I don't think they know what they're doing. I think there are two people at the top that understand what they're doing but they're not communicating that down. The people that work down in the organization have absolutely no clue what they're doing. They're scared to death that they're gonna be out of work, frankly.

[01:17:17] I: how does it feel... I mean does it help that you're sort of fighting the fight, or... that you're being part of it?

[01:17:25] Brian: Yeah it makes me feel like, at least I'm trying. I'm not just sitting back and letting it happen... But I keep kicking.

Appendix C3

Transcribed Interview: Bonnie

[00:05:00] Interviewer: In what way would you say your daughter is more medically involved?

[00:05:05] Bonnie: Bridget's more medically involved in that she's an insulin dependent diabetic, and has been since age five. In addition to the fact that, um... her behavioral problems seemed to manifest themselves earlier, and become more difficult than what my son's were. My son's almost came...he was a more manageable younger child and he was more around that less than...Bridget was always, um...somewhat more difficult with behaviors. Transitions were difficult with her and so forth and so on. You know? She was always a bit more argumentative or strong-willed. Which she never really learned to utilize in a good way. If you can understand what I mean. She always struggled with everything, with that strong will. Uh...as opposed to learning how to use it to her advantage.

[00:06:04] I: So Would you say that most of the behavioral difficulties that you experienced with her, I guess I'm hearing you describe it as strong willed, was largely a matter of non-compliance, or were there other difficulties?

[00:06:15] Bonnie: Just that she had difficulty, I guess - transition was so hard for her, even from when she was an infant - that she...she just did not...um...she did not make...change well. She had difficulty even with, uh...teething, and different things that Bill didn't have difficulty with when he was a child. She was fickle. She was an easy, more compliant child, to deal with. Brian and I said, that if we had the children in reverse we maybe would never had had the second child. Because she was much more challenging from a much earlier age than Bill, and yet, many people take to her very easily, personality wise. I don't quite get it but they do. They find her to be sweet and charming until she decides not to be.

[00:07:19] I: Is she still demonstrating those behavioral difficulties now that you guys have...I guess it's been seven or eight months now that she's been out of the home? Is that right?

[00:07:28] Bonnie: Yes, but we're transitioning her very slowly, with caregivers, and I do find that she's having more difficulty now than she did initially. Because she initially, she had people that she knew, and then we gradually added to it. And now that we're probably...at a little bit beyond the halfway point in transitioning her, she's having more difficulty. So, but that would be typical of behaviors that she has really shown, since she was very young. So... alright, go ahead with wherever you want to get me. I'm sure we'll wind up back here.

[00:08:11] I: Just to start the...I know I said I would ask a series of open ended questions. But I like to start with a very specific question. If you wouldn't mind describing your view of specifically what the diagnoses of you son and daughter are, and the functioning level that you see them having.

[00:08:36] Bonnie: Ok...um...both of my children have been diagnosed with a delayed diagnosis of static encephalopathy of unknown origin. And Brian and I have, I think it was about ten years ago, the last time that we went to a geneticist to see if there was anything new that we could learn about the children's problems and got no answers from that. So we've been to the [state college], and then [out of state hospital] and now [other out of state hospital] and gotten no real answers. Lately, just recently, in the last six months to a year, I suppose, because the definition of Autism has been constantly changing, and that it's a disorder that has a range to it...both the psychiatrist and the behaviorist have been talking about both children fitting into the Autism Spectrum. Which I think, I mean Brian and I had always thought that they had autistic tendencies, but they never seemed to have what we saw as true Autism, which was more of a withdrawal type situation. Particularly Bill, who has always been social. But apparently that is no longer part of the definition; it's been expanded vastly. So I guess they would fit into that disorder, because they do have those characteristics. But that was not a medical diagnosis.

[00:10:16] I: And so, how would you describe the functioning level of both of...?

[00:10:22] Bonnie: Both of them function...with varying skills, but...on a cognitive scale, they would probably be considered pre-schoolers, with some skills going beyond pre-school. I mean...they understand more than they give you back....umm... they have better...receptive language than expressive, in both cases.

[00:10:55] I: How far from them do you live currently?

[00:11:00] 162. We live about half an hour from Bill and we live about ten minutes from Bridget.

[00:11:05] I: And then the last of these starting questions: how often do you see each of them?

[00:11:12] Bonnie: I see Bill maybe once a month...if that. He really...since he's moved out seems very happy with that type of an arrangement. He usually comes home on the holidays. I find the half of an hour a little bit more than I like it to be. It becomes a challenge, because it's really an hour, each way...uh...the ten minutes with Bridget works much better. I see her...in my case...probably four times out of...seven in a week. And it's partly that's because of transitioning too. We're filling in shifts. Ok? I don't anticipate that when she's fully staffed that we will have that much contact. But personally, it's not just seeing Bridget. I think it makes a difference for us to see the staff. I'm sure Brian probably explained to you that we were part of the [state initiative]. With self-determination? Well, with [initiative] as part of the pilot. So. I can't tell you how

invaluable that experience was for us, and how disappointed I am that they no longer have that program. That was probably the best thing that ever happened to my family. And it gave me...I had reached the point that I was quite discouraged, and it gave me a new lookout, or outlook on life, rather...um...for the kids, by having that experience. Letting me go back, dream dreams that there was some kind of a life that I could provide for them. And it gave me the power to do it. And frankly, I think it saved my family, that it came at the time that it did. I want to add that in right there, because this was involved in the [local community service organization] and that made a significant difference to that we've all survived to this point.

[00:13:34] I: Can you, can you describe...so that's, that's a really strong statement, that you felt that the [incorrect name of initiative]...

[00:13:42] Bonnie: Through the [clarifies the name of the initiative]...yeah, yes. Which is different from the [incorrect name of initiative].

[00:13:49] I: , ok, so the [initiative] was different. Can you briefly describe? I would love to know more about that...in how, or what way the support did that you felt "saved your family?"

[00:14:07] Bonnie: It...it... it took me back from a place where, my kids were in a terrible situation, and that I had grown dependent on trying to get [state disability department] to respond to their needs. Which was very challenging, to get a response, to get a case manager who responded to you in the first place, to move on from there, was very challenging. Everything had waitlists for it, and there was...no help at that point. My children were becoming young adults and there was no transition program at that time, and Bill was reacting to...um...the fact that he was taken from one program and put into another program. In order for us to get him into that other program and be able to afford it, we wound up having to relocate from one county to another so that we could get affordable transportation for him. Because we were living in [town] at the time, and [town] hadn't agreed to transport. Even though they were transporting Bridget from the same household to the same school program, on the same grounds as the work program that Bill was going to, they charged us, what we thought was an excessive amount of money to be able to do that. The bus was coming to the same house, there were five kids on the bus, and they made Bill pay a fifth of the cost even though the pick-up and the drop off was the same. I'm not sure that was a fair way to do it. And so the cost for us was over a \$1000 a month. And that was over eighteen years ago. We wound up relocating so that we could keep him in that program, because at the time there were no programs for him in [county]...

[00:16:10] I: And you said that this was a workshop program?

[00:16:10] Bonnie: Yes it was a workshop program at [company]. The transportation at that time cost more than the program cost. And we were dependent to pay for the program at that time as well. Because there was no funding for that particular program because it was something that the school had provided because there were too many kids

that were graduating and there was nowhere for them to go. [Former state disability department], would look at my children because of their functioning level and then they became an issue for [current state disability department]. So, we relocated to [new county] and we had very poor assistance in the first county. And that's the other thing: counties seem to make differences what type of services you were provided, and [first county] services looked at Bill and said, "Well, not such a big problem...we can give you a case manager, but there's not a whole lot that we can do for you as a family except for some respite services that are available." And so Bill's functioning level really didn't make him a great candidate for respite services, because they didn't necessarily have the right ratio for him, in order for him to be protected, you know, in those programs. So he went to some of them, they were not something that Bridget could actually use, and of course because our income was higher, the children didn't qualify for any Medicaid services. We did not receive any state services until after my children were over eighteen.

[00:17:51] I: And so did the [initiative] services...?

[00:17:54] Bonnie: [Initiative] services came after we moved to [new county], Bridget became eighteen years old, and the, uh...intake coordinator came and took a look at the family and unlike the one from [first county] said, "Geez, this family's in distress, and this child is going to be a very difficult placement, when her placement comes up, so therefore, I'm making the decision to put her on the waiting list at that time." And because we were on the waiting list with Bridget, we were offered the pilot program, when the pilot program for [initiative] came up.

[00:18:34] I: Was this a waiting list for...?

[00:18:37] Bonnie: It was a waiting list for housing.

[00:18:39] I: Ok, so you guys put her on a waiting list for housing at age eighteen?

[00:18:43] Bonnie: At age eighteen because of her needs. According to the intake person at that time, she said, "Because of the layers of behavior, as well as cognitive, as well as medical," Bridget was going to be a greater challenge for residential placement. So therefore it was already...like, six years, other than an emergency, it was saying six or seven years for placement, and...so she was going to be more of a ten or a twelve year challenge for placement, whether we wanted it or not. I remember when we got the paperwork, I sat down and cried, because I really wasn't looking at Bridget, at that particular time, for her to go into a residential placement. But that didn't mean that she was going in, it just meant she was eligible for it. So then when they began the pilot program for [initiative], everybody who was on that list, was eligible, for that pilot program. Ok? And when we went to the first meeting - everybody was invited to meetings and so forth - and we went to the first meeting, and at the time Brian and I both listened to them. I felt, I don't know, I didn't think it was necessarily appropriate for my children, but I had nothing... so I was willing to take something... because it was better than nothing. And what that program offered us was an ability to give them, the one-on-one attention that they needed. It also offered them, the opportunity to have some time

away from Mom and Dad as their main caregivers, because I was allowed to bring support into the house. And the support did not have to be agency support, they could be people that we knew getting paid to support the children, so if we met someone that had very good rapport through the school system or who was a friend of somebody's child or whatever, that we could hire them to be companions and take the children out into the community. And that made an enormous difference, because it wasn't just...it wasn't just a home health aide. It was somebody, in their case, at that particular time we hired a lot of people that were age appropriate, more age appropriate for our kids, who went out and took them into some normal activities that young people would do. Go out to lunch with them, take them to a movie, do the things that Mom and Dad could do, but it's not the same as Mom and Dad doing because it's somebody that jokes with you...and that you like to be with. Umm....and that's helped them, and it's helped us, because it gave us some time together, without the kids...because Brian and I did not have a lot of family support. uh... we didn't have a lot of family that lived near us or that were able or willing to provide us with real family support. Some families do, but we were not one of them. So it provided both the children and ourselves with a lot of help in not being at that point, you know? Bill was twenty-three, twenty-four years old, and I had asked for Bill to be included in this group as well as Bridget, um...because I didn't feel I could do it for one child and not for the other one. And it was super, we fit in it, until we moved... and we kept Bridget in it, and we traded Bill's place in it because we felt he needed more peer interactions and he is not a good candidate for...making friends on his own. So our thoughts were that we would participate by putting him in a group home with peer interactions and that he would be happy with that. He is!

[00:23:07] I: You said... so that's an interesting point. You're saying that it was your...at least part of your decision, based on the thought that he would benefit from living with peers in a group home?

[00:23:22] Bonnie: Yes.

[00:23:23] I: So that was your expectation going into the process. Has that been that your experience, that he's benefitted from living with peers in a group home?

[00:23:29] Bonnie: Uhhh...it's, it's been my experience that it...it has been a mixed bag, and that Bill became very happy to live there, from the moment that he moved in. He transitioned into that house remarkably well. He likes being there. I think he annoys some of the guys that he lives with, and he's just pretty complacent with them. He talks all the time, he perseverated constantly, and he can get very, very loud, and the problem with a group home is, there isn't a structure that's permitted to really contain that. Um...because, well, I think it's being recognized now more with this autistic approach because I think there has been acceptance now that in his case, he needs that structure, to contain him, and that everybody's got to be on board with it as far as the staff is concerned, because he doesn't have limits if you don't create limits for him. But basically, the group home concept is that they're adults living in their own home, and as long as they're not going to harm somebody, they kind of have a lot of leeway, even when it's inappropriate behavior.

OK? And in his case the noise, the fact that he repeats so much, is part of the inappropriate behavior. He's not physically harming anybody so it's ok for that. But...

[00:25:04] I: How do you feel about how that's been managed in the group home?

[00:25:08] Bonnie: I feel that it's hasn't been managed in the group home. That they've given him more leeway than what I gave him at home. Um... But they say that they have restrictions on them, as far as how much control they can place on him. Uh... We would very simply say to him, "If you can't calm down..." He's a big television watcher, he gets very excited for the action packed stuff, and he gets so into it, he's yelling and screaming and so forth. At home we would just say to him, "If that's the way you're going to react, we're going to have to shut it off until you calm down." They tell me that that's taking away his right to watch TV. And, I don't agree with that. I guess it could be but in his case, he needs that control over him. Because he can't do that on his own.

[00:26:11] I: Ok, but you said that things had changed since he had received the diagnosis on the Autism Spectrum?

[00:26:15] Bonnie: Well, I think the concept now is that because he is, they're seeing him as autistic and he's gotta contain that behavior somewhat, that they're more willing to put a little bit more structure into his life. We just, this is pretty new to us. This new, ummm... approach. And we haven't really had anything laid out to us, but it seems that they're putting him on a timer thing, and some of the behaviorist, you know, type thing. Brian and I had used a behaviorist with the kids too, when things got very hectic again, even under self-direction, we, we, went to a... again it wound up being through [state school], I think. That they were the behavioral group. We were fortunate that we finally got through to them after waiting for a year and half or two years, to get assistance. They came in and spent, um, probably, they visited us on and off for about a year. And got us on a better keel, in the household. The household was really tough. The interactions between the two kids had become difficult, and then we were drawn into it in order to protect their well-being, because they had started at one point to become physical with one another. With, you know, I guess, Bridget being the, basically being the agitator, and Bill then having behavior problems, but it seems to come in that order, that you know, he'd took about as much of it as he could and then he reacted more than being the aggressor. Um...I don't know. A lot of history a lot of year, but anyway, which...That was part of the reason that we transitioned Bill out into a group home setting also, but we chose the group home instead of doing what we did with Bridget, because we felt that he really needed the interaction with other young men, and that if we moved him into his own space he would not have that, and that he would miss it a whole lot.

[00:28:29] I: How did you guys come to that decision? Do you mind sort of walking me through that? That's an interesting, you know...

[00:28:36] Bonnie: Um how did we come to that decision...? Just by observing him, personality wise. And he always had that social need to relate to guys, he gets too much in their face, and they may reject him. And he gets loud, and he's got some inappropriate

behaviors that makes them find him unacceptable. But he seems to really like being with them. Ok? Bill smiles a lot. He's a happy guy for the most part. He had one particular caregiver, who was... who happens to be the son of a caregiver that was working with my daughter who had been... who is a teacher at the school. She was working with Bridget. She suggested to us that her son might be an appropriate companion for Bill in the community. He was. He was fantastic. He now has his own life. I guess he is approaching forty, and he has his own children and his wife who need his attention. And in the last year he has, gone his own way, basically. I think Bill misses him a whole lot. Bill considered him a friend. You could see his face light up as soon as he saw him. [friend] would take him out in the community as I said, to movies, to try different things. Take him for a ride in the car. Take him as a companion. He played in a band. He'd take Bill with him to band practice and give Bill some drums or tambourines or whatever, and have him contribute part of the...um...band doing things. And he took him into the [Museum] one time, unbeknownst to me, [laughs], and took him in on the [public transportation] and gave him a whole different set of experiences than most guys like Bill get to have. And Bill loved it. He loved the attention, and [friend] was able to manage him quite well. Even after Bill moved into the group home, we continued to provide [friend's] services to him until this last year or so, independent of the group home, because it gave him a different aspect. He goes to the family's dinner, and has dinner as a friend would have dinner with him. They invited him to their wedding party. You know, different things like that. And that, um...was all initiated through the [initiative] program. Because, we couldn't possibly have afforded to pay all of these people. I know people talked about natural supports in the community, and that's great if you can find natural supports in the community, but frankly, our family has never been able to do that. We, we, that's what I said, you know? Family members, they stepped back. I had a couple of nephews who I paid, like, babysitting fees to, who, they interacted with Bill, and neighborhood kids while they were growing up. But no one that freely came and said, "Gee, I'd like to spend an hour or two with Bill, or Bridget, just because I like them." That just didn't happen. And I don't have a problem with the fact that people needed to be reimbursed for their time. If they gave them quality time that's what was important to me.

[00:32:27] I: Ok, um... so real quick, it sounds as if, you guys saw that, you know, from your experience with, was it [friend's name] that you said?

[00:32:39] Bonnie: Yes, [friend's name] that's correct. And he was a wonderful influence in Bill's life. He was a little bit younger than Bill. He grew up in a household where special needs people were part of his life, because his mom taught in the business, and she always had her...guys come in, like on days off from school, and interact with the population, and there was a comfort level, and they kind of treated them pretty equally, with other people.

[00:33:10] I: So, it sounds like Bills' experience with [friend] and seeing that, and with some of the services that he got following, you know, you guys getting [initiative] resources. Was part of your decision that he would need a little more peer support, and that's why you went to the transition out of the home?

[00:33:29] Bonnie: Right, right, yeah, we had the option at Bridget's thing to do... It gave us the option if we wanted to do an individual apartment or home, or two-up, or four-up, and we decided that the four-up would give him ...um...peers. And that we... and we asked that two of the individuals be higher functioning than Bill because we wanted to see role models around him, and that didn't necessarily work out the way we thought it would. It has a little bit with one guy, but the other guy has had some regressions, since he moved into the house and I, I ... You don't get to pick who your child moves in with, except if you do it under [initiative] support, and therefore, it becomes...you know, kind of like getting a dorm room. You don't necessarily like the people that you wind up with. In Bill's case, I think he liked all of the guys. There's one of the guys, who just has a personality that comes across as if... he's not necessarily a happy person. He crabs about everything, and Bill's one of the things he crabs about. But I don't think it bothers Bill quite as much as it bothers me...ok? [Laughs], to be perfectly honest? He kind of loves being there, and he's happy when he's home...in his house.

[00:35:07] I: So considering that, that, you know... I think that's a really good example where you felt less satisfied about the placement than maybe Bill has...

[00:35:15] Bonnie: Right.

[00:35:16:] Has that led you...can you describe that sort of dynamic, where you disapprove of something but Bill, that Bill...I'm trying to get a sense of how you balance that dynamic between things you approve of when Bill does not, or when Bill likes something that you do not, how...

[00:35:46] Bonnie: Well you make choices. You, you say, "Well, he's happy with his roommate, and...I'm not about to change them." I mean two of his, two of his housemates - they each have their own roommates actually - since he's been in there, in this ten year period, they each only had one parent each, and they both of them have lost their surviving parent. So they have no parents. The brothers - they each have a brother - and their brothers are in their point of life where they're raising families. And so their brothers are not around as much as their parents would probably be. And so they have some issues based upon the fact that they're by themselves now too. The one young man who's more personable, grumpy, but personable person, has found other outlets. And, um...the other has some support, but he just continues to still be grumpy, so I don't know that much about his personal situation, so it's hard for me to say. It's just that he may have health issues, I just don't know. Bill tends to get on his nerves. I think he doesn't bother Bill as much as Bill bothers him. And I just have to let that go. I'm not looking for a change in housemates, or anything like that. I have not been happy with the way that the group home...seems to run. Ok? Group homes, seem to...not...[sighs]...Under [initiative] I had a lot of support people in our home, and I was still here. And so I guess I've set the trend in the household as if I was the manager, Brian and I were both house managers of the group home that we were in. We interacted with our staff. We had daily staff interaction when they were here. We were still partners at home, we never left...except during their presence, we spent fifteen to a half an hour or more, interaction with them. I think that's something that staff need. Is interaction with a manager, or someone where they feel they

know what's going on, or that somebody cares about them as well, or otherwise it just becomes a job situation, like a nursing home, where people go on from their job and go onto the next job, because a lot of staff people that we have found work several jobs, whether they're group home workers or...individual support people that Bridget has. They work multiple jobs in order to leach a living, because their salaries are down in the bottom, of the barrel. And, um...most of them barely make ten dollars an hour. You can't live in [state] at that rate. Um...so...they work multiple jobs. I assume that they're tired, to a great extent. I mean I know that we have some people working with Bridget that are working two or three jobs...and that's kind of mind-boggling to me, in how you do that. And we've been pretty particular about personalities of the people that work with her. I think we have very competent people, I'm not questioning their skills. I don't find that things carry over to the people in Bill's house, in the agency that he's with. I do find, and my contact is very small, with substitutes that come from other houses to work in his house, that it's not necessarily... well, we think that something is not just quite working right. We've had a lot of issues with the managers in Bill's house. It's just...the position that we're trying to work on right now. But frankly, I've had to accept the fact that his clothes are not well cared for, which make him look like, less than presentable, in many instances. Um...food is based upon other people's values that come in as staff people, as far as what quality of the food that they put on the table is...And the residential placement that he's in has been very trusty about no McDonalds all the time, no pizza all the time, but it's still, it's the individuals. They get a lot of freedom and choices that they make about the food. And it hasn't always been good choices for them. And we've had a lot of problems with the choices in the past year. Bridget's caregiver actually has been watching the lunches and reporting to the work program people that, you know, Bill's got some ridiculous lunches this year. And, so it's the clothes, his lunches, it's that some staff is lazy and if they can get away with it, they do. We've seen all of that, we felt that those were not situations...and, and, we're limited in what we can do about it, because we have to go to the directors of the organizations and they have certain rules that they have to follow before they can react to whatever the complaint is. So it takes a long time if somebody's not doing their job to...report it and get somebody to do something about it. So we felt that was not a situation that would be healthy for Bridget to be in.

[00:41:55] I: So, it's still with Bill, after ten years, it sounds as if you see that things in his life or decisions in his life are not being made correctly, or the way you would make them. What would you say that you do about that?

[00:42:11] Bonnie: If we see that things are not working well, the first thing that I usually do is talk to the manager of the house, so that she can talk or that he can talk to the staff people in the house. If then it's still not dealt with, then I go to the director of residential. Ok? And, trust me, we've been there so frequently, that I'm almost embarrassed that I keep coming back. But it's that slow in order to get change to take place. So based upon that experience, is why we made, well, was one of the reasons we made the decision to do the [initiative] support with Bridget, so that in effect, we can manage her life.

[00:42:58] I: Ok, so you would say that, that's a good change. One of the things I think I heard you say earlier, was that when he was at home you sort of played the "house

manager" role, and now I hear that with Bridget that you, you know, "manage" her life. So how would you say... or it sounds like you still sort of view yourself as managing for Bridget, how would you...?

[00:43:27] Bonnie: Oh, we will always...And because of [initiative], I can't imagine how that would be instead if Brian and I are no longer here. That's the problem with it. That's gonna be the issue with it at some point. Because particularly now, the state has pulled back financially on a lot of things, and...um...I just, I haven't gotten that far. Brian and I are taking the um....perspective that we will deal with that when we need to deal with that. When we get down to one parent. We'll have to deal with it. And right now, we're going to give her as much time...that we can. Um...while we can manage it. And when we can't, we'll deal with that. But...that's, we, we see that as being a problem.

[00:44:21] I: So you're keeping a high level of management...or your role still stays high in oversight for Bridget.

[00:44:28] Bonnie: Yes. Yeah. Brian does all the accounting work involved in it. I mean, 'cause there's a whole lot of accounting...for it. I do all Bridget's shopping. I do...um...Brian and I are still doing the cleaning. The staff is doing some of the cleaning, but it needs better cleaning than staff does. Partially because there's no staff there during the day to do it when she's not there. And she's not able to do it. And I prefer the staff spend the time with her. They do minimal things, but they don't do any of the heavy work basically. So...Bridget still, we still haven't worked that out. Because it's our own home that we are renting to her, is how it's working, because there's not program to buy a home, and a decision was made by us, 'cause unlike her brother, Bridget is social, but not, in her life. Um... she's social if she goes someplace and she feels like interacting, but overall she's not a social person that her brother was. And...therefore, we were originally going to place her with another individual. We selected a home that had two bedrooms for that purpose, and then the other family pulled away for their own reasons and when we thought about it, we had one of Bridget's former caregivers that had worked with for about twelve years say to us, "Are you sure that you want a roommate for her? A housemate? Because remember how happy Bridget was when Bill left." And we said..."Let's think about that a little bit," and we discussed it and we decided that at least initially, that that was the better way to go with her. That she has such a transitioning problem, that it would only complicate her ability to move out, trying to get her personality and someone else's personality to blend well enough to do that. And that she would be very comfortable getting all of the attention because that's who she is.

[00:46:46] I: So it sounds as if that that decision to get a single person household was made by you guys but it was assisted on by...?

[00:46:56] Bonnie: By a caregiver that had spent twelve years with her. Yeah, one of the caregivers, her job coach actually, who had been with her in...um...situations where she was with a lot of other people, as well as spending time in the household with her, when her brother lived her, and when her brother was no longer here.

[00:47:16] I: So that was a source of support in...planning for some of Bridget's transition?

[00:47:23] Bonnie: Yes, oh yeah, with Bridget's transition, as well as with Bill, we formed a circle or board of people who were involved in their life, so that we got input from them, as well as ourselves. Because we wanted to make sure that, we weren't the only ones looking at what their needs were. That people who were looking from a different perspective also got input, into what they felt was valuable to them. And that was something that was encouraged by [initiative], was that you take input from family members and friend and people who had contact. In both cases we asked people who were former teachers, or from former work programs to providers, or speech therapists. People who had known the kids in all different levels of their life, to come and give input.

[00:48:28] I: So, how would you say that your role as a parent, differs, from the managerial role that you say that you sort of take on with Bridget, compared to Bill? How would you define your role with Bill now that he's been out of the home for ten years?

[00:48:45] Bonnie: Bill, now that he's been out of the home for years, I visit his house so that I can see what the condition of how things are in the house so that I make sure that he has...all the support that he needs in order to be healthy and thrive. Then Bill visits me so I can see his level of happiness, kind of, and I go to the program that he's with a lot, with him. Social activities, including like, uh, they have a Christmas party, they have a picnic in the summertime, so that I can see how he looks, whether he's happy, or how comfortable he is in that group environment. I have conversations, on a regular basis, with every level of management. And try to have, conversations with staff, which, the turnover is much, much too great. The turnover is enormous, uh...in his life, which is, he's been managing the best that he can. But in the last two years, he's starting to show some issues of that.

[00:50:13] I: So it sounds as if, with Bridget it's more managerial, and with Bill it's more, as you said, overseer?

[00:50:24] Bonnie: Right, right. Whereas we had much more ability to control Bridget's situation. We had one person to work with Bridget, who was a very nice person, but a very controlling personality that did not work with my very controlling daughter, and she wasn't giving Bridget choices. And I had other staff talk to me about it, because I had a relationship with them. Because I talk to them. They came to me, I think three of them came to me, and said, "This lady's not...this is not the way it should be, this is not good." So we let her go...um...based upon their opinion as well as our own, but it was more their opinion in that particular case than it was our own. Would we have probably given her more time? But it was pretty adamant about the fact that...they didn't like the way that she was handling Bridget. So that told me a whole lot, because that would never happen in a group home

[00:51:37] I: That's really interesting that you, would sort of...that right there that the decision was made based on the experiences and advice of the other staff there.

[00:51:49] Bonnie: I have one woman that's been with us about fourteen years working with Bridget, she's worked with both Bill and Bridget. She's been with Bridget for fourteen years. I have a lot of respect for her. The day after she had an interaction with the person that we let go, she was off from work that day, she called me and she said, "I have to tell you what I experienced last night." It was nothing that put Bridget in any harm's way. It was just less respectful of Bridget and Bridget's home than she thought was proper. And she was upset about it. And she was the one that kind of pushed me over on it. Another woman that had worked for Bridget for two years had commented about it too. And another person who worked with her for ten or twelve years said she just didn't have a comfort level with her. And none of them... none... we didn't ask any of them, they came to us. And that's why I'm saying, the initial people that worked with Bridget had worked with Bridget at home. And if one person came to me with a complaint, I think it was a personality conflict possibly, but when three people come to you, you have to answer to it.

[00:53:12] I: So, one question, one thing that you mentioned there was, was the effect on Bridget, you know, that she had been not allowing for Bridget to have enough choice. My question that I sort of wonder: since Bridget and Bill have moved out, if they were to exercise their choice and make a decision that you didn't necessarily agree with. Earlier we talked about if staff makes a decision that you don't necessarily agree with. But if Bridget or if Bill made a decision that you didn't necessarily agree with how would you manage that scenario?

[00:53:51] Bonnie: I would override them because of their cognitive level.

[00:53:56] I: How would that...how would you do that? If you could think of an example that would be great.

[00:53:59] Bonnie: Well, there are certain things I can't do. For instance, this morning, Bridget's caregiver called and said that Bridget had urinated on herself, and that she had told her that she needed to go in the bathroom and take a bath, and take a shower and change her clothes, and Bridget was absolutely refusing to participate in it. And she had done her best to motivate her, and, uhhh... then called us to let us know what the situation was, because she said "I don't want to leave her the way she is, because I don't want her, being diabetic, to wind up with skin problems." So she called us and Brian immediately went over there to get Bridget to go into the bathtub. Because he will say, "Get your butt into the bathtub." Ok? He will override her. Ok? Staff won't do that, well, most of them won't. And, and she's playing games because this is a newer staff person and, we know what she's doing, because we know her, she's our daughter, and we know how she is with her life. And she's asserting herself, and she has to understand that, you know, when it comes to health reasons, she can't do that. I mean, health reasons in Bridget's life are pretty much everything, because they encompass food. I mean, if she wants food that she can't have, she can't have it. I mean, it's just not...she'll try. But we

put locks on the cabinet. You know, the child safety locks, and that's part of what we expect staff to do: to contain that. Bridget has recently been taking her anxieties, I guess, or her...building up from all these new people coming into her life, and she's [engaging in a compulsive behavior]. That's one of the things that she does is she [engages in the compulsive behavior]. She [engages in the behavior], and things like that, now her [behavior] has progressed to [adding other objects to behavior] and [increasing the behavior]. Um...I won't permit her to do that. I want [objects] taken away from her, because it's an inappropriate thing to do. So, my instructions are, "You take that away from her." Her closet is now locked so that you can't get her things and [engage in the behavior], because the OCD, kind of behaviors, kind of thing, and we, we're not going to go there if we can avoid it. And then we'll discuss it when she sees her psychiatrist, we'll discuss it with her, and see if she can give us any other directions, other than that to follow.

[00:56:58] I: How about with Bill?

[00:57:03] Bonnie: How about with Bill? Bill has some similar type behaviors...

[00:57:09] I: I was sort of saying in terms of if Bill were to make a decision that you didn't sort of agree with, how would you manage that?

[00:57:20] Well, when Bill first went into the group home he had similar problems, his were with [using too many clothes], which we told them when he was moving in. And he has a walk in closet in his bedroom, and we told them that he needs to have that walk-in closet locked so that he doesn't have access to all of his clothes, and we recommended just putting some of his clothes in his drawers that he could have access to. And they said they couldn't do that because the state requires all kind of backup information in order to lock a door to a closet and so forth and so on. So we said, "OK, well, we're just telling you what our experience has been." And Bill continued doing it, and continued exactly what he had done at home before we learned to control his situation, and so eventually they had to go through the paperwork with the state but that took weeks, or months before they did it. The result wound up the same. So yes we will override...If, if it's something that's in his best interest, we will override it. It's like I was talking to his substitute house manager yesterday, about, Bill, you can't allow him to have too much of certain foods, because he'll overeat them, and then you'll have a problem with him having diarrhea which will also become a problem for Bill. So Bill doesn't understand that, so you have to understand that, and control the situation. So yes, we will override, he... he can't have three apples, he can only have one, or a half of one, or whatever works best for his system...so in that regard, if we have a manager that is willing to have conversations with us about it, we will do the same thing. And we will also discuss it with his psychiatrist, as to whether, you know, there's some other way to deal with this, trying our best, and I will say the residential placement he's in, they're not big advocates of medication. They have gotten Bill way down on medication that he's been on since he first got in there. He's on a minimal amount of medication, and they're very good about that. Both in work program, as well as in his residential placement. So... that, that's one of the things that I'm very happy with... them for.

[01:00:08] I: How would you say your role as a parent for Bill - let's use Bill specifically 'cause it's been longer that he's been out of the home - how would you say that your role as a parent has changed from the time that he was living with you, until now?

[01:00:23] Bonnie: My time with Bill, I have less one-on-one contact with him.

[01:00:28] I: And how would you say that changed your role as a parent, if at all..?

[01:00:34] Bonnie: Well, both of my children, the fact that they have moved out has distanced me from them. In that...they are not as warm and loving towards me. And...I try to be with them, but they are really...they...their perceptions... Bridget's are that I'm still Mom. I'm more of the caregiver that moved on, because I'm not the direct care person anymore. If that makes any sense. Um... That was difficult for me. But, I think the fact that they are...in settings that they're accepting means that it was the right decision, for me to make. I'm getting old. I would like a little bit more of a life for myself. Although, I'm not seeing that I'm getting it. I'm not seeing that either situation is giving me the support that I'm comfortable walking away from. Um... Even the group home situation... I mean, I suppose, I could close my eyes to the negative things. I certainly see other parents that do that. It's not my nature. So, I'm not able to do that. I see other parents - who must have similar situations that they're dealing with - and have...are just so happy that they don't have the responsibility full time, that they seem to be able to accept it. I have...less ability to do that. Um... maybe my kids are more dependent too. In that, they're, they're levels of...of abilities are less than some of these other families. I don't know. It's hard for me to say. I do know that I have a friend with a very highly functioning kid. He is... he is in his glory. He moved out of the house about two and half, three years ago, into a ordered apartment, and she's still putting in a tremendous effort there too. And, and she's the main person to take him to all kinds of services and all kinds of things, because the transportation situation with most of these, uh...housing arrangements are not the best, if you're not in a full group home. So...I don't know. I don't know what the answers are to it, frankly. I know I have expressed to my husband lately that I am frustrated and tired. [Sighs]. It's really a challenge to care for...two individuals that still need you to look after them, in that you are the person that... I still know Bill better than anyone else knows him. And I wish I didn't. I wish they knew him better. He's ten years in the group home. I wish they truly knew him better. They don't. Um...

[01:04:03] I: So it sounds as if you were expecting that your role would be lesser than it is right now. What do you think if anything, if you had to guess...has...prevented that, or has led you to continue to be the person who knows Bill best?

[01:04:24] Bonnie: I think the turnover that they have in home, has a lot to do with it. I think the turnover is a huge problem. I, I think that the individuals, that they hire, that stay, for the most part, that...are...well-trained and -thinking people, better maybe...It's not just education. It's heart. I don't know how else to explain it. It's not just level of education. It's...the...personality of the individual, who is dealing with them, as to whether they actually care about the people. Um...so it's a combination of their skill level, and their caring.

[01:05:24] I: If you could change any aspect of, I get a sense of it, but if you could change any aspect... You know. How do you anticipate your role changing, as a parent, over the next five to ten years, for... let's start with first Bill, and then Bridget, since they're in very different situations.

[01:05:50] Bonnie: How do I anticipate...? I don't see my role changing very much with Bill. Except that I will be able to do less of...some of the things. I try to send a meal down to the house quarterly, or once a month. I do better in the winter than I do in the summer. Just because I spend more time here in the house, so I'm able to. Due to snowstorms I do more cooking. I try to bring a dessert or something down, I would guess, if, if we're lucky enough to economically be able to weather the next...twenty years of our life without major health issues and things, then I could see our funds...that I will continue to do that. But if I... it's a financial thing, I understand that. If you can't afford that, you can't. So it means a lot to all the guys if I bring food down to the house. They come downstairs... [laughs], they come out of all their rooms, and they're like, "Well, what did you bring!" And they're very excited. So I hope to be able to continue that kind of an input. I don't know that I'm going to be able to be the shopper who purchases people clothes. For example, in the group home, Bill's jacket disappears, and nobody seems to care. Um... They have to pay attention to these things because he can't. He doesn't know when he hangs his jacket someplace, and then he picks it up afterwards, that it's his jacket, that in his eyes is similar to his, because it's black. Ok? It's a black ski jacket, one black ski jacket is the same as another. I hope that I can convince them that it's alright to spend some of Bill's money to send some dress shirts to a dry cleaners so that they look pressed. Because they're not willing to press them. That they bring food into the house that has...that they have more control over meals. That they're putting nourishing meals on the table. That's all the stuff that I don't want to be involved with. I'd like to know that they could do that. But really the caliber of people that they get in there, it...it doesn't seem to be a concern. It seems to be that there's a lot of... They claim that they're busy with paperwork all the time. That they're so buried with paperwork, with the state and the group home. I don't know if that's the case or not, that's what I hear from the managers. They've had a very, very difficult time holding onto managers. And the manager to me is, well the manager does... the manager sets the tone, for the way that everyone's going to treat the people who live in the house, or understand the people that are living in the house. They have asked through the years, the agency, as to how that we think we can build up a better rapport between the families and the staff. I have suggested, - and they have never tried to implement this - that they provide a circle of support situation, for once or twice a year in the house. So that they get the staff together with the families, and that anything that the staff doesn't understand, that they can say to the families, "I don't understand this aspect of Bill's personality, can you tell me how you handle this situation?" or, "How I can better communicate with him?" or, "What his likes are or what his dislikes are?" And that I can say to them, "Well, why is it a problem that you can't do this, or can't do that. Is there some way I can help you understand that he needs it? Maybe the other guys don't need it but he needs it." And that you open the communication, and they have not chosen to do that. I think it would help things. If you could get staff that stays long enough to get together every six months. I think communication is lacking. I

think that's one of the biggest things that I see as a problem, is the ability to communicate between staff and families and management.

[01:10:55] I: How would you say... So I have two more questions. How would you say, or what would you say you did differently with Bridget as a result of having Bill move out?

[01:11:14] Bonnie: ...What did we do differently...?

[01:11:18] I: Or what did you take away from Bill's transition that you maybe applied to Bridget's transition.

[01:11:25] Bonnie: Well we learned from Bill's transition that Bill was actually a lot more adaptable than Bridget, and that... We originally were going to what had been done with Bill, which was Bill went into a house that was all...um...set up, and staffed at the time that he went in. So he left our home and went someplace where he didn't know any of the staff, and really only knew the people that he was going to be living with, the other tenants, slightly. He didn't know them well. And he was ok with that. He handled it remarkably well. I mean we thought he was going to need to transition in a couple of weekends, and then gradually move in. And that was what we were planning on doing. In Bill's case, he spent one weekend, and he was reluctant to come home. He seemed like..."You know? I'm ok here." So we made the decision to move him...he started transitioning the week before Thanksgiving. We were planning on transitioning him over the next four weeks or so. He did so well, right after Thanksgiving we moved him back in on a permanent basis. So...you know, we were pleased with how he reacted. He seemed to let go very easily, he just was happy. So we went for it. In Bridget's case we were going to do a similar thing, we were trying to set up all the staff before we got her in. We were having big issues with getting, from the one funding program to another funding program, with getting it qualified, we had been sitting on the home for a year, because it was draining on us, and we felt that the staff, our staff that was working with her, was ready to go into Bridget's home place. Bridget was ready, we were ready, and so we just said, "The heck with it, we'll just go in with what we have, and we'll be the support people." And I think that since we were forced into it with her that way, it probably was a better way for her. Because, what's happening now, as she's getting other people in, we're seeing more of a reaction from her. If she had gone in with all new people, I think she would have possibly had a problem, so, you know, that's hindsight. It wasn't the plan, it's what happened

[01:14:28] I: Ok, so my last questions would be, you know, I'd just like to in general...Is there any advice you might have for other parents who are about to have their son or daughter move out or who are considering it, in regard to what parents should expect for themselves. Not necessarily what are the most typical problems in the group home, but what should the parents expect for themselves, what piece of advice would you have for the parents.

[01:15:02] Bonnie: It's so difficult. Because a lot of it depends upon, how they've lived their life. Even within their home. I'm mean I've been really, really fortunate in that I have the spouse that I have, who...from my observation, compared to many families, there's more females involved with their kids than males. Ummm... men seem to back away from, caregiving, particularly as the guys get older, and Brian has...I've always needed him. Bridget has always been very difficult with transitions, and, I, I've been an easy pushover for her. I've always had a difficult time with getting her to do things. So, Brian has always been very involved with her, including bathing. Uh... he's been unbelievable with dealing with it. Um... Many other dads, even very good, involved dads, draw a line there, and I've been fortunate with that he just didn't. So my situation may not be like other people, from what I've heard, because moms are the ones who are the people that are moving things forward usually. The moms, therefore, are pretty exhausted before they get this accomplished, and they...initially feel like, "Oh, I'm glad that we've gotten it done." Because it's not an easy thing to do. It's not an easy thing from a practical point of view, and getting funding for it, and getting it done, and it's emotionally, draining to do. It's not, it's not something you want to do, it's something you need to do, and therefore, you do it, at least that was what it was for me. And...umm...I still, 'til today, would want my kids to be able to be at home, but, my experience was that I watched Bill in his house, and I watched the two young men...particularly the first one who only had a dad when he moved into the house - mom had died like two or three years before - and his dad was not in good health. And his dad died about six or eight months after he moved into the house. And I watched how he handled it so much better because he had his own space...He didn't have to go through, um...the transition of, moving because he no longer had parents. And...I think...that the direction that the state is going in, right now, where they're not placing people until it's an emergency placement for most community-based people is horrible. I think there's an age when...as adults, and you've aged, that they need to move on with their life. That's it's not really a benefit for them to be home, and that's the only reason that my kids have moved. Um...That's the main reason, and that everybody's gotta reconcile that in their own mind. I mean I cried a lot of tears for my kid leaving, and I've been very happy that Bill has happiness in his life, by being somewhere else than here. And I feel that in his case, very comfortable, that even though he might not get the care that I'd like him to get, that he has a place that he thinks he comfortable in. Ok? And that means the world to me, ummm... We still involve ourselves, we still take Bill to camp, twice a year. He has a life he goes to there, and it gets him away from the environment there and I think that's very valuable too, because he vacations with people that he lives with, once a year for four or five days, but that to me is not a true vacation. He separates from them, for three weeks a year and goes to a separate place that different individuals that he only sees occasionally, and I think that's a healthy thing for him. And then transitions back at the end. And that's our hope for Bridget too, that even though she's living independently she needs some kind of a vacation away from her staff. That she leaves her staff and then transitions back to her staff. You know? I'm gonna die. I don't know when, and this makes me feel like what I'm doing is the right thing to do. I have a friend right now, you know, he just got diagnosed with something, and I'd be surprised if he's with us at the end of the year. And that's not enough time to do this if you're an emergency placement. It's taken us years, to do each of the kids houses. Because that's the way that the system is set up. So the system is broken.

It's very broken, and the changes that they made, they may be some good ones, but it's not making it a lot better a lot faster. So...

[01:21:00] I: So I don't have any more specific questions, but is there anything else that you feel there is about transitioning either Bill or Bridget out of the house that you feel is particularly important?

[01:21:09] Bonnie: Uh, no...It's so individualized, it really depends upon the abilities of the, child, you know, involved. And, you know, when you talk about whether you override them or not, I know kids that deserve the right to express themselves even when you disagree with them, but except that there are issues such as medical and certain financial things and so forth that you need to override them. We have two children that require total and complete guardianship, as opposed to some people, so you know, everything is based upon the needs of the individual, and the abilities of the family. I mean, this, this has also been costly. With us. There's been a financial responsibility in both situations. Bill's home placement was not the normal placement Brian and involved ourselves in it because we wanted to get it done and we actually it was the time that housing prices were very high, and we bought a house and sold it back to the agency at the cost that they could pay for it, and he needs to be safe on a road that is not a main road, and...mostly what they could afford to buy was where there was traffic, and that was going to be a problem for him. And... um... so we intervened and took some of the costs the best that we could, but we recognized that most families cannot do something like that. So they put their children in more of a compromised situation that maybe that they prefer to. There's a lot of variable with moving a child out. And people have to pay more attention to it. Because again, you've got these managers that are ones that are supposed to be the first line people doing this, I mean everything is so bureaucratic it becomes... The system rarely shows the compassion that it should, and this is a compassionate act. I'm not talking about moving a six year old out or whatever, I'm talking about adults that are thirty years and older, out of the house. This is a compassionate act, because most people by the time their children are thirty years old uh...are...close to this thing. So...anyway...you must know from Brian we tend to run off at our mouths, so I will end!

Appendix C4

Transcribed Interview: Clara

[00:01:57] Interviewer: I do want to start with how old is your son?

[00:02:03] Clara: He is thirty-four.

[00:02:03] I: OK, and he moved out about ten years ago?

[00:02:05] Clara: Yes, almost ten.

[00:02:13] I: Just about ten years ago? OK. What is his diagnosis again?

[00:02:17] Clara: Intellectual disabilities, and he is legally blind. He has cerebral palsy and seizure disorder.

[00:02:24] I: And how far away from your son do you live?

[00:02:27] Clara: Fifteen minutes.

[00:02:29] I: Fifteen minutes. OK, good to know. Alright, so just to start. So... when did you begin your whole planning for your son to move, rather, to find a residential placement? When did you first start looking for residential placement?

[00:02:46] Clara: Um, we always, we always had it in mind, with new individuals living in their own homes from the time that he was very young child, that he would have his own home. We were very involved in the disability community, my husband is an attorney and he does advocacy work for and I'm on the ARC, The Arc of [City] Board. He was on the board for twenty-two years. We knew other individuals who had their own homes, from the time that Charlie was probably about five years of age. So in our minds, we've had it, had it, for a long time. The actual planning, uh...you know, was, pretty spontaneous. We were... we had him on the developmental disabilities, uh...service...list. From the time... as soon as we could. As soon as... and I don't remember what age he was. But we've, we had him on the critical needs list for, I think, looking for services from the time he was, well... I guess we could have done it much earlier, but probably from the time that he was about twelve or thirteen. So...for some kind of service, so that his name was on the...the state knew his name

[00:04:12] I: So basically you began planning early? When did you begin specifically planning?

[00:04:17] Clara: Well, um, he actually came to us, and said that he wanted to, move in, get an apartment. His sister got married, and moved out of the house, and that spurred

him to...um... want to move out of the house. He came to use, when he was only twenty-one. In my mind, he would have been in his mid-thirties or so when we moved him out, when we...find his own home. But he was twenty-one and he said that he and [friend] wanted to get an apartment, so we started moving to find one.

[00:04:48] I: [Friend]?

[00:04:50] Clara: Yes, his best friend. The first home that he moved into was with two guys. Um...and that was when he was twenty-two years old.

[00:05:01] I: OK. Alright. So, can you describe, what your, your role was during the actual transition process out of the home?

[00:05:14] Clara: Um...well, I wasn't, I wasn't mentally ready for him to move out. We had just lost a child to a [sudden death]. She was just sixteen. So I wasn't really ready for him to move out. So I took a pretty backseat. My husband was...um...the one who, who met with the people from the ARC [city], to put together his, uh... his proposal for funding, for his own home. [Former Governor] was the governor at the time, and he had set aside some monies for...for... transitioning use, and, and for, you know, individuals moving into their own places of...uh...their own homes. And so it was a five year chunk of money. And my husband saw that if Charlie was in a mindset where he would be able to easily start living on his own, mentally, that we should move on it. So that's what we did. So my husband was the one who really met with the people from the ARC [City], he was more proactive in it than I was.

[00:06:27] I: So, you think that your role during the transition, was smaller than...smaller than, say, your husbands?

[00:06:35] Clara: Yes, initially.

[00:06:35] I: Has it evolved since then?

[00:06:36] Clara: Yes. Most definitely. I just wasn't...I wasn't able to be very involved emotionally.

[00:06:46] I: How would you say it's evolved since then? Or where has it evolved to?

[00:06:50] Clara: Um...well, I'm the one that does all the, or most of the interacting with the people who serve and support Charlie in his home. He has a...well, I won't get into that right now...I'm more involved, basically, on a daily basis, with the people that live in his home.

[00:07:10] I: On a daily basis.

[00:07:12] Clara: Definitely. I'm not there physically. But I'm at least on the telephone with people.

[00:07:19] I: OK. What, what, tends to happen on a daily basis?

[00:07:24] Clara: It's mostly Charlie and his wife, now, he's been married for nine years. They pick up the phone and call their parents, not with complaints, just conversationally, probably four times a day. [Laughs], four or five times a day. We laugh about it all the time. If something that occurs to them that they would like to say to us, they just pick up the phone and call us. So we talk a lot. Yeah.

[00:07:49] I: And is that, is that been a stable number of phone calls throughout his time?

[00:07:55] Clara: Sure, it's very comfortable for him and for us. It's, um... and for her mother. Her parents also. It's... it's very comfortable. Yeah. It doesn't seem to be excessive to us. It may seem to be excessive to other people. But it's just part of who they are. [Laughs]. So... and they're lovely.

[00:08:17] I: Would you mind giving me an example of, say, a typical series of phone calls, or one typical phone call that you might get from him on a daily basis?

[00:08:27] Clara: Um... Uh.... Either reporting something that just happened, even if it's something funny that...that, he just wants...he wants me to be part of the conversation, and so he uses the telephone for that. So it might be reporting something, or it might be asking a question, or someone might say, "I need to let your mom know about x, y, or z," just in a general way, and he'll pick up his cell phone and call me and say, "You need to know this," or, "[Aide] wants you to know this." So it's just kind of a knee jerk...uh. When he is here, he does the same thing with his wife. He calls her repeatedly. So it's just kind of his way...

[00:09:13] I: Calls her about similar things it sounds like?

[00:09:14] Clara: Exactly. Just, you know. We have him here, once a week to have dinner with us. Without his wife, so that...um...so that he's free to talk about any issues without hurting her feelings, when there are issues. It started when they were having problems adjusting to being married. Right in the beginning. And it has grown. So on Tuesday nights, and actually, this week it was Wednesday. On Tuesday he is here, every single week. And we will continue to do that until he tells us he doesn't want it, or need it anymore.

[00:09:48] I: That would be up to him.

[00:09:49] Clara: Yeah.

[00:09:50] I: So...I do want to get into... You know? Let's cover it right now. That's interesting, it sounds like, nine years ago he got married. That was after he moved into... after he moved out of your home. Um...can you go over the process of how that happened? And...

[00:10:11] Clara: Sure. He was at work. Well, he moved...he moved into a home with two other gentlemen. And... uh... that was pretty tumultuous, because the other two gentlemen were fighting, and so... Charlie is a real peaceful guy, and so he was really upset about the amount, the amount of noise and anger in the house. And we were pretty quiet people, so he wasn't used to the hollering, and...so that was difficult. But he was determined to stay and try to make it work. I mean, he would be... he never said he wanted to move out. But it was a difficult existence for a while. And then they had a house fire, and so he was back at home with us while the repairs were going on with the house. Um...

[00:11:01] I: How long was he back home?

[00:11:02] Clara: Only...hmm...well... I shouldn't split it that way. Before the house fire he met Carrie. And they fell in love. And they...started talking about getting engaged. Then there was a house fire and he moved back. And he was only at home about three months when... um...gosh, I'm not recalling it correctly I don't think. Because they were engaged for over two years...But instead of moving back into that house because of all the turmoil, and he was...he is legally blind, and was in the shower when the house fire occurred. And... he had to be dragged out of the shower and helped, someone just threw a towel around him. And he was standing in the front yard, evidently with just a small towel. It was very emotional. So, um... rather than moving back, he and Carrie... yeah they were engaged at the time. So we talked to them about living together, before they actually got married, and they were all supportive about that, because her situation wasn't great. She was with a woman that she didn't even know, in her own home. So, they... Charlie never did go back to live with those two gentlemen, He moved in with Carrie. Well he was only back in our house for maybe five months?

[00:12:22] I: So... um...one of the things I'm interested in... Well I'll stay as vague as possible. Would you mind describing...I'm hearing two things. One, the moving in with Carrie, and two, the decision to get engaged and married. Can you go over how those two decisions were made? You can choose which ever one you want to start with.

[00:12:47] Clara: Sure. Well they met on the job. Charlie and Carrie were both working at a retirement community, and his job coach actually... There are people in the field that really try to encourage, um...loving romantic relationships with individuals with disabilities, because it's difficult for them to initiate themselves. So people that support them, a lot times, will help to... if they see a spark between a man and a woman, they will, you know, try to help them get together socially, outside of the workplace. Let them have outlets for romance. And for love. In this community. In, um...it was the ARC [City] that I'm talking about. And so, his job coach was saying to him, "You and Carrie, you really make a cute couple." And so he literally went up to her one day and said, "So, do you wanna try the boyfriend/girlfriend thing?" [Laughs], so we thought that was really cute. Several of our single friends have said, "I gotta use that line." [Interviewer laughs]. They say...isn't that great? So he said "Do you want to try the girlfriend/boyfriend thing?" And she said, "Sure." And Charlie was interested in other women, through the years, but...um...this was different. This, he just wanted to be with her. He wanted to spend time

with her. It was not just...silly stuff. It was...they just became very, very close friends, and so we assisted in...We're Catholic, and her family is Catholic, and we belong to the same parish. And I had seen her involved in the Catholic Mass. She was on the altar, I don't know if you know anything about Catholicism. She was a Eucharistic Minister in our parish. And I thought...she has Down syndrome, and I thought, "That's awesome, that a young woman with Down Syndrome is that involved with the Mass." I've thought that throughout the years, and then we end up getting to know her, and then she ends up our daughter-in-law which is really neat. Um...Charlie would have liked to be more involved with Mass, but with the vision, and he's physically limited. So we didn't pursue that for him... At any rate we, um... uh... her parents were very opposed to...the engagement, and to a marriage. They are almost twenty years older than we are, and they...she is their baby, and they were really afraid of her, getting hurt. Um... and that they would go through the whole process of getting married and they Charlie would walk, for some reason or another. Um...And one of the things that they realized mightily about her, is that she has Obsessive Compulsive Disorder. And OCD, plus intellectual disabilities is just very, difficult. It's just very difficult. And the thing that she was obsessed with was my son, to a fare-thee-well. So when he moved into the apartment, he couldn't even take a shower by himself. She was in the bathroom when he...he... It was difficult. And so... uh...I'm sure they thought, "Nobody has the patience to deal with how Carrie can be." But Charlie does. And ongoing he has that patience, because he loves her. So...they're doing fine. They're doing great. But the first couple of years were pretty tough. But I've jumped...what did you ask me?

[00:16:24] I: No that's fine, that's fine, you...The first two years were pretty rough you were saying...

[00:16:29] Clara: Yes. They were. And so...you are involved as a parent much more than you would ever be with a person without disabilities, just because of the nature of the beast. Like my daughter has been married for fifteen years, and...I know that she and my son-in-law disagree and have issues...but I will know when things aren't great, if they're having difficulties, but I know *none* of the details, absolutely none. Because I... I had the freedom in the beginning to say "I don't want to know details about it, because I will harbor resentment, and you will get over it, and you will go on, but I will harbor resentment towards him, so I do not want to know. Unless you're in an unsafe situation, then I want to know." So I have the freedom allow her to resolve things. Whereas with Charlie and Carrie, and her parents know so much more than they ever wanted to know to. But they talk to us about absolutely everything. And they need help processing, um... what's going on too... So yeah, the first couple of years, they were tough for all us. In fact the parents were fighting with each other... and...it was very politely, but [Laughs], but still, they were very defensive of Carrie's actions, and we were defensive of Charlie's. So we had to actually, meet at the ARC [City], with a psychologist. The... the two... not Charlie and Carrie, the two sets of parents, to discuss our issues. And... um... that turned all around. We had a better understanding of each other. And we are actually now good friends. So...That's all worked out well.

[00:18:18] I: And you described some of the ways that you're involved, including that he would come for dinners. How, how else?

[00:18:25] Clara: Yeah, what happened is...she was...she would get his feelings hurt about something, and Charlie is a crier, he's a very gentle soul. And he would...he would call and be crying on the phone. And we would say "Well, why didn't you talk to us when this was happening, when she would say..." And he said, "I can't, she's always right here." And with... with the obsessiveness, she was always right with him. And so we started... we thought it would maybe be a couple of months where he would come once a week for dinner. And it's Tuesday nights, and we've said to him a couple of times, "Whenever you want to stop this." Initially, she was really upset by it. Um... and... then she...she totally got over it. And it's routine. She gets that he comes here. And, it's... now there are no issues. Very rarely are there any issues, but he likes...likes that time, that he gets with us, all by himself. And it's been a good balance. And she now goes to her parents, and she has for years. And they have their night, you know? So...yeah.

[00:19:32] I: Thank you. That was excellent. And if you have any more on that topic, please do let me know. Jump in with it at any time you feel like.

[00:19:41] Clara: Yeah, it was just, it was just the need to...for him to be able to vent, free of anything else. And... and like we...she, she would call...she would probably...initially, she would call fourteen to fifteen times. Um... and so...now we don't get any phone calls. But what we did was we said, "The phone is off for dinner." And when she would come here for dinner, she would see that we didn't answer the phone during dinner for anyone. So that settled her down. Initially she was very upset when we wouldn't answer the phone. But now, over the years, she's seen that that is a rule in this house: we don't answer the phone during dinner. So...um... that's come all about. We just needed to give him a pocket of time... and a pocket of time that he could look forward to on a regular basis. Um...

[00:20:30] I: And you said he used it to vent? Is that mostly what it was for?

[00:20:33] Clara: Yes. Initially. Yeah. It was...And he never, never asked to end the marriage. Absolutely never thought about moving out, never asked to move back in. He did after the house fire. When he moved back in, when he lived with the...even before the house fire, when he was living with the two guys, and there was such...you know...It was sooo, frenzied around there. He asked if he could come back home. And that was a killer, because once you go backwards in this process...if you...once you secure funding, if you lose that funding, god only knows how long it would take to...to get it back. And... and that's what we felt...We didn't explain that to him. We just said, "You know, this is awesome that you have your own place." We just encouraged him in that way. But we said, "There are some problems here, we gotta work out the problems, but you don't wanna move back in with your mom and dad when you have the chance to have your own house." You know? So we did things like... we had the guys invite their families for dinner...to their home, you know? So they had more of a sense of their own home, you know? And they were inviting others. And... and we had them invite friends... um...for

dinner or for cards, or... to their home. Just to give them a sense of ownership. But that really never worked out that well with those three guys because that wasn't ever really meant to happen. But it has worked out with Charlie and Carrie. They...they very much have a sense of... having their own place, and, inviting people over, and... you know? Not once since he's moved in with his wife has he asked to come back home.

[00:22:16] I: Um... I guess to go back a little bit. How much...did anyone else, whether that's residential staff, school staff, whoever, describe to you, or prepare you for what your role would look like? Or what your role should be? As a parent?

[00:22:34] Clara: That's a good question... um...no, because I feel that...it changes from person to person. Um...depending on who is living with him. And we've had many changes. It's very difficult to keep these direct care workers. Wm...because we...the state pays them so little. So... there's a big turnover. Um...that's an issue for every...Oh my gosh, I have this gorgeous cardinal sitting on my porch... Um...so...that depends... especially with having these poor ladies that move into this house to... [laughs] supervise Charlie and Carrie's home...um...have two sets of very sets of very involved parents, so they have a lot of, [laughs] a lot of people to deal with. So...some react very negatively to that. And some just embrace it. So...

[00:23:40] I: When you say very involved, what does that mean?

[00:23:44] Clara: Well, I will talk to [aide], the person that's in their now, probably about three times a week. That sounds like a lot. I was trying to think this through before this phone call. And I would say probably three times a week...And I don't complain, they're not complaints. Sometimes they are. But they're just touching base...Well, I'll tell you why. Charlie has a terrible time processing correct information, accurate information. So something will sound just not quite right, so I'll call her to verify what he just said to me...and...I just... I think that would...if you're just trying to run a house and dealing with...it's just Charlie and Carrie, no one else lives in that home, so that's easier, or a little easier than a lot of direct care workers have it, so... they could, you know, easily have four very separate individuals with very separate lives and I would think that's a lot more difficult. But...but...I don't know. If she's dealing with me three times a week, I'm assuming she's talking to [Carrie's mother] that much or more. That's just...you must feel like you're answering to people a lot, and I think that would be tough. I try very...I try mightily not to make her feel that way: like she's answering to me. But I need clarification so often. And then there are...I'm still involved with Charlie's doctor quite often...my background is nursing, so...I take him to his doctors' appointments, so there are those kinds of things too, that...we have to talk to the staff about. And that's just my own preference. She would...she would, in any other home, be doing those appointments but, that's just my own...with the seizures, Charlie still has ongoing seizures...so I...it's not just the neurology though...he has...uh...nerve, nerve problems in the eyes that causes the blindness. Causes him to be legally blind, and this particular problem can lead to more, more issues. More blindness. He could lose more and more vision as he gets older. So far he's been stable and he's thirty-four, and that's awesome. But those...kinds of...his medical issues like that I like to stay on top of.

[00:26:07] I: So that's, that's interesting, you mentioned medical issues as an area of his life in which you find yourself slightly more involved in. Are there any other areas of his life that you're more, or less involved in?

[00:26:23] Clara: Um... that's an interesting question too. He's become more and more independent. When he moved out of our home...he was very much a mama's boy. I had, I had very much...um...uh...nurtured to... over-nurtured, as far as his daily living skills. I didn't bathe him, I mean he was independent in his bathing, as I put down on the survey. Um...he's been independent in bathing, but... um... things like eating, um... he had never prepared, and he still doesn't though, prepared his own food. But he, with the cerebral palsy he doesn't... he can't even cut his own food. So, things had to be done for...you know... cutting up had to be done for him. Um... and I continued to give him everything in bowls, because...he doesn't really use a fork. He uses a spoon for almost everything. He doesn't really manipulate a fork correctly, or didn't. And then he moved out, and others didn't follow up on that stuff, and he had to learn to adapt. I mean, so... he still doesn't cut his own food, but he uses a fork, and he doesn't have everything given to him in bowls. He's just... He's just much more, uh, developed, than he was with me. Um... and I think emotionally also, I definitely think emotionally developed. Because he's had to process, I mean he's had to figure things out. He's been left without the...the immediate support that I gave him... um... this is even in travel. People don't... he's not a fan of the white cane, and he needs it in unsafe places, I mean unfamiliar places, and so, and so... when he wouldn't take it, I would just give him my arm, and I would be his sight guide. I mean, not holding his hand like a child but... Well, do you know anything about sight guiding? You just offer your arm to a person, like a stand.

[00:28:35] I: The crook of your arm?

[00:28:35] Clara: They stand... pardon me?

[00:28:39] I: The crook of your arm? Or, do you... uh... I don't quite... could you describe it?

[00:28:44] Clara: Yeah, you can...you can bend your arm... the person stands just behind you. The...just a tiny bit behind you and to your side, and they just put their hand under your arm, and you know, it's like... grab under your arm. You can leave your arm straight or bend it... it doesn't really matter. And then the person is traveling right next to you, but it's pretty fluid, it's nice. It's a nice way to... you're not holding the person's hand, or making them feel young, you're just giving them that guidance... they just take uh... it's kind of a companion kind of... So, Carrie is quite a bit shorter than Charlie, and she... she doesn't like being a sight guide. She likes to be like other couples and just hold his hand. So he's really had to... um... I don't know how to say it. He will always take our arm with us, but he, he's just too proud to... take others' arms, so he's... he has become a.... It's amazing how he travels. He does really well. He just, um... he makes it... he figures it out. But he... he gets around without the cane, and without a proper sight guide, but he doesn't fall, and he doesn't... so he's doing alright. He's doing things I never thought he would do.

[00:30:11] I: Ok, so. I've heard a number of different ways that he's more independent from you since he's moved out. I guess my one question that I have is: how have you personally reacted to his...evolving into more of an independent person?

[00:30:33] Clara: Oh, I couldn't be prouder. I couldn't be more proud... I, um... he's accomplishing things that I never, I never would have expected. Um... and... and he's...to see him as peaceful, and proud, it's, it's... my reaction is to his reaction, to what he's doing... He has his certain chores around the house. Just the simple things like taking the trash out and so, believe it or not, he's the one who vacuums the house. So what the guy's who's got...very little, not very little vision, but less vision than others in the house, he does the vacuuming, and he does a really good job. But, I mean the trash and the vacuuming... oh... well...He plunges the toilet! Who would have ever! [Laughs]. I mean, I mean he does stuff that I, that I didn't think he would do. But when asked, because people didn't hold back...and they just, they didn't realize his limitations, or didn't want to realize his limitations? Or I was creating limitations that really weren't there? Um... and so he's doing... so my reaction is to, his... to him, is reflective of how proud he is of himself... Getting the mail! That's the other thing. We get all this snow. He goes out in the middle of the snow. I mean he could have broken a bone, when he goes out to get the mail. No matter what the weather's like, no matter what the pavement is like, he has his job so he's got to get the mail. He's just...it's neat, it's really neat.

[00:32:13] I: Well would you say that, so I guess I'm hearing a couple of notes of this, but would you say your surprised? Or it's unexpected how independent he would be?

[00:32:23] I: Yes. Absolutely. Absolutely unexpected. It's a very nice surprise. Nice for him. I concentrated on... I think I concentrated on what he couldn't do. I gave him a lot of...because of my husband... You know there are so many mothers who are raising individuals with disabilities alone. Because many men walk, and, and if I had been by myself, I don't know that Charlie would ever have gotten... I doubt sincerely that he ever would ever have gotten married, or would have ever...I mean, I mean, my scenario in my head was that he'd be in his late thirties, mid to late thirties, and I'd be going to him like, "Well, it's time for you to move out." I will always embrace that, that he needed to have his own home. Um... but... and then I said to... I thought that he would say to me, "What do you mean? This is my home. What do you mean I have to move out?" And then his heart would be broken, and my heart would be broken. Little did I know that he would ever come to me at twenty-one years of age and say to me and say, "I want to get my own place." Part of the problem was that, we had just lost our daughter. She was sixteen and a half and it was a [sudden death], and... she was... she was a singer, and there was music in the house all the time. And then I just couldn't hear music. The whole house changed, the whole atmosphere of the house changed, and I think that was... I mentioned that my other daughter got married and that's true, but I think the big catalyst to get him out of the house was it just wasn't the same place. So...so anyway... it... it happened, and even though I wasn't ready for it, it happened. But looking back on it, He's just sooo much better off. Um... having to figure things out on his own. You know, it's just, he's just... just having to figure them out ... and he's not on his own, but... but... the expectations of him are more in the people that have been living with him than they would have been if

he was staying with me. They... they expect him to be able to do things, and not in an unfair or unkind way, they just have... they have, um... higher expectations than I did. Now I'm different, but back, back then? It didn't... I didn't have the expectations that I should have had, 'cause he certainly rises to the occasion.

[00:34:41] I: I think you came close to touching on my next questions but...you did mention several times, that you had a vision in your head of what it would look like when he did move out eventually. I mean, he came to you before then and chose to move out... but would you mind comparing if there are any other differences or similarities, the vision you sort of saw... of what it would look like once he moved out, and what it's actually been?

[00:35:09] Clara: Yeah...I did worry, when I would think about it, that people wouldn't know to cut up his food, and that...that he wouldn't... eating as much he'd be... it's as if... that he'd be falling, that he wouldn't get the right sight guide... just that... that people couldn't do what I did for him. That... effectively. One of the reasons that we were happy to get that put in place while we were still healthy, young and healthy - I'm sixty-one - um... is because, you can do quality assurance checks, you can arrive, and I do, without notice. I don't... I don't call. I just arrive at the doorstep, and... um... so, you can do the quality assurance checks. The people that wait until they're very ill, or, or one spouse is gone and the other is virtually... you know, the, the desperate situations that are out there. And then you've got the person with disabilities having lost a parent, *and* then they've got to get used to their own home, so you've got that difficulty. If you can get it done while you're still young and able to... to do your quality assurance checks, you know, and be on top of it. It's a much, much better scenario. What I imagined was people not getting Charlie. People not getting him. He's a complex kind of guy. And that he wouldn't be... that he wouldn't be eating well because they wouldn't be helping him with the food, and he's always been independent in his bathing. But I mean, choosing his clothes, he can't see to match things, and that I didn't think anyone would care to help him. And, you know, that kind of thing. So thinking of him, quote-on-quote, on his own out there, was so frightening for me... It was just: "Nobody can do what I do for him." Because he won't speak up for himself. That's the other thing: he's really, really proud, and he won't complain. He doesn't want to seem... um...weak. And so we won't, or he won't tell you certain... Well, as it turns out, he's just so much more adaptive than I thought he would be. He figured out how to make it, to make it happen. 'Cause there are times where, like I've said to you, he now uses a fork. He never used a fork, and I thought he couldn't. I guess that's probably the main thing. Things that I thought he couldn't do, he can do. He does them limitedly, but he can do them. Does that make sense?

[00:37:50] I: Yeah, yeah, that does! So one thing that you said in there was that you really expected that people really weren't going to get Charlie like you did, or they weren't going to do the things for him, that you could do, or that you did. Yet you always sort of envisioned that he would be moving out? Can... I mean so those seem like two conflicting ideas to me...

[00:38:18] Clara: Right, well, that was because of our exposure to the disability community, and the number of older adults that I saw...having to adjust to this lifestyle because...it...there was a girl, the woman that lived across the street from us. And her father had died while they were all young, and her mother, and her sister slept in the same bed as her mother. Her sister had Down syndrome. Slept in the same bed as her mother. And she was in her forties and her mother got cancer and passed very quickly, so never did anything... I mean there were other sisters, but none of them...were willing to take her into their home... so she was left having to adjust to... her own place, you know? Sleeping by herself for the first time in her life, and in her own place, *and* the loss of her mother. And she had a terrible, terrible time...the, the, um... the emotional adjustment was just a... I mean she's doing great, but initially it was just awful. And I thought that's never going to happen to Charlie. We've... and that's, actually when I met [woman] is when I started to pull back from Charlie a little bit. So I'm painting this picture that I did so much for him up until the day he walked out of the house, that's not true. He was probably in his teens, early teens when I met [woman]. And I started encouraging him to do x, y and z. It... it opened my eyes. So even though I didn't think he was going to move out until his early thirties or something, I started helping him to be a little more independent. And the first thing I did was I went back to work. And that was interesting. He would have to get off the bus, and we had a great big long driveway, 350-feet long driveway. He would have to come down the panhandle hill and down the long driveway and let himself in with his own key. And, now it took him almost a year to figure out how to do the key correctly. And that... so that year I was looking for a job but I didn't go back to work until I knew he could do the key. And I had neighbors who were checking... I mean I had all kinds of backup, so it was a safe environment for him, but that was *HUUGE* for me emotionally, to, to be working... I really enjoyed working and I mean that was... it was really great for him. He'd get in the house and he'd me call right away so I knew he was OK. And he hated it, initially. He'd call and he'd be crying. And it was breaking my heart. But it really... uh... that was huge. So... um... so I went off again, didn't I?

[00:41:00] I: No, not at all, no, no.

[00:41:05] Clara: So, yes, I did, I did... Even though I was afraid, I always knew I wanted him to have his own home. Ok. Yeah. Part of it, the big help...with, with, with parents, is to get out and talk like we... [husband] and I would go to the, because he was on the board of ARC [City], we'd go to the national conventions... and you'd hear other stories. You'd hear how other people solved these issues, and what their stories were. And so... the big thing, like what your doing is just great. You know, to, to... the more we talk to each other, the more we learn. And you hear that people are doing it, they're out there doing it.

[00:41:48] I: So hearing other people's stories helped you, you know, decide, or make some decisions for yourself and plan a bit?

[00:41:55] Clara: Yeah, we had him in the [specialized school] and...

[00:42:01] I: Was it the residential program, it doesn't sound like it?

[00:42:03] Clara: It is a residential program, but he didn't reside. Eighty-some percent of them reside Monday to Friday, all of them go home on the weekend, but reside there Monday to Friday. But he didn't live there. We didn't, we just... we would take him to and from school. Or he went on the bus. He was a day student. But, um...when he was a teenager, and because of going to these conventions and hearing all of this stuff about inclusion, inclusion, inclusion, and we were feeling guilty. But, I loved that school, and I thought it was the best thing for him. And my husband was gently was prodding me along. And we pulled him out when he was in his late teens. And his last four years of his education were in a normal high school... in a secluded, in a segregated classroom, but he was integrated in like, art, and gym, and lunch. But that exposure was fabulous for him. I was scared to death, but he did it. And, when he graduated, they gave him the...they called him the "mayor of [town] high school," because he got to know absolutely everybody. So it was pretty awesome.

[00:43:14] I: So, that was perfect, thank you for that. I feel bad for jumping in and saying anything because I think you were doing a great job sort of describing everything I'm looking for so...

[00:43:27] Oh, well, good. He's kind of my favorite topic of conversation. [Laughs].

[00:43:33] I: Well, good. I mean if there are any other anecdotes that describe, or anything that you think is particularly descriptive of your experiences, either during the transition out, or since he's been moved out, please just go ahead and interrupt me and jump in with them.

[00:43:52] Clara: OK.

[00:43:53] I: And you know what was important in your experience better than I do. So don't think you have to answer my questions, my questions are just a simple guide, I'm... I try to go off what you're finding to be important.

[00:44:06] Clara: Ok, yeah.

[00:44:08] I: So I guess in regard to that though, is there anywhere... is there any aspect of your role or your involvement in his life that you would like to see changed in any way?

[00:44:23] Clara: Huh... [long pause]. I don't know. We've evolved nicely, I think. It would be interesting to see what my husband would say. It would be interesting to see what he would say. If he would want him to be more independent of me. Not that... I don't feel that way. I think that...well I don't think he would... I guess what I'm talking about is all the phone calls and stuff. Whether he would want that to be different. But I don't think he would. He doesn't seem the least bit irritated with it. I don't... and he's very close to Charlie. I'm sorry he didn't answer the survey. He's a [occupation] and he's overwhelmed right now, so all of his work stuff is going out of his head, so I apologize for the timing.

[00:45:19] I: Don't feel bad at all, you're being very, very helpful with this, so I'm getting, a great deal of important information.

[00:45:28] Clara: Ok good. So you're saying do I think that my role should change?

[00:45:34] I: Or is there any way that you would like to see it change? Or yeah, or should change? Or anything.

[00:45:40] Clara: Yeah, yeah. Um... I don't think so. I think we've come to a nice balance here. And... I do think that the... like, the current person who is the supervisor of Charlie's home, is a young mother, she's a single mom. She's got a little boy, and they live downstairs. When she gets a break on the weekends, there's another person that comes in and stays on the weekend. We have someone there 24/7 because of his volatile seizure activity, so... We got approved for... um... And the fact that we have someone living there rather than just having shift work, like some of the agencies, or all the agencies do in some homes, just having people coming in shifts and...

[00:46:29] I: How does that work having her live there, how does that look?

[00:46:36] Clara: Well it's a split level home and... so she lives in the bottom portion of it, and... but they've made it up to... It's almost like in-laws quarters, and she has her own kitchen and everything, so that when she's there on the weekend she still comes up and uses the main kitchen but... but she... everybody that's been with Charlie for all these years, we've had people, found people that will live... and it's really, it's really interesting because we - both sets of parents - initially wanted it to be like a big family. And... it's been refined that the individuals that do this work, really they're, they're good. They're respectful of Charlie and Carrie, but they don't want to look at it as a family, they want to do their job. They look at it as an important job, and it is. But, like, they never... we have not found one person - and there have been several that have been there at the house - that, like, sit down and have dinner together. They... they fix Charlie's and Carrie's dinner, and Charlie and Carrie have dinner and then they kind of do their own thing. So it's, it's different than what I've anticipated. I thought that we'd have a family atmosphere, and we haven't. They're there to support them, and, you know, to do things to help them, and... organize them, and keep them safe. But we have not found anybody who looks at it like a family. And that's probably better, because there is a turnover, and it's in every home. Everybody that has their kid, that have their young adults in homes, everybody experiences this. And if, if your son or daughter gets too close, too emotionally close to the person... um... that's really hard. Change is hard. Change is hard for everybody, but it's really hard for people with special needs. So, um, this has been more... they have adapted to... um... they've adapted nicely to... Well, she's a nice person, but it's not... like the first lady, the first couple of ladies, they would call "my [name of aide]," "my girl." They would try to personalize it. And then they just set themselves up for disappointment. So to see that growth in them is really good too. They've, been able to balance that while... but... and just the common sense that you expect to see in people... um... that sometimes... that's another reason that I'm on the phone, is because... sometimes you think, "Well, that just didn't, that just doesn't make sense. Why would you

do that?" You know? Just kind of... and... basic common sense sometimes, is, is, not there. Uh... It's an interesting, it's a difficult balance, because you want independence for your child, and yet you want guidance. Um... and people in the field, a lot of times will say, "I didn't, or I wanted him to have his independence, so I didn't want to push this or push that." And I get that, you want to be respectful. You want to be respectful of them. But you also, the reason you're there is to provide some guidance, so... I don't want them, or expect them to mother him... but it's ...you know, if he's going out to something that's important and he's... like, he's put on something that just got... been sitting in a ball in the bottom of the clean laundry basket, so he's full of wrinkles from head to toe, could you, could you not say, "Charlie, let's see if there's something else that you could wear today." So he doesn't walk out the door looking like, a... so. Just little things. Such little things in the bigger theme of things, but... um... that's a balance always, and... always, always.

[00:50:55] I: One thing you... or that I heard you say a little bit earlier, was that your role has evolved over the years. Can you give me an example, and you have given me some examples of *how* it has evolved, but are there any points at which, you think there were major changes, or evolutions? Or any incidents that you recall that caused you to...to reevaluate what your role was?

[00:51:20] Clara: Yeah...um...there have been several. And, and each... the thing that I've learned to do is to step back and reflect on what just happened. Because, like, for instance, his neurologist, when we go the neurology appointment, he... every year - and you would think a neurologist whose specialty is seizures, he would have the respect for the person with ID, to speak to them, directly to them. If they, can handle the, um... And so, every year we go through the same thing, and the first time Charlie did it, it blew me away. This doctor would turn to me and say, "How has his year been?" And, finally Charlie said. Charlie... um... I turned to Charlie and said, "Charlie would you like to tell Dr. BlahBlah how your year has been?" And I'd redirect, I'd do it with all of his doctors. But this time, he did it again, he spoke to me, but Charlie leaned in front of me and said, "My year has been ok." And then he started this whole conversation, and I thought, "That's awesome! [laughs, happily], He just took it over! *He* just did it." Then there's, there's that, but...that I need to think... Wow. You know, he... *he* did that. And here's another one with the vision. We were meeting, he was in high school, this was his second year in the regular high school and I was waiting with the teacher of the week before school, and there was a lot of construction going on in before school. So I wanted to walk around the building with him, to let him familiarize himself with where the construction was, you know, just for safety. And so, we were there, maybe an hour. We weren't there very long. And then the teacher met us in the principals' office, and she said, "Well, lets go down the hall and catch the elevator." And he said "The elevator's blocked at the end of the hall." And I didn't realize that. I didn't... that didn't sink in when I was walking around, but he did. So the things that I've watched him adapt to, and learn, have been... The eating that's another thing. The dressing himself. The choosing of the right, level of jacket to wear. You know? I just thought to ask the person that's living there, he came out it was a lighter jacket, and I said, "So did you set out the lighter jacket for Charlie?" Um... "No, no! He went in the closet and got the lighter jacket." "He did? Ok." So each

time I'm surprised...pleasantly surprised, I... I try to remind myself to reflect so that it sinks in. You know? To pay attention to the progress.

[00:54:21] I: So, I guess, a couple more questions. One is, how, if at all, you see your role, or involvement changing over the next five or ten years?

[00:54:37] Clara: Well, I'm still healthy. So I'm still definitely going to be involved. I... One of the things that we have talked about doing, is making sure that our daughter knows where everything... Well, we're very fortunate, we're very blessed. My daughter is very involved in Charlie's life, peripherally. But as far as the business part, part of it, we want to make sure that she... um... has what she needs to advocate for him, and to know where different accounts are and all that kind of thing. We're going to get her more involved. But her husband, who never had a person with disabilities in his life until he got to know Charlie, is on the Arc of [City] board. That's how involved he's gotten. So we're really, really fortunate that we have, these two in our lives. So, I would continue to get ready for the next [laughs], the next step, I would guess. But personally, with Charlie... I don't really see... we've come such a long way, I think that, I think we have pretty much... over the next five to ten years, hmm, that puts me into my seventies... Um... I just think that... we're at a good level, so I don't see it changing I don't see any pulling back more from him. We've been pulling back kind of effectively. I think I sound like I'm patting myself on the back, I don't mean it. I don't know.

[00:56:15] I: Another thing that I wanted to touch on briefly was, that you mentioned that sometimes that you... I think the example was when you feel like a certain decision was made without common sense. When something happens, when a decision is made, or Charlie ends up in a position, or deciding something that you disagree with, how do you handle that? What is your role when something happens when you're not, that you don't necessarily agree with?

[00:56:52] Clara: [Pause]. That's a real good question. Um... I'm trying to think...

[00:57:03] I: And if it helps, if you could give an example of sometime that something came up that you wouldn't have done or didn't agree with, and what you did.

[00:57:12] Clara: Right... hmm, you know? When there was... questions like that in the survey and I went to answer, and um... I guess it's mostly when I would intervene, would be if I felt that something wasn't safe for him, or something like that. But for judgment calls, or relationships, well there... yeah, I would intervene if he was getting into a relationship that was... unsafe. There's one, there was one man that they bowl with. And, we sat Charlie down and asked him to "please, don't..." We didn't take him out of bowling, we didn't take him out of that environment. But this guy is known to get really upset and punch people. So I guess my involvement would be to talk to Charlie, and to help him reason through it. We sat down with Charlie and his friend, they're both big guys. They're both very, very gently souls and, we said, "Just stay away from [other man]. Just stay back. Even though he uses inappropriate language, don't correct him. It's not your role, you know. He could hit you." And I started... I said to Charlie, "You

wouldn't see it coming, would you? Would you see a fist coming at you?" "Well, no." And I said, "Well, think about that." So I guess we had to sit down and reason with him. But something else as far as my changing: I do need to pull away from... uh... medical appointments over the next five to ten years, and have other people take him, so that it's a comfort level, because he's going to obviously need his doctors and that care, for the rest of his life. So that, I have been, not willing to back off, and I need to have other... so that he has a comfort level with other people taking him. That's for sure one area that I have to... um... and the other thing is that I'd love to get more involved, or try to find out more technology for people with vision issues, and introduce more things to help Charlie with that. We just recently got him a... I saw at the State Arc Convention, a talking... talking calendar. Which is really awesome. It's really awesome. And that's been huge, he really loves it. You know, he already has a keychain that has a talking watch on it, and he uses that all the time, and at home his alarm clock is talking, but not a talking calendar, which is pretty cool. So, that...

[01:00:00] I: Um... quick questions. How would you say your life, or your and your husband's lives, have changed since Charlie moved out?

[01:00:12] Clara: Well, we've been able to travel. Which we've absolutely loved. It's been really a wonderful thing, um... for us. We really enjoy traveling, because, we feel so comfortable with, the security that he... with the quality of people that are in his life. And he, when we would travel, in the past, would... really have a hard time. He'd be, um, he doesn't act out. He's not a hyper kind of guy at all, but he'd be depressed. He'd just basically be depressed and he wouldn't eat well, and he'd really have a tough time. And that has grown where, he has now, trying to understand time difference, he can't get that, but, um... so we get calls at like three in the morning [laughs], it's really interesting. But... he's so much more accepting, I think with everything. It's the same with Charlie. Once you just keep doing it. Even though he might...you know... if you keep doing it, even though he might be having a tough time with it in the beginning, he'll eventually adjust. But that's been great for us, for our marriage, to be able to do some traveling. It's been really nice. We were never able to do that.

[01:01:34] I: Ok, so I think the last direct question I have is, if... and something I've found that has been useful. Is there any advice that you would have for other parents, who are, either entering the process of having their son or daughter transition out, or considering it? Specifically regarding, what...their role is going to look like, or how their life is going to change or anything like that?

[01:02:05] Clara: Well, I think it's...it's...most definitely the right thing to do for everyone, for everyone involved. I, I don't believe that... a sibling should have the responsibility of taking in, um... their sibling. And just because, it can... I think marriage in this day and age is hard enough, without extra stressors, and that, I think, would definitely be an extra stressor. For the individual with disability themselves, the fact that they have a sense of their own home, and, they can invite people to their home, and their sense of ownership, and they can be like you, they see you, they see, well kind of a... you have been a role model for them all through the years. And for them to step into shoes

kind of similar to yours is *huge* for them. I've seen it over and over again. Just huge. And one thing that I did that um... when I was so scared about him moving out, is... it's this tiny little thing, but we have this thing where I went into his bedroom, when I knew he was going to be moving out within a month or so, and I said "Goodnight, and..." Or no, I said, "Sweet dreams." And he would usually say, "You too," when he was going to bed. And he was on the phone, and I said to him, "I'm not leaving this bedroom until you tell me you too." You know, just goofing around. Well that kind of developed into our thing that we absolutely say to each other every single night. If I'm out, and he leaves a message on our phone he'll say, "Sweet dreams, and you too, Mom." He'll say both. And it's just a one little consistent thing that we have as mother and son. It's very small, but it's a security blanket for him I think. I think... and it's helped *me*, I thought "I'm going to do this." When, when he said, "You too," I thought, "I'm going to do this every single night when he's in his own place. He can call, and we can say this to each other every single night." And that's been a really neat thing. Um, when out friends hear about it they're like, "Oh my god, that's awesome." That's just something that he needs to say, that I need to hear, and that I need to say and he needs to hear. So anyway, if there's something that a parent can develop, even if it's a certain handshake, or I don't know, just something that you can make with that child... and that's been interesting. The other thing I would say is, as frightening as it is, when you let them try, they will... I think people with intellectual disabilities get it. They can get it. They just need more time. They... if they are given time, they can get it, they can accomplish, it's just that we, in our fast paced, in our society, we have these expectations. We have these immediate expectations. And if you keep the expectations, don't ratchet it down, but wait. And they will get it.

[01:05:15] I: Thank you, just one specific question, just a short answer. How often do you go, or will you go to his house? It sounds as if you see him for dinner once a week, and he calls several times a day. How often will you be at the house?

[01:05:33] Clara: Umm, I'm at the house... well, just... like, other than picking him up for doctor's appointments, maybe... I don't know... once, maybe twice a month? Yeah. But like in the beginning, when the person first moves into the house, I will stop in most definitely once a week. Um, just unannounced, just so I can have a feel for what it's like around there. Because Charlie and Carrie don't complain. Neither of them... so... they wouldn't... if something seemed off to them, they wouldn't be telling their parents.

[01:06:13] I: Is there anything else that I haven't asked about that you think is important for me, or for other parents to know?

[01:06:21] Clara: Just that I do think that if you can get it done, it's the thing to do. I have no regrets. No regrets, over any of it. In fact, Carrie's parents were very, very, um...opposed to the marriage. And we just went to her mother's eightieth birthday party, where... and she announced to everyone in the room that they didn't want the marriage, and now it's been the best thing that ever happened to her. Um... It's just um... you know. I don't have any regrets over any of it. The first couple of years when they were having such a tough time, I thought, "What have we done here?" And, "What has Charlie done here?" And, "what have we helped do?" because it took a lot of help from us to get this

done. And, uh... but... but it was... He has a constant companion. I mean she might be irritating, she might be this, she might be that, *he* might be irritating, he might be this, or might be that, but they are dedicated to each other. So he has this constant companion. And when this child is born to you, and he's lying there with... he had this hydro-cephalic head, and you just... it... he's... we thought he was totally blind, in complete darkness, and I thought, "Will he have any friends? Will he have friends?" And he has this loving companion. It's just amazing. So, and I would say to people, not necessarily man/woman, because a lot of people are afraid of that, but, to nurture relationships, have your son or daughter's friends to your house and nurture relationships from the beginning. Because our kids don't think to invite their friends over. They're like... Well, what would we do... But Charlie, with [friend from first house], he was at our house every single Friday night. Every Friday night, and that's it. That's something I would encourage to do, when their kids are teenagers to nurture friends like that.

Appendix C5

Transcribed Interview: Denise

[0:00] Interviewer: [Reads intro script]

[1:23] Denise: OK.

[1:34] I: First off, when did you begin planning for your son to find a residential placement, do you remember?

[1:41] Denise: Uhhh, hopefully or realistically? I mean, hopefully, probably from the time that he turned twenty-one, because we did register him with DDD, which is what everyone told us to do.

[1:59] I: you registered him at twenty-one?

[2:03] Denise: maybe it was eighteen, no, I think it was eighteen. We did the guardianship and all that, all at the same time. So we were hope, hoping that something would change within the [state], that when he turned older there would be a place for him. Realistically speaking, with the waiting list the way it is in [state], it didn't seem to become a realistic option after a while, and then, um... when the [name of residence] presented itself, probably as a gem of an idea, um... I would say it was probably ten years ago, that's when we started thinking there might be a place for him to move to when the time came.

[2:57] I: OK, so it sounds as if you only realistically began planning once there was a realistic, in your view, option for him?

[3:09] Denise: Right. And then I mean, the [name of residence] it started out as an idea, I would say, about ten years ago, and then about eight years ago, the property was purchased, so it seemed to become something that was going to actually occur. But then it took another six years before the house was actually built and they could move in. So it was a very lengthy process, um... I know the person who is the executive director, had many, many, many, many issues because he was going a different route than had previously been done. So I know there were times when I thought it would never get accomplished. But it did! And he came in at the very beginning. I think he's been there two years, and ... I guess it's been almost two and a half years now.

[4:14] I: Ok. So, do you mind if I ask what your expectations were, for the, for the actual transition process itself?

[4:27] Denise: The transition from our home to the apartment?

[4:30] I: Mmhmm.

[4:32] Denise: Well, we started preparing Dylan way back when, and in some ways, I guess I was a lazy mother. I said, “You want breakfast, you make it,” “you want lunch, you make it,” “you want your room to be neat and tidy, you take care of it.” So I guess we always expected, um, Dylan to take care of the same things his brother would take care of. And when the idea of moving into the apartment became more real, we started working on things like the laundry. Because before it was easier for me to do it, you know? [Laughs]... But then we realized he was going to have to deal with things on his own so we started separating his clothes and started having him to do his laundry, you know, and instead of letting him do a so-so job of cleaning the room, we started to get a little more picky of what was really done. Because before, if he did it, it was really good enough, but now that we weren’t going to be there watching over him we wanted him to do a better job. So, I mean those were two examples of the types of things we started to do...

[5:59] I: I see, so you started preparing him, as it, as it became a realistic...

[6:05] Denise: Once it became a realistic situation, we saw that within a year or two he was going to be moving out, we started to work on those things that he needed to do to take care of himself.

[6:19] I: Did you have any expectations on how you would feel, or what you would experience during the transition process itself?

[6:28] Denise: Well, you know, we went through it with my younger son, so, I think it’s kind of a mixed bag because you want them to be out on their own, and be independent, but you do hate it when they leave home, [laughs]. But he was only moving seven miles away so, we knew we would still see him and everything. But it was an adjustment of attitude. I mean, like one of the things, um... we always had to be careful about what we said around Dylan, because it would get repeated, and sometimes it would get a little misinterpreted, and you would hear something from someone and wonder, “Well, where did you hear that?” And it would be from Dylan. Now we don’t have to worry, hah, about it, we can say whatever we want and we don’t have to worry about it being heard, or being repeated. So, I mean it’s a small thing, but, you know, [laughs], it’s just one of those things. And you know, we’re free to come and go as we like now, and last year, we went to [southern state] for four weeks, this year we went to Europe for three weeks. We never would have been able to do that if Dylan was in the home alone, and so we kind of feel we kind of reached our rewards in life and we’re going to take advantage of it.

[7:57] I: Ok, so, um... so it sounds like one of the experiences that you had, were both that, well, one is that you found you had more time to travel and to do things for yourself, but also that you felt less guarded at home, is what you said?

[8:16] Denise: Yes, well, Dylan has a tendency to kind of repeat everything, so, um... I mean that was I think was one of the things... there's so many little things that, you know, [laughs], I mean you're not, you're not cooking as much food, you're not cleaning as much, you're, you know, when any child leaves the home, you have less things to do because instead of four people, you have three, or two people.

[8:42] I: Was it surprising to find that you felt less guarded and that you had more time?

[8:45] Denise: No, not at all, it was what we were hoping for. [Laughs].

[8:51] I: Ok. To discuss the actual transition itself, did... were... did it work out the way you expected? Were there any surprising moments?

[9:01] Denise: Well, it actually was much better than we expected. Well, let me tell you a little story. The executive director had realized that the parents were going to be very involved, especially one of the parents. So what he said was, "Alright, the first week, when you're moving everybody in, that's OK, because you're getting everybody settled." But it was his suggestion that after the first week or two, that the parents kind of stay way a little bit, I, you know, come over take them out to dinner, but stay out of the apartment, and let them get used to the place being their own. Well, we thought it was a great idea, I mean what better way to adjust, you know, but having staff there, and take care of things, and settling into a new routine. We talked to Dylan every day, so that was not... so I mean it wasn't like we were totally disconnected. Well, there were a couple of other parents who were like, "You can't tell me not to come, I'm going to go over there as often as I want." So, looking back, I think the parents that were, were a little too involved, after that first, second week, their kids had more problems, whereas we took a little back seat, and I think the adjustment went smoother in the long run, because he found out he could take care of things himself.

[10:35] I: How was that experience for you, being, you know, having it requested that you not, uh...?

[10:41] Denise: Well I agreed with it. I, I thought I was a great idea. I mean, you have to let these kids... I, I, we call them kids, we shouldn't be doing that. They're young adults. You know? You let them get settled into their place, and let them figure out what they need to do things, and you know, I mean, I was fine with it. [Laughs].

[11:08] I: Ok, so you were fine with it?

[11:11] Denise: I was fine with it, I didn't have a problem. No.

[11:14] I: Ok. Um...so it sounds like you mentioned that some people, you know, gave you some advice, like the director, on what to do throughout the transition. But did

anybody else, including that director, describe to you what, uh, the transition would be like? Or prepare you for the transition?

[11:40] Denise: Yeah, not really. But you know, part of it, I guess, the other part of it was, we were so involved with this whole project, I mean, we have known, the [family of Dylan's housemate], we have known the [other family] since practically the day that Dylan was born. They were one of the first families that came and talked to us when Dylan was born, and their daughter is seven months older than Dylan. So they kind of had to do things first, and we sort of followed, and they offered advice along the way. So it wasn't like we didn't know anything at all about the project, and were walking in cold. We were a part with it, through fundraising, and planning, and strategy sessions, from day one. So I think because we were so involved from day one, we had a pretty good idea what the vision was going to be, and it matched with what we wanted for Dylan, and what he wanted. He wanted his own place, next to his girlfriend, and, I don't know, he was going to take care of himself, and that's what we wanted for him, so it kind of all came together, and we trusted that it would be the right, um, setting.

[13:02] I: How much thought did you give to what your role would look like, um, as a parent, following his moving out of the home.

[13:09] Denise: Well, we knew that, um, we'd still be getting the daily phone calls, um. In the beginning, I think it was more still with every little thing that, you know, he needed, or had a question about, we got the first phone call. So he wasn't really going to the staff in the beginning, and he is now. But that's typical Dylan. I mean, um... we went away for the four weeks down in [southern state], and the first week he was constantly calling us in the day. And so I finally told him, I said, "Dylan, we're on vacation here, so, you know, jot down what you want to tell us and make it one phone call, you know?" So then he dropped down the number of calls, and by the third week, he wasn't calling anymore, heh, so, you know, that tends to be the pattern. When things are new and tend to be a little different, he calls more often, or he, you know, sends an email more often. And then when he gets into that pattern where, you know, we're not there all the time, he settles down and figures things out for himself sometimes.

[14:21] I: So it sounds like from his past, you were prepared for that level of him contacting you at the start?

[14:29] Denise: I think so, I, um... You know, again, we're only three miles away, so if there was something, we could be over there in five minutes, and take care of what needed to be taken care of. Did I also have questions as to whether or not it was going to work out for him? Of course we did. 'Cause, you know, we never thought it would be realistic. We thought it wouldn't happen, but when it actually did, there were some things that had to be taken care of, but, you know...

[15:03] I: There were some things that you needed to take care of?

[15:06] Denise: Yeah, like a light bulb burned out and he didn't know how to change the bulb, you know? So the first time we go over there, you show him how to do it, and he calls the next time you're like, "Well, can you get someone from staff to take care of this, because, you know, we hate to keep running over there to change a bulb." But I think in the beginning we were there for all those little things that came up, but now less so, two years later.

[15:36] I: So you said you found yourself, relying more on staff to assist him with some things.

[15:42] Denise: Well, that's... I mean, they're getting paid to be there for him, so, you know, it was part of their job to offer support services for, so, you know, we wanted him to rely more on them than calling us every time some little thing came up. And that's what happened, so, I mean now, we know everything that's going on, but he does go to staff first for certain things.

[16:12] I: Um, if you could, this an open ended question: in your own words, could you describe what your current role is in Dylan's life?

[16:22] Denise: I'm still his mother, [Laughs]! I still remind him that, um, you know, that he needs to do certain things, certain ways, and most of the times he does follow through on it. Um, we, well, I guess, I am (unintelligible) we still tend to take care of all the medical visits, you know? Eye doctor, and the regular doctor. Um, that's just something I don't feel comfortable letting the staff handle that. Um, you know, we still wanna know exactly what's going on with health issues. I don't want to have to second guess what somebody told him, so we, we still tend to take care of all the medical visits. He does see a psychologist, once a month, with his girlfriend. We call it relationship counseling, but he is a psychologist, just to have that outside, you know, person talking to them, and you know having them to be able to discuss their personal things without a parent being around all the time. So we still take him to that. Any major clothing purchases, we take care of. You know I'll take him to the store, and I'll buy it and bring him there, or return it. But simple things like socks and t-shirts or whatever, he handles that himself. But if it's a major purchase, like a suit or a jacket or something, we take care of that. Um... Checkbook we usually go over at least once a month with him. He does pretty well, but we learned that, he, um, every time that bank statement comes in it's a good time just to double check, because if you wait two months there will be some mistakes that just seem to multiply. So major banking things we still take care of. Um... I guess that's it. Medical, major clothing purchases...

[18:38] I: Well, one thing you said early on, um, and this may seem vague, but you said "I'm still his mother." You know, could you just go into an example, of maybe not

specific decisions or areas of decisions, but how, “I’m still his mother” works, in your own words?

19:00] [Denise: You know, well, if I go over to his apartment, and I see that it’s not as tidy as it should be, I’ll say something. Um... you know, if I see that his toenails need clipping, I will say something about that. You know, it’s kind of funny, because I never say that stuff to my other son, but I do to Dylan. So the other guy can take care of it by himself, but, uh... but Dylan he still needs reminders, so... you know, you’re still, you’re still the mother, just making sure everything is being done the right way, you know? I talk to staff, and make sure everything is ok from their perspective. You know? Um... uh... I mean, you.... You know, my mother once told me: “It doesn’t matter how old you are, I’m still gonna be your mother.” He’s still, he can be fifty years old, and you’re still the mother, [laughs]. So...you know, you want things to be right for them, you want them to be somewhat easy for them, and if you can make it easier, or make things better, then you do it, you know.

[20:17] I: One thing that you brought up was your other son. Um... and, like you said, your mother with you said, “I’ll always be your mother.” And I assume you always expect to be, uh, the mother to [brother], as well, but could you describe to me, are there any other major differences. I mean you’ve done a good job already, but differences in what “I will always be [brother]’s mother” means from, “I will always be Dylan’s mother”

[20:46] Denise: That’s definitely a good question because in [brother]’s case, especially now that he’s married, I will never tell them how to do something. But if they ask for my opinion, which they occasionally do, I will give it to them. With Dylan, I don’t wait to be asked, I just tell him what my opinion is. Because, yeah I still feel that, he needs guidance, he needs to be pointed in the right direction, whereas with [brother], if he’s coming to us with a question, you know, it’s a little more heavy, it’s a little deeper. I mean he’s living in [European city] now, so he was going to [European city] whether or not we agreed with it or not, but he did ask us, “What do you think about us going to [European city]?” And, I mean, my husband started, with, “Well, the job... well the job experiences that you’re going to get are wonderful.” And I said, “Well, you know, you’re going to a different country, so you have to think how your life is going to be different over there.” So, generally, it’s an, “If I’m asked, I’ll offer some of what I feel” with him, but with you know, with Dylan, we are always still giving it, whether or not he wants to hear what we’re giving to him.

[22:08] I: You’re giving advice, even if you haven’t been asked? Or I think you said you’d make decisions. Are their areas of his life in which you’re more apt to do that than others?

[22:23] Denise: Well, you know, things like vacations, family trips, are always our decisions. I mean, if...

[22:31] I: He still accompanies you on your...?

[22:33] Denise: Like we're going to the family visit at Christmas time, and we're telling Dylan, "This is what we're doing, these are the days we're going, this is when everybody will be there." He's more or less has to go along with that, because, it's a limited time that everyone's in one place at one time, so we work around everyone's schedule, um... So, you know, we try to certainly take his schedule into account. This year the whole week got mixed up because there was confusion about who was coming, when... So, we had told Dylan he could go to this fall, um... Christmas gala, that we always go to. But then the week switched around and, um, now my husband is gonna bring him home for the dance and bring him back the next day, because we can't tell Dylan, "he could go, now you can't go". So those are the things we make the decisions on. Um, financial, it's pretty set now, he gets his social security, his paychecks, he knows which he should cash, which he deposits, he writes his checks for rent and cable, and, um... and the phone is automatically deducted, so he doesn't have to do that. He has guitar lessons, so he takes care of that. There was one problem. I didn't know why he was spending so much money all of a sudden, so again, we stepped in, and said, "Dylan, what's going on here?" And we had to add some money to his account. He was on a little spending spree for a while there. It wasn't anything drastic, but I mean we had to rein him in, because he didn't realize he was down to about \$200 in his checking account. So those types of things we definitely oversee.

[24:38] I: What would you say is the biggest difference between your role as a parent while Dylan was in the house and now that he's living independently?

[24:49] Denise: The biggest difference...um...well, obviously when he was home we certainly were more involved with his day-to-day, you know? We ended up doing a lot of driving that we don't have to do now. He's taken care of some of his schedule, and we're at the point where I don't need to know which Wednesday he's going to which meeting. Because, um, you know, he's taken care of it now. So when he was living at home, it was certainly much more involvement, it was much more involvement on our part in the scheduling of activities, and getting him there, um, cooking and cleaning, was certainly more involved. Now I go over to the apartment maybe two, three times a year and do a real thorough cleaning maybe two, three times a year, get it really clean, you know? Well that's, I guess, the biggest difference, is the day-to-day scheduling of things. Um... you know, he comes home from work and he calls us and he's, you know, that the conversation is never more or less than it was when he was here and we would sit around the dinner table and talk, um... You know, as soon as that was done he went upstairs to his room, he never watched television with us, or anything, unless we had company, and

he stayed downstairs. But for the most part he would be upstairs. I think the driving around is the biggest difference really. And then it was always coordinating. You know, a lot of times we shared the driving with other parents, so there was always talking with other parents, about who was going to do which way for which activity, and all of that. So we don't speak to those parents as often as we did before.

[26:59] I: Are there areas in your life where you expect not to be involved in what Dylan decides, or what he does?

[27:09] Denise: Uhh, well, food shopping, we're not involved in that anymore. Occasionally, he wants me to pick something up, but for the most part he does his own food shopping, you know? We realize he's probably overpaying for things, but that's part of the cost of not living at home, I mean, if he's buying orange juice, he doesn't look to see which one's on sale, he just buys the one he wants, so, you know, we don't get involved in that anymore, and it is what it is. So if he spends more in a grocery store, that's part of what it is living away from home. Umm... like I said before, medical we're still very involved. Fortunately he's very healthy, so there aren't any major issues, he goes to the dentist twice a year, he goes to the eye doctor once every two years, and gets a physical, you know. If he were sick, I would... I don't know, we might even bring him home if he were sick. So far we haven't had to do that. So, um...you know, he goes to work five days a week, and so we have to be involved with that. The job, the second job he got we really didn't have anything to do with that. It was, [adult disability organization] who took care of that. So it was like they called us up, and they had this job in the works, and was it agreeable with us, and we said, "Of course it is!" A job out in the community. And that was pretty much the end of our role there, because they did the job training, they'd go over every once in a while and see how things were going. I would assume if there were problems, we'd get a phone call, he... but so far that hasn't happened.

[29:26] I: A phone call from?

[29:29] Denise: From the place of employment.

[29:32] I: Um, were there any, you know, was there anything you were, surprised about, um... either that you had a larger role than you expected, or did more than you expected, or that you had to do less than expected?

[29:54] Denise: You know what surprises me? It's nice to have a little help. You know when your mother tells their son to do something they'll balk at doing it because it's Mom telling them to do it? Now, when his girlfriend tells him what to do, he's ok with it. It's kind of funny, because I find her annoying sometimes, you know, when she's telling him what to do and how to do it, and he just goes along with it, and it's perfectly fine. Whereas if I were to tell him the same thing, he'd be mad at me, or give me the, "Aw,

Mom". So I think that was a big surprise. Now, how he acquiesces to her, she's basically telling him the same stuff that I was telling him to do, but coming from a girlfriend I guess it's different. I think that was the probably one of the biggest surprises.

[30:59] I: Was he going out with this girl before he moved out of the house?

[31:03] Denise: Uh, they had been a... what did they call themselves...? They called themselves a promised couple, and that happened either eight or nine years ago. I've lost track of things now. So they were always in a boyfriend/girlfriend relationship, but now they're living next door to each other, they had an adjoining door between the two apartments, so whatever goes on over there is their business.

[31:33] I: "Their business."

[31:35] Denise: Yeah it's their business, I stay out of it.

[31:39] I: Ok. Um, so the surprising parts were that you found that he relinquished, some... or he would listen more to his girlfriend, was there anything surprising about how much you do, or how little you had to do in any area?

[32:03] Denise: No, I think that things went pretty much the way we expected things were going to go. That he would be more dependent in the beginning. And we had hoped that it was less than as time went on, and it certainly did, which, you know, we felt comfortable going away on the time that we did knowing that staff would take care of things, and that Dylan would be able to take care of things. So, um, you know, I guess our expectations were realistic, and then they were met. So, you know.

[32:43] I: Was there anything that happened, since the transition, that you wish you had prepared for differently?

[32:53] Denise: I'm going to switch phones because this phone is losing battery, and I don't want to lose you.

(Switching phones)

[33:17] I: Was there anything that happened, since the transition, that you wish you had prepared for differently?

[33:31] Denise: Um...I don't... I really can't think of anything...

[33:44] I: That's fine. Can you describe how you personally reacted, emotionally, if possible, to the transition period itself?

[33:55] Denise: Well... I didn't find it terrible, I was really happy, I go back to a promise that someone made to me, years and years ago. They had the older child, the

more medically involved child than we did. And she said, we were talking one time, and she said one time, "I just want to be mom, and not mommy anymore." And I looked at her, and I knew exactly what she meant. When the, the child still needs you for a lot of day-to-day things, you're the mommy, and it's not until they start getting older, and start becoming more independent that you become the mom. Do you understand what I'm saying?

[34:45] I: I think, if I didn't before, you've described it very, very well.

[34:50] Denise: and that comment that that person made always stuck with me, and when you know, when you have children, as much as you hate to see them leave the nest, if you're a good parent, you've prepared them to leave the nest, and you *want* them to leave the nest, you want them to be out on their own, and to have a happy life, and all those wonderful things you want for your kids. And with Dylan, he was becoming twenty-eight or twenty-nine years old. We got old, and I don't know about [husband,] but I was always tired of being the mommy, because you're always still doing everything for them, sometime just because it's easier. And so when he was gone, it was like, "Ha, I finally can have my life, I can do what I wanted to do, and not have to think about, well you know I gotta drive Dylan over here, and I gotta go pick him up at eleven o'clock." So, I mean it was nice to, to just, be...be the two adults in the house again, like it was thirty-five years ago, without the everyday responsibilities of having children. Not that you don't worry about them or think about them but it's nice not to have to deal with it 24/7.

[36:22] I: Were there any resources or services that prepared you for the transition, or the post-transition, or that assisted during or after the transition?

[36:34] Denise: Uhh, just the other parents. I mean, before anything happened, when Dylan turned twenty-one and left the public schools, all of a sudden all your supports that you had in school and the life you had as a parent of a disabled child, when they turn twenty-one that was it. You were out on your own, you know, trying to find a job, you're trying to work with [state disability department], you're trying to work with [county disability department], you're really out on your own, doing all this, and Dan and I are pretty involved in organizational stuff. You know, as Dylan grew there were different groups, so I think we had a pretty decent idea, you know of what thinking or what programs were out there. What [state disability department] has to offer and you know all those different things that you can get to help you along the way, but, um...you're still the one doing everything. And now you, you know... so that was from twenty-one on, where you're, you know, pretty much we found [recreational org] and [work related org] for him. Now you're talking about working, it wasn't any formal group that we could go and talk to and hear step, one, two, three, four, five. "This is what you do when your child is moving out of the home." You kind of hope you're prepared for it. I mean we kind of had the luxury of having the other residents and parents, most of home we know since the

kids were babies, I mean, [other resident] went to the same middle school that Dylan did. They weren't all in the same class at the same time because of the age difference, but we've known these parents for thirty years and we've always been close. I think this is one of the things that's hurting the parents that are still pro-inclusion. All of the parents with children in the same program in school, and different programs as they got older, and we were all good together sharing information, because all of our children had Downs, and were all pretty much on the same level. I think these parents who are all pro-inclusion, they don't even know the names of other family in the district who have handicapped kids, because there's no communication between them. Everything's confidential. So, um... So although we didn't have a formal program, transition program, we had each other to help out along the way, especially [Dylan's girlfriend's] family. I mean her family, we are very, very close, and as well as being in a similar situation, so if one of us finds out something we automatically share the information. If she sees something isn't right, in the apartment, she lets me know, if I see something in [girlfriend's apartment] I do. So that's the support that I can think of?

[40:16] I: Thank you for letting me know that. That was, thank you. That was excellent. Are there any changes that you would want to make in your role as his mother, you know as you said, still being his mother?

[40:35] Denise: Well, you know, I hope that I'm balancing the right amount of letting Dylan do his own thing, but when he needs help, I step in and help him, and Dan is really good too. I mean when I was working and he was retired, he took a lot of things I used to do. So I think together, I think we have a good balance going, where if he needs help, we're there and if he doesn't need help we let him be.

[41:15] I: Can you describe what "needing help" would be, or how you would know that he needs help?

[41:21] Denise: Well, he's pretty good at verbalizing. I don't want you to get the idea, that everything is wonderful and perfect. I mean we've had a few incidents with Dylan, we had some behavior where we had to step in. I know things that we did not handle well, because we were just so overwhelmed, and we had problems, because what we saw happening, because we were not clear on the situation, he wasn't clear on the situation, and I mean it just got overwhelming for everybody. So I went to the psychologist, and said, "I don't know what to do here, can you help us out?" And well, she asked a few question and got the story from Dylan, and calmed it down, and, you know, got us all back on track. Now if something similar were to happen again, we would handle it differently. So I mean we're learning as things come up, and, and first time we didn't handle perfect, next time we'll do better.

[42:42] I: Not to pry obviously, but would you mind either giving details about what it was that you felt overwhelmed during, or letting me know what area of this life it fell into?

[42:55] Denise: Well, um...Dylan...Umm, I'm just gonna say it, Dylan just sometimes, has a problem with inappropriate behavior, where he doesn't stop things. [Recounts incident regarding Dylan's romantic relationships]. So there was a whole big to-do about that, and well, what happened, what didn't happen, who said what, and so things got very convoluted.

[43:45] I: And so, what did you find? One of the things you said, you felt, you feel, um... that you felt overwhelmed, and two, that the psychologist helped you through it. So let's start with that. What about what you had to do, from your end, made you feel overwhelmed?

[44:13] Denise: you know... um... we were so upset with the whole thing, because how could he do something like that? [Recounts more details of the incident]. So you get this whole drama thing going on, and I felt maybe it was the mood of the day or whatever, but we just started yelling, and the more we yelled, like, "How could you do this? What were you thinking?" You know, not realizing Dylan doesn't have the mental processes to, you know, keep his mouth shut about what happened, or, um, you know, figure it out for himself and resolve it. It's too complex an issue for him. And the more we ranted and raved, he just got surly, disorganized, you know? And he didn't know what he was saying anymore, then it was no matter what we said to did it was not the right thing. So it was not a good situation, so, you know... We realize his limitations, and that he does things without thinking, and they all do. I mean one of his teachers, said, "You know how races are 'ready, set, go?' These guys are just 'ready, go'." They don't take that extra minute, and it's part of his disability, they can't process it like that. I don't know, I guess he just forgot that for the moment, [laughs].

[46:04] I: One of the things I did hear you say was that you feel as if it were to happen again, that you would know how to handle it differently. In what way would you handle it differently?

[46:15] Denise: Well, we wouldn't rant and rave. We'd have to be calm about certain things, or otherwise, you don't get the answers you need. You have to ask the right questions, you have to step back and take a moment and you know, think the whole thing through, before you start questioning, or blaming, or whatever [laughs]. But it kind of took us by surprise, we weren't prepared for that. So I guess that does back to an earlier question. Yeah it was a surprise there.

[46:53] I: And, um, one thing that you also said was that you went to Dylan's psychologist for assistance, did he already have that psychologist?

[47:02] Denise: Oh yes, [girlfriend] and Dylan have been going to see her for...gotta be six years now, and I, you know, looking back, it was one of the things both parents agreed that if they were going to move in to this independent living situation that it might be a good idea to have an objective person help them through the changes. They've been going there for quite a long time. She was talking to them about living on their own, and living together as a couple, because they share certain activities together, they each make their own breakfast and lunch, but they share dinners together. You know, if they're both there, they'll cook and eat dinner together. So, you know, that was one thing. It was them talking about being in a relationship with someone that you're practically living with you know.

[48:14] I: Do you see her, that psychologist, how do you find yourself envisioning what to take to her, or whether or not her role has changed?

[48:27] Denise: Well, I think she's just that outside perspective on things, when, both [girlfriend's mother], we met with her, and this is bringing back memories that I had forgotten about. [Girlfriend's mom] and I, well, first of all, we got her recommendation from a very, um, uh, involved person with the ARC. And we went up and met with her first, to make sure that we were all on the same page. You know, that she shared out philosophy, of how the two should be living together, and, you know, our general philosophy of life. And we both liked her the first time we met her, so they've been going to see her for quite a long time now. And it's just, you know, [girlfriend's mom] is very involved in her daughter's life, and we're somewhat involved in Dylan's life, and she's just that outside viewpoint, and she's just listening to the two of them, and offering her perspective on things.

[49:46] I: And do you think that, the role she played during this, would have been similar or different, if Dylan had still been in the home?

[46:59] Denise: Well, I don't if we would have gone to a psychologist if it wasn't for Dylan and [girlfriend] having this relationship.

[50:10] I: But it sounds as if they were having a relationship before Dylan moved out of the home, and that you were also seeing this psychologist, before moving from the home.

[50:22] Denise: Yes that is true, because they had been seeing her much longer than they have been living in the house. But I think part of the reason we went to her is that we thought they were going to be moving in a lot sooner. Like I said we bought that property six years ago.

[50:43I:] So searching her out was to assist them...

[50:48] Denise: Getting them ready for the move and that type of thing. But it did take longer than we expected.

[50:55] I: And I guess the question I'm trying to get at is, and I'm trying to let you lead as much as possible, I'm interested in if you think you...allowed her to play a larger role in this situation than if... or if you played less or more of a role, than if this had occurred while Dylan was living at home?

[51:28] Denise: Well, the same thing would not have happened at home, because the [details of the incident], because we, I mean, like I said, we've known these kids for thirty years now, and we know which ones have the potential to do certain things that may not be acceptable. So that is, it never would have happened if Dylan was living at home, because it wouldn't have had the opportunity to happen.

[52:10] I: So, that makes a lot of sense. But I guess I'm using this as a way of asking whether if you think that something difficult like this arose that you relied more than you would have on the psychologist to assist him, rather than necessarily mommy to assist him.

[52:32] Denise: Yes, yes. Because we were all so distraught, that you know we just needed her to kind of fall back, and clarify the situation, and speak sensibly about it. I don't know why that hit us so hard, but it did. I don't know. For things to go along so well, and then to have this happen, and you know, then it was the old "he said, she said" for what really happened, you know? Who was more to blame. And we were all, "Wait a second here," you know? [Laughs]. So...

[53:11] I: How do you foresee or expect your level of involvement in Dylan's life to change in the next five years if at all?

[53:21] Denise: Next five years? Well, there's a couple of answers to that question. One is that there probably will be a very strong possibility that we are going to leave [town] and move to [separate state], which is three hours away. Dylan will stay here because everything is established here: he has his therapy and his place of residence. If we were to... I mean if we were to bring him to a different state we would have to start all over again. That's one part of it. The other part of it is that I don't think he would ever leave [girlfriend], so there's going to be in another, indefinite period, where, I mean we'll not be in the same town. So in that regard our involvement is naturally going to lessen, because, you know, instead of seeing Dylan once a week, it'll likely be once every three weeks or once a month. And we will still talk to him. On the other side of that question, you have to take into account that when Dylan's aging, um... his abilities may become less. So... is the independent living situation going to be the most appropriate for him, or is it going to be somewhat more...? You know... I don't...you know? To have 24/7 group home time type situation would be a bit much. I think it would be nice to have something in

between, at this step. So... you know, I mean again, Dylan has been pretty healthy, we've been very fortunate in that regard, but if you know anything about aging of individuals with Down syndrome, they age... more... then you know more quickly than a normal person, so....you know, I would expect that in five years he'd still be in the same place, but...

[55:48] I: But it sounds as if you've prepared for...possible transitions further down the line.

[55:55] Denise: Uh, there could be a change down the road where it's not... I guess it would be the safety issue, if we felt, I mean if we felt that he wasn't able to take care of himself anymore, and maybe independent staff hours weren't offering enough support, I don't know if they'd increase them then, because, they're all going to be in the same situation. Um...so...I mean we look at both sides, it could continue as it is now, very well, or it might be that he's going to change. It depends what happens.

[56:36] I: Have you... um... it sounds as if you've made, uh, you have expectations of both practical consequences, and expectations about actual level of contact based on this upcoming move. Have you, do you have any expectations on... emotionally, or as you're, as a mother, you will be, the move will be for you?

[57:05] Denise: Well, I'm having more of a problem with it than my husband is. He was born in [other state they may move to], so he feels like he's returning home...um...[out of state town] is a very nice community and I really like it up there, but I was born here in [current state], [laughs], you know? All my roots are here, all my friends are all in [state]. So I'm having a little bit of a problem with that part, plus, you know, can we really leave Dylan on his own? And be three hours away? You know....

[57:48] I: So there's some, you have some concerns with that?

[57:52] Denise: Absolutely! Absolutely, uh...

[57:56] I: What concerns might you have?

[58: 02] Well, you know I just wonder if...Well, first of all, I wonder how I really am going to adjust up there. I am very involved in a lot of different things here in [state]. So if I leave [state], I have to find new things to get involved in. Because I can't just sit home and... work the garden or [laughs], I have to be involved with other things. So, I would have, I would have to start all over again, you know. Um...With Dylan, [exhales], you know, I...I ...right now I don't think it will be a problem, but I don't know! To be gone permanently, you know right now, we've been doing these short little vacations, to get away, and he's been managing. I know Dan talks about "you know, maybe we need to hire, or each need to hire someone, who would not be associated with [housing set up]" We'd need an outside observer, who'd go over there maybe once a week, who could be, you know a substitute mom, [laughs]. To just make sure things are ok, and....he's doing what he should be doing, rather than hearing from a staff person that everything's fine.

We'd have that outside person come in and... tell us everything was fine, that we're paying that person, and they're reporting to us, you know? [Laughs]. I mean, we might consider doing that...if we see there's a need for that.

[59:50] I: So I just have two more questions... um... one is, have you... have you or will you, um, sought any support for yourselves throughout this process?

[1:00:09] For ourselves? No, I mean, Dan and I have each other, we have a lot of family that we're very close to... um... I think just the freedom of not having to take care of a disabled child 24/7 is something that we're happy with, you know? I mean we love Dylan, we love [brother], but I don't miss that. [Laughs loudly]. I don't miss that 24/7. I was not the kindergarten mom who stood on the curbside crying my eyeballs out because they were going off to school. I, you know, I was like, "Alright, what are we going to have for breakfast at the diner?" [Laughs]. You know? I think it's just the freedom of not being on call 24/7 is very nice and...you know, like I said, we have our other interests together and separate. You know, we've worked our twenty-seven years, and now we want to sit back and enjoy things while we can, while we're still able to, because we've seen too many cases where people wait to retire and then something happens to the one spouse and they're not going anywhere then. Our neighbor across the street is in that situation. So he had a stroke, and he's only sixty, and for the last five years he's in a hospital bed in their dining room and she's sitting there taking care of him, so all their plans of traveling and doing things were gone, were out the front door. So we didn't want to be in that situation. We wanted to be able to, you know, when we were raising the kids we did our little vacations, but we certainly didn't do any European trips or going away for more than a weeks. And we, you know, we worked hard and we saved our money and now we can do things that we enjoy doing.

[1:02:24] I: And so for my last question. Is, is there any advice that you would give to a parent who is about to enter this same transition process, about the transition itself, or life afterwards, about what to expect?

[1:02:45] Denise: Well, the biggest thing that I would say to any parent is: after your children leave the home, you have to have your own interests. You have to have hobbies or activities or volunteer work, or something you enjoy doing to fill your days. Because once the kids are gone, your schedule totally changes, I mean, gone are the days of... you know, baseball games and soccer games, plays, and everything else. So, you know, a lot of people I've seen after their kids go off to college, they sit there and they look at each other like, "what are we going to do?" And I don't think that's different whether you have a normal child or a disabled child. Um... hopefully you have a good marriage and you enjoy being with your husband again, hah, and doing things together and also doing things separately. As far as having a disabled child and having them move out of the home, it certainly is a little more worrisome, than sending a normal child out into the world. So you just have to, you know, decide what you want for your child and then hopefully find a program that matches the child's needs, your needs, trusting that everyone can live with that and grow towards, you know, more independence, or whatever it is you want, more freedom, more independence. And that's a tough one. I

mean, you have to be well-informed and you have to make the decisions, gathering all the information on local facts, and hopefully find the right place where it'll all come together and work... I can tell you right now, just knowing the number of people that we've known over the years, because Dylan was in, let me think, one, two...two different programs up to the age of five, and all through the public schools. And then I actually went back as a volunteer at one of the programs that he was in. And, I mean, there was a very definite change in attitude, I mean, when Dylan and his friends were growing up, they were in a self-contained classroom, and if they were capable of being mainstreamed for another class, they were. And I was also a middle school librarian so I saw the current crop of middle school students. And, I mean, the difference in the attitude among the parents has changed, very, very much in the last thirty years that I've been involved with this community. And I think even among our friends there are parents who have different attitudes. And I'm thinking of one parent in particular. She would never, ever, send her child into an independent living situation. I think they will eventually, maybe send her to a group home, if there is no other resource available. She already told me that she said her other daughter, um, said that she would take the handicapped sibling. And we never expected that of [brother]. We always believed that he needs to live his own life. We hoped that he will always be involved in his brother's life, but we never expected him to end up taking care of his brother. We have friends who, um, feel that that's not right, "Why shouldn't [brother] take him in?" I just hope that you get enough of the very opinionated folks so that you can see that there are different sides to this. There are people who'd never do this, and there are people who want their kids out of their house when they're eighteen. So...we're one small perspective on the topic.

Appendix C-6

Transcribed Interview: Dan

[00:00:27] Interviewer: Ok. Do you recall when you began planning for your son to find a residential placement out of the home?

[00:00:39] Dan: Years before

[00:00:43] I: Years before. can you elaborate? Do you recall how many years before?

[00:00:48] Dan: No, but it was since my son was twenty-one, he and I have done a lot to advocate to find housing for the disabled population, in fact we had gone out to [city] and testified and I've testified in different venues around the state, so it's been an ongoing thing for years

[00:01:17] I: Ok, you guys were advocating before finding the location for...

[00:01:25] Dan: Yeah, in fact, Dylan testified in front of the [state] assembly.

[00:01:35] I: Wow. How was that for you guys?

[00:01:39] Dan: It was very positive, it was very positive. It was back before the [state project] was put into effect, and the [state project] was to find housing for 10% of the people on the waiting list every year. And you know that has helped in freeing money from the state to open up new spots.

[00:02:11] I: So, regarding your own role of after the transition process, can you describe to me your expectations for what the process would look like?

[00:02:23] Dan: You mean once we managed to find living arrangements outside of the house?

[00:02:31] I: Yes

[00:02:33] Dan: Umm, there was, you know, lots of questions: How would it work? How would he adjust How much support would he need from his mother and father? The staff at his semi-independent apartment house, how much would they provide? Would it be as efficient? How long would it take him to sufficiently be able to cook his meals, you know and make grocery lists, and wash his clothes? So, there's a lot of unknowns when he left the house.

[00:03:16] I: So, even at the point at the point he was leaving, it sounds as if you weren't sure of how it would work?

[00:03:27] Dan: Very uncertainly. You know, I have confidence that he was capable of learning. We knew he was very much looking forward to being more independent. But you never know until you try it.

[00:03:42] I: Was there somebody that you went to with your questions?

[00:03:49] Dan: No, because, there wasn't an answer. I mean, we had, you know, we knew that he would be able to learn a lot of that stuff, but we didn't know how it was going to work out.

[00:04:05] I: So there wasn't an outside, or anyone else that was able to...?

[00:04:12] Dan: Well, sure there was lots of people but they didn't have the answers to, you know, individualized questions concerning Dylan. No one knew him better than we did

[00:04:26] I: Ok, so, did anybody, did you get any sense from anyone else about what your role might look like moving forward once he moved out?

[00:04:40] Dan: I'm not sure we got it from anyone else. We knew that we would always be involved in regard to any medical issues. We knew that we would always be involved in helping with his finances, his checkbook, his money issues. We knew we would always taking him shopping for clothes and that sort of thing. So, you know, we had expectations along those lines, and that pretty much worked out as they have. The one thing we were thankful for is that the staff there you know, did very well with him as far as the you know, taking care of the apartment, and the cooking, the grocery list, the washing the clothes, and folding, and that kind of stuff.

[00:05:42] I: So it sounds as if, you were sure of the fact, that, for example, you continue to play a big role in his financial concerns.

[00:05:56] Dan: Oh, definitely, yeah.

[00:06:01] I: You helped your wife respond to a survey I sent a few months ago, in which we covered financial concerns, and it sounds as if you guys would have control over some major financial decisions in his life, but that he would have control over smaller ones.

[00:06:28] Dan: That's correct. He's pretty good, he pays his monthly rent bills, cable bill, phone bills. And gets his check from work and cashes it, and uses it to buy groceries and all that kind of stuff, so that's you know, that's going pretty well.

[00:06:52] I: So, considering how certain you were, it sounds like you planned to play a big role with the finances. Since you expected to play a large role, has that been the case, have your expectations been met in that area?

[00:07:09] Dan: They've... you know, actually? He's done better than we thought he would. You know, most months his checkbook is correct. I mean we get the bank statement and balance it. So, he's doing quite well.

[00:07:27] I: So you check in on his finances?

[00:07:31] Dan: Oh, definitely.

[00:07:33] I: But you expected to do more? Before he moved out, you expected to do more?

[00:07:41] Dan: Yeah, we didn't know, we didn't know if he would just be spending all his money on things, or what he would be doing, but he's done OK.

[00:07:52] I: OK, and you said there were other things where you were fairly sure you would play a continued to play a large role?

[00:08:06] Dan: Well, you mean what other areas?

[00:08:10] I: Well, you said there were a few where you felt a little more sure that your role would continue...once he moved out of the home?

[00:08:22] Dan: Well, you know any medical issues where he has to go to a doctor, we're the ones who take him because we want to be there. You know if he needs clothes, we want to take him to make sure that he gets stuff that fits and looks good and is good quality. You know we stay in for social events and we have him over here for dinner frequently. That kind of thing.

[00:08:55] I: So you're level of contact with him is still high?

[00:09:01] Dan: Well, I don't know what your definition of high is. We talk to him every day and see him every week. But it's not, not, we don't see him every day.

[00:09:12] I: That's interesting, I would like to ask about that a little bit more if possible. So you said that you speak to him every day and see him once a week. Did you have an idea before going into the transition how much you would see him?

[00:09:32] Dan: We, you know, we didn't know. I guess I'm not surprised, because he was getting independent before he moved out. He would spend a lot of time in his room playing his games and on the phone and that kind of stuff.

[00:09:54] I: Well, so it sounds as if, by saying, "I'm not surprised", it seems as if he's shown a level of independence from you guys.

[00:10:08] Dan: Yes, yes, he's making more decisions by himself without calling us. At first you know he called us quite a bit, but, he's getting better, he's, you know... Most of the time he makes the right decisions.

[00:10:29] I: So did you expect... I'm trying to let you describe the situation yourself, and you're doing a very good job. It sounds as if... I'm trying to think of how to say this. What level...? Pardon me if I'm repeating myself. What level of contact, or what level of independence did you expect him to have from you?

[00:11:08] Dan: Well, I guess... we expected the regular day-to-day stuff, he would be independent on, and you know, and to the extent necessary, lean on staff. But any medical issues, or employment issues, anything at work, or, um, financial issues he'd rely on us.

[00:11:47] I: So any medical, financial, or occupational issues he would rely on you.

[00:11:55] Dan: Yeah the biggest issue of moving out of the house is that for twenty-nine years, Denise and I drove him all over the place like you would a teenager. You know, every weekend there's some social event going on, and, you know, you're driving him here, you're driving him there, and then thankfully for work, he was able to get transportation. But that's the biggest thing, from our perspective. It frees us up, we don't have to, you know, plan our schedule around his schedule. Our, you know, detailed days.

[00:12:40] I: Has that been surprising?

[00:12:44] Dan: No, it's been wonderful.

[00:12:46] I: But you were expecting that?

[00:12:51] Dan: Yes, that was the biggest thing. So, anybody that leaves the house, they have to have transportation is what I'm saying.

[00:12:58] I: Transportation was one of the biggest concerns going into the process, or that you've discovered since the transitions?

[00:13:05] Dan: When you have a handicapped child it's always a major issue. You know, you don't want your child to be homebound. You have to get them out and do things, and somebody has to do the driving. It's just like teenagers.

[00:13:30] I: Could you describe, to go back a little more generally, what process, whether it was other people, or your own discussions that you had, in defining what the process would look like?

[00:14:06] Dan: The process of finding residential placement for him?

[00:14:08] I: Of once he moved out. Did anybody prepare you or describe to you what your role would be? Or did you guys discuss what your role would be?

[00:14:23] Dan: Um... yeah, there was the executive director of the not-profit where he lives, did have communication with the parents, and gave us his view of what our role would be and what we would be responsible for. In that regard, yeah.

[00:14:52] I: Can you give me an example of how, one thing you said was that, pardon if I'm jumping around. One thing you said was that you spend much less time in his transportation now that he's moved out of the home. Can you give me an example of what that's been like?

[00:15:18] Dan: Yeah, every Tuesday afternoon, we're not driving to the bowling alley, and then two hours later driving back to pick him up. There would be one or two things every weekend that he would go to that we would have to provide transportation, or carpool with other parents if their child was going there. While he was home it was hard for us to go away. You know? So it worked out well for us, he left the house just at the time we were retiring.

[00:16:03] I: So, you have been able to go away and spend more time, and travel more.

[00:16:12] Dan: Yeah, we just got back from being away for three weeks.

[00:16:17] I: One thing that you said earlier also, was that he called you more when he first moved out, but that he's become more independent since then?

[00:16:28] Dan: Oh yeah. At first he was calling, it seemed like every hour, it wasn't but it seemed that way. With every little thing that came up, you know and as time has gone on, he's more confident making a lot more of the smaller decisions.

[00:16:50] I: Smaller decisions?

[00:16:51] Dan: Yeah.

[00:16:53] I: Can you give me an example of what the smaller decisions that he's been making by himself now?

[00:17:00] Dan: Like, um... what to buy at the grocery store.

[00:17:08] I: So he used to call you and ask you that?

[00:17:10] Dan: Yeah, he used to call for all kinds of stuff, that, just everyday stuff.

[00:17:17] I: And so, at what point did you first notice, or was it clear, that he was relying on you less for those small decisions?

[00:17:27] Dan: Oh I would say after a few weeks.

[00:17:33] I: So, fairly quickly?

[00:17:36] Dan: Yeah, yeah. I think at first he just wanted to know we were... you know... still easily reached. You know, that we were there to support him.

[00:17:53] I: So you felt that he was, making that you were there more to...?

[00:18:01] Yeah, he was a little, you know, nervous about it or anxious, or whatever you want to call it. He got more comfortable very quickly.

[00:18:10] I: And how about you, sir?

[00:18:13] Dan: I would say we were anxious about how it would all work out, and as time when on we got more comfortable too.

[00:18:22] I: Can you give me an example of something you were anxious about, that you feel more comfortable about now?

[00:18:30] Dan: Well, just about how he would adjust to living away from home. I mean it was a big step for him.

[00:18:39] I: So, you would say that you feel satisfied, or that you're feeling surprises about the big step he's taken.

[00:18:47] Dan: Oh absolutely, he is, he feels very good about himself. And one thing you need to realize is that he's got a brother that's about three years younger, who went to college and then after college, you know got a job and moved into his own apartment. So, Dylan really wanted to move an apartment like his brother did. And, he was really proud of the fact that he was able to do that. So...you know, that was a big thing to him.

[00:19:33] I: So, you went through the process, of having another child, a son without DD, move out before [Dylan]. Did you apply anything you learned from your experience of your younger son moving out to prepare you for Dylan moving out?

[00:20:02] Dan: There was no correlation whatsoever. Our other son was very mature, and went away to school for four years, and when it was time to go to work, he was very ready to do it, and we didn't have any worries whatsoever that it would work out fine. We viewed it as two totally different situations.

[00:20:32] I: Ok, from the start you viewed it as two totally different situations?

[00:20:36] Dan: Dylan is always going to need support, and it's just a question of how much and who provides it.

[00:20:45] I: I like how you put that, and if you don't mind I'd like to expand on it. Can you give me an example of how Dylan is always going to need support?

[00:21:01] Dan: Well, you know, he mentally is, I guess like a thirteen year old. So he's going to make immature decisions, you know, on a regular basis. He, you know, sometimes... deciding to take a day off from work because someone else at the apartment isn't working that day. Um...or, you know, spending money foolishly, or whatever. It's just going to be that way.

[00:21:47] I: And so you described both things with work, and financial concerns. We discussed financial earlier. But you said that you expect that he'll always need support in those areas. Do you mind elaborating where do you expect that support to come from?

[00:22:07] Dan: Well, we are thankful that this organization here, the sheltered workshop, the [name of workshop] where he has worked at a number of years, and they're very helpful, in the finding of a job for two days a week in the community, in a store. And they provide a job coach, and oversight, and whatever he needs to do at the store. If it's a new function they will have the job coach learn it and stay with him and teach him it until he gets it.

[00:22:50] I: And does that include the decisions like, "I should skip work just because my friend...?"

[00:22:57] Dan: Yeah, part of what the coach talks to him about, is the proper behavior out in the store with customers, and the proper way to greet customers, and that kind of stuff.

[00:23:13] I: So it sounds as if, um... you guys have allowed for the idea that a lot of external supports, or, you know, other services will be able to help him with some of those decisions?

[00:23:31] Dan: Yeah, in fact, we have found that it's really necessary, because, as parents there are times where, whatever we say to him, he just shuts down. No different than a teenager, with a parent constantly telling him this is the right way to do this. So we've found we need other people to, you know, teach him the proper way to do things, and etiquette, and so forth, so that we're not always harping on it, because then he shuts down.

[00:24:19] I: OK. And how do you feel about... you said it's been necessary to allow for others to help him through some of those decisions. How do you feel about that idea?

[00:24:36] Dan: Um... I feel good about it, because it works. Whatever works is good.

[00:24:49] I: So the others are helping. You feel that the other people have been helping him efficiently?

[00:24:53] Dan: Sure... between... you know, the staff at [emp. org] and the staff at the apartment house, he gets a lot of good decisions, and they keep him focused on the right things. And when he does something he shouldn't be doing they stop it right away and it doesn't become an issue, and you know, parents can only go so far, especially parents that aren't there. So, it's very necessary for handicapped child to get that sort of support. Especially for someone like Dylan, you know, who is a high functioning Downs adult. But he's still immature, and will always be immature.

[00:25:53] I: Earlier you described that there were a couple of situations in which you do expect to be told about, including medical concerns, or financial concerns. Can you describe to me, how your role is different in those areas compared, or how you decide which areas in to play a larger role?

[00:26:26] Dan: It has to do with... what are bigger issues and what the appropriate role is for us to play.

[00:26:41] I: Can you describe those bigger issues, and how to find the appropriate role?

[00:26:48] Dan: Sure, if he's sick, or there's something wrong there, I think he needs a parent with him to go to the doctor to make sure that the doctor hears the right story about what's wrong, and that we hear the right story about what to do to get better, and to see that is followed through on.

[00:27:19] I: So, you would feel that your presence is necessary to ensure for accuracy?

[00:27:34] Dan: Well, for his well-being. You've got to remember. The staff at the [house] they're you know, every eight hours people are changing. People leave, people start new. There's certain issues, that, you know, there needs to be continuity, and someone that really knows him.

[00:28:06] I: So, it sounds like that one thing that you've described, is that you do trust other people a great deal to help assist him with some things. But I'm interested in this idea that there are some decisions or some areas where you expect that you need to play a role in.

[00:28:26] Dan: That's right.

[00:28:30] I: So, they seem to be, I think your phrase was: "Issues of his well-being"?

[00:28:38] Dan: Yeah, because no one has his well-being more at the top of their list of concerns than his parents.

[00:28:48] I: And so, mostly because I'm trying to get your sense of it - because well-being can be a big thing - I'm interested in knowing how you define well-being?

[00:29:00] Dan: Um...his general health. Um... the work he does and how he performs it. If there's a problem we need to get involved in that. You know, if he's gonna switch jobs, we want to be part of that to make sure it's being done for the right reasons.

[00:29:30] I: You, "want to be part of that?"

[00:29:32] Dan: Yes, like, when he went over to work in the store in the community. We were consulted, and we talked about it and Denise even went over and talked with the owner of the store. We don't want him to get in a situation that will be bad for him.

[00:29:55] I: So, I guess my concern was not why would you want to be part of it, but what you meant by "being a part of it." That you would be consulted? Can you describe... in what way you'd be a part of it?

[00:30:11] Dan: Well, that we would be consulted, and to the extent that we felt it necessary, we would look into it.

[00:30:19] I: You would "look into it?"

[00:30:23] Dan: Like I just said, Denise went over to the store and met the owner and got a feel for what the place was and what the owner was like, and that it would work for him.

[00:30:33] I: Ok, and do you mind if I ask - I think this a very good example – whose decision was it to have for him to work there?

[00:30:47] Dan: Well, it was his. He wanted to work out in the community, and so, [emp org] was looking for an opportunity for him in the community.

[00:31:01] I: Do you feel that there might have been a decision in this regard that you might have overruled? Or did you just want to know? Was there a point in which you guys would have stepped in to make your own decision regarding it?

[00:31:18] Dan: Um, I wouldn't make our own decision, but maybe overrule. Part of the discussion was that he talked about wanting to do office work. He can't do that, he can't type, he couldn't take messages off a phone. He could file, he could sort mail, he could deliver mail, but how much of that is there today? So we got involved to say, you know this really isn't something that's gonna work out, and we convinced him that it wasn't going to work out.

[00:32:02] I: Ok, so you counseled him or convinced him on the job placement?

[00:32:11] Dan: We wanted a job that would be suitable for him.

[00:32:12] I: Is that sort of idea... that pattern of, you know, getting consulted, and then, if necessary, stepping in, is that what you anticipate your role would be in other situations as well? Can you give me an example of what areas you anticipate that being your role?

[00:32:42] Dan: Well, you know, if he was being [unintelligible] in the apartment, and not keeping the place clean, or, not eating appropriately, and the staff couldn't work it out with him, they would come to us, and we would do what was necessary to get it back on track.

[00:33:14] I: Ok, I was just wondering, because if you would be able to describe... because this is exactly what I'm looking to find. But what would you expect would be an example of, "Do what is necessary," in some of those instances.

[00:33:34] Dan: Well, it could be, just sitting and talking, and coming to an agreement with him that what he was doing wasn't going to work out going forward and he had to change. Or it would be, sitting and saying, "You're not going to be able to stay here if you keep going." And it depended on the situation, what he did.

[00:34:06] I: So, it sounds as if there are some decisions, are there some decisions that he's made that you have not necessarily agreed with, but did not step in?

[00:34:21] Dan: Yeah, but they're small things. Like buying some clothes that didn't make sense, or, you know, he might wear once, but never wear again. But, you know, it was the small things so why make an issue of it?

[00:34:36] I: So it sounds as if, there is a line where he would go beyond consult and advice, and you guys would, if it felt necessary, step in. But on some decisions, even if he made a decision that you didn't agree with, you would not step in to change it?

[00:34:58] Dan: Yeah, we really tried to step back on the small stuff, the not-important, you know, not say anything about, because you can only say something about so many things. You know, if you harp about every little thing, when there's a big thing, he might not listen. So, it's no different than, um, you know a husband and wife, you gotta pick your battles.

[00:35:34] I: So, that, um... so it suggests that there are still parenting battles that are existing, even though he's in..?

[00:35:47] Dan: Sure there are.

[00:35:51] I: Are you... is that what you expected? Or is the level or number of battles that you've had...?

[00:36:05] Dan: We knew Dylan mentally was a young teenager, and he would always be a young teenager, and we would have those type of issues going forward.

[00:36:20] I: And that view has stayed the same in the two years...?

[00:36:29] Dan: , if anything I'd say it's improved, to the sense that he has really settled in and calmed down and, he's doing better than I expected.

[00:36:45] I: Ok, so it sounds as if there are areas in which he's more independent now in making decisions, and we talked about the small decisions...

[00:36:55] Dan: Yeah, and I think he's matured a little bit too.

[00:37:01] I: Are there areas in which you expected more independence, and you find yourself playing a bigger role than expected?

[00:37:10] Dan: No, I don't think so not at all.

[00:37:16] I: So across the board there are a few where he's become, you know, you're playing a smaller role than expected, but none in which you feel you're laying a bigger role than you thought you would?

[00:37:25] :Dan: Yeah, and that's, you know? That type of question really gets to the type of person I am. And I... see problems before I see the good stuff. I'm the pessimist. So I'm always worried about the bad things that are going to happen, not that, it'll get better. I just focus more on the negatives first.

[00:37:58] I: Can you give me examples, I think that this is interesting, can you give me an example of some of the problems that you anticipated going into the process, and what's come up... what your actual experience has been in those situations?

[00:38:18] Dan: Well, you know, we talked about the cooking and that kind of stuff. I expected there to be problems there, and it has gotten better, and it got better faster than I anticipated. Um, I thought there might be more behavioral issues, there really haven't been many. You know? So most of the things I was concerned about, actually turned out better than what I was envisioning.

[00:38:52] I: Can I ask what behavioral issues did you anticipate there being?

[00:38:59] Dan: Just you know, staying up all hours of the night, blasting the music, or you know... silly, boy prank stuff...

[00:39:19] I: Alright. So, one thing we have not discussed is, sort of, did you give any thought to what your level of involvement would be in his romantic or sexual choices?

[00:39:42] Dan: Yes...

[00:39:49] I: What, uh... can you tell me what the results of those... would you mind discussing what you anticipated your role to be in that area?

[00:40:01] Dan: Um... I think I'll skip on this little part...

[00:40:06] I: You'll skip, OK. I know that can be... a little squeamish regarding, you know, that issue. Let's see... So earlier you said health concerns where you anticipated your involvement to be having a larger share, or having more input on those decisions. On the form that I asked, it sounds as if you anticipated he would... is that mostly having to do with illnesses and major surgeries or...?

[00:40:57] Dan: Well, it really hasn't been any issues because, Dylan is the healthiest [Down Syndrome] individual we have ever come across. I mean, it's like he's hardly ever sick, so there hasn't been many issues. But, if there were any, I feel we would have to be involved in it as parents.

[00:41:34] I: Illnesses? So, illnesses you would feel you would need to be involved in...?

[00:41:37] Dan: Yeah, like, right now, he's just, we take him for his annual physical. We take him for his annual eye exam that kind of stuff. But he really hasn't been sick, you know, other than a little cold or diarrhea for one night since he's been in the apartment. So there's been virtually no issues.

[00:42:04] I: Regarding sort or smaller, or non-illness parts of his health, one of the things that you guys put down was that he would be able to have independent control over his diet and whether or not he used alcohol...

[00:42:25] Dan: Yes... You know, he's not a big drinker. He has one beer every now and then, and I think he's had maybe more than one once or twice in his life. So it's not an issue, he has beer in the refrigerator, and if he wants to have one, he has one.

[00:42:52] I: And his diet?

[00:42:54] Dan: Well, his diet, they have staff that helped with the grocery list. And, you know, reviews the meals and checks the refrigerator to make sure the food is still good and that type of stuff, so we are comfortable that he's eating a healthy diet.

[00:43:23] I: If Dylan were to... Have you given any consideration - I know you said you worried he might stay up all night or something like that - was there any consideration... you know... I'm going to skip that actually... Let me try to think... what do I have left. Are there any areas in Dylan's life where you have been disappointed in your level of involvement? Whether that's you wanted to be involved more, or you wanted to be involved less?

[00:44:06] Dan: No, I think it's you know... given the situation and his capabilities, I think it's turned out appropriate... Our level of involvement with his brother is a lot less, but you know, he's much more capable and responsible.

[00:44:41] I: Can you give me an example of how, an area in which it's less for his brother than for Dylan?

[00:44:53] Dan: There's no comparison. It's like comparing the young teenager with the adult.

[00:45:05] I: So I know it's going to be difficult, but I'd like to try to expand it. Can you think of one example of a decision or a part, of [brother's] life where your level of involvement is completely different, or a little different, or anything.

[00:45:35] Dan: Every level. He doesn't call every day, he doesn't call and say, "[Staff] is have having a membership meeting, should I go?" He doesn't call and say, "I got paid today, here's what I got." He doesn't call and ask about what to wear to this affair. I mean it's totally different.

[00:46:11] I: So for example, the one example that was clear to me, where he wanted a certain job, and you guys persuaded him not to take that job; how is that different, if at all, from what you would do with [brother]?

[00:46:38] Dan: Let me be clear, we didn't persuade him not to take the job, we made him understand there would be no such job available to him. So, it wasn't like there was a job offer. We didn't want [emp. org] to find him a job we didn't think they could find him such a job. And if they found him one, we wouldn't want it. It just didn't seem like a good use of time.

[00:47:12] I: OK, so you felt that, um... so you guys, you stepped in when it was in the application process. Can you describe I guess if [brother] intended to apply for a type of job that you did not think would be available, how that would be different... your involvement would be different?

[00:47:39] Dan: We wouldn't get involved. [Brother]'s over in [European city] now. And he was in [US city] and he talked about the possibility of getting a two year assignment over there, and he talked with us about what we thought about it. And we gave him our input, and then he went and did what he thought was right, and we were accepting of it, whichever way he went, because he can make those decisions.

[00:48:20] I: So with [brother], he asked for your input, with Dylan...

[00:48:30] Dan: With Dylan, it was just, "I want a job in an office. I want to do office work"

[00:48:42] I: And did you do anything different than giving your input?

[00:48:47] Dan: Yeah, we basically explained to him why there was no such job there for him. And if they did find him an office job we said, "Now what could you do there? Can you type?" "No" "Can you take messages?" "Well, no."

[00:49:06] I: I know I asked about that a couple of times, I just wanted to get details.

[00:49:17] Dan: I figure you have a reason for what you're doing.

[00:49:19] I: Well it's just... I think your examples are very enlightening, and exactly what I'm looking for so. How, if at all... What do you anticipate in Dylan's life five years from now?

[00:49:50] Dan: In Dylan's life? Pretty much the same as it is today.

[00:50:01] I: How... Is there any area, whether that's his romantic life, his residential life, his occupational life, his finances, that you expect, or anything else, that you anticipate your role changing?

[00:50:27] Dan: I don't... I don't... As I sit here today [Denise comes in, participant talks with Denise]... As I sit here today, his moving up the learning curve in all those areas, I don't see much more. There was distinct improvement in the learning curve in a lot of areas when he first moved out after the first year. Going forward, I don't see any more, and probably when he gets to fifty, from what I hear, he'll probably start moving down the learning curve. And then the whole issue...

[00:51:37] I: How old is Dylan now?

[00:51:39] Dan: Thirty-one. And then the whole issue of moving from a semi-independent apartment to a 24/7 group home group thing will come into play.

[00:51:53] I: So you've given some thought already to... that's twenty years in the future when he might need to move yet again.

[00:52:04] Dan: Yes.

[00:52:05] I: Have you made any specific plans?

[00:52:10] Dan: [Laughs]. How can you make plans when you don't know when it's going to happen?

[00:52:15] I: But have you sort of... so you haven't made any concrete plans, you just know that it will need to come up?

[00:52:24] Dan: That's right.

[00:52:25] I: One thing I did see in the survey, was that [brother] is the next guardian if anything were to occur to you or your wife.

[00:52:40] Dan: That's correct.

[00:52:40] I: What, if any, discussion or plans have you made in case? May I ask about specifics about what plans you've made in those regards?

[00:52:56] Dan: Yeah, [brother] is very aware of what's going on with Dylan, he's very aware of his capabilities. We have, I don't know what we call it, Denise calls it a "document book." You know, all of our contacts for Dylan: all his doctors, and the people we deal with in the disability community, like the executive director of the [county] ARC, the executive director of the [house] where he lives. We have all those people so [brother] would have their addresses and phone numbers to contact for assistance if he needs it.

[00:53:52] I: So for plans like that where you've accumulated a lot of contact information...what was the decision making process behind that? Did someone advise you to make that? Did you guys think...?

[00:54:09] Dan: Yeah, in fact we went to some presentation made by some disability attorney, and they talked about the need to have all the relevant documents and information available in one place as if we were, one day, not there. So we've got copies of his social security card, his Medicaid card. You know? All the different types of document that you would ever need to file for the state for anything.

[00:54:59] I: Are there any other resources that you've found particularly helpful for preparing for the run up to when he moved out, or since he's moved out of the home, for preparing you? Were there any resources that you went to, people or otherwise, who helped you shape your expectations for what the transition, and what your role would be?

[00:55:29] Dan: I think it's a very personal decision. And, you know, we know parents who would never think of having their disabled child leave the home until it was absolutely necessary. Um... But as far as anybody sitting down with us, and talking about how our life would be different, how his would be different, or what to expect, no, I don't know of anybody that we actually sat down with. We just knew that it was the right thing for him, and the right thing for us. And thankfully this opportunity came up, which is, you know, not a state funded facility. 'Cause if we had to wait for a state placement, we'd be waiting years, and years, and years.

[00:56:36] I: So. I think you've described it to me already, but I'd like to ask you in a general sense. What is largest change in your life that you've seen, in being Dylan's father that you've seen since he moved out?

[00:56:57] Dan: Change in Dylan?

[00:56:57] I: Change in your life.

[00:57:00] Dan: In my life. I've got the flexibility to go and do things like a retired couple now. We could never leave for any length of time.

[00:57:20] I: Alright. Is there anything else that you think it particularly important, or that you would want to say to somebody else going through this process about what to expect?

[00:57:37] Dan: Yeah, I would say, where your disabled child goes, there will be staff. Um, ninety-nine point nine percent of the time the staff will be caring, and will do what's best for your child. But you have to recognize, staff is staff, they're not parents, they won't treat your child, and look after your child like a parent would, and the place they go to is not your home, and it's not going to be run like you ran your home. Things will be different.

[00:58:29] I: And, because I would love to follow up a little bit on that... Specifically how would you say that's different?

[00:58:51] Dan: The reason I made that statement is, we know a lot of other parents who have children at this apartment, assisted living apartment house, as well as people that have their children in group homes. And they're always complaining: "They're not doing this for my child, they're not doing that, this is different, why aren't they doing this", and it's mostly, just small stuff and it's because their child isn't cared for like they cared for their child when they were home. So unless you're willing to let go, and understand it's going to be different, you know, you'll have trouble with it.

[00:59:41] I: Did you find that it was hard for you to let go in that way?

[00:59:49] Dan: No not at all, 'cause I had thought about that and I was aware of it and had accepted it, and knew that Dylan very much wanted to be as independent as he could.

[01:00:07] I: So you expected that letting-go process to occur?

[01:00:10] Dan: Yes.

[01:00:13] I: Ok. And what led you to know that that was coming?

[01:00:24] Dan: It comes over time, and like I said, Dylan saw how his brother left home, and was in an apartment, and working early on his own, and he wanted to be like his brother.

[01:00:46] I: And so it sounds as if, you knew that you would need to let go a bit more based on [brother]'s experiences, and the experiences of other parents with children like Dylan?

[01:01:03] Dan: Yeah but it wasn't an issue with me because I was, I knew it and I was accepting of it.

[01:01:17] I: Ok, you knew that it was coming and you were accepting of the fact that they were not exactly, be like you guys were with Dylan?

[01:01:28] Dan: Yeah, and there would be stuff that went wrong, and he would show up at work dressed inappropriately, and he would, maybe, not take a shower every day and whatever. There's gonna be things like that that will happen. And if that's all that happens I'm happy.

[01:02:02] I: I think I've gotten most everything I wanted to touch base on. Without going into details I was wondering: would you be able to say, in regard to your expectations, I know you were hesitant to discuss this, but in regard to your expectations about his romantic and sexual life, would you say that your expectations, without going into details about what those were... have been correct, or has there been anything surprising about that? In regard to your role, as to what you guys anticipated your role to be.

[01:02:40] Dan: My role has been, much more than I envisioned, or ever wanted.

[01:02:51] I: Since he moved out? Or in general with Dylan?

[01:02:56] Dan: Since he moved out.

[01:02:58] I: OK, so your role, in that area, has been larger than you anticipated it being?

[01:03:04] Dan: And much larger than I ever wanted. He's got... one of the things... he's got a girlfriend in the apartment house, and it's created a lot of other issues. If [brother] gets a girlfriend, I don't hear anything about it other than, "I got a girlfriend," so...

[01:03:37] I: So that's actually one area where you've found your involvement has been more than you thought it was going to be?

[01:03:45] Dan: Ah... yes.

[01:03:49] I: OK, that's good to know, thank you very much. [Closing statement].

Appendix D

Table of Superordinate Themes

<i>Table of Superordinate Themes</i>	
Balancing independence and protection	
Decisions regarding placement	<p>Anna: <i>transitioning into the group home, that is up to the parent.</i></p> <p>Brian: <i>Bill, we put in a group home...</i></p> <p>Clara: <i>...[Charlie] said "I want to get my own place"</i></p>
Establishing the locus of control	<p>Bonnie: <i>He needs that control over him.</i></p> <p>Anna: <i>...that was kind of a slap in the face...my role was taken away.</i></p> <p>Dan: <i>...staff is staff, they're not parents.</i></p>
How and when to step in	<p>Clara: <i>...my involvement would be to talk to Charlie.</i></p> <p>Dan: <i>I wouldn't make our own decision, but maybe overrule...</i></p>
Redefinition of the parent's identity	
The ongoing parental relationship	<p>Bonnie: <i>The fact that they've moved out has distanced me from them</i></p> <p>Denise: <i>I just want to be "mom", and not "mommy" anymore.</i></p>
Life apart from their child	<p>Anna: <i>I have this tremendous freedom.</i></p> <p>Denise: <i>You have to have your own interests</i></p>
Levels and types of contact	<p>Brian: <i>I see Bill once a month.</i></p> <p>Denise: <i>We could be over there in five minutes...</i></p> <p>Clara: <i>They call their parents...maybe four, five times a day.</i></p>
Managing the transition	
How parents prepared for the transition	<p>Brian: <i>We always had it in the back of our mind.</i></p> <p>Denise: <i>I would say it [started] ten years ago.</i></p> <p>Anna: <i>What if something happens to me?</i></p>
Experiences following the transition	<p>Dan: <i>At first he was calling, it seemed, every hour.</i></p> <p>Anna: <i>I was there a lot in the beginning</i></p> <p>Clara: <i>If they are given time, they can get it.</i></p>