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# The experiences of parents of adolescents with disabilities during the transition to adulthood

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Thesis

**THE EXPERIENCES OF PARENTS OF ADOLESCENTS  
WITH DISABILITIES DURING THE TRANSITION TO ADULTHOOD**

by

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B.S., The University of North Carolina at Chapel Hill, 2014

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**ABSTRACT**

Research indicates that parental involvement in transition planning for adolescents with disabilities is associated with more successful adult outcomes as well as higher family well-being and parental satisfaction. Given that parents invest more time and energy into transition planning for their child with a disability than one without, and that parental involvement is associated with transitional success, it is important to understand parental experiences during transition so that the best and most comprehensive support can be provided to them. This qualitative study examined how parents of youth with disabilities describe their own, personal experiences of their son or daughter's transition to adulthood. A conceptual model was developed to describe the tension between parents' preparedness for and their emotions regarding the transition process. This tension ultimately contributes to a sense of uncertainty about their son or daughter's future.

## Table of Contents

Acknowledgements.....	iv
Abstract.....	v
List of Figures.....	viii
Introduction.....	1
Emerging Adulthood.....	1
Parental perspective on emerging adulthood for typically developing adolescents. ..	1
Parental perspective on emerging adulthood for adolescents with disabilities.....	3
Transition Planning.....	5
Parental involvement in transition planning. ....	6
Impact of parental involvement in transition planning. ....	8
Parental Perspective on the Transition Process.....	10
Research Question.....	12
Methods.....	12
Participants.....	12
Focus Groups.....	13
Reflexivity.....	13
Data Analysis.....	16
Findings.....	18
Parental Judgement on Services.....	21
Satisfaction with services.....	21
Dissatisfaction with services.....	22
Parental tasks and knowledge.....	25
Additional parental duties.....	25
Directing the transition process. ....	26

Sharing information between parents. ....	27
Suggestions for improvements to the transition process.....	28
Parental emotions about the future.....	30
Pride.....	30
Guilt.....	31
Fear of the future.....	32
Uncertainty about the Future.....	33
Negotiating independence.....	33
Hesitation with future plans.....	35
Discussion.....	36
Implications.....	39
Limitations.....	41
Conclusion.....	41
Appendix A.....	43
Bibliography.....	46
Vita.....	51



## List of Figures

Figure 1: Conceptual model of the parental experience during their son or daughter's transition to adulthood.....	20
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## **Introduction**

### **Emerging Adulthood**

For adolescents in Western countries, the transition to adulthood is a period marked by change and often uncertainty. Arnett (2000) introduced the term “emerging adults” to describe the population of youth who have graduated high school and may be working or attending a university, but are not fully independent from their parents. A critical feature of this period is that emerging adults do not view themselves as truly having achieved “full adulthood;” that is, they do not yet perceive themselves to have the stability and responsibility that coincide with complete independence (Arnett, 2000). Emerging adulthood is a period of identity exploration which may include the search for identity centered work or meaningful interpersonal relationships. Typically developing adolescents in Western society are often encouraged to use this transition to explore different options for their future, with or without parental input, in order to make the best choices for themselves.

**Parental perspective on emerging adulthood for typically developing adolescents.** Just as emerging adulthood is an ambiguous period for young people, it can be an equally uncertain process for their parents to understand and negotiate. Parental reactions to their son or daughter’s transition to adulthood are complex and based on a variety of personal factors, such as the parent-child relationship and expectations for the future (Cichy, Lefkowitz, Davis, & Fingerman, 2013; Kloep & Hendry, 2010; Nelson, Padilla-Walker, Carroll, Madsen, Barry, & Badger, 2007). Researchers hypothesize that the nature of the relationship between parents and offspring is predictive of how parents

cope with their son or daughter's impending independence. When asked to describe their feelings regarding their child's impending independence, for example, the majority the parents in one study described an attempt to "hold on to" their children's youth (Kloep & Hendry, 2010, p. 826). Even though their children were all either employed or studying at university, these parents still viewed their children as needing guidance and care.

Parental perception of emerging adulthood is also shaped by expectations for their son or daughter's future (Cichy et al., 2013; Nelson et al., 2007; Kloep & Hendry, 2010). In the United States, societal expectations for adulthood generally include moving out of the parents' home, establishing a career, getting married, and having children (Cichy et al., 2013). When a young person's life-views and definition of success are aligned with those of their parents, their parents are more likely to view the son or daughter as a competent adult (Kloep & Hendry, 2010). Nelson et al. (2007) conducted an online survey of parents and their emerging adult children to determine the criteria that each group considered as standards for adulthood. Though parents and offspring shared a common top priority (accepting responsibility for one's actions), lower priority goals were highly discrepant between the two groups. This pattern indicates a sharp divide between parent and offspring priorities, a divide that may influence parents' willingness to accept that their son or daughter is an adult. This phenomenon highlights a hallmark of emerging adulthood for many adolescents; regardless of their parents' expectations, they are afforded an opportunity to explore their own values and make their own choices about what is important.

### **Parental perspective on emerging adulthood for adolescents with disabilities.**

Parental expectations of adulthood for youth with disabilities are neither as well-defined nor as consistent as those for typically developing youth (Blacher, 2001; Henninger & Taylor, 2014; Poon, Koh, & Magiati, 2013). Some expectations are consistent with those of parents of neurotypical children; most parents want their son or daughter to have a job, live on their own, and establish meaningful relationships regardless of his or her ability level (Henninger & Taylor, 2014). Parents also want their child with disabilities to have good mental health (Blacher, 2001; Neece et al., 2009; Henninger & Taylor, 2014), a high quality of life (Blacher, 2001; Neece et al., 2009), and a functional role in society (Henninger & Taylor, 2014).

Parents of youth with disabilities, however, often have to consider options for the future that parents of typically developing children rarely think about. For example, parents of adolescents without disabilities usually do not worry about their son or daughter developing the functional skills required for independent living, yet this criterion was the fourth most important determinant of adult success for parents of adolescents with disabilities (Henninger & Taylor, 2014). Often, parents do not expect or even want their son or daughter with a disability to marry or have children (Blacher, 2001; Poon et al., 2013). Rather than hoping their child will learn to accept responsibility for their actions, parents of teenagers with a disability are most concerned about their son or daughter's long-term safety. In fact, many parents of a son or daughter with a disability view his or her safety as a greater concern than either employment or social satisfaction (Blacher, 2001; Poon, Koh, & Magiati, 2013). For parents of neurotypical

children, safety was only mentioned in conjunction with personal and social responsibility, such as refraining from drunk driving and committing petty crime (Kloep & Hendry, 2010).

Further complicating the transition to adulthood for people with disabilities is that their opportunities and expectations often vary depending on their level of impairment (Blacher, 2001; Poon et al., 2013). Adolescents whose disabilities result in more severe physical or cognitive impairments are not typically expected to move out of the home, as it is often impossible for them to live independently. Parents of children with learning disabilities or executive functioning impairments, on the other hand, may hope for their child to live in a group home, or even to be employed in a supported workplace environment (Neece Kraemer, & Blacher, 2009; Chou, Lee, Lin, Kroeger, & Chang, 2009).

In spite of the wide variety of expectations parents have for their son or daughter's future, they are often doubtful that their child will meet them. Whitney-Thomas and Henley-Maxwell (1996) found parents of a child with a disability have less optimistic expectations for their child's future, face greater stress during transition, and view the process as more painful than parents of children without a disability. Poon and colleagues (2013) studied the discrepancies between parents' goals for the future of their child with autism spectrum disorder, intellectual disabilities, or Down syndrome and the parents' perceived expectation of the child's success in these outcomes. There were significant differences between the items parents viewed as important for their son or daughter to achieve and the parents' confidence that he or she would achieve them. These

differences could be predicted by the severity of the child's condition. On the whole, parents of children with disabilities are significantly less comfortable with their son or daughter's emerging adulthood than parents of children without disabilities (Whitney-Thomas & Henley-Maxwell, 1996).

### **Transition Planning**

Because expectations and outcomes for adulthood are so variable for youth with disabilities, there are services in place to help them and their families navigate their transition to adulthood. Special education services for children with disabilities in the United States are mandated by the Individuals with Disabilities Education Act (IDEA) of 2004 (Individuals with Disabilities Education Act, 2004). Teachers, parents, social workers, and other professionals work together to develop an individualized education program (IEP) for the child that outlines specific accommodations and supports the child will need to be successful in academic, functional living, or career-based skills. In most states, the responsibility of providing these services falls primarily to the schools while the student is between the ages of 3 and 22. After age 22, however, the student must receive services from another agency, be it a post-secondary institution, vocational training or supported employment program, or residential services. Plans for this transition should begin when the student is 14 and must begin no later than age 16 (Individuals with Disabilities Education Act, 2004).

In spite of the provisions set forth by IDEA, research indicates that adult outcomes for youth with disabilities are less than satisfactory. Although the majority of youth with autism expected to continue their education, only 36% were actually enrolled

in a post-secondary institution after high school (Anderson, McDonald, Edsall, Smith, & Taylor, 2016; Roux et al., 2015). Youth with autism also live independently, acquire jobs, and participate in the community at far lower rates than young adults without a disability (Roux et al., 2015). On a broader scale, overall quality of life in adulthood is somewhat related to type of disability; adolescents with intellectual disabilities or multiple disabilities generally had poorer outcomes in all areas of life (housing, employment, quality of life, etc.) than their peers with learning or speech disorders (Bambara, Wilson, & McKenzie, 2007).

The awareness of these poor adult outcomes has increased the amount of research dedicated to improving the transition process and, as a result, certain elements of transition services have been linked to more positive futures for youth with disabilities. Some of these characteristics include: vocational education; student-centered programming that specifically addresses the students' interests, skills, and needs; and collaboration between the various service providers (i.e. schools, employers, and adult services) (Bambara et al, 2007.) In spite of this knowledge, however, many schools and disability service agencies do not follow these recommendations for practice (Bambara et al., 2007). Interagency coordination is uncommon, students' interests are not always considered in their transition plan, and responsibility often falls on parents to facilitate the best transition possible for their son or daughter.

**Parental involvement in transition planning.** While interagency collaboration and the involvement of skilled professionals will likely help improve adult outcomes for youth with disabilities, the value of parental input in the transition process cannot be

overlooked. Including parents in the transition process can improve long-term outcomes for these youth as well as their families (Blacher, 2001; Martinez, Conroy, & Cerreto, 2012; Whitney-Thomas & Hanley-Maxwell, 1996). Data collected from the National Longitudinal Transition Study-2 (NLTS-2), an expansive research initiative focused on identifying adult outcomes for people with disabilities, indicate that only 60% of parents of youth with autism were included in their son or daughter's transition planning (Roux et al., 2015). Of those parents, 80% were satisfied with the planning process, indicating that involvement is a key feature of transitional success. Additional literature indicates that both parents and students want increased involvement in the transition process (Smith & Anderson, 2014). Blacher (2001) proposed a three-factor model of successful transition planning based on parental expectations and successful outcomes, which included: (1) the adolescent's individual factors such as cognitive level and adaptive skills, (2) environment and cultural considerations including socioeconomic status and social supports, and (3) family involvement in transition planning. Student cognitive levels and culture are relatively fixed entities; however, it is possible to change level of parental involvement in the transition process to promote successful outcomes. Therefore, resources should be provided to parents to support their participation in this process and to help them guide their son or daughter to the next stage of their life.

Research indicates, however, that adequate parental supports for participation in transition planning are not always provided. For example, though the IEP team sets goals for the adolescent's future and identifies any supports he or she may need, it is not required that specific service providers or options be mentioned during the meeting



(Individuals with Disabilities Education Act, 2004). Parents, therefore, may take on the responsibility of navigating the adult disability service system, as schools and states often lack the resources to provide them with sufficient guidance or information (Turnbull, Beegle, & Stowe, 2001). In a qualitative study on the role of parents as managers of their son or daughter's transitional stages, Bambara and colleagues (2007) found that parents judged disability service systems to be 1) inconsistent, 2) complex, and 3) unresponsive. Parents liken the termination of school-based services to “falling off a cliff,” because their resources diminish rapidly and they must suddenly acquire services for their child with limited or no assistance (Roux et al., 2015; Smith & Anderson, 2014). As such, 26% of young adults with autism receive no services whatsoever (Roux et al., 2015); the number of young adults with other disabilities who are not receiving services is unknown and likely even larger.

**Impact of parental involvement in transition planning.** The process of locating and procuring adequate support for their son or daughter increases parents' stress level, which can lead to avoidance coping strategies in many parents. Often they may avoid thinking about a transition plan for as long as possible because it is too overwhelming (Chou et al., 2010; Martinez, Conroy, & Cerreto, 2012). In a survey of parents from Virginia with teens aged 14–17 who have developmental disabilities, Martinez and colleagues (2012) found that the majority (36 out of 45 parents) either did not have a transition plan in place, were unaware of any existing transition plan, or were deferring the process to the last moment. Common statements made by parents were that they “did not want to think about it,” or to assure the interviewer that they would make

arrangements at a later point (Martinez et al., 2012, p. 284). A select few parents address these concerns early, and begin planning the transition well before their child turns 14; for others the fear of the unknown turns into avoidance for several years (Stoner et al., 2007). Some parents begin fearing the transition process when their children are as young as six years old (Stoner et al., 2007). Similarly, Heller, Caldwell, and Hasazi (2006) conducted “Future Planning Training” workshops for parents and families of adults with disabilities to provide a direct resource for all pertinent transition information. When asked why they did not have a plan established already, participants cited the daunting legal component behind transition as a key barrier to making plans, as well as their difficulty trusting the service providers, emotional barriers involved with fighting for services, and lack of information on legal and financial planning (Heller, Caldwell, & Hasazi, 2006).

However, many of the participants in these studies were caregivers of either adults or older adolescents with significant disabilities who will likely require long-term residential care rather than live independent. Interestingly, the parents whose children had less severe disabilities were the least likely to have a transition plan in place (Chou et al., 2012). This finding parallels the idea that the future is more uncertain for adolescents with mild to moderate disabilities than those with more severe impairments. If parents are uncertain of their child’s options for the future and likelihood of success in adulthood, it follows logically that they may be more anxious to begin the complicated process of transitioning to that stage.

The stress associated with navigating the disability services systems can have an adverse effect on family quality of life during an adolescent's transition to adulthood (Boehm, Carter, & Taylor, 2015). Family quality of life is an important factor to consider during the transitional period because significant differences have been found between higher quality of life and satisfaction with transitional services; higher family well-being was associated with transition satisfaction while lower well-being, and particularly maternal stress, were associated with low transition satisfaction (Neece et al., 2009). This correlation indicates a paradoxical relationship between parental involvement in the transition process and transition outcomes. As previously mentioned, youth with disabilities are more likely to have successful adult lives when their parents are actively involved in the transition process (Martinez, Conroy, & Cerreto, 2012; Whitney-Thomas & Hanley-Maxwell, 1996). The psychological and emotional impact of that involvement, however, are actually predictive of lower transition outcomes for adolescents (Boehm et al., 2015; Neece et al., 2009).

### **Parental Perspective on the Transition Process**

The intertwined relationship between parental involvement in transition planning, the lack of supports they receive for navigating adult disability services, and familial stress levels makes understanding parents' actual experiences during their son or daughter's transition a complicated process. Very little research has examined how parents cope with and conceptualize their son or daughter's transition to adulthood. In the aforementioned "Future Planning Training" program, Heller and colleagues (2006) did ask parents specifically about the emotional component of transition, but these parents

were seeking long term residential care for their adult child with severe disabilities. Even less is known about the emotional experiences of parents whose sons or daughters with disabilities may be able to live independently. Gillian and Coughlan (2010) conducted a qualitative analysis of Irish parents' perceptions of their child's transitional stage, asking what the transition stage meant to them and what emotional impact the transition had on them. Parents indicated emotions ranging from stress and anxiety to frustration, disempowerment, and helplessness (Gillian & Coughlan, 2010). This study was conducted retroactively; the sons and daughters in question had already experienced the transition to adult life and disability services. Therefore, parents' reflections on their emotions during the transition may have been influenced by the outcome. Additionally, Irish disability and health care services differ from those in the United States, as Irish adolescents only receive services till age eighteen. Little is known about the individual experiences and subsequent emotions of American parents during transition process for their son or daughter with a disability.

The existing literature provides an understanding of parents' goals for their child with developmental disabilities in adulthood, as well as their current level of involvement in transition planning. While the goals and expectations of transition services are important, they are only one piece of the overall transition puzzle. Parents must also learn to negotiate their child's desire for independence with their desire for their children to remain safe and happy. As parents of typically developing children struggle to let go of their adult children, it is reasonable to expect that parents of children with disabilities experience similar or possibly even heightened experiences of hesitancy or anxiety.

## **Research Question**

The current research was conducted to address the following research questions:

(1) How do parents of adolescents with developmental disabilities describe their personal experiences during their son or daughter's transitional stage? and (2) What emotions are indicated during discussions about transition, and how do parents identify those emotions, if at all?

## **Methods**

### **Participants**

In this qualitative research study, data were collected from four focus groups conducted with parents or legal guardians of transition age youth with social, emotional, or cognitive disabilities. The total number of parent participants was 14, with their sons and daughters ranging in age from 15 to 21 (the average age was 19.17). Parents were recruited through community organizations, clinics, private special education schools, school districts, and special education administrators. All participants lived in the Northeast United States.

In order for their parents to be eligible for the study, adolescents must have either received or currently be receiving special education services for ASD, emotional/behavioral disorder (EBD), traumatic brain injury, or intellectual disability. Of the 14 youth whose parents participated in this study, 7 had a diagnosis of ASD, 7 were diagnosed with emotional or behavioral disorders, and 3 had a diagnosis of intellectual disability (some youth had multiple diagnoses). Parents of youth who use a wheelchair for mobility were excluded. Seven students were receiving services from their public or

private high school, while 6 were enrolled in either a transitional, residential, or post-secondary program.

### **Focus Groups**

Focus groups consisted of 2 to 5 parents of an adolescent with a disability, one facilitator, and either one or two additional assistants recording field notes. The meetings lasted between 90 and 120 minutes and were semi-structured by the facilitator asking guiding questions (see Appendix A). Parents discussed their son or daughter's current activities, living arrangement, their hopes for their son or daughter's future, what they thought their son or daughter's hopes for the future were, their son or daughter's current functional ability, and the functional skills that they believed their son or daughter still needed to develop. Each session was audio recorded and then transcribed by a graduate student research assistant.

### **Reflexivity**

In qualitative analysis, it is important for researchers to identify how their involvement in data collection and analysis, as well as any preexisting assumptions, life experiences, or worldviews affect their interpretation of data (Primeau, 2003). My roles as an occupational therapy student, the daughter of parents who have another daughter with disabilities, and a research assistant all influenced my interpretation of this data.

As an occupational therapy student, I am trained to consider all aspects of a person's life: their personal characteristics, the environment in which they live and work, and the day-to-day tasks they complete. When listening to parents describe how transition planning for their son or daughter with a disability was like "a full-time job," I inherently

wondered what other roles and occupations they may be neglecting due to their investment in one singular process. This consideration informed my research question, as I wondered how the emotional responses to transition planning may impact parents' experiences in other aspects of their life. I am also learning the importance and value of client as well as family- centered care, which increased the level of attention I gave to parental hopes and concerns.

My family background was a strong motivator for this research; my eldest sister has both physical and cognitive disabilities and my parents have struggled for many years to determine the best possible outcome for her future. I have clear memories of her transition from school-based services to adult services and the associated stress and fear felt by my entire family, particularly my parents. Given these experiences, I now approach the topic of transition planning with an inherently family-based perspective and am particularly sensitive to parental emotions experiences. My sister's transition to adulthood was ten years ago, but my family is entering a new transition stage as my parents begin to negotiate how much longer my sister can continue to live at home with my parents as her primary caregivers. These discussions with my parents regarding if and when my sister should move out of their home initially peaked my interest to the dissonance that seems to exist between parents' logical plans for their child's future and their emotional preparedness for that future.

This particular study came about through my work as a research assistant in the Families and Autism Research Lab. It was my responsibility to transcribe 3 of the 4 focus group sessions and the research questions posed by this study stem directly from thoughts

that emerged while I was transcribing the data. I began to draw connections between my parents' experiences and the stories of the parents in the focus groups, wondering if there were potentially common experiences among parents negotiating their son or daughter's life transitions. I was also present at one of the focus groups and met the parents involved in the study, asked them questions, and spoke with them after the meeting concluded. My interactions with the research participants and prior experience with the data may influence my analysis of the data. My presence at the focus groups enabled me to experience tension and body language that may not have been inherently present in the data, and I am more aware of their hesitancy during the transition process because I compare them to my parents.

It is also important to consider the participants themselves when discussing reflexivity in qualitative research. Participants who self-select to participate in a research study may have different characteristics than the overall population; these traits must be incorporated into the interpretation and application of the study findings. Many of the parents who attended these focus groups were likely contacted by the transition coordinator of a community program for people with disabilities. They had already begun their son or daughter's transition plans and were seeking further resources or support to help them in this process. Given that many parents delay transition planning due to stress and lack of support, it is possible that these data are not reflective of all parental experiences during a son or daughter's transition to adulthood.



## **Data Analysis**

Data analysis was guided by grounded theory principles: the focus groups for this study had already been completed at the time of data analysis which did not allow for true grounded theory processes. However, the three levels of grounded theory coding (open, selective, and axial) were employed to conceptualize themes in the data. Ultimately, a framework for understanding parents' experiences and emotions during their son or daughter's transition to adulthood was developed (Charmaz, 2006).

NVivo software and Microsoft Word were used to organize data for initial analysis. The first level, open coding, involved a line-by-line analysis in NVivo of each focus group transcript to identify any experiences or emotions explicitly stated by parents during the focus groups. Instances when parents discussed their own experiences during their son or daughter's transition — as distinct from what their child or a professional had done — were marked for initial coding. Experiences included, but were not limited to, attending conferences, teaching skills, hiring lawyers, or organizing employment and volunteer opportunities. Any emotions, positive or negative, that were either directly stated (“It is very fearful.”) or contextually implied (“I’m not going to sleep tonight.”) were also identified. In addition, any type of parental judgement on their son or daughter's current services, past services, or the transition process in general were identified for coding as well. These judgements were coded separately from emotions to potentially analyze any interaction between experience, judgements made about those experiences, and emotion.

These open codes were labeled by identifying the main idea of the parents'

statement, whether it be “fear of the future” or “additional parental duties” done for their child. For example, parents often told stories about teaching their son or daughter specific skills and attending conferences to learn more information about the transition process. These stories were coded as “additional parental duties” in reference to the increased duties and challenges the parents experienced compared to those of parents without a son or daughter without disabilities. When these themes occurred in other focus groups, the appropriate pre-existing code was applied. Caution was taken, however, against only searching the data for these codes; new themes were frequently identified and given a new open code.

The initial codes were organized into a Microsoft Word table in order to categorize them based on common concepts or emotions. These broader categories provided a more complete picture of how parents discussed their own experiences during transition, but did not yet provide any relationship among categories. Careful analysis of the axial codes, not only how they were similar to or different from one another but also for ways in which they may be related to one another, eventually led to the understanding of the connections between the categories. This process involved referring back to the data in order to determine which codes frequently occurred together, as well as any concepts that never occurred together. This detailed analysis of potential relationships between these ideas led to the eventual development of a conceptual framework to aid in the understanding of parental experiences during their son or daughter’s transitional period.

Once the conceptual framework was complete, the data were analyzed for

potential alternative explanations of parental experiences. As many of the judgements and emotions in the framework were primarily negative, positive emotions were sought in this analysis of the data. Coding parameters were expanded in order to capture as many emotions as possible; parental emotions and experiences regarding their son or daughter's personal development were also coded in addition to merely experiences with disability services. Although the adolescent's development is not a parental experience, it is possible that parents' feelings and opinions about their son or daughter's experiences influence their judgement on the transition process. These codes were analyzed separately from the original analysis using both NVivo and Microsoft Word, then compared to the original analysis.

### **Findings**

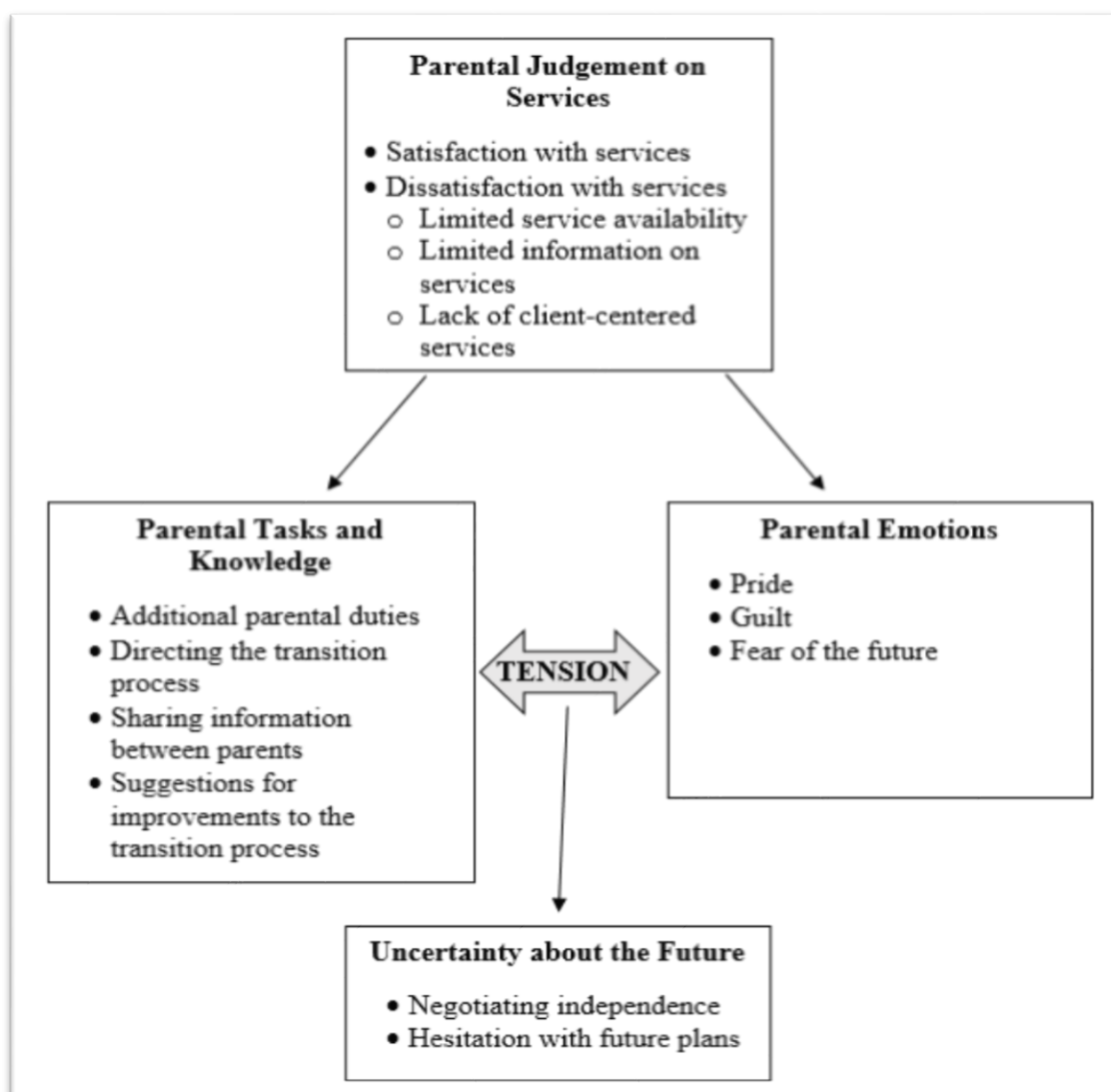
The findings from this study suggest that the transition to adulthood for youth with disabilities is a complex time for parents to navigate both logistically and emotionally. Parents' personal experiences are complex, and often the same experience was observed to lead to multiple, conflicting viewpoints. These experiences appear to create an overarching tension between parents feeling prepared for their son or daughters transition due to the tasks they have accomplished and knowledge they have gained, and the varied emotions that stem from parenthood and the interactions with disability service providers. A conceptual framework was developed (see Figure 1) to illustrate the factors contributing to this tension as well as the impact that the tension appeared to have on parental experiences of their son or daughter's transition.

Parental judgements about services appeared to inform both how parents felt during the transition and what actions they took. Both satisfaction and dissatisfaction with these services were reported in the focus groups. Satisfaction typically stemmed from the quality of the employees at a facility and the adolescent's personal accomplishments, while dissatisfaction was commonly attributed to the limited number of services available, the difficulty in obtaining information about these services, and the lack of client-centered services. In terms of how these judgements influenced parental actions and knowledge, parents often worked to fill the void they saw in transition services by taking on several tasks and learning as much as they could about disability services. These tasks included additional duties as a parent, directing the transition process, sharing information with one another, and suggesting improvements for services and the transition. Judgements about services also impacted how parents felt about their son or daughter's abilities and hopes for the future. Although parents typically expressed pride in their son or daughter's growth, they also felt guilty about their investment and fearful for their adolescent's safety.

The conflict between parental knowledge about the transition process and the fear and guilt they felt created uncertainty about the future. Parents were uncertain of what their son or daughter's future held because the transition to adulthood was often ambiguous and unclear. This uncertainty led parents to attempt to negotiate their son or daughter's independence through supported housing options or moderated guardianship. Uncertainty also seemed to lead parents to hesitate or completely avoid making definitive plans for their son or daughter's future; they never felt certain in their knowledge of all

available options, so they did not want to make the “wrong” choice and cause their son or daughter harm.

*Figure 1:* Conceptual model of the parental experience during their son or daughter’s transition to adulthood



## **Parental Judgement on Services**

**Satisfaction with services.** Personal experience with and judgement on special education services, and specifically transition service providers, was a primary source of knowledge about the transition process for parents in these focus groups. A select few of these judgements were positive, including praise of their son or daughter's progress or explicit remarks about the structure of the program in which he or she was enrolled. One parent commented that her son had "blossomed, he's done really well" since entering a new program with appropriate supports. Similarly, a mother who had enrolled her daughter with Down syndrome in a transition skills program at her local YMCA remarked that "She's becoming very independent...she tells me she works hard, she gets good reports." Another mother whose son has autism commented that he was able to participate as a member of a school stage crew and be very successful due to the match between his personal behavior and the demands of the activity: "He didn't have to totally interact with people...but he worked near people and he became very comfortable and it ...he got rookie of the year as a freshman for how often he participated."

Parents were also able to cite attributes of the transition programming they appreciated, including both curriculum and staff. One parent appreciated the diversity of the curriculum, particularly in regards to employment, and reported that her son was "[exposed] to different things, which is, I think, really terrific." Another parent had similar words of praise for the independent living skills taught by the program in which his son was enrolled, saying "I think it's...really good for him, what's happening there...the weekends are filled with...laundry...he has to save up and spend [money] on

his, you know shampoo and stuff like that...which is good.” The students and staff also contributed to parental satisfaction, as one mother said her daughter had been at her current program “for about a year...and likes it very much. She’s comfortable with the kids, comfortable with the staff. I feel that everyone knows her... we’re happy to be here.” Another father explained “the quality of the people is the most important thing and at [a previous program], we found the quality of the people was really — they’re fantastic people....” He did, however, use this comparison to emphasize slight dissatisfaction with his son’s current school “It’s not quite as good at – at [current program], maybe because it’s away from the city and um... they’re not quite as good.” While he was still moderately satisfied with his son’s school, he was disappointed to find that staff members do not exhibit the same level of expertise at each location.

**Dissatisfaction with services.** Most of the parent’s negative judgements regarding both transition program structure and individual staff members were much more specific than their praises. Lack of services, inexperienced or overworked staff, limited resources, and lack of client-centered planning were all emphasized as reasons parents believed their son or daughter’s transition programming was less than ideal.

**Limited service availability.** An overarching complaint was the simple lack of available services; transition programming is sparse and programs fill up quickly. One mother was particularly worried about where her son would live as an adult because “He may need to be in mass institutional care for the rest of life, which is not available by the way, so it’s tricky.” Parents also stated that the services at their son or daughter’s program were not always up to their standards. If students were unable to secure a place

in the limited number of transition-specific programs, they received their special education services at school. Parents felt the teachers at school were not well-trained or properly qualified to teach transition skills. For example, it was frequently cited that academic teachers also taught transition classes even though, as one mother stated:

“The people are special educators working in our high schools, so they have no experience of teaching [life skills]....They didn't go to college for that, they just did it themselves because they got forced to go off to college and they learned to do laundry at college. They're special educators, that's their job, not life skills educators.”

***Limited information on services.*** Another overarching criticism was focused on the bureaucratic barriers involved in the transition to adulthood, specifically with regards to procuring services for one's son or daughter. Parents frequently mentioned searching for and attending conferences and seminars on adult disability services to learn as much information as possible for their son or daughter's future. While sometimes grateful for the information, parents were equally frustrated to have found these resources on their own and that there were no professionals who could provide this information. Parents felt they were “totally on [their] own” in terms of navigating the “bureaucratic minefield” of disability services. Often, their son or daughter received services from a variety of agencies; coordinating the provision and funding of these services is a “confusing and... overwhelming” process. Parents expressed their constant worry of missing crucial information or deadlines that would prevent their child from receiving adult services. For example, one father expressed concern over his son's future housing options: “If, you



know, you get on these lists...and if they mail you something and you don't respond, they drop you off the list...Wouldn't it be nice if someone else would worry about that and respond.”

*Lack of client-centered services.* The most common judgment on services was neither administrative nor bureaucratic, but related to the overall values of the program and the value that society places on adolescents with disabilities. Parents felt as though their son or daughter's unique needs and skills were not attended to, and frequently voiced the need for person-centered transition services. One mother whose son has learning disabilities described her frustration that her son's assigned guidance counselor did not want to create a personalized plan for him, but merely cared if he was on the “graduation track” or the “not-graduation track.” The mother responded “Well, what about the [son's name] track?” indicating her distaste for the dichotomous system. Similarly, a mother in a different focus group expressed the need for teaching styles that fit each individual child: “What your daughter needs and my son are so different. You can't just clump them and say ‘Ok we're doing this.’”

Parents were also frustrated with society's tendency to assume that all people with disabilities want and need similar accommodations. In the eyes of these parents, disability services were too broad to address the specific qualities of their son or daughter. As one mother of an adolescent with autism stated, “You want to move all of this, all of our programming to where there is public transportation. No! My son does not want to live in an urban setting! I don't care that the bus and the train can go that way and into the city... He's not interested.” Making the general assumption that people with disabilities need

access to public transportation was only one example of the overarching generalities made by disability service programs. Another mother in the same focus group agreed that programming often catered to broad stereotypes rather than accommodating for differences in individuals. She said “the programming out there is very, very limited in scope based on what the presumption of our society is ‘Oh well if you have a disability this is all you can do.’ Instead of doing it the other way around and looking at the person first.” These parents felt as though their son or daughter was not receiving the individualized services and instructions that would best prepare him or her for a viable future.

### **Parental tasks and knowledge**

The parents who participated in the focus group have strong judgements regarding their son or daughter’s transition programming and plans. They identified many gaps in the provision of services, including ineffective life-skills instruction, poor coordination of services, and lack of client centered planning. These judgements led many parents to seek out additional knowledge and expand their typical parental role to fill the gaps in their son or daughter’s learning and development on their own.

**Additional parental duties.** When their son or daughter was not learning the appropriate skills for adulthood in school or their transition program, parents reported that they began teaching these skills at home. These tasks are in addition to the typical tasks of parenthood and typically are not necessary for children without disabilities.

During the focus groups, parents were prompted to consider if or how their son or daughter with a disability learned these skills differently than their typically developing

children. Most parents responded that their typical children simply did not need instruction. One parent said “it just happens,” for her neurotypical adolescent, but that each individual skill needed to be deliberately taught, step-by-step, to her son with a disability. Parents described numerous strategies they employed to teach their son or daughter these skills; one mother even brought a chart she had created to track her son’s progress in certain skills as they were taught at both home and school. She expressed frustration at the school’s lack of instruction, saying “So you can see these were the things the school was actually working on...not quite a lot...even though every year I’d give them this chart.” This mother felt as though it was her responsibility to fill in the gaps in her son's education left by the school's instruction. Another mother homeschooled her daughter throughout middle school because she thought she could teach her daughter daily living skills more effectively on her own, while yet another created an entire First-Aid curriculum that she teaches groups of students with special needs because she felt the school was lacking in this crucial knowledge.

**Directing the transition process.** Through these additional efforts, parents became knowledgeable about their adolescent’s strengths, limitations, as well as the transition process as whole. Some parents utilized this knowledge to spearhead their son or daughter’s transition process. Directing the transition process is an even more demanding parental role than life-skills teacher, and many parents expressed frustration at their inability to find, understand, and utilize resources to prepare their son or daughter for adulthood. Many parents compared the transition to a “fight:” fighting to have certain skills taught in school, fighting to place their child in a program, or even fighting

logistical barriers simply to access information. Facing a lack of opportunities, many parents created their own transition-like programs from which their adolescent could gain work or life experience. The mother who homeschooled her daughter for a portion of her education stated that she is taking this year to have her daughter explore employment options:

“This year, I said, this is all exploratory, so this was supposed to be the idea...to spend 9 months looking at 10 different places. Going and seeing what a florist does, and what they do at a restaurant, and what they do at a bank, and what they do at places, a child care center.... She has no idea what she would do there, so she needs to see it.”

Similarly, another mother contacted numerous different employers to set up employment opportunities and education for her son:

“I cold-called people, like ‘Would you like to be part of this?’...I can make myself sound like very professional like, in a sense like ‘You'd be doing a great service to him!’ ...it was wonderful to get these people to do it. You know I couldn't have been happier.”

Facing a lack of services, these parents took charge of their son or daughter's transition to adulthood separately from their school-based education. They created opportunities for their son or daughter to learn the skills that the parents believe are most important for their future.

**Sharing information between parents.** Apart from learning about the transition process from their own active involvement, parents of adolescents with disabilities also

used one another as resources. Parents frequently referred to their peers as vital resources of not only support, but information on available programs or ideas for their own children. This component of the transition experience, while incredibly helpful in the eyes of most parents, was also taxing. It was viewed as another job, as parents constantly “have [their] antenna out to friends with older kids in this situation.” Parents also spontaneously shared information during the focus groups, exchanging names of lawyers, websites, and certain programs in which their children either were or had been enrolled. This exchange frequently appeared to be the sole source of parents’ information, as one mother said “...those are the kinds of [housing options] we're going to be looking at, too, but you don't know unless somebody tells you.”

**Suggestions for improvements to the transition process.** Many of the parents were so passionate about the need for improvements to the transition process that they spontaneously generated ideas during the focus group discussions. Some of these suggestions were ways to improve existing services, such as including field trips to vocational colleges, hiring special education guidance counselors with transition-specific training, and facilitating personalized volunteer experiences. Other ideas, however, were entirely new and unique. One group of parents who were frustrated by the school’s inability to find volunteer sites for their sons and daughters suggested that they build connections with employers themselves: A mother offhandedly stated “I bet you two or three of us could go out walking business zones, and round up 10 employers in one day.”

Where parents struggled, however, was in addressing how these ideas might be implemented. They said the school needed money and would not want to take the time

and effort to provide these services. As such, many parents stated that they began taking on the additional roles of life-skills teacher and “transition coordinator” for their son or daughter with a disability. The commonly proposed solution to improve this aspect of the transition process was to have specifically trained “transition coordinators;” either guidance counselors or other professionals who were responsible for providing information on adult disability services to parents and their offspring. These parents were not satisfied with professionals within their son or daughter’s program who fulfilled this role. While high schools provide guidance counselors for all of their students, these parents of adolescents with disabilities expressed discontent that the counselors were only aware of future options for typically developing teens. For example, schools use a program called Naviance™ to track which students from that school go to which college. One mother suggested that they have a similar program for the students with disabilities, saying

“My older son had Naviance. He can see what everyone like him- where they went to college... if your SAT scores are around here these are some options, here are the kids that went from [school name], but if you’re B., there's no ‘Here's other peers and where they went.’ So I'm like ‘Everybody had to have gone somewhere, where'd they go?’”

This general lack of information was reflected almost unanimously across focus groups, and parents felt that the appropriately trained professional could help fill these knowledge gaps for them. One mother of a younger adolescent with autism (age 14), stated that her son’s school recently hired a transition coordinator to take on these

responsibilities. Another mother in the same group, whose son attended a different school, worried that there was a transition coordinator but she “just [didn’t] know it....and that’s sad.” This lack of knowledge reflects the disorganization of the transition process that parents reported. While schools in Massachusetts are in fact required to have a transition specialist (Massachusetts Department of Elementary & Secondary Education, 2013), many schools have not yet filled this requirement, or the individual has not successfully made his or her presence and skills known to parents.

### **Parental emotions about the future.**

Despite the additional time and effort put forth into preparing for their son or daughter’s transition, most parents still expressed many fears, concerns, or hesitations about the future. Similarly to parental tasks and knowledge, these emotions were often informed by parents' judgements on services their son or daughter had received. The love, pride, and protection parents felt for their son or daughter was often in contrast to the quality of services he or she received; the adolescent's strengths and attributes were frequently overlooked or certain skill development was ignored. The specific emotions reported or conveyed in the focus groups were pride, guilt, fear of the future, and uncertainty about the future.

**Pride.** Parents were eager to comment on their son or daughter's best traits, such as work ethic, positive attitude, intelligence, and creativity. Parents discussed their son or daughter's strengths that would help them through the transition, both generic personality strengths and specific skills. Personality characteristics included: “He’s striving very hard to be a successful adult,” or “He’s very outgoing...I think he’s really empathetic,” In

terms of specific skill strengths, one mother discussed why her daughter could have a career working with animals: "She's very gentle. She helps feed them, she has responsibilities to take care of them... I think she has a... place in her heart for all those animals."

Most of these observations were noted when the data were further examined for additional explanations or interpretations of parental experiences during their son or daughter's transition to adulthood. This additional analysis focused on understanding how parents were affected by their son or daughter's qualities, actions, and growth. Interestingly, this analysis provided a supplemental rather than alternative explanation of conceptual framework. The parents in these focus groups seemed to be well aware of their son or daughter's strengths, but these comments were typically followed by negative judgements about lack of client-centered services. Perhaps parents felt so frustrated with transition services because services and professionals do not consider or support the adolescent's strengths as much as parents do.

**Guilt.** Parents often voiced regrets or guilt about not acquiring services they believed would have been beneficial to prepare their son or daughter for the future. As previously mentioned, one father was concerned that he would miss certain deadlines for services simply because he didn't receive a letter. One mother whose daughter did not get into an independent living transition program lamented that "it's not doing her a service to live at home for the rest of her life because she would fall into a trap. When she has to she can step up to the plate." This mother had arranged several opportunities for her daughter, but was still worried that there were gaps in her transitional education that were



not filled because she, as a parent, had not been able to enroll her daughter in certain programs.

Another source of parental guilt was potentially having done too much to support their son or daughter at home, and worrying that this support had resulted in their adolescent's dependency. Parents were conflicted about their role as life skills teacher, wondering if their teaching, prompting, and support of their child's living skills may have actually rendered their son or daughter dependent on help. A mother whose son has cerebral palsy voiced this concern about her son's independent living skills: "I also now [wonder about] giving prompting... would he have caught on to the laundry by himself if I hadn't done this?" This conflict over level of investment in their son or daughter's future seemed to contribute to uncertainty about the future; parents do not know if their efforts would enable their child to live on their own, or if much of what they had done had rendered their child dependent on them.

**Fear of the future.** Perhaps the most prevalent emotion conveyed both implicitly and explicitly by parents in the focus groups was fear. In addition to expressing general concerns, nearly every parent labeled this emotion when discussing their son or daughter's transition. The most common source of fear was for the child's personal safety. Whether it was strict adherence to the rules, lack of common sense knowledge of how to behave around strangers, or getting lost and not knowing how to find a way back, parents expressed concerns about the level of support their son or daughter needs in order to remain safe. The mother of a young woman with Down Syndrome stated that there was nothing she could do to teach personal safety, and that these concerns still loomed over

all aspects of the future: “it's very, very fearful...that to me underlies every skill because I don't know if she'll ever get it and I don't know how to teach it..” Other parents echoed these concerns closely; they expressed concerns that their son or daughter would be taken advantage of, that they had no one to trust, or that they would get lost on their own. Other concerns aside from safety included fear of poor housing options; one parent stated that she and her husband were “horrified about what’s going to happen” to their son, because he may not qualify for certain services.

### **Uncertainty about the Future**

The coexistence of transition readiness and transition hesitancy appears to create a complex experience for parents during this time period. Because of the time and effort they have dedicated to learning about the transition process and resources, parents were aware of the imminent need to plan as much as possible. However, their fear and uncertainty about what will happen to their son or daughter after the transition process often caused them to hesitate or avoid transition planning altogether. Their tendency was to try and negotiate, or put limitations on, their child’s level of independence. In other words, parents wanted their son or daughter to be independent in some aspects of his or her life but not all.

**Negotiating independence.** In some cases, this negotiation needed to occur due to the adolescent's poor self-awareness of their abilities. A mother spoke of her son's goals, saying “he says sometimes that he wants to live independently but he couldn’t possibly at this point...he couldn’t.” Many parents, on the other hand, were somewhat willing to allow their child some independence as long as it was moderated. One mother

found a supported college program for her son because "he wanted to go away so bad! I had to find him something." Another parent said that her high-school aged daughter "definitely wants to live independently, she's made that clear, so I'm going with that...as much as I can."

It seemed as though many parents took solace in understanding that their son or daughter needed supports, and would rather err on the side of support than independence in order to keep their child safe. These plans for moderated independence, however, also may have contributed to parental stress because of the uncertainty of how to achieve it. Parents did not know if limited guardianship was an option, and struggled to identify specific programs that would provide the best level of support for their son or daughter. The uncertainty surrounding this objective of moderated independence may contribute to transition hesitancy; parents may not want to start transition planning until they are absolutely certain of all their son or daughter's options.

The topic of guardianship arose in many different focus groups as parents discussed the appropriate method for protecting their son or daughter without stripping them of certain rights. One mother wanted her son to be able to vote, but still wanted control of his medical health and finances. Parents also frequently stated their assumptions that their son or daughter would never live without some sort of familial or professional support. Often these assumptions were fairly realistic and related to the adolescent's practical skills: "He thinks he wants to live completely independently of anybody, he wants to live by himself so...but the truth is he can't and he won't. I'm going to get guardianship for him...he's going to need some support." Many times, however,

guardianship or supported housing options were brought up in reference to some fear or anxiety the parent felt. For example, the mother who felt that personal safety was her daughter's primary underlying concern immediately followed up her comment by saying "She'll never be 100% independent that's OK with me. I don't expect her to live independently. She'll always have another person there."

**Hesitation with future plans.** The most substantial indicator of tension and uncertainty, however, was parents' hesitancy to take certain steps toward solidifying their son or daughter's future plans. Parents often expressed contradictory viewpoints and goals even in the same sentence, without seeming to be aware they were doing so. While discussing the reasons she had not started looking for housing for her son, one mother then exclaimed "But I know that it *takes* years...if you're going to do a house..." Similarly, two other parents had taken the first steps to procuring housing for their son or daughter, but then stopped the process saying "I haven't even looked at them [housing matches] yet...I figured it's a few years off," and "They wrote to us a while ago and we didn't do anything, but I think they'll take him... hopefully." Parents were also clear in acknowledging that some sort of transition will eventually need to happen, as "his father's 67 and I'm 58, you know, we're not going to be around forever," but either had not or could not address it at this time. Uncertainty about the future seems to play a large role in parents' willingness to make concrete plans, which further perpetuates the stress and uncertainty they feel as their son or daughter nears the age of transition.

## Discussion

Overall, parents in the present study were not satisfied with the transition services their son or daughter was receiving. The lack of client centered supports, limited number of services available, and scarcity of resources regarding the existing services often led parents to do the majority of their son or daughter's transition planning on their own. These parents had invested a great deal of time, effort, and dedication to their son or daughter with a disability, willingly doing almost anything they thought would help their adolescent have a successful adulthood. In spite of this preparation, however, many parents are still fearful of their son or daughter's future. They felt guilt over the choices they had made in raising their son or daughter, fearing having done either too much or too little, and were often pessimistic about his or her outlook. The combination of preparedness and worry parents feel during their son or daughter's transition to adulthood seems to create a tension that parents struggle to negotiate.

As previously stated, the analysis of the data was impacted by my own familial experiences, work as a research assistant, and role as an occupational therapy student. It is likely that I was sensitive to the tensions surrounding transition planning because I have witnessed my parents attempt to navigate this process themselves. I may have made assumptions about the home life and additional experiences of these parents outside of the focus groups based on my own background. However, the search for alternative explanations of parental experiences as well as the connections between the present findings and previous literature suggest that my interpretations of the data still hold merit in spite of preexisting viewpoints.

Many of the parental emotions and experiences highlighted by this research align with the existing literature on the transition to adulthood for adolescents with disabilities. It is well documented that parents are typically responsible for navigating the disability services systems, and that they do not feel competent in their abilities or supported in this process (Roux et al., 2015; Smith & Anderson, 2014; Turnbull, Beegle, & Stowe, 2001). In terms of emotional experiences, parents of youth with disabilities have expressed emotions such as stress, anxiety, frustration, and even helplessness when faced with the prospect of their son or daughter's future (Gillian & Coughlan, 2010). The literature is unclear, however, about the impact of parental involvement in the transition process on long-term outcomes of adolescents with disabilities. Parental involvement in the process is associated with positive adult outcomes, yet parents have also reported feeling more anxious, fearful, and stressed (Gillian & Coughlan, 2010; Chou et al., 2010; Martinez, Conroy, & Cerreto, 2012). These negative emotions can decrease quality of life, however, which is associated with poorer adult outcomes for people with disabilities (Boehm, Carter, & Taylor, 2015; Neece et al., 2009). Rather than viewing the parental experience from this "either-or" standpoint, the present study acknowledges the duality and tension of this experience and provides a model for understanding its complexities.

It is important to note, however, that in spite of their ambiguity and stress, parents also described many positive experiences of raising their son or daughter. Parents felt proud of their son or daughter, which may be reflected in their commitment, efforts, and desire to make their child happy and successful. Previous research into parental experiences of raising a child with a disability frames some of the "additional parental

duties" in a positive light; they are viewed as adaptations and accommodations, not as burdens that were forced upon them (Maul & Singer, 2009). Many of the parents in the present study seemed to echo this mindset, as their chief concern was not the work they had done, but the lack of support they received. The stressful and negative experiences parents reported may have been emphasized by the nature of the focus group questions (see Appendix A), which were specifically targeting parents' satisfaction with transition services and the skills their son or daughter was learning. Had the questions probed more generally about life with their son or daughter, parents may have been more likely to report positive experiences.

Previous studies examining the impact of raising a child with a disability on parents' lives support the notion that there are many positive elements of this experience. Stainton and Besser (1998) conducted interviews of families of kids with special needs asking only positive questions and found themes including joy, increased sense of purpose and growth, increased family unity, and increased tolerance and understanding for all people. One of their findings somewhat paralleled the findings of this research—parental interactions with professional service providers. When service providers did not treat the family with respect and sensitivity to their unique situation, it often increased rather than decreased the stress the family feels. This sentiment was also reported by Kearney and Griffin's (2001) research, in which they interviewed parents of young children with disabilities about both the positive and challenging aspects of their lives. Much like the tensions reported in this study, Kearney and Griffin found that parents are often torn between joy and sorrow. Researchers noted, however, that parents often cited

"dealings with other people" as the source of their sorrow, while interactions with their child inspired joy (Kearney & Griffin, 2001, p. 585). With these findings in mind, it is less surprising that the present analysis resulted in mostly negative parental experiences being reported, because the questions were targeting parental interactions with other people and services. As such, these findings are of value not only to transition service providers, but to parents as well. If school personnel and adult disability service providers acknowledge how parents are feeling and understand the help they need, perhaps parents will feel less negatively toward them and their anxiety will abate. It is important, however, for providers to consider the present results in conjunction with the previous research regarding the joy of raising a child with a disability in order to have a holistic understanding of the family experience.

### **Implications**

Although preliminary, this research has potential implications for improving the transition to adulthood for youth with disabilities and their families. On a surface level, we now have a more thorough understanding of parents' initial judgements on transition services: what resources are useful and effective as well as those that need improvement. This information will help providers of these services to create specific improvements, which may lead to better future outcomes for youth.

This research also has positive implications for occupational therapy practitioners as providers of transition services. Occupational therapists are skilled in providing both client and family-centered care, and would be the ideal professional to coordinate family goals with the goals of service providers. Additionally, occupational therapists are trained



to identify both physical and cognitive barriers to any task. The proposed conceptual model may assist occupational therapists in further clarifying any potential emotional barriers parents may feel when facing their son or daughter's transition. The occupational therapist can connect these emotional barriers to challenges parents or children are facing in acquiring or maintaining services. Crucially, occupational therapists work with their clients to develop strategies that will overcome or compensate for these barriers. Occupational therapists can work with the entire family to work through complicated emotions in order to generate action plans to achieve important milestones during the transition.

An unexpected outcome of this research was the call from parents for a "transition coordinator." Numerous parents voiced their need for a highly trained transition professional who could not only find appropriate services for adolescents, but manage the logistical and legal aspects of the process as well. While some school systems are beginning to fill this role, no national legislation is in place to ensure that all families benefit from this service (Massachusetts Department of Elementary and Secondary Education, 2013). Even in areas where transition coordinators are provided, many parents are not aware of their duties and responsibilities (as evident from the experiences of the parents in the present study). This research highlights the need for the transition coordinator role to be well-known and wide-spread. Such a professional would greatly alleviate parental stress during the transition process which, as previously discussed, may result in improved long-term outcomes for their sons and daughters who have disabilities.

**Limitations**

One clear limitation in this study was the inability to conduct a true grounded theory analysis. With the focus groups all completed before data analysis, I was unable to generate themes and questions to probe additional focus groups in order to refine my concepts. My interpretations were not checked by parents, and therefore may not be the only representation of their emotions and experiences. Additionally, the limitation on data collection may have led to some themes being neglected from my analysis. Had I been able to ask new questions, perhaps different relevant concepts would have been discovered.

The focus groups themselves were another limitation to this study. The participants all lived in middle class towns in the New England area and were all White and spoke English as their first language. It is likely that people of different socioeconomic statuses, races, or cultures do not experience the transition to adulthood in the same way. Therefore, the proposed conceptual model cannot be generalized to all parents of adolescents with disabilities. Future research should explore the parental experiences of a diverse group of people to gain a more complete understanding of the factors that contribute to this process.

**Conclusion**

The transition from adolescence to adulthood is a complicated and emotional time for all young people and their families. The future is inherently unpredictable, and young adults can feel overwhelmed and anxious about their possibilities. Young people with disabilities, however, may face even greater uncertainty of their future due to the limited

supports available to them and the uncertainty of their potential. Parents invest immense time and energy to ensure that their child with a disability has the best future possible, but the current study indicates that they are often still wary of the future. This preparation coupled with hesitancy creates a tension that persists throughout the transition process. Understanding the complexity of parental experiences and emotions regarding their son or daughter's transition to adulthood may help service providers not only create better programming, but also better support families in order to promote the best outcome for everyone.

## Appendix A

### Parent Focus Group Questions

1. Let's start by having each of you tell us a little bit about your son or daughter.

We will go around the room for this question.

2. What is a typical day like for your son or daughter?
  - a. What is his or her day like on weekdays?
  - b. What is his or her day like on weekends?
3. How satisfied are you with his or her current daily activities?
  - a. How satisfied do you think your son or daughter is with his or her daily activities?
4. What are your hopes for your son or daughter for the next 5 years?
  - a. What do you think your son or daughter's hopes are for the next 5 years?
5. What does your son or daughter need to do to get there?
  - a. What are the skills that your son or daughter still needs to develop to get there?
  - b. Why are those skills so important?

*Transition Script:* Now we are going to focus a bit more specifically on functional living skills. Sometimes people refer to these skills as adaptive behavior, daily living skills, or life skills. For the purposes of our conversation today, we want to talk about the ability to manage the life tasks that are needed for independent and community living.

1. Describe your son or daughter's ability to manage their own functional living skills.

- a. Tell me about skills your son or daughter developed with ease.
  - b. Which skills have been more challenging for your son or daughter to develop
  - c. Are there functional living skills that you think are important for your son or daughter's success that require further development?
  - d. If so, what are the functional living skills that you would like your son or daughter to develop?
2. What have you done, as parents, to help your son or daughter be more independent in their living?
    - a. On a day to day basis, how do you try and help your son or daughter manage their daily basis?
    - b. What types of supports do you think would be helpful to you in this process? [probe strategies]
3. What types of services or interventions does your son or daughter receive to address their functional living skills? [probe school as well as community agencies]
4. What types of experiences have you had with these services and supports?
    - a. Have you worked together with school personnel or service providers in teaching these skills?
    - b. Are there other ways you would like assistance from school personnel or service providers in working on these skills with your son or daughter?

5. If you have other children, describe how you helped them to develop the skills necessary for independence in adulthood. [probe birth order]
  - a. How does the approach you use to teach your son or daughter that you've been discussing today compare to the approach you use with your other children?

### Bibliography

- Anderson, K. A., McDonald, T. A., Edsall, D., Smith, L. E., & Taylor, J. L. (2016). Post-secondary expectations of high school students with Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities, 31*(1), 16–26.
- Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist, 55*(5), 469–480. doi: 10.1037/0003-066X.55.5.469.
- Bambara, L. M., Wilson, B. A., & McKenzie, M. (2007). Transition and quality of life. In S. L. Odom, R. H. Horner, M. E. Snell, & J. Blacher (Eds.) *Handbook of Developmental Disabilities*, (pp. 371–389). New York: Guilford Press.
- Blacher, J. 2001. Transition to adulthood: Mental retardation, families, and culture. *American Journal of Mental Retardation, 106*(2), 173–188.
- Boehm, T. L., Carter, E. W., & Taylor, J. L. (2015). Family quality of life during the transition to adulthood for individuals with Intellectual Disability and/or Autism Spectrum Disorders. *American Journal on Intellectual and Developmental Disabilities, 120*(5), 394–411, 476, 478.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide*. London: SAGE Publications, Inc.
- Chou, Y. C., Lee, Y. C., Lin, L. C., Kröger, T., & Chang, A. I. (2009) Older and younger family caregivers of adults with intellectual disability: Factors associated with future plans. *Intellectual and Developmental Disabilities, 47*(4), 282–294.

- Cichy, K. E., Lefkowitz, E. S., Davis, E. M., & Fingerman, K. L. (2013). "You are such a disappointment!": Negative emotions and parents' perceptions of adult children's lack of success. *Journals of Gerontology: Series B; Psychological Sciences and Social Sciences*, *68B*(6), 893–901.
- Gillian, D., & Coughlan, B. (2010). Transition from special education into postschool services for young adults with intellectual disability: Irish Parents' Experience. *Journal of Policy and Practice in Intellectual Disabilities*, *7*(3), 196–203.
- Heller, T., & Caldwell, J. (2006). Supporting aging caregivers and adults with developmental disabilities in future planning. *Mental Retardation*, *44*(3), 189–202.
- Henninger, N. A., & Taylor, J. L. (2014). Family perspectives on a successful transition to adulthood for individuals with disabilities. *Intellectual and Developmental Disabilities*, *52*(2), 98–111. doi: 10.1352/1934-9556-52.2.98
- Individuals With Disabilities Education Act, 20 U.S.C. § 1400 (2004).
- Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: Being a parent of a child with developmental disability. *Journal of Advanced Nursing*, *34*(5), 582–592. doi: 10.1046/j.1365-2648.2001.01787.x
- Kloep, M., & Hendry, L. B. (2010). Letting go or holding on? Parents' perceptions of their relationships with their children during emerging adulthood. *British Journal of Developmental Psychology*, *28*(4), 817–834.
- Martinez, D. C., Conroy, J. W., & Cerreto, M. C. (2012). Parent involvement in the transition process of children with intellectual disabilities: The influence of



inclusion on parent desires and expectations for postsecondary education. *Journal of Policy and Practice in Intellectual Disabilities*, 9(4), 279–288.

Massachusetts Department of Elementary and Secondary Education. (2013). Guidelines for the transition specialist endorsement. Retrieved from

<http://www.doe.mass.edu/edprep/advisories/TSEguidelines.pdf>

Maul, C. A., & Singer, G. H. S. (2009). “Just good different things:” Specific accommodations families make to positively adapt to their children with developmental disabilities. *Topics in Early Childhood Special Education*, 29(3), 155–170. doi: 10.1177/0271121408328516

Neece, C. L., Kraemer, B. R., & Blacher, J. (2009). Transition satisfaction and family well being among parents of young adults with severe intellectual disability.

*Intellectual and Developmental Disabilities*, 47(1), 31–43. doi:

10.1352/2009.47:31–43

Nelson, L. J., Padilla-Walker, L. M., Carroll, J. S., Madsen, S. D., Barry, C. M., & Badger, S. (2007). “If you want me to treat you like an adult, start acting like

one!” Comparing the criteria that emerging adults and their parents have for adulthood. *Journal of Family Psychology*, 21(4), 665–674.

Poon, K. K., Koh, L., & Magiati, I. (2013). Parental perspectives on the importance and likelihood of adult outcomes for children with Autism Spectrum Disorders,

Intellectual Disabilities, or Multiple Disabilities. *Research in Autism Spectrum Disorder*, 7, 382–390.

- Primeau, L. A. (2003). Reflections on self in qualitative research: Stories of family. *American Journal of Occupational Therapy, 57*(1), 9–16.
- Roux, Anne M., Shattuck, Paul T., Rast, Jessica E., Rava, Julianna A., and Anderson, Kristy, A. *National Autism Indicators Report: Transition into Young Adulthood*. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2015.
- Smith, L. E. & Anderson, K. A. (2014). The roles and needs of families of adolescents with ASD. *Remedial and Special Education, 35*(2), 114–122. doi: 10.1177/0741932513514616
- Stainton, T. & Besser, H. (1998). The positive impact of children with an intellectual disability on the family. *Journal of Intellectual and Developmental Disability, 23*(1), 57–70.
- Stoner, J. B., Angell, M. E., House, J. J., & Bock, S. J. (2007). Transitions: Perspectives from parents of young children with Autism Spectrum Disorder (ASD). *Journal of Developmental and Physical Disabilities, 19*, 23–39. doi: 10.1007/s10882-007-9034-z
- Timmons, J. C., Whitney-Thomas, J., McIntyre, J. P., Butterworth, J., & Allen, D. (2004). Managing service delivery systems and the role of parents during their children's transitions. *Journal of Rehabilitation, 70*(2), 19–26. doi: <http://search.proquest.com.ezproxy.bu.edu/docview/236325398?accountid=9676>
- Turnbull, H. R., Beegle, G., & Stowe, M. J. (2001). The core concepts of disability policy affecting families who have children with disabilities. *Journal of Disability Policy*

*Studies*, 12, 133–143. <http://dx.doi.org.ezproxy.bu.edu> 10.1177/

104420730101200302

Whitney-Thomas, J. & Hanley-Maxwell, C. (1996). Packing the parachute: Parents' experiences as their children prepare to leave high school. *Exceptional Children*, 63(1), 75– 87.

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Presentations

Haver, C. E., Smith, D. J., & Jacobs, K. (2016, April). *Inclusion, adaptation, and occupational therapy in children's literature*. Poster presented at the American Occupational Therapy Association Annual Conference and Expo, Chicago, IL.

McKinnon, S., DeMarinis, J., Haver, C., E., McWherter, W. E., & Toegemann, B. (2016, April). *The use of ecotourism as co-occupation and the various occupational roles that exist in an ecotourism community in Ecuador*. Poser presented at the American Occupational Therapy Association Annual Conference and Expo, Chicago, IL.

Orsmond, G. I., Wong, J., Coster, W. J., Cohn, E. S., Erspamer, B. & Haver, C. E. (2016, March). *The focus of educational goals for transition-age youth receiving special education services*. Poster presented at the Gatlinburg

Conference on Research and Theory in Intellectual and Developmental  
Disabilities, San Diego, CA

Honors and Awards

Phi Theta Epsilon, 2015– present

Phi Beta Kappa, 2013–present

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