

**UNDERSTANDING THE ROLES OF PARENTS OF YOUNG ADULTS WITH  
INTELLECTUAL DISABILITIES DURING POSTSECONDARY  
TRANSITION**

by

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## **DEDICATION**

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## TABLE OF CONTENTS

LIST OF TABLES .....	viii
ABSTRACT .....	ix

### Chapter

1	INTRODUCTION & LITERATURE REVIEW .....	1
	Background.....	1
	Overview of Literature .....	2
	The Early Years .....	3
	The School Years .....	4
	The Postsecondary Years .....	6
	Summary.....	8
	Purpose .....	9
2	METHOD .....	10
	Design.....	10
	Participant.....	10
	Data Collection.....	15
	Analyse .....	16
	Trustworthiness .....	18
3	RESULTS.....	20
	How Parents/Guardians Perceive Their Roles .....	20
	Advocate – One who pleads the cause of another .....	20
	Protector – One who shields another from injury .....	22
	Encourager – One who inspires and gives hope.....	24
	Provider – One who supplies something for sustenance or support.....	26
	Influencing Factors and Change .....	27
4	DISCUSSION.....	31
	Four Major Roles.....	31
	Shifting Roles and Tensions.....	32

Changes Over Time .....	34
Value of the Parent Perspective.....	35
Implications for Practice.....	36
Implications For Research.....	38
Limitations.....	39
Conclusion.....	41
Parent Advice to Other Parents of Young Adults with ID .....	42
REFERENCES .....	44
Appendix	
A PARENT QUESTIONNAIRE .....	49
B IRB APPROVAL .....	52

## LIST OF TABLES

Table 2.1	Demographic Characteristics of Participants.....	12
Table 2.2	Demographic Characteristics of Young Adult with ID .....	13
Table 2:3	Young Adult Levels of Independence as Described by Participants.....	15



## **ABSTRACT**

This qualitative study explored how parents of young adults with intellectual disabilities (ID) perceived their roles and how they might have changed over time, focusing especially on what they perceived their roles to be in their children's postsecondary years. Data were collected from eight parents of young adults with ID through semi-structured interviews. Topics explored in the interviews were: description of past and present roles, supports they may or may not provide, and what, if any, information/education they had received about the role of a parent post-school. Data were analyzed through constant comparative methods and cross-case displays in search of patterns and themes. The findings suggested parents in the study saw themselves as having the roles of advocates, protectors, providers, and encouragers. These roles were evident across the major life areas of their young adults. Parents expressed their roles and level of advocacy had changed over time in response to their perceptions of the significance of their child's disability and growth in independence. Parents indicated they had received limited preparation for their postsecondary roles from educators and professionals and relied instead on applying their own knowledge of the adult world in a "trial and error" fashion. Implications for further research and professional practices that better prepare and support parents of young adults with ID during postsecondary transition are discussed.

## **Chapter 1**

### **INTRODUCTION & LITERATURE REVIEW**

#### **Background**

The purpose of my thesis was to examine the phenomenon of parents' roles in their continued efforts to support their young adults after leaving the school system. It was my intent to explore and better understand the potential impact their continued involvement may have, or has had, on postsecondary outcomes. As a professional in the field of postsecondary education and employment, I have worked with many parents over the years. My perceptions of parent roles are based upon observation and experience, and I desired to verify "what I think I know." Through conversations and meetings with parents, I was aware of barriers, parental over protection, real concerns, and fears. I have witnessed a variety of outcomes that have been both positively and negatively impacted by parents' involvement in employment and postsecondary education settings. It was because of these experiences I chose to do an exploratory, qualitative study to examine this phenomenon. I wanted to more systematically examine and understand the significance of parent roles as they pertain to the postsecondary transition experiences of individuals with ID. My preliminary review of the literature suggested a majority of the research conducted in the last twenty years has focused on parent roles from perspectives other than their own during the

transition period from high school to immediate post-school; relatively little addresses parent roles from their perspective once the secondary school system is no longer involved. I think further research in this later transition period has the potential to inspire a dialogue for system change, the development of education programs, and peer mentor support groups for parents during the postsecondary years.

In this chapter, I review the literature on parent roles with children who have intellectual disabilities, and how their roles as advocates, protectors, providers, and encouragers influence their young adult's levels of independence, and postsecondary experiences. Following a general overview of parent roles and influences, the literature is organized into three sections. Section one takes a brief look at parents' roles, through their eyes and the eyes of others, during the early years when they received intervention services and family-centered supports. Section two speaks to parent roles and involvement during the school years and their influence on career and postsecondary goals. Section three presents information about parent roles during the postsecondary years, through the eyes of parents, educators, and young adults, and from data collected on postsecondary outcomes.

### **Overview of Literature**

To establish a foundational basis for the study, and to gain a broader perspective, I looked at literature from the early years through post-school transition. Parents are an integral part of who we are, influencing our cognitive and social growth. They play a major role in their children's attitudes toward work and life.

With their set of expectations from the time we are born, to their aspirations for us as we grow and their hopes for us as we transition into independent adults, parents are powerful forces in our development. Through interviews with young adults, parents, and educators, several studies (e.g., Bianco, Garrison-Wade, Tobin, & Lehmann, 2009; Lindstrom, Doren, Metheny, Johnson, & Zane, 2007; Penick & Jepsen, 1992) have indicated that parents act as advocates and protectors throughout the life of their child, and influence the future of their young adult. Parent concerns and fears about safety, individual levels of maturity and independence, employment, and future living arrangements are heightened for many parents of individuals with disabilities, in comparison to parents of individuals without disabilities.

### **The Early Years**

A plethora of research and literature, through observation of programs and practice, examine and detail extensive early intervention programs and supports provided for children with ID and their families from birth to kindergarten (Bailey, Raspa, & Fox, 2011; Brekken, 2011; Bruder, 2010; Byington & Whitby, 2011; Connelly, 2007; Turnbull, Summers, Turnbull, Brotherson, & Winton, 2007). When a child is diagnosed with a disability at birth, a variety of professionals enter into the life of the family. Medical professionals, social workers, early interventionists, and special educators arrive on the scene offering support and education to the family. Through interviews with families Dempsey & Dunst (2004), determined the goal of early childhood intervention should be to provide optimal benefits to the child and to families through the access to resources of support and the acquisition of help-giving

techniques to increase family empowerment (Dempsey & Dunst, 2004). Families are faced with new challenges as they learn how to best support their child. They have significant concerns about their child's health care needs, stages of development, communication, and eventually academic readiness.

During the early years, services during this transition period are family-centered. A family-centered approach is a practice and philosophy that respects and values family involvement and provides them with the necessary supports during this time period (Dunst, Trivette, & Hamby, 2007). This method of practice views the family as a partner and recognizes the family as the experts on the skills and abilities of their child. Families, when their children are young, are empowered as collaborators and advocates. In their observations of a three year old and his parents participating in an early intervention program, Byington & Whitby (2011) discussed the importance of supporting a parent in becoming a strong advocate for their child. The earlier a child is diagnosed with a disability, the more likely the child will benefit from early intervention and the family will benefit from the support they receive during the transitions from birth to pre-school, and from pre-school to the school system (Dunst, 2007).

### **The School Years**

As a child grows, enters the school system in kindergarten, and continues onto middle school, the family-centered philosophy appears to change as the student becomes the center of the educational planning process. Much of the literature on parents' roles, as described by parents during the school, years characterizes them as

partners, decision makers, and collaborators with school personnel in making educational decisions (Docherty & Reid, 2009; Ryndak, Orlando, Storch, Denney, & Huffman, 2011; Saaltink, MacKinnon, Owen, & Tardif-Williams, 2012). Correlations between family involvement and student achievement or family quality of life are often highlighted. Engaging families in the transition process before their student exits school and providing them with training and education in postsecondary options increases the probability of positive and successful outcomes (Bianco et al., 2009). However, some parents report feeling devalued and unempowered by school professionals (Ankeny, Wilkins, & Spain, 2009). In the exploration of a mother's view of twelve years of advocacy, Ryndak et al. (2011), described her experiences from kindergarten to sixth grade as continuous times of frustration, despair, and decision-making, and interactions with educators who did not foster a relationship.

During the later school years, parents are introduced to the importance of transition planning in preparation for postsecondary experiences (Benz, Lindstrom, & Yovanoff, 2000; Scorgie, Wilgosh, & McDonald, 1999). Research provides us a glimpse of what parents of young adults with disabilities have to say about their involvement and support during the school years. Through interviews with families and students, parents were described as protectors and advocates and as having influence on their young adult's ability to be self-determined (Griffin, McMillan, & Hodapp, 2010; Morningstar, 1997; Morningstar, Frey, Noonan, Clavenna-Deane, Graves, Kellems, McCall, Pearson, Bjorkman-Wade, & Williams-Diehm, 2010).

Everson & Moon (1987) described parent roles as ranging from case managers and chief advocates, to having no active involvement in their child's later school years. Parents' roles and how they influence employment and postsecondary choices has been documented (Dixon & Reddacliff, 2001; Lindstrom et al., 2007; Morningstar, 1997). Family expectations, concerns for safety, levels of involvement and advocacy have shown to influence the career choices of young adults with learning disabilities. Whitney-Thomas & Hanley-Maxwell (1996) explored parents' experiences as their children prepared to leave high school, and found parents of students with disabilities share some of the same concerns as parents of children without disabilities. They found parents to be concerned with their young adult's finances, ability to live independently, and to make good decisions. Students have indicated their families have been integrally involved as they plan their futures in both college and in finding a job (Morningstar, 1997). This is not unlike the influence a parent has upon a young adult without a disability. Kraemer & Blacher (2001) explored in-school transition experiences of families of young adults after they had exited. Parents shared they were actively involved as advocates in the transition process, but found that time period filled with challenges and unknowns.

### **The Postsecondary Years**

Transition literature suggests that parent's continuing roles directly impact outcomes of young adults' post-school experiences. Yet, there are few studies that describe the parent roles during the postsecondary period. Also, there is limited information about later influences on parent roles. Families have a clear influence on

career development and successful employment outcomes, however, relatively few studies have explored the role that families play in influencing postsecondary employment (Lindstrom et al., 2007).

A study by Davies & Bemish (2009) found that young adults with ID have poorer postsecondary outcomes in employment and living independently, which placed additional stress on the family due to the young adults' dependency. The authors also noted that large-scale studies involving parents have provided few findings related to parent involvement in the postsecondary transition process. We know from research most individuals with ID tend to live with their parents/guardians during postsecondary years (Lindstrom et al., 2007; Mock & Love, 2012; The Arc, 2011).

A small number of studies provide insights about parents' perspectives on their later postsecondary roles. Bianco et al. (2009) investigated perceptions of nine parents regarding the roles they played in their young adult's life post-school. Parents perceived their roles as mentor, role model, instructor, protector, evaluator, decision maker, and advocate. This study reported parents' descriptions of the post-school years as being a time of adjustment in their roles as advocates and challenges with knowing when to support their young adult in making their own decisions. Rueda, Monzo, Shapiro, Gomez, & Blacher (2005) exploring transition through the eyes of Latino mothers, found parent roles to be those of advocate and protector, and identified the lack of information and training for parents in preparation for postsecondary life.



## **Summary**

Literature supports the identification of parent roles as advocates, mentors, decision makers, collaborators, and protectors. These roles may change over time, and are influenced by the parent's perception of their young adult's potential to achieve or attainment of a certain level of independence. The parent's perspective of their son/daughter's limitations is based upon their own observations and experiences.

Parents may move between roles of advocate, protector, and decision maker throughout the years, as their young adult matures. Parents play an important role in transitioning young adults with intellectual disabilities (ID) from school to work or postsecondary education. They have been actively engaged and have taken on a variety of roles in the lives of their children from early diagnosis, through the school years, and as they transitioned into adulthood

Parents' roles influence the postsecondary experiences of their young adult in areas of independent living, employment, money management, and autonomy. Much has been written about the roles of parents through the eyes of educators, professionals, and students from the early years through exit from school. However, there is little research from parents themselves during the postsecondary years as to how they perceive their roles, what their roles may look like as their young adult matures, and what types of education and support they may require to better understand their roles.

**Purpose**

The purpose of this study was to gain a better understanding of parents' postsecondary roles from their perspectives; including how and why parents have assumed these roles, insight into perceived challenges with their roles and how they might have changed over time, and to explore any need for supports and resources. By positioning myself as a listener and giving them the opportunity to share their story, I believed I would gain valuable information about their level of involvement in postsecondary experiences, employment, transportation, social activities, and independent living. I was seeking to find out if they perceived their roles to be stagnant or changing as their young adult transitioned through life, and to seek information as to their roles being influenced by external factors.

Chapter 2 presents the methods I used to learn about the parent perspectives. Chapter 3 describes the study findings focusing on major themes expressed by the parents. In chapter 4, I discuss implications of the findings for practice and research.

## **Chapter 2**

### **METHOD**

#### **Design**

This qualitative, multiple cases study was conducted through semi-structured interviews, using a sampling of convenience, with eight parents of young adults ages 19-34 with intellectual disabilities. Through actively listening, documenting, and analyzing their responses, I explored parent roles, through their eyes. During analyses of the data, I searched for commonalities and prominent themes to better understand their roles as well as their perspectives and rationale for particular roles. I followed quality indicator guidelines for qualitative studies in special education as outlined by Brantlinger, Jimenez, Klinger, Pugach, & Richardson (2005) through the appropriate selection of participants, administration of reasonable non-leading questions, and the protection of collected data, ensuring sensitivity, confidentiality, and fairness.

#### **Participants**

Participants were recruited through an email campaign inviting their voluntary participation. I sent an initial email of introduction with a cover letter and detailed description of the project to vocational rehabilitation counselors, employment service providers, and transition specialists throughout Delaware. These partners offered to distribute the information on my behalf, and I was informed by phone of the number

of emails sent by each contact. A total of 125 emails were distributed through this effort. This resulted in receipt of seven interested individuals, to whom I emailed consent forms. Of the seven potential participants, three returned signed consents by email and confirmed by phone the scheduling of their personal interview. The remaining four never responded after a second email attempt to gain consent.

To increase participation, I recruited through an email to my professional contacts at local agencies serving individuals with ID and their families and received no responses. I then contacted a parent I knew by telephone to seek participation, and she agreed. This resulted in her referring two more parents/guardians who agreed to participate and who also knew of my position at the University of Delaware's Center for Disabilities Studies. My final attempt to obtain participants was two-fold; through word of mouth from one participant to another and through referral by a colleague to parents with whom she had contact. This resulted in the addition of two participants bringing the total number of participating parents to eight.

My final sample of participants consisted of eight parents of young adults with ID who were residing at home and between the ages of 19-34. I had been briefly introduced to six of the participants' young adults at some point in time during the last four years, and the remaining two I had worked with over three years ago in a university-affiliated program. Six of the participants were married, one widowed, and one divorced. All were of white ethnicity, with family economic statuses between \$60,000 and \$100,000+, and had achieved some level of higher education. Seven resided in Delaware and one lived in a neighboring state. All participants were

biological parents and included six mothers, two of whom had guardianship of their young adults, and two fathers. My sample of convenience resulted in an equal number of male and female young adults with ID.

Among the eight participants, only Parent 1 had two children with a disability; the other parents had one. I was aware other family members, such as siblings and extended family members, may have had influence in the postsecondary years. However, I specifically focused on the parents and how they perceived their roles. Table 2:1 shows the demographic characteristics of the participants.

Table 2.1 Demographic Characteristics of Participants

Parent	Guardian	Gender	Marital Status	Children in Family	Family Income Range	Level of Education
1		Female	Married	5	\$100,000+	Bachelors
2		Female	Married	2	\$100,000+	Masters
3		Female	Married	2	\$100,000+	Masters
4		Male	Divorced	3	\$100,000+	Community College
5		Male	Married	1	\$60,000-\$100,000	Community College
6	yes	Female	Widowed	5	\$60,000-\$100,000	Bachelors
7	yes	Female	Married	2	\$60,000-\$100,000	Bachelors
8		Female	Married	2	\$60,000-\$100,000	Bachelors

Table 2:2 shows the demographic characteristics of the young adults. As reported by the participants, two young adults had autism, two had learning

disabilities, three had Down Syndrome and one had Williams Syndrome. Five of the young adults were employed, one was in a workshop assessment, one was a fulltime college student, and one was a part time college student and also employed. Only two of the young adults had earned high school diplomas, and the other six received certificates of attendance/completion.

Table 2.2 Demographic Characteristics of Young Adult with ID

Young Adult	Gender	Age	Parent Label of Disability	Years out of School	Diploma	Certificate	Current Status
1	Male	20	Autism	8 mos.		Yes	Employed
2	Female	21	Learning Disability	2 years		Yes	Employed
3	Male	19	Autism	8 mos.	Yes		College
4	Male	23	Down Syndrome	2 years		Yes	Employed
5	Female	23	Williams Syndrome	2 years		Yes	Workshop Evaluation
6	Female	26	Down Syndrome	8 years		Yes	Employed
7	Female	34	Down Syndrome	13 years		Yes	Employed
8	Male	26	Learning Disability	5 years	Yes		College/ Employed

Table 2:3 shows the young adults' levels of independence in daily living categories as described by the participants. Six of the young adults were reported as being very independent in cleaning rooms within the home, and two required some support. Two young adults did not cook at all, four were able to use the stove and

microwave independently, and two required some support to cook. Although all participants were unsure how much support or what type of supports their young adult received in the workplace, four reported their young adult did not receive support, and four reported they were aware their young adult received some type of support. Two young adults were very independent in shopping for themselves, three of them shopped for groceries or clothes with some support, and three chose not to shop.

Money management was a concern, but also identified as an important skill. Participants admitted worrying about their young adult overspending and having no concept of the value of money. Seven young adults had ATM or bank cards and the ability to deposit payroll checks with support. The remaining one participant admitted her young adult had no interest in or understanding of money. Two of the eight young adults were fairly independent in managing their money, although parents expressed that both occasionally had issues with overspending.

Participants expressed their desires for the future living arrangements of their young adults. Three expressed the perfect arrangement would be for their young adult to live independently or with a roommate. Two participants believed their young adult would not have the ability to live without a roommate; two participants believed in the possibility of a group living arrangement; and one participant had already made arrangements for the young adult to live with a sibling when no longer able to provide care.

Table 2:3 Young Adult Levels of Independence as Described by Participants

Young Adult	Cleans	Cooks	Shops	Money Management	Receives Supports at Work	Independent Living (future)
1	I	I	WS	I	Yes	WS/ Alone
2	I	I	WS	WS	No	WS
3	I	I	No	WS	No	WS/ Alone
4	WS	WS	WS	WS	Yes	Group
5	I	WS	I	WS	Yes	WS
6	I	WS	No	WS	No	Siblings
7	WS	WS	No	No	Yes	Group
8	I	I	I	I	No	WS/ Alone

I Totally Independent WS With Some Support

### Data Collection

Demographic data and consents were received by email or postal delivery from each participant, and I made individual appointments to meet with them to conduct the interviews. Participants were given the choice of where they would be most comfortable in meeting. One participant chose his/her home, one chose my office, one preferred a phone interview, and five elected to meet at a local coffee shop. I conducted semi-structured interviews of approximately 45 minutes in length, using questionnaires (Appendix A) consisting of both open-ended and structured response questions. I audio-recorded all interviews except for the last one, which was conducted over the telephone. I made brief written notes while conducting the face-to-face interviews. During the last interview I made extensive notes, transcribing the parent's exact words as much as possible. The first section of the interview process included confirmation of demographic data and collection of background information about the



young adult and the participant using structured-response questions. The second section explored in-school, age 18-21 transition experiences as well as postsecondary experiences related to career choices, transportation, safety concerns, independence, employment, and a brief history of integrated experiences. The audio recordings were transcribed and encrypted within three days of each interview. After transcription and during initial data analysis, I contacted three of the parents/guardians by telephone to seek clarification. While interviewing Participant 5, I added two additional questions to the study, Questions #21 and #22. I emailed the first four participants with request to respond to the additional questions I found pertinent to the study. During the interview with Participant 7, two more questions developed. Because I was interested in other participants' responses, I sent another email to the first six participants to gain their responses to Questions #23, #24.

All print data were secured in a locked file cabinet, and digital material such as audio recordings and word processing documents were encrypted and then stored on a secured electronic server at the University of Delaware.

### **Analyses**

I conducted a qualitative constant comparative analysis (Merriam, 1998; Mertens & McLaughlin, 2004) of the phenomenon of parent roles and potential impact on postsecondary outcomes. As I transcribed interviews, I made notes about major issues mentioned by the participants and how their responses corresponded to my initial ideas about parent roles and those described in the literature. After transcribing the first five interviews and inserting the responses to the first two additional interview

questions, I created a chart to capture participants' responses related to their postsecondary roles in the areas of planning and preparing for postsecondary education or employment, transportation, money management, "special considerations" in postsecondary settings or in the workplace, and how they described the overarching nature of their role and how it might have changed over a course of time. Through this exploratory process, I looked for themes, patterns, and challenges, to gain a better understanding of how parents' roles may or may not change postsecondary. As I received the responses to the last two interview questions, I incorporated them into my preliminary analyses. I then transcribed the remaining three interviews.

My next round of analysis involved organizing the various activities that participants described into major role categories such as advocate and protector. Once I had identified the first two roles, I further examined the data and found two more roles, encourager and provider. To further explore and test my findings, I revisited the literature to examine the correspondence with my findings and to clarify my understanding of parent roles. I also had my advisor review the interview transcripts and discussed my findings with her and another faculty member who had conducted research on parent transitions. Finally, I selected illustrative quotes to characterize major roles, how those roles had changed over time, and factors that may have influenced those changes.

## **Trustworthiness**

To establish the credibility and trustworthiness of my research findings, I referenced Brantlinger et al. (2005). I provided a first level member check by offering all eight participants the opportunity to comment on the accuracy and completeness of the interview transcripts. Four of the participants declined and the remaining four participants made no suggestions or changes. To support the dependability of my findings, I looked carefully at each case and the data reflecting the answers to my research question. Categories were established from each case review and looked at independent of one another. I referred to each written transcription from the participants to confirm their responses and verify I had accurately portrayed their perspectives and experiences. Once the categories were fleshed out and organized from the data, I began a cross-case analysis.

I developed a categorical chart of common participant responses, enabling me to look carefully at consistencies as well as inconsistencies in my organizational scheme. I also referred back to the literature for outside perspectives on the categories emerging from the data. Because I wanted to understand the participants' perspectives, it was imperative I minimize my biases in the representation and understanding of these roles. To help me maintain a focus on the participants' perspectives, I provided a thick description of their responses, using their own words to describe their experiences, and I offered direct quotes as illustrations and descriptions of how they viewed their roles.

Peer debriefing was provided by my advisor in charge of the thesis, the professors serving on my committee, and by another faculty member familiar with parent roles in the lives of young adults with ID. This provided another check on my interpretations of the data. For clarification purposes, participants in the remaining sections of the study will be referred to as parents.

## **Chapter 3**

### **RESULTS**

Parents viewed themselves as serving in a variety of roles, dependent upon their perceptions, experiences and understanding of their young adult's capacity for independence and significance of the disability. Parents took different roles at different times during their young adult's transition in the postsecondary period. How parents perceived their roles fell into four common categories: advocate, protector, encourager, and provider. In the next section I describe these four roles, and then present findings regarding how parents described changes, tensions, and factors having influence on their roles.

#### **How Parents/Guardians Perceive Their Roles**

##### **Advocate** – *One who pleads the cause of another*

All eight parents viewed themselves as their son or daughter's advocate both during school and post-school and perceived this would be a role that would continue for the rest of their lives. Although the level of advocacy may have changed over a period of time, five of the parents were still actively involved in advocating for their young adult in postsecondary experiences. "When there are issues, we might make a call, we might try to offer behind the scenes support" (Parent 5). Parent 7 shared,

“Everything I have done, I have done because it was good for her. I have to allow her room for growth, but she can’t be independent, things she can’t do, and it is my role.”

Parents’ definitions of advocacy were fairly consistent over time, with changes in the level of advocacy and frequency varying by settings and experiences. While their young adults were in school, they viewed themselves as having to make sure IEP goals were being met, educational and vocational services were adhered, and holding educators accountable for equitable treatment. “I found high school teachers to be rude and obnoxious to him, and I had a hard time with the cruelty in the schools” (Parent 8). Parent 2 saw her role while her daughter was in school as someone to help eliminate barriers, to create opportunities, and to advocate when necessary and then back off. “Sometimes, I had to rethink my goals, and to step back.”

It was apparent they saw themselves as advocates for getting their young adults the services they needed and to step up and strongly advocate when they thought areas of their young adults lives weren’t going well or the way they had planned. “Fighting injustices within the school, bringing in an attorney when needed, I don’t want to ever look in a mirror and say I didn’t do anything to help” (Parent 5).

As young adults exited the school system, parents shared that some of their advocacy efforts started to change. Parent 5 said, “I will always be her advocate, to ensure work found for her is within the scope of her abilities.” “The role has changed from learning how to be an advocate when he was young and applying what I learned to help him grow-to now learning how to let go” (Parent 3). “When she was in school, I had to be her voice and make sure she was involved in activities to help her reach her

potential, and by 8<sup>th</sup> grade, I was beginning to work with her to speak up for her own needs. I don't speak up for her anymore, she now has the skills to do it" (Parent 2).

Three parents admitted they viewed their roles as their young adult's advocate well into the future, because they did not believe their young adult had or could acquire the skills necessary to become their own advocate across all domains in life. "Though the role has changed, it never goes away" (Parent 6).

**Protector – *One who shields another from injury***

Two parents were more fearful than other parents about the welfare and safety of their young adult outside of family settings. Six parents felt it was important to be careful and cautious and shared safety is a concern of every parent for their child. All eight parents hoped for greater independence based upon their own experiences with their young adult and the significance of their disability. Overarching comments indicated that parents wanted their young adults to be as independent as they could be, dependent upon the environment and the experience (Parents 1, 2, 3, 5, and 8). "I'm a little better at letting go, because I've had to let go several times already. It's not easy" (Parent 1). "I do have more to worry about, but within that realm, let my young adult go as far as she can; the parameters are a little bit different" (Parent 2). Parents shared similar concerns to those of any parent of a young adult in wanting to know where they were, who they were with, and were they safe.

Parent 6 offered similar responses, however, clearly defined only certain areas of independence would be achieved by parent choice. Money was handled with supervision, shopping and cooking were monitored, and level of independence was

described as “guarded”. “Giving independence, guarded independence, I’m not gonna allow some things to happen in her life, somebody needs to take responsibility, and that is part of being her guardian” (Parent 6). Six parents expressed in similar terms the need for “guarded independence.” “Safety is primary, safety is a non-negotiable” (Parent 7).

One parent was more cautious than the other seven about the activities of her young adult. The responses could have been misinterpreted, without clarification, and taken out of context as controlling. This parent shared she was making a concerted effort to find a balance between overprotection and letting go as the young adult matured. She recognized the strengths and weaknesses of the young adult, and believed she had reasonable concerns for safety. “I am willing to let her take some chances, but not where I do not feel she would be safe; I see my role as her protector as something that will always be there” (Parent 7).

Safety concerns with public transportation varied across parents based upon their own experiences. Issues included the difficulty of making appointments, late pick up and drop off times, and overall safety of the individuals that use the system. “It is personal safety from both outside and internal influences within the public transportation system. You think with all you are hearing, that maybe a portion of it could be true, and even if a portion is true, we just aren’t going to be involved” (Parent 4).

Six parents admitted worrying about their young adult and how they spent their money, often making purchases without thought of consequences. Parents shared their



experiences with negative bank balances, and purchases made by credit cards that exceeded what they had been allotted to spend.

Fear of failure for their young adults, and knowledge of academic challenges, showed five parents in agreement their young adults would require intensive supports to succeed in academic settings. Parent 5 expressed, “although there may be a desire for postsecondary education, if academics is not a strength or interest, why push.” “It’s the nature of being a parent, to find it hard to see your child fail at something” (Parent 3). Five parents believed postsecondary education was not an option. “Reading levels would be too high” (Parent 2). “I have gone to Delaware Technical College, I have looked at the types of students that go there. I have looked around, not asking questions, just looking to see if that is the kind of environment I would like her in; the answer is no” (Parent 6). They recognized their son’s/daughter’s interests in perhaps wanting a postsecondary education experience, but realized they would most likely be the one to provide the supports. “I would have to go with her, and I just don’t know how I would find the time” (Parent 2).

**Encourager** – *One who inspires and gives hope*

The encourager may be a role birthed through the change from advocate while the young adult was in school, to the role of supporting greater independence in the postsecondary years. Parent 1 described her involvement as the encourager, the supporter; believing the balance came in knowing when support needs should be at the forefront of their role and when to fade supports. She stated, “It’s more allowing of his or promoting his independence; people tell me all the time that I shouldn’t be as hands

off as I am, but I know my son better than anybody else. People think that you have to ‘smother’, drives me crazy.” Other parents also expressed the beliefs that the young adult can and should make decisions about additional education if interested, be given as much independence as possible, and to know when to let go and step back, allowing for natural consequences and failures from which to learn.

Parents expressed they wanted nothing more than for their young adult to have a job, to be happy, to be treated fairly, and to live a full life. “I am pushing for the security of a job” (Parent 2). “I just want her to be happy whatever she does, and if she wanted to go be a ditch digger, then I would find a way for her to be a ditch digger” (Parents 5). “Having a job is wonderful for him, but has almost made him too independent, and he is hardly ever home” (Parent 8). “You know in a perfect world, there should be the same standard as everybody else, we are not in a perfect world, and if an employer agrees to hire an individual with a disability, then there should be two sets of defined expectations, to be fair to all” (Parent 5).

Having the opportunity to learn to drive, to be more autonomous was important to one participant who shared, “He has his driver’s license, but he doesn’t drive. He never asks for practice time, so my hope would be that by the time he’s mature enough to drive independently, he can experience that freedom” (Parent 3). Two parents were encouraging their young adults to take a driver’s course and test and learn for themselves if they have the skills required to get a driver’s license (Parents 1 & 2).

Parent 1 stated, “[I act] as a total cheerleader, if you will, and encourager in all things that he can possibly do, and not allow him to rest on his laurels.” Three parents

expressed their belief that individuals with disabilities want to meet expectations, and therefore they should not set limits, but encourage the young adult to reach goals and to achieve successes in their lives within the scope of their disability. They were realistic in admitting their young adults may require more encouragement in certain areas of their lives, but not in all. Four parents were very clear their young adults would need a lot of encouragement and support in pursuing postsecondary educational opportunities. The remaining four described their role of encourager as someone who is supporting their young adult in reaching out to friends, engaging in social activities, getting involved in their community, and learning how to become more independent with a 'can do' attitude.

**Provider** – *One who supplies something for sustenance or support*

Eight parents saw their roles as providers of shelter, food, and money. Four saw themselves as social secretaries, and they discussed the role of chauffeur - some part-time and others full-time. Two parents did all the clothes shopping for their young adult and expressed their young adults were not the least bit interested in selecting and purchasing their clothing. Parent 7 shared, "She hates shopping for anything, like clothes, she does not like to do it and is not interested." Parent 6 was very clear she and her daughter do not agree on clothing tastes, and said, "She likes it when I just go buy something, she hates shopping."

Five of the eight parents appeared to be comfortable with their young adult handling money to the best of their ability and learning from their mistakes. Parents

were cognizant of the limited income received by their young adults and felt they had to provide supplemental funds to cover typical expenses and medical care.

Five parents supported their young adult in making medical appointments, because it was more efficient or their young adult's disability prohibited them from making appointments independently. The writing of notes and supporting the young adult in delivery to their employer fell into the role of provider.

### **Influencing Factors and Change**

All eight parents expressed their roles as their young adult's advocate had changed in some way since exit from school. They responded their roles had changed and been influenced through the transition stages from early childhood to young adulthood. "My role has changed from learning how to be an advocate when he was young and applying what I learned to help him grow...to now learning how to let go" (Parent 3). Parent 8 shared, "I had to be more of an advocate during the early childhood years, and he went to a lot of different schools, so I had to help him." "I've always been her advocate, only now it's looking like we look longer term" (Parent 5).

They voiced concerns regarding what the future holds for their young adult: whether independent living would become a reality, would they date or get married, would they ever want children, and who would support them when they could no longer care for them. All eight parents believed their roles were defined by love for their child. Three parents shared "one size does not fit all" in describing how no two children are alike, and the ways in which you support one child, might be different than how you support the other child. Parents knew their young adults would have to

find their own way, but were unsure what that would look like as they continued to mature. “Needs have changed over the years, I’m not changing diapers, I’m not going to therapy sessions, or getting into more programs” (Parent 6). “When he becomes more independent, I can be less involved; I was much more avid and engaged in the young years” (Parent 3). “In the beginning, it was more centered around school, now it is different, she lives life and does things differently now” (Parent 7).

Parents 1, 2, 3 and 8 saw their roles in similar ways. For example, Parent 2 stated, “I was very involved in high school, now in many ways my role has kinda changed.” Learning to step back, allowing for mistakes and natural consequences, encouraging independence, and supporting as needed was a change in role from high school to postsecondary. “Social cues, executive functioning, social thinking are the biggest challenges” (Parent 3). This parent was supporting the young adult in driving alone, and one day living independently with minimal supports, and becoming less involved; “When he can work and perform daily living skills expected of an adult, then I’ll be able to remove myself from his day-to-day life.” Parent 1 encouraged her son to be more independent in day to day tasks, “If there is something needed for work, and he does not have it when getting to work, then a phone call to me is necessary, as opposed to sticking it in the backpack, making sure everything needed is there because I did it.” Some parents were less confident about their young adult’s capacity to become independent and saw a continuing need for significant supports. For example, Parent 7 stated, “My young adult can’t be independent, things she can’t

do, so whether I am doing those things or somebody else is doing those things, she is never going to have that level of independence.”

“While my role has changed, it’s still an important role, it never goes away, it changes with growth, and there are certain things that are none of my business anymore”, were examples of sentiments shared by all. None of the parents could think of anything that could influence or cause them to re-examine their roles as they saw them at that time. They confirmed their roles had changed from learning how to be an advocate when their young adult was younger and in school, to applying what they had learned along the way to help them grow. It was apparent these parents hoped for greater independence for their young adults, taking into consideration any limitations based upon the significance of their young adult’s disability. Overarching comments are paraphrased as “We want our young adult to be as independent as they can be” (Parents 1, 2, 3, 5, and 8). “I’m a little better at letting go, because I’ve had to let go several times already. It’s not easy” (Parent 1).

Parents indicated they had no prior preparation or knowledge as to the nature of their roles before going through the many transitions with their children. When parents were asked what information had been received regarding their roles, they were unanimous in their responses stating they had never received any education, training, or information as to what their roles should look like; either while their young adult was in school or as they were exiting. Parent 2 shared; “Zero, self-education. I educated myself on this whole trip.” Four of the participants admitted they turned to their own experiences and looked for support people and role models, admitting they

were not easy to find. “I don’t think we received any. I think it was non-existent because there were not any expectations that somebody like my child could succeed in that environment [education/work]” (Parent 4). Parents stated; “dumb luck”, “no one told us anything”, “absolutely nothing, no one told us anything about what our role would look like, from the very beginning.” All parents confirmed they had “no idea”, nor had anyone ever spoken to them about what their relationship was to look like when their young adult transitioned into employment or into postsecondary education programs.

Five parents admitted they read books, or asked others, and three admitted it was “trial and error”, “doing what they thought was in the best interest of their young adult”, and “the role is much harder now, because when she was little it was more like you take care of any small child.” Parents agreed they were learning to “pull back”, learning to “let go”, and in some areas, they would always remain in the role of protector. They admitted it had been a steep learning curve without a lot of support in preparing to “let go”. Parents with other young adults in the family appeared to have an easier time, having experienced them going off to college or moving away because of employment. Five participants described having other children move out or go to college influenced their role with their young adult with ID. Shifts in parent roles may be attributed to growth and the increased independence of their young adult, and perhaps a result of the lack of resources available to them postsecondary.

## **Chapter 4**

### **DISCUSSION**

The purpose of my thesis was to examine the phenomenon of parent roles in their continued efforts to support their young adult with ID in the postsecondary years. It was my intent to explore and better understand the potential impact their perceived roles may have had on postsecondary experiences. I was seeking to determine why parents have assumed these roles, to gain insight into any factors that might influence their roles and how they might have changed over time, and to explore any need for supports and resources.

#### **Four Major Roles**

In examining the results of the study, the parents who participated identified with four major roles: advocate, protector, encourager, and provider. They saw their roles as changing over time, shifting roles as their young adult matured or gained more independence. Parents' expressed the tensions and balance between the role of advocate and the roles of encourager and protector, based upon the strengths and weaknesses of their young adult and his/her life experiences. These results were similar to findings of Bianco et al. (2009), as parents reported their desire to find balance between the role of an advocate and determining when to give more responsibility to their young adult. Rueda et al. (2005) and Ryndak et al. (2011),



characterized parents as decision makers, evaluators, protectors, advocates, and role models. These studies also reported parents indicated additional resources and supports would be helpful in understanding their roles.

Parents described the advocate role as eliminating barriers and creating opportunities for their young adult. They expressed their concerns for the safety of their young adult, fear of them failing at something, and being taken advantage by others, resulting in the role of protector. The encourager, expressed by the parents, was someone who promoted their young adult's independence, and did not believe in setting limits. The encourager supported social relationships, getting out in the community, doing things for others, and development of a "can do" attitude. Providers saw themselves as personal shoppers, part-time chauffeurs and social secretaries, and the suppliers of food, shelter, and financial resources as needed.

### **Shifting Roles and Tensions**

The "letting go" of a young adult postsecondary does not come naturally to parents. Consideration should be given to the needs of the families, and how best to prepare them for this period of transition. Kraemer & Blacher (2001) found parents of young adults with severe mental retardation to be fairly satisfied with transition programming; yet unprepared to "launch" their young adult out of the home (protector), believing no one could care for them as well as the family.

The parents who participated in the study expressed they could see themselves shifting back and forth through the identified roles, from advocate to encourager back to advocate, or from protector to provider for the rest of their lives. Shifting from

advocate to encourager heightens in postsecondary years, as parents advocate for the young adult to be doing more of the work, resulting in more independent thinking. Parents may also encounter tension between roles. The growth and maturity of their young adult, along with their changing needs directly influenced the level of advocacy or protection required by the parent. If the young adult was capable of greater independence and had proved they could handle it, parents were willing to consider stepping back. Constant reality checks and trying to find balance between roles, such as when to act as the advocate, and when to act as the encourager were described as “balancing acts,” dependent upon the parent’s determination of what was in the best interest of the young adult. Dixon and Reddacliff (2001) characterized parents as struggling between encouraging independence and their need to keep their young adult safe; the encourager-protector dilemma.

The advocate and protector roles are discussed in Lindstrom et al. (2007) documenting parents’ admissions; “I do her checkbook for her”; “She talked about going to college, but it is not feasible for her because she has a disability”, “She needs to learn that I’m not always going to be there.” In 2002, Cooney examined parent perspectives on transition during their young adult’s last year of high school. The study supported parents’ concerns in wanting to keep their young adults safe, and emphasized the importance of them leading lives with some purpose.

In the study, parents disclosed they were the ones doing most of the transporting of their young adult, for convenience and concerns for safety, and share the role of both provider and protector. Parents expressed they could see themselves

moving in and out of provider and protector roles, as their young adult gains additional skills in time management, organization, executive functioning, and self-awareness, resulting in increased independence.

### **Changes Over Time**

Parents saw their roles as changing over time. They described different ways in which they supported their young adult in their postsecondary years and how those roles were influenced during the postsecondary years. Learning to step back, allowing for mistakes and natural consequences, encouraging independence, and supporting only as needed were changes in roles from high school to now. By supporting their young adult in learning to drive and preparing them to one day live independently, they shared their roles as protector and provider would change. They recognized they would be less involved on a daily basis as their young adult's level of independence increased over time.

They believed their young adults' level of independence was dependent upon the significance of their disability; individual strengths and weaknesses, ability to recognize when they might be taken advantage of, and the ability to recognize when they were in unsafe situations. The parents in the study expressed they have struggled in knowing how and when to back off, or let go, and in attempting to find balance in that role while encouraging increased independence. They described their young adults as being independent in some areas of their lives, but only one parent described their young adult as being almost totally independent. Life skills such as cooking, making their own appointments, scheduling transportation, and knowing the value of

money were concerns the parents shared as to why they assume the roles of protector and provider. Parents' experiences with having other children grow up and move out of the home also were influencing factors in preparing them for "letting go", and "stepping back." They also uniformly indicated that they had received no formal preparation or guidance about how they might fulfill those roles.

Their roles may vary dependent upon the significance of their young adult's disability, but dependent upon the particular tasks or activities in which they are engaged. Parents' very real concerns for the safety of their young adult are not without reason, and supported by their concerns for the welfare of their child. Parents providing shelter, shopping for clothes, not permitting the individual to use a stove, and handling their young adult's monies may not be considered 'controlling', but are roles parents assume due to the perceived inabilities of their young adults to handle those tasks independently. Definitions of independence, whether "guarded" or "within reason" is dependent upon so many variables, and what might appear to be independence for one young adult might look very different for another young adult.

### **Value of the Parent Perspective**

My perceptions of parent roles had been based upon observation and experience, and in my desire to verify "what I thought I knew", the study opened my eyes to another way of looking at parents of young adults with ID. Through conversations and meetings with parents, I was aware of barriers, parental over protection, real concerns, and fears. However, the results of the study showed me a different way of looking at parents.

It is valuable to understand parent roles from parents' perspectives to gain a better awareness of their universal concerns. Insights into how their young adult's disability impacts their roles and in what settings, and the identification of causations for any change in roles over time, provides a basis for better understanding how best to support parents in the postsecondary years. It is important to recognize when engaging and working with parents how their roles in some ways are no different than those of a parent of a child without a disability. Their young adult does not desire to be "parented" or treated any differently than anyone else.

### **Implications for Practice**

Parents in the study shared that the limited amount of information and resources available to them in the postsecondary years had sometimes made it difficult for them to be certain of their roles and how far to go in transferring control over to their young adult. They explained they did not receive information from their respective schools as to future opportunities for their young adult and had received no preparation or guidance for their roles post-school. No one taught these parents about the role of an advocate.

While the young adult is still in the school system, state agencies, educators, and professional practitioners for young adults with ID should consider providing parents with the education and resources to support them in preparing for the postsecondary years. The study, although a small sampling, supports further examination into the need for parent education prior to the time a young adult exits the school system. Choices made and preparations for adult life as a young adult leaves

the school system are decided are influenced and decided within the family (Morningstar, Turnbull, & Turnbull, 1995; Whitney-Thomas & Hanley-Maxwell, 1996). Parents have voices, and we need to be listening. They are powerful influences in the lives of young adults with ID and influence postsecondary outcomes (Davies & Bemish, 2009; Doren et al., 2007). The more educators and key stakeholders actively listen to parents and acknowledge a basic understanding of their roles, the greater the opportunity for collaboration, engagement, and trust. In seeking successful outcomes post-school, it would be beneficial for schools to provide adequate information about postsecondary education and vocational training options to parents, before exiting the system.

Pleet and Wandry (2010) described the importance of partnerships with families during the transition years as being critical to the successful outcomes of these young adults, and stated if educators do not embrace parents as collaborators, instructors, decision makers, and peer mentors, there will be little improvement in postsecondary outcomes. Parent to parent programs, model demonstrations projects, and the development of informational materials would be a recommended next step from the findings in the study. “Parents who have been mentored often go on to mentor other parents” (Pleet & Wandry, 2010, p. 103). Engaging parents in telling their stories, examining how best to serve and support them, and providing opportunities for them to gain knowledge about their roles would be a natural next step for professionals.

## **Implications For Research**

The findings of the study were consistent in both themes and commonalities with other research on the roles of families across major life periods. Bruder (2010) recognized the importance of the role of the family during the early years and their role as caregivers. Families of young children receive supports and benefits through intervention services preparing children to be ready for the school years (Dunst, 2007). The school years offer insight into slight changes in parent roles as they move from caregivers to advocates and decision makers (Saaltink et al., 2012; Whitney-Thomas & Hanley-Maxwell, 1996). Research examining family involvement and influence on postsecondary outcomes (Davies & Bemish, 2009; Griffin & Hodapp, 2010; Morningstar et al., 2010) has been well-documented. However, documented research over the past twenty years exploring the roles of parents, described by parents, and the specific impact of these roles on young adults with ID, has been limited. Doren, Lindstrom, and Miesch (2011), in addressing employment outcomes for young adults with disabilities, determined family factors are worthy of further study.

Families have a clear influence on career development and successful employment outcomes, however, relatively few studies have explored the role that families play in influencing postsecondary employment (Lindstrom et al., 2007).

There have been similar findings to the ones in the study. Rueda et al. (2005), found parents to have roles as advocates and protectors. Parents are unprepared and uneducated in preparing to “let go” of their young adult post-school (Kraemer & Blacher, 2001). The tension between the role of protector and encourager was

similarly characterized by Dixon and Reddacliff (2001). This study adds to the limited research that is available about parent perspectives, from the parents' point of view, during the postsecondary years. Further studies are needed to better understand their postsecondary roles and under what conditions those roles have developed, and during what period of time might they initially begin to change.

There remain many unanswered questions. How have these roles developed over time? When did the roles emerge and during what time periods? How different might the roles look in other cultures, in examining a more impoverished or less educated population? What could professionals be doing differently to better prepare parents for their roles in the postsecondary years? How might schools go about better engaging and preparing parents for the postsecondary years? Would the development of resources focusing on the postsecondary years and parent education programs during this time period make a difference?

Additional research would support professionals working with parents and families to better understand their roles, identify the needs of these individuals in the postsecondary years, and develop programs to support them.

### **Limitations**

A sampling of this size and one of convenience does not give full representation of the many challenges parents are faced with during the postsecondary years, nor does it reflect perspectives which might look very different within more diverse populations of cultural, marital, and socioeconomic demographics. The participants in the study were all white, upper middle class, and educated parents. This



demographic, in itself, is limiting. It is not a fair representation of the demographics in Delaware or in the surrounding states. It did not provide a sampling representative of diversity in ethnicity, culture, socioeconomic status, and education.

The study was exploratory and was not intended to identify generalizable findings, as the participants' demographics represent a fairly narrow demographic. Therefore, even for an exploratory qualitative study, the transferability of the findings may be limited. Findings were dependent upon the perspectives of individual informants within a family, and different responses might have been received from other adults in the family. Also, because several participants were familiar with my professional role, they may have reported what they thought I wanted to hear in a response. They may have been telling a story quite different from their actual experience. My own understanding of parents through my career may have resulted in opinions and prejudices and interpretation of the data with bias. My goal was to increase my knowledge and awareness of parent perspectives from their point of view. Therefore, I made every effort during the analyses to minimize influence of my experiences and highlight the experiences of the parent participants in their own words.

Despite the study's limitations, the perceptions of these parent participants may have value for professionals and other parents who wish to broaden their understanding of the experiences of some families who continue to support their young adults post-school.

## **Conclusion**

Parents within the study saw the family as the major source of support for their young adult with ID. They offered compelling insights into the lives of their young adults and clear explanations of their views of their young adult's postsecondary life skills and abilities. Parents of young adults with ID in the postsecondary years identified their multiple roles as advocate, protector, encourager, and provider. Parents expressed awareness of shifts and tensions between the roles and acknowledged their roles had changed over time based upon the changing needs, growth and maturity, and level of independence of their young adult. Parents' experiences with having other children move out of the home, get married, or leave for college were influencing factors in preparing them for their roles in the postsecondary years. The study suggests that as young adults with ID mature and their level of independence increases, the roles of their parents has the potential to change.

Educators, service providers, and state agencies should acknowledge parents' perspectives on their roles and work collaboratively to develop and implement programs that support them with the resources and guidance they need in the postsecondary years. Partnering with parents is essential if we expect to see increased outcomes in both employment and participation in postsecondary education programs. Additional research is needed to look at the factors influencing parent roles and to compare and contrast differences within a more diverse population. Hearing directly from the parents as to the challenges they face and the types of support they are seeking would help guide the development of parent education programs and the

provision of support and resources. A better understanding of the roles of parents of young adults with ID during postsecondary transition has the potential to inspire a dialogue for system change, and to substantiate the creation and implementation of new programs.

### **Parent Advice to Other Parents of Young Adults with ID**

At the conclusion of the interviews, parents were asked if they had any advice to offer other parents of young adults with ID to support them in their transition into the postsecondary years. The statements summarize their hopes, intentions, and recommendations for other parents who are seeking to understand their roles as advocates, protectors, encouragers, and providers. Their responses are as follows, without identifiers:

*I would tell them to accept their child the way they are.*

*Don't let anyone influence how you view your child, don't go and try and compare them to others.*

*To listen to our children. To let them lead the way. Let them show us what they are able to do, then step back, and let them.*

*If they are going to fail, let them, but remain supportive. Work towards as much independence as you can. Don't set any limits.*

*People want to meet expectations. If you set limits, you may be understating what the person can achieve.*

*Families need to be engaged, and that is one thing we sadly have not seen throughout the whole process of my daughter being in school.*

*Let them make mistakes, so they can learn to do it differently.*

*One size does not fit all.*

*My role is tempered with love. What works for one individual and is right for them, may not be right for another.*

*With a normal child, your role diminishes, and while my role is changed, it's still an important role and it will never go away.*

*You have to allow room for growth and there are certain things that are none of my business anymore, and you know, you learn to keep your mouth shut.*

*Don't hesitate to advocate as needed, or as may be required, but only if you are asked to by your young adult!*

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## **Appendix A**

### **PARENT QUESTIONNAIRE**

#### **Demographic Questions**

1. Name of participant
2. Employment, level of education achieved, family income range
3. Marital status – choice of M, S, D, other
4. Number of children, number of children with disabilities
5. Ethnicity
6. Name of young adult
7. Age of young adult
8. High School young adult attended
9. Graduation date, diploma or certificate, participation in 18-21 year old program, where and for how long?
10. Employment history of young adult, if employed, where and for how long; if no longer, where, for how long, and reason for unemployment?
11. Postsecondary education, where and when
12. Postsecondary training, where and when

## **Family Questions**

1. How would you describe your role during your son's/daughter's time in high school?
2. How has your role changed since your son/daughter exited the school system?
3. In what specific areas do you see you son/daughter as being independent?
4. How do you see your role in planning and preparing for postsecondary education?
5. What are your son's/daughter's career or postsecondary goals? How do these align with your career or postsecondary goals for your son/daughter?
6. What do you think your role will look like (or what is your role) when your son/daughter is enrolled in a postsecondary education program?
7. What information have you received as to the nature of your role once your son/daughter is enrolled in a postsecondary education program?
8. How do you think your son's/daughter's support needs might impact their postsecondary experience?
9. If your son/daughter is or has been in a postsecondary education program, what is or was the nature of your relationship with the program?
10. How would you describe your role during your son's/daughter's employment, or during their search for a job?
11. How do you think your son's/daughter's support needs might impact their job?
12. What information have you received, or did you receive as to the nature of your role with employers once your son/daughter was employed?
13. If your son/daughter is or has been employed, what is or was the nature of your relationship with the employer?
14. How do you believe arrangements for time off, absences, medical appointments, and vacations should be handled with your son's/daughter's employer or postsecondary program?

15. Do you believe “special considerations” should be offered by an employer or postsecondary education program in working with an individual with an intellectual disability? If so, what does that look like to you?
16. Who arranges for your son’s/daughter’s transportation to and from school/work? If you provide transportation, please explain why? If not, what is the mode of transportation?
17. Who manages your son’s/daughter’s income, monies? Please describe what that looks like.
18. What is your understanding of “natural consequences” in the workplace? In a postsecondary education program?
19. What other information should I know in order to best understand your role in your son’s/daughter’s post-transition experiences?
20. What advice would you give to families/guardians about supporting the post-transition experiences of their son/daughter who has ID?

#### **Questions Added Post Personal Face to Face Interviews**

21. Do you think your role has changed at all through your son’s life transitions?  
From diagnosis to early intervention, to middle school, and out of high school?
22. Do you think your level of advocacy has changed over the years?
23. Is there anything you can think of that could influence or lead you to re-examine your role as it is now?
24. Do you ever see your son living independently and what might that look like?

**Appendix B**  
**IRB APPROVALS**



DATE: December 21, 2011  
TO: Wendy Claiser  
FROM: University of Delaware IRB

STUDY TITLE: [290885-1]  
Understanding Parent/Guardian Roles with Young Adults  
who have Intellectual Disabilities during Post-School  
Transition

SUBMISSION TYPE: New Project

ACTION:  
APPROVED APPROVAL

DATE: December 21, 2011

EXPIRATION DATE: December 20, 2012

REVIEW TYPE: Expedited Review

REVIEW CATEGORY: Expedited review category # 7

Thank you for your submission of New Project materials for this research study. The University of Delaware IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a study design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received Expedited Review based on the applicable federal regulation.

Please remember that informed consent is a process beginning with a description of the study and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the study via a dialogue between the

researcher and research participant. Federal regulations require each participant receive a copy of the signed consent document.

Please note that any revision to previously approved materials must be approved by this office prior to initiation. Please use the appropriate revision forms for this procedure.

All SERIOUS and UNEXPECTED adverse events must be reported to this office. Please use the appropriate adverse event forms for this procedure. All sponsor reporting requirements should also be followed.

Please report all NON-COMPLIANCE issues or COMPLAINTS regarding this study to this office. Please note that all research records must be retained for a minimum of three years.

Based on the risks, this project requires Continuing Review by this office on an annual basis. Please use the appropriate renewal forms for this procedure.

DATE: November 30, 2012  
TO: Wendy Claiser  
FROM: University of Delaware IRB

STUDY TITLE: [290885-3]  
Understanding Parent/Guardian Roles with Young Adults  
who have Intellectual Disabilities during Post-School  
Transition

SUBMISSION TYPE: Continuing Review/Progress Report

ACTION:

APPROVED APPROVAL

DATE: November 30, 2012

EXPIRATION DATE: December 20, 2013

REVIEW TYPE: Expedited Review

REVIEW CATEGORY: Expedited review category # 7

Thank you for your submission of Continuing Review/Progress Report materials for this research

study. The University of Delaware IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a study design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received Expedited Review based on the applicable federal regulation.

Please remember that informed consent is a process beginning with a description of the study and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the study via a dialogue between the researcher and research participant. Federal regulations require each participant receive a copy of the signed consent document.

Please note that any revision to previously approved materials must be approved by this office prior to initiation. Please use the appropriate revision forms for this procedure.

All SERIOUS and UNEXPECTED adverse events must be reported to this office. Please use the appropriate adverse event forms for this procedure. All sponsor reporting requirements should also be followed.

Please report all NON-COMPLIANCE issues or COMPLAINTS regarding this study to this office. Please note that all research records must be retained for a minimum of three years.

Based on the risks, this project requires Continuing Review by this office on an annual basis. Please use the appropriate renewal forms for this procedure.