Parents' Perceptions of Postschool Years for Young Adults With Developmental Disabilities

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Abstract

This qualitative study investigated parents' perceptions of the various roles they played in their adult children's lives during the post–high school years. Individual face-to-face interviews were conducted with 9 families of young adults with developmental disabilities. Findings indicated that families perceived the complexity of their roles as balancing between advocating for their adult children's needs while promoting independence and self-determination. The roles parents assumed as their children entered into adult life were those of collaborators, decision makers, and program evaluators, role models, trainers, mentors and instructors, and systems change agents. Parents often felt they were the safety net for their children and the back-up plan for service agencies. Parents' quotes illustrated the complexity of the roles they played as their young adult children with developmental disabilities entered adulthood.

Entering adulthood is a time of transformation for young adults and their families. This period of time is frequently met with excitement, enthusiasm, and some stress. Most young adults learn how to navigate their freedom and independence and take on more responsibilities while relying less on their families for supports. As typical young adults approach the age of 21, parent involvement and control over their lives generally fade as these young adults take on more responsibilities that previously had been managed by their parents (Tobin, 2003). For individuals with disabilities, this period of time is usually quite different for them and their families. Instead of breaking ties with their family support system, young adults with developmental disabilities may find themselves even more dependent on parents to help and offer supports (Lloyd, Wehmeyer, & Davis, 2004). For many parents of young adults with disabilities, involvement in their child's life does not diminish on the 21st birthday. In reality, their involvement increases in level and intensity for an extended and somewhat uncertain amount of time (Brotherson, Berdine, & Sartini, 1993; Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995). The families

involved in Tobin's (2003) study perceived that they were involved in as "a continuous process of planning, implementation, observation, evaluation and balancing the details of their own lives (e.g. careers, use of financial resources) with those of their son's or daughter's, to ultimately achieve a integrated quality of life for the entire family" (p. 143). Although parents recognize the central role they play in the lives of their young adults (Rueda et al., 2005), they are not always prepared for the intensity or complexity of their involvement.

Researchers have explored parents' concerns related to various aspects of the school to adult-life transition process for their children with disabilities. Cooney (2002) explored multiple perspectives of the transition process, including those of parents. In this qualitative study, Cooney discussed parents' feelings of powerlessness during high school transition meetings and helplessness when faced with unfamiliar procedures and unexpected barriers in the adult service world. Parents expressed apprehension and fear associated with learning how to navigate through adult agency support systems and frustration with the inability to secure necessary

supports in a timely manner. Parents were also concerned that the postschool program options discussed during transition meetings did not parallel their child's full capabilities.

Other researchers have identified similar parental concerns. Specifically, these concerns include (a) identifying residential living options, (b) determining available employment opportunities, (c) locating and planning for social outlets for their adult child, and (d) finding available agency assistance (Chambers, Hughes, & Carter, 2004; Cooney, 2002; Hanley-Maxwell et al., 1995; Whitney-Thomas & Hanley-Maxwell, 1996). According to Whitney-Thomas and Hanley-Maxwell, these legitimate concerns "mirror the areas of need and problematic outcomes identified in the literature" (p. 84). Parents' dilemmas are exacerbated further by the limited resources in the adult service system. As a result, extra demands are placed on parents as they end up filling in the voids that exist (West & Fuller, 2006). The complex nature of parents' roles as their children leave the school system has been described as a linchpin or case manager (Timmons, Whitney-Thomas, McIntyre, Butterworth, & Allen, 2004). Parents are often confused and concerned about what role they play or will play in helping their child access needed supports (Cooney, 2002).

Given the intensity of parental involvement (Timmons et al., 2004) and obvious concerns for their young adult children's outcomes, additional information is needed on the roles parents fill after their child has exited the school system. Although there is an adequate body of knowledge regarding parents' perspectives during the transition process, less is known about parents' roles in the post–high school years. Having more insight into parents' experiences during this critical period would help secondary educators, transition coordinators, and adult service providers understand the gaps parents currently fill in supporting their children and the resulting needs of both the systems and families. A deeper understanding of the multifaceted roles parents assume may foster meaningful collaborations between parents and service providers and highlight the need for professionals to better prepare parents for the future that awaits them.

The purpose of this study was to solicit parents' voices to provide a better understanding of parents' experiences and perceptions of their roles during the post–high school years for their children with developmental disabilities. This qualitative study entailed interviews of 9 parents and revealed their perceptions of this phenomenon.

Method

The qualitative approach used was phenomenology. *Phenomenology* is the study of the meaning people ascribe to events they experience (Moustakas, 1994). In phenomenology, the researcher is committed to understanding the social phenomena of participants' experiences. The phenomenon of interest was the transition from mandated public educational services to adult living as experienced and perceived by parents of young adults with cognitive disabilities.

In phenomenological inquiry, the researcher has a personal connection to the social phenomena being investigated (Creswell, 1994; Moustakas, 1994). In this study, the researcher's (R. T.) personal connection to this inquiry was as a parent of a young adult with intellectual disability who has experienced transition from school to adult living. Her credibility was increased by the fact that she had also been employed as a community service–based parent advocate.

Participants

A process of purposeful sampling was used to secure names of participants for the study. The developmental disabilities adult services system agreed to mail a packet to families who met the criteria of having young adults who had graduated or "aged-out" of educational services between 2 and 5 years prior to the study. The packet contained a letter of support from the agency director, a study abstract, an invitation to participate in the study, and a return form indicating willingness to participate in the study. Forty-nine families were identified whose children met the criteria; 26 families agreed to participate; however, only 9 families were available for interviews during a 6-week period. Table 1 illustrates a summary of the demographic information about the participants and the young adult child they described. Pseudonyms were used to protect the identity of study participants.

Four of the families had sons and 5 had daughters labeled as having intellectual disability. These young adults were eligible for and engaged in the adult developmental disabilities service system. Although the disability labels were the same, it

Table 1 Demographics of Participating Families

Parent name(s)	Young adult's name	Gender	Age	No. of siblings	Place of residence
Carla M.	Jeff	M	24	1	Group home
Teresa S.	Janelle	F	27	1	Host home
Carolyn H.	Monica	F	25	5	Lives with parents
Michelle K	Alex	M	26	1	Host home/parent owned
Helen R.	Deborah	F	26	0	Host home/parent owned
Ann S.	Lucy	F	26	1	Host home/parent owned
Rachael and Mark W.	Paul	M	24	3	Group home
Joyce H.	Sue	F	27	1	Host home
Karen J.	David	M	25	1	Apartment with supports

became clear during the interviews that the young adults demonstrated a range of abilities and required varying levels of supports. For example, some of the young adults required extensive supports to live in a supported living environment and needed assistance and monitoring for most aspects of their lives (e.g., cooking, shopping, medical care, money management, household maintenance, organizing recreational activities). Several of the other young adults required more intense, pervasive supports, including having another person actually do daily living tasks for them (i.e., cooking, dressing, grooming, shopping).

The young adults' mean age was 26 years old. All were employed in a vocational facility that provided both sheltered employment and supported employment options. In terms of residential settings, 1 of the young adults was living with her parents, 5 lived in host homes (i.e., foster care with no more than three consumers in the home), 2 lived in group homes with three other consumers, and 1 lived semi-independently in an apartment.

Three of the families were single-parent households and the other 6 were two-parent households. The parents engaged in a variety of occupations, including owning their own businesses, accepting employment in a community business, and working in the field of education and in the health care profession. The average level of education for both mothers and fathers was slightly higher than the average reported for adults in the state where the study was conducted (i.e., Colorado; U.S. Census, 2000). All of the parents had completed at least a high school education and most had some college education. The median income level of the participants was between $60,000 and $80,000 per year. Eight of the 9

families had other children in addition to the focus individual. All were Caucasian, monolingual English speakers living in a small city with a population of 125,000.

Data Collection

Data were collected using face-to-face, semi-structured interviews. As illustrated in the Appendix, open-ended questions and associated prompts were developed to elicit parents' responses around themes of experiences, types of supports needed by their young adult child in various settings (home, work, social), parents' roles in providing supports, typical daily schedules, resources needed and the people who provided them. For example, participants responded to the query, "Tell me about your experiences as a parent since your son/daughter exited high school?" For this question, prompts included, "In what ways are things the same as when your son/daughter was in high school and in what ways are things different?" Both parents (if it was a two-parent household) were invited to participate in the interviews although only 1 of the 6 fathers chose to do so.

The researcher interviewed each of the 9 participants one time. She had no prior relationship with any of the participants. Interviews were audiotaped and lasted approximately 90 min each. The audiotapes were transcribed verbatim, resulting in 174 single-spaced pages of data. Data analysis techniques involved inductively sorting participants' transcribed perceptions into codes, following a process described by Patton (1990). In the first phase of analysis, each interview was reviewed line-by-line and key phrases, short stories, and coherent thoughts were bracketed into 70 distinct segments. Data segments across all interviews that touched on

similar topics were clustered together and given a thematic name, reducing the data to 28 codes. For example, these codes were sorted by the interview questions they addressed so that the researcher could analyze the answers (Miles & Huberman, 1994). Ideas that were found in multiple responses across all of the questions became five broad themes (i.e., involvement, vision for their children's future, relationships, school system issues, and adult service issues). This article focuses on one theme: parents' perceptions of their roles when their children completed high school.

Several steps were taken to address researcher bias. The researcher used HyperRESEARCH (ResearchWare, 2000) management software to assist with data management and to create an audit trail. In addition, the researcher kept field notes of observations and interpretations at the time of the interviews. These notes were later used to clarify any vagaries found in the interviews. The researcher disclosed to participants that she is the parent of a young adult with developmental disabilities. She also shared her beliefs about the need for inclusion and the value of promoting individual's self-determination. Two researchers familiar with qualitative methodology were also asked to review data coding and reach consensus regarding data categorization and identification of themes (Gliner & Morgan, 2000). Trustworthiness and transparency were further assured by asking participants to review the "parent involvement" theme (i.e., member checking) and comment on its veracity. All the participants reviewed the interviews; participants' responses indicated that their perceptions had been captured.

Results

Parents' responses to the interview questions shown in the Appendix captured their perceptions regarding the roles they played in supporting their children in the post–high school years. The participants perceived they had few opportunities to learn about the new roles they would play after their children graduated or exited high school and, therefore, felt poorly equipped to deal with a heightened level of responsibility and the realities that awaited them. Parents described an increase of intensity with regard to time, effort, and the complexities of their post–high school involvement in their children's lives. Consequently, parents reported feeling stressed, anxious, and fearful in

performing these roles. One parent stated, "Everybody is different but with a handicapped child the transition is much different than when your regular kids leave. It's much more drawn out. You worry about them at a different level." Similar to Kraemer and Blacher's (2001) study, these parents discussed the lack of available adult service options after their child left school. This is evidenced by one parent's statement, "But then she graduated and then they had no place for her—She was on a waiting list. And so she was home with me for about 4 months."

The roles articulated by the participants in this study match and confirm those conceptualized by Wandry and Peet (2003) as, "Parents as collaborators; parents as decision makers and evaluators; parents as role models, trainers, and mentors; parents as instructors; parents as systems change agents" (p. 12). Each role is described and illustrated with parents' quotes. The categories of trainer and instructor have been collapsed because these roles are similar in context.

Parents as Collaborators

Collaboration refers to establishing partnerships based on a common vision (deFur, 2003), parity, and trust (Friend & Cook, 2007). In the current study, parents described their need and desire to establish collaborative relationships with adult service agencies and direct service providers. For parents, establishing these relationships was critically important to ensure that existing service gaps were filled and that the young adult's needs were met, thus providing a sense of relief for the family. In some cases, the collaborative partnerships were successful, whereas in others they were not.

Parents viewed successful collaborations as trusting relationships that offered support and a shared concern for their adult child. One parent described how her relationship with her son's employers offered a sense of support and relief when they noticed and responded to her son's signs of ill health.

Yes, he's worked there for 6 years, when they first opened. It's really cool cuz the people at work also kind of are caretakers for him. Cuz when he's not feeling well, when he wasn't feeling well, they said "we're concerned about David."

Parents appreciated relationships that felt like extended family. For example, 1 parent described how her daughter was included in the provider's family celebrations.

And oh and there's, yeah—usually there's something—like next week is Polly's (granddaughter) birthday so then there's always the big birthday parties and she always goes to all the families' things like that.

Many parents in this study did not always feel that their relationships with agencies and service providers were welcomed or collaborative. In fact, as expressed by this mother, parents did not feel listened to.

Sometimes I feel as though in dealing with the different agencies; in dealing with people at BB [adult service agency], at DD [adult service agency] or even dealing with her own provider, that I am viewed as either being too lackadaisical about things or not really being as concerned as I should be, or just plain dumb.…I just want to go up and shake people and say, "You know I carried this child in my body. I've been with her for all of this time and we've been through a lot and by golly I think I know how she is going to react to situations or how she's going to cope with this or you know, please listen to me. I'm not just talking through my hat."

For other parents, establishing collaborative relationships with service providers proved difficult because of high turnover and constant change. This was a common complaint and cause of frustration that filtered many discussions. The rapidly changing support staff meant parents had to deal with the unpredictability of having to be available at all times to act as back up anytime paid support persons quit or were unavailable. This sentiment was clearly expressed by 1 parent: "So whenever someone didn't show, then I was on call. Plan B—I was Plan B." Another parent expressed her frustration with rapid turnover and described her experience in this way:

Well, again, we got hit with that staff turnover type deal. Some lady came out and interviewed us and then quit 2 weeks later. Right, we always had somebody different. The whole SLS [supported living services] experience was horrible for the same reason. We dealt with 3 different people in that short amount of time; Three different ones for Paul because of the turnover.

Many parents also expressed concern regarding how constant change precluded their adult children's ability to form trusting relationships with support providers.

Yeah, and here we are trying to hire people to become his friends and he doesn't understand that they're still employees and they have to live by those rules and not the rules of friendship. It's just so hard for him to understand…He had a couple of helpers but the helpers never stay very long. You know two or three months and then they moved on to something else.

This sentiment was expressed again by another parent. "And she [Sue] got so lonesome [living in

her own apartment] and of course when you have to rely a lot on providers, it just doesn't work because they come and go so often."

Parents articulated that service providers did not fully appreciate the value of their contributions as collaborators; however, it seemed clear to parents that service providers depended on them to fill in the gaps. Parents frequently spoke about the unpredictable nature of having to readjust work schedules or having their personal lives in flux, while acting as back-up support to provide direct care. These activities were not perceived as collaborative by parents, because when and if parents stopped performing them, the services would end. Parents expressed concerns that their roles were dictated by the reality that the adult service system was fraught with the rapid turnover of part-time workers.

With each change in personnel, parents had to help new staff learn how to care for their adult child. When service providers were not available, parents had to provide direct care themselves. In these roles, parents had to act as instructors, trainers, role models, and mentors.

Parents as Instructors, Trainers, Role Models, and Mentors

Kolb (2003) referred to parents' potential to act as trainers, role models, and mentors for other parents. In our study, parents did not describe their influence on their peers but talked instead about how they provided instruction, training, and supervision for their adult children and service providers. Families spoke about taking on a variety of roles in response to situational needs such as acting as case managers and providers of direct service through a variety of activities, such as developing opportunities for work or recreational activities, monitoring daily events, supervising the handling of bookkeeping and paperwork required by adult service systems, and specific supervision and training of personal attendants.

Parents spoke about their roles in teaching their children job-related skills. For example, 1 mother spoke about being a job developer and job coach for her child: "I was the main support [for a job] and I'm also the main reason why we're not doing it still. Because it became unwieldy and I did not have enough time to be that support person."

Another parent spoke of her need to keep constant vigilance over the day-to-day concerns for her daughter:

When she was home in her apartment, every night at 9:00 she would call me. And we would go through the list. "Now did you lock your door? Did you check behind the door?" Every night. And if I called her and said "you know I'm going to bed early tonight," it didn't matter. She still called at 9:00. It was such a routine.

Parents also reported the need to closely train and monitor service providers. Their concern stemmed from their perceptions that the service providers were usually young, untrained people who did not stay with their jobs for long and did not really understand how critical their support was for the young adults. Every family had stories about service providers who did not show up when scheduled and the problems that ensued as a result. One mother expressed her frustration by stating, "And that's the part that was really hard to get them to understand. 'It's an hour. I'm only here for an hour.' Yeah but, that's an important hour for Sue."

Similarly, another parent talked about her need to supervise and train providers with important financial bookkeeping tasks.

And then as far as supervising—I made sure that they did what had to absolutely be done. Like send in pay stubs into SSI or things like that. Things that couldn't be passed over from one week to the next. Some of it you kind of let slide, but a lot of it, you can't.

One mother spoke of her involvement in providing specific training for attendant care and her sense of relief when she was able to find a housemate to take on her role as a caregiver and provide the same level of care she once provided. "At any moment it could crumble away but since the beginning of February, Deb has had the most excellent, excellent housemate who moved in and she's responsible. She's actually me Monday through Friday."

In some cases, providing support was short term; however, for many parents, the level of support they provided was intense and required long-term commitment, as illustrated in the following account: "Our weekend person, so-called anyway, was hired at the beginning of the summer but couldn't begin until August 1. So I've been the weekend person still."

Although parents did not discuss their roles as mentors for other parents, they clearly saw the need for peer mentors and role models (Kolb, 2003) to help navigate their roles. For example, when asked what advice they would give other parents in a similar situation, this mother statement summarized what many parents shared:

Watch and see what other people are doing who have family members who have a similar profile. To look for mentors…. it's like seek out, find those examples that can show you what those possibilities are. Why would you try so hard if you always thought it was always going to be just like this? So seek out those stories, make connections with—it doesn't take a lot of people—it only takes one who can show you your possibilities.

Parents as Evaluators and Decision Makers

Clearly, a critical role for parents was to make decisions and to monitor the quality of services provided to their children. In schools, this role is associated with accountability in the individual education planning process and school monitoring (e.g., school improvement teams; Schoeller & Emanuel, 2003). In the role of evaluator and decision maker, parents will generally rely on their experiences about what has worked and what has not worked for their child (Schoeller & Emanuel, 2003). Participants in this study perceived evaluation and decision making to be tied directly to their child's daily activities: "Well, we're there anytime there's a decision to be made. Anytime there's a new caseworker, or payroll or the checkbook things. So we're, still there to support her anyway that she needs it."

As evaluators and decision makers, parents had to constantly assess the match between their child's needs and the care they needed or the quality of care they were receiving. One mother described a situation in which the person providing support had limited understanding of her daughter's emotional needs, and, as a result, the mother had to decide if a new support person was needed.

She [Lucy] is a very emotional person. Always has been and I think always will be. And I think this is part of when we have run into problems with our host home situation, it's been on an emotional level…And we are sort of at the point now of trying to determine if perhaps her provider is still going to be a good provider for her or perhaps it's time to find someone new.

Several families described the need for frequent evaluation of their child's adjustment and making important decisions based on their judgments. The following quote represents how 1 parent's evaluation of her daughter's living arrangement led to the decision to look for a host home:

She had lived on her own for four years in an apartment and that was with supported living services and that took a lot of effort on my part to help her maintain that. Even with the supported

living service—I mean we tried 20 some hours with that—and that did not work. It was just too many people in our life and lack of consistency and so I finally made the decision to go for the host home.

Parents found themselves responsible for identifying, anticipating, and planning for services their children would need as they moved into more independent living situations. Planning, in this situation, meant understanding the constraints of adult supports. For example, because residential opportunities are scarce in this time of large waiting lists, parents planned for and created alternative residential placements. Three families in this study invested in homes for their young adult children to live in. With the location secured, these families were able to concentrate on bringing the appropriate supports to their young adult. In doing this, parents found themselves in new roles: ones in which they had to advocate for needed services, relinquish some control, and nurture self-determination and self-advocacy in their adult children.

Parents as Systems Change Agents

Parents discussed situations in which they had to advocate for required services. They also advocated for their sons' and daughters' independence from them. As advocates, parents actively monitored services and then requested changes and modifications in services based on their adult child's needs. Parents described the fights and battles they engaged in with adult agencies to obtain needed services. They worked to obtain employment, more and or different services, and fought when their children were denied what parents perceived to be critical support. The terminology used to describe these situations was often adversarial as shown in the following representative quote:

When he first went to "BB" [adult service agency], he was very unhappy because they had him in like a basic skills type classroom. They didn't go anywhere and he was just tied up in that classroom. They warehoused him and he did not like that…we had to fight—push them into getting him into a community program and so gradually we got him out a few hours a day. And now he's out pretty much most of the time.

Parents described the post–high school years as a time when they were striving to release some of their parental roles by advocating and supporting their sons and daughters in making their own decisions and choices. Along with parents' relinquishment of control came a responsibility for them

to step back, observe, and then step back in as necessary—constantly monitoring, always striving for balance. Although parents sought to develop independence, self-advocacy, and self-determination for their adult children, these desires were often mediated by their children's ongoing needs for assistance. One parent shared,

So I stepped back and thought, Okay, Deb [fictitious name] is agreeing to these activities. Let's see what happens….You're always rebalancing. Because you don't just stop from being the person who makes all the decisions. You're clumsy and graceless about it sometimes. And what I've told people who are housemates is, you know, part of your job is pushing me out of the door.…And I continually step back so that I'm not micromanaging.

Striving to achieve balance required that the family support the young adult as a more active decision maker but be willing to intervene on their child's behalf as necessary. Families trained their children and the service providers about self-advocacy. For example, when 1 young adult needed medical testing, his mother decided to let the professionals work with her son without her. This mother wanted her son to learn to speak for himself. She stated, "When he did the sleep lab, I said, I'm leaving him. You'll have better communication with him without me there. Because if I'm there, he always turns to me and waits for me to answer the questions."

One mother identified the need for self-determination as a necessary life skill, a skill that would help her daughter when she was no longer alive:

Yeah, I could be killed. And everyone—and it can happen to anyone. And that's why I put the most energy into getting Deb to describe her own needs. Our focus has been to push Deb in situations so that she's the one who decides if someone is doing an incompetent job or needs to be fired. Because the day will come that I can't make the call. And the sooner Deb's able to make that discrimination, the safer she is.

Summary

The families interviewed provided vivid descriptions of their experiences, responsibilities, and roles they played in supporting their children's entry into adult life. These parents were active participants in their children's lives at this juncture; they provided hands-on support as they exercised their new roles as collaborators, trainers, and change agents. The advent of their child's completing high school and moving away from home

was celebrated with caution, as parents' realized the intensity and complexity of their roles while they navigated the maze of adult services.

Discussion and Implications

This study revealed several key themes regarding parental involvement in the lives of young adult children with developmental disabilities. Parents detailed their involvement in their adult children's lives and often compared and contrasted their experiences to those of parents who have typical developing children. Parents' discussions also centered on their necessity and availability to support situation needs, particularly when support services and personnel were unavailable, inconsistent, or inadequate. As a result, parents perceived themselves as acting in several different but related roles. Moreover, parents described their desire to strive for a healthy balance between being an advocate for their adult child and relinquishing some control so their child could individuate and become a self-advocate. Striving to achieve this balance required that parents continually ascertain when they needed to defer to their young adults and when to act on their young adults' behalf. One of the primary challenges parents faced was reconciling their young adults' needs to detach from the family with the service system's need for families' continued interventions. The ongoing involvement in their children's lives was time intensive and emotionally demanding.

This study illustrated the complexity of the roles parents play as their young adult children with developmental disabilities enter adulthood. This study supports Wehman's (1996, 2006) description of parental involvement in transition as a multiphase process. First, parents need to demonstrate an awareness of transition planning. They must also be ready to follow up on the implementation of these plans. Last, parents take on a role of accountability, making sure that transition plans are working and achieving positive outcomes for their adult children.

The families who participated in this study had varied levels of knowledge about what to expect after services from the educational system ended. Although many parents anticipated being actively involved in their children's postschool lives, they were surprised by the level and intensity of involvement. They felt their lives were unpredictable, as they had to constantly adjust work and personal schedules to fill in service gaps. Parents were also surprised by lack of adult service agency supports. Although federal law addresses the need to provide training for families (Individuals With Disabilities Education Act, 1997), school systems apparently do not give this a high priority. These parents perceived they had few opportunities to learn about the roles they would play in the post–high school years and, therefore, felt unskilled and unprepared to deal with the realities that awaited them.

The study's participants described the ongoing nature of parental involvement. This meant acting as service coordinator and case manager for their children. As the lives of these families unfolded, the role of advocating for appropriate supports and services became a key aspect in achieving desirable outcomes for their adult children. These parents had the willingness, skills, and means to provide hands-on support whenever needed. Many families and adult children with disabilities are not so fortunate.

Findings from this study have important implications for teacher educators, secondary teachers, transition coordinators, parents, and adult service providers. All stakeholders need more information and a better understanding of the continued support parents provide their young adult children after they leave high school to grasp the types of support young adults need to develop independence and self-determination. The complexity and importance of parents in their children's lives suggest that teacher preparation programs offering coursework in transition and secondary services emphasize communicating and collaborating with parents. This focus should extend beyond the traditional view of parents as partners in the development of individualized education programs (IEPs) into developing communication strategies for discussing tougher issues and preparing for the realities of dealing with overburdened adult service agencies. For example, teacher preparation programs should include critical dialogue regarding the need for parents to help their children become more independent within the context of an inadequate service system (Sitlington & Clark, 2006).

Many of the families in this study reported feeling unprepared to navigate the adult service agency network. It is probable that the participants in the study had not envisioned what supporting their children to achieve adulthood would entail.

One way to empower parents may be to encourage secondary teachers and transition coordinators to work with parents and engage in community resource mapping (see West & Fuller, 2006, for a complete description). Although there are many methods for conducting the mapping process, the end result should be a resource directory, guide, or database that can be used by all stakeholders. Engaging parents in this process before their children exit high school gives them an opportunity to explore all options and available resources. In addition, school personnel involved in transition planning should continue to forge strong inter-agency links and partner with these agencies to provide ongoing parent training on postschool options, including training and employment, housing, transportation, social and recreational activities, financial management, and health and safety.

Parents should be encouraged to form informal support groups and peer-mentoring programs. As evidenced in this study, parents reported feeling stressed, anxious, and fearful. Some of the identified fears were global in nature whereas others were more specific. Parents frequently discussed general fears concerning their child's social isolation and loneliness. Other fears were more specific, including (a) the loss of a particular support person, (b) the death of the other parent, and (c) the implications of their own mortality. Parents are encouraged to seek out other families to mentor them and create informal support systems as they navigate their new roles and confront their concerns.

A final recommendation includes recognizing the importance of continuity with case management services and the need for consistent relationships with families. As reported here, parents experienced a great deal of frustration and insecurity with the constant change of service providers. Rapid turnover did not allow sufficient time to build trusting relationships, which for families was a critical component in being able to relinquish some responsibility and control.

The study's findings are consistent with the previous 20 years of research about parents (Benz & Halpern, 1987; Everson & Moon, 1987; National Longitudinal Transition Study, 1989; Olsen et al., 1983). It seems little has changed; parents both then and now perceived themselves as playing a fundamental part in their children's adult lives, and the tension between parental oversight and adult system provision of services continues. Perhaps, it is time to acknowledge that parents' support of their adult children is needed to assure quality of life for the young adults and the family. Parent intervention and monitoring are necessary because the current adult system is overburdened and underfunded. The reality of the dynamic is that it is an uneasy partnership, with unspecified boundaries and roles.

The limitations of this study suggest areas for future research. First, this study examined the experiences of 9 families in one middle-class community. This small, homogeneous sample restricts the ability to generalize these findings to other parents. Furthermore, all parents in this investigation were Caucasian, monolingual English speakers. Future researchers should include a larger, more diverse sample of participants from differing communities to examine racial, ethnic, cultural, and socioeconomic influences in the roles parents fill in their adult children's lives.

References

Benz, M. R., & Halpern, A. S. (1987). Transition services for secondary students with mild disabilities: A statewide perspective. *Exceptional Children*, *53*, 507–514.

Brotherson, M. J., Berdine, W. H., & Sartini, V. (1993). Transition to adult services: Support for ongoing parent participation. *Remedial and Special Education*, *14*(4), 44–51.

Creswell, J. W. (1994). *Research design: Qualitative and quantitative approaches*. Thousand Oaks, CA: Sage.

Chambers, C. R., Hughes, C., & Carter, E. W. (2004). Parent and sibling perspectives on the transition to adulthood. *Education and Training in Developmental Disabilities*, *39*, 79–94.

Cooney, B. F. (2002). Exploring perspectives on transition of youth with disabilities. Voices of young adults, parents, and professionals. *Mental Retardation*, *40*, 425–435.

deFur, S. H. (2003). Parents as collaborators. In D. Wandry & A. Pleet (Eds.), *A practitioner's guide to involving families in secondary transition* (pp. 27–40). Arlington, VA: Council for Exceptional Children.

Everson, J. M., & Moon, M. S. (1987). Transition services for young adults with severe disabilities: Defining professional and parental roles and responsibilities. *Journal of the Association for Persons With Severe Handicaps*, *12*, 87–95.

Friend, M., & Cook, L. (2007). *Interactions. Collaboration skills for school professionals* (5th ed.). Boston: Pearson Education.

Gliner, J. A., & Morgan, G. A. (2000). *Research methods in applied settings: An integrated approach to design and analysis.* Mahwah, NJ: Erlbaum.

Hanley-Maxwell, C., Whitney-Thomas, J., & Pogoloff, S. M. (1995). The second shock: A qualitative study of parents' perspectives and need during their child's transition from school to adult life. *Journal of the Association for Persons With Severe Handicaps, 20,* 3–15.

Individuals With Disabilities Education Act Amendment of 1997 (IDEA). PL 105-17, 20th U.S.C., 1400.

Kolb, S. M. (2003). Parents as trainers, role models, and mentors. In D. Wandry & A. Pleet (Eds.), *A practitioner's guide to involving families in secondary transition* (pp. 59–70). Arlington, VA: Council for Exceptional Children.

Kraemer, B. R., & Blacher, J. (2001). Transition for young adults with severe mental retardation: School preparation, parent expectations, and family involvement. *Mental Retardation, 39,* 423–435.

Lloyd, R. J., Wehmeyer, M., & Davis, S. (2004). Family support. In D. E. Broli & R. J. Loyd, (Eds.), *Career development and transition services* (4th ed., pp. 94–116). Upper Saddle River, NJ: Pearson Prentice Hall.

Miles, B. M., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks, CA: Sage.

Moustakas, C. (1994). *Phenomenological research methods.* Thousand Oaks, CA: Sage.

National Longitudinal Transition Study. (1989, March). *The transition experiences of youth with disabilities: A report from the NLTS.* Paper presented at the Division of Research, Council for Exceptional Children Annual Meeting, San Francisco.

Olsen, D., McCubbin, H., Barnes, H., Larsen, A., Muxen, M., & Wilson, M. (1983). *Families: What makes them work?* Beverly Hills, CA: Sage.

Patton, M. Q. (1990). *Qualitative evaluation research methods* (2nd ed.). Newbury Park, CA: Sage.

ResearchWare, Inc. (2000). HyperRESEARCH (Version 2.0) [Computer software]. Randolph, MA: Author. Available at http://www.researchware.com

Rueda, R., Monzo, L., Shapiro, J., Gomez, J., & Blacher, J. (2005). Cultural models of transition: Latina mothers of young adults with developmental disabilities. *Exceptional Children, 71,* 401–414.

Schoeller, K., & Emanuel, E. (2003). In D. Wandry & A. Pleet (Eds.), *A practitioner's guide to involving families in secondary transition* (pp. 41–58). Arlington, VA: Council for Exceptional Children.

Sitlington, P. L., & Clark, G. M. (2006). *Transition education and services.* Boston: Pearson/Allyn & Bacon.

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, 20*(2), 19–26.

Tobin, R. (2003). *Transition to adulthood: Experiences of parents of young adults with developmental disabilities.* Unpublished doctoral dissertation, Colorado State University, Fort Collins.

U.S. Census Bureau. United States Census 2000. Retrieved July 20, 2006, from http://quickfacts.census.gov/qfd/states/08/08069.html

Wandry, D., & Pleet, A. (Eds.). (2003). *A practitioner's guide to involving families in secondary transition.* Arlington, VA: Council for Exceptional Children.

Wehman, P. (1996). *Life beyond the classroom. Strategies for young people with disabilities.* Baltimore: Brookes.

Wehman, P. (2006). *Life beyond the classroom. Strategies for young people with disabilities* (4th ed.). Baltimore: Brookes.

West, M. D., & Fuller, W. E. (2006). Housing and community living. In P. Wehman (Ed.), *Life beyond the classroom* (4th ed., pp. 369–385). Baltimore: Brookes.

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

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Appendix Interview Protocol

Interview questions

1. Tell me about your son/daughter.
2. Tell me about your experiences as a parent since your son/daughter exited high school?
3. Please describe for me what a typical day and week is like for your son/daughter.
4. What is your role now in supporting your son/daughter's transition?
5. Did the school system prepare you and your son/daughter for life after school?
6. What resources do you think would help you in supporting your son/daughter?
7. What are you concerns for the future given your son/daughter's current situation?
8. What are your hopes for the future?