Mothers’ Experiences of Transition Planning for Their Children With Disabilities

Elizabeth Madson Ankeny | Julia Wilkins | Jayne Spain

Transition is an ongoing process of planning, implementing, evaluating, and balancing the details of parents’ lives with the details of their children’s lives to achieve an integrated quality of life for the entire family. Parents are the consistent thread in their children’s lives, and the responsibility for obtaining and following through with adult services for their children typically falls on them. Although families piece together support networks, invest personal resources, and juggle multiple roles and responsibilities to help their children achieve fulfilling futures, teachers must ensure that they equip parents with needed information and resources. Current service-delivery models place families in a central role in determining services, and educators now realize that they must furnish supports for parents so that they can participate effectively in this complex transition process (Caldwell, 2006; Kreider, Caspe, Kennedy, & Weiss, 2007).

Parental and family involvement in the transition of youth with disabilities from school to the adult world is vital. The No Child Left Behind Act (NCLB) of 2001 emphasized the important role that families play in their children’s education, and the Individuals With Disabilities Education Improvement Act (IDEA) of 2004 mandated parental involvement in educational planning. Research indicates that student and family participation remains one of the five national challenges facing secondary education and transition services (Johnson, Stodden, Emanuel, Luecking, & Mack, 2002; see box “Challenges Facing Secondary Education and Transition Services”). To provide best-practice strategies for involving parents in the successful transition of youth from school to adulthood, this article reviews the transition literature and then presents findings from our interviews with four mothers of children with disabilities.

We also furnish a list of transition-related Internet resources for youth, families, and professionals.

Adolescent Development and Family Stress

People typically describe adolescence as a time of turmoil, distress, and conflict between the adolescent and the family. Families of youth with disabilities face additional sources of stress concerning their children’s social–sexual adjustment, vocational options and career choices, guardianship and advocacy issues, financial security, and needs for recreation and leisure. In addition to their traditional roles and responsibilities, parents often spend their days making telephone calls or writing e-mails to teachers,
setting up and coordinating appointments with agencies, completing applications and evaluations, participating in team meetings, and providing documentation to insurance companies to obtain needed services that schools do not provide (Kochhar-Bryant & Greene, 2009; see box, “Adolescent Development and Family Stress: Suggestions for Case Managers and Teachers”).

Team Collaboration and Roles of Families

During transition, families rely on educators and other professionals to furnish information about future options for their children (Whitney-Thomas & Hanley-Maxwell, 1996). In fact, findings from the National Longitudinal Transition Study-2 (NLTS-2; Wagner, Newman, Cameto, Levine, & Marder, 1996).
in which the orientation of Latina mothers and the service delivery system were strikingly at odds. In particular, the system viewed youth as autonomous individuals, although mothers viewed their children as embedded in the family. Also, the mothers believed that educators devalued and ignored their personal knowledge of their children, whereas educators promoted the belief that professional expertise was correct. For the mothers in this study, the absence of shared perspective led to confusion, misunderstanding, and isolation.

Another study of culturally and linguistically diverse (CLD) families indicated that parents placed much more emphasis on transition-related tasks than school professionals gave them credit for. This situation occurred because families chose to prepare their children for adulthood through family and community experiences rather than through school-based approaches (Geenan, Powers, & Lopez-Vasquez, 2001). Similarly, LandAdam, Zhang, and Montoya (2007) indicated that although CLD parents often did not understand the jargon of special education (for example, more than one third of parents in that study were not familiar with the phrase transition planning), they did possess a great deal of knowledge about their children that was useful for the transition planning process.

According to the NLTS-2, transitioning youth with disabilities most often rely on their family members and friends for support when making important decisions or facing problems (Wagner et al., 2007). Because parents are likely to know their child best, professionals should respect parents’ knowledge and use parents as resources (Everson & Zhang, 2000). They should also make sure that family members understand the formalities of the transition process. Research indicates that families experience higher levels of satisfaction with services if they have even limited involvement in aspects of service delivery (Neely-Barnes, Graff, Marcenko, & Weber, 2008; see box, “Team Collaboration and Roles of Families: Suggestions for Case Managers and Teachers”).

**Employment for Transitioning Youth**

A crucial component of transition planning for students with disabilities is early exposure to employment activities. Numerous studies have indicated a strong positive association between paid work experience during high school and postschool job success for youth with disabilities (Benz, Yovanoff, & Doren, 1997; Luecking & Fabian, 2000; Wittenburg & Maag, 2002). Everyone must view job development as a joint responsibility that educators, vocational rehabilitation counselors, students, and families share rather than as the sole responsibility of any one person (Everson & Moon, 1987; Ferguson, Ferguson, & Jones, 1988).

Families are likely to have a strong influence on the career development process for their children (Penick & Jepsen, 1992; Whiston & Keller, 2004). Morningstar, Turnbull, and Turnbull (1996) reported that students with disabilities more often secured employment through parent contacts than through professional agency sources. Transition teams should therefore consider family networks when planning for students’ future employment (see box, “Employment for Transitioning Youth: Suggestions for Case Managers and Teachers”).

**Postschool Roles of Families**

The process of transition begins in early childhood when families encourage their children to develop independence, decision-making skills, and social skills (Turnbull & Turnbull, 1990). During adolescence, the roles of families may include providing material and emotional support, as well as acting as advocates for appropriate services. Families often become the backup system for limited services, with their support continuing indefinitely over their child’s lifetime (Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995). Several studies have indicated that the family remained the only consistent source of support for individuals with disabilities after they graduated from
high school (Hanley-Maxwell, Pogoloff, & Whitney-Thomas, 1998; Morningstar et al., 1996).

In reality, no one agency provides all the necessary services for an adult with a disability. The period from 1992 to 2004 saw an increase in the number of states that offered young adults with developmental disabilities the opportunity to choose their service providers. As this market-based system shifted key responsibilities from state education departments to families, the system became more complicated for families. With their increased role in seeking out programs, families must gain the necessary skills to find appropriate programs for their children (Breihan, 2007; see box “Postschool Roles of Families: Suggestions for Case Managers and Teachers”).

**Interviews With Mothers**

Findings from the NLTS-2 indicated that levels of parental involvement in the individualized education program (IEP) process related to characteristics of the families themselves. Compared with families with limited parental involvement, the following situations correlated with high levels of parental involvement:

- Retaining more family resources, such as higher incomes or higher levels of parental educational attainment.
- Having two parents residing in the household.
- Securing external supports.
- Belonging to support groups for families of children with disabilities (Newman, 2004).

To provide the perspectives of informed parents, we interviewed four mothers who fit the aforementioned profile of highly involved parents. Myers (2000) proposes that when in-depth descriptions are essential to the goals of the study, “small qualitative studies can gain a more personal understanding of the phenomenon and the results can potentially contribute valuable knowledge to the community” (p. 9).

**Method**

We recruited four mothers who had conducted a panel presentation at a local professional conference about their experiences as mothers of children with disabilities (see Table 1). We contacted all mothers by telephone or e-mail, and they agreed to be interviewed about their transition experiences. The first two authors each interviewed two mothers in the mothers’ homes or places of work. We conducted the interview by using a semistructured interview protocol, and each interview lasted between 1 and 1.5 hours. We audio-taped all interviews and subsequently transcribed them verbatim.

We implemented inductive qualitative data-analysis procedures (Coffey & Atkinson, 1996; Marshall & Rossman, 1999; Miles & Huberman, 1994) and completed initial coding individually. First, we read each interview transcript in detail to obtain a general sense of the whole interview. We then reread each interview transcript to begin

<table>
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<th>Table 1. Interview Participants With Child Information</th>
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<tr>
<td><strong>Mother</strong></td>
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<td>Pam</td>
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<tr>
<td>Val</td>
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<tr>
<td>Joan</td>
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<td>Sharon</td>
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**Postschool Roles of Families: Suggestions for Case Managers and Teachers**

- Point families to resources that they can use for support (e.g., organizations, professionals, community members).
- Encourage parents to join advocacy groups and network with other families.
- Contact community resources on behalf of parents, if necessary.
- Help families make contact with student disability services at postsecondary institutions.
- Provide information on supported employment programs that offer integrated sets of services.
- Help parents understand the Social Security work incentive provisions and the redetermination process for youth at age 18.
- Provide information for parents on how to access a variety of adult service providers (e.g., Department of Health and Human Services Administration on Developmental Disabilities, Departments of Education and Labor, Centers for Medicaid and Medicare Services, Social Security Administration).
recognizing the need to “protect” them. That’s pretty close to what he’s doing like other young adults while also reflecting positively upon their children’s experiences of inclusion, mothers of daughters expressed concern about the influence of typical peers. In particular, mothers struggled to accept the desires of their teenage daughters to date and marry and grappled with internal conflicts over wanting their daughters to live like other young adults while also recognizing the need to “protect” them from such lives. In another example, Val described how her son was “like any other child” and stated, “Other kids grow up, leave home, get married; well, obviously not get married [italics added], but live their own life. And that’s pretty close to what he’s doing now.” To understand their children’s independence, these mothers had to reinterpret their expectations of what it meant to be living “like any other child.” One mother referred to her son’s living in a group home with 24-hour support as independence inasmuch as it involved his moving away from home, and other families created experiences that simulated those of typical peers, such as celebrating graduation from transition programs and referring to such programs as “college.”

Joan discussed the role that she played in removing her daughter from an unsuccessful job experience that she described as “total chaos.” Joan not only had to advocate for her daughter in removing her from the work setting but also had to continue coordinating such services as transportation and home support around Kate’s new schedule. Even when Kate was working, her mother was primarily responsible for managing these day-to-day activities. Such examples highlighted the ongoing support that parents still had to provide for their children when they were in the workplace.

Although mothers described the role that other people, such as group home staff, played in helping their children achieve independence, they clarified that “most of the important decisions still come through us.” Sharon explained, “medically, financially, we do all that stuff for her . . . people don’t see that additional stress of caring for a child that’s an adult but still has significant needs.” Pam explained that the preparation that she and her husband furnished for Adam in his transition to adulthood involved their volunteering together at the public library and a local animal shelter, as well as allowing him to scan groceries and handle money when shopping. Pam commented, “We are trying to prepare him for real-world things, but it often takes so long for him to do something that I just rush in and do it myself because I’m not patient.” Both she and her husband worked in demanding full-time jobs, and the need to maintain regular communication with Adam’s teacher and adult service providers—in addition to attending meetings, exploring employment and housing options, setting up a special needs trust, and wading through complicated Social Security and medical assistance applications—were additional responsibilities that they had to juggle.

The stories that mothers shared illustrated the reality of independence for these young adults with disabilities. Parents needed to perform certain tasks on their children’s behalf, and mothers understood that they would need to provide lifelong support. Even though these young adults faced limitations in what they could achieve independently, their mothers emphasized the importance of giving them opportunities to explore themselves and their options. In the words of one mother: “You’ve got to make sure you don’t close the door on someone right away because they make a mistake.”

### Transition as an Ongoing Process

The mothers described the transition process as a journey that began the day that their child was born. Joan reflected, “I’ve been very appreciative and blessed that in our journey, we’re not alone. Not that we were planning on going on the journey, but it’s not a bad journey.” Sharon reiterated the importance of the support of others on this journey: “It’s hard, so it’s nice to have people around you to support you. Not to coddle you, just to support you.”

The mothers viewed the transition process as an ongoing quest for options and opportunities for their children. They spoke of personal research as a means to better understand their child’s particular disability, as well as a means of coping and making sense of their unplanned roles as mothers of children with disabilities. Joan offered that her method was to “read and read and study and study and study.” The mothers also appreciated the knowledge and information that professionals shared. Val explained, “They knew all the places and people to get into contact with, opportunities, choices we had.”
Each of the mothers spoke of the importance of initiating the transition process early, as an end-in-mind process. Joan described this end-in-mind process as looking . . . beyond school. We know that school ends, but I think as parents we tend to live in the today and the now, but transition should start our brains thinking about what life is going to be like when school ends and then to make a picture of what that’s going to look like and how we’re going to get there.

Sharon rationalized the urgency of starting the process early by contrasting the transition process for her children without disabilities with the transition process for her daughter who had a disability. She explained, “With a child with a disability, you’re constantly thinking of what’s going to happen to that child when you’re not around . . . you start the process earlier because there are so many more unknowns.”

Val echoed the importance of initiating the process early and recommended that parents make a conscious decision to acknowledge that their child will someday leave home. She stated, I would tell them [other parents] to start preparing now. That’s one of the biggest things; parents like to put it off so they’re not facing their child leaving home, and it’s a mistake because it’s a lot harder to do later.

Pam focused on the difficult experience of going through the legal aspects of adulthood. She explained:

The guardianship was the hardest. You spend all these years celebrating all his competencies in these minor areas, like counting money, he could find the butter in the grocery store without being told where it is, or something like that, and then you basically go to a judge and have him judge your child to be incompetent. And it has to be done so that he’s not able to sign legal contracts and things like that and be taken advantage of in a big world. But it is still a really tough day.

All mothers discussed the importance of preparing their children with realistic skills that help make them ready for adulthood. They spoke of the need to include more opportunities for their children to develop skills in real-life environments, including learning such streetwise skills as how to behave with strangers. Joan suggested,

Just getting out into the real world, even if it’s just an hour-a-day job situation and getting a change and a little less under the wing of the intensive support that we sometimes provide students; they’re not going to get that [in the future]. It’s not like you are going to have your own little para follow you around at work.

Although some consider the transition process to be completed when an individual has secured a job and a satisfactory housing situation, the mothers in this study challenged that notion. Joan considered her daughter’s present situation and the future:

I think her housing situation is a really good fit for her right now. It’s still hard for me to picture any less restrictive setting for her right now . . . . Just because it’s working right now doesn’t mean it has to stay that way.

Joan shared similar thoughts about her daughter’s employment situation:

I would like to see her moved into a different type of work rather than just cleaning . . . . It’s very easy to just sit back and relax . . . . She’s still growing and learning . . . . If you look at your own experiences or your other kids, they’re still taking in those life experiences . . . . and we are never done; I know that. And I want to give her the same window of opportunity that we would give anybody.

Communication and Support From Teachers

The mothers valued consistent and respectful communication from teachers. Pam stated,

We e-mail the teacher at least once a week, if not five times a day, depending on what’s going on. She knows that Adam doesn’t report accurately so if something odd happens, she will e-mail that this is what happened and I have no idea what Adam will tell you, but this is what really happened.

This type of information from the teacher assisted Pam when she communicated with Adam at home. Mothers encouraged teachers to honestly and bravely address the tough issues with parents. Sharon commented that when teachers engaged in respectful dialogue with her, she was more prone to accept what she considered to be questionable management of her daughter. She shared, “I thought how they treated her shutting down wasn’t appropriate, but I never felt like I was looked down on; they were respectful of me.”

All mothers expressed gratitude that teachers provided information about community resources and future programming opportunities. Pam stated, It’s been hard to go through all these different steps, but the social service people and the school people have continually reinforced, “Have I done these things yet?” “Are you remembering that this happens when he turns this age?” Things like that. So they are constantly prompting and educating us as we go through these different phases of his life.

She also requested that teachers share the information, and share repeatedly because “people don’t retain what they don’t expect to use.” Joan expressed the disappointment that some parents experienced when the lines of communication were weak: “You hear repeatedly from parents, ‘I didn’t hear anything about that from the school.’ You just get a little sad that there’s a breakdown there someplace.”

One of the mothers explained:

There are flyers all the time at school when you are in first grade, things just come home all the time. In middle school and high school, those flyers stop and the kids are supposed to know what’s going on and you get no information coming home.
**Table 2. Transition Resources**

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<tr>
<th>Name of Resource</th>
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<tr>
<td>Annie E. Casey Foundation [(<a href="http://www.aecf.org">www.aecf.org</a>)]</td>
<td>This organization serves children in foster care and children who are at risk for poor educational, economic, social, and health outcomes. It provides printed resources on a wide variety of topics, including a page for Youth Transition/Youth Development.</td>
</tr>
<tr>
<td>Family Village: A Global Village of Disability-Related Resources [(<a href="http://www.familyvillage.wisc.edu">www.familyvillage.wisc.edu</a>)]</td>
<td>This site furnishes information, resources, and opportunities available on the Internet for individuals with disabilities, their families, and service providers. A wide variety of links to Web resources pertain to transition.</td>
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<tr>
<td>Healthy &amp; Ready to Work National Center [(<a href="http://www.hrtw.org">www.hrtw.org</a>)]</td>
<td>This site gives connections to nationwide health and transition expertise and focuses on understanding systems, access to quality health care, and increasing the involvement of youth. It also includes resources needed to make informed choices.</td>
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<tr>
<td>National Center on Secondary Education and Transition [(<a href="http://www.ncset.org">www.ncset.org</a>)]</td>
<td>This site furnishes resources, offers technical assistance, and disseminates information related to secondary education and transition for youth with disabilities. Many resources are available in English and Spanish.</td>
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<tr>
<td>National Dissemination Center for Children with Disabilities [(NICHCY; <a href="http://www.nichcy.org">www.nichcy.org</a>)]</td>
<td>This site provides a wealth of resources from a variety of nationally-recognized sources. It includes Web pages with links to Transitions 101, resources for parents, resources for students, resources for professionals, and transition and specific disabilities.</td>
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<tr>
<td>PACER Center [(<a href="http://www.pacer.org">www.pacer.org</a>)]</td>
<td>This site includes a comprehensive catalogue of publications. The mission of the PACER Center is to enhance the quality of life of children and young adults with disabilities and their families and is based on the concept of parents helping parents.</td>
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<tr>
<td>Technical Assistance on Transition and the Rehabilitation Act [(TATRA; <a href="http://www.pacer.org/tatra/index.asp">www.pacer.org/tatra/index.asp</a>)]</td>
<td>The TATRA project at the PACER Center and other parent information and training projects help families learn how they can assist young people with disabilities prepare for independent adult life in the community.</td>
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<tr>
<td>Parenting Postsecondary Students with Disabilities [(<a href="http://www.heath.gwu.edu/node/209">www.heath.gwu.edu/node/209</a>)]</td>
<td>This site, from the nation’s clearinghouse on postsecondary education for individuals with disabilities, discusses how to become a mentor and advocate to promote the needs of young adults.</td>
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<tr>
<td>Directory of Independent Living Centers Nationwide [(<a href="http://www.virtualcil.net/cils">www.virtualcil.net/cils</a>)]</td>
<td>This site provides a nationwide map with links to centers for independent living that furnish several core services: advocacy, independent living skills training, information and referral, and peer counseling.</td>
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<tr>
<td>The Arc of the United States [(<a href="http://www.thearc.org">www.thearc.org</a>)]</td>
<td>The Arc is the world’s largest community-based organization for people with intellectual and developmental disabilities. The site includes an array of information with links to state and local chapters.</td>
</tr>
<tr>
<td>National Secondary Transition Technical Assistance Center [(NTTAC; <a href="http://www.nsttac.org">www.nsttac.org</a>)]</td>
<td>NTTAC provides support and information to states, local educational agencies, practitioners, researchers, parents, and students regarding effective transition education that can enhance postschool outcomes.</td>
</tr>
<tr>
<td>National Youth Leadership Network [(NYLN; <a href="http://nyln.org">http://nyln.org</a>)]</td>
<td>NYLN furnishes a national voice for young leaders with disabilities. The Web site includes a variety of resources, including a list of young leaders who speak on a variety of topics.</td>
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about dances, football games; you get nothing. So it is lovely when the teacher e-mails us or forwards something and says, “oh did you know this is going on?” It is extra work and extra time, but we really appreciate it.

Pam emphasized the importance of getting involved in community organizations: “I know who to call and I know what my options are, but if I had not been in these committees or gone to the seminars, I would not have a clue.” Joan also issued a cautionary reminder; parents need guidance about how to ask the right questions. She commented,

Too often it seems like if you don’t ask the right question, you won’t get the right answer. But if you don’t know the right question, how are you going to know? I think that is the dilemma that parents have.

According to Lustig (2002), the degree to which family members possess strategies for seeking help can affect their caregiving experience. Given this situation, it is worth noting Pam’s recommendation for parents: “Go to the school meetings and keep questioning people and stay involved. It all comes to you when you need it if you have your hand in it.”

The mothers conveyed that they felt supported by teachers who shared similar or enhanced visions of their children’s abilities and future outcomes. Sharon described her daughter’s transition-process experience in this way: “[It was] more smooth than I ever expected due to the teachers and the support I felt from them.” Referring to Lisa’s case manager, she said, “She had the same vision I do that to the best of Lisa’s abilities, we are going to pursue areas that she can do . . . and allow her to be herself.” Pam shared a similar appreciation and delight for the teacher’s belief in her son’s abilities:

She is very aware of his skills and she’s watching to pick up and take the ball and go run with it with him and I think she will actually get him to do more things with him than I would think possible.

Final Thoughts

The case manager plays a crucial role in communicating with parents and in fostering collaborative transition planning. Case managers should acknowledge the family stress that revolves around the student’s ongoing needs and should give parents connections to community supports and resources (see Table 2). To nurture parents’ involvement in the transition-planning process, case managers must maintain honest and respectful communication with parents while respecting the family’s vision for their child’s future. Furthermore, case managers must view all family members as knowledgeable and valued participants in planning. The case manager should look beyond the student’s current status and provide opportunities for him or her to learn needed skills in environments that are as real-life and age-appropriate as possible, allowing each child the opportunity to grow into an independent, successful, and happy adult.

References


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