

# The Role of Parents as Advocates for the Transition Rights of Their Disabled Youth

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**Abstract:** This article describes the need for parents to be equal partners in the transition programming of their disabled child. Parents play a crucial role in the lives of their disabled children even after their son or daughter has made the transition to adulthood. Parents have a role to play in ensuring that the rights mandated to their disabled children by Federal law are made available to them. Parents can assist in making sure their children understand the services available to them after they leave school. Several barriers to parent participation are discussed and strategies offered to empower parents to serve as advocates for their son or daughter.

Each year young adults with disabilities make the transition from school to work. The enactment of the Individuals with Disabilities Education Act (IDEA) of 1990 had as one of its mandates the assurance that students with disabilities receive "a coordinated education designed to enhance the transition to employment, further education and training, and independent living" (Phelps & Hanley-Maxwell, 1997, p. 198). Parent participation in transition plans has been found to vary significantly depending upon the category of disability. Students with a learning disability (LD) were much less likely to have family members participate in the development of their transition components than other disability categories (Grigal, Test, Beattie & Wood, 1997). Many transition programs in schools allocate only a limited role to the parents. Some treat parents as ancillary stakeholders to be provided only with information rather than being viewed as essential partners in program development and implementation. Repetto & Correa (1996) state:

Families of students with disabilities are often involved early on in their child's school career, but become less involved over time either because of poor communication with teachers or because the school takes the lead in planning for their child's schooling (p. 559)." Other school transition programs give little relevance to the role parents play in the success of transition program outcomes. (Stodden & Boone, 1987; Edgar, 1987; Everson & Moon, 1987; Johnson, Bruinicks & Thurlow, 1987; Brotherson, Berdine & Sartini, 1993; Repetto & Correa, 1996; Grigal, Test, Beattie, & Word, 1997).

The present paper posits that parents are a necessary component in ensuring that their disabled children are provided with the services mandated to assist in the successful transition from school to adulthood and work. Schools need to re-examine their present transitional plans and

develop a systematic and meaningful process for making the disabled child's parents an essential component in transition programming. Peters, Templeman & Brostrom (1987) stated,

It is the position of the authors that the schools must go a step beyond an individual teacher, or even a school district, to look unilaterally at needed skills in future environments and to involve community-based service providers and support personnel in the longitudinal planning and program development process (p. 532).

### **Method**

Literature was gathered using extensive computer-based searches of several electronic databases covering the past 15 years, including the ERIC database and psychological abstracts. Search descriptors delimited to include transition, parents, disabled youth, school transition programs, career, employment and policies. The content of articles, reports and chapters deemed pertinent to the central topic of the review was systematically analyzed.

### **Parent's Roles, Needs and Barriers in the Transition Process**

Brotherson, Berdine and Sartini (1993) advocated for parent participation and indicated successful transitions into adulthood for disabled youth must include the involvement of parents and be supportive of their parents or primary care givers. The transition movement, however, has been primarily concerned with the post school employment status of youth with disabilities. Little emphasis has been directed toward the role parents have in their disabled child achieving economic and residential independence. Of the studies reviewed, only two evaluated interventions which involved features of family participation (see Morgan & Hecht, 1990; National Center for Disability Services, 1994).

The Morgan & Hecht study included such practices as providing school-to-work transition information to families, encouraging family attendance and participation at planning meetings, and having family members evaluate the student's transition program. The National Center for Disability Services included practices in which family members were trained as mentors to promote their child's self-determination. Unfortunately, none of the studies provided direct evidence of the impact of family involvement on transition outcomes.

Benz & Halpern (1987) stressed that parents can have a significant impact on their children's values and expectations in terms of independence and social integration. Parents are the one constant in a disabled child's life. Parents can set an example and promote positive attitudes for their disabled child regarding school and the need for an education. They can advocate for the continuity of services for their child between school and adult services. In many ways, the parent has the most to gain or lose when it comes to the progress their disabled child is able to make concerning academic, social and vocational skills. Yet very few programs directly address the needs of the parents of disabled youth. These needs may influence parent participation in transitional programs and the success of their children achieving economic and residential independence. When a child has been identified as disabled, parents of that child discover that their lives are forever altered. They frequently experience guilt, remorse in "lost" dreams of the child's future and marital conflict. They often feel totally unprepared and overwhelmed by the responsibility and needs of caring for a disabled child.

Schools and community agencies have treated parents of disabled children as a homogenous group with similar needs, characteristics and capabilities. Agencies have failed to recognize that parents vary regarding their energy level available to deal with a disabled child, their problem-

solving skills, their level of education and economic resources, their differing extended family support systems, and their capability of serving as the child's case manager. (Brotherson, Berdine, & Sartini, 1993).

Johnson, Bruininks & Thurlow (1987) identified a number of parent complaints in attempting to be advocates for their disabled child. Parents often encountered a lack of coordination among service agencies, a lack of information regarding services available, differing application procedures for each service agency, a lack of systematic organization of transition services, discontinuity of services based on changing geographical areas and varying planning cycles and fiscal years of service agencies. For any parent, these can be overwhelming obstacles.

These barriers are in addition to factors such as: the stress associated with raising a disabled child, the lack of educational skills and economic resources of many parents, limited knowledge regarding what services would be best for their child and whether these services are available. Combining these issues, it is easy to understand why parents express feelings of helplessness, frustration, anger and being overwhelmed. It is little wonder why, as Brotherson, Berdine & Sartini (1993) remarked, parents are "burned out", feel isolated, perceive little community acceptance and decrease their participation in intervention efforts in the schools.

Gilliam & Coleman (1981) indicated parent opportunities for participation often are fairly rigid and intimidating. Johnson, Bruininks & Sartini (1987) noted that parents' participation in the educational and transitional program planning decreased with the age of their child. They suggested that parents often felt intimidated by the team of professionals at meetings, frequently felt they were not treated as equal members of the planning process and in some instances other stresses in the parents' life may have caused the decision not to participate. Grigal, Test, Beattie & Word (1997) in their study of transition components of high school students IEPs' found only 4.3% included a thorough statement reflecting student or family dreams for the future.

All of the studies reviewed emphasized the importance of the parents in the transition process. Benz & Halpern (1987) stressed the importance of parent involvement and support of classroom activities. They also encouraged attendance at educational planning meetings, lobbying for community services and encouraging their child to value the transition process. Brotherson, Berdine & Sartini (1993) indicated the importance of parents to help their child develop positive expectations related to community living, work and independence.

Parents have an important role to play in the transition process as collaborators with their disabled child, schools and community. It is the parents who can often provide essential information regarding their child's strengths, weaknesses, needs, preferences and interests crucial to developing effective transitional components. Parents often are the key individuals who can articulate clear and realistic outcomes for the child's future. Parents may be best suited to select the appropriate person to coordinate the transition team.

It is the parents that can guide, encourage and empower their disabled child to take an active role in the transition program. Parents are essential in helping their disabled child identify life and career goals and in providing the opportunities to attain those goals. Parents can identify friends, family and community members who can provide information helpful in transition planning as well as assume an active role as part of the transition team (Baer, McMahan, & Flexer, 1999).

Parents serve as primary mediators between the school and community. It is the parents who can facilitate the procurement of identification cards, Social Security funds and transportation passes for their child. Parents play a central role in seeking assistance from community and residential services. Parents can provide an environment where their disabled child can try out adult roles, responsibilities and work experiences.

Additionally, parents are the key persons for developing any long-term planning for their disabled child which may include such concepts as long-term financial support, trust funds and other supports (Baer, McMahan, & Flexer, 1999). Figure 1 identifies some of the key areas where parents can serve as advocates for their disabled child.

Parents do impact the success of the transitional process and continue to play a major role in the life of their adult son or daughter. A study by Liebert, Lutsky & Gottlieb (1990) found that nearly half of the sample of transitional adults with severe physical disabilities rated their parents as very important in the development of career plans and obtaining employment. Blackorby & Wagner (1996) in discussing the findings of the National Longitudinal Transition Study (NLTS) cited that often it

### **Figure 1**

#### Areas where parents can serve as advocates for their disabled child in transition planning

1. Determine to what degree their child is able to self-determine career goals and future living plans:
  - a. For the child capable of developing life goals, more guidance and less direct intervention is required of the parents
  - b. For the child who is unable to identify personal life goals, direct intervention on behalf of the child is required of the parents, while still protecting the right of the child to make "wrong" choices, just as typically developing people do
2. Involve the child in all aspects of transition planning
3. Identify the child's strengths, weaknesses, needs, goals, preferences, desires and dreams
4. Collaborate with the school in the following curricula areas:
  - a. functional life skills
  - b. academic goals; postsecondary goals
  - c. vocational evaluation
  - d. developing employment skills
  - e. independent living skills
  - f. social skills training
  - g. community work experiences
  - h. inclusion with non-disabled adults
  - i. life-long learning activities
  - j. related services (i.e., speech therapy, physical/occupational therapy, counseling)
5. Develop linkages to community services and agencies
  - a. vocational rehabilitation
  - b. summer youth employment programs
  - c. mental retardation & developmental disabilities services
  - d. mental health services/programs
  - e. non-profit agencies (including traditional agencies such as the Arc; also may include disability advocacy groups)
  - f. employment agencies
  - g. Social Security
  - h. Independent living centers

was the parents who were better able to report the transitional experiences of their child. Stodden & Boone (1987) reported that nearly two-thirds of disabled children continue to live with their parents after leaving school. Finally, Ysseldyke, et al. (1992) stated that family skill in coping with the support needs of the student influences both the progress toward educational outcomes and the overall success of the individual in the adult community. Clearly, parents play an integral role in the transition success and life of the disabled son or daughter. The question remains, how

can parents be more fully supported and encouraged to contribute to the transition process and program planning and implementation.

### **Strategies to Support Parents**

Schools and community agencies must begin to recognize that parents of disabled children represent a heterogeneous group of individuals. Rather than envisioning them as having similar skills and needs, an individualized assessment that would identify the strengths and weaknesses of each parent and the family system is required. This would enable service providers and programs to target the individual needs of parents and provide the appropriate support that each parent and family requires.

Parents and families with limited problem-solving skills need to be provided with training to promote and enhance effective coping and problem-solving strategies. Parents with limited education and/or financial resources may be intimidated by professionals and agency personnel. These parents can be empowered by teaching them what information is needed regarding their child and what the gathered information means. Parents and families often do not know what questions to ask when requesting information and/or services for their child from community service agencies. Helping parents develop the skills necessary to effectively communicate with community service agencies and schools may enhance the parents' abilities to advocate for their children and increase their participation in transitional programming. As Brotherson, Berdine & Sartini (1993) pointed out, professionals need to communicate with parents in a manner that respects their style of communication and respects them as individuals.

Everson and Moon (1987) presented suggestions for special educators to involve parents in the transition process. These included providing information, making team members aware of the needs of families, involving other service agencies and training parents in skills supportive of the secondary curricula. Their recommendations are fairly typical approaches to addressing parent participation. Unfortunately, these recommendations do not adequately address the individual needs of the parents. These recommendations while on the surface present a supportive intent, create an atmosphere where parents are "acted upon" rather than viewed as integral members of a transition team. The recommendations support an approach that perceives parents as unequal to other team members. Unless this type of approach is changed, parents are likely to continue to view themselves as unequal to other team members, feel intimidated, and perceive little value for themselves from the team process in gaining skills to help their child. Without support and a meaningful role in the planning process, parent participation in the transition program will likely continue to decline.

Transition into adulthood is a stressful time for parents of disabled youth. Historically, there has been a lack of professional support in helping parents of disabled youth deal with the stress associated with the transition to adulthood (Brotherson, Berdine & Sartini, 1993). Parents of disabled youth are unaccustomed to change. Their children for the most part experienced a rather consistent developmental pattern and school programming sequence. The transition to adulthood challenges that consistency and worries regarding their child's security and safety become key issues. As a result, many parents may prefer to maintain the status quo and resist programming that makes their child potentially vulnerable to the outside world (Ferguson & Ferguson, 1986). Schools and community service agencies need to be cognizant of these fears.

Professionals need to help parents work through and resolve these issues. Additionally, schools need to start transition programming early in the child's educational experience. This will help the parent develop insight into planning for their child's future. Turnbull, Summers & Brotherson

(1986) stated that parents do not know how to make future plans for their disabled child whereas they feel more comfortable making future plans for their child without disabilities.

IDEA as amended in 1990 by P.L. 101-476 required transition planning statements in the Individualized Education Program (IEP) for student's age 16 or older. The 1997 Amendments of IDEA (P.L. 105-17) mandated transition statements at an earlier age in the IEP. Making transition plans part of the child's IEP as soon as the child is identified as having a disability will assist the parent in thinking about future plans much earlier in the child's life. This earlier planning will also help the parent become more familiar with their child's legal rights and services available to their son or daughter.

Another key role parents can have in their children's life is empowering their children to make choices regarding the rights available to them. Mitchell (1988) found that some children with disabilities felt smothered by their parents. They felt over protected, unable to make choices and not permitted to fail. Professionals and agencies need to encourage and support parents in allowing their disabled child to make choices and decisions about their lives. As Wehman (1990) suggested, schools and service agencies also need to promote the right for the disabled child to have an input into the decisions being made about their life. The earlier this can begin in the child's life, the more capable that child will be in making decisions about the future and the more comfortable parents will be in advocating for their child's rights.

### **Conclusion**

Parents play an integral part in the lives of their disabled children. Transitional success is less likely without their participation. Parents continue to have an influence on their disabled children even after the child's transition to adulthood. Parents have a significant role to play in assuring that the rights mandated by law are provided to their children. The severity of the child's disability will influence the degree of advocacy the parent needs to assume. The findings of the NLTS indicated that youth generally were not accurate respondents about issues related to receipt of services, parents reported more accurately (Blackorby & Wagner, 1996).

To ensure that disabled children receive the services that are available to them as adults, transitional programs need to build into their efforts more support for parents. Wood & Cronin (1999) pointed out that since P.L. 101-476 the emergence of a new professional has come to the schools, the transition specialist. This individual may be the resource that is able to address and provide the needed centralized database of services available within the community for disabled youth. This will enable parents or the disabled youth the resource needed to identify the appropriate service(s) and agency(ies) that can best address the individual needs of the disabled youth.

Schools need to re-examine the support and role given to parents of disabled youth in the transition program. Parents need to be treated as equal partners in the transitional program for their disabled child. The needs of the parents, their disabled youth and the family must be addressed on a case by case basis. Parents must be provided with the necessary support, training and skills required that will empower them to serve as advocates for their disabled youth. Research needs to be conducted that investigates the effectiveness of parents serving as their child's advocate. At present, there is a lack of research that links specific transitional program interventions with any particular outcomes. There are designs that look at correlational relationships but few confirmatory studies.

The challenge remains to develop programs that encourage the participation of parents of disabled youth, provide them support and treat them as equal members in the transitional intervention plans of their children. Increased participation of the parents can only enhance the

success of disabled youth in obtaining the services they need and making the transition successfully to adulthood.

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