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Transition to Adulthood for Students With Severe Intellectual Disabilities: Shifting Toward Person-Family Interdependent Planning

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The transition from high school to adulthood is a major life change for most young adults and their families, and generally it is depicted as an especially stressful time for young people with disabilities and their families. Adequate planning is required to address the challenging impact of this stage of life on families. The purposes of this paper are to provide a general overview of person-centered planning and family-centered planning and to suggest merging these two approaches into person-family interdependent planning to better meet the needs of this challenging time.

DESCRIPTORS: person-centered planning, transition, families

The transition from high school to adulthood constitutes a major life change for most young adults and families. This period is marked not only by growth and change but also by increased uncertainties and challenges. It is generally depicted as a stressful time for both young adults and their families (Lichtenstein, 1998). For young adults with severe intellectual disabilities and their families, this period appears to be especially stressful and chaotic (Ferguson & Ferguson, 2000; Jordan & Dunlap, 2001). Consequently, transition success correlates highly with the quality of life of individuals with disabilities as well as of their families (Blacher, 2001). To buffer challenges to young adults with severe intellectual disabilities and their families in this stage of life, adequate planning is required. This article provides a general overview of person-centered planning and family-centered planning, and suggests that a new approach—person-family interdependent planning—is needed that merges these two processes to

capitalize on the strengths of both. Figure 1 compares the three planning approaches and describes their values, and Table 1 compares person-centered, family-centered, and person-family interdependent planning.

Person-Centered Planning

The term *person-centered planning* refers to “a family of approaches to organizing and guiding community change in alliance with people with disabilities and their families and friends” (O’Brien & Lovett, 1992, p. 5). These new approaches emerged in the mid-1980s as important tools in planning and delivering services primarily to adults with disabilities (Holburn, Jacobson, Vietze, Schwartz, & Sersen, 2000). Typically, the adult with disabilities and his or her circle of support (e.g., family members, friends, professionals, community members) develop person-centered plans collaboratively to tailor supports to individual strengths, needs, and preferences with the goal of fostering self-determination and community inclusion (Holburn et al., 2000). Specific approaches to person-centered planning include: Individual Service Design (O’Brien & Lovett, 1992), Personal Futures Planning (O’Brien & Lovett, 1992), Life-Style Planning (O’Brien & Lovett, 1992), McGill Action Planning System (Vandercook, York, & Forest, 1989), Essential Lifestyle Planning (Smull & Harrison, 1992), Planning Alternative Tomorrows With Hope (Pearpoint, O’Brien, & Forest, 1993), and Group Action Planning (Blue-Banning, Turnbull, & Pereira, 2000). These approaches fundamentally challenge the culture of most human service agencies, which typically value uniformity and predictability more than individual needs (Holburn et al., 2000; O’Brien & Lovett, 1992).

Schwartz, Holburn, and Jacobson (2000, p. 238) identified eight hallmarks of person-centered planning, regardless of the approach:

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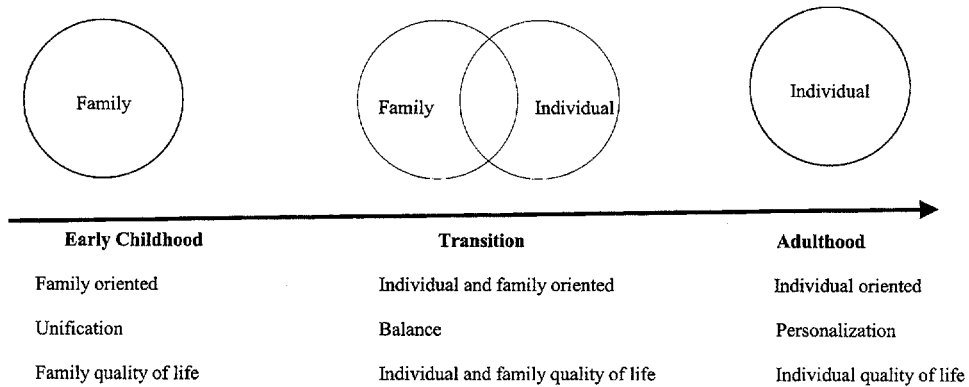


Figure 1. The three planning approaches.

1. The person’s activities, services, and supports are based on his or her dreams, interests, preferences, strengths, and capacities.
2. The person and people important to him or her are included in lifestyle planning and have the opportunity to exercise control and make informed decisions.
3. The person has meaningful choices with decisions based on his or her experiences.
4. The person uses, when possible, natural and community supports.
5. Activities, supports, and services foster skills to achieve personal relationships, community inclusion, dignity, and respect.
6. The person’s opportunities and experiences are maximized and flexibility is enhanced within existing regulatory and funding constraints.
7. Planning is collaborative and recurring and involves an ongoing commitment to the person.
8. The person is satisfied with his or her relationships, home, and daily routine.

Family-Centered Planning

In contrast to a person-centered approach that focuses primarily on adults, a family-centered approach emerged in the mid-1980s in the field of early childhood services and research. The family-centered approach reflected a new way of thinking about supporting families: that families are active decision makers and services should focus on and meet their needs (Turnbull, Turbiville, & Turnbull, 2000). The family support movement has used a variety of labels, including family empowerment (Dunst, Trivette, Deal, 1988), family-focused intervention (Bailey, Simeonsson, et al., 1986), and family-centered care (Shelton, Jeppson, & Johnson, 1987). Based on the synthesized definition that Allen and Petr (1996) suggested through a comprehensive literature review, family-centered service delivery across disciplines and settings sees “the family as the unit of attention, and organizes assistance in a collaborative fashion and in accordance with each individual family’s wishes, strengths, and needs” (p. 64).

Table 1
Comparison of Person-Centered, Family-Centered, and Person-Family Interdependent Planning

Value Base	Person-Centered Planning	Family-Centered Planning	Person-Family Interdependent Planning
Choice	The person is informed. The person chooses services and supports	The family is informed. The family chooses services and supports.	The person and his/her family are informed. They choose services and supports.
Goals	The person chooses and attains his/her goals.	The family chooses and attains their goals.	The person and his/her family choose and attain their goals.
Rights	The person exercises his/her rights.	The family exercises their rights.	The person and his/her family exercise their rights.
Security	The person has economic resources.	The family has economic resources.	The person and his/her family have economic resources.
Satisfaction	The person is satisfied with his/her services. The person is satisfied with his/her life situations.	The family is satisfied with their services. The family is satisfied with their life situations.	The person and his/her family are satisfied with their services. The person and his/her family are satisfied with their life situations.

Note. Adapted from *Outcome measures for early childhood intervention services* (p. 15), by the Accreditation Council on Services for People with Disabilities, 1995, Landover, MD: The Accreditation Council.

Despite difficulty in defining specific characteristics of a family-centered approach, three elements seem to be common across family-centered models: family choice, family strengths perspective, and family as the unit of support (Allen & Petr, 1996). The first component of a family-centered model, family choice, is the valuing of families as the ultimate decision makers regarding the goals for their children and themselves (Allen & Petr, 1996; Bailey, McWilliam, et al., 1998; Turnbull, Turbiville, et al., 2000). A family strengths perspective, the next component of the family-centered approach, embodies the belief that every family has strengths and also acknowledges families' needs, preferences, visions, and resources (Saleebey, 1996). The final component of a family-centered approach is the consideration of the family as a functioning social support unit, calling for a family system approach for understanding and supporting the interdependence of all family members (Leal, 1999).

Shifting Toward a Person-Family Interdependent Planning Approach

The relationship between young adults, especially those with severe intellectual disabilities, and their families can be compared to a pair of chopsticks. One of a pair of chopsticks can function alone by poking foods such as meatballs, but it still needs the other of the pair to handle difficult food challenges such as spaghetti. For the use of its full capacity, the chopsticks must work as a pair since they function best when acting interdependently.

In recent years, there has been an increasing trend in the disability field to use the concept of quality of life as the criterion for assessing the effectiveness of services to people with developmental disabilities (Dennis, Williams, Giangreco, & Cloninger, 1993; Schalock, 1994; Schalock et al., 2002). This awareness has also been useful for evaluating transition programs and services (Halpern, 1993). In an attempt to enhance quality of life for young adults with disabilities, some researchers have highlighted person-centered planning (Hagner, Helm, & Butterworth, 1996; Whitney-Thomas, Shaw, & Honey, 1998).

The focus on person-centered planning stems from the individual quality of life movement (Schalock et al., 2002). Considering that quality of life factors are affected by context (Dennis et al., 1993)—that is, most young adults with severe intellectual disabilities live with their families—the following discussion provides two primary rationales why person-family interdependent planning approaches warrant special consideration, especially during the transition period.

Transition is not a discrete time in life affecting only the individual; the family as a whole is often affected by the process and outcomes of transition (Marshak, Seligman, & Prezant, 1999; Szymanski, 1994). Students

with severe intellectual disabilities have more stressful transition experiences, partly because of limited adult services (Ferguson & Ferguson, 2000; Kraemer & Blacher, 2001) that often result in the individual staying at home after finishing high school (Blackorby & Wagner, 1996). Moreover, families of young adults with severe intellectual disabilities express fears and concerns that show that these families also are affected by their children's transition problems (Ferguson & Ferguson, 2000; Kraemer & Blacher, 2001; Lustig, 1996). To be successful, transitions must take into account this close relationship between the quality of life of the family and the quality of life of the individual (Blacher, 2001; Dennis et al., 1993). Thus, conscious efforts to address an individual's quality of life must also consider the family's interpretation of quality of life (Bailey, McWilliam, et al., 1998; Park et al., 2003).

Self-determination is a fundamental component of the preferred outcomes specified in the transition literature and federal legislation, as well as in quality of life core principles (Wehmeyer & Schalock, 2001). Self-determined persons choose how to live life consistent with their own personal choices and preferences on which person-centered planning relies. However, individuals with severe intellectual disabilities may have cognitive and functional limitations in independently making some quality of life decisions, and in these circumstances they may need to rely on a variety of supports. Wehmeyer (1998) asserts that "to the extent that supports are provided to enable that person to retain control over the decision-making process and to participate to the greatest extent in the decision-making or problem-solving process, he or she can be self-determined" (p. 10). To actualize self-determination, young adults with severe intellectual disabilities can engage in self-determination with appropriate, ongoing supports from those who know them well and are concerned with their best interest (Jordan & Dunlap, 2001; Turnbull & Turnbull, 2001a). Thus, the young adults and their family should work together to enhance their quality of life (Turnbull & Turnbull, 2001a).

Typically, person-centered planning approaches have focused almost exclusively on promoting the quality of life of the individual with the disability, only indirectly addressing the family's quality of life as a priority outcome. Family-centered planning approaches prevalent in early intervention and early childhood services stress the family choice by considering the entire family as the unit of attention or recipient of support, but this may cause conflicts, especially when there are disagreements between family members or between family members and professionals (Allen & Petr, 1996). Thus, responding to particular challenges to young adults with severe intellectual disabilities and their families during transition calls for a shift toward a new focus—that is, the merging of family-centered and person-centered approaches. We are suggesting that the term

person-family interdependent planning be used to describe an approach designed for young adults with disabilities and their families to enhance improved overall individual *and* family quality of life as the desired outcomes of transition services. Person-family interdependent planning approaches are grounded on the following premises:

1. The transition of a young adult with a severe intellectual disability influences and is influenced by the family system (Lustig, 1996; Marshak et al., 1999). In addition, family reactions to transitions of young adults vary as a function of variables such as family characteristics (e.g., cultural background), family interactions (e.g., siblings and individual with a disability), family functions (e.g., economics), and family life cycle (e.g., ages of parents and other children) (Turnbull & Turnbull, 2001b).
2. Young adults with severe intellectual disabilities and their families have choices concerning their lives (e.g., friends, personal assistants, where to live and work, with whom to live and work, what sorts of recreation to pursue) (Turnbull, Turnbull, Bronicki, Summers, & Roeder-Gordon, 1989).
3. No person is fully competent in all of life's decisions and domains (Jordan & Dunlap, 2001). Self-determination of young adults with severe intellectual disabilities maintains that they can control decisions in their lives but may be supported by some level of external influence, mostly exerted by their families, in regard to complex decision making (Ferguson, 1998; Jordan & Dunlap, 2001; Turnbull & Turnbull, 2001a). The culture of the individual and his or her family also contributes to how they view self-determination and work together to demonstrate it (Turnbull & Turnbull, 1996, 2001a).
4. Plans for the future should consider the needs of young adults with severe intellectual disabilities and their families. Although planning focuses on supporting individual needs, it is critical to consider that other family members also have needs. Just as all family members have their own needs, they also can serve as resources for future planning for young adults with disabilities (Turnbull, Turnbull, et al., 1989).
5. Comprehensive policies and programs providing social, emotional, and financial supports for young adults with severe intellectual disabilities and their families should be implemented (Leal, 1999; Turnbull, Turbiville, et al., 2000).

Person-family interdependent planning approaches emphasize thinking about transitions into adulthood from the perspectives of persons with disabilities, their parents, and other family members. To the greatest extent possible, however, planning should consider the

choices and preferences of young adults with severe intellectual disabilities. In addition, person-family interdependent planning approaches strengthen the capacity in young adults with severe intellectual disabilities and their families together to build formal and informal support circles that ensure that the young adult will be active in family and community life (Mount & O'Brien, 2002). Young adults need various and meaningful opportunities for self-determination, and they and their families need genuine support (i.e., professionals and community members working collaboratively) to address complex challenges across a broad number of life domains and environments as the transition to adulthood occurs (Thorin, Yovanoff, & Irvin, 1996; Turnbull, Turnbull, et al., 1989).

In summary, there is currently an emphasis on conceptualizing and measuring outcomes within all human service areas (Dennis et al., 1993; Schalock, 1994). There appears to be a consensus that positive quality of life is an appropriate outcome of policies and services (Bailey, McWilliam et al., 1998; Park et al., 2003; Schalock et al., 2002). The transition of young adults with severe intellectual disabilities involves not only the young adults but also their families (Ferguson & Ferguson, 2000; Lustig, 1996). We recommend that service providers move toward merging what we know about family-centered planning and person-centered planning and to look more holistically at person-family interdependent planning for delivering transition services to young adults with severe intellectual disabilities and their families. We feel that this will enhance the quality of life for both the individual and his or her family. Finally, service providers should respect the uniqueness of families and consider these three approaches carefully. The family's environment and its culture, values, preferences, and needs should be factors in decisions regarding appropriate approaches.

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