FOCUSON EXCEPTIONAL Children

Self-Determination: A Life-Span Perspective

Susan B. Palmer

Self-determination is a construct involving causal agency and perceived independence, usually associated with transition to adulthood and adult abilities. However, some proponents conceptualize self-determination as a life-span approach (Abery & Stancliffe, 2003; Abery & Zajac, 1996; Sands & Wehmeyer, 1996). Viewing self-determination as a lifelong process can broaden and enhance the construct, using developmental trajectories of stated essential elements of self-determination to build the case for understanding a continuum of activities to build capacity, opportunity, and competence over a longer period of time (Wehmeyer & Palmer, 2000).

This article will summarize the key literature from early childhood through adulthood to continue to establish self-determination as a life-span concept in support of individuals with disabilities and their families. Work related to young children has primarily encompassed alterations to the environment (Brotherson, Cook, Erwin, & Weigel, 2008) and ideas for parents to support the development of self-determination at a later age (Erwin et al., 2009). The article will also detail the emerging conceptual understanding of implementation during elementary and middle school levels (Palmer & Wehmeyer, 2003; Palmer, Wehmeyer, Gipson, & Agran, 2004) in preparation for senior high and effective transition to adulthood. It will then discuss cultural implications in light of the individual nature of self-determination, so that families can support choices and decisions for their children, young adults, and more mature family members with disabilities within family systems and community constraints and opportunities. It introduces a lifelong transition guide to help family members, teachers, and others have high but realistic expectations for individuals with disabilities as they move toward self-determination.

SELF-DETERMINATION: A LIFE-SPAN PERSPECTIVE

Self-determination, a construct in the field of disability, is often used with adolescents and adults, focusing on activities such as making decisions about life, including training or education, employment, housing, and leisure activities—all elements of a good plan for transition to adulthood (Wehmeyer, Agran, et al., 2007). However, for some time, advocates have supported building capacity for self-determination at earlier ages, to better prepare children for effective transitions from school to a self-directed life as adults, with help as needed (Abery & Zajac, 1996). As depicted in Figure 1, this article discusses self-determination as a life-span approach that

(a) builds capacity for people with disabilities through supportive people, activities, environmental adjustments, and education during early years;

Dr. Palmer is an associate research professor, Schiefelbusch Institute on Life Span Studies, Beach Center on Disability and Kansas University Center on Developmental Disabilities, University of Kansas, Lawrence, KS.

- (b) sees students engaging in involvement and selfdirection of educational aspects during secondary school and transition to adulthood; and
- (c) enhances a full range of capacities and opportunities for people with disabilities to have a desired quality of life as adults.

High expectations for any individual are part of the encouragement and awareness that supports self-determination across the lifespan.

Although young children cannot engage in as many independent or self-directed activities as adolescents or adults, building the capacity for self-determination can begin in the early years (Palmer & Wehmeyer, 2002). This discussion of self-determination will not be limited by age, capacity related to disability levels, or family values. Results of intellectual testing may not necessarily predict efforts to become self-determined (Wehmeyer & Garner, 2003). However, in the case of individuals with more significant disabilities, even if choices and opportunities are limited, some aspects of life can always be self-directed to support a desired quality of life (Wehmeyer, 1996).

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Cultural aspects of self-determination should be considered, but self-determination is a construct that is individually determined, especially by people with disabilities operating within their own family systems, which are uniquely influenced by cultural, socioeconomic, and preferential constraints. Even in the case of a family unit's values not aligning completely with the western principles that form the core of self-determination, aspects of this construct can be shaped to support an individual with disabilities to gain the level of independence desired within their family's and culture's beliefs and values (Lahat, Helwig, Yang, Ran, & Liu, 2008). A review of values of other cultures shows more similarities than differences in what families wish for their children and young adults (Zhang, Wehmeyer, & Chen, 2005). Work in self-determination within other countries beyond the United States, the United Kingdom, and Australia, such as Korea (Lee & Wehmeyer, 2004), China (Zhang et al., 2005), Israel (Duvdevanny, Ben-Zur, & Ambar, 2002), Japan (Ohtake & Wehmeyer, 2004), Spain (LaChapelle et al., 2005), and Italy (Nota, Ferrari, Soresi, & Wehmeyer, 2007) is providing additional perspectives for this primarily western construct (Lee & Wehmeyer, 2008).

A number of researchers view self-determination as an ongoing process (Abery & Zajac, 1996; Brotherson et al., 2008; Erwin & Brown, 2003; Wehmeyer & Palmer, 2000). Self-determination for Wehmeyer (2006) "refers to volitional

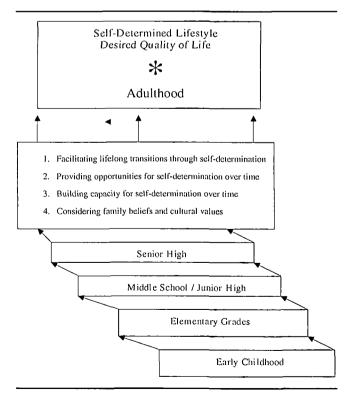


FIGURE 1
Life-Span View of Self-Determination

actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life" (p. 117). Volitional refers to making or being able to make conscious decisions based on one's own will (Agran & Wehmeyer, 2008). Ongoing scholarship within self-determination ranges from the philosophical, to promotion of elements of self-determination early in life, to empirical studies of intervention throughout school and into adulthood. In addition, a focus on transition across the ages will be provided later in the article to encourage high expectations for individuals with disabilities. According to Erwin and colleagues (2009), "Simply growing older does not provide all the needed opportunities to acquire the abilities to make choices and decisions that promote later self-determination" (p. 28).

THE CONSTRUCT OF SELF-DETERMINATION FOR INDIVIDUALS WITH DISABILITIES

The word self-determination appears in a variety of contexts, not only within a disability orientation. Hughes and Agran (1998) listed a number of themes that can assist in our understanding of self-determination as a concept to support the quality of life of people with disabilities: as a political and basic human right, as a personal characteristic, as a set of skills, as a communicative or social relationship, and as a systems-change issue.

Within a political and basic human rights context, self-determination is defined as the right for a people to be self-governed (Wehmeyer, 2003). Some cultures, including some Native American communities, use self-determination within the context of governance, as collective, not individual, determination (Frankland, Turnbull, Wehmeyer, & Blackmountain, 2004). Self-determination is also conceptualized as an individual capacity associated with disability rights, related to assuming control and the right to make decisions rather than being acted upon by others.

Wehmeyer (2003), in describing self-determination as a set of *personal characteristics*, proposed that volitional self-determined actions can be grouped into four characteristics:

- Acting autonomously, with a minimum of support, if needed
- Acting in a self-regulated manner, with personal control over one's actions
- Initiating and responding to events in a psychologically empowered manner
- 4. Acting in a *self-realizing* manner, to understand the effects of one's actions on others and the environment in which one lives

A number of essential elements or a specific set of skills supports self-determined behavior and actions that include but are not limited to choice-making; decision-making; problemsolving; goal-setting and attainment; independence, risktaking, and safety skills; self-observation, evaluation, and reinforcement skills; self-instruction; self-advocacy and leadership skills; internal locus of control; positive attributions

of efficacy and outcome expectancy; self-awareness; and self-knowledge (Wehmeyer, 2003). These skill sets represent a place to start in working toward later self-determination for younger students. Building capacity with people with disabilities using the essential set of skills encourages volitional action within their lives in desired areas, as supported by cultural values and as accepted by individuals and families. These component skills provide building blocks for the confidence, empowerment, self-advocacy, and opportunities that build self-determined lives for people with disabilities within a communicative and social context.

Finally, to complete the listing of Hughes and Agran's (1998) themes, self-determination as a systems change issue calls for more support for political and community entities to improve disability policy to enhance self-determined lives. Wehmeyer (1996) stated, "until people with disabilities are enabled to be self-determined, they will remain dependent upon systems and other people." (p. 32). Snow (1998) mentioned the "powerful interests that overpower these people's efforts to make their presences, ideas, needs, and wishes known" (p. 40), especially within service systems that focus on the "incompetence of difference" rather than on dignity and respect for personhood. Infusing self-determination principles into legislative action drives services that are respectful and supportive of people with disabilities as individuals.

Theories of Self-Determination

By combining fields of study (i.e., community psychology, philosophy, education, and principles of political action and governance) researchers have formulated theories of self-determination (Wehmeyer, 2003). These theoretical foundations of self-determination promote its construction as a life-span concept. Much of the basis for volitional action combined with causal agency within self-determination stems from the work of Bandura (1997), which suggested the concept of human agency or proxy agency for those who do not have direct access or need support to make things happen in their lives. In personality psychology, Deci and Ryan (1985) expanded initial work on causal agency to form their self-determination theory (Deci & Ryan, 1992), mainly explaining intrinsic motivation or the tendency to "seek out novelty and challenges, to extend and exercise one's capabilities, to explore, and to learn" (Ryan & Deci, 2000, p. 70). But this theory may not adequately describe the need for people with disabilities to be empowered beyond self-direction within their lives. For people with disabilities, self-determination has a broader but more targeted interpretation, encompassing the development of abilities over time, supports needed to build capacity, opportunities provided to experience self-determined actions, and the eventual outcome of a desired quality of life (Wehmeyer, 2003).

A social ecological approach to self-determination (Abery & Stancliffe, 2003) includes complex interactions that occur between person- and environment-specific variables that account for changes in human behavior and enhanced human

functioning (Walker et al., in review). This theory rests on the work of Bronfenbrenner's (1977, 1989) social ecological systems framework of the complex nature of individuals of any age within an environment. Within social ecological theory, both the capacity of the person and the expectations of the environment or context can be adjusted to match the strengths of individuals or groups through use of supports, as needed. Realizing that self-determination does not occur in a vacuum, a reinterpretation of the social context of this model relies on variables of social effectiveness (i.e., ability to use social skills, strategies, and competencies), social capital (i.e., networks and relationships of social connections), and social inclusion (i.e., presence and acceptance of people with disabilities in environments) to promote self-determination (Walker et al., in review). These facets of the social ecological systems model outline needs for people with disabilities to use social skills, community networks, and to be involved in activities not necessarily designed for people with disabilities that provide a social context and natural supports. Community interest groups that a person with disabilities might join could be as diverse as an organization for people who enjoy bluegrass music or a group that organizes the library benefit book sale. Attending with a friend might be a way to ensure inclusion, but often people with disabilities are valued members of such groups that naturally occur in many areas.

Mithaug (1993) explored several facets of self-determination to pose theories related to self-regulation and maximization of gain. Although self-determined activity is not always positive in nature, some people are more self-determined than others because of the way they adapt to situations and expectations (Mithaug, 2003). Wehmeyer's functional theory of self-determination (1999, 2006) builds on this work of Mithaug to integrate the ideas of motivation with human agency and personal control.

In the functional theory of Wehmeyer (1999, 2006), aspects of the social ecological systems approach, especially environmental and personal supports, are interwoven. In general, individuals with disabilities who exercise self-determination can act autonomously (i.e., making choices and decisions, as needed) through self-regulation or having some personal control over actions or behavior, in order to be psychologically empowered (i.e., feeling and acting capable) and to understand the effects of their actions (Palmer & Wehmeyer, 2002; for a more complete discussion of the characteristics of self-determined behavior, see Wehmeyer, 1996). Essential skills, or what Wehmeyer (1999) refers to as component elements of self-determination, are important to build capacity (i.e., choice making, decision making, problem solving) to achieve these characteristics of self-determined behavior. But abilities within the essential skills sets should not be markers for readiness to attain self-determination, since they are not necessary or sufficient to promote self-determination for all. In order to build capacity, individuals with disabilities of any age and their families, teachers, and service providers can focus on these skills sets and support the building of abilities over time by providing ongoing opportunities for individuals with disabilities to use choice or decision making or one of the other skills that encourage self-determination to develop over time. People with a disability might need someone to go with them the first or second time they visit a local restaurant (accommodation), but by going frequently, making clear menu choices, and using advocacy skills such as speaking clearly and making wishes known, they can become more self-determined in this setting. Thus, by building capacity through providing accommodations and numerous opportunities to use skills, self-determination training and support are an integral part of the life-long journey of becoming self-determined. Selected skills, accommodations, and opportunities to practice within natural environments are necessary parts of a model of intervention based upon a functional theory.

INFUSING PRINCIPLES OF SELF-DETERMINATION

Self-determination provides the organizational construct for individuals within families, schools, adult services agencies, community organizations, and a host of other entities to support people with disabilities in having life experiences that lead to a self-selected quality of life. Families have a foundational role in infusing self-determination into the home environment and activities in the community. For schools, the impetus for increased educational support for self-determination was highlighted by Ward (1998), specifically supporting career development and transition activities through Department of Education, Office of Special Education initiatives. According to Ward, self-determination requires a great deal of preparation and practice.

Self-directed learning provides supports for students to learn to take action on their own in order to be more independent learners. Self-determination is important in student involvement in planning their education curriculum and in the transition from school to adulthood (Morningstar, Kleinhammer-Tramill & Lattin, 1999; Test et al., 2004; Test et al., 2009). Wehmeyer and others (Copeland & Hughes, 2002; Lee, Wehmeyer, Palmer, Soukup, & Little, 2008; Wehmeyer Sands, Knowlton, & Kozleski, 2002) addressed principles of self-determination infused into classroom practices to support access and progress in the general curriculum for all students. Algozzine, Browder, Karvonen, Test, and Wood (2001) found interventions on self-determination to be effective through a meta-analysis. In addition, Cobb, Lehmann, Newman-Gonchar, and Alwell (2009) gathered reviews, meta-analyses, and other information to form a narrative metasysthesis supporting multi-component self-determination intervention as having positive effects.

Adult service providers and community representatives are aware of the process of infusing self-determination into the lives of people with disabilities in general but especially linked to legislation and the systems in which people with disabilities receive a range of services. The alternative to infusing self-determination into daily life would be

paternalization and charity (Wehmeyer, Abery, Mathaug, & Stancliffe, 2003).

Establishing a way to incorporate self-determination within any system can be difficult. Ohtake and Wehmeyer (2004) investigated values from the Japanese special education system for students with disabilities and their alignment with self-determination principles to effectively introduce self-determination and a teaching model to Japanese special education. On a smaller scale, researchers can align specific skills of self-determination with academic standards and benchmarks of instructional practice. This both ensures the presence of self-determination skills and emphasizes the need to strategize learning concepts through elements of self-determination.

A number of surveys of professionals have studied the infusion of self-determination into school settings (Agran, Snow, & Swaner, 1999; Carter, Lane, Pierson, & Stang, 2008; Cho, 2009; Wehmeyer, Agran & Hughes, 2000). The questions moved from familiarity with self-determination (Agran et al., 1999), to availability of resources to teach self-determination (Wehmeyer, Agran, & Hughes, 2000), and asking middle and high school special and general educators about their knowledge and confidence in their ability to implement strategies for promoting self-determination in high school (Carter et al., 2008). But only a recent study asked elementary special and general education teachers about their knowledge of the concept of self-determination (Cho, 2009). General and special elementary educators did not differ in indicating that self-determination is of high value and that it is important to include teaching of specific skills for moving toward selfdetermination. Across both sets of teachers, however, the ratings of importance were much higher than the time they indicated was spent in teaching these skills.

Having high expectations for students with disabilities is another pathway that supports the infusion of self-determination in schools (Wehmeyer et al., 2002). Mithaug and Mithaug (2007) suggested that reorienting instruction from teacher- to student-directed will empower students to learn how to learn and to become more self-determined. In the follow-up of a 5-year study of self-determined student leisure activity, Johnson and Bullock (2005) reported that teachers' expectation for student potential for 20 schoolaged students with disabilities was low. Often, teachers involved in the study did not reinforce student leisure skills, knowledge, and self-determination. However, Johnson and Bullock noted, "In each and every case, we found that once we got to know a student, his or her capabilities were greater than we expected" (p. 217) and that students were more capable than reported by either teachers or their families.

FAMILIES, CULTURAL CONTEXTS, AND SELF-DETERMINATION

Schools and adult service agencies should also consider the perspectives of families when infusing self-determination into ongoing practices. Turnbull and Turnbull (2001) defined self-determination as living one's life consistently with one's values, preferences, strengths, and needs. This definition highlights self-determination filtered by individually determined choices, decisions, and goals that take into account parents and families, as well as other aspects of cultural and community contexts (Shogren & Turnbull, 2006). Indeed, Barrera and Corso (2002) confirmed that a family's culture and values influence a child's passage to adulthood.

Erwin and Brown (2003) suggested that self-determination should be personally and culturally determined by families. According to Hanson (1998), cultural values of families with Anglo-European roots focus on independence, freedom, assertiveness, equality, self-help, and self-directedness. For families of other cultures, a continuum of values is more relevant to cultural influence on self-determination. moderated by the time a family has lived in the United States and their orientation to acculturation of the values in their present location (Kalyanpur & Harry, 1999; Lynch & Hanson, 2004). Mitigating factors of socioeconomic status, educational level, time of arrival in a country, experiences prior to arrival, proximity to others from similar and diverse cultures, age, gender, language proficiency, and sociopolitical climate shape the ways that individuals and families live (Hanson, 1998). Zhang and colleagues (2005) compared family and teacher efforts in fostering self-determination in the United States and Taiwan using a quantitative survey instrument and found that teachers in both countries had similar views in promoting self-determination. Although the level of family support differed depending on the country. there were more similarities than differences between families overall.

Erwin and colleagues (2009) suggested a number of considerations for practitioners (teachers, therapist, or others) to reflect upon with families to better understand how family values influence the context of self-determination:

- What is the family's idea of what it means to become a successful adult?
- 2. What skills does the family identify as needed to fulfill adulthood?
- 3. How does the family approach the decision-making process, and who is involved?
- 4. How is "choice" supported or not supported for young children by the family?
- 5. How does the family address needs for decision-making?
- 6. What adaptations are currently being made to support the child in the family's everyday routines and activities?

Through discussion with families, practitioners can be better prepared to understand how a family views or encourages self-determination for an individual with disabilities. Families provide the first step in the lifespan journey of self-determination.

SELF-DETERMINATION ENHANCES TRANSITION THROUGHOUT THE LIFE SPAN

"A consistent frustration faced by families as they seek and maintain services for their child and to maintain these services throughout the life span is the lack of a truly seamless service system" (Thompson et al., 2002, p. 3). Morningstar, Turnbull, and Turnbull (1995) agree with the need for more collaboration and establishing supports:

It is critically important for special education leaders from across the age span to collaborate in the development of family-student-school partnership models. From the earliest ages, these models need to incorporate a much stronger emphasis on self-determination in enhancing students' autonomy, even during early childhood years, to express their preferences for activities and to assess their strengths and needs. (p. 258)

Abery and Stancliffe (2003) describe the start of self-determination as rudimentary, but "maturation, in conjunction with experience, results in the development of a complex system that provides the individual with the potential to exercise personal control" (p. 30). In order to capture this process that does not start or end during adolescence, a consortium of educators, related services providers, and this author met throughout the spring and summer of 2000 in Lawrence, Kansas. The task was to devise a grid for a life-span transition process, outlining abilities and general levels of attainment for everyday activities in the lives of children, adolescents, and adults. The result is a multi-page handout, Transition across the Ages, for families and educators supporting individuals with disabilities across the life span (i.e., early childhood, elementary and junior high, and high school and adult) in which the principles of self-determination and specific skills are discussed in terms of developmentally appropriate expectations (Transition Council of Douglas and Jefferson Counties, 2000). Table 1 presents the developmentally appropriate expectations for the two age groups in the early childhood life span: birth through age 2 and ages 3 to 5. Tables 2 and 3, respectively, present the developmentally appropriate expectations for the two age groups in the elementary and junior high years and the high school and adult years. Written in the first person voice of an individual with disabilities, the document a) helps to place the focus squarely on the individuals to be supported and encouraged, b) provides relevant expectations to have and work toward, if not already present, and c) provides strategies to mobilize families and professionals to support individuals as they move from one age range to another for effective transitions throughout life.

The following sections of this article highlight each of the generalized age spans listed on *Transition across the Ages* to illustrate self-determination as both a life-span construct and a means to promote a seamless transition throughout life.

Young Children Birth to Age 5 and Self-Determination

A young child can make choices and decisions about activities within the immediate environment, whether home

or elsewhere, with support from family and others. Essential skills of self-determination (e.g., choice and decision-making) begin in early childhood and develop over time (Brown & Cohen, 1996; Sands & Doll, 1996; Wehmeyer & Palmer, 2000). The opportunities to develop these abilities are highly dependent upon the family's perspective and the value or importance the family places on these skills, but all children have the capacity to make their wants and needs known, even nonverbally. Culturally based beliefs about child-rearing practices can have a significant impact on the child's opportunities for learning essential self-determination skills (Kalyanpur & Harry, 1999). For example, discussing choice and some level of independence at younger ages may not be appropriate or welcomed with some families in the Hmong culture (Kalyanpur & Harry, 1999), and Navaho families may embrace group identity versus individuality (Frankland et al., 2004). Furthermore, as noted by Hanson (1998), although independence and privacy are an integral part of American culture, this value is emphasized less in Mexico, Central and South America, and Asia.

Many of the essential skills and components of self-determination, such as choice, decision making, and goal establishment, are evident at a fundamental level very early in life and may be demonstrated by eye gaze, early motor behaviors, and general self-regulation by infants and toddlers. Making choices and decisions can provide the initial experience and practice for children to begin the life-span journey toward self-determination. Wehmeyer (2003), however, reminded us that self-determination is not simply choosing among options provided by another but rather goes well beyond. That is, he cautioned us that the act of choice-making is limited to choices available, narrowing the number of options and the ability to engage in behavior related to higher level skills. Thus, we must remember that choice is only one of a large array of essential skills. For example, young children can also participate in simple problem-solving and some decision-making, broader capacities than choice.

Self-regulation, one of the characteristics of self-determined behavior, is also of significant importance for young children with and without disabilities (Bronson, 2000; Erwin et al., 2009; Gillespie & Seibel, 2006). Self-regulation in childhood can be conceived as the child's ability to gain control of bodily functions, manage powerful emotions, and maintain focus and attention and can be linked to later self-regulation of individuals at older ages (Shonkoff & Phillips, 2000). In her discussion of self-regulation, Bronson (2000) emphasized goodness of fit between child and parent temperament and thinking about the surrounding environment. Gillespie and Seibel (2006) gave several suggestions to caregivers in their interactions with the young child to encourage better self-regulation, including observe children closely, respond appropriately, provide structure and predictability, arrange the environment, develop ageappropriate limits, and show empathy and caring. Self-regulation may focus on infancy and toddlerhood (Kochanska, Coy, & Murray, 2001) or be expressed in developmentally

TABLE 1 Early Childhood: Transition across the Ages through Self-Determination

Birth through Age 2 Ages 3 to 5 I want you to accept me as a child first, not just a child How I Learn I need help to begin to see myself as to Know separate from my parent, when I am older with a disability. Myself than one year. My brothers and sisters and I are all different people. I need you to take time to enjoy being my Please enjoy our different interests and abilities. parent. Please support my cause-and-effect learning. Allow me I need ways to explore my environment. to make mistakes; this is how I can learn. I need to have my signs and signals recog-I communicate in lots of different ways. Let me express nized. Please respond to my cries and feed my wants and needs, so that I can learn to commume or cuddle me when I need it. nicate better. I also need for you to respond to my babbling, Show me how to learn to get along with others by setgestures, and words. I might need other ting limits on my behavior. Keep me healthy with well-child check-ups and visits ways to communicate. After I am one year old, depending on my level to the doctor when I am sick. of responsiveness and delay, set limits on I should eat and know about healthy nutritious foods my behavior so that I can learn self-regulaand how my body works. tion. Keep me healthy with well-baby visits. When I am sick, please take me to the doctor. **Finding** Please structure where I live and other Help me find an inclusive peer group (other kids my What I surroundings to give me opportunities to do age who do not have disabilities). Help me learn who Would Like typical activities that young children do. to trust and how to be safe. Support my play, since play is how I learn. to Know Please do not make me do things faster than I can Play with me, please. move or understand them. Take me out to new places so that I can learn Support my play, since play is how I learn. Play with about new things and other people in the me, please. security of your care. Take me out to new places. The more I see, the more I learn. Planning Help me learn to make choices. Use a small Support my ability to make choices. Use three things for the number of things (two) so I can choose one. to allow me to make a choice. **Future** Take me out to new places. Find someone or a group who will support our whole I want you to have a vision or plan for me when family (maybe someone who has a child with a dis-I get older that will support my growth and ability who can share ideas). development now. Please hold your vision for my future in mind to help I want my parents to have a balance between me grow and learn. their needs and mine. I want my parents to continue to have a balance between their needs and mine.

appropriate ways throughout the preschool years and early school years (Bronson, 2000), on into adolescence (Diamond, Barnett, Thomas, & Munro, 2007), and beyond.

More research within the essential elements of self-determination in early childhood is needed. Several studies have been conducted (Brotherson et al., 2008; Cook, Brotherson, Weigel-Garrey, & Mize, 1996), but the literature on self-determination related to the early ages has primarily included advice and suggestions for families and educators to enable young children to start the process of

later self-determination (Cho & Palmer, 2008; Erwin et al., 2009; Shogren & Turnbull, 2006). Brotherson and colleagues (2008) looked at self-determination and the home environment using qualitative methods identifying four categories of strategies for supporting families:

- 1. Engagement with the home environment
- Choice and decision making in the home environment
- 3. Control and regulation of the home environment
- 4. Support of self-esteem in the home environment

TABLE 2 Elementary and Junior High: Transition across the Ages through Self-Determination

Elementary Middle/Junior High School I need to know that it is important for me to feel good How I Learn I want to feel good about myself and know to Know that this is important. about myself and who I am. I need to know how to talk with others. I need friends. Myself I need to know how to communicate to make both with and without disabilities, who understand my ideas and thoughts known to others. You my feelings and share their feelings with me. may need to help me learn when it is okay to Although I might not be the same size or know as talk, what to say, and with whom it is all right to talk. much as some of my friends, I need you to understand and help me to grow and change. I want you to know that I might not be the I need to be able to ask for accommodations for my same as others my age, depending on my learning and physical limitations only if I need them. I disability. But I will continue to grow and need to be encouraged to do it myself. change and need help to understand this. I know what is good (foods, sleep) and bad (drugs, I have friends because I "talk" to others, they smoking) for my body. When I get sick, I should "listen" to me, and I "listen" to them. We have know it and be able to ask someone for help, such shared ideas, experiences, and fun. as a teacher or family member. I know what is good (foods, sleep) and bad (drugs, smoking) for my body. When I get sick, I should know it and be able to ask someone for help. I need to know that doing my best at school is impor-**Finding** School can help me learn lots of new tant to get a job that I like. What I things. Encourage me to pay attention and I will choose and participate in several activities I like to Would Like do my work. do with others and some I like just to do by myself in to Know I should try different group and individual my free time. activities to find out what I enjoy doing in my I should be learning how to find information about careers, the types of skills that jobs require, and why I need to be responsible for my actions and these are both important. what I say. If I need help with my schoolwork I need to know how to apply for a job and start to gain or with someone in school, please help me experience in jobs that might interest me. to work on this, but don't do it for me. I need to learn about new people and places to widen I need to start learning about many different my world and expectations for my life. jobs from my family, teachers, and others. I should be learning to make more complex decisions at **Planning** I should be able to make simple decisions school and at home and take responsibility for them. for the at school and at home. Help me do this I need to know about the different roles in life and how **Future** until I learn to do this myself. these interrelate. I may need help to become an active partici-I need to be thinking about my future by exploring pant in my meetings (educational planning or interests, ideas, and dreams. person-centered planning). I need to tell the people at my educational meetings I should understand about different kinds of about my goals and which ones are most important jobs and how people prepare for them. to me.

In a pilot study, Cook and colleagues (1996) found that although parents wanted to make home modifications for their children, they were uncertain about which ones to make and how best to make them, thus inhibiting these changes.

The environments of the early childhood years, likely driven by parental attitudes, parenting style, and visions for

the future, set the stage for later self-determination. A new theory related to quality of life, called family quality of life, is based in family systems theory and posits that the family as a whole experiences a quality of life that transcends the individual quality of life experienced by a person with a disability. Family quality of life is described as an interactive process and theory that looks at family

TABLE 3
High School and Adult: Transition across the Ages through Self-Determination

	High School	Adult
How I Learn to Know Myself	I need to feel good about myself and know that this is important. I need to ask for accommodations for my learning abilities and physical limitations only if I need them. I need to be able to have a chance to do it myself first. Help me use good communication skills to interact with others by listening well and expressing myself. Help me use person-centered planning to work out my present and future plans with you and others with whom I choose to share them. I should learn to balance my various roles in my family, school, and community. I will know how to keep myself healthy and talk with my parent(s) and doctor about healthcare.	I should know how to feel good about myself and what I do without others telling me. I need to be able to understand what is happening when things change, both before and after. I need to know how to interact with others by listening well and expressing myself. I will be assertive without being aggressive. I need to be a friend and have friends who will take turns deciding what we talk about and what we do. I will know how and when to call a doctor when I need one.
Finding What I Would Like to Know	I need to know that doing my best at school is important to get a job that I like. I should understand how to find, use, and think about career information and decide what jobs I want to try. I should choose group and individual activities that I enjoy in my free time. I need to learn how to get around in my community. I should understand why I should work at a job that I both like and that provides for my financial needs. I need to help decide how money is spent for my needs. I should know how to look for a job, keep a job, and change jobs if I want to do so.	I need the skills to enter and participate in education and/or training. I need to know that even if I am out of school now, I can still continue to learn both at my job and in the community, where I can be included at church, volunteer opportunities, and with friends. I should choose activities at home and/or in the community that I like to do in my free time. I need to know how to get, keep, and change jobs so that I can build a long-term career.
Planning for the Future	I need to continue to make decisions, with help from parents, teachers, and others in my life. I need to know about the different roles in life that people have and how these interrelate. I need to know about how to plan for my future and all the things I want to do with my life (live, work, play, etc.). Help me to learn how to understand long-term goals by breaking them into short-term objectives. I should know how to lead my planning meetings and see that my dream for the future guides the planning of	I should be making most of my own decisions related to my life and take responsibility for the outcomes. I need to know how my job affects my individual and family life. I need to know the skills I have to live as independently as I want to and how to find the help when I need it. If I use a team to help support me, I should lead that team, be able to share my

dynamics, characteristics, and beliefs within the context of supports, services, and practices. This theory may also help drive work in early self-determination (Zuna, Turnbull, & Summers, 2009). Shogren and Turnbull (2006) wrote that encouraging family support for young children with disabilities may also "empower families to more effectively advocate for needed resources and supports" (p. 349), depending on needs and preferences.

goals and objectives.

Early education programs using child-directed philosophies and materials provide not only environmental support but also teacher facilitation for the development of self-determination, though the focus of programs may not specifically include the development of self-determination. For example, early education programs implementing a Montessori curriculum include choice, child-directed activities, and a teacher trained to facilitate the child's active self-directed

identifying objectives.

vision, life plan, and goals and be good at

engagement in activities (Epstein, Schweinhart, & McAdoo, 1996). Both the High/Scope Curriculum (Weikert & Schweinhart, 1993) and Reggio Emilia curricular approach (Edwards, Gandini, & Forman, 1994) see children as active learners in a child-centered environment designed for optimal child interaction and materials usage, including use of interests, decision making, and problem solving. Each of these preschool curriculum approaches places the teacher in a role of facilitator of learning and the child as active learner, a process that can also facilitate the development of the essential skills of self-determination. An overall concern for any early education program is that even if the curriculum focuses on decision-making and problem-solving opportunities and choice and teachers use them, are children with disabilities actively participating? Kopp (1982) asked whether caregivers and teachers are aware of individual differences among children, reminding us that children need to experience predictable settings in terms of people and places. Educators must ensure that supports are in place to stimulate all students' engagement in classroom activities.

Erwin and Brown (2003) provided some reflective questions that focus on what a preschool child might do in situations during the day, such as upon arrival, center time, music and dance, snack time, or departure time. Adults can support children's self-determination by understanding challenging behavior as communication, providing breaks for a child when needed, allowing a child to complete an activity at a different pace than others, and giving opportunities for a child to use problem solving, all while honoring the family's culture, beliefs, and values. In addition, questions about preschool environments should focus on accessibility of materials, cultural diversity and developmentally appropriate practice, availability of alternate spaces for children, and reflection of children's preferences and interests in visual displays and projects. Furthermore, the teacher should ask whether each individual child, including those with disabilities, can communicate preferences; request a break; terminate an activity appropriately; move about freely when needed; demonstrate their unique skills, interests, and talents; and express anger, frustration, and protest in an appropriate manner. Through the use of these questions, teachers and families can determine a child's opportunities and current skills for expressing selfdetermination and use the knowledge gained to plan learning environments and activities (Erwin & Brown, 2003).

Some key transitions occur between birth and 5 years of age for children with disabilities. If infants and toddlers receive early intervention services, they transition between IDEA Part C (Infant Toddler Program) services and Part B, starting at age 3. Families could be well served by being prepared to let professionals know what they wish their children to achieve both now and in the future, with suggestions gleaned from *Transition across the Ages* (Tables 1 through 3) or a similar document.

Students in Elementary School

Transition from early childhood services to elementary school, beginning at age 5 for many children, can involve

foundational skills to build capacity for later self-determination. Sands and Doll (1996) confirmed "the capacity for and expression of self-determination is a developmental process that families and school professionals must foster in the earliest elementary grades" (p. 64). As in early childhood (birth to 5 years), the call for fostering essential skills of self-determination has begun to generate some information starting in early elementary including the kindergarten year, but this literature is limited by a lack of targeted materials and strategies specifically identifying self-determination processes and the lack of specific measurement instruments for this age.

As in birth to age 5, discussion of context alterations supports building self-determination. Brotherson and colleagues (2008) mentioned adjusting environments to promote higher functioning for students with disabilities to contribute to a trajectory of behaviors that can serve as foundations for later self-determination. A study by Blakely-Smith, Carr, Cale, and Owen-DeSchryver (2009) of six students between age 5 and 11 years on the autism spectrum looked at the environmental fit between student capacity and adaptability in the school setting. In general, curricular and other modifications decreased the level of problem behavior, increased task performance, and improved general affect over time, setting the stage for development of abilities that support self-determination.

Preparation for active participation in the development of IEP plans is the focus of a number of studies of self-determination as students are involved in transition to further schooling or work (Martin et al., 2006), and a study at the elementary level showed that younger students could practice self-direction of their meeting and achieve success. A multiple baseline single subject research design was used by Danneker and Bottge (2009) with four elementary students between the ages of 9 and 13 years to assess the impact of participation in their own IEP planning process on the development of self-direction and self-determination skills. The students each received six 20-minute lessons to prepare for their IEP meetings and participated in the meeting quite effectively. Outcomes included making the student focus of the meeting and fostering self-determination skills and collaborative problem solving. Overall, the authors concluded that younger students can be more involved and self-directed about their education but noted some barriers related to lack of adult facilitation. Barriers included the perception that the special educator is most responsible for an IEP (rather than other team members, particularly parents and the student themselves), a low level of awareness of self-determination skills, and a special educator's limited knowledge of how to prepare students to be a part of their IEP process.

Although self-determination is not often a focus in elementary school, several studies in the literature promote some of the essential skills of self-determination. Reid, Trout, and Schwartz (2005) conducted a meta-analysis of the use of self-monitoring, self-monitoring plus reinforcement, self-management, and self-reinforcement with 48 students with a variety of disabilities, between the ages of 5 and

12 years. The results noted large effect sizes providing evidence that these interventions were effective in producing meaningful improvements in on-task behavior, academic productivity and accuracy, and reduction of disruptive behaviors.

Palmer and Wehmeyer (2003) used the Self-Determination Learning Model of Instruction (SDLMI: Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000) to effectively teach problem-solving and goal-setting strategies to students in grades K-3. Fourteen teachers worked with 50 students with disabilities enrolled in kindergarten through third grade to implement this self-regulated problem-solving and goal-setting model of instruction. Using the SDLMI, a student sets goals, develops a plan, and evaluates the goal or plan through a series of 12 student questions supported by teacher objectives and educational supports, such as instructional interventions in choice, goal setting, self-management, and others. Results of goal attainment scaling (GAS) as an outcome measure for student goals showed students were capable of setting and meeting standards to achieve goals in academics (mean GAS score of 52.90 indicating goal attainment slightly above average). This confirmed studies by Guevremont, Osne, and Stokes (1988), Nicholls and Miller (1983), and Woolfolk (1990) that young children can effectively set goals with teacher support. A Parent's Guide to the SDLMI (Palmer & Wehmeyer, 2002) has been developed using the successful SDLMI model but with a focus on being a tool that parents can use to collaborate with teachers. The SDLMI was also used in a study by Fowler (2007) with young students with emotional or behavior disorders. A single subject multiple probe across behaviors design with 4 participants in grades 1 through 4, ages 6 to 10 years, involved success in academic goal attainment, writing achievement, and classroom behavior. This study extended the use of the SDLMI to young students with behavior difficulties.

The use of another self-regulated strategy in writing performance with 9 second grade children with emotional and behavior difficulties was studied by Lane and colleagues (2008). A clear relationship between completion of the Self-Regulated Strategy Development (SRSD) and improvement in writing resulted. The SRSD program was used to teach students strategies for writing along with self-regulation, goal setting, self-monitoring, self-reinforcement, and self-instruction skills to help manage writing strategies and tasks for progress.

Elementary grades provide an excellent time to build capacity and provide opportunity to practice elements of self-determination. As children move from elementary school to middle school or junior high, the expectations for displaying more self-determined behavior rise, with transition to adulthood services beginning.

Middle School or Junior High

A number of interventions related to self-determination for secondary students have been developed, some specifically for middle or junior high school (Lee et al., in review; Palmer et al., 2004). Lee and her colleagues looked at the impact of student-directed transition planning using Whose Future Is It Anyway? adapted for middle school students (Wehmeyer et al., 2004) using computer support. The program Rocket Reader (Davies et al., 2008) was used with half of the 168 middle school participants with disabilities and supported students with lower reading ability to use the curriculum. Overall, students in middle school attained skills helpful for understanding self-determination, self-efficacy, and outcome expectancy, and transition planning knowledge, showing that students can benefit from instruction in student involvement to support more positive outcomes.

Palmer and colleagues (2004) used the SDLMI approach described earlier to support middle school students with intellectual disabilities to set and work on goals to support their active access to the general curriculum. Goal completion, again as rated by GAS, showed above-average goal attainment, such that goals were met at a better than expected level. Thus, middle schoolers with intellectual disabilities benefited from the infusion of self-determination into additional classroom support, primarily related to problem solving and study plans. Martin, Marshall, and Sale (2004) used a survey to assess the changes in knowledge and perceptions of middle and high school students as to their roles and responsibilities in transition and IEP meetings. Specifically, their survey of meeting participants across a 3 year period found that while middle school participants knew the reasons for the meeting more so than high school participants, the high school participants talked more, shared interests and decision-making examples, and seemed to feel better about the meeting than middle school participants.

Senior High School and Transition to Adulthood

Self-determination has been well documented as a support for successful outcomes in the transition to adulthood (Powers et al., 2001; Wehmeyer, Palmer, Soukup, Garner, & Lawrence, 2007). Test and colleagues' (2004) literature review provided support for active student involvement in transition planning as a best practice and as a means to promote self-determination in young adults with disabilities. Self-determination and student involvement were linked in a study of 180 students 14 to 21 years of age, showing the importance of self-determination in the process of transition planning (Wehmeyer, Palmer, et al., 2007). Overall selfdetermination regardless of disability category and specifically student self-regulation and self-realization contributed to student transition planning knowledge and skills reciprocally, providing capacity to build self-determination enhances transition.

Wehmeyer and colleagues (2003) wrote, "Not surprisingly, promoting self-determination has become a primary focus in the education of students with disabilities, particularly within the context of providing transition services" (p. vii). IDEA 2004 uses age 16, but previous IDEA 1997 legislation identified age 14 as a milestone for introducing

transition-related objectives. Many persons involved in the transition process believe that the earlier students and families shape a plan for the future through self-determination, the better. Unfortunately, an unintended outcome of individualization to meet student needs is that students see adults having control of learning processes and conditions, rather than these being self-directed. Sands and Doll (1996) see interest in self-determination as a "direct response to quests for service delivery systems that empower rather than protect students with disabilities" (p. 59).

Even students with significant disabilities should be exposed to the same general curricula as students without disabilities, provided that adequate supports such as modifications, alterations, and accommodations are made available. Although a number of existing curricula support selfdetermination (Field & Hoffman, 2005; Halpern, Merr, Doren, & Wolf, 2000; Martin, Hughes, Marshall, Jerman & Maxson, 2000; Powers et al., 2001; Van Reusen, Bos, Schumaker, & Deshler, 2004; Wehmeyer et al., 2004), it is more likely that a practical infusion of self-determination principles into general education will expand student-directed learning and the expectations of special educators as well as general educators for the achievement of students with disabilities. The use of the SDLMI has also shown some promise in support of students in high school on both academic and transition to adulthood outcomes (Wehmeyer, Palmer et al., 2000; Agran, Wehmeyer, Cavin, & Palmer,

Certo and colleagues (2008) called for a seamless transition between high school and adult services for individuals with severe intellectual disabilities. Not only are three public systems (i.e., public schools, rehabilitation, and developmental disabilities systems) primarily responsible for transition from school to work and adult living, but legislation encompassing the transition is diverse as well. One way to begin working toward a seamless transition is a realignment of priorities that includes the idea of social capital (Trainor, 2008) infused into key supports for transition including selfdetermination. According to Trainor, "Insufficient attention has been dedicated to the forms of capital possessed by young adults with disabilities" (p. 148). Social capital is the social connections and networks or links within an individual's school, community, and family system on which to build effective transition. Not only have teacher's expectations for the role of social capital been low during high school, this has not been a strong focus for postsecondary outcomes either. Lee and Wehmeyer (2004) agree that many educators have low expectations of self-determination for their students, especially students with severe disabilities.

For people with significant disabilities, especially intellectual disability, self-determination does not have to imply the independent performance of behaviors but can relate to whether individuals exert control over their own outcomes, with appropriate supports matched to their capacity (Wehmeyer & Garner, 2003). Retaining control of the process of decision-making is important (i.e., a person with multiple

care needs may not be able to independently perform activities of daily living but can choose who performs these tasks and when they are done).

Person-center planning is one tool that seems to align with student-directed transition planning in that both of these aspects seek to ensure the involvement of the individual (Agran & Wehmeyer, 2008). MAPs, or making action plans (Falvey, Forest, Pearpoint, & Rosenberg, 2002), involves a facilitator meeting with the individual with disabilities and a group of family, friends, peers, and personnel from the school and adult service systems to make sure that a coordinated plan evolves based on history, dreams, fears, strengths, and needs. Thus, person-centered planning enhances opportunities for organizational or environmental adjustments to bring about success, while student-directed planning focuses on building the capacity of the individual in strategies and learning to bring about more self-management, rather than just facilitation to achieve future outcomes (Wehmeyer & Palmer, 2003). Both concepts include self-determination, but neither is sufficient alone. A vision for the future is a necessary part of transition, along with the tools to make it happen, which should include self-determination (Thoma & Getzel, 2005). In a series of focus groups of postsecondary students conducted by Thoma and Getzel (2005), self-determination was identified as being important for success in life. Many colleges and universities provide student support for adolescents and young adults with disabilities, which should include skill training and supports towards attaining selfdetermination (Field, Sarver, & Shaw, 2003).

Adulthood

Educational practices must align with awareness of adult opportunities in the community and any existing programs and supports to ensure seamless transition through selfdetermination. Families need to be particularly aware of what programming exists and what can be created for individuals with needs that extend into adulthood. A qualitative study by Bianco, Garrison-Wade. Tobin, and Lehman (2009) asked parents about their roles in supporting their young adults following their exit from school. Families identified these roles as including evaluators, role models, trainers, mentors and instructors, and systems change agents. The families outlined a complexity of roles between advocating for needs to be met and supporting independence and self-determination of their young adult. In many cases, with careful and thoughtful planning, individuals with disabilities can use established social networking and capital to find a niche in life after formal schooling (Trainor, 2008). Several studies conducted with families and young adults with disabilities after their exit from high school show that students with disabilities who are more self-determined during high school have better postschool outcomes (Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997).

Disability policy should energize the infusion of selfdetermination into daily life. The Developmental Disabilities Act of 2000, slated for revision in the near future, names some activities in which individuals with developmental disabilities, with appropriate assistance, might engage:

the ability and opportunity to communicate and make personal decisions; the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individual receives; the authority to control resources to obtain needed services, supports, and other assistance; opportunities to participate in, and contribute to, their communities; and support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities. (Walker et al., in press, italics mine).

Although a number of self-determined actions are named, these are not guaranteed.

Quality of life has been conceptualized as a multidimensional concept composed of eight core dimensions, one of which is self-determination (Schalock, 1990). The other seven indicators of the quality of life are emotional wellbeing, interpersonal relations, material well-being, personal development, physical well-being, social inclusion, and rights. Each of these dimensions is individually determined and varies in importance among persons and within their lifespans (Wehmeyer & Schalock, 2001). One way to think about quality of life within a lifespan approach is to consider who determines what is quality and how these standards can best be applied (Schalock, 1990). This would depend on the ability of a person to express outcomes and levels of support needed to achieve a desired quality of life, but self-determination can be a key factor in adjusting expectations for a good quality of life.

Aging naturally brings about changes in health, job status, and roles. These issues also affect older adults with intellectual disabilities, but according to Heller, Miller. Hsieh, and Sterns (2000), this group is rarely informed about pending status changes, resulting in lack of knowledge, awareness, and opportunity. In a mixed methods study of later-life planning, 60 adults (mean age, 56.92 years) were part of either a no-treatment control or an intervention group receiving instruction in later life planning and increasing life satisfaction and choice. After receiving instruction on aging, person-centered planning, and available choices, approximately 87% of participants in the training program met or partially met goals that were set and analyzed qualitatively in the context of heath, work, leisure, and place of residence. In addition, significant positive changes in measures of curriculum knowledge and daily choice making were found for the intervention group as compared to the noninstructional control group, showing the efficacy of providing instruction and support related to aspects of selfdetermination for older adults with intellectual disabilities.

The ongoing employment difficulties, poor postschool outcomes, lack of effective transition policies, and perceived disincentive to work that may still exist as a result of various government programs administered through the

Social Security Administration (SSA) make awareness and reform of statutes even more important for transitioning students and also for adults (Certo et al., 2008). Currently the SSA has a number of programs that are eliminating disincentives to work, but the perception that people with disabilities might lose SSA benefits may still be present unless transition teams include a member who understands and explains the benefits of the state in which a young adult lives (Parent, 2004). Other improvements outlined in IDEA 2004 that are beginning to make an impact, according to Test (2008), are state reports of graduation and dropout rates, implementation of achievable transition outcomes, and a written summary of performance for each student to carry on to the next level, as monitored by school districts and a state department of education review.

Transition through self-determination could build capacity, support, and a desired quality of life, depending on aspects of the system of funding and/or services provision that seem to be less than perfect, reflecting general, not individualized applications. Abery and Stancliffe (2003) remind that self-determination is dynamic, since, as people change, so do issues and relationships change during adult life, suggesting that the need to be self-determined is an ever-changing within-person construct, not static in nature. Reaching adult status does not guarantee a particular level of selfdetermination; we still need to make sure capacity is extended and opportunities abound for individuals with disabilities. Wehmeyer and Bolding (1999) matched adults with intellectual disabilities by intelligence level, age, and gender and found that living and working environments differed. Self-determination, autonomy, satisfaction, and opportunities for choice making were greater in less restrictive settings, proving impetus to continue support for people to live and work in their communities.

SUMMARY AND NEXT STEPS

Self-determination characterized as a life-span concept provides ongoing support for individuals with disabilities throughout the years. It is critical to involve families and others who are responsible for instruction, support, and services to promote, support, and infuse principles of selfdetermination into the lives of people with disabilities. Transition across the Ages provides age-appropriate expectations across the life span to ensure that all who support young children, adolescents, and adults are striving to build capacity and abilities for self-determination and a self-selected quality of life. We still have work to do to support self-determination as a life-span concept. Thus, more instruction and research should be undertaken on essential elements of selfdetermination at early ages. Raising awareness that what we do at early ages can make a difference in later years for students with disabilities and linking the skills attained at earlier ages to secondary transition and adult abilities is critical. Inclusive services in alignment with access to the general curriculum can provide not only social interaction but immersion in content areas such as literacy and math during early years.

The practice of infusing self-determination into elementary grades should be further encouraged to continue building capacity and providing opportunities to learn and practice essential elements of self-determined behavior. In junior high school, effective and age-appropriate transition needs to be encouraged, and student-directed learning should be the rule, not the exception. Senior high students should be better prepared for life in the community and should be responsible for understanding the connections that need to be made to adult services, if needed. Adults can be selfadvocates at any number of levels of involvement. Throughout the school years, we need to know more about the possible discrepancy between opinions and perceptions of parents and teachers regarding student capacity and opportunity for self-determination and other critical features of transition across the ages. At the very least, adults with disabilities should have an idea of their rights and resulting responsibilities for these rights, as well as be involved in the community and activities that are pleasing to them to attain a desired quality of life.

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