



# A National Gateway to Self-Determination

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## A Series of Papers on Scaling-Up Efforts to Promote Self-Determination

### Paper 3: Self-Determination Across the Life Span: Issues and Gaps

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## The National Gateway to Self-Determination

The National Gateway to Self-Determination (SD) is a consortium of University Centers for Excellence in Developmental Disabilities (Missouri, Kansas, Oregon, New York, Illinois) in partnership with a National Self-Determination Alliance (including self-advocates, families, and numerous national partners). The overall goal of this project is ***“to establish a sustainable, evidence-based training system that enhances self-determination training programs that lead to quality of life outcomes for individuals with developmental disabilities throughout the lifespan.”***

There are a number of important beliefs upon which this SD initiative is founded. They include:

- SD is best considered in the context of a ***social-ecological framework***
- Development of SD is a ***lifelong process***
- Scaling-up SD training activities must occur within an ***evidence-driven*** framework
- The development of SD is a means to obtaining an ***improved quality of life***
- People with developmental disabilities ***must be equal partners***

The purpose of this Paper and the others in the series is to fill existing gaps in the SD literature related to these beliefs. If you would like to see a complete listing of the Papers in this series, please visit the National Gateway to Self-Determination website: [www.aucd.org/ngsd](http://www.aucd.org/ngsd).

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## Table of Contents

Introduction, 1
Self-Determination Across Life Stages, 1
Early Childhood and Elementary School Years, 1
Adolescence, 2
Adulthood, 3
Aging, Later Life, and End of Life, 5
Cross-Cutting Issues in Self-Determination, 7
Abuse and Neglect, 7
Employment, 8
Health and Wellness, 9
Conclusions, 11
References, 12

As discussed in the second paper, the self-determination construct has been conceptualized primarily in the context of adolescent development and the process of individuation. The process of becoming a self-determined person, though, begins in early childhood and continues across the life span. Within the social-ecological approach to promote self-determination, a life-span approach is particularly important since it takes into account the role of families, friends, and the community/environment in supporting and expanding opportunities for people with disabilities, across the life span, to become more self-determined. This article synthesizes the literature on self-determination across the life span with a focus on identifying gaps that exist between theory, research, and evidence-based practices. We look first at issues using a life-stages approach, examining issues across life phases, and then examine cross-cutting topics (employment, abuse and neglect, and health) that are relevant during several age ranges.

## **Self-Determination Across Life Stages**

Although self-determination is conceptualized as a disposition relevant to adolescence and adulthood, there is a trajectory for its development that begins in early childhood (Doll, Sands, Wehmeyer, & Palmer, 1996). While this is an area in which research and practice is just emerging, it is an area of potential importance.

**Early Childhood and Elementary School Years.** Birth through age eight are critical years for cognitive, motor, language, social, and emotional development and, similarly, for the development of skills and abilities leading to later self-determination.

Adolescents will have difficulty becoming self-determined young adults unless their early family and education experiences have laid a solid foundation upon which to build more sophisticated skills and capacities. There are valid societal and developmental reasons young children are not seen as self-determined: young children are not yet developmentally or emotionally capable of acting autonomously and self-regulating their behavior. This does not abrogate the importance of enabling all children, including children with disabilities, to learn and develop the attitudes and abilities needed to become self-determined young people.

A review of the child-development literature supports the proposal that a focus on promoting self-determination needs to begin early (Doll et al., 1996). Self-regulation of behavior and activities, making simple choices, engaging in supported problem solving, and making decisions about everyday activities can be matched to a child's interests and capacities and become a focus of early intervention. At younger ages, discussions about self-determination can address component elements such as choice-making, decision-making, and rudimentary goal setting and build capacity in these elements over time. Hauser-Cram, Bronson, and Upshur (1993), for example, found that the degree to which children with disabilities exercised choice in their activities was related to increased social interaction, higher rates of peer engagement, higher levels of persistence on tasks, and less distraction from tasks. Only a few studies, however, have data-based information regarding the development of self-determination or have evaluated interventions to promote self-

determination in the early years (Brotherson, Cook, Erwin, & Weigel, 2008; Palmer & Wehmeyer, 2003). The limited data that do exist suggest that the support of parents and families for choice-making and other rudimentary abilities related to self-determination is important, particularly in the way home environments are structured. Brotherson and colleagues (2008), for example, showed that families of young children with disabilities used engagement with the home environment, choice and decision-making, control and regulation of the home environment, and support of self-esteem in the home environment to increase opportunities for self-determination.

Another area of potential focus early in life is the development of self-regulation skills. Self-regulation refers to the ability to examine one's environment and coping responses, to make decisions on how to act, to take action, to determine the outcomes of the action, and to revise plans, if necessary. The skills associated with self-regulation include goal setting, self-monitoring, and self-reinforcement (Wehmeyer, Abery, Mithaug, & Stancliffe, 2003). Each of these domains has a developmental course. Self-regulated problem solving refers to the idea that self-determined people persistently regulate their problem-solving to meet their own goals in life (Wehmeyer et al., 2003). The *Self-Determined Learning Model of Instruction* (SDLMI; Wehmeyer et al., 2000) was developed to teach students a self-regulated problem-solving process that enables them to set and attain educational goals. Palmer and Wehmeyer (2003) evaluated the use of the model with students with children in kindergarten

through 3<sup>rd</sup> grade at risk for developmental delay. The model was effective and these younger children were effective at setting and attaining goals with support.

**Adolescence.** Due primarily to a U.S. Department of Education initiative in the 1990s, there is now a substantive and growing literature base that adolescents with disabilities, including intellectual and developmental disabilities, can become more self-determined and, if they do so, that they experience more positive adult outcomes, including an enhanced quality of life (Wehmeyer & Schwartz, 1998), greater independence, and more positive employment outcomes (Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997). There are numerous reviews of this literature (Algozzine, Browder, Karvonen, Test, & Wood, 2001; Wehmeyer et al., 2003; Wehmeyer, Agran, Hughes, Martin, Mithaug, & Palmer, 2007) that include details about interventions and instructional strategies evaluated with adolescents with intellectual and developmental disabilities. Also, recent reviews of the literature and extant programs and strategies (Test, Mason, Hughes, Konrad, Neale, & Wood, 2004) have shown that students can acquire skills to be involved with educational planning and benefit from doing so.

Given the extensive literature base in this life stage pertaining to self-determination, we simply conclude that there is sufficient evidence that students with intellectual and developmental disabilities can become more self-determined, that there are multiple interventions to promote this outcome, and that students who leave school as more self-determined achieve more positive adult

outcomes. Readers are referred to Wehmeyer et al. (2003) and Wehmeyer et al. (2007) for details.

**Adulthood.** Self-determination has been associated with a variety of positive outcomes for adults, including enhanced employment outcomes (Fornes, Rocco, & Rosenberg, 2008; Wehmeyer & Palmer, 2003), improved health and psychological well-being (Johnson & Krueger, 2005), enhanced quality of life (Lachapelle et al., 2005; Nota, Ferrari, Soresi, & Wehmeyer, 2007), and greater independence (Wehmeyer & Palmer, 2003). Research has also shown that adults with intellectual and developmental disabilities place high value on self-determination (Schalock et al., 2005).

Unlike most adults, many adults with disabilities often continue to live with parents through adulthood or live in congregate settings with rules that restrict choices and staff who may not honor or know their desires. Large congregate settings, in particular, have been identified in several studies as significant barriers to the development and expression of self-determination (Heller, Miller, & Hsieh, 2002). Adults with more severe disabilities living in such settings typically have limited opportunities to make major life decisions and little input into the choice of staff in their home or with whom they share their residence. This is true even in those residential settings in which person-centered approaches to service planning are practiced (Stancliffe, 2001). The expression of self-determination is greatest for adults living semi-independently, which is most conducive to greater overall decision-making as well as choice over

where and with whom to live (Stancliffe, Abery, & Smith, 2000a).

Although many promising approaches exist for supporting the self-determination of children and youth, much less is known about how to effectively facilitate the self-determination of adults with disabilities. Research does suggest that living at home with family (Duvdevany, Ben-Zur, & Ambar, 2002) leads to greater opportunities for choice as does residing in smaller living units in which support staff are not always present (Stancliffe, 2001). For adults with more severe disabilities, one strategy for promoting self-determination is through Person-Centered Planning (PCP). Abery, Scholin, Paris, & Smith (2009) found that when family, friends, and peers were involved in the PCP process, adults with severe disabilities exercised higher levels of self-determination. Stancliffe and colleagues (2000b) found that people with no guardian or conservator exercised more personal control than those with a guardian. Most family members and youth with disabilities do not recognize the contradiction between self-determination and substitute decision-making and possessed only a limited understanding of guardianship and its alternatives.

Because most adults with intellectual and developmental disabilities need some level or type of support, the organizations that provide these services and the individuals who work for them (i.e., direct service professionals — DSPs) play critical roles in facilitating self-determination. Stancliffe and colleagues (2000a) found that a number of variables associated with community-living environments (e.g. program operation, program policies, and daily routines)

contributed to residents' self-determination. Adults with severe disabilities exercise more personal control in settings in which the policies and practices support autonomy and greater individualization.

Over the past two decades, policies directed at enhancing the self-determination of adults with disabilities have been adopted by community-living organizations and regulatory agencies. These policies have promulgated practices that emphasize consumer-directed supports. Although initial results of such efforts have been promising (e.g., Conroy, 2000; Conroy, Yuskas, & Sprent, 2001), such programs have not yet been consistently found to significantly enhance self-determination. In fact, research suggests that the daily interaction between DSPs and the people they serve often inhibits self-determination. Meyer, Donnelly, and Weerakoon (2007) found that conflict often ensues when persons with disabilities express a desire to control their supports while service staff persons prefer to determine how and when their work tasks are carried out. Participants reported that they had greater control over the assistance they received at home when their staff had not been professionally trained. Both agency rules and government regulations have the potential to prevent support staff from respecting the preferences of the persons they serve (Stancliffe et al., 2000a; Stancliffe, 2001).

What the available data demonstrate is that when person-centered approaches to service planning and consumer directed community support programs are not followed by the ongoing delivery of *person-centered services*, self-

determination over major life decisions and aspects of service delivery is unlikely to increase (Abery et al., 2009; Abery & Ziegler, 2008). One strategy to increase self-determination in residential, work, and other environments is to provide training to direct-support staff. Abery and Stancliffe's (2003) tripartite ecological theory of self-determination forms the basis for one of the few curricula (Abery et al., 2008) developed for this purpose. Initial research results indicate that adults with intellectual disability living in community-residential settings in which staff receive training through this program exercise greater self-determination than peers in similar settings where staff have not been trained. The impact of this training, however, decreased over time (Abery et al., 2009), leading to the addition of active coaching and follow-up components to the program. A similar approach to staff training based upon the ecological model has been reported by Wong & Wong (2008), who developed a multi-component curricula to enhance staff skills, attitudes, and knowledge relevant to self-determination. Preliminary findings indicate that the program facilitated staff members developing competencies supportive of self-determination of residents with intellectual disability.

Training for people with disabilities may also provide increased self-determination through self-directed supports. They could benefit from ongoing education, training, and tools to support all aspects of self-direction and informed decision-making. *Find, Choose, and Keep Great DSPs: A Toolkit for People with Disabilities and Families* (Hewitt, Keiling, Sauer, McCulloh, & McBride, 2006) provides strategies to help individuals with I/DD and



their families recruit and retain quality DSPs, with a focus on PCP and self-advocacy. However, its effectiveness in increasing self-determination of adults with I/DD has not yet been tested.

### **Aging, Later Life, and End of Life.**

Issues of self-determination are as important at the end of one's life as they are at the beginning. People experience age-related changes differently, with some subgroups of adults with developmental disabilities experiencing earlier aging (e.g., Down syndrome). *Supports Outcomes Model of Aging Well* (Heller, 2008), a conceptual model developed to explain aging in individuals with developmental disabilities, emphasizes the primacy of the environment and individualized supports in influencing outcomes for individuals across the lifespan. Outcomes of aging well are 1) maintaining health and function (physical and mental health and independence); and 2) active engagement with life (friendships, contributions to society, and community participation). Inherent in this model is the assumption that aging is a life-long process and that how well one ages in later life is dependent on events occurring at younger ages. This model emphasizes that aging successfully evolves from exercising self-determination to create a successful and productive life. It is a dynamic process involving individuals in their environment including the historical and cultural context.

Effective supports employ consumer-directed models that are person-centered. These supports fluctuate throughout the lifespan. The physical, social, and attitudinal environment within the home, community, and society play a large role in aging well. As a person ages, these environments also undergo changes,

such as moving out of a family home into supported housing or with a sibling when a parent dies. It is important to consider aspects of self-determination that provide support and opportunities for people with disabilities as they experience age-related physical and psycho-social changes as well as changes in their social and physical environments. Key tasks related to aging and self-determination include person-centered planning for later life and for end of life and consumer-direction in supports and long-term care to enable "aging well."

### ***Person-Centered Planning and Later Life.***

Later life planning incorporates multiple domains, including health and wellness, work and retirement, leisure, residential and financial arrangements, and end of life care. Older adults with developmental disabilities typically have had few opportunities to exercise self-determination in their lives (Heller, Factor, Sterns, & Sutton, 1996) and hence often have little understanding and skills to express their desires. In a training and advocacy intervention focused on increasing choice-making, goal-setting, and goal attainment using the curriculum *Person Centered Planning for Later Life*, older adults with intellectual disabilities increased their understanding of the concept of choice-making, more frequently articulated their preferences (Heller et al., 1996) and increased their daily choice-making, and attained most of the goals they had set (Heller, Miller, Hsieh, & Sterns, 2000). Building on this study, a peer support intervention was developed to support caregivers and adults with developmental disabilities in separately and jointly planning for the future using the *Future Is Now* curriculum (Heller & Caldwell, 2006). In



addition to significant increases in developing and taking action on plans, daily choice-making increased and unmet leisure needs of adults with disabilities decreased. Mahon and Goatcher (1999) found that a person-centered later life planning training program focused on leisure resulted in greater life satisfaction for the participants. While there is evidence that older adults can learn the skills and set goals, a supportive environment is vital to goal attainment, with staff and family members playing a large role (Heller et al., 2000).

**End-of-Life Care.** Another aspect related to self-determination and aging is addressing end of life care. Dealing with decline and death seems contrary to the values of growth and development, independence, and productivity. Yet end of life can also offer new opportunities for self-determination, emotional connectedness, and spirituality. Until recently, there has been little attention to the ways that people with intellectual and developmental disabilities experience and process grief and loss. People worry about their capacity “to understand” and often try to shield them from participating in funerals and other mourning rituals. Several curricula have been developed to help address various aspect of end of life care including *Person-Centered –Planning for Later Life: Death and Dying-A Curriculum for Adults with Mental Retardation* to educate adults with intellectual disabilities about death concepts and about ways to deal with grief and mourning, such as participating in funerals. To provide people with disabilities the opportunity to express self-determination and dignity to the end of their life, it is helpful to view it not as decline but as journey, and to give people

as much choice and control as possible in the final stages of life. It is also important to focus on the importance of relationships and connections to the past, present, and future and to pay attention to the spirituality needs of individuals. Kingsbury’s (2009) *People Planning Ahead: Communicating Healthcare and End-of-Life Wishes* provides person-centered guidelines for ensuring that individuals with intellectual disabilities receive care respecting their wishes and conforming to their personal, cultural, and religious beliefs during times of chronic and terminal illness, or severe disability.

**Consumer Direction in Long-Term Care and Support.** Most adults with developmental disabilities live with families although the likelihood of moving into a supported residence increases with age (Braddock, Hemp, & Rizzolo, 2008). As people age and require more supports for their activities of daily living, work, or recreational activities, they may require modifications to their homes and communities that allow them to remain in their current settings and to participate in community life. Environmental interventions (EI) to adapt or modify home/living environments and assistive technologies (AT) have shown positive effects on function and on participating in desired activities for persons with developmental disabilities (Hammel, Lai, & Heller, 2002). A useful approach in the delivery of such supports is the consumer-directed collaborative goal-planning strategy (ATLAS) involving persons with disabilities, their families, and service providers in goal planning. Mirza and Hammel (2009) found that older adults with intellectual disabilities participating in the

ATLAS intervention reported at follow up higher levels of performance and corresponding satisfaction related to goals they had identified. Assistive devices and systems-level advocacy and actions were the two most frequently set goals. While this generation of older adults with I/DD has generally had few opportunities to make their own choices regarding their daily lives and have had restricted options regarding supports in the community as they were growing up, the next generation of adults with I/DD and their families are likely to have higher expectations from the service system.

### **Cross-Cutting Issues in Self-Determination**

Across the life span, people with disabilities face a number of cross-cutting issues that affect both their development and expression of self-determination. They may have unique challenges in areas such as health and wellness and employment, at various stages in their lives, and a focus on promoting self-determination may be particularly important in those contexts and life stages.

**Abuse and Neglect.** Abuse and neglect are critical issues for people with intellectual and developmental disabilities across the life span. Instances of abuse and neglect occur at a much higher rate and for longer durations for this population than for people without disabilities and often include malicious acts directly tied to the person's disability (Chang et al, 2003; Horner-Johnson & Crum, 2006; Powers et al, 2002). The types of abuse targeting people with intellectual and developmental disabilities include physical, sexual, emotional, and verbal abuse, as well as withholding supports, financial exploitation,

manipulation of medications, and harming equipment (Powers et al., 2002).

Prevalence rates of abuse of people with disabilities vary from three to seven times more than reported for people without disabilities (Horner-Johnson & Crum, 2006) although this is almost certainly underreported (Oschwald et al, 2009; Powers et al., 2002). Many contextual or ecological factors place people with disabilities at heightened risk for abuse as well as inhibit reporting and stopping abuse, including a) reliance on abusive caregivers for care and support (Chang et al, 2003; Oschwald et al., 2009); b) lack of accessible alternative options to leave an abusive situation (Chang et al., 2003; Powers et al, 2002); c) limited social opportunities to building social intuition (Curry, Hassounah-Phillips, & Johnston-Sliverberg, 2001; Hassounah-Phillips & Curry, 2002); and d) tendency of support professionals to discredit reports of abuse (Curry et al., 2001; Powers et al, 2002).

There are critical skills and information necessary for preventing and stopping abuse that may occur due to these contextual factors. People with disabilities often lack necessary information about abuse as well as problem-solving, decision-making, and assertiveness skills to effectively address circumstances of abuse. They often do not understand what constitutes abuse, that they have a right to stop it, and the steps to take to stop it (Khemka, Hickson, & Reynolds, 2000; Oschwald et al., 2009; Powers et al, 2002). Too often, they possess a strong desire to please others and are too compliant and thus tend to tolerate abusive situations (Chang et al, 2003). Taking action against abuse requires the promotion of problem-

solving skills, including the ability to perceive potential harm, generate alternative courses of action, weigh the relative risks and benefits of action, and choose a course of action (Khemka, Hickson, & Reynolds. 2005).

Often, the tendency to protect people with disabilities has inadvertently denied opportunities for people with disabilities to develop problem-solving and interpersonal skills important for preventing or responding to abusive situations (Powers et al., 2002). People with developmental disabilities may not have had opportunities to learn to be assertive, learn that it is acceptable to be assertive, and practice being assertive (Chang et al, 2003; Curry, Hassounah-Phillips, & Johnston-Silverberg, 2001; Powers et al, 2002). Among the many steps needed to address these issues are several that involve promoting and enhancing self-determination, including teaching self-awareness and problem-solving skills to recognize potential abusive situations, taking charge of support providers, understanding rights and options, and developing a plan for responding to abuse before it happens (Oschwald et al, 2009). A shift from focusing on protection to focusing on empowerment (via self-determination) needs to occur. People with disabilities need the tools and information to prevent and stop abuse, connect with support networks, and proactively advocate for the right to be safe (Oschwald et al., 2009).

**Employment.** People experiencing the advantages of increased self-determination also tend to gain the additional benefits associated with working competitively in community-based jobs. Transition-age youth and adults with

disabilities are more often employed if they have higher self-determination, and those that are working typically have better jobs and higher wages than their peers who are less self-determined (Wehmeyer & Palmer, 2003). In addition to more positive outcomes, individuals who are more self-determined are frequently better prepared to choose their jobs, assist with the placement process, speak up about their needs, request support and accommodations, contribute to problem-solving, and develop social relationships. Self-determination is the essential element for enhancing individual control and involvement in employment and ultimately job satisfaction and success (Brugnaro & Timmons, 2007).

The evidence-based practices of supported employment and customized placement provide a means for people to exercise greater self-determination and achieve their employment goals (Wehman, Inge, Revell, & Brooke, 2007). These approaches entail identifying the strengths, preferences, and interests of the person, determining the needs and opportunities of the employer, and negotiating or supporting any differences that may exist between the two. As a result, options such as carved or created jobs, self-employment, resource ownership, or business-within-a-business expand the options for employment available to people with intellectual and developmental disabilities (Parent, 2004). Supported and customized employment provides a mechanism for individuals to be in the driver's seat and direct their career paths. Creatively blending formal and informal supports, funding resources, and innovative job ideas promote "outside the box thinking" and

leads to individually driven employment outcomes.

The relationship between enhanced self-determination and improved employment outcomes is well documented. Despite this, people with disabilities continue to experience high unemployment rates (National Council on Disability, 2007). While the number of people in integrated employment has grown during the last twenty years, the percentage of people who are working in integrated jobs has declined in relation to the increase of those who are participating in segregated day and sheltered work programs (Kiernan, 2009). This sharply contrasts with the preferences of individuals with disabilities themselves, who state that they want to work and be actively involved in their employment process. Low expectations, funding restrictions, service delivery practices, and lack of information often drive the employment-related decisions of people with disabilities, rather than their own choices, further limiting their opportunities to exercise critical self-determination skills.

### ***Strategies Leading to Employment.***

An essential element of making decisions is knowledge of alternatives. People benefit from experiences that allow them to know the differences between segregated day programs and integrated employment as well as the variety of potential career options and job choices within the competitive employment arena. Exploring jobs and careers, providing community-based experiences, and promoting self-expression are strategies that can lead to employment. Site visits to employment sites, personal contacts, and referrals from friends and families help individuals in identifying potential jobs and careers. Other

important resources are websites and videos illustrating a variety of jobs and employee interviews (e.g., *The Fun Works* and *Mapping your Future*).

In providing community-based work experiences, it is important to start with multiple work sites and gradually become more specific as interest areas emerge, using options such as situational assessments, job try-outs, and on-the-job training. To promote self-expression, it is important to facilitate self-assessments that break down component parts of a job, allowing an individual to discriminate between the important factors considered for a good job match and their support needs (Parent, in press). During individualized planning meetings (e.g., IEP, IPE), employment must be established as a first option for individuals, creating a culture from a young age in which employment is the preferred choice.

**Health and Wellness.** Self-determination has potential for improving the health and wellness of people with disabilities. Studies demonstrate that active involvement and management of one's own health care results in improved health outcomes for people with disabilities (Stuifbergen & Becker, 2007; Lennox et al., 2004). People with disabilities often experience disparities in health when compared to people without disabilities. People with disabilities are at greater risk for secondary and chronic conditions. They have higher rates of preventable complications and premature death. They are more likely to engage in poor health behaviors and are less likely to obtain affordable and appropriate medical care, early disease identification or preventive screening, or access health promotion

activities (Drum, Horner-Johnson, & Krahn, 2008; Haverkamp, Scandlin, & Roth, 2004). Both person and environment-specific variables are necessary to achieve greater self-determination with regard to health and wellness. Research demonstrates that for people with disabilities, being self-determined and achieving positive health outcomes are significantly influenced by both societal- and individual-level factors (Graham, 2004).

**Children's Health.** There has been a recent recognition of the importance of early acquisition of self-management skills to promote greater self-determination in health (Butz et al, 2000; Lieu et al, 1997). The process of beginning to observe and acquire the component elements of self-determined behavior (See Wehmeyer, 2007) as early as possible has implications for preventing or reducing physical and behavioral problems, thereby enhancing quality of life and controlling economic costs of chronic illness and disability throughout the lifespan (Lorig et al, 1999; University of California, 1994). Unfortunately, research regarding how parental behavior can affect the capacity for self-care and health self-management in children and adolescents is lacking.

**Transition from School Age to Young Adults.** Youth with disabilities face a range of health-related challenges as they become more independent and self-aware. Acquiring and practicing skills and attitudes related to self-determination, particularly decision-making, self-efficacy and self-advocacy facilitates the avoidance of health risks and presents the opportunity for youth to engage in healthy alternatives. The transition from pediatric to adult health care is complicated by the lack of provider

guidelines or best practices for the transfer of children at the primary care practice level, regardless of disability (Sherlafi, Ciliska, & O'Mara, 2009). Since entering adult health care requires patients to self-advocate, set health goals, and make decisions about treatment, transition-age youth with disabilities should be a target of health-related interventions to promote self-determination. Transition programs generally fail to incorporate health care transition and goals in IEPs (Burke, Spoerri, Price, Cardosi, & Flanagan, 2008).

**Adults.** With adulthood, health-related choices regarding medical services and treatment and activities of daily living come into play. Adults with disabilities take on increased responsibility for making decisions about their own medical care and their rights as patients. Simultaneously, they are responsible for making decisions about the activities they engage in, including health promotion activities. Practicing a healthy lifestyle is particularly important considering that adults with disabilities experience much higher rates of morbidity than non-disabled adults (Reiss & Gibson, 2002). Older adults are faced with making key decisions regarding such issues as aging in place, nursing home care, end-of-life matters, and additional supports. Abery, Simunds, & Cady (2006) found that older individuals desired to exercise significantly less control over health care decision-making than younger adults although they did not differ in level of self-determination

**Health Interventions.** Although there are numerous interventions related to health incorporating self-determination, there is a limited body of evidence-based research regarding outcomes, particularly

long-term outcomes. Several well-known interventions that target health utilize strategies that enable participants to acquire or reinforce skills, behaviors, and attitudes related to self-determination while simultaneously being introduced to, and engaged in, new health-related content areas. Common components of health-related interventions include: 1) Understanding the impact of personal behavior on health; 2) Developing personal health goals and plans; 3) Using “resource tools” to engage in goal-driven behaviors and to self-monitor and self-evaluate progress toward goals; 4) Maintaining and reinforcing health goals and plans over time; and 5) Working with support people to facilitate goal achievement and sustainability.

Promising interventions that can be used or adapted to promote self-determination in health include health interventions with some evidence base (e.g. Baylor College of Medicine, 2009), evidence-based self-determination interventions targeted at other life issues that might be adapted to health (e.g., Marks, Heller, & Sisirak, 2006), and health interventions designed for non-disabled populations that may be adapted for people with disabilities.

An exciting new approach for promoting self-determination in health and wellness among people with disabilities involves the use of technology. This includes: internet-based technology that fosters consumer-driven models, software and hardware that allows for customizable

design and for independently accessing and interacting with pre-programmed pictures, video, and audio instructions, and telemedicine technology (remote patient-provider interaction) that can facilitate health information, communication, and access to care and supports. Individuals with intellectual and developmental disabilities can effectively access the Internet when using tools designed specifically according to their needs, and technology-based approaches can improve care for people with chronic conditions and the frail elderly (Davies, Stock, & Wehmeyer, 2003). While further assessment is necessary, technology represents a major advance in the management of personal health for this population across the lifespan, overcoming barriers related to location, access, literacy, and cost.

### **Conclusions**

A life span approach to self-determination takes into account both the developmental stage and the social ecological aspects. The expression of self-determination is also shaped by opportunities in family, school, vocational, and residential environments. Also such practices and policies such as consumer-direction in supports and training interventions that teach elements of goal-planning and choice-making and self-regulation contribute to greater self-determination of individuals with developmental disabilities.



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