

# NATIONAL GATEWAY

## TO SELF-DETERMINATION



SEPTEMBER 2012

Research to Practice in  
Self-Determination

Issue 3:  
Self-Determination  
and Health

### LEARN ABOUT:

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Determination in Reducing  
Health Disparities

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Health Self-Management

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## Research to Practice in Self-Determination Series

### Introduction

People who are self-determined make things happen in their own lives. They know what they want and how to get it. They choose and set goals, then work to reach them. They advocate on their own behalf, and are involved in solving problems and making decisions about their lives.

The purpose of this series, Research to Practice in Self-Determination, is to describe key issues in the field of developmental disabilities that can be enhanced by considering efforts to promote self-determination. Each issue is prepared with a social-ecological framework in mind. This framework calls for strategies for intervention and support to take into account both the capacities of the person and the demands of the environment. Interventions to promote self-determination should focus on enhancing personal capacity, improving opportunity, and modifying the environment. A series of seven issues will be produced, each focusing on a specific topic: self-advocacy, health, employment, community services, aging, family support, and siblings. The format for these issues will include definitions, a brief review of the literature, promising practices, applied examples, and targeted recommendations for

scaling-up efforts. This series is intended for use by people with developmental disabilities, family members, professionals, state and federal agencies, and academic programs. By collaborating with and enabling each of these entities, the goal of full inclusion for people with developmental disabilities can be realized.





# NATIONAL GATEWAY

TO SELF-DETERMINATION

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# Self-Determination and Health

David O'Hara, PhD

This Research to Practice Guide will focus on the potential of promoting self-determination in health which has only recently been explored as a means of reducing the ongoing and significant health disparities experienced by people with intellectual and developmental disabilities (I/DD).

The existence of persistent health disparities among people with I/DD was first confirmed by the Surgeon General's 2001 report, *Closing the Gap*. Since then, the Healthy Athletes Program of Special Olympics has consistently demonstrated high levels of unmet health need in the areas of vision, hearing and dental care (Corbin, Holder & Hood, 2005). A recent study of Medicaid expenditure data found that people with I/DD were six times more likely to have Type II diabetes than people without intellectual disabilities, as well as having an average of four other chronic health problems (Reichard & Stolze, 2011).

Until recently, health care strategies to deal with these health disparities have tended to focus on better training for primary care physicians, dentists, and other health care providers (Corbin et al., 2005) or the use of checklists by practitioners to identify unmet health needs (Robertson, Roberts, Emerson, Turner, & Greig, 2011). Not until the international conference held at the Westchester Institute for Human Development in 2003, was it suggested that promoting self-determination in health should be a key strategy in reducing health disparities. (Scheepers et al., 2005). Articles in this Guide by Vitale, and Marks & Sisarak describe some of only a limited number of projects that have specifically focused on providing accessible information, supports, and tools directly to the person with I/DD or their caregivers in order to achieve better health.

This Research to Practice Guide reviews the current state-of-the-art efforts to reduce health disparities among people with I/DD by increasing opportunities for self-determination in their health care; that is, opportunities for health self-management, self-advocacy, decision-

making, and choice. It will describe the current small body of research focused on enhancing self-determination in health for people with I/DD, but will not be limited by this. While existing formal research on the role of self-determination in health might be incomplete, this Guide will also tap into a more extensive body of expert knowledge — from the experiences of self-advocates, family members, and professionals — that is ready to be translated into practice.

Among the barriers to effective health care is the issue of how well a person understands and follows health instructions, usually defined as how health literate they are. But the Institute of Medicine reported in 2010 that only 12% of Americans have “proficient health literacy”; in other words, only 12% follow health instructions well enough to achieve better health care. So almost by definition people with intellectual disabilities are not likely to meet current standards of health literacy. This Guide explores existing and developing practices that can support what we are calling “functional health literacy” for people who have reduced potential for achieving existing definitions of health literacy. Several articles describe successful peer-supported models of health promotion based upon curricula designed for people with I/DD. Technology will also play a significant role in supporting people with cognitive limitations to become more involved in their health care. The Guide includes an article by Stock, Davies & O'Hara summarizing research underway to design health self-management applications for direct use by people with I/DD, employing accessible smart technologies such as touch screen tablets and mobile phones. Viewing health literacy as a behavioral concept, this article describes how prompting and coaching features of smart technologies can help people with intellectual disabilities follow healthy routines, for example in nutrition and exercise, to alter their lifestyles and achieve better health.

Much of the “knowledge-to-practice” incorporated into the Guide comes

from people with I/DD themselves and their families, who see opportunities for better health self-management, self-advocacy, and self-direction in their current experiences with the health care system. They are looking for organized ways to make their voices and opinions heard in order to increase their personal involvement with, and control of, their health care experiences. The Guide presents several articles by self-advocates and parents who share experiences about how to promote self-determination in health self-management. Recently, existing health care surveys have been translated into accessible formats for use by people with I/DD, allowing them to express their satisfaction with the services they receive and directly express their opinions about choice- and decision-making in their daily lives (O'Hara, Davies, et al, 2010). . Using customer feedback to improve services and health outcomes is an important trend in health care, and the ability of people with cognitive limitations to provide such feedback, is a significant development.

Good health for people with I/DD depends on successful ongoing interactions between the person and caregivers with their health care team. Therefore, training health care professionals to support people with I/DD in achieving health literacy and self-determination is another important topic covered in the Guide. Those who educate health care professionals have developed training curricula and health practice guidelines to accomplish these goals. Specific competencies include; how to enhance the individual's experiences with health practitioners, skills for effective communication, and methods that make it more likely that people with I/DD will adopt better health promotion, wellness, and prevention activities (See the articles by Vitale, and Marks & Sisarak). This Guide also contains articles by several practitioners who describe their efforts to incorporate self-determination promotion into their practices. It describes several new and promising curricula designed to enhance



the skills of people with I/DD and those who support them, in working with their health providers to become more actively involved in their health management.

Finally, the Guide brings a real life view and important perspective through personal stories by people with I/DD, family members, and practitioners, about what works and what does not. Our task is to create a climate for integrating what we know about individual empowerment and self-determination in health for people with I/DD, with effective professional training and a supportive environment. In this way, the health care community will be equipped with, and able to use, a range of effective communication strategies, cognitive and behavioral supports, and adaptive technologies to better engage people with I/DD in taking charge of their own health.

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# The Role of Self-Determination in Reducing Health Disparities Among People with Intellectual and Developmental Disabilities

David O'Hara, PhD

In 2003, an international group convened at the Westchester Institute for Human Development and made one of the first explicit statements identifying the promotion of self-determination as a core strategy in the reduction of health disparities among people with intellectual and developmental disabilities (I/DD). The group stated, "All processes to reduce health disparity should include a focus on promoting and enhancing individual education and choice over healthcare and health-related decisions" (Scheepers et al., 2005). Among the recommendations from this international group were the ideas that "support systems should enable" people with I/DD to exercise self-determination, and they should be assumed to be capable of exercising "greater control over their lives."

These recommendations have a lot of history to overcome. An early report found

that for over 50% of people with I/DD, others make health care decisions and choices for them (Wehmeyer & Meltzer, 1995; Shogren et al., 2006). In fact, the ability to exercise self-determination at all often depends on the living environment of the individual with I/DD (Stancliffe, Abery & Smith, 2000). A recent study from the Netherlands interviewed people with I/DD about their diabetes and their health care and found an almost complete absence of efforts to improve the health status of their study groups by promoting their active engagement in self-determination activities in their health care experience (Cardol, Rijken, & van Schroyensteen Lantman-deValk, 2012). However, the accumulation of evidence on the extent to which intellectual ability relates to specific health disparities should now provide us with an impetus for change. For example, people with

cognitive limitations are almost six times more likely (19.4% vs. 3.8%) to experience Type 2 diabetes than the general population (Reichard & Stolze, 2011).

But enhancing self-determination on its own will not be enough to substantially reduce health disparities. As the international group also found, there are other factors at work. The concept of disparity in health is often used to highlight population inequalities which are politically important, such as health disparities between different racial and ethnic groups. But for people with I/DD this simple relationship is less clear. There can be several reasons for differences in health such as poor access to healthcare for people or an increase in personal disease susceptibility as a result of a genetic syndrome such as Down syndrome. An understanding of health disparity as it relates to people with I/



DD must reflect multiple factors. The international workgroup found evidence to propose four working definitions of health disparity, characterized by: (1) decreased life expectancy; (2) increased morbidity, such as the co-occurrence of chronic health conditions; (3) increases in negative determinants of health, such as poverty; and (4) differences in both access to health care and the quality of services.

The term, “cascade of health disparities” has been used to capture the cumulative impact of these different sources of health disparity and their contribution to poorer health outcomes for people with ID/DD (Krahn, Hammond, & Turner, 2006). Many people with I/DD start life with multiple adverse health conditions or begin to experience the health consequences of coping with multiple chronic health conditions throughout their life course (figure 1).

These health disparities are particularly striking when comparing the prevalence rates for chronic health conditions (figure 2, Reichard, Stolze & Fox, 2011).

Access to appropriate health care then adds its own contribution to the health disparities between people with I/DD and the general population. Again, Medicaid expenditure survey data highlight the critical importance of access to preventive care for people with I/DD, and that they are often at a disadvantage (figure 3, Reichard, Stolze & Fox, 2011).

The importance of regular health check-ups to either identify or ensure attention to critical health care needs is gradually gaining acceptance (Robertson, Emerson, Turner, & Greig, 2011). Compounding the problem of health

disparity among people with I/DD is the adverse impact of socio-economic conditions on access to health care (Emerson, Hatton, & McLean, 2007).

There is limited research that specifically addresses how increased self-determination for people with I/DD might improve their health experience and health outcomes, but the research that does exist offers several indicators of such a positive effect (Shogren et al., 2006). For example, Wehmeyer and Palmer (2003) found that youth who left high school with higher levels of self-determination were more likely to be employed in jobs with higher wages and health insurance. This suggests the potential of self-determination to positively impact socioeconomic status, one of the fundamental determinants of health for people with I/DD (Graham, 2005). The right to consent to medical treatment is another critical first step in promoting self-determination in health. Wehmeyer and Metzler (1995) found in their survey of opportunities to express self-determination in everyday life that only 18% of people with I/DD indicated they independently consented for medical care, another 26% indicated they consented with support, but the majority, 56%, indicated someone else consented for them. Yet research has demonstrated that people with mild to moderate intellectual disabilities do have the capacity to consent to standard medical treatment, and that with support they can also take an active role in decisions about more complex treatment (Cea & Fisher, 2003).

Other research on the concept of the quality of life indicates that there is interaction among the core dimensions

(Schalock et al., 2002), so that efforts to promote self-determination have the potential to influence the health-related dimensions of physical and emotional well-being. Thus the skills and resources that promote self-determination in general should also have the potential to enable people with I/DD to better manage their own health and medical care and achieve better health and wellness outcomes. Research on the leading evidence-based model of chronic disease care (Wagner et al., 2001) has demonstrated that chronic disease self-management educational programs are effective. Participants in such programs achieve improvements in health behaviors, self-efficacy, health status, and healthcare use. New smart technologies provide a variety of accessible and appropriate health promotion and wellness materials designed to enable people with I/DD to learn about their health needs and engage in behaviors that promote positive health and medical outcomes (see articles in this Guide related to the “*My Health, My Choice, My Responsibility*” and “*Self-Determination, Technology and Health*”). By increasing the skills of people with I/DD so they can become more engaged and effective in the management of their own health and wellness, and enhancing the capacity of health delivery systems to provide access and cognitive supports, the important goal of reducing health disparities for this population may finally be within reach.

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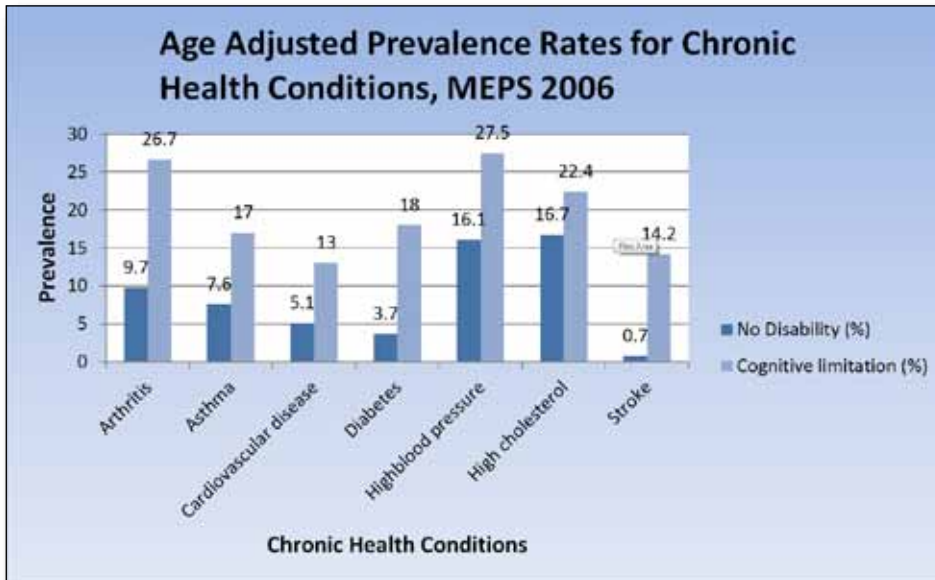
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**Figure 1**  
**Higher Rates of Adverse Health Conditions for People with I/DD**

Condition	Ouellette-Kuntz et al., 2005	Krahn et al., 2006
Communication limitation	~30%	
Physical Disabilities	~30%	21-49%
Behavioral/ psychiatric	~30%	10-99%
Sensory (hearing, vision)	~10-20%	17-70%
Epilepsy and neurological disorders		33-63%
Dermatology		11-43%
Fractures/ lacerations		8-10%
Gastrointestinal		9-45%
Cardiovascular		

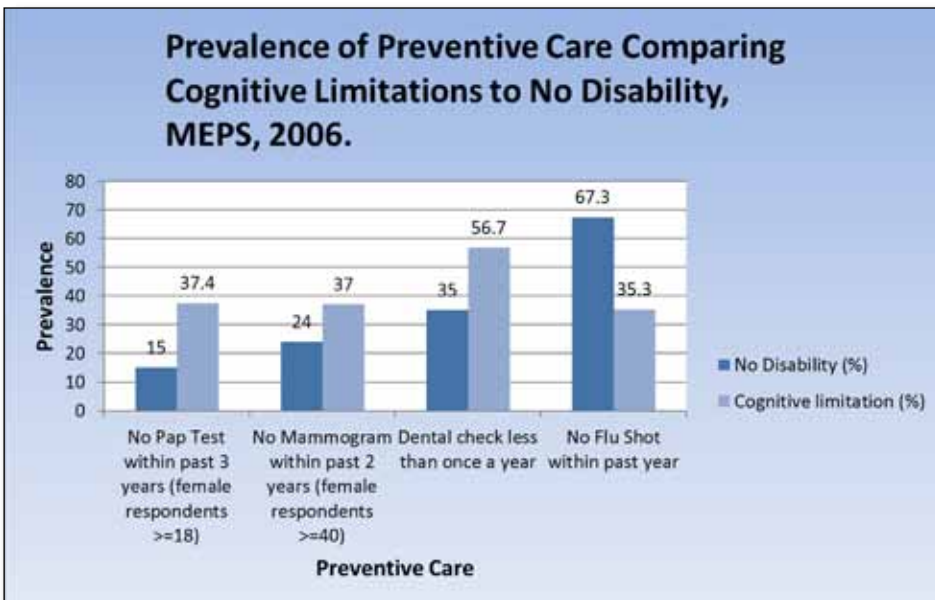


Figure 2



Reichard, Stolze and Fox, 2011

Figure 3



Reichard, Stolze and Fox, 2011

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# Health Matters for People with Intellectual and Developmental Disabilities: *Take Charge!*

Beth Marks, RN, PhD and Jasmina Sisirak, PhD, MPH

People with intellectual and developmental disabilities (I/DD), along with their families, and community-based organizations (CBOs) have advocated for their rights and opportunities in many areas of community life, including education, employment, housing, recreation, commerce, and civic engagement (Marks, Sisirak, & Heller 2010a). Access to health care, health promotion, and disease prevention is critical in being able to achieve and sustain community engagement; however, people with disabilities continue their struggle to receive accessible (e.g., affordable, available) and acceptable (e.g., culturally relevant, satisfactory) health care. Like other under-served populations, health promotion activities can enable people to take control over and to improve their health (Pan American Health Organization, 2001).

Extending advocacy to health and wellness activities is a key element for bridging equity gaps and achieving self-direction among people with DD. HealthMatters™ CAP is an NIH-funded collaboration which aims to enhance health status and optimize full community participation of people with I/DD across the lifespan. Through HealthMatters™ CAP, we are introducing a new approach, in which, two CBOs (NorthPointe Resources of Zion, IL and ARCA of Albuquerque, NM) and an academic institution (University of Illinois at Chicago) are working together to find practical

solutions using evidence-based curricula and training to improve health. Currently, we are building the HealthMatters™ CAP infrastructure to facilitate and sustain healthy choices and behaviors among people with DD to improve their health status through the following:

- **workforce capacity development for health promotion in community sectors;**
- **health advocacy capacity building for people with DD; and,**
- **active participation among people with DD in health promotion and health advocacy ([www.HealthMattersProgram.org](http://www.HealthMattersProgram.org)).**

## Community Engagement

With the need for equality in health care for people with DD, CBOs supporting people with DD have a leadership role within their communities to advocate for improved access to quality health services, including health promotion and disease prevention. Disability services professionals are key liaisons to provide training across community sectors to improve health literacy among people with I/DD, their families, and professional and direct support people.

The **HealthMatters Train-the-Trainer Workshop: Becoming a Certified Instructor** (Marks & Sisirak 2008) is an evidence-based, interactive workshop instructed by Advanced Certified Instructors. During the workshop, participants from community organizations are provided organizational and individual support to implement a tailored 12-week physical activity and health education program that can be personalized to meet the needs of people with DD. This program uses the evidence-based curriculum entitled *Health Matters: The Exercise and Nutrition*

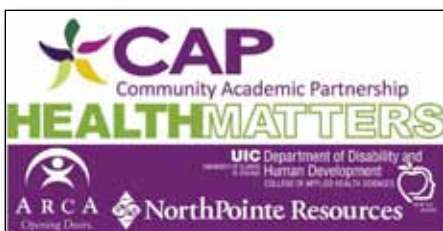
*Health Education Curriculum for People with DD* (Marks, Sisirak & Heller 2010b).

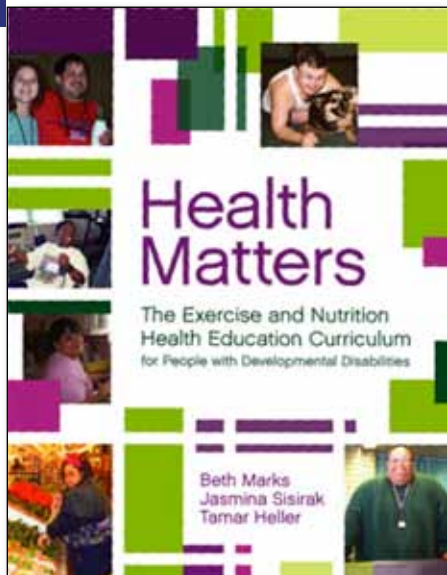
The one-day workshop aims to teach participants how to do the following: 1) start and implement a physical activity and health education program using the *Exercise and Nutrition Health Education Curriculum*; 2) identify strategies for motivating and engaging individuals with DD in a physical activity and in health education; 3) teach core concepts related to physical activity and nutrition (e.g., heart rate, blood pressure, use of equipment, safety); 4) support people with DD to incorporate physical activity and healthy lifestyles into activities of daily living, and, 5) evaluate the effectiveness of a health promotion program.

People with DD have a right to receive education and services that promote their health. The *HealthMatters Workshop* incorporates the concepts of choice, self-determination, self-efficacy, self-advocacy, rights and responsibility. ***For maximum involvement of people with DD in making and achieving physical activity and nutrition goals, having the power of direct support staff and organizational support in the provision of health promotive rather than curative activities can improve health outcomes.***

## Health Advocacy

The lives of people with DD incorporate a culture of interdependency in that many people live their entire lives relying on their family members and multiple professionals for support (Carnaby 1998). People with DD continue to lack control over situations and practices influencing their lives and health status. As such, in addition to the need to build skills among individuals with DD, ***building collective efficacy among proxy agents*** such as health care professionals





and direct care professionals is imperative in our efforts to foster self-direction.

The *Building Capacity to Promote Health Advocacy among People with DD* workshop uses an evidence-based curriculum (Marks Sisirak & Cutler 2008) that aims to increase understanding of the health care experiences and the needs of adolescents and young adults with DD among health care professionals and their caregivers. This workshop covers the following four critical areas for increasing and supporting health advocacy skills among people with DD:

- **Health Care Interactions: Charity to Advocacy** - Review the historical factors that impact attitudes, beliefs, and treatment of people with DD.
- **Health Promotion: Beyond Illness Care** - Discuss determinants of health and issues related to nutrition, physical activity and fitness, and sexuality.
- **Universal Design: More Than Ramps** - Identify concepts related to universal design and strategies to achieve physical, communication, and programmatic access.
- **Health Advocacy: Culturally Relevant Care** - Obtain information about community-based and web-based resources to advocate for culturally relevant care.

Building individual health advocacy skills increases an individual's confidence in changing behavior as well as the ability to role-model to peers. Developing collective self-confidence for health advocacy can strengthen a common voice, improve health advocacy, and increase

group and self-directedness to promote social change in health care for people with I/DD (Bandura, 2000,1994).

## Peer Support

People with DD can contribute to their own well-being by becoming knowledgeable about their health and health resources, and by becoming active participants in health promotion activities. The *Peer to Peer: HealthMessages Program* (Marks, Sisirak, Medlen & Magallanes 2012) provides an evidence-based workshop for people with DD to become a Healthy Lifestyle Coaches (HLCs) and deliver health messages to their peers. HLCs are leaders who can give their peers new health information and can show them how to take better care of their bodies over a period of time. Through corresponding *Weekly HealthMessages Booklets* and *HealthMessages Wristbands*, peers are encouraged to *Take Charge* and *Pass On* the weekly health message. This program provides tools for people with I/DD to increase confidence, knowledge, and health advocacy in becoming peer HLCs, and builds social support, knowledge, and advocacy.

Health promotion must be based on the needs and lifestyle preferences of individuals. Support from health and allied health professionals and caregivers, and increased access to health promotion, health education, and disease prevention activities can reduce the health disparities experienced by people with I/DD resulting from under-diagnosis and misdiagnosis (US Department of Health and Human Services, 2001). Having community support that helps an individual promptly access comprehensive health care can promote self-direction and full and sustained community participation.

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# Special Olympics: From Health Disparities to Athlete Leadership Programs

Matt Holder, MD, MBA

Since its inception over 40 years ago, Special Olympics has provided sports opportunities for people with intellectual and developmental disabilities (I/DD). For more than a decade Special Olympics has vigorously pursued ways to use this sports platform to reduce health disparities and improve the health of people with I/DD. Through its cooperative agreement with the U.S. Centers for Disease Control and Prevention, Special Olympics has conducted and supported research designed to improve the health of people with intellectual and developmental disabilities through the development of health promotion programs that support self-determination (for example the self-directed exercise and nutrition programs of Marks & Sisarak in this guide). It has also developed new programs and strategies such as “Unified Sports” and the “The Healthy Athletes Program” designed to support everyday participation in sports activities by people with I/DD as a means by which they can achieve better health. The Unified Sports Program has furthered the inclusion/integration movement by creating competition opportunities for sports teams that consist of athletes both with and without I/DD. And one of the highlights of the athlete empowerment movement at Special Olympics is the Athlete Leadership Program.

This evolution in the role of Special Olympics took a critical step with



Loretta Claiborne, a Special Olympics athlete, testifying before U.S. Senate Appropriations Committee hearing

publication of the report “Changing Attitudes, Changing the World: The Health and Health Care of People with Intellectual Disabilities” (Corbin, Holder, & Hood, 2005). This summarized the results of a series of research studies that described the persistence of health disparities and almost universal absence of any focus on the care of people with intellectual disabilities in medical and dental student and residency programs. One avenue for improved health that continues to be pursued is how to create an accessible and transportable health record for athletes participating in Special Olympics programs around the world to help improve their access to appropriate health care. Another is through collaboration with various University Centers on a range of health promotion interventions designed to improve the overall health of people with I/DD. A third focus is on achieving better health outcomes through the improvement of health professional education and the development of focused curricula and health professional education experiences.

The fourth and most recent strategy –*the Athlete Leadership Programs*– is designed to empower individuals with I/DD to become leaders in their communities promoting participation in sports as a pathway to improved health. These Athlete Leadership Programs are now in existence in 67 countries around the world. Athletes who participate in Athlete Leadership Programs work with mentors to enhance their communication abilities and presentation skills so that they can confidently participate in any public forums and conversations about the link between participation in sports and improved health.

Some of the graduates of the Athlete Leadership Programs are selected as Sargent Shriver International Global Messengers. These Global Messengers become extremely adept at telling their personal story, sharing their opinions and inspiring others. A key goal is that, by

example, Global Messengers demonstrate the potential for people with I/DD to play active roles shaping policies and practices that create opportunities for improved health and quality of life.

**Our Reach Globally**

- Nearly 4 million athletes
- Nearly 50,000 competitors around the world each year—more than 136 competitions hosted each day
- More than 1 million coaches and volunteers
- 32 Olympic-type summer and winter sports
- Special Olympics Assembled Programs in more than 170 countries
- 7 Global Regional Offices—China, Egypt, Ireland, Panama, Singapore, South Africa and the United States

**Unified Sports**

Unified Sports® gives individuals with intellectual disabilities (athletes) and individuals without intellectual disabilities (partners) side-by-side on competitive sports teams. As the fastest growing sports initiative within Special Olympics, Unified Sports has been shown to raise the self-esteem of all participating athletes—with and without intellectual disabilities.

**Health Disparities**  
Findings from past four Special Olympics World Games (average ages 23)

HEALTH PROBLEM	PERCENTAGE
Unrevised Tooth Decay	45.7%
Referred for Urgent Follow-Up Care	12.5%
Failed Hearing Tests	35.2%
Low Bone Density	13.4%
Eye Disease	13.3%
Gulf Abnormalities (Heart)	45.6%
Bone Deformities	15.2%

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# Self-Determination, Technology and Health

Steven E. Stock, Daniel K. Davies, and David O'Hara, PhD

AbleLink Technologies, Inc.

The collective health disparities faced by individuals with intellectual and developmental disabilities (I/DD) are well documented (Shogren, Wehmeyer, & O'Hara, 2005; Scheepers, et al., 2005). Disparities have been identified in major health domains such as accessing and participating in health promotion activities, having affordable and appropriate medical care and preventive screening procedures, engaging in physical activities and exercise, and managing ongoing chronic conditions such as high blood pressure or diabetes.

Various strategies have been attempted to address these differences. For example, activities directed toward increasing the education and knowledge of health professionals about the unique needs of people with I/DD have been implemented, but with limited apparent effect on reducing these health disparities. Another approach aimed at this population itself is to increase opportunities for self-determined behaviors in areas related to positive health and wellness outcomes (Krahn, Hammand, & Turner, 2006; Shogren, et al., 2005; Scheepers et al., 2005). Examples of self-determined behavior in relation to health issues include providing one's own consent for standard medical treatments, participating in educational activities to promote self-management of chronic conditions and healthier lifestyles, and practicing self-direction in residential and vocational services.

## Technology and Self-Care: Scheduling and Prompting

The new smart devices such as iPhones, iPads, and other touch screen tablet computers, with built in scheduling and multimedia capabilities, offer many ways to use technology as a support for a variety of self-directed health care activities by persons with I/DD. These include dietary management and meal

preparation, coached exercise programs, and self-management routines for chronic and episodic health conditions such as taking your own blood pressure.

Another example of prompting systems that can be effective in supporting self-direction in health self-management was demonstrated in a study conducted with a group of 32 seniors in various stages of early cognitive decline. Each participant attempted to complete the familiar task of taking one's own blood pressure, as well as the completely unfamiliar task of filling a weekly pill organizer for another person, using a step-by-step multimedia task-prompting system operating on an Apple iPad (Davies, Stock, Qualls & Doffings, 2010). Senior participants were collectively able to follow the system's prompts to fill a pill organizer at a 99.1% accuracy rate with no prior knowledge of how many or what type of pills to put in the organizer for each time of day (e.g., morning, noon, evening, etc.).

## Technology and Healthy Living

Other areas where technology can provide opportunities for consumer choice and participation in wellness and health promotion activities include nutrition planning and meal preparation, dieting, and exercise. In two studies, picture-based "smart" software was used to support increased involvement in menu planning and achieving a healthy diet (Stock & Davies, 2003; Stock & Davies, 1997). In each project, computer-generated prompts and food pictures guided users with I/DD through the process of completing a series of daily menus.

The first study demonstrated significant decreases in the amount of staff assistance required to complete menu-planning activities, and also resulted in menus with improved nutritional values (e.g., lower fat content, more varied food group representation). This was accomplished in part by a software flow that prompted users to "now choose

something from the vegetable group" during meal planning to assure inclusion of underrepresented food groups. The second study confirmed these findings and provided additional insight into important aspects of menu planning software. For example, actual digital images were found to be more effective than clip art images of food, and food images needed to accurately depict recommended portion sizes of food items. Additionally, like many mainstream menu planning software systems, the second prototype was built with the capability to automatically adjust what food items were presented during menu planning based upon previous selections; in other words, if the ceiling of fat calories set for a given day or meal is being approached while the menu is being built, the system automatically reduces the availability of high fat items during subsequent menu planning.



Nutranet – a self-directed picture-based meal planning program to facilitate independent living and nutrition education

Once those meals are planned, technology can assist with meal preparation. A partnership between AbleLink Technologies and Attainment Company has developed a series of over 60 different step-by-step multimedia meal preparation applications for the iPad based on tasks from Attainment's *Look-n-Cook* cooking instruction series. Features of the *Visual Impact* app allow each step to be replayed if needed, or for previous steps to be reviewed. An



upgrade to the *Visual Impact Pro* system also makes it possible for someone to create one's own multimedia instructions for preparing favorite meals. *Visual Impact Pro* provides a simple to use interface on the iPad that employs the built-in camera to take pictures, and includes on-screen controls to record instructions for each step in the meal.



Screens from the Visual Impact Pro iPad app

The concept of creating personal, customized multimedia training tasks using utilities such as *Visual Impact Pro* or *iPrompts* has implications for self-directed health care that reach far beyond healthy eating. This multimedia task analysis approach provides the opportunity to create instructional sequences for virtually any health-related self-care task and health management activity in areas such as diabetes management, completion of therapy routines, the proper use and maintenance of prosthetics and devices, and many others.

### Technology and Travel: Getting to Appointments

The need for greater self-determination in health care does not end within the home or school environment. Accessing community health resources has also been identified as an area of

significant health disparities for people with cognitive disabilities because of limited support for independent transportation and communication (Shogren et al., 2005). Global Positioning Systems (GPS) have shown promise in increasing transportation options, including use of public transit systems (Stock, Davies, Wehmeyer & Lachapelle, 2011). This study demonstrated how a specialized GPS-supported multimedia software/smart phone system could provide customized prompting for navigating public bus systems.

This commercially available GPS system, called *WayFinder*, allows travel trainers to create travel instructions for navigating specific bus routes using GPS-based audio and visual prompts. For example, audio cues can be launched based upon the specific location along a route, to prompt travelers to “Stay on the bus, this is not your stop” or “You are almost to the doctor’s office, so pull the cord now to signal your stop.” Picture cues of landmarks can also be incorporated to support faster learning of new routes. To promote community safety, and thus encourage opportunities for independent community access, this system also offers an option that allows the location of the user to be tracked via Google Maps by a parent or caregiver. Research on *WayFinder* has demonstrated significant reductions in travel training requirements for learning new bus routes, which could enable greater independence in accessing community health resources. Additionally, an agency-wide evaluation of the *WayFinder* system headed by a large adult services agency in New Mexico has documented an 85% increase in use of fixed bus routes and an estimated cost savings to the agency of \$55,000 over a six month period.

### Technology, Communication, and Remote Monitoring: Telemedicine

Researchers have recently noted the importance of augmentative communication devices to support health literacy, communication, and collaboration, to ensure successful health outcomes for young people with I/DD and complex communication needs (CCN) who are transitioning to the world of

adult health care (Naughton, Balandin, Kennedy & Sandmel, 2010). This is a two-way task involving “a need to help youth with CCN prepare for adult health care services, and to assist adult health care service providers in learning how to work with individuals with CCN.” The variety of speech support devices and software systems available is well beyond the scope of this paper, and people should consult with an augmentative and alternative communication specialist to find systems and devices that meet their needs.

Another area of difficulty for many people with I/DD is reporting their health status to caregivers and health care professionals. Particularly for individuals living in independent or semi-independent community living situations, sleep problems, minor injuries, or issues around follow-up care often go unreported without face-to-face contact with a caregiver. The senior care industry is largely driving the development of numerous remote health monitoring and reporting systems designed to provide these types of supports. For example, American Telecare’s *Life View Patient Station* provides easy to use tools targeted at older Americans that support independent wound care, therapy compliance, and medication verification. Often, these “telemedicine” systems are relatively expensive, requiring ongoing service fees, and they aren’t designed to be independently usable by individuals with cognitive disabilities. Fortunately specialized tools designed specifically for individuals with I/DD are currently undergoing research and development.

While much of the work has been done in support of health monitoring, the emphasis on *preventive* health care is increasing. For example, AbleLink Technologies has recently begun work on a new two-year project to develop a GPS-based system to support walking exercises for individuals with I/DD. The system will provide a game-like format where users earn points and rewards for successfully completing neighborhood walking routes while locating designated landmarks under a “treasure hunt” metaphor.

In summary, demographic trends and the escalating cost of health care continue to drive innovative research and development in technologies that can increase self-direction and

self-determination for people with intellectual disabilities, autism, traumatic brain injuries, and dementia. Innovations like those discussed in this article will provide an increasing array of resources designed to promote personal involvement and control over one's health status, thereby enhancing both self-determination and cost-efficiencies through assistive technologies.

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Using Nutranet – a self-directed picture-based meal planning program to facilitate independent living and nutrition education

## Using Technology as a Support for:

- Scheduling and Prompting
- Guide for Healthy Living
- Getting to Appointments
- Remote Monitoring



# My Health, My Choice, My Responsibility: A Curriculum to Promote Health Self-Advocacy

Marilyn S. Vitale, MA

“I want to eat healthier, but Tommy always has potato chips and he leaves them on the kitchen counter for all of us to eat. I know it’s not good for me, but I can’t help eating them. I don’t know what to say or do about it.” This comment was part of a discussion on healthy choices and how to speak up in order to achieve a healthy lifestyle—key components of being self-determined in the health arena.

For persons with intellectual and developmental disabilities (I/DD) to achieve these two goals, they need to have the knowledge to make informed choices and the skill to advocate for what they need to be healthy. A training program developed at the Westchester Institute for Human Development, entitled *My Health, My Choice, My Responsibility*, focuses on both these areas—health information and health self-advocacy—by incorporating activities that develop skills and increase knowledge. The format involves eight group training sessions conducted by two trainers, one of whom is a self-advocate. During sessions participants learn the material through discussions, activities, and visual aids.

Session topics include such areas as:

- Take charge of your health
  - Healthy lifestyles – Not being sick doesn’t make you well
  - Setting goals, getting support, following through
- Develop a health plan
  - Knowing your health history
  - Understanding your own health and wellness needs
- Be a health self-advocate
  - Preparing for medical appointments
  - Speaking up for good health

Each session consists of information on the topic, as well as “*Things to Remember*” bulleted summaries, activities to promote advocacy, and a *Goal Form*. The session

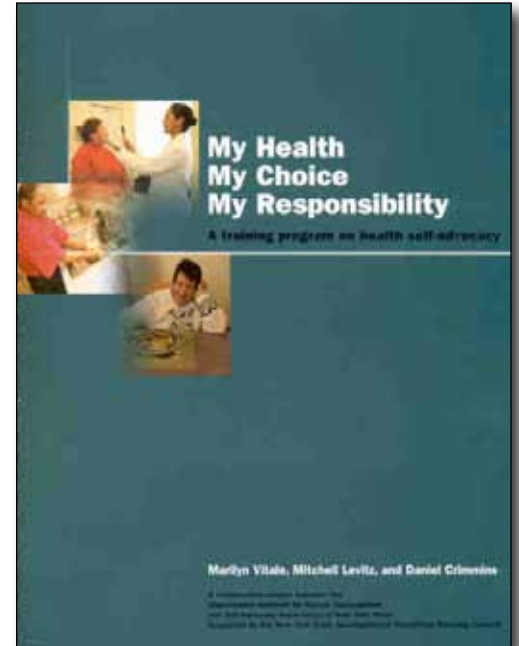
begins with a list of “*Things we’ll do today*” and a list of “*After this session I will*” that states what participants will know by the end of the session. Participants set goals to work on for the next session. They are encouraged to identify the steps they need to take to reach their goals and to get support if they need it. Participants may decide to include these goals in a long-term health plan. Personal stories are included throughout the curriculum, and participants are encouraged to share their own stories.

The program includes three tools to help participants take control of their health. *My Medical Appointment* is a form to help prepare for medical appointments and to help follow through with a doctor’s instructions. It prompts the user to focus on the reason for the visit and to write down questions. The *Health Information Form* is a record of the person’s health needs and medical history. *My Health Plan* contains health goals developed during the course of the program. These are also available online.

The session entitled *Be a Health Self-Advocate* is a good example of combining information and self-advocacy skill-building. It includes details on what occurs while visiting the doctor for either an annual exam or when one is sick, information on making medical decisions, advice on talking with your



The screen display for the online version of the curriculum “My Health, My Choice, My Responsibility” for health self-advocates



doctor, and ideas about preparing for a medical appointment. Self-advocacy activities include a role-play in which the “physician” speaks only to the support person, an exercise asking questions using *My Medical Appointment*, and an activity exploring the risks and benefits of a surgery by dividing the group in two groups to look at both sides of the issue.

A *Trainer’s Manual* offers guidelines for discussion for each session, sample activities, training techniques, suggestions for room layout and structure of the group, and community and other resources. Trainers are encouraged to make contact with persons from the community who can add their knowledge and skill to the content of the various sessions. Examples include physicians, nurses, physical trainers, nutritionists, psychologists, and social workers.

A pre/post survey was developed to measure improvement in understanding content or change in behavior in each session. Initially, the program was conducted with two focus groups and three replication groups totaling 32 participants. All five groups completed pre and post surveys; the surveys were revised significantly after the focus groups.

Subsequently, eight groups from seven agencies across New York State completed the program totaling 47 participants. Pre and Post Surveys were received from seven out of the eight groups. The questions in the survey were rated either “Usually” “Sometimes” or “Hardly Ever.” The greatest improvement from the pre to the post survey occurred in the following questions: I speak up when I have an idea; I speak up when I need information about my health; I have a health plan (yes or no); I ask questions when I go to the doctor; I know what to do if I forget to work on my healthy goals. These questions



A do-it-yourself health education screen from the iPad application “My Health, My Choice, My Responsibility”

most reflected self-advocacy skills. All 47 participants completed *My Health Plan* and were ready to work on goals.

There continues to be a strong interest in the *My Health, My Choice, My Responsibility* training program. Individuals, families, and providers across the US and New Zealand have downloaded it through the WIHD website. It is also available now as an iPad application on iTunes through a partnership with AbleLink Technologies ([www.ablelinktech.com](http://www.ablelinktech.com)). The iPad app allows individuals to hear and see the material and engage in an interactive question and answer review. It can be used individually, with a support person, or in a group with a facilitator. A *Facilitator’s Guide for the iPad Application* is also available.

There is a tremendous need for individuals with intellectual disabilities to be informed consumers of health care and to learn what is needed to be advocates for a healthy lifestyle. Many have medical issues that would benefit from healthier behavior. Individuals need to have accurate information and to understand the importance of speaking up for good health. Having support persons

as part of the program – either attending the sessions or assisting the participant in achieving goals in the community – is a way to help participants succeed in an environment that does not always encourage good choices in health-related areas. The training provided in *My Health, My Choice, My Responsibility* encourages self-determination as it empowers individuals to become self-advocates, to make good choices and decisions, and to take more control of their health.

*My Health, My Choice, My Responsibility* can be found online at [www.wihd.org](http://www.wihd.org). It has also available as an iPad application at <http://itunes.apple.com/us/app/my-health-my-choice-my-responsibility/id428382635?mt=8>

*Marilyn Vitale, MA is a Program Coordinator at the Westchester Institute for Human Development, a University Center for Excellence in Developmental Disabilities, in affiliation with New York Medical College. She is also the author of My Safety, My Responsibility, My Plan, a training curriculum on emergency preparedness for people with I/DD.*

## My Safety, My Responsibility, My Plan: A Curriculum on Emergency Preparedness

“A hurricane is coming. Do you know what to do?” An essential part of self-determination and health is to know what to do in an emergency situation and to be prepared before an emergency occurs. My Safety, My Responsibility, My Plan is a training program to help individuals reach these goals. The program combines group activities, discussion, community activities, and tasks at home in order for participants to learn about types of emergencies and to develop their own Personal Emergency Plan. They are encouraged to think about important issues that can be affected in emergencies, such as their medical, daily living, transportation, and communication needs; their support system; their emotional reaction; their interaction with first responders; and what items, information, and documents they need. In the area of health preparedness, it is vital that all health related items, such as supplies of medications, phone numbers of doctors and other health providers, needed medical supplies, equipment and records, and insurance information are part of the Personal Emergency Plan.

Individuals who wish to complete the program on their own can download the curriculum and follow along with the videos located on the new interactive site located at [www.wihd.org](http://www.wihd.org). They can see and hear about emergencies, and will be guided step-by-step to complete a Personal Emergency Plan. A supplemental Family Guide was also developed for those individuals who live with their families and must be part of a Family Emergency Plan.

# Health Self-Management: A Self-Advocate's View

Mitchell Levitz

Self-advocacy means speaking up for myself by sharing my ideas and thoughts with people about what is important to me. One way I advocate for myself is to speak up about my health. As a self-advocate, I would like to share with you some of my personal experiences related to how I advocate for my own health.

## A Circle of Support

We need to consider the decisions we are capable of making on our own, and the kinds of decisions we should get help in making. I don't need help deciding what to eat for lunch or what to wear for work. But I do ask for advice when making financial or legal decisions, and dealing with medical problems.

I have family and friends who I trust and can give me good advice. Putting together a circle of support was a very important part of person-centered planning for me. I decided who I wanted in my circle of support to help me to make important decisions in my life.

My circle includes the people who know me very well. They each have knowledge in particular areas to support me in making decisions. Of course, I wanted my family to be a part of my circle of support, including my parents, my sister, an aunt who lives nearby, and a cousin who is an accountant. And I also invited some family friends (especially a few my own age) including a lawyer, a doctor, and a nurse. As other people come into my life in the future, I might ask them to join my circle of support to play certain roles.

## Health Self-Management and Taking Charge of My Health and Wellness

I created a computer document to keep track of all of my medical appointments. This reminds me when I need to make appointments with my doctor and specialists. Before going to appointments, I find out if I need to bring any information.

I also check my records to see if I will need to get new prescriptions while I am at the doctor's office. When I go I bring my health insurance information, and I am prepared for how I am going to pay.

Sometimes my parents drive me to the appointments and help me fill out forms such as my medical history. They also help explain information that is hard for me to understand. But the final decisions are for me to make after getting their input and having the information I need to know.

And if someday, if something major happens to my health and if I am not able to make medical decisions myself, my circle of support will be there to determine what is best for me. That is why I have a health care proxy and a living will. I keep a copy of my health proxy card with me in my wallet for emergencies.

## Transportation

This is sometimes a challenge for me. But my primary care doctor and my dentist are close by so I can walk there on my own.

I take a bus into town to go to appointments with my foot doctor, so I can set up these appointments according to my own schedule.

I also see some specialists. But I have to coordinate getting a ride from one of my parents to go for my gum care and to my appointments with the eye doctor and ENT. Last year, I had an infection that needed to be removed by a surgeon. When I went to see her, she recognized me because we had been neighbors, so I had a very easy time speaking with her. I had one of my parents go with me during the procedure but I was able to handle the aftercare on my own.

## Communication is a key to health self-advocacy

I am very comfortable speaking with the doctor and the other office staff who are very friendly. But before I go, I write down questions to ask the



Mitchell Levitz enjoying kayaking

doctor and I take that list with me to my appointment. Some people I know ask the doctor to draw a picture or diagram to help explain a medical problem.

Sometimes, if I am having a more serious health problem, I ask one of my parents to go to the appointment with me, but I make sure that the doctor speaks directly to me, even though I brought my parents along for support.

When I have my annual physical I usually go by myself. Last year, my doctor suggested that I have my heart checked at the hospital, so I made an appointment for a special test. I walked there early to give myself plenty of extra time. People on staff showed me where to go and helped me register. I had a backup plan and a cell phone in case I needed to reach my family.

## Taking Medicines

It is important for me to remember to take my medicine and vitamins every day. I use a special pill box marked with each day of the week. I do a lot of traveling, sometimes for work and sometimes to visit with my family. I plan ahead and I count out the right number of pills to take with me.

I go to the drug store to buy supplies that I should keep on hand. A few times each year, I go through my medical supplies and check the expiration dates. That way I can tell what I need to throw out.

## Prevention

This is another part of healthy living. I put on sunscreen as part of my daily routine after taking a shower in the morning. I always wear my bike helmet when riding. Since I walk all over the place, I always try to pay close attention to traffic, especially when I am crossing streets.

## Eating Right

Healthy eating is a good way to maintain the right weight. For me, losing weight is very hard. I usually only eat when I am hungry. I plan out a weekly menu so that I know what foods I need to buy.

On work days, I make my lunch to bring to the office. But on my days off, I love going out to eat at restaurants. I eat vegetables and fruits, low fat milk and whole wheat bread every day.

When cooking, I am careful about cutting with a knife and using a frying pan. I always make sure to turn the oven off when I leave the house, and make sure that I have enough money or a credit card to do my shopping. When I am at the supermarket, I check the last day of sale on the food items. I also check the food in my refrigerator before eating something by checking for mold and for foods that smelled spoiled. I also check the prices to make sure nothing is overpriced and I try to buy foods when they are on sale. Sometimes I go food shopping with my father when he is going to a supermarket.

My mother often prepares home-cooked meals for me that I keep in my freezer, and that I can just microwave. When I do cook, I make something that is easy to cook like eggs, pasta, a sandwich or salad.

## Getting Good Sleep

Just like me, many people have sleep problems. I have learned that to get a good night's sleep, it is important that I do not stay up too late.

I have sleep apnea so I sometimes get drowsy during the day and start to fall asleep during meetings and workshops. This is only when I am not active and physically moving around. Two strategies that I figured out are to have a drink with me or to stand in the back of the room.

I have had a sleep problem since I was young. I had a sleep study done and surgery to help with this problem. It only helped a little. One treatment recommended was to use a “c-pap” machine at night. It worked for one of my friends, but I found it very uncomfortable. I also tried a tongue-guard. Through these experiences, I learned a valuable lesson. It is important to know myself and realize what works for me and what doesn't. I also learned that I can figure out strategies when I need to.

## Final Thoughts

My message is that having a healthy lifestyle can have a good impact on your life. It can help you feel better about yourself. I realize that each person has his or her own way of doing things and choosing how to be healthy. For me, I hope that being in charge of my own health and making good health decisions will help me live a long, active and healthy life.

*Mitchell Levitz is the Self-Advocacy Coordinator at the Westchester Institute for Human Development, a University Center for Excellence in Developmental Disabilities, in affiliation with New York Medical College. He is the co-author of the book, Count Us In: Growing Up with Down Syndrome.*

# Key Points: A Self-Advocates View of Managing Your Health

1. Self-advocacy means speaking up for yourself with doctors and other health professionals.
2. A good circle of support—family and friends—can help you make good medical decisions.
3. Taking care of your health means keeping track of appointments, taking your medications, and learning what to bring to the doctor's office.
4. If you can, learn how to travel to your medical appointments. Family, friends, and support staff can help you learn how to do that.
5. Whenever possible, choose doctors and other health professionals who listen to you and make you feel comfortable.
6. Practice how to talk with your doctor and ask questions. You should understand what to do to get and stay healthy before you leave the office—how to take a new medicine or care for an injury at home.
7. Eating right, exercising, and getting enough sleep are important ways you can take charge of your own health.
8. Preventing illness before it starts is the best way to stay healthy.



Mitchell Levitz at work at WHD



# In Our Own Words: Parents Advice on Promoting Health Self-Advocacy for Individuals with Developmental Disabilities

Barbara Levitz, Anita Abraham-Inz, Stephanie K. Brenner, KimLori Devine, Amy Lieberman and Susan Ugliarolo

## Introduction

Health is an area of particular and ongoing concern for families because health is a key determinant of quality of life throughout the lifespan. Parents play a natural and pivotal role in accessing, obtaining and coordinating health services and supports for their family member with intellectual and developmental disabilities (I/DD). However, as their children grow and develop, especially during a transition from pediatric to adult health care, the parents role begins to shift incrementally from advocating on behalf of their son or daughter, by managing nearly all health decisions, to a role of supporting self-determination by encouraging greater health self-advocacy, self-direction and self-management. Parents have a vested interest in helping their sons and daughters with developmental disabilities, to the greatest extent possible, begin to attain knowledge, understanding, self-awareness, and skills to be able to: speak out about health issues in their everyday lives, assume increased responsibility for personal actions that impact on health, and have more control of their health care choices and decisions.

In the fall of 2011, family faculty from WIHD/UCEDD sent questions on how to promote health self-management for individual with I/DD to five former LEND family discipline trainees who are parents of teens or young adults with disabilities. This article is based on their responses to the questions and provides strategies and recommendations for how families, physicians and other health providers can enhance health self-advocacy and self-management for individuals with I/DD.

## Question 1: How can families encourage health self-advocacy and self-management?

- **Determine if the individual wants to be more self-reliant.** If not, then first work on getting him or her to “buy into” being more independent.
- **Model a healthy lifestyle.** Help the family member form good habits. Be sure that daily routines follow a schedule, and remind nicely and with consistency. Plan family activities together, plan and cook meals together, and develop consistent routines for sleep, exercise and meals.
- **Set up as many routines as possible or use strategies that work** in other aspects of the person’s life. Use tools such as checklists and calendars to remind about scheduling appointments.



KimLori Devine and her daughter, Mallory

- **Break down tasks into manageable portions** and work up to the whole.
- Teach, teach, and teach. The method you use depends on the individual – his or functioning skills, capabilities, and also their living situation. The process requires sequencing --breaking a large task down into small parts.
- **To the extent possible, everyone in the family should treat a child with a disability as others are treated.** Don’t make excuses. There is a difference between a reason and an excuse. Siblings are great with this - they don’t give slack.

## Question 2: How do you find good health practitioners who support health literacy and health self-management for their patients with I/DD?

- **Speak with other families** (about qualified practitioners). Network with physicians, a good teacher or a care coordinator/service coordinator. Search disability-specific publications, websites, newspapers, magazines, local, regional, state and national support groups/organizations.
- **Find doctors who understand the needs of individuals with I/DD.** If experiences in a doctor’s office result in a relationship based on trust and respect, individuals will be more responsive to following doctor’s advice and will make and keep his or her regularly scheduled appointments.
- **Find doctors who encourage greater self-reliance in health.**



Doctors who help their patients with developmental disabilities develop a better understanding of what constitutes a health issue, how to communicate an issue and who best would address that issue.

- **Registered dietitians** often have experience with individuals with I/DD and special health care needs.
- Part of the stroke of luck is that our son's primary doctor has a family member who has special needs. So he is very well "trained" by the school of life.
- **Look beyond conventional medicine and education when it doesn't have all the answers** --- but how to decipher all the various ideas and treatments? My husband and I decided if it is not invasive, not very expensive, than why not try it? If invasive or expensive, there needs to be research. For example, we tried vision therapy. It took some time and money, had some research behind it, but was not invasive. Applied Behavior Analysis was expensive, but not invasive, and was heavily researched, so we used it. But an intravenous treatment was invasive and had no real research behind it. No deal for us.

### Question 3. What are characteristics of good health practitioners who encourage patients with I/DD to become more health literate and responsible?

- **Our doctor addresses our son directly** and gives him an opportunity to express his concerns. The doctor gives our son a chance to look to us for support in answering questions before asking us for more information. He reviews the plan of action and asks our son if he has any other questions. He plans enough time to meet with us so that we do not feel rushed.
- **The doctor takes his lead from us, he listens, he cares** and he refers us to other specialists very easily the minute I mention anything about our son that suggests this is needed.
- **I feel that we are treated with dignity and respect.** The doctors in this group make a point to speak to both the patient and the parent. They are then able to develop a treatment plan based on personal needs, choices and abilities of the patient, in coordination with parent's abilities and concerns.
- **One thing most of the doctors in this group do right** is that

they almost always ask my children how things currently are going in school. The doctors recognize the relationship that school stressors have on the health of children with I/DD.

- **My son's doctor speaks to him** about his exercise habits, drinking and smoking and the kinds of food he eats.
- **While this is not discussed at every visit**, it is addressed more frequently now that my child is 17 -- her lack of self-care impacts her health at times.

### Question 4. What can health care practitioners do to improve their practices and better accommodate the needs of their patients with I/DD and their families?

- **Be flexible with appointments.** Ask the family and individual if information can be shared with each other; keep the family in the loop; talk about a healthy life style; have office staff that "gets it" about working with folks who have a disability.
- **Develop a patient-specific checklist of additional questions to ask at each visit.** For example, check in at every visit on the last date of visit

## Key Points: How Parents Can Help Their Children to Manage Their Own Health

1. Discuss your child's health issues with him or her, including diagnoses, medical terminology, and medications.
2. Assess their readiness to become involved in caring for their own health. What role can they realistically take on?
3. Start early, with medical issues your child can manage, like eating well, personal cleanliness, and taking medications.
4. Break everything down into small steps. Keep repeating the steps.
5. Provide your child at all ages with opportunities for choice and decision-making.
6. Find doctors who listen and speak directly to their patients with I/DD and want to teach them about their own health care.
7. Encourage your child to speak with the doctor, ask questions, and ask for accommodations.
8. Practice health care visits at the doctor's office, dentist, pharmacy, and hospital.
9. Share ideas with your health professionals about what they can do to help patients with I/DD become more involved in their health care.
10. Be a good role model for your child in terms of healthy habits, and how you take care of yourself.



Barbara Levitz with her son Mitchell, working together at the Westchester Institute for Human Development

with psychiatrist/other specialist and the outcome of that visit.

- **Inquire about hobbies, leisure activities during free time and how often the child gets together with friends.** I believe the doctor would gain valuable info in understanding my child and their specific health needs if the doctor updated this type of information at every visit.
- **Be informed** by going to conferences and seminars, reading and networking with other doctors, and listening to their patients, families, and siblings.
- **Better training to know more about my son's type of disability.** However, the most important factors are not ignoring the patient, not just talking to me, but to my son, and being open to having him as a patient and learning.
- **Speaking appropriately to my child and allowing sufficient time for my child to process and respond.** The doctor subsequently continues the conversation with me.
- **The doctors will talk to other doctors when requested to do so.** However, no doctor or specialist has ever coordinated my child's care. This responsibility falls solely on me and I do not have any medical training. Often, I need to remind each specialist of my child's specific health issues/disabilities because each specialist looks mostly at the health needs related to that specific specialty and not the comprehensive needs of the whole child.
- **Help parents in their quests for the right treatment.** For example - what are the best schools to go

to? Can you refer us to someone who would know? There is so much stress, especially after the diagnosis, and at each major change in life – for example, a change to a new school. It would be nice to have some guidance from a doctor or a referral to someone else, since **they are the center of the person's medical status.**

### Question 5. What can parents do to effectively work with health practitioners to encourage health self-management?

- **Help your adolescents or young adults learn to self-advocate** and prepare for doctor visits by helping them write down their questions and comments prior to an office visit.
- **Encourage dialogue between your child and the doctor** by asking leading questions as conversation starters (for example, John, did you have a question about your medicine? or Can you tell the Dr. about your headaches?)
- **We ask prior to our appointments if our son would like to talk to the doctor privately.** The doctor does this as well when we start an appointment. During examinations, our son's privacy is respected.
- **Chart energy, mood, medication, school events, etc. on a daily/weekly basis using a child friendly chart** I found on a web-based resource. The process of using a simple chart helped my teenager understand cause and effect between sleep patterns and behavioral patterns. This information was then shared with the doctor.

### Question 6. What can parents do to promote a smooth transition of their family member with I/DD from adolescence to being a responsible adult in terms of managing individual health conditions?

- **It is no different than any other part of life.** It helps if there are other people who our son is

comfortable with: like the doctor and nurse at the doctor's office and the pharmacists at the drug store.

- **We worked in the same way as we did with our typical children.** We explained how often he should see his doctor and dentist in order to stay healthy. It requires consistent reinforcement and explanation as to the need for doctor's visits.
- **Assume competence - assume the potential for competence.** You may have to talk in shorter sentences, or sign, or teach in a different method, but believe that your child has the ability to learn, and even if your child can't express himself, doesn't mean he or she doesn't know or have an opinion.
- **Incorporate the young adult more directly in developing the treatment plan** so that he or she can develop ownership. Then find one thing or piece of the treatment plan that the child can take responsibility for. Provide visual or mnemonic cues for the treatment plan.
- **To the extent possible, parents should discuss with their young adult** whether he or she, realistically, is fully capable of managing his or her own health affairs independently at the time they become a legal adult. If there is any doubt at all, parents should consult with an attorney to determine if it is reasonable for their young adult child to sign a health care proxy, or alternatively, give his or her parent "Power of Attorney" solely over matters relating to health. As the situation changes, these decisions can and should be revisited.



Stephanie Brenner with her son, Michael

## Conclusion

We have learned from the parents' perspective about several critical issues in promoting health self-advocacy and self-management for a family member with I/DD. It is important to develop a good family/professional partnership that will guide the acquisition of positive health-related knowledge, skills, and attitudes for individuals with I/DD. Increasing health literacy and independence requires thoughtful and systematic planning, establishing mutual trust and respect, building self-confidence, and having patience and motivation. It is also vital to begin early and work incrementally, especially through the transition years to young adulthood. Health self-management is a continuous life goal that is achieved through an evolving process that has its ups and downs. But once accomplished, it can have a positive, lasting impact for both the person with I/DD and their family. For the individual, it is a critical component of becoming more self-determined. For the family, it can create a feeling of reassurance that their adult child can now manage some important issues on their own in a complex world.

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# Starting Early: Paving a Path Towards Interdependence in Health Management

## Michele Juda

"Mom, the aide did not thicken my juice. You forgot to tell them." Thus began our family's journey on the road to self-determination and self-advocacy in health care. My son has both developmental disabilities and special health care needs. How old was he when we ventured onto this path? Eight. Let me explain.

Fall is a busy and exciting time as parents send their children off to school. For parents of children with special health care needs, the back-to-school checklist is certainly a bit longer and more complicated. Sometimes despite our best efforts, something gets overlooked. This was the situation I found myself in on the first day of Devon's after-school instructional program. As a result of a swallowing disorder, he requires his drinks be thickened. That afternoon I realized I had not asked who Devon's after-school aide would be, nor did I assure they were aware of the need to thicken his juice. Oh boy! Knowing the school had always prepared his juice properly in the past, and that this need was well documented in his IEP, I decided a phone call wasn't necessary. That decision provided the opportunity to learn some valuable lessons.

I arrived to pick Devon up and immediately after pulling out of the school parking lot he excitedly shared with me he had juice in the after-school program. When I asked what kind of juice, thickened or regular, he grinned like a Cheshire cat as he announced it was regular juice. And that is when Devon took delight in reminding me not only did the aide not do what they were supposed to do, but I too was culpable in my failure to instruct them. He was bubbling with sheer joy at the idea of catching the adults in his life dropping the ball.

Lesson One: By necessity, we as parents of children with disabilities and special health care needs often focus

on what makes our children different. We are either faced with it every day, or need to highlight the differences in order to gain access to needed programs and services. We don't always consider all the ways in which our children are exactly the same as all other children. Kids love to catch their parents in the act of some mistake; it somehow levels the playing field for them. My son was no different.

Lesson Two: Devon knew he wasn't supposed to drink the un-thickened juice...he knew!! Despite all our best intentions (and what parent doesn't want to keep their child safe?), we had created a learned helplessness in which our son failed to act in a way to keep himself healthy, and instead was relying on external supports and parental involvement to do the job for him.

I realized we were at an important juncture. Suppressing my first reaction -- which was to turn the car right back around, march into the school, and firmly ask why the IEP had not been followed -- I instead stopped the car and looked Devon directly in the eye. I shared with him that he obviously knew it was wrong to drink the regular juice. I reminded him that his favorite doctor had ordered the thickened drinks for him and why she did so -- that without them he coughs a lot and gets really sick. And most significantly, we discussed the importance of him making good decisions to keep himself healthy. He never saw it coming...that we might actually expect him to be a partner in his good health!

Of course, I called the school the next day to report what had happened and ask for their help in assuring it wouldn't happen again. But it was evident that they found it somewhat refreshing when I told them we also had discussed with our son his role and responsibility in keeping himself safe at school.



I began to give thought to all the ways in which children with and without disabilities are more alike than different, and subsequently how their parents are as well.

In addition to my youngest son, my husband and I are busy raising a teenager. And I mean a teenager in every sense of the word: a driver's permit, dating, and the weekend social scene are the foundation of his excitement and the source of our dread. Teenagers by definition are in a rapid period of change marked with the task of developing a unique identity distinct from the one they have within their families. They are trying new roles on for size and experimenting with making their own choices. Why would teenagers with disabilities be any

the skinned knees, nothing compared to watching the look of joy on my son's face when he realized he was in charge of how fast he would go and in which direction he would steer. I understood that moment because I remembered what it was like to be the child who had just been set free, wind blowing in my hair, suddenly able to explore in an entirely new way, and just as suddenly seen in a whole new light by her parents.

When considering self-advocacy and self-determination in health care management and decision-making for young adults with disabilities, the stakes are obviously high. Individuals will have unique needs, strengths, and capabilities. In fact, notice that I didn't mention teaching my youngest son to ride a bike;

he is not able to do so, at least not without training wheels at this point in time. For him, mistakes can have consequences much more severe than an occasional skinned knee. Notice too that when parents "let go of the bicycle seat" they are likely to do so either in their driveway or



Michele Juda with her son Devon

different? And parenting by its very nature involves worry and the desire to protect our children; wouldn't parenting a child with special health care needs only create a stronger desire to do so?

I remember teaching my oldest son how to ride a bike. Many beautiful afternoons were spent walking alongside him as he struggled to gain his balance, and eventually running behind him desperately holding onto the bicycle seat. There came a moment when the decision had to be made to let go. I remember that moment vividly. It wasn't an easy decision; in fact I was filled with fear. Although it was hard to watch the inevitable crashes that come with learning, and to bandage

on a quiet street. It would not be advisable for parents to take their child onto a highway to learn how to ride a bike, or to allow their child to ride in the dark.

Self-advocacy and self-determination exist on a continuum; the trick is to provide just enough supports to maintain safety while maximizing the benefits derived from taking an ownership role in one's own life. Parents will always be in the background, creating safe spaces in which their children can explore. Just as we put on the training wheels when necessary, we must experiment with letting go. It is only in letting go that our children can become the fullest expression of themselves.

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## The National Gateway to Self-Determination is on Facebook, Twitter, and YouTube

Check these sites to get updates on new resources, information about upcoming events, or to watch videos of self-advocates talking about self-determination in their lives. Find us at:

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# Healthy Relationships, Sexuality and Self-Determination

Leslie Walker-Hirsch

## Sexual Expression and Self-Determination

Sexual expression in the context of caring relationships is a natural part of everyone's lives. Healthy sexual relationships are a part of good health. We know from research and what people with I/DD have told us, that learning about their sexuality and being able to express it in the context of healthy relationships is important to them (Johnson, Hillier, Harrison & Frawley, 2000). But they report many obstacles stand in the way – lack of information, skill, opportunity, support, and acceptance. Many in the field of developmental disabilities services believe they have a responsibility to enable people with I/DD to have an appropriate sexual life. Sexuality education therefore, should be about giving people with I/DD the skills and opportunities to have fulfilling relationships within which their sexuality can be expressed. Armed with appropriate information and experience, people with I/DD can make healthy and informed choices about their sexuality.

The goal of sexuality education is to help young people become self-determined with respect to their sexuality. This means they have learned to be sexually happy, safe, and responsible adults in the decisions and actions they take within their cultural communities. In recent years, many more opportunities for a fully inclusive community life have become available to people with intellectual disabilities. Parents, professionals, and support staff have done much to prepare them for a broader range of adult activities and greater independence by providing for example, job coaching, literacy education, social skills training, and access to public transportation. However, a critical requirement for success in school, work, community recreation, and relationships is meaningful sexuality education.

## Self-Determination and Consent

Families, schools, adult service providers, and health care practitioners play important roles in addressing the sexual health and social well-being of individuals with I/DD. One key component of sexuality for adults with I/DD that directly correlates with self-determination, is the individual's capacity to consent. This is a complex issue that must be fully addressed at the educational level because it has such an important impact on life planning, choice, and decision-making. Capacity to consent also has ethical, legal and policy mandates that impact on the responsibilities of caregivers and service providers (Eastgate, 2011). Self-assessment tools are widely available to evaluate an individual's capacity for consensual sexual relationships. However, one must recognize consent is not an all or nothing issue, and any identified lack of capacity should not be used to limit or prevent all types of sexual expression.

## The Importance of Sexuality Education

Sexuality begins early and continues throughout life, whether or not a person has an intellectual disability. Families and schools can and often do ignore the sexuality of children with disabilities -- that is, until puberty. When physical maturation occurs, there is no way to continue to ignore "the elephant in the room." For youngsters with intellectual disabilities, puberty occurs on schedule with their chronological-age peers who do not have disabilities. But the corresponding social, intellectual, and emotional maturities, as well as necessary social behaviors, are likely to be later in developing.

Sexuality education is the way we are socialized to show our femininity or



masculinity. Cultural expectations dictate the acceptable behaviors and expectations for men and women in the various stages of the lifespan. Sexuality education is lifelong, and occurs every day, in every household and in many familiar situations not normally associated with such education. These include experiences with family modesty, expressing affection, feeling physical enjoyment, making and keeping friends, recognizing sexual exploitation, maintaining physical health, pursuing spiritual well-being, having a romance, learning about reproduction, and forming long-term relationships. Clearly sexuality means more than having sex, and sexuality education covers more than learning where babies come from.

## Adapting Sexuality Education for Students with I/DD

Over the past two decades, students with intellectual disabilities have been included in regular classes to the greatest extent possible, including Health Education, within which sexuality is often taught. Although this inclusive effort is a good thing, it is frequently not sufficient for meaningful sexuality education to occur for students with I/DD. The rate of instruction is likely to be too fast for this group, and is typically aimed at a more mature and experienced student population. Not enough time is allotted to employ special education techniques that support learning for the students who may require them -- for example, repetition, behavioral strategies, role-playing, rehearsal, or use of non-language based instruction. Health



teachers are very knowledgeable about the subject matter of sexuality, but often have had little or no training in the use of special education techniques. Special education teachers are very skilled in applying unique learning strategies, but have little or no training/experience in addressing sexuality with their students. For this reason among others, students with special educational needs do not get the meaningful sexuality education they need for happiness and success.

## Key Components of Comprehensive Sexuality Training

Following is an outline of six critical components that any meaningful education curriculum should cover that is intended to enhance the self-determination of people with I/DD with respect to sexuality:

1. **Adult Self-Care.** Toileting, bathing, personal sexual hygiene.
2. **Anatomy and Physiology.** Learning the names for sexual anatomy and knowing what is healthy sexual function; distinguishing health from illness, sexually transmitted diseases.
3. **Empowerment/Self-Determination.** Exercising personal autonomy, improving social/sexual decision-making, developing an internal locus of control and a sense of right and wrong, enhancing self-direction,

masturbation. (Note: this component is not usually taught directly to the general student population.)

4. **Relationships.** Starting, evaluating and maintaining a continuum of social relationships, improving social judgment, consenting to sex, developing self-protection and intimacy, contraception.
5. **Social Skills.** Making needs and wants known while remaining likeable, having good manners, using social negotiation, appropriate sexual expression in public.
6. **Social Opportunity.** Accessing a broad pool of social contacts, using email and the internet, being mobile within local geography, enjoying community health, and social resources.

## Sexual Abuse

People with I/DD should be taught to recognize sexual abuse and how to report it. Research indicates that sexual abuse is common among people with I/DD, and they are far more likely to be sexually abused than members of the general public (McCarthy & Thompson, 1997). It is estimated that this population group is between six and ten times more likely to be sexually abused than their same age/sex peers without disabilities. Children, teens and adults who are unaware of their body integrity and privacy rights, and

who have not received a meaningful social sexual education, are more vulnerable to the predatory behavior of others. This also applies to those individuals who do not have a strong social support network of family members and friends both with and without disabilities. People who are not informed about their sexuality, or who are lonely and bored, make easy targets for sexual predators and exploiters. When someone is desperate for companionship and relief from loneliness, any small bit of attention from another person becomes exquisitely attractive, even if it comes with a tag marked “sexual abuse included.”

## Opportunities for Sexual Discovery

Sexuality education takes place in many settings and includes romantic experimentation outside the formal education system. Everyone’s sexual understanding and experiences evolve over time. People with intellectual disabilities need opportunities to figure out how to express romantic attraction and with whom. They do not teach this in school! Opportunities for romance and age appropriate sexual discovery are an important aspect of sexuality education that is rarely discussed, and even more infrequently available to individuals with intellectual disabilities.

When students and adults demonstrate their mastery of social boundaries and

# What school professionals can do to improve sexuality education for students with intellectual and developmental disabilities

1. Colleges and universities can offer a course to their teachers-in-training that helps them understand and manage sexuality in the classroom.
2. School districts can encourage teachers to acquire knowledge of sexuality education for special education students as in-service training.
3. Additional teaching time can be devoted to sexuality education, outside the health class setting, by the school social worker or nurse who has had training.
4. After-school social programs can incorporate social/sexual education into their offerings.
5. Transition programs can pay extra attention to sexuality education before sending students out of the public education sector into adult services.
6. Teachers and parents can work cooperatively to determine comprehensive methods and strategies for sexuality education in their districts.

show their mature use of privacy by acting safely and responsibly, they are exercising self-determination. Under these circumstances, family members are more likely to offer more independence for socialization, privacy, and romance.

## The Role of Parents

Although parents are the first and most important sex educators, they are frequently embarrassed or uninformed about how to educate their children with special needs about sexuality and self-determination. They fear that if they do it incorrectly, their child might be ridiculed, or might even make a sexual error that they may have inadvertently precipitated (Jones, 2012). No one expects parents to be expert sexuality educators for their child with I/DD, but parents do have an important role. Here are some actions that parents can take on their own, and in partnership with schools, to promote healthy sexual development for their child with I/DD:

- Develop an in-depth, objective, multi-dimensional portrait of your child, not colored by parental hopes, fantasies, love, and enthusiasm.
- Role model appropriate and honest relationships with the people you know and support.
- Support positive social interactions that you see your child having by complimenting your child. Encourage his or her attempts to change immature social behavior into more adult expressions of emotion, in both language and behavior.
- Watch a TV program or video with your child to get an informal idea of how much your child understands about the relationship dynamics in the sitcom or animation.
- Work in tandem with your school district to initiate meaningful sexuality education programs that go beyond inclusion in the standard school health class.
- Join with other families and/or professionals that you know



to share successful strategies that you can adapt to your child's situation and abilities.

- Support your child's participation in transition or person-centered planning, and help him or her develop the skills required to turn those hopes into reality.
- Encourage socialization and provide varied opportunities, both structured and unstructured, for participation in generic and specialized recreational and social experiences.
- Recognize the signs of sexual abuse, including sexual bullying.
- Use the "teachable moment" to help your child manage sexual interest and expression in ways that are socially acceptable.
- Remember that sexuality education consists not only of facts but includes the development of social judgment and reasoning; there will be errors and setbacks along the way.
- Advocate for a "Socialization and Sexuality Category" in the Annual Review, IEP, and/or team meeting process.

Above all, treat the child's emerging sexuality in a respectful way that better prepares that child for adulthood. Because parents are not expected to be sex educators, and because they often avoid that aspect of parenthood to the extent that they can, sexuality education and training is often left up to the schools. This arrangement has not always been successful. Parents and school districts can make changes to better promote healthy sexual development and self-determination for students with I/DD by adopting a curriculum in sexuality education that has been designed for use with this group and has been widely employed as a best practice. (See accompanying box on what schools can do.)

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### Resources

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Leslie Walker-Hirsch



## The CIRCLES Curriculum Series

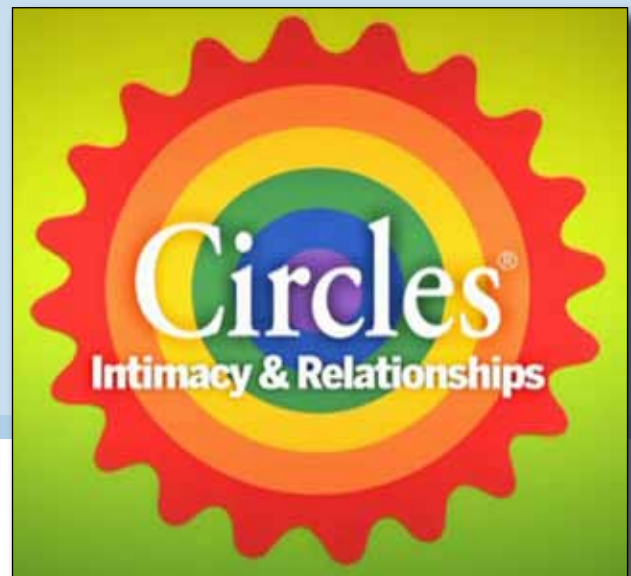
The CIRCLES® Curriculum Series has been successful in explaining the social expectations and requirements in relationships to students with intellectual disabilities in an enjoyable way.

CIRCLES® is a multi-modal learning curriculum that incorporates the tried and true foundational special education teaching and learning strategies into a social learning program. It consists of short, high interest videos, a life size role play floor mat defining various degrees of closeness with a rainbow of colors and has a desktop size replica of this diagram for students to use to create their own individual depiction of the relationships that each student has and enjoys.

The CIRCLES® concept is simple: How you act with someone else depends on the kind of relationship you have with that person.

Six color-coded concentric circles categorizes the array of relationships a person can have into some broad categories and attaches social boundaries and expectations of Touch, Talk, and Trust to each different degree of intimacy in a relationship. (See chart below).

Young adults can use the CIRCLES principles of social boundaries to recognize when others are attempting to take sexual (or other) advantage of them. Students can learn to protect their boundaries by recognizing early signs of sexual encroachment (when another person oversteps their personal boundaries) and by recognizing and reporting sexual incursion to a safe person in any environment who will help decide what next steps should be taken. Self-protection involves learning to report sexual abuse as well.



# The Physician's Role in Promoting Health and Self-Determination:

## An Interview with Dr. Sheryl White-Scott

### Q: What is your area of medical specialization?

A: I practice internal medicine, which is the area of adult health care. I completed a fellowship program in both primary care and developmental disabilities. My practice today includes physician training and health care administration, combined with a clinical and consultation practice focused on adults with intellectual and developmental disabilities (I/DD).

### Q: How many years have you been seeing people with I/DD?

A: Twenty-four years. After I finished my residency, I was a fellow in developmental disabilities for two years. After that, I directed the fellowship program, so I have a good deal of experience in this field and have watched it evolve over the last few decades.

### Q: How does an internist view the health issues that affect people with I/DD?

A: There are two groups to consider. Many people with a mild intellectual disability, not related to a genetic syndrome, have the typical health problems that affect the general population: high blood pressure, diabetes, obesity, cholesterol problems, and gynecological care. We actually don't know if statistically they differ from the typical adults we see. We are studying that right now.

There is another group of people with I/DD who are more severely challenged and may have a genetic disorder like Down Syndrome or Fragile

X, where we know there are going to be physical health problems that go along with their intellectual disability. Those problems are often pulmonary (breathing), gastrointestinal (gut), cardiac (heart), neurological (seizures), or psychiatric (behavioral). These patients need specialized care, and they need specialists who can communicate with them effectively and form a partnership to help them manage their health over the lifespan. Many doctors are not used to working with patients who are not able to communicate easily, and they must be taught how to adapt their language and use tools and techniques to explain to these patients how to take care of their condition

### Q: What are the challenges that people with I/DD and their families face in accessing high quality health care?

A: The first challenge is that, unfortunately, many doctors are still not trained to deal with patients who may have intellectual or communication issues, and they find this work challenging and even frightening. Doctors are used to being in control and knowing what to do, and in the case of working with a patient who may not be able to report pain or how they are feeling, these doctors are very uncomfortable. We need to offer training about the techniques that exist to listen to patients who have trouble speaking; how to assess health literacy and break down information so it can be understood by patients and caregivers; how to use pictures and videos; and how to establish a good working relationship



with all types of patients. This can be done, but it takes time and training, and doctors often don't have enough of either.

### Q: What are some common misperceptions about caring for people with I/DD?

A: There are many, but I'll try to give you the main ones.

First, believe it or not, many doctors still think that people with I/DD will live a very shortened life span, which is of course no longer true. Life expectancy for most people with I/DD is similar to the general population. The important point here is that doctors must understand that people with I/DD will live well into adulthood and into a geriatric phase, and therefore chronic health problems cannot be ignored in children and young adults with I/DD.

Second, there is still the perception among many that people with I/DD live in institutions. I often must explain to doctors that this has not been true for decades, and that most people with I/DD live in the community and therefore are entitled to receive medical care from community practices.

Third, doctors often believe that because a patient has an I/DD, the doctor no longer has to discuss sexually transmitted diseases, smoking, drug abuse, or other so-called adult social health issues. Or that these patients are not capable of understanding medical issues and therefore nothing has to be explained to them. Both these ideas obviously are false and are very dangerous to people with I/DD. Adults with I/DD must receive the same health education and sexual counseling that we would



provide to any young adult. They are not immune to these problems and must be given information so they can take care of themselves properly and make good decisions like any young adult.

Fourth, incredible as it may seem, I often have to explain to doctors that people with I/DD, even those who cannot speak, have thoughts and feelings and can communicate effectively through body language, facial expressions, and other behaviors. Doctors must become more astute to these signs and signals in their patients with severe disabilities. They must be able to pick up subtle cues, assess pain and discomfort, and use every method possible to do this. I have never had a family member be wrong when they told me that “something is wrong” with their daughter or brother, that he is in pain or uncomfortable. Often this will declare itself eventually as an intestinal blockage, broken bone, or toothache and the doctor missed it completely because they didn’t listen or look carefully enough.

By the way, once doctors get into doing this, they tell me that it makes them better doctors for all their patients. It teaches them to listen better, and look for new sources of information about how all their patients are feeling. That’s another positive result that comes from this type of cross-training.

**Q: Are there any special accommodations you make in your practice that support people with I/DD to become more health literate and involved in their own care?**

A: One, I focus on health literacy and finding a way to communicate effectively. Information must be conveyed in a way that it is understood. I use pictures sometimes—pictures of pills, for example—when I am coaching someone to be responsible for their medications: What do these pills look like, and what are they for?

Two, I call it “pairing and partnering.” I try to meet each patient where they are coming from, to understand their feelings and concerns. To do this best, it’s helpful to have a peer, family member, or staff member they trust at this discussion, if the patient chooses. This person can

offer support and encouragement, and sometimes help translate what I am saying because they know the patient so well.

Three, I encourage my patients to prepare for each appointment by writing down any questions or worries they have so they don’t forget to bring them up at their appointment.

Four, I explain very carefully to each patient what will happen at the office visit. I’ll show them the equipment we will use and the steps we’ll go through to make them comfortable. I try to do this at a visit before the actual procedure. When a person is comfortable, things go much more smoothly.

**Q: How can people with I/DD and their families work effectively with their doctors to actively manage their health care?**

A: I think having the right information is key to good health care. So the first thing I encourage, whether transitioning to adult health care or to a new practitioner, or even working with your current doctors, is to keep a complete medical record and share it with all new doctors. It can be low tech—just a file folder or notebook with test results, lab reports, and past summaries, or high tech, on a computer. But either way, giving any doctor you are going to see the most complete and up-to-date information will help them get to know you better right off the bat, and not make mistakes or have to do unnecessary tests. They need to know what has been normal for you in the past, so they know what the danger signs are for you as an individual. Be sure to make copies of everything and keep the originals in your files.

Another thing is to communicate with your doctor about how you wish to be cared for. For example, I try to learn from my patients and their families or caregivers where to take blood, how to examine them, how to transfer them and support them comfortably. Many doctors (although they won’t want to admit it) will know less about your particular syndrome than you do. Respectfully try to educate them about your condition and how it affects you.

Finally, develop a communication strategy with your doctor. Make it clear that you want to be directly involved

in understanding your health care and participating in all decisions. Advocate for your proper role at the center of your own health care plan.

**Q: Where is medicine going with respect to caring for people with I/DD?**

A: It is still the case today, unfortunately, that there is no required curriculum in medical schools that deals with the care of adults with I/DD, and some doctors graduate and go through their internships and fellowships with almost no formal training in the care of individuals with intellectual disabilities. As a consequence, when they set up their practices, they do not feel prepared, have misconceptions, and are reluctant to see these patients. There is still no certified fellowship in developmental disabilities on the adult side, no certification or recognized specialty. This is not true in pediatrics of course, but we need training for adult practitioners. So we have to do a better job of educating and exposing medical students to our patients with I/DD, and providing recognized professional accreditation.

We also need to have all doctors aware and capable of treating patients with I/DD in the general community practice setting. While we need specialists for referrals and consultations when things get complicated, family doctors and internists should be able to care for most of the routine medical needs of patients with I/DD, if they can only get over their concerns.

One of those concerns is financial. It does take more time to see some patients with I/DD because of physical challenges, communication issues, and the complexity of evaluating people who cannot always describe how they are feeling. So as we move into managed care, reimbursement rates must take this into account. But I am optimistic. Things are changing for the better, and it is certainly a good thing that we now have to learn how to care for people with I/DD even as they advance into “old age.” These are problems we’ve never had to deal with before, but that’s real progress!

*Sheryl White-Scott MD, FACP is Medical Director for Brooklyn Developmental Disabilities Services and Assistant Professor of Medicine at New York Medical College.*

# Promoting Self-Determination in Oral Health

Patricia Seagriff-Curtin, DDS and David O'Hara, PhD

Even for those who are able to maintain good oral health and have access to good preventive care, the occurrence of periodic dental pain or gum disease is still an unsettling health experience. Effective treatment cannot come soon enough. Yet for too many people with intellectual and developmental disabilities (I/DD), access to good dental care is the exception rather than the norm. Despite several barriers that limit access to care, there is now a body of knowledge on how to provide effective care for people with I/DD. And one study has demonstrated the effectiveness of personalized digital technology to support self-determination and self-management of oral hygiene.

For the past twenty years the oral health agenda for people with I/DD has

health and quality of life. At the same time it identified the existence of significant oral health disparities based on the social determinants of health: education level, income, race, ethnicity and disability. The report provided the basis for key goals in Healthy People 2010 and 2020 aimed at achieving major reductions in oral health disparities. However, to date there has been little progress in reducing oral health disparities among underserved populations because limited access to dental care limits their ability to benefit from significant advances in our understanding of how to prevent tooth decay and gum disease. Adoption of the evidence based-programs for community water fluoridation and school-based dental sealant programs

how critical good oral health is to overall health, nor do they acknowledge the long-term health and economic benefits of increasing access to preventive care services, particularly for children, that are known to work (U.S. Department of Health and Human Services, 2005). There has been little progress in improving the oral health for these underserved groups. In fact the reverse may be true. A Government Accountability Office report in 2008 described a situation in which under existing Medicaid provisions "the extent of dental disease in children has not decreased and millions are estimated to have untreated dental decay." For adults the situation is even worse since dental care is an optional service under Medicaid, and many states provide no coverage for adults at all.

The situation for children with special needs and adults with I/DD is particularly critical. Approximately 13% of U.S. children and adolescents ages 17 and under (over 10 million) have a special care need. This means that one in five households include children with special needs (Anderson, 2010). For children with autism, which affects one in every 88 kids and one in 54 boys (CDC, 2012), oral hygiene may be the most important risk indicator for new cavities (Marshall, Sheller & Mancl, 2010). Children with special needs have higher rates of poor oral hygiene, gingivitis, and periodontal disease than the general public in part because medications, special diets and oral motor habits put them at increased risk (Moursi, Fernandez, Daronch, Zee & Jones, 2010). Dental care is the leading unmet health care need among children with special needs across all income levels. Children with special needs are almost twice as likely to have an unmet oral health need than their peers without special needs (Lewis, Zhou, Novak & Grembowski, 2010).

The picture is worse for adults with I/DD because oral health coverage is a



Dr. Seagriff-Curtin working in the dental van

been defined by the Surgeon General's report on the oral health of the nation published in 2000 (U.S. Department of Health and Human Services, 2000). The report stressed how integral good oral health was to a person's general overall

offers the possibility of reducing dental caries by 40-60%. And for people with access to dental care, these services have led to major improvements in oral health. But access to dental care is still driven by policies that do not yet acknowledge



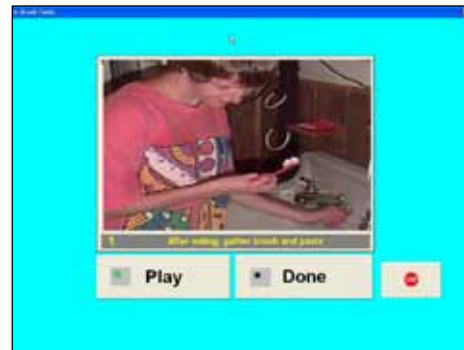
state option in Medicaid. In 2007 only 16 states provided comprehensive dental care coverage under Medicaid. Fifteen states provided either no coverage at all or only for related craniofacial emergencies (McGinn-Shapiro, 2008). In 2005 the President's Committee for People with Intellectual Disabilities described the status of dental care for people with intellectual disabilities as "appalling", and called for their recognition and designation as a "an underserved population in dental health care" (U.S. Department of Health and Human Services, 2005). The poor oral health status of adults with I/DD was summarized in a report by Special Olympics on the oral health of athletes whose average age was 24 (Corbin, Malina & Shephard, 2005). It found that nearly one in eight people with intellectual disabilities had a pain-causing lesion in their mouth, one in six had untreated decay, and one in four was already missing teeth. While it is estimated that over half of people with I/DD have periodontal disease, some sub-populations with specific neurodevelopmental diagnoses, such as Down syndrome, have periodontal disease rates as high as 96%. Periodontal disease, a chronic infection caused by oral bacteria, has been linked with an increased risk of stroke, myocardial infarction and the likelihood of having a premature, low birth-weight infant (U.S. Department of Health and Human Services, 2005).

The Surgeon General's report on oral health (2000) found that the two most common factors contributing to the poor oral health status of adults with I/DD were the lack of provider education and poor provider reimbursement. This picture will not change until there is greater understanding of the impact

of poor oral health on the quality life and general health of all people, but especially people with I/DD, coupled with renewed support for a public health campaign to extend effective oral health preventive services to everyone.

To improve the oral health of older children and adults with I/DD there is yet a third strategy that can also encourage and support better oral health – providing supports and services that promote good oral hygiene practices. Achieving and maintaining good oral hygiene practices certainly starts with support for families of young children with special needs through accessible and appropriate dental care, but it is a lifelong issue. It is critical that older children, adolescents and adults with I/DD are supported in taking as much direct responsibility as possible for maintaining good oral health. In 2005, the Westchester Institute for Human Development in partnership with AbleLink Technologies completed a study exploring the potential of personal digital technologies to prompt and coach adults with I/DD to follow good oral hygiene practices (O'Hara, Seagriff-Curtin, Levitz, Davies & Stock, 2008). In this study, participants began with computer-based training, narrated by a dental care provider that the adults with I/DD knew, in how to follow a two-minute tooth cleaning sequence. Then, based on their success in navigating the dental health education program, each participant was provided with a touch screen small personal digital assistant (PDA) that was programmed to turn itself on at times selected by the participant to coincide with mealtimes. At this prompt, the PDA played a pre-recorded message instructing each participant on how to follow the oral hygiene video instructions.

Almost 40% of the participants in this study did show gains in their oral hygiene at the six-month follow-up point.



"Janice after you eat every meal you need to go brush your teeth, so get your brush and your toothpaste and go to the bathroom."

Despite the major obstacles to improving access to oral health care for children with special needs and adults with I/DD, significant progress is being made in the creation of practice guidelines for oral health providers, families and caregivers.

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## Tips for Taking Charge of Your Oral Health

- Learn how to brush, floss and rinse properly
- Get an adapted toothbrush that fits your hand properly
- Follow the same routine every morning and night
- If you need help, ask your support staff or family
- Tell your dentist about other medical conditions you have, the medicines you take, and how you are feeling
- Ask your dental and dental hygienist to explain to you what they are going to do at each visit
- Tell the dentist or hygienist if you are nervous
- Tell the dentist or hygienist if you have pain
- Eat a balanced diet, go easy on the sugary foods and drinks and exercise
- Speak with your dentist if you are not happy with the way your mouth looks and feels

# Hard Wired for Health: Clinical Teaching Resources for Training Health Professionals to Promote Self-Determination and More Effective Health Care for People with Intellectual and Developmental Disabilities

Carl Tyler, MD, MS

Over the past several years, with support from the Ohio Developmental Disabilities Council and participation by individuals with intellectual disabilities, family members and direct care staff as well as colleagues from the Cleveland Clinic, we have been developing and evaluating clinical training strategies designed to promote effective, direct interaction between a patient with intellectual and developmental disabilities (I/DD) and their doctor and other members of their health care team.

This has included such standard training techniques as the videotaping of physician-patient interactions with “simulated” actors or “real” patients in actual health care settings. The patient simulations are also provided by people with I/DD who want to play ongoing roles with us in furthering the training of health professionals. But the overall goal of this project has been to change medical and other health professional education in ways that promote the creation of effective health care delivery for people with I/DD. We call it becoming “Hard Wired for Health.”

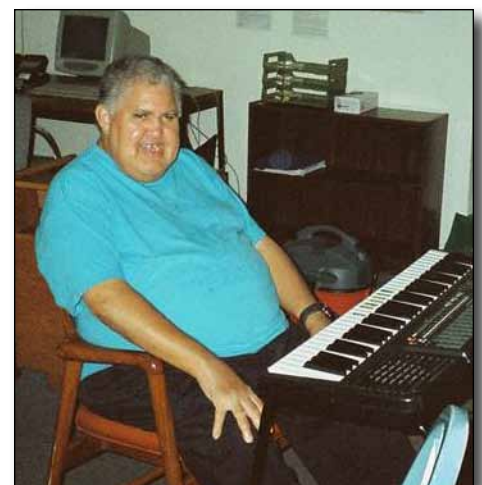
We start with two key ideas that we think are central to optimizing the primary care of individuals with intellectual and developmental disabilities. First, everyone is important: we want to make sure that everyone on both sides of the health care process – patients, family members, direct care staff, and the health care team of providers, front desk and medical records staff, patient aides—all see themselves as critical to our on-going health care role. The second key idea is that the health

care team must understand and know how to support community providers and families in negotiating health care and disability policies, reimbursement, and other issues that shape long-term care in addition to their clinical health care roles.

With that perspective we have developed a range of clinical resources and training modules designed to help patients with I/DD become effective in asking questions about their own health and what is being proposed for their care. These resources and training modules include:

**Photovoice Project:** Self-advocates, their family members and direct support professionals were given disposable cameras and asked to photograph their health care experiences. We specifically asked them to document what they liked and did not like about their health care. We compiled their photographs, totaling over one hundred, met together as a group, and each participant described the content and meaning of his/her pictures. The photographs and themes identified from them were then incorporated into the DVD curriculum materials for professional training. Our Photovoice Project was summarized in a set of posters for public and academic presentation and displayed at the Health Frontier for Intellectual Disabilities Conference in May 2011 and at the annual Agency on Healthcare Research and Quality conference in September 2011. Our Photovoice Project was awarded first place in the category of academic educational poster presentations at the Ohio Family Physicians Education and Research Conference in March 2011.

**Videotape Review:** Videotape Review has become a central part of our residency training program. In the three years of being supported by the Ohio Developmental Disabilities Planning Council, we developed a behaviorally-anchored evaluation instrument for use in evaluating videotaped health care encounters. All family practice residents are videotaped in their patient encounters; these videotapes are then evaluated by the Videotape Review Team. The team includes a self-advocate, a family member, a direct support professional, a health care educator, and a health



**Theme: Self-Care**  
**Support Professional:** Nick wanted to take some pictures at his day program to try to talk about things that he does to make himself feel better when he doesn't feel good at home, and maybe he's on a different medication or it's making him nauseated, or he just doesn't feel good. These are some things that they try to do to help him feel better and get through the day.



Theme: Health Professional/Patient Interactions, Behavior, Communication. Style: People who get anxious about going to the doctor's office usually don't mind going to Dr. B. He talks a lot and jokes with people.

care professional. The feedback from the team reviews is forwarded to family practice residents and is designed to focus on how doctors can improve their communication skills to directly engage the person with I/DD in their care.

**Video Education:** At the core of the training project are three instructional DVDs. Part 1 is directed to persons with I/DD; Part 2 to families, direct support professionals, and disabilities service professionals; and Part 3, to medical students and family medicine resident physicians. Trainings using these instructional DVDs are targeted to respective constituents through collaborating medical schools, family medicine residency training programs, residential service providers, disabilities services training programs, and advocacy organizations. The DVDs include information relevant to the health care of the underserved population targeted - aging adults with I/DD, and their elderly caregivers.

**Educational Partnerships:** Training of physicians often fails to acknowledge and incorporate teaching about larger health, service, governmental, and support systems that profoundly affect the health and well-being of individuals with I/DD and their families. Family medicine residencies, desiring to improve the health care and training related to their patients with I/DD, will need to understand these forces and systems beyond the walls of their own health care facilities. Many family medicine educators typically have little knowledge and few relationships with local and regional stakeholders who are also interested in individuals with I/DD and their families. We will assemble

partnership-building teams comprised of individuals who are familiar with key individuals, associations, groups, and systems, who are involved in the lives of individuals with I/DD. These partnership-building teams will identify and link local and regional partners to participating family medicine residency training sites to form local partnerships.

These local partnerships will then work with family medicine residency programs to:

1. Enhance family medicine resident physician training curriculum to include broader systems-related information and considerations; and
2. Generate Quality Improvement Projects informed by the perspectives of all stakeholders. Measurable improvement in health care service delivery for individuals with IDD is a requirement of the residency training program. This requires that:
  - Individuals with I/DD are identified within the practice. Even in health care systems with sophisticated electronic health record capacity, individuals with I/DD often remain "hidden." Condition-specific registries are often necessary to identify, track, and improve the health care of specific sub-populations. In each family residency practice, foundational preliminary work necessary to conduct QI will include site-specific methods to identify individuals with I/DD receiving care in a medical practice.
  - Complexity of health care service is recognized. Meaningful Quality Improvement (QI) targets acknowledge many forces and processes involved

in health care service delivery and in implementation of health care treatment plans. Local partnerships will assist family medicine residencies to formulate QI projects that improve health care through comprehensive, effective, and sustainable means.

**Nothing about us without us:** In order for this training program to demonstrate improvement in health care, everyone involved in the process of health care is heard and has a voice. This means listening to the perspectives and insights of individuals with I/DD, their families, and direct support professionals. We will also examine the health care delivery process through the eyes, ears, minds and hearts of medical receptionists, nurses, physicians-in-training, faculty, x-ray technicians, nutritionists, etc. Our training and QI projects will acknowledge and address the many social determinants of health: the fact that how and where individuals eat, work, play, and socialize profoundly affects their health.

Ongoing institutional support will enable us to disseminate the products and results of this training project to interested Family Medicine Residency programs and other health professional training programs.

For more information on this project, the curriculum and the educational DVD "Optimizing the Primary Care of Individuals with Intellectual and Developmental Disabilities" contact Dr. Carl Tyler at [Catyle@ccf.org](mailto:Catyle@ccf.org).

*Carl Tyler, MD, MS is the Coordinator of Geriatric Education and Research and the Family Practice Residency Program at The Cleveland Clinic.*

## Typical Thematic Issues Identified on Videotape Review



- Communication and interaction
- Structure and organization of office visit
- Clinical data gathering & decision-making
- Difficult or challenging situations
- Personal issues of learner

# A National Gateway to Self-Determination

UMKC  
Institute for Human Development  
215 W. Pershing Rd., 6th Floor  
Kansas City, MO 64108  
[aucd.org/ngsd](http://aucd.org/ngsd)

## The National Gateway on Self-Determination

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.



COMING IN THE NEXT ISSUE:  
Self-Determination and Family  
edited by the Beach Center on Disability,  
KUCDD