

Promoting Self-Determination in Health and Medical Care: A Critical Component of Addressing Health Disparities in People with Intellectual Disabilities

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Abstract As increased attention has been directed toward the disparities experienced by people with intellectual disabilities in achieving positive health outcomes, the importance of promoting the active involvement of people with intellectual disabilities in efforts to reduce such disparities and promote positive health and wellness outcomes has been acknowledged by researchers and policymakers. This parallels the larger movement within the disability field to promote the self-determination and empowerment of people with intellectual disabilities. The authors more explicitly discuss the implications of self-determination, as it has been conceptualized in the disability field, for promoting positive health and wellness outcomes in people with intellectual disabilities. They review the current research on self-determination and its impact on health, as well as the implications of this research for the development of strategies that promote self-determination in the achievement of health and wellness outcomes in people with intellectual disabilities. The authors posit the need to extend an understanding of the implications of self-determination for promoting health in people with disabilities not only to the disability field, but also to the medical and public health fields. They also provide recommendations for future research and practice.

Keywords: health disparities, health promotion, intellectual disability, medical care, self-determination

In recent years, increased attention has been directed to the systematic differences in health – typically referred to as health disparities in the United States and as health inequalities in Europe (Graham, 2005) – experienced by people with intellectual disabilities. Research has demonstrated that people with intellectual disabilities face significant disparities in accessing and engaging in health promotion activities (Association of State and Territorial Health Officials, 2003; Durvalsula & Beange, 2001; Fisher, 2004; Havercamp, Scandline, & Rother, 2004; Marks & Heller, 2003) and in accessing affordable and appropriate medical care (Reichard, Sacco, & Turnbull, 2004; Reichard & Turnbull, 2004). For example, people with intellectual and developmental disabilities are significantly less likely than their peers without disabilities to routinely exercise and more likely to live a sedentary lifestyle (Havercamp et al., 2004; Rimmer, Braddock, & Marks, 1995). These health behaviors increase their risk for secondary health conditions (e.g., cardiovascular disease, obesity, osteoporosis) and poor health outcomes. Although health education and health promotion campaigns have become common-

place in our society, few efforts have specifically been targeted to or adapted for people with intellectual disabilities, many of whom, as a function of their disability, experience more difficulties in developing an understanding of the effects of their behavior on their health (Havercamp et al., 2004; Horwitz, Kerker, Owens, & Zigler, 2000; Ouellette-Kuntz, 2005).

Additionally, people with intellectual disabilities experience significant disparities in preventive screening utilization (Durvalsula & Beange, 2001; Fenton, Hood, Holder, May, & Mouradian, 2003; Fisher, 2004; Webb & Rogers, 1999); for example, females with intellectual and developmental disabilities are significantly less likely than their peers without disabilities to have had routine breast and cervical cancer screenings (Havercamp et al., 2004; Lewis, Lewis, Leaker, King, & Lindermann, 2002). And, even if chronic conditions (e.g., cardiovascular disease, cancer, diabetes) are identified in people with intellectual disabilities during routine screenings, these conditions tend to be poorly or improperly managed by healthcare providers (Fisher, 2004). Relatedly, people with intellectual and developmental disabilities have been found to have higher rates of high blood pressure, cardiovascular disease, diabetes, and chronic pain than their peers without disabilities (Havercamp et al., 2004). Again, however, very few efforts to educate healthcare professionals about how to work collaboratively with people with intellectual disabilities and their families

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and/or support providers within the context of community-based health care have been implemented (Durvalsula & Beange, 2001; Lennox, Diggins, & Ugoni, 1997). Lennox and Kerr (1997), in a review of research largely conducted in the United Kingdom, summarized the status of community health care for people with intellectual disabilities:

If a community-based population of people with intellectual disability receiving primary care were examined, one was likely to uncover three main findings: (1) untreated, yet treatable, simple medical conditions; (2) untreated specific health issues related to the individual's disability; and (3) a lack of uptake of generic health promotion, such as blood pressure screening. (p. 366)

As increased attention has been directed to these disparities, and to the social, economic, and political inequities that underlie them (Leeder & Dominello, 2005; Ouellette-Kuntz, 2005), there has been a concomitant increase in the number of research and policy initiatives focused on developing strategies to promote positive health and wellness outcomes, and to reduce and eliminate the inequities in health outcomes experienced by people with intellectual disabilities (e.g., Arbuckle, Buchanan, & Armstrong, 2004; Beange, Lennox, & Parmenter, 1999; Department of Health, 2001; Jobling, 2001; U.S. Department of Health and Human Services, 2003; U.S. Public Health Service, 2002). In 2002, the U.S. Surgeon General released *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation*. The report acknowledged the barriers people with intellectual disabilities face in staying healthy and accessing appropriate health and medical care, stating: "they [people with intellectual disabilities] feel excluded from public campaigns to promote wellness. They describe shortages of health care professionals who are willing to accept them as patients and who know how to meet their specialized needs. They struggle with unwieldy payment structures that were designed decades ago . . ." (U.S. Public Health Service, 2002, p. xi). Perhaps more importantly, however, the Surgeon General's report also acknowledged the role that people with intellectual disabilities could, and should, play in future efforts to improve their health and wellness:

This dedicated community [of people with intellectual disabilities] can teach us a great deal. They can help us all to better understand and face their unmet needs, which are significant and all too common. Perhaps the greatest lesson is that as a society we have not really been listening and paying attention to them. We have been too likely to expect others, without mental retardation, to speak to their needs. We have found it too easy to ignore even their most obvious and common health conditions. Just as important, we have not found ways to empower them to improve and protect their own health. No one who cares would suggest that this is acceptable. Nothing, however, will flow from this effort unless we help our society better understand and appreciate that these per-

sons are an integral part of the American people, with much to give if they, too, enjoy proper health (U.S. Public Health Service, 2002, p. v).

The Surgeon General's position, with regard to the importance of promoting the active involvement of people with intellectual disabilities in efforts to address health disparities and promote positive health outcomes, parallels the larger movement within the disability field to promote the self-determination and empowerment of people with intellectual disabilities (Nerney & Shumway, 1996; Wehmeyer, 2001). The Surgeon General's position, which has also been endorsed by other researchers and practitioners in the intellectual disabilities field (Lennox & Kerr, 1997; National Council on Disability, 2004), provides an impetus to more systematically consider issues related to self-determination within the context of developing strategies to address health disparities in people with intellectual disabilities. In fact, more recently, the International Association for the Scientific Study of Intellectual Disabilities' (IASSID) Health Issues Special Interest Research Group (SIRG) contributed to a report on reducing health disparity for people with intellectual disability (Westchester Institute for Human Development, 2005). This report, the outcome of a Health Issues SIRG annual roundtable held in Westchester, New York, in 2003, provided numerous recommendations to address the problem of health disparities, including recommendations pertaining to the role of people with intellectual disabilities and self-determination in this process. The report (Westchester Institute for Human Development, 2005) recommended:

- All processes to reduce health disparity should include a focus on promoting and enhancing individual education and choice over health care and health-related decisions. This includes supports that enable people to be more effective in this regard and participate more fully in such activities, and the promotion of individual self-determination.
- People with intellectual disabilities are capable of assuming greater control over their lives, and they deserve the opportunity to do so and to be supported in doing so as fully and effectively as possible. (p. 47)

This paper expands upon these recommendations, provides a limited review the self-determination literature, and highlights its implications for promoting positive health and wellness outcomes in people with intellectual disabilities. It begins with an overview of the emergence of the self-determination construct in the disability field, reviewing what research has suggested about the impact of self-determination on valued life outcomes. We then consider the implications of this research for the development of strategies that promote self-determination in the achievement of health and wellness outcomes in people with intellectual disabilities. Finally, we discuss the need to extend an understanding of the implications of self-determination for promoting health in people with disabilities not only to the disability field, but also to the medical and public health fields.

SELF-DETERMINATION AND PEOPLE WITH INTELLECTUAL DISABILITIES

The first use of the term self-determination in the disability field occurred as the normalization movement was being introduced to North America. In Wolfensberger's (1972) influential text, *Normalization: The Principle of Normalization in Human Services*, Nirje (1972) wrote a chapter titled *The Right to Self-Determination*. Nirje's use of the term was both an expression of the inherent right of people with disabilities to self-determination and a call for individuals with disabilities to have increased opportunities to express personal self-determination, issues Nirje viewed as fundamental to the normalization movement. Although the importance of self-determination to people with intellectual disabilities was not immediately recognized, the normalization principle exerted significant influence on the disability field. It began the process of fundamentally reshaping the delivery of services and supports for people with intellectual disabilities and the conceptualizations of disability that undergirded their delivery (Scheerenberger, 1987), laying the groundwork for the (re)emergence of the self-determination construct in the early 1990s. Today, self-determination refers to efforts to ensure that people with disabilities have the skills, opportunities, and supports to act as causal agents in their lives.

In the early 1990s, self-determination began to receive increased attention within the field of special education as a means to promote and enhance the autonomy, self-regulation, psychological empowerment, and self-realization of children, youth, and adults with intellectual and developmental disabilities (Wehmeyer, 1992; 1996; 2001; Wehmeyer, Abery, Mithaug, & Stancliffe, 2003). Within the service delivery system, self-determination also came to be seen as a means to align the delivery of adult services and supports with the personal preferences of people with disabilities and their families through consumer-controlled service delivery models (Nerney, 2002; Nerney & Shumway, 1996; Shumway, 1999). Central to the (re)emergence of the self-determination construct were the fundamental changes that occurred in the way people with intellectual disabilities received services (e.g., the movement from institutionalization to community-based supports) and in the way disability was understood (e.g., the movement from a medical to a social/environmental model). Essentially, for people with intellectual disabilities to be viewed as capable of being self-determined, conceptions of the abilities of people with intellectual disabilities had to shift (Wehmeyer, Bersani, & Gagne, 2000).

Self-Determination and Valued Life Outcomes

Self-determination has been identified both as a means of enabling people with intellectual disabilities to achieve valued life outcomes (i.e., equality of opportunity, full participation, independent living, and economic self-sufficiency) and as a valued life outcome in and of itself. Research has demonstrated that youth

who are more self-determined when leaving high school experience more positive adult outcomes than youth who are less self-determined. Wehmeyer and Schwartz (1997) measured the self-determination of 80 students in the United States with learning and intellectual disabilities and then examined their adult outcomes 1 year after they left high school. Students who were more self-determined were more than twice as likely as youth who were not to be employed and earned, on average, \$2.00 per hour more than youth in the low self-determination group who were employed. Wehmeyer and Palmer (2003) conducted another follow-up study, examining the adult outcomes of 94 students with learning disabilities and mental retardation in the United States 1–3 years postgraduation. One year after high school, students in the high self-determination group were disproportionately more likely to have moved from where they were living during high school. By the third year, students in the high self-determination group were still disproportionately more likely to live somewhere other than their high school home, and were significantly more likely to be living independently. For employed students, those scoring higher in self-determination made statistically significant advances in obtaining job benefits, including vacation, sick leave, and health insurance, an outcome not shared by their peers in the low self-determination group. Overall, there was not a single item on which the low self-determination group fared more positively than the high self-determination group.

Preliminary research has also suggested that individuals with intellectual disabilities who participate in consumer-directed service delivery programs feel more empowered and in control of their lives, and experience greater community integration outcomes than people in traditional service delivery programs (National Council on Disability, 2004). This research is supported by findings from a number of studies that suggest, even after controlling for level of intelligence, people with intellectual disabilities who live or work independently (Wehmeyer & Bolding, 1999), or semi-independently (Stancliffe, 1997; 2001; Stancliffe, Abery, & Smith, 2000), have greater opportunity to express more personal control and self-determination than people who live in congregate settings.

Self-determination, along with issues related to health (e.g., physical and emotional well-being), has also been identified as a core dimension of quality of life for people with intellectual disabilities. The concept of quality of life has emerged as a unifying theme in the field of intellectual disabilities that is "rooted in individual perceptions and values and capable of contributing to the identification of necessary supports and services" (Schalock et al., 2002, p. 458). The concept of quality of life serves the primary purpose of guiding efforts to bring about change at the individual and societal level to enhance individual well-being. Eight core dimensions of quality of life have been identified: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and individual rights (Schalock, 1996; Schalock et al., 2002). These dimensions interact and influence each other to shape an individual's perception of his or her

quality of life. For each person, there will be variability in the relative contributions of each of the dimensions to his or her quality of life over time, based on personal preferences and cultural beliefs. However, even with this variability, research has suggested that there is a link between the level of self-determination and the quality of life of people with intellectual disabilities. Wehmeyer and Schwartz (1998) assessed self-determination and quality of life in 50 adults with intellectual disabilities. Using discriminant function analysis, they found that the level of self-determination predicted group membership based on quality of life scores. That is, people who were highly self-determined tended to report experiencing a higher quality of life; whereas people who lacked self-determination tended to report experiencing a lower quality of life. Additionally, people who self-direct their supports through consumer-directed service delivery models also report having a higher quality of life than individuals who participate in traditional, agency-directed service delivery models (National Council on Disability, 2004). However, it is critical to recognize that opportunities to become self-determining and to achieve positive health outcomes are significantly influenced by both societal-level factors, such as the labor market and the welfare system, and individual-level factors, such as socioeconomic status, gender, and ethnicity (Graham, 2005).

SELF-DETERMINATION AND HEALTH OUTCOMES

There is a very limited body of research examining issues of self-determination as they relate to health and medical care. For example, as discussed above, 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 with health insurance. This suggests the potential of self-determination to positively impact socioeconomic status, one of the fundamental determinants of health for people with intellectual disabilities (Graham, 2005). People with intellectual disabilities tend to have high rates of un- and underemployment (Yamaki & Fujiura, 2002) and correspondingly high rates of poverty, which has been demonstrated to negatively affect health across the lifespan (Graham, 2005). If promoting self-determination has the potential to lead to higher levels of employment at higher wages, there may be an indirect effect on the health outcomes experienced by people with intellectual disabilities. Further, the potential of enhanced self-determination to promote increased access to employer-based insurance coverage has implications for the affordability and accessibility of health care for people with intellectual disabilities (Reichard et al., 2004). In countries like the United States, where a significant proportion of the population of people with intellectual disabilities are dependent on public health insurance programs (Reichard et al., 2004; U.S. Public Health Service, 2002), there are significant barriers to accessing quality health services. The low reimbursement rates, administrative burdens, and restrictive rules about covered services that characterize public insurance

programs dissuade many community-based providers from accepting patients with this form of insurance (U.S. Public Health Service, 2002). There is still a critical need for reform in public health insurance programs to ensure that people who remain on these programs have access to high-quality care of their choosing (National Council on Disability, 2004) and have the option to maintain coverage as they transition to full employment from un- or underemployment.

In an early survey (Wehmeyer & Metzler, 1995) that assessed the opportunities people with intellectual disabilities had to express self-determination in their everyday life, respondents were asked one question about their self-determination in medical care, *Do you give consent for medical care?* Of the 4,544 individuals with intellectual disabilities who participated in the survey, 18% of respondents indicated that they independently consented for medical care, 26% indicated that they consented with support from others, and the majority, 56%, indicated that someone else provided consent for them. Although there are complex issues surrounding consent to medical treatment by people with intellectual disabilities, it is imperative that the right of people with intellectual disabilities to provide consent be respected, and disability status not be used, *a priori*, by professionals to disqualify people with intellectual disability from being involved in decisions regarding their care. Research has demonstrated that people with mild to moderate intellectual disabilities have the capacity to provide consent to standard medical treatment, and that even in the context of more complex treatment decisions, with support and educational strategies, people with mild to moderate intellectual disabilities can take an active role in decisions about their care (Cea & Fisher, 2003). Innovative strategies for developing partnerships between people with intellectual disabilities, families, and healthcare providers have been developed (Levy, Anastasio, Weisbaum, & Morrel, 2004), and must continue to be refined and evaluated. These partnerships provide guidance for promoting the involvement of people with a range of cognitive limitations and varying support needs in decisions related to their medical care – even if it is simply considering the preferences of the person within the context of discussions between the health provider, the family, and/or the support provider.

Research on the impact of consumer-directed service delivery systems on the health outcomes experienced by people with intellectual disabilities suggests there are no differences in the health status of people with intellectual disabilities based on their participation in consumer- vs. agency-directed systems. At this point, it would appear that people with intellectual disabilities experience no greater risk of negative health outcomes when they and their families assume control over services (National Council on Disability, 2004).

Research on the concept of quality of life indicates that there is interaction among the core dimensions (Schalock et al., 2002). Thus, efforts to promote self-determination have the potential to impact the health-related dimensions of physical and emotional well-being. The skills and resources that promote self-

determination in general should also have the potential to enable people with disabilities to better manage their own health and medical care and achieve better health and wellness outcomes. For example, with chronic illnesses, such as rheumatoid arthritis, patients who learn how to actively participate in their care, through the "Arthritis Self-Management" educational program, demonstrate improvements in health behaviors, self-efficacy, health status, and healthcare use (Shoor & Lorig, 2002). However, as this research has demonstrated, for these outcomes to be realized, it is critical that people be educated about how to become active participants in managing their health and wellness outcomes, particularly as the traditional system of care encourages patients to take a more passive, uninformed role (Chan, 2002; Shoor & Lorig, 2002). Promoting self-determination provides a framework for targeted educational programs that enable people with intellectual disabilities to learn more about their health, the relationships among their behaviors (e.g., eating, exercising, smoking, drinking, etc.) and their health, and the importance of engaging in proactive behaviors to promote long-term health and wellness. As Jobling (2001) noted:

The adoption of a healthy lifestyle requires skills and knowledge that need to be linked to an understanding of health. This understanding, developed through education, can then be used to formulate attitudes and values, which subsequently form the basis upon which individuals can take responsibility and begin to self-regulate their own health behaviors. As a result, individuals undertake a range of actions that they believe improve their health. (p. 313)

More accessible and appropriate materials and programs must be developed for people with intellectual disabilities to enable them to learn about their health needs and to assume greater responsibility for engaging in behaviors that promote positive health and medical outcomes (Arbuckle et al., 2004; Lennox et al., 2004; Pomeroy, Everson, & Guillory, 2000). Some evidence-based programs, such as the "Arthritis Self-Management" educational program (Shoor & Lorig, 2002), could be used as the basis to create modified programs for people with intellectual disabilities to learn to self-manage their health and/or their chronic conditions. Research has demonstrated that people with intellectual disabilities can learn and effectively implement self-management procedures across a variety of environments and behaviors (Hughes, Korinek, & Gorman, 1991).

Further, strategies developed within the field of special education to promote the self-determination of children and youth with intellectual disabilities could be modified to focus more explicitly on issues related to health and medical care. For example, the *Self-Determined Learning Model of Instruction* (Mithaug, Wehmeyer, Agran, Martin, & Palmer, 1998; Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000), was developed to support teachers in enabling students with intellectual disabilities to engage in a self-regulated problem-solving process to set a learning goal, develop and implement an action plan to achieve that

goal, and self-monitor and self-evaluate progress toward meeting that goal, making adjustments to the goal or plan as needed. This model has been adapted for use to enable adults with intellectual disabilities to self-regulate goal-setting and decision-making pertaining to job identification and attainment (Wehmeyer et al., 2003). With relatively minor modifications, this instructional model could be used to support youth and adults with intellectual disabilities to engage in a self-regulated problem-solving process to set a personally relevant health goal, develop a plan to achieve the goal, and self-monitor progress toward the goal. And peer education models, which have been implemented across the world and train youth and adults to educate their peers about healthy behaviors (Harvey-Berino & Rourke, 2003; Mikhailovich & Arabena, 2005; Pearlman, Camberg, Wallace, Symons, & Finison, 2002), could be modified and used to train and support people with intellectual disabilities to work as peer educators on issues related to healthy behavior, communicating about health issues, and accessing healthcare services.

As consumer-directed service delivery models have become more widespread and people with intellectual disabilities and their families have assumed more control over the types of health and long-term care services they receive, research has demonstrated that self-direction of services has a significant positive impact on the health and wellness outcomes of people with intellectual disabilities (National Council on Disability, 2004). However, critical to the success of funding mechanisms that support self-direction and promote positive health and wellness outcomes is the need to provide education and supports for people with intellectual disabilities and their families about how to effectively self-direct their services. As the National Council on Disability (2004) noted: "the absence of education and skills training can be a significant barrier to consumer-directed care" (p. 86). Innovative programs to support people with intellectual disabilities and their families or support providers to learn the skills and access the resources necessary to self-direct their services, including education on healthy behaviors and accessing community-based health services, need to be developed and evaluated.

As discussed above, encouraging self-determination in health care may well be a key strategy for reducing the health disparities experienced by people with intellectual disabilities. It has the potential to significantly alter many of the issues that are most commonly identified as the sources of health disparities, including health system factors (e.g., how health care is financed and structured, and how health promotion activities are designed and delivered), patient-level factors (e.g., how well patients understand and follow through on health promotion activities and medical advice), and patient/provider communication issues (e.g., how effectively patients can communicate their health needs and develop a trusting relationship with their physicians) (Aaron & Chesley, 2003; Smedley, Stith, & Nelson, 2002; U.S. Department of Health and Human Services, 2003). However, consumer self-determination in health care by people with intellectual disabilities will need to be embraced by the public health and medical fields to be a successful force for improved health. The

willingness of healthcare and other support providers to work directly with the person with intellectual disabilities as a full member of the treatment team will significantly influence the health and wellness outcomes experienced.

Within the public health field, increased attention has been directed toward the importance of health promotion for people with disabilities. *Healthy People 2010*, the national agenda for health promotion and disease prevention developed by the Office of Disease Prevention and Health Promotion, included a chapter on people with disabilities for the first time. In the chapter, the long-standing failures of the public health field to recognize the distinction between disability and health were acknowledged:

Because disability status has been traditionally equated with health status, the health and well-being of people with disabilities has been addressed primarily in a medical care, rehabilitation, and long-term care financing context. Four main misconceptions emerge from this contextual approach: (1) all people with disabilities automatically have poor health; (2) public health should focus only on preventing disabling conditions; (3) a standard definition of “disability” or “people with disabilities” is not needed for public health purposes; and (4) the environment plays no role in the disabling process. These misconceptions have led to an underemphasis of health promotion and disease prevention activities targeting people with disabilities and an increase in the occurrence of secondary conditions (medical, social, emotional, family, or community problems that a person with a primary disabling condition likely experiences) (U.S. Department of Health and Human Services, 2000, p. 6-3).

Because of the prior emphasis on the equivalence of health status and disability, little attention had been paid to secondary health issues (e.g., the health issues that affect the entire population) among people with disabilities. This lack of understanding of the factors affecting health status was a key contributor to the health disparities that people with disabilities currently experience (Fisher, 2004; Lollar & Crews, 2003; U.S. Public Health Service, 2002). *Healthy People 2010* set a number of goals related to promoting the health of people with disabilities. Through the U.S. Centers for Disease Control and Prevention, funding has recently been made available to 16 states to implement “disability and health” programs that focus on expanding health promotion activities for people with disabilities (Association of State and Territorial Health Officials, 2003). Although not specifically directed toward people with intellectual disabilities, these programs represent a broad shift within the public health field. As experience with these health promotion programs grows, the developmental disability field must push for their adoption as key tools for the promotion of health and self-determination in people with intellectual disabilities.

The health disparities experienced by people with intellectual disabilities have received increased attention as a result of the Surgeon General’s Conference on Health Disparities and Mental

Retardation (U.S. Public Health Service, 2002) and the IASSID Health SIRG initiatives. The U.S. Department of Health and Human Services (2003, p. 18) has identified “individuals with special health care needs, specifically children with special needs, the disabled, people in need of long-term care, and people requiring end-of-life care” as a “priority population” for the systematic collection and analysis of data related to disparities in access to quality healthcare services. However, research continues to document the difficulties that people with disabilities face in receiving attention for health needs not related to their disability when they see medical professionals. In a qualitative study on barriers and facilitations to health and wellness in people with disabilities, Putnam et al. (2003) found:

There were many participants who expressed concern about the way the medical field treats people with disabilities in general. One participant stated, “I often see the medical profession and society in general as wanting to make health and wellness to be an either/or situation, that you’re either healthy or you’re sick. You’re either disabled or you’re not disabled, and this is probably one of the greatest fallacies that the medical profession, society . . . operates within.” Another participant said, “no matter what I go in for, they look at the disability first and forget about whatever I’m talking about, whether it has to do with a disability or not. Everybody just stops and says I have to go to a specialist for this and that” (p. 41).

However, other research has assessed the characteristics of physicians who engage in wellness promotion with their patients with disabilities. Down, Wile, Krahn, and Turner (2004) found the degree to which physicians engaged in wellness promotion with their patients with disabilities was related to their general attitudes toward the importance of wellness promotion. For example, physicians who tended to take a “more comprehensive view of the importance of wellness promotion” were more likely to be active in promoting wellness in their patients with disabilities, while physicians who took a “narrower view of wellness (i.e., those who rated some wellness behaviors as much less important than others)” (p. 307) were less likely to be active in promoting wellness in their patients with disabilities. This encouraging work suggests that factors associated with the ways healthcare professionals recognize the distinction between disability status and health status will be less critical than their general perceptions of the importance of health and wellness promotion for all people in shaping the individual experiences of people with disabilities as they access future community-based health services. Further, the creation of standards for health care for people with intellectual disabilities, such as the European Manifesto on Basic Standards of Health Care for People with Intellectual Disabilities (Meijer, Carpenter, & Scholten, 2004) and curriculums for medical professionals, such as the Core Curriculum for Specializing in Intellectual and Developmental Disabilities: A Resource for Nurses and Other Health

Care Professionals (Nehring, 2005), has provided increasingly accessible resources for community-based practitioners working with people with intellectual disabilities. As the medical field continues to direct more attention to the issues of persistent health disparities among people with intellectual disabilities, it will be critical to ensure that training programs are developed that focus on supporting people with intellectual disabilities to play an active, self-determined role in their health and health care, rather than the traditional, passive patient role.

CONCLUSION

Addressing the health disparities faced by people with intellectual disabilities is an important and timely effort. To effectively support people with intellectual disabilities to achieve positive health and wellness outcomes, however, it is imperative that issues pertaining to consumer control and self-determination in health and medical care remain at the forefront of such efforts. Future efforts must work to build the research base demonstrating the impact of self-determination on health outcomes; to develop, evaluate, and disseminate innovative programs for promoting health among people with intellectual disabilities; and to develop collaborative partnerships between people with intellectual disabilities, professionals in the disability field, and professionals in the medical and public health fields to inform and guide practice in each of these areas.

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