

## The State of the Science of Health and Wellness for Adults With Intellectual and Developmental Disabilities

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### Abstract

Historically, people with intellectual and developmental disabilities (IDD) have experienced health disparities related to several factors including: a lack of access to high quality medical care, inadequate preparation of health care providers to meet their needs, the social determinants of health (e.g., poverty, race and gender), and the failure to include people with IDD in public health efforts and other prevention activities. Over the past decade, a greater effort has been made to both identify and begin to address myriad health disparities experienced by people with IDD through a variety of activities including programs that address health lifestyles and greater attention to the training of health care providers. Gaps in the literature include the lack of intervention trials, replications of successful approaches, and data that allow for better comparisons between people with IDD and without IDD living in the same communities. Implications for future research needed to reduce health disparities for people with IDD include: better monitoring and treatment for chronic conditions common in the general population that are also experienced by people with IDD, an enhanced understanding of how to promote health among those in the IDD population who are aging, addressing the health needs of people with IDD who are not part of the disability service system, developing a better understanding of how to include people with IDD in health and wellness programs, and improving methods for addressing the health care needs of members of this group in an efficient and cost-effective manner, either through better access to general medical care or specialized programs.

**Key Words:** *health; health care; wellness; IDD*

The 2002 report *Closing the Gap: A National Blueprint to Improve the Health of People with Mental Retardation* notes that people with intellectual and developmental disabilities (IDD) experience “poorer health, shorter lifespans, and less access to professional health care than people without this condition” (U.S. Public Health Service [USPHS], 2002). A follow-up report, *The Surgeon General’s Call to Action to Improve the Health and Wellness of Persons with Disabilities* (USPHS, 2005), noted many of the same concerns related to the health status of people with disabilities as the 2002 report and urged action to improve the accessibility and quality of health care for individuals with disabilities. The report went further and promoted the belief that health and disability were not mutually exclusive and that people with disabilities should

also be encouraged to adopt healthy lifestyles. The Institute of Medicine (IOM) issued *The Future of Disability in America* (Field & Jette, 2007), which identified concerns similar to those noted in the 2005 and 2007 Surgeon General reports. Both entities identified reasons for these health disparities resulting from a number of problems including the failure to include people with IDD in public health programs, lack of access to primary care, inadequate professional education, and poor access to prevention activities (Field & Jette, 2007; USPHS, 2002; USPHS, 2005).

The two Surgeon General reports and the IOM report resulted in substantial work over the last decade in assessing the health status of people with IDD, creating health promotion programs to enhance health status, and training of health care

professionals. There has been a rapid growth in publications that describe measures of health status and areas in which there are disparities, but fewer reports on the results of evaluations of health promotion programs, and only a small number of publications that describe the training of health professionals. These publications represent a growing evidence base that will have the potential to improve practices and reduce health disparities for people with IDD. Given the breadth of topics related to health and disability and the varying health service structures that provide care to individuals across countries, this summary of the literature will focus mainly on adults with IDD living in the United States. However, many of the areas discussed are relevant across age groups and geographic regions.

### **Prevalence and Risk Factors for Health Disparities**

People with IDD experience a wide range of health disparities including decreased life expectancy and greater rates of co-occurring conditions (Scepters et al., 2005). Such persons are more likely to experience increased rates of sensory impairment, epilepsy, psychiatric disorders, limited mobility, and gastrointestinal disorders than those without IDD (Traci, Seekins, Szalda-Petrie, & Ravesloot, 2002). They are also more likely to develop common health conditions such as high cholesterol, hypertension, and cardiovascular disease (CVD); and are more likely to experience multiple chronic conditions. (Bodde & Seo, 2009; Draheim, 2006; Krahn, Hammond, & Turner, 2006; Reichard & Stolze, 2011; Reichard, Stolze, & Fox, 2011; Tyler, Schramm, Karafa, Tang, & Jain, 2010).

### **Oral Health**

Poor oral health is often a concern for people with IDD (Traci et al., 2002) with research indicating that they experience high rates of periodontal disease, caries, and related outcomes such as decay, missing molars, and restorations (Anders & Davis, 2010; Morgan, et al., 2012; Pezzementi & Fisher, 2005). The limited literature on dental care for people with IDD also suggests insufficient preventive dental care (e.g., sealants; Pezzementi & Fisher, 2005).

### **Aging**

Aging places additional demands on the IDD population. Elevated rates of dementia in aging

adults with IDD, particularly for people with Down syndrome (DS) is well documented with current estimates suggesting that more than half of the population of people with DS over the age of 50 will experience dementia. (Zigman & Lott, 2007). In addition, women with DS appear to enter menopause earlier than their peers increasing their risks for dementia and early mortality (Coppus et al., 2012). Individuals with IDD who have neuromuscular disorders (e.g., cerebral palsy) are more likely to experience a range of problems as they age, including increased pain levels, sarcopenia, osteoporosis, and arthritis (Strax, Luciano, Dunn, & Quevedo, 2010). Osteoporosis is further exacerbated by medications often prescribed to people with IDD (e.g., phenytoin, SSRIs). These medications can lead to increased bone loss when coupled with a sedentary lifestyle and poor nutrition (Strax et al., 2010).

Finally, end-of-life care as it pertains to people with IDD deserves more attention (Sinai, Bohnen, & Strydom, 2012). Hospice and palliative care is under utilized by people with IDD (Freidman, Helm, & Woodman, 2012). Barriers include ones that are common across populations such as late diagnosis of a terminal illness; however, others are specific to people with IDD, such as challenges with obtaining informed consent or lack of knowledge on the part of palliative care professionals (Friedman et al., 2012). Disability service providers may also have a hard time meeting the end-of-life needs of people with IDD. In a survey of agencies that provide some type of support service to older adults with IDD, only 19% of the respondents reported that their agency had a model to provide effective end-of-life care (Botsford & Heller, 2004).

### **Obesity-Related Factors**

Obesity is a secondary condition to many types of IDD, as well as a significant risk factor for other common health and chronic conditions experienced by people with this disability. Some studies of adults with IDD have found a higher prevalence of obesity among people with IDD than in the general population (Krahn, Hammond, & Turner, 2006; Melville et al., 2007; Rimmer & Yamaki, 2006). Other research suggests that, for people with IDD who do not have a known genetic condition, the prevalence of obesity is less than or similar to that of people living in the same communities and receiving similar health care (Bhaumik, Watson,

Thorp, Tyrer, & McGrother, 2008; Moran et al., 2005; Stancliffe et al., 2011). Obesity and overweight prevalence based on BMI is likely to be inaccurate for people with disabilities, which likely underestimates the true prevalence (Rimmer, Wang, Yamaki, & Davis, 2010). Reliance on self-report and the difficulties stemming from weighing and measuring the height of people with physical disabilities are two of the reasons noted as reasons for inaccurate prevalence (Rimmer et al., 2010).

Reported obesity rates of people with IDD living in the United States since 2000 range from a low of 21% (Moran et al., 2005) to 33.6% (Stancliffe et al., 2011). Other research in the last decade found obesity rates as high as 70.7% in adults with Down syndrome (Rimmer & Wang, 2005). Some of the variability in obesity rates can be explained by severity of IDD, specific diagnosis, recreational and fitness services provided, and living arrangements. People with more severe IDD and those who were living in more restrictive environments generally have fewer independent choices about timing and quantity of food intake and lower rates of obesity than do people with milder IDD (Moran et al., 2005; Stancliffe et al., 2011). However, people with IDD living in the home of a family member or in a home of their own experience the highest rates of unhealthy weight gain, obesity, cardiovascular disease (CVD), and CVD-related mortality (Bryan, Allan, & Russell, 2000; Draheim, 2006; Tyler, Schramm, Karafa, Tang, & Jain, 2010).

Poor nutrition and inadequate physical activity are known risk factors for obesity and related conditions such as diabetes and CVD (Racette, Deusinger, & Deusinger, 2003; Weinsier et al., 1998). The available evidence suggests that in community group homes the diets of residents tend to be nutritionally poor (Bertoli et al., 2005; Humphries, Traci, & Seekins, 2009), and individuals with IDD have limited involvement in food shopping, meal planning, and food preparation (Sisirak, Marks, Riley, & Heller, 2008).

Access to and participation in physical activity is also an area of concern related to the health and wellness of people with IDD. Individuals with IDD tend to lead very sedentary lifestyles and are not achieving a level of physical activity that would positively affect health (Mann, Zhou, McDermott, & Poston, 2006; Peterson, Janz, & Lowe, 2008; Seekins, Traci, Bainbridge, & Humphries, 2005). Other risk factors for obesity for people with IDD

include age (with higher rates among older adults), gender (with higher rates among women), and mobility status (with lower rates for those not independently mobile; Bandini, Curtin, Hamad, Tybor, & Must, 2005; Bhaumik et al., 2008; Melville et al., 2007; Rimmer & Yamaki, 2006; Stancliffe et al., 2011).

Diagnoses such as Down syndrome are associated with higher risks for certain conditions, including overweight, obesity, and related health problems (Braunschweig et al., 2004; Draheim, 2006; Melville Cooper, McGrother, Thorp, & Collacott, 2005; Melville, Cooper, Morrison, Allan, Smiley, & Williamson 2008; Stancliffe et al., 2011) as is Prader Willi syndrome. Individuals with spina bifida with ID are also at higher risk for obesity (Bandini et al., 2005).

Polypharmacy is common among adults with IDD, with a reported mean of 6.5 medications for people living in community-based settings (Sisirak, Marks, Riley, & Chang, 2008). Commonly prescribed medications for co-occurring major mental illnesses may also lead to increase rates of obesity and diabetes (Sinai et al., 2012).

## Poverty

An important and sometimes overlooked risk factor for health disparities in the IDD population is poverty. Poverty is associated with multiple poor health outcomes (Braveman et al., 2010; Larson, Lakin, Anderson, & Kwak, 2001). People with IDD are more likely to experience poverty and poverty-related health disparities (Emerson 2007). The link between childhood poverty and delayed development has long been established (e.g., Fujiura & Yamaki, 2000; Leonard & Wen, 2002). Socioeconomic status (SES) influences other health outcomes in as well. Health outcomes are tied to SES on a continuum, with increasing morbidity and mortality having an inverse relationship with SES (Roux & Mair, 2010). SES influences health outcomes in direct and indirect ways, including the ability to access quality health care, level of exposure to environmental toxins, and exposure to stress (Roux & Mair, 2010). Neighborhoods also influence health inequities indirectly. Access to safe public spaces, transportation, recreation, healthy foods, and social connections are all factors linked to conditions such as hypertension, diabetes and obesity (Roux & Mair, 2010).

Emerson and Hatton (2007) analyzed the responses of more than 1,200 adults with mild to

moderate ID and found that self-reported health status was in large part explained by social indicators such as hardship, defined as having to do without needed items due to lack of money. Given the levels of poverty experienced by people with IDD, this is an important factor to consider when intervening to address health disparities.

### **Health and Wellness Interventions**

Interventions aimed at improving health-promoting behaviors of persons with IDD are one strategy to address obesity and cardiovascular health (Marks, Sisirak, & Chang, 2013; McDermott et al., 2012). Interventions have taken a number of approaches to addressing health behavior such as utilizing individuals with IDD as co-trainers in wellness programs (Marks, Sisirak, Medlen, & Magallanes, 2012), providing nutritional supports to people with IDD and their staff (Humphries, Traci, Pepper, & Seekins, 2009; Humphries, Traci, Olson, & Seekins, 2009), and teaching knowledge and skills that lead to improved health self-advocacy and health behavior (Abdullah et al., 2004; Holburn, Cea, & Gordon, 2008). Evaluations of these programs have demonstrated a number of positive outcomes. Health and wellness interventions have been shown to increase self-efficacy for exercise; lower depression; improve cardiovascular health, muscular strength and endurance; improve weight status; improve GI health; improve nutritional quality and adequacy of available food; result in an overall improvement in knowledge and health-related behavior for at least some of the participants; and decrease maladaptive and increase adaptive behavior (Abdullah et al., 2004; Eller, McCubbin, Drum, & Peterson, 2011; Holburn et al., 2008; Humphries, Traci, Olson, & Seekins, et al., 2009; Mann et al., 2006; McDermott et al., 2012; Marks et al., 2013). As in most programs that target lifestyle change, outcomes for people with IDD are modest and evaluations have rarely measured change longer than one year following program completion. In addition, there are currently few health and wellness interventions that include the training of support staff and the creation of health-promoting environments in residential and vocational settings.

Examples of nutrition programs that demonstrated some success include an intervention that adapted a national nutrition public health program (to meet the needs of people with IDD. Nine one-

on-one sessions were delivered to adults with IDD who were ambulatory and who had a BMI over 30 (Melville et al., 2011). A family member or caregiver was also involved in the sessions. The program worked on reducing caloric intake by 600 kcal per day and focused on choosing appropriate portion sizes from each of the food groups with the goal of meeting macronutrient intake of approximately 50% carbohydrates, 20% protein, and less than 35% fat (Melville et al., 2011). In addition, at least 30 minutes of daily activity five times per week was encouraged along with general increases of physical activity related to increased participation in activities such as household tasks. Finally, behavioral changes were supported through teaching goal-setting and self-monitoring. The results of the program showed statistically significant decreases in weight and BMI for the 47 program participants that completed the intervention (Melville et al., 2011).

Nutritional interventions also include group education. A program designed to address weight loss, nutrition, exercise, and stress reduction (Steps to Your Health) was adapted for individuals with ID (Mann et al., 2006). Eight classes were delivered by community services providers and provided concrete examples of each concept and participatory activities. A total of 324 individuals with BMIs of 25 and over participated in the classes. The results of the program demonstrated improvements in diet, increased physical activity, and increased overall knowledge about health and wellness, with 26% of the participants reducing their weight and BMI (Mann et al., 2006).

Another approach to nutritional intervention is to provide nutritional supports to people with IDD and their staff in order to address the noted nutritional inadequacy of meals of many community residences (Humphries, Pepper, Traci, Olson, & Seekins, 2009; Humphries, Traci, Pepper, & Seekins, 2008). As the authors noted, direct support staff play a significant role in determining the food environment for people living in community residences. Supports were derived for community residences that covered all aspects of meal planning and preparations, and also focused on environmental support and the inclusion of the individual residents in decision-making about menus (Humphries, Pepper, Traci, Olson, & Seekins, 2009; Humphries, Traci, Pepper, & Seekins, 2008). A pilot test in four community residences of this program ( ) showed that menus improved as

demonstrated by increased fruit and vegetable consumption and the inclusion of more lean protein and whole grains (Humphries, Pepper, Traci, Olson, & Seekins, 2009; Humphries, Traci, Pepper, & Seekins, 2008).

Physical fitness interventions are often built into health and wellness interventions rather than in exercise-specific interventions. However, there is some evidence that a regular schedule of cardiovascular and strength training can improve the fitness of individuals with developmental disabilities (Rimmer, Heller, Wang, & Valerio, 2004). In one intervention, 52 adults with DS met in small groups three times weekly for 12 weeks to participate in 30 minutes of cardiovascular training and 15 minutes of strength training supervised by an exercise physiologist. Statistically significant improvements were observed in cardiovascular fitness as measured by peak  $\text{VO}_2$  measures, peak heart rate, time to exhaustion, and maximal workload over controls (Rimmer et al., 2004). Bench and leg press also showed statistically significant gains when compared to a control group (Rimmer et al., 2004).

Alternatives to intensive fitness intervention programs have been tried, such as the use of virtual reality games to improve fitness (Lotan, Yalon-Chamovitz, & Weiss, 2008). In this study, 30 adults with IDD participated in a 6-week fitness program that involved playing commercially available active video games twice per week for 30 minutes. Participants were matched with a comparison group on age, level of IDD, and functional abilities. The intervention group showed increased physical fitness as measured by a modified 12-minute walk/run and the Total Heart Beat Index (Lotan et al., 2008). The Energy Expenditure Index, a method to estimate the energy expended from walking based on heart rate, did not show statistically significant differences between the intervention and control group (Lotan et al., 2008).

### Access to Health Care

People with IDD are significantly more likely to report unmet needs for health care, mental health care, prescription medications, and dental care than the general population (Anderson, Larson, Lakin, & Kwak, 2003; Krahn et al., 2006). Parish, Moss, and Richman (2008) conducted focus groups with self-advocates, family members, and paid caregivers. While the majority reported having a usual source

of medical care (93.1%) far fewer reported having a dentist (44.8%). Nearly two-thirds (62%) reported no dental care in the prior year and 6.9% reported no physician visit. Focus group participants also reported that they were not receiving preventive care such as mammograms (only one woman reported having one; Parish et al., 2008). In another study using focus groups with self-advocates and family members, participants reported difficulty finding providers, particularly in areas such as dentistry, gynecology, ophthalmology, and mental health care (Ward, Nichols, & Freedman, 2010). When a provider was identified, lengthy wait times for appointments were common (Ward et al., 2010).

There are a number of reasons for these disparities including: a clinical focus on IDD as the primary disability rather than prevention and management of secondary conditions that limit function and participation, lack of appropriate professional training, and issues of poverty and associated social determinants of health. The failure of clinical guidelines to adequately address the health needs of people with IDD further exacerbates health access. In an examination of clinical guidelines from seven countries, Mizen, MacIe, Cooper, and Melville (2012) found that most clinical guidelines failed to address people with IDD as being at high risk for particular conditions when appropriate. They also noted that guideline development groups do not include people with IDD experience on the committees developing guidelines (Mizen et al., 2012).

The reliance of most people with IDD on public insurance programs with poor reimbursement further decreases access to care, as medical and dental providers may be reluctant to provide services to patients for which they believe they will not be adequately reimbursed (Birenbaum, 2009; Martin, 1997). In addition, there has also been a lack of attention to this population by the field of public health (Krahn & Drum, 2007; Patrick, 1997).

A survey of family members, case managers, and physicians of adults and children with IDD identified health care access problems that stemmed from physical accessibility challenges (e.g., physical barriers to physicians' offices), communication barriers (e.g., health care professionals discussing symptoms and treatment options with caregivers rather than with the person with IDD), physician attitudes regarding providing

services to persons with IDD, and inappropriate referrals involving both a failure to refer to specialists and, in other cases, referring to specialists too frequently when health issues could be addressed by the primary care provider (Reichard & Turnbull, 2004). Ward et al. (2010) reported similar problems with persons with IDD not receiving thorough physicals, providers directing communication at the caregiver rather than the individuals, insensitive office staff, misdiagnoses, and reduced quality of care for persons with challenging behavior (e.g., care was not given or care was given under anesthesia).

Physicians surveyed report barriers to effective health care as entailing their own lack of training with respect to this segment of the population, inadequate reimbursement from Medicaid, inadequate exposure to and discomfort with to people with IDD, and lack of time to adequately deliver health care services to people with intellectual limitations (Reichard & Turnbull, 2004). Medical students have been found to exhibit poorer performance caring for patients with IDD compared to others in tasks varying from taking a medical history, conducting physical exams, and ordering laboratory tests (Brown, Graham, Richeson, Wu, & McDermott, 2010).

Training dental students to treat people with IDD has also been challenging (Clemetson, Jones, Lacy, Hale, & Bolin, 2012). Despite a 2006 accreditation standard that requires dental schools ensure that their graduates are competent in treating people with special needs (Commission on Dental Accreditation, Accreditation Standards for Dental Education Programs, 2004), Clemetson and colleagues (2012) found that students are still inadequately prepared to meet the ongoing treatment needs of individuals with IDD, thus perpetuating access challenges in dental care. Coupled with the lack of training in this area available for dental students, the reluctance of dentists in private practice to accept Medicaid patients due to poor reimbursement rates and overall lack of dental coverage in state Medicaid plans makes access to even the most basic dental care a challenge for people with IDD (Waldman & Perlman, 2002).

Medical homes may have the potential to address health care access issues for people with IDD. Medical homes emphasize chronic care management and encourage coordination of both health and social services in a shared decision-making model. The Healthy Outcomes Medical

Excellence (HOME) project, operated by the University of Utah since 2000, was developed to provide medical and mental health care to children and adults with IDD and mental health challenges (Weedon, Carone, Bilder, O'Brien, & Dorius, 2012). HOME provides comprehensive care using a team that includes a family physician, a pediatrician, psychiatrists, advanced practice nurses, behaviorists, social workers, and care coordinators. Since its inception, HOME has decreased hospital bed days and hospital readmissions, and has improved clinic outcomes such as vaccine uptake and diabetes management (Weedon et al., 2012).

Telemedicine and other technologies may have the potential to be an important tool that can effectively address access to care challenges for people with disabilities. However, in one review of the literature examining the benefits of smart home technologies and its effect on health care and community care outcomes, the reviewers determined that there was not yet enough evidence to determine the efficacy of these technologies (Martin, Kelly, Kernohan, McCreight, & Nugent, 2008). A second review of the literature found that using a telepractice intervention to provide assessments and behavioral support was a potentially effective means of delivering support to caretakers and educators of people with autism spectrum disorders (ASD; Boisvert, Lang, Andrianopoulos, & Boscardin, 2010). Much more work needs to be done in this area.

## Gaps in the Literature

### Research Methods and Data

Although significant progress has been made in better understanding health disparities and approaches to address those disparities, the extant literature is by no means robust with respect to either its rigor or scope. Studies of successful programs and approaches to enhancing the health and well-being of persons with IDD are being published, but the field is young and a strong evidence base for most interventions does not yet exist. One of the most critical gaps in the research is the lack of rigorous intervention trials, replications of successful approaches, and data that allow for better comparisons between people with and without IDD living in the same communities. Better data sources with the ability to compare health outcomes of people with IDD to other

groups would help develop a fuller understanding of the health and wellness as well as unmet health care needs of people with IDD (Schrojenstein Lantman-de Valk, 2005).

National health surveys of the general population frequently do not use reliable methods or tools to identify people with IDD, and national health surveys often exclude group residences from participation (Krahn & Drum, 2007). The most recent survey in the United States in which strategies to specifically recruit individuals with IDD were used was the 1994–1995 National Health Interview Survey (Hendershot, Larson, & Lakin, 2003). Although other large-scale survey programs (e.g., the American Community Survey) are fielded regularly, the broad definition of disability uses groups of people with IDD grouped together with individuals with mental health diagnoses, Alzheimer disease, and dementia. In a review of health surveys in 12 countries, the reviewers found that all 12 screened for general disability, but identifying people with IDD was problematic (Fujiura, Rutkowski-Kmitta, & Owen, 2010). Although some countries periodically fielded IDD-specific surveys, the authors recommended incorporating better identification measures into already standing health surveillance tools (Fujiura et al., 2010).

The National Association of Directors of Developmental Disabilities Services developed the National Core Indicators Survey (NCI) in order to learn more about the needs of people with IDD. The NCI, however, is not currently administered in all states, nor does it include a comparison group of people without IDD limiting comparisons across populations and geographic regions. The NCI does provide the best available data, based on random samples at the state level, regarding the life experience of people with IDD (Bradley & Mosley, 2007; Smith & Ashbaugh, 2001).

### **Health Needs of People Not Receiving Formal Supports**

A gap also exists in our knowledge about both the health status and health needs of people with IDD living in the community who are not receiving support services and are often unknown to state and local agencies that oversee services to people with IDD (Emerson, 2011; Fujiura & Taylor, 2003; Tymchuk, Lakin, & Luckasson, 2001).

Programs such as the NHIS-D, which include non-institutionalized populations, report a much

higher prevalence of IDD than would be expected through the sole use of administrative data sets including state and Federal Medicaid records. Most research among individuals with IDD is done with people receiving services because they are most easily identified and recruited. There are likely a significant number of people with mild IDD living independently who are not known to disability service providers, but who have similar support needs and vulnerabilities as those receiving disability-related support services from their state. (Emerson, 2011; Fujiura, 2003). This group needs to be included in research in more meaningful ways. Researchers need to extend their recruitment efforts to members of this group, and more importantly, to use strategies successfully to reach other hard-to-reach groups (e.g., first generation families or “New Americans”) to better understand their health care and health promotion needs. Innovative research strategies and the development of health promotion programming that promotes the full participation of people with IDD will be an important step to close this gap (Humphries, Traci, & Seekins, 2009; Jurkowski, 2008; Patrick, 1997).

### **Autism Spectrum Disorders**

The diagnosis of autism spectrum disorders (ASD) has been increasing dramatically in the past two decades (CDC, 2013). Most research related to people with ASD has been with younger age groups, and little is known about how ASD affects the aging process (Ladinski-Muaetova, Perry, Baron, & Poverly, 2011; Perkins & Berkman, 2012). However, given the multiple co-occurring disorders experienced by younger people with ASD (e.g., gastrointestinal problems, insomnia, autoimmune problems, mitochondrial disease, epilepsy) a better understanding of aging and people with ASD is needed (Ladinski-Mukaetova et al., 2011; Perkins & Berkman, 2012).

### **Aging**

As individuals with IDD are living longer lives, many heretofore unknown health effects related to aging are becoming relevant. Of particular concern to aging people with IDD are the effects of long-term use of medications, and the additional risk when such pharmaceuticals are combined with a sedentary lifestyle (Peterson, Gordon & Hurvitz, 2012; Strax et al., 2010). Care guidelines specific to people with IDD who experience age-related

conditions (e.g., cancer, arthritis, and hypertension) are not currently available (McCallion & McCarron, 2004).

### Policy Issues

A significant policy change in the United States is the Patient Protection and Affordable Care Act (PPACA). It has the potential to improve access and decrease health care inequities for people with disabilities. Some provisions of the act which benefit people with disabilities include prohibiting insurance denials based on preexisting conditions, prohibiting annual and lifetime coverage limits, making essential the coverage of rehabilitation and habilitation and mental health services, and assuring that dental care is also deemed essential (Caldwell, 2010). More importantly people with IDD are identified as a priority population, meaning that specific training programs will be enacted for both primary care and dentistry (Caldwell, 2010). The ACA also provides provisions which have the potential to improve access to health care for people with IDD, including Medicaid payments for medical homes to provide health care to people with chronic health care needs (Reinhard, Kassner, & Houser, 2011). The act also promotes the integration of benefits and increased cooperation between federal and state entities, which may improve health care access for people who are dually eligible for Medicaid and Medicare (Reinhard et al., 2011). At this time, much of the PPACA has yet to be implemented so the long-term implications on the health of people with IDD are as yet unknown.

### Future Research

Directions for future research related to the health and wellness of people with IDD fall into two general areas: epidemiologic studies to quantify the health status of people with IDD of varying types and severity, and research related to the systemic issues that influence health outcomes. A greater emphasis on randomized intervention trials, case control studies, and other study designs to test the ability of health promotion to reduce risk or improve outcomes for people with IDD is needed.

Policy intervention research is as important as person-level interventions in addressing health inequities. In order to change health inequities, upstream interventions at the policy level need to be considered and evaluated for their effectiveness

and likelihood of scalability using multidisciplinary community based research approaches (Koh et al., 2010).

Future research also needs to focus on strategies to reduce or minimize health risk factors, identification of protective factors including methods to improve our understanding of how to support people with IDD in learning the skills needed to live healthy lives, and effective advocacy for their health support needs. Research must examine the personal capacities necessary to enhance health care self-determination, and the environments in which people with IDD live and work and how these environments affect their health.

Over the past 30 years, there have been significant changes in the health care delivery system. These changes are likely to be associated with a host of as yet unknown changes in health outcomes. Future research needs to take into account, or control for, influences related to health care reform, including accountable care organizations, care coordination, and the Patient Protection and Affordability Act, and how these reforms affect access to and the quality of health care for people with IDD. This research also needs to address how health promotion interventions that are proven effective can be more broadly disseminated to reach their target audiences. Advances in health care and the services and supports received by people with IDD have also resulted in their living longer and facing many of the challenges of aging. Further studies are also needed to better understand the processes and strategies through which people with IDD, with and without lifelong comorbidities, can live not just longer, but healthier, more productive lives.

Relevant and timely research in the field of health and wellness for people with IDD needs to investigate how aging-related conditions (e.g., diabetes or CVD) can be better monitored and managed to ensure successful aging for people with IDD. Similarly, more research is needed on the manifestation of typical age-related conditions (e.g., cancer, arthritis, and hypertension) in this population in order to establish appropriate care guidelines. Although significant progress has been made in recent years, additional studies are necessary to develop and evaluate alternative techniques and technologies that better include people with IDD in health promotion activities.

A second general area of need entails the growing emphasis on programs to train health care



professionals to more effectively interact with and meet the health care needs of persons with IDD. Future research is needed to develop best practices and evidence-based approaches to train physicians, nursing, and dental staff to effectively provide care to people with IDD in a person-centered manner.

As described earlier in this paper, little is currently known about the health care needs of people with IDD who are not part of the disability services systems in their states. Further research is needed to understand how to impart health advocacy skills in order that such individuals and others with IDD are equipped with the skills, knowledge, and attitudes and beliefs that allow them to play a greater role in managing their own health.

Although national health care reforms appear to be positive for people with IDD, many questions with respect to how reform will have an impact on their access to health care and its quality remain to be answered. Research that focuses on the development and validation of effective monitoring systems is therefore required so that we can be sure that health care organizations are in fact improving health care access and reducing health disparities for people with IDD. Further research is also needed on changing societal forces that have an influence on public policy, such as the aging population, and how this will influence both the means of delivering health care as well as by whom care will be delivered (Fujiura & Parish, 2007).

For the most beneficial and cost effective decisions to be made, evaluation should continue into the practices of creating specialized health interventions for people with IDD or adapting current interventions for the general population to better serve the unique needs of people with IDD. This work will need to address age, SES, sex/gender, and cultural differences among persons with IDD who access health care supports as well as those who provide such supports. Further research into technology and how this can better meet the health needs of individuals with IDD in order to address access issues should be an important part of the development and evaluation of models of health care delivery.

### Conclusions

Given the longstanding health disparities experienced by people with IDD, an increased focus on program development, evaluation, and rigorous research in this area is both warranted and long

overdue. Effective programs of evaluation and research related to health and wellness for this segment of the population over the next decade have the potential to facilitate the development of a substantial evidence base and best practices in the health care arena. Health research has moved beyond studying primary disabling syndromes and specific causes of such syndromes, to include important epidemiology of IDD, health outcomes that are not disability specific, health promotion and disease prevention. We now have a greater understanding of the health disparities experienced by people with IDD and their causes ranging from lifestyle (e.g., lack of physical activity) to policy-related (e.g., Medicaid's lack of dental care coverage) to social factors (e.g., poverty). Additionally, more research related to promising interventions in health promotion in order to address preventable chronic conditions related to lifestyle is being conducted. Despite the increased knowledge in health and wellness that has accumulated over the past several decades, given the multiple health-related needs of this segment of the population, the surface has barely been scratched and we must conceptualize the body of research available today as but a beginning.

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les enfants et les adultes ayant une DI. Cet article résume (a) l'état de la recherche en ce qui concerne le soutien aux familles qui offrent un soutien à domicile aux personnes ayant une DI, (b) présente les préoccupations actuelles en ce qui concerne le soutien pour ces familles, et (c) les priorités de futures recherches relatives au soutien des familles.

### **Inclusion sociale et participation communautaire chez des personnes ayant une déficience intellectuelle**

**Angela Novak Amado, Roger J. Stancliffe,  
Mary McCarron et Philip McCallion**

Comme plus de personnes ayant une déficience intellectuelle sont physiquement incluses dans la vie communautaire, les écoles, les quartiers, le travail, les loisirs et les congrégations, le défi d'aller au-delà de l'intégration physique et d'être inclus socialement est de plus en plus apparent. Cet article résume l'état de la recherche sur la participation communautaire et l'inclusion sociale, résume certains débats et points de discorde, note les thèmes de recherche émergents, et met en évidence les besoins de recherches futures. Il est clair que la plupart des recherches ont été réalisées avec des personnes qui sont dans des services rémunérés et il y a de grands besoins de compréhension de la participation communautaire d'individus qui vivent seuls ou avec leurs familles, ainsi que des recherches sur l'inclusion sociale en mettant l'accent sur les attitudes et les expériences des membres de la communauté, et non seulement sur les personnes ayant une déficience et les prestataires rémunérés.

### **L'état de la science de l'emploi et de l'autosuffisance économique pour les personnes ayant une déficience intellectuelle**

**Derek Nord, Richard Luecking, David Mank,  
William Kiernan et Christina Wray**

L'emploi, l'avancement de carrière et l'indépendance financière sont très valorisés aux États-Unis. Les attentes, elles, sont souvent inculquées dès le plus jeune âge et favorisées tout au long de l'âge adulte. En dépit de leur importance, l'emploi et la suffisance économique continuent à être hors de portée pour la plupart des personnes ayant une déficience intellectuelle. Au cours du dernier quart de siècle, des recherches et des efforts ont été engagés pour la compréhension et l'amélioration de ces phénomènes.

Ce document résume cette recherche sur l'emploi par une recension des écrits scientifiques portant sur l'efficacité du système de soutien à l'emploi actuel, des interventions spécifiques à l'emploi et de l'économie et des coûts/bénéfices de l'emploi chez les personnes présentant une déficience intellectuelle. Des recommandations et des orientations pour la recherche future sont également présentées.

### **L'état de la science de la santé et le bien-être des adultes ayant une déficience intellectuelle**

**Lynda Lahti Anderson, Kathy Humphries,  
Suzanne McDermott, Beth Marks, Jasmina  
Sisarak et Sheryl Larson**

Historiquement, les personnes ayant une déficience intellectuelle (DI) ont vécu des disparités en lien avec leur santé qui sont reliées à plusieurs facteurs incluant : un manque d'accès à des soins de santé de haute qualité, une préparation inadéquate des professionnels de la santé pour répondre à leurs besoins, les déterminants sociaux de la santé (ex. : pauvreté, ethnie, genre), et le manque d'inclusion des personnes ayant une DI dans les efforts de santé publique et d'autres activités de prévention. Durant la dernière décennie, des efforts ont été effectués pour identifier et répondre à la multitude de disparités en lien avec la santé des personnes ayant une DI par le biais d'activités incluant des programmes sur les modes de vie équilibrés et par une plus grande attention portée à la formation des professionnels de la santé. Des manques dans la littérature incluent le manque d'essais d'intervention, la réplication des approches gagnantes, et des données qui permettent une meilleure comparaison entre les personnes ayant une DI et les personnes sans DI qui vivent dans la même communauté. Les implications pour les recherches futures permettant de réduire les disparités reliées à la santé des personnes ayant une DI incluent : un meilleur suivi et traitement des conditions chroniques fréquentes dans la population générale qui sont aussi présentes chez les personnes ayant une DI, une meilleure compréhension des moyens de promouvoir la santé auprès des personnes vieillissantes ayant une DI, aborder les besoins de santé des personnes ayant une DI qui ne reçoivent pas de services en déficience, développer une meilleure compréhension des manières d'inclure les personnes ayant une DI dans les programmes de santé et de bien-être, et améliorer les méthodes pour régler les problèmes reliés aux besoins de soins de santé des

membres de ce groupe d'une manière efficace et rentable, soit par un meilleur accès aux soins de santé généraux ou par des programmes spécialisés.

### **Autodétermination et choix**

**Michael L. Wehmeyer et Brian H. Abery**

Schalock et ses collègues (Schalock & Verdugo, 2002; 2012) ont identifié l'autodétermination comme étant une dimension importante de la qualité de vie, et depuis les deux dernières décennies, les efforts pour promouvoir l'autodétermination ont été associés avec des résultats plus positifs à l'école, dans la communauté et à l'âge adulte chez les personnes ayant une déficience intellectuelle (DI) (Wehmeyer, Abery, Mithaug, & Stancliffe, 2003; Wehmeyer, Agran, Hughes, Martin, Mithaug, & Palmer, 2007). De plus, les occasions de faire des choix et d'être autodéterminé sont devenues une partie importante des demandes faites par les personnes ayant une DI dans les mouvements de défense des droits et ces idées ont été intégrées dans le mouvement faisant la promotion de l'empowerment et des droits de ces personnes (Wehmeyer, 2004; 2011; in press a). Les efforts pour promouvoir l'inclusion sociale et la qualité de vie des personnes doivent inclure des efforts pour promouvoir et soutenir l'autodétermination. Cet article examine l'état des connaissances dans le domaine de l'autodétermination auprès des personnes ayant une DI.

### **Utilisation des données probantes de la recherche pour éclairer les décisions de politiques publiques**

**Charles Moseley, Harold Kleinert,  
Kathleen Sheppard-Jones et Stephen Hall**

L'application de données scientifiques dans le développement et la mise en œuvre de politiques publiques saines est une pratique bien établie, mais il semble y avoir moins de consensus sur la nature des stratégies qui peuvent et doivent être utilisées pour intégrer les données de la recherche dans les décisions politiques. Cet article décrit la promesse et les défis de l'utilisation des données de recherche pour informer les politiques publiques. Plus précisément, nous démontrons comment l'application d'un ensemble de données à grande échelle, les indicateurs nationaux de base (NCI), peut être utilisée systématiquement pour prendre des décisions politiques au niveau des états, et nous décrivons un exemple d'utilisation des données du NCI par un état afin d'apporter des changements significatifs pour les personnes ayant une déficience intellectuelle. La nécessité de poursuivre la recherche dans ce domaine est mise en évidence.

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