

Abstract

Adults with Intellectual and Developmental Disabilities (I/DD) experience more health disparities than nondisabled counterparts in the general population. Training resources are needed for primary health care providers serving this population. A review of literature identified barriers and challenges this population experiences when trying to obtain quality health care and areas of training needed by medical staff.

Key words: adults, intellectual and developmental disabilities (I/DD), health care, medical needs, health promotion, medical providers, doctors, nurses, preventative screening, emergency room visits, cancer, dental, oral hygiene, communication, mental health, behavioral health, sexuality.

Prevalence, Etiology, Definitions

In 2013 it was estimated approximately 4.5 million people in the United States had an Intellectual and Developmental Disability [I/DD] (Lind & Archibald, 2013). Prevalence rates vary depending on the study and research design, but according to the World Health Organization the prevalence of I/DD is close to 3% of the population (Understanding Intellectual Disability and Health, 2014). In many cases a diagnosis is not given at birth because the features of the disability are not evident until a few years later when major developmental milestones are not achieved (Boyle, Yeargin-Allsopp, Doernberg, Holmgreen, & Schendel, 1991). A specific reason or cause of the disability can only be determined in approximately 25% of cases (Shapiro & Batshaw, 2011). Some of the most common known causes of I/DD are Autism, Fetal Alcohol Spectrum Disorder (FASD), Down syndrome, Fragile X syndrome. Other causes include infections during or after birth, such as measles or meningitis and exposure to environmental toxins (The ARC, 2014).

Under the Developmentally Disabled Assistance and Bill of rights Act, adopted in 2000, Developmental Disability means a severe, chronic disability of an individual that:

1. is attributable to a mental or physical impairment or combination of mental and physical impairments;
2. is manifested before the individual attains age 22;
3. is likely to continue indefinitely;
4. results in substantial functional limitations in 3 or more of the following areas of major life activity: (i) Self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi)

capacity for independent living, and (vii) Economic self-sufficiency; and

5. reflects the individual’s need for a combination and sequence of specialized, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated (Administration on Intellectual and Developmental Disabilities [AIDD], 2014; The ARC 2011 & U.S. Department of Health and Human Services [DHSS], 2014).

The American Association on Intellectual and Developmental Disabilities (AAIDD) defines Intellectual disability as “...a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18 (AAIDD, 2014)”. The AAIDD estimates the prevalence rate is close to 2.5% of the population experiences I/DD.

The exact definition of I/DD used for eligibility criteria and access to services may vary depending on the setting or funding source of the agency (AAIDD, 2014). For example, the Individuals with Disabilities Education Act (IDEA), guarantees a free and appropriate public education for children with disabilities. The Americans with Disabilities Act (ADA) is legislation-protecting people with from discrimination in the work place and promotes independence (Health Policy Institute of Ohio, [HPIO], 2014). The Social Security Administration may use a different set of criteria when determining if services and support are available for those with disabilities (Social Security Administration [SSA] and disabilities, 2014).

Background

Individuals with disabilities have a long history of discrimination and disadvantage, most notably was placement in institutionalized settings. In the 1960's and 1970's, with grassroots efforts and increased public awareness because of the civil rights movement, the treatment of individuals with disabilities improved. The deinstitutionalization movement began and ushered in new federal legislation, specifically the Rehabilitation Act of 1973, which helped decrease barriers for individuals with disabilities. It gave people with I/DD the opportunity to live with their families and participate in the community (Krahn, Klein Walker, Correa-De-Araujo, 2015). Although many improvements have occurred over the past 50 years, there continues to be misunderstanding, prejudices, and inequality of treatment for people with I/DD in comparison to the general population (AAIDD, 2014).

Scope of the Problem

A review of the literature verified there is a great deal of disparity between services received by adults with Intellectual and Developmental Disabilities (I/DD) and those in the general population (Center for Disease Control and Prevention [CDC] & National Center on Birth Defects and Developmental Disabilities [NCBDDD] 2009; Krahn, Hammond & Turner, 2006; Krahn, Klein Walker, & Correa-De-Araujo, 2015; Lahti-Anderson, Humphries, McDermott, Marks, Sisarak, & Larson, 2013; Ward, Nichols, & Freeman, 2010). People with I/DD have greater difficulty and face more barriers, than nondisabled people, when trying to obtain quality medical care (Sullivan, Berg, Bradley, Cheetham, Denton, Heng, Hennen, Joyce, Kelly, Korossy, Lunsy, & McMillan,

2011). These barriers include access issues, lack of disability trained health care providers, lack of coordinated services, lack of health promotion and prevention, discrimination, cost, affordability, communication & personal decision-making (The ARC, 2012). People with I/DD report a greater number of secondary health conditions than their non disabled peers (i.e. cancer, hypertension, depression, bowel obstructions, ulcers, dental caries, hearing loss, vision issues), yet have poorer health outcomes, have less access to preventative health services or don't seek care at all, except in emergency situations (Drainoni, Lee-Hood, Tobias, Bachman, Andrew, & Maisels, 2006).

People with disabilities and their families report great difficulty finding a health care professional who understands their disability (Hanson, Neuman, Dutwin, & Kasper, 2003). They also report there are gaps in services, greater delays in services, or undiagnosed medical needs (Drainoni et al., 2006). Research indicates changes can and should be made to decrease the disparities in health care for this population (U.S. Department of Health & Human Services, 2005). In order to better serve the healthcare needs of people with I/DD, studies suggested system wide changes in the following areas:

- Better coordination of services between agencies
- Better management of complex health conditions
- Better coordination and structuring of funding sources
- Increased specialized training, for health staff, specific to disabilities
- Inclusion of patient's with I/DD in health promotion
- Early detection /screening programs

(CDC & NCBDDD, 2009; Krahn, Klein Walker, & Correa-De-Araujo, Lind & Archibald, 2013; Engquist, Johnson, & Courtland-Johnson, 2012).

Medical providers want to provide quality care to all their patients, yet they face a number of barriers that impede them from providing quality health care to adults who have I/DD. The complex and challenging health care needs of individuals with I/DD makes it more challenging for practitioners to care for these patients (Krahn et. al., 2006, Sullivan et. al, 2011).

Barriers have been cited as: difficulty communicating effectively with patients, lack of training specific to disabilities, time constraints and lack of specialized equipment for use with this population (i.e. exam tables that are accessible for handicapped individuals in remote settings), educational resources and materials that can be easily read and clearly understood by these individuals (Atkinson, Smith, Tew, Heath, Reed, & Miller, 2014). General practitioners in Taiwan indicated the need for more specialized training and experience to adequately work with patients having I/DD and training to improve communication skills needed for interviewing and disseminating health information (Jin-Ding Shang-Wei, Chia-Feng, Ying-Ting, Chia-Ling, Chu, & Ching-Hui, 2009; Sullivan et. al, 2011).

Changing delivery models is a paradigm shift, which will take time, and significant effort, from multiple agencies to achieve the necessary changes needed to improve health outcomes for people with I/DD. The intent of this project is to provide training resources for primary health care providers. The literature review indicated medical providers needed more specific training regarding I/DD as it relates to:

Communication Skills, Behavioral Health, Health Promotion and Preventative

Screening, and Sexuality.

Communication Skills

Health care providers have identified communication skills as a professional competence that demands special training and extra time (Koski, Martikainen, Burakoff, & Launonen, 2010). Survey results from health care providers in Alaska indicated communication and time constraints as a concern when interacting with patients who have I/DD (Atkins et. al. 2014). Due to impaired cognitive and/or motor skills communication can be difficult for patients with I/DD, making it difficult for them to convey their thoughts or speak clearly. Data from the Australian Institute of Health and Welfare (AIHW) indicates almost 60% of people with intellectual disabilities have significant communication issues (AIHW, 2008). When a patient cannot clearly explain or articulate their symptoms or problems, then medical providers must spend extra time trying to accurately obtain information regarding the nature of their problem or the reason for the visit. When communication difficulties and breakdowns occur it can result in frustration for both providers and patients (Finlay & Antaki 2012). Lack of understanding can potentially lead to extra costs because unnecessary tests or procedures might be done in an effort to diagnosis and treat patients (Chi, Masterson, & Wong, 2014; Lunsy, Lin, Balogh, Klein-Geltink, Wilton, & Kurdyak, 2012).

The use of Augmentative or Alternative Communication (AAC) strategies such as pictures, gestures or objects is one type of accommodation medical providers and their staff can use to improve patient relations (Koski et. al., 2010). Finding strategies and

AAC systems that are suitable for individuals is not a one case fits all and cannot be predetermined based on the person's developmental age or disability, however awareness of different communication means and systems is a start (Mirinda 2009; Prelock, 2007). Because medical concepts and language are very complex, offices should strive to make all health literature easy to read and verbal information easily understood, regardless of age and background (DHSS, Fact Sheet: Health Literacy Basics, 2014).

Behavioral Health

People with disabilities face a number of societal challenges related to poverty, housing, employment and recreational opportunities, all of which directly or indirectly affect physical and mental health (HPIO, 2014). The most common coexisting health condition for people with I/DD is psychiatric or mental health related (Lunsky, et al., 2012 & AIHW, 2008). "The National Core Indicators Survey of 2011-12 found an estimated 31 percent of adults served by country boards of developmental disability had a co-occurring mental illness or psychiatric diagnosis while 50 percent took medication for a mood, behavior or anxiety or psychotic disorder" (HIPIO, 2014). The nursing profession has noted higher rates of mental problems and gaps in services for patients with I/DD (Krahn, et. al., 2006). Behavioral health includes conditions that affect individuals with I/DD issues such as Generalized Anxiety Disorder, Obsessive Compulsive Disorder, Oppositional Defiant Disorder, Panic Attacks, Depression, Bi-Polar and more significant psychiatric issues. Although medical providers and mental health workers are well versed in behavior issues they often lack specific training for working with individuals that have I/DD. A survey, of psychiatrists working in Israel,

indicated “90% of participants reported having limited training in the diagnosis and treatment of people with intellectual disabilities, while between 34% and 72% reported having inadequate knowledge in specific areas” (Werner, Stawski, Polakiewicz & Levav, 2013). Lack of qualified providers in the area of behavioral health increases the difficulty patients and their families have in finding adequate therapy services (Matson, Neal, & Kozlowski, 2012; Raghavan, Newell, Waseem & Small, 2009).

Suicide in people with I/DD has typically not received much attention from health care providers and clinicians. Research indicates the I/DD population has the same suicide risk factors as the general population and higher rates of mental health problems, which could put them at greater risk for suicide. Research has found that emotional supports, counseling and physical activity can help prevent certain health problems such as heart disease and depression. Individuals with low cognitive abilities do experience mental health issues and need more supports in the community (Mollison, Chaplin, Underwood & McCarthy, 2014).

Health Promotion & Preventative Screening

People with developmental disabilities have an increased risk for chronic diseases and other health problems, such as heart disease, hypertension, diabetes, obesity, seizures, hearing and vision problems, low bone mineral density, and poor fitness (Van Riper & Wallace, 2010). Lack of regular physical activity in this population puts them at greater risk for health problems and increases the risk of heart disease and diabetes (Finlayson, Jackson, Cooper, Morrison, Melville, Smiley & Mantry, 2009). People with

I/DD have rates of obesity equal to or greater than the general population but data indicates health promotion classes can lead to a significant reduction in weight and body mass index scores (Marks, Sisirak & Chang, 2013). Common medical data has proven tobacco smoking can exacerbate asthma and raise body mass index. Research indicates that asthma mortality may be higher in people with I/DD than the general population. A very high proportion of patients with I/DD and asthma were found to be current smokers and/or obese. (Gale, Naqvi & Russ, 2009).

Cognitive impairment makes patients with I/DD less likely to seek out and understand health care, which then places them at greater risk for adverse health and well being. Low health literacy is reported to have negative consequences on patient understanding of health-related information (Nair & Cienkowski, 2010). This is an area where medical providers need to work in partnership with caretakers and individuals with I/DD to create more active lifestyles (Marshall, McConkey & Moore, 2003). Social workers can play an important role in “...Training health care providers to enhance their understanding of the physical and psycho-social needs of people with I/DD..” in an effort to reduce health disparities (Robinson, Dauenhauer, Bishop & Baxter, 2012).

Sexuality

“The presence of an intellectual or developmental disability, regardless of severity, does not, in itself, justify loss of rights related to sexuality” (The ARC, 2008). Sexuality is a basic human need. It encompasses self-esteem, interpersonal relationships and social experiences relating to dating, marriage and the physical aspects of sex.

(National Down Syndrome Society [NDSS], 2014).

When there is lack of access to appropriate sex education some individuals may engage in sexual activity, which results in manipulation, unwanted pregnancies, abuse and transmission of disease. Providing appropriate sex education to individuals with I/DD will help to reduce the risk of unwanted pregnancies, disease transmission and & sexual abuse; and increase individual's knowledge and quality of life (NDSS, 2014). One study found patients with I/DD indicated self-advocacy would increase their knowledge related to sexual health services and increase access to services (Friedman, Arnold, Owen, Sandman, 2014). Identified topics which health care providers need to address included: educating patients about reproduction, birth control options, abstinence, safe sexual practices, sexual orientation, sexual abuse, and sexually transmitted diseases (The Arc, 2008).

Conclusion

A review of literature indicates there is a disparity between the quality and type of health services received by people with Intellectual and Developmental Disabilities (I/DD) when compared to the general population. People with I/DD have more barriers to accessing appropriate, high quality health care than the general population. They experience more negative social determinants (i.e. less education, lower income, greater issues with transportation, limited social networks and less insurances coverage) than the general population, all of which impacts their ability to access health care more than the general population. The presence of cognitive and physical impairments ensures that individuals with I/DD have little capacity to overcome the effects of these negative determinants, thus the health care system and providers must

be proactive in educating patients and offering low cost and high quality of care.

Additional factors, which increase disparity in health services for all populations, but were not addressed in this review, include social determinants such as poverty, race, and gender.

Areas needing attention to decrease these disparities includes: better access to general health care and specialized programs, increased training for health care personnel, efficient and cost-effective treatment options, better monitoring and treatment for chronic medical conditions, and promotion of health needs and wellness programs.

“As a society, we have let go of people with ID since the deinstitutionalization movement of the 1970s. Given full rights to citizenship, this group has been absorbed into the fabric of society; however, they remain disenfranchised, they experience health disparities, and they scrape by in low socio-economic circumstances. Special tools need to be developed in order to address the health disparities experienced by people with ID. Future research should move away from the theoretical, and jump into the application of current knowledge to address real-world health concerns of people with ID.” (Wells, Clark, & Sarno, 2012).

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