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RUNNING HEAD: DISABILITY DISPARITY

Adults with Developmental Disabilities as a Health Disparity in the Community

Senior Honors Thesis

Honors College, University at Albany, SUNY

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According to the Institute on Community Integration, a developmental disability is originated at birth or during childhood, is expected to continue indefinitely, and substantially restricts the individual's functioning in several major life activities (www.ici.umn.edu). Examples of developmental disabilities include autism, Down syndrome, mental retardation, and behavior disorders. Adults with developmental disabilities experience many health disparities due to their disability. This population has physical, mental, and social barriers that hinder their ability to access quality, specialized care for their health concerns. Having a developmental disability increases the likelihood of developing obesity, diabetes, sedentary lifestyles, undetected vision and hearing problems, dental concerns, and mental illnesses. Adults with developmental disabilities are also less likely to have necessary screenings for various cancers and chronic conditions. The large disparity between the quality of health care the general population receives and the care that adults with developmental disabilities receive further puts this population at risk of developing chronic health concerns.

Although recent research and studies are showing an interest in developing resources that improve the quality of care adults with developmental disabilities receive, history has not always shown this compassion. Historically, evidence was not accurately collected on the treatment of adults with developmental disabilities (Trent, 2004, pg. 6). Institutionalization of this population dates back to the 18th Century, when Jean-Marc Itard and Edouard Seguin believed that "much of the intellectual functioning of persons with mental deficiency was not innately limited, but could be developed by training" (Trent, 2004, pg. 7). This training would take place in institutions, and inspired the creation of national societies and organizations aiming to meet the needs of adults with developmental disabilities.

The 19th century sparked the beginning of the eugenics and euthanasia movement for this population. During this time, it was believed that “mental deficiency, criminality, delinquency, prostitution, and alcoholism were seen to result from the defective genes of the individual” (Trent, 2004, pg. 9). Fearful of the future, society felt it best to sterilize adults with developmental disabilities in order to prevent the passing of their “damaged genes” on to their offspring. Society also implemented the killing of mentally defective babies and children through the euthanasia movement. Even the American Psychiatric Association endorsed the legal euthanasia of mentally retarded children (Trent, 2004, pg. 10). Although these were presented as humane to the general public, these attitudes greatly influenced the treatment of individuals living in these institutions. Until the early 20th century, institutions were viewed as a place where individuals with developmental disabilities went to live for the remainder of their lives.

Attempts were made to control this population through sterilization and institutionalization, leading to several unmet health needs. As a result of the surgical sterilization, adults with developmental disabilities became exposed to poor hygiene management, diminished global gynecological care, and increased risk for becoming sexually abused and contracting sexually transmitted diseases (Servais, 2006, pg. 48). As this population began to increase in size, the local communities became more aware of the poor treatment of adults with developmental disabilities who were institutionalized. This heightened awareness “that these individuals have sexual experiences, desires, and needs that must be supported through both education and health services” led to the transition from the eugenics movement towards self-determination for adults with developmental disabilities (Servaid, 2006, pg. 48).

By the end of the 20th century, awareness about the health needs of this population started reaching the legal system. In 1999, two women with developmental disabilities who had been

institutionalized for over six years in Georgia against their will sued the institution for discrimination. The ruling in this case proved to be controversial and confusing, and it was ultimately decided by the U.S. Supreme Court that “no qualified individuals with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination in any way” (Mathis, 2001, pg. 395). This ruling later became Title II of the Americans with Disabilities Act (ADA). The U.S. Supreme Court ruling also found that unnecessary institutionalization was a form of discrimination by reason of disability (Mathis, 2001, pg. 396). As a result, states across the country began revisiting their own Medicaid programs to ensure that they were not violating any rights of individuals with disabilities.

Today, society is encouraging adults with developmental disabilities to become self-determined to take responsibility and pride in their decision making abilities. Rather than having family members be the ultimate deciding factor with regards to health concerns, individuals with developmental disabilities now have more rights and more power over their actions and decisions. Considering the fact that all adults, regardless of ability, have the right to make their own choices with provided community supports, the same should apply for adults with disabilities. This new focus on self determination within this population promotes independence for adults with developmental disabilities, while also providing enough services and supports to meet their complex health needs. Including adults with intellectual disabilities in the decision making process may be a step in the right direction for reducing health disparities within this population.

Current Health Disparities

According to the National Association of Chronic Disease Directors, a health disparity is “a difference in the incidence, prevalence, mortality, burden of disease, and other adverse health conditions or outcomes that exist among specific population groups in the United States” (<http://www.chronicdisease.org>). Adults with developmental disabilities are not the only minority group that experiences health disparities. One method for determining health disparities is the Fundamental Cause Theory, which states that multiple disease outcomes, multiple risk factors, access to resources that determine risk, and reproduction of illness and disease influence the creation of health disparities (Link, Phelan, and Tehranifar, 2010).

The first part of their theory demonstrates that if a population is at risk for developing multiple diseases due to their identity, then this population may be experiencing health disparities. A population that experiences health disparities will also be exposed to multiple risk factors that affect the outcomes of diseases. As a health disparity states, the outcomes of certain risk factors and diseases will vary from the general population. For example, a population that has higher prevalence of a certain disease as compared to the general population is experiencing a health disparity.

Poor access to resources that can be used to avoid or minimize the outcomes of disease once it occurs is the third factor in the Fundamental Cause Theory. Having limited access to resources that may help treat a health concern is a characteristic of a population experiencing a health disparity. Finally, if the association between cause and health is reproduced over time, a health disparity exists within that population. Many populations experience health disparities, including the aging, those of low socioeconomic status, and racial and ethnic minorities.

Individuals of racial and ethnic minorities have several factors that influence the creation of health disparities for this population. Due to higher levels of discrimination, individuals of racial and ethnic minorities are at a greater risk of high levels of stress, which increases the likelihood of developing health concerns. In general, “stress exposure has a much more substantial impact on the risks of psychological distress, depression, and other psychiatric disorders than researchers originally believed” (Thoits, 2010, pg. 43). For racial and ethnic minorities, “discriminatory experiences are significantly associated with self-rated poor health, chronic health conditions, disabilities, high blood pressure, psychological distress, among other conditions, even when other life stressors are controlled” (Thoits, 2010, pg. 45).

Aside from stress, African Americans and Hispanics are at risk for additional health concerns. In the United States, “African Americans and Hispanics have a higher morbidity, disability, and mortality rates than whites” (Thoits, 2010, pg. 43). In the past fifty years, the lower longevity rates for African Americans when compared to whites have been consistent, proving that individuals of racial and ethnic minorities experience health disparities. When looking at longevity, research shows that “white men and women outlived their black counterparts by 7.4 and 9.3 years, respectively, in 1950. Although life expectancy has increased for all groups over the last half-century, in 2006 white men still lived six years longer than their African American men and white women had a four year advantage over their black peers” (Williams & Sternthal, 2010, pg. 16).

The limited number of services available to African American and Hispanics results, in part, to socioeconomic and racial segregation. For these groups, “segregation produces the concentration of poverty, social disorder, and social isolation” (Williams & Sternthal, 2010, pg.

51). All of these consequences of segregation are influencing factors in creating health disparities for this population.

Similar to individuals in racial and ethnic minorities, individuals of lower socioeconomic status are also at risk of experiencing health disparities. People of lower socioeconomic status have limited access to resources and financial support for services, which increases the likelihood of developing health concerns. In general, “persons with low education, income, or occupations prestige have the highest rates of mortality, disability, mortality, psychological distress, and mental disorder development compared to those in more advanced socioeconomic positions” (Thoits, 2010, pg. 51). As the Fundamental Cause Theory states, limited access for a group of individuals is a characteristic of a health disparity.

Adults with Developmental Disabilities as a Health Disparity

As previously stated, there are several populations in the United States that experience health disparities. Individuals with developmental disabilities are at greater risk for developing health concerns due to their disability. This population is large, and “nearly 4 million American adults are currently estimated to have intellectual disabilities” (Campbell, Fox, Jesien, Krahn, & Ramon, 2010, pg. 156). Considering the great number of individuals affected by developmental disabilities, meeting the health needs and overcoming the health disparities experienced by this population would increase the overall health of the American population.

Adults with developmental disabilities experience several barriers to receiving services that meet their complex health concerns. This population has limited access to quality, specialized, resources, cancer screenings, and are more likely to be obese, have undetected vision and hearing problems, and be at risk for overmedication. Women in particular experience

additional social barriers that influence their health care. With regards to their sexual health, “women with mild to severe intellectual disabilities are reported to experience stigmatization for their decision to be pregnant, and having borderline to mild intellectual disabilities has been implicated for developing substance abuse-related problems” (Campell, et al., 2010, pg. 155). Women with developmental disabilities also attend fewer gynecological and breast cancer screenings. A recent study found that “11.5% of women with developmental disabilities reportedly had never visited a gynecologist”, and “16.8% of women with developmental disabilities age 40 or older in this study never had a mammogram” (Havercamp, Roth, & Scanlin, 2004, pg. 421). Even within this minority group, varying health disparities exist for adults with developmental disabilities.

Regardless of gender, this population is at risk of living with several health concerns. Although life expectancy rates for adults with developmental disabilities are increasing, the overall quality of available and utilized services is not. This means that this population is living with the same health concerns for longer. Several health concern risks and outcomes are experienced by adults with development disabilities, resulting in great health disparities for this population.

Helicobacter Pylori (HP) Infections

The difference between living in a community residential unit, living in the community independently, or living with family influences the likelihood of developing different health concerns. A Canadian study found that “80% of participants who had been formerly

institutionalized suffered from HP, which is 3-4 times higher than for adults who never resided in an institution” (Haverman, Heller, Lee, Maaskant, Shooshtari, & Strydom, 2010, pg. 61). The difference in these rates can be accounted to the increase in human interaction that takes place for individuals living in a community residential unit instead of living at home.

Oral Health Care

Adults with developmental disabilities are also at greater risk of developing oral health care concerns, including dental caries, gingivitis, and periodontal disease. According to a recent study, “oral health problems are among the top ten secondary conditions that cause limitations in the daily activities of adults with intellectual disabilities” (Haverman, et al., 2010, pg. 62). This indicates that oral health care is a major health concern within this population. When compared to the general population, “individuals with developmental disabilities were more likely than those in the No Disability group not to have had their teeth cleaned in the past five years or never to have had their teeth cleaned” (Havercamp, Roth, & Scanlin, 2004, pg. 421).

Untreated dental concerns are also more likely to occur for individuals with developmental disabilities who do not live in a community residential unit or institution. Overall, the “prevalence of untreated dental caries is higher among people with intellectual disabilities, particularly those living in noninstitutionalized settings” (Haverman, et al., 2010, pg 62). In a 2002 Core Indicators Report, “67.4% of the community sample reported that they had been to the dentist in the past year”, compared to 100% living in a residential facility (Core Indicators Report, 2002, pg. 13). The difference in dental visits could be accounted to the fact that many residential units housing individuals with developmental disabilities are federally or state mandated to attend a certain number of health care appointments, screenings, and check-ups.

Obesity and Weight Management

This population is more likely to develop obesity, which increases the possibility of developing additional, chronic health concerns. A recent statistic states that “80% of adults with mild to moderate intellectual disabilities who resided in community settings in the U.S. tended to be overweight or obese, including 8% morbidly obese” (Haverman, et al., 2010, pg. 63).

Findings also show that adults with Down Syndrome are at greater risk for developing obesity, and individuals with Prader-Willi Syndrome are at greater risk for becoming morbidly obese.

Adults with developmental disabilities experience several barriers to exercise, an activity that may address weight management issues within this population. According to Haverman, et al. (2010), cognitive and social emotion barriers, accessibility, and lack of staff motivation to promote physical activity hinder the likelihood of adults with developmental disabilities exercising. Adults with developmental disabilities tend to have a lack of motivation, self-efficacy, and expect to have poor outcomes when referring to exercise. This population also has limited accessibility to different exercise programs due to restricted or minimal transportation, equipment, and money (Haverman, et al., 2010, pg. 63).

Included in the likelihood of developing obesity is the higher rate of sedentary lifestyles among adults with developmental disabilities. According to a study that included 103 participants with intellectual disabilities using Premier Healthcare in the New York State Developmental Disabilities Profile – 2 data collection, “70.9% of adults experienced or engaged in challenging behaviors that occurred weekly or more often”, 33% were overweight, 36.9% were obese, 10.7% had diabetes, and 30.1% of the sample experience constipation (Levy, Botuck, Damiani, Levy, Dern, & Freeman, 2006, pg. 197). All of these health concerns are a

result of poor diet and weight management. The findings relate these health concerns to sedentary lifestyles, stating that “the higher rate of obesity, constipation, and diabetes may be due to the sedentary lifestyles of people with developmental disabilities, coupled with the prevalence of poor food choices available as they gain more independence” (Levy, et al., 2006, pg. 199). The multiple disease outcomes associated with having a developmental disability create health disparities for this population.

Additional Disorders and Conditions

Aside from the health concerns associated with developmental disabilities alone, this population is also at risk for developing additional mental illnesses, disorders, and conditions. The 2002 Core Indicators Project found that adults with developmental disabilities are 3-6 times more likely to develop mental health problems. The increase in mental health concerns for this population is associated with their diminished support. The Core Indicators Report in 2002 found that “men and women with developmental disabilities are known to have significantly less social support than people in the general population. The absence of social support has been found to correlate with poorer quality of life and mental health problems, such as depression” (pg. 9). When looking at individuals living in the community, 20.6% were also found to have a diagnosis of schizophrenia, and 13% were found to have depression (Core Indicators Report, 2002, pg. 11)

Emotional Support

The 2001 Behavioral Risk Factor Surveillance System and North Carolina National Core Indicators Survey found that “adults with developmental disabilities are seven times more likely to report inadequate emotional support, compared with adults without disabilities” (Havercamp,

Roth, & Scanlin, 2004, pg. 418). New York State conducted a similar survey attempting to collect information on emotional support for adults with developmental disabilities, and found that of the 710 individuals in their sample, 43.9% said they did not have friends who asked to do things with them, and only 30.9% have gone on a date in the last six months (NYS Core Indicators Report, 2009, pg. 12). These statistics indicate that adults with developmental disabilities are at risk of isolation and poor emotional support.

Lack of community integration and emotional support could also lead to adults with developmental disabilities having behavior problems. The Core Indicators Report found that “often it is the behavioral problem, not mental retardation, that prevents individuals from successfully living and working in the community (2002, pg. 11). This demonstrates that behavioral reactions to poor emotional support are limiting access of community resources for adults with developmental disabilities. This limited access aids to create health disparities within this population.

Needed Improvements

In order to address these health disparities, improvements need to be identified. Currently, there are several areas that are failing to meet the needs of adults with developmental disabilities. Many resources need to be improved and made available to the population in order to attempt to decrease the amount of health disparities adults with developmental disabilities experience.

Training and Program Adaptations

A recent report on the health of people with developmental disabilities in Arkansas found that there are needed improvements in staff training and health care access. Current programs

need to be adapted in order to meet the specific, complex needs of this population. The report states that “public health programs need to be made available to person with all types of disabilities, including people with developmental disabilities. This means developing materials in alternate formats, and using inclusive messages and methods in public awareness campaigns” (Arkansas Disability & Health Program, pg. 2). Expecting adults with developmental disabilities to comprehend materials created for the general population further produces inaccurate data on the health needs of this population. Accommodating the different comprehension abilities of adults with developmental disabilities by adapting current materials and trainings would allow for researchers to move forward in their attempts to decrease health disparities for this population.

Module and Data Collection

Currently, many states rely on the Behavioral Risk Factor Surveillance System (BRFSS) to collect information about the health concerns of the entire general population, including adults with developmental disabilities. Although this method does collect information about health problems, it does not provide accurate information about the specific health care needs of adults with developmental disabilities. The objectives of HealthyPeople2010, a recent initiative to address health care concerns implemented across the country, are to “increase quantity and quality of life and to eliminate disparities in health among the American population, including disparities related to disability status “(BRFSS Health Status & Disability Project, pg. 1). For many states, this means collecting information using the BRFSS.

While the BRFSS does collect information about health disparities, it is biased against people with disabilities. The BRFSS is a telephone survey, which excludes individuals who may

not be able to physically answer the telephone or who do not own phones. The BRFSS also does not reach out to institutions and residential units who may house adults with developmental disabilities. This survey also does not accommodate individuals with hearing, speech, cognitive, or other communication impairments that may prevent these individuals from completing the survey. The BRFSS and surveys similar to this adjust their methods of data collection in order to provide more accurate information about the health disparities experienced by adults with developmental disabilities.

Healthcare Provider Relationships and Role, and Insurance Definitions

Over the past 50 years, the roles of patients and those seeking help have evolved. Patient roles have become “more active, diverse, long-term, and risk-based” (Boyer & Lutfey, 2010, pg. 81). This means that healthcare providers are relying more on the patients to advocate and identify their health concerns. The lower attendance rates to health care screenings and appointments indicate that adults with developmental disabilities struggle with self-reporting their concerns and recognizing poor health. These new changes in “health, illness, and medical care meant that being a patient was not necessarily the short-term, acute role that it once was. Instead, the role of a patient became longer-term, sometimes even life-long” (Boyer & Lutfey, 2010, pg. 82).

Individuals with DD struggle with this more active patient-hood. It is difficult for them to self-advocate and vocalize their needs, let alone accurately identify their health concerns. As we have seen, this population is at greater risk for developing several health concerns. This population also experiences fewer screenings and receives regular health care services less frequently than the general population. Health care service providers are depending upon their

patients being more active in their health care. These findings, coupled with the newer development of an “active” patient, create an even bigger health disparity for this population.

In addition to changing patient-provider roles, insurance definitions of disability and coverage need to be changed. Insurance definitions and diagnoses need to be altered to include the higher increase in health care visits this population needs. Individuals with DD have similar health care coverage as the general population; however their health concerns develop differently, at different rates, and are experienced differently. Complete comprehension of the health needs of this population is needed, and “sensitivity to patients’ expressions of their illness beyond diagnostic categories is a clinician responsibility” (Boyer & Lutfey, 2010, pg. 90). Although it is the duty of the clinician to have patience and compassion for their patients, it is up to the “patients and families to communicate their needs as clearly as possible” (Boyer & Lutfey, 2010, pg. 90). A balance between the physician’s understanding of the needs of adults with developmental disabilities and the ability of this population to communicate their needs will have to be created in order to decrease this health disparity.

Transportation

Recent findings have shown that “addressing social and environmental factors, such as participation, relationships, feelings of inclusion in communities, and access to transportation, were identified as areas that required more attention” (Campbell, et al., 2010, pg. 158). Limited access to transportation prevents active lifestyles, health care appointment attendance, and access to needed resources. Transportation is such a vital role in access to services for any population, especially for adults with developmental disabilities who may not be able to drive independently. For this population, “transportation and staffing limitations present unique barriers to

interpersonal relationships as well as to recreation and physical activities” (Havercamp, Roth, & Scanlin, 2004, pg. 424).

Not only is transportation crucial in access to health resources, but it is also a necessary resource for adults with developmental disabilities to interact with others. For this population, “transportation and staffing limitation were cited as barriers to spending time with friends and family” (Havercamp, Roth, & Scanlin, 2004, pg. 421). As previously stated, emotional support and community inclusion is important for this population in order to help ensure that the needs of adults with developmental disabilities are met.

Tracking and Participation

Due to the negative stigma that is associated with disabilities, individuals with developmental disabilities may be less likely to self-identify as having one. According to the Center for Disease Control (CDC), “the percentage of the population identified with intellectual disabilities drops dramatically among post-secondary-school-age young adults. They ‘age out’ of the education systems and its records and may be missing from or unidentifiable on social service rolls” (2009, pg. 1). Tracking after high school is needed in order to ensure that their health concerns are being managed, that they have access to services, and that they are safe.

Collaboration between services may address this deficit in post-high-school tracking of adults with developmental disabilities. The CDC identified that “ascertaining the severity of intellectual disabilities could be valuable in investigating health disparities, but severity is difficult to measure without access to school, medical, or other administrative records” (2009, pg. 3). Cross-referencing would allow for more accurate tracking of health care needs and of individuals with developmental disabilities after high school services.

Definitions and Survey Expansion

According to a recent meeting between the Center for Disease Control and Prevention (CDC) and the National Center on Birth Defects and Developmental Disabilities (NCBDDD), current methods of survey and data collections are not accurately measuring what they intend to. At their April 2010 meeting, the CDC and NCBDDD decided that a few things need to happen in order to collect more accurate information about adults with developmental disabilities. Their action plan consists of defining intellectual disabilities operationally, compiling and synthesizing a knowledge base, extending past analyses of existing data, pilot state and regional demonstrations, and develop sustainable approaches to expand surveillance (CDC and NCBDDD, 2010).

In addition to this action plan, the CDC and NCBDDD concluded that expanded, population-based surveillance strategies need to be created in order to track and monitor this population's health participation, associated and secondary conditions, demographic variables, and health care. This surveillance system will allow states to allocate resources and create more programs based on operational definitions and demographic information. At their April meeting the CDC and NCBDDD also realized that community productivity in meeting the needs of individuals with developmental disabilities might increase if local resources, such as health care providers, dentists, Medicare, Medicaid, and hospitals, collaborated.

Assessments

Another area that could be improved are assessments of health care needs for adults with developmental disabilities. At the Tampa Scientific Conference on Intellectual Disabilities, Aging, and Health in 2004, conference members identified several areas that need expansion in

order to recognize health issues in this population. Six needs were stated at the conference: address informational deficiencies inherent in all-age reports neglecting to focus on older age populations, understand more fully the lifespan effects of childhood disabilities, identify the roots of geriatric medical conditions stemming from diseases, examine disease and disability trajectories to identify prevention and treatment strategies in middle and later age, identify and address older-age associated and related conditions, and identify life style conditions and practices that contribute to healthy aging (Davidson, Heller, Janicki, & Hyer, 2004, pg. 3). Information about each of these six areas of concern could be collected from accurate assessments. Improved assessments are needed in order to collect information about health care resources being utilized and to better identify health care needs.

Overall Health and Available Programs

As previously stated, adults with developmental disabilities are at risk for high obesity rates, diabetes rates, dental concerns, poor diets, and sedentary lifestyles. Stronger programs need to be developed in order to address these health concerns within this population. Evidence exists that “physical activity reduces mortality and morbidity not only in coronary heart disease and hypertension, but also on obesity, type 2 diabetes, constipation, and osteoporosis for people with and without intellectual disabilities (Haverman, et al., 2008, pg. 63).

In one study on physical activity in adults with developmental disabilities, findings concluded that “less than one-third of this population engage in sufficiently robust physical activity” (Haverman, et al., 2008, pg. 64). In a pilot study of physical intervention for aging adults with developmental disabilities, findings showed that “92% of the participants experiences improvement in at least one domain of physical functioning” (Haverman, et al., 2008, pg. 64).

Programs need to be developed that address the lack of motivation and access to exercise opportunities for this population in order to decrease their likelihood of developing these chronic health concerns. These programs also need to include nutritious and healthy food options, especially for individuals living in a residential facility.

Emotional Support

Considering the fact that adults with developmental disabilities are seven times more likely to indicate inadequate emotional support, strong resources providing emotional support need to be created for this population. These resources will increase social skills, advocacy skills, and overall happiness and healthiness of adults with developmental disabilities.

A recent finding states that “24% of adults with developmental disabilities reportedly had either no one to talk with about personal things, or often felt lonely (Havercamp, Roth, & Scanlin, 2004, pg. 421). This population is lacking sufficient resources to help meet their social and interpersonal skills. Programs and resources that promote interact and community inclusion could address the moderately high depression rates among adults with developmental disabilities.

Healthcare Options

In order to qualify for Social Security Disability Insurance (SSDI) or Social Security Income (SSI), individuals must demonstrate “a medically determinable mental or physical impairment that results in the inability to engage in substantial gainful activity” (Henry, Hooven, Hashemi, Banks, Clark, & Himmelstein, 2006, pg. 108). Although this may cover the majority of individuals with developmental disabilities, the phrasing of their qualifications is very vague in

terms of “substantial gainful activity”. Each of these insurance and income opportunities use language that applies to the general population, with very few conditions specific to the complex health concerns of adults with developmental disabilities. Due to their specialized health needs, basic coverage may not completely encompass all of the services needed for this population. Opportunities for additional income are difficult for adults and developmental disabilities, and as a result this population may be settling for insurance coverage that does not meet their needs.

A Massachusetts Buy-in program for healthcare for adults with developmental disabilities found that many individuals in this population are non-working and therefore cannot afford specialized healthcare, which these individuals greatly need. The conditions of the program are that “those who work 40 hours per month or more pay a family income adjustment premium. Those who are working less than 40 hours per month, or at not working, must meet a one-time deductible based on family income, and also pay a family income adjustment premium” (Henry, et al., 2006, pg. 108). Their findings showed that individuals with developmental disabilities who also had co-occurring disabilities and disorders had the lowest rates of earnings. These individuals in particular need very specialized healthcare options, however, they are the least likely to be able to afford those services. Programs need to be created to accommodate this population’s low income and provide health care options correlating with their special needs.

Family Training

A study in Australia found that adults with developmental disabilities staying at community residential units were more likely to visit their general practitioners than individuals living with their families or living independently. In a twelve month period, “participants with developmental disabilities living in the community [residential units] were found to visit a

general practitioner two to five times more frequently than those living at home” (Iacono & Sutherland, 2006, pg. 159). Trainings about the specific health needs of this population would address the lack of knowledge and awareness among parents and health care practitioners alike. The Australian study found that “the general lack of association between health screenings and type of disability would seem indicative of the lack of health professionals’ knowledge about the nuances and particulars of the various developmental disabilities” (Iacono & Sutherland, 2006, pg. 160). As previously stated, general practitioners “are using guidelines developed for the general population, with little knowledge of specific considerations for people with developmental disabilities” (Iacono & Sutherland, 2006, pg. 161). Awareness of the specific health concerns relevant to adults with developmental disabilities would allow general health practitioners to adapt their practice to better meet the health needs of this population.

Practitioners are not the only individuals who need to become more aware of the specific health needs of adults with developmental disabilities. Considering that many adults with developmental disabilities live with families, the need “to educate family and people with developmental disabilities about the long-term benefits of appropriate health screening” is extremely important (Iacono & Sutherland, 2006, pg. 161). Families need to be trained and made aware of recommended frequencies of check-ups, visits, and screenings in order to advocate for their family member with developmental disabilities.

Outpatient Services

Social policy needs to be created in order to develop small-scale, localized, specialty outpatient healthcare services for adults with developmental disabilities due to the special health needs and current disparities this population experiences. Adults with developmental disabilities

demonstrate a wide variety of health needs, and “localized specialty outpatient healthcare practices that provide coordinated physical and mental healthcare services for people with intellectual and developmental disabilities” are a necessary resource for this population. Collaboration between current healthcare service providers as well as combination resources providing multiple services could address the need for specialized services catering to adults with developmental disabilities.

Cooperation with Service Providers

An Audiological Rehabilitation Program (ARP) in the Netherlands failed to be successful due to a lack of cooperation from participating organizations. Involvement from all levels (micro, meso, and macro) needs to take place in order to provide high quality and consistent services for adults with developmental disabilities. This program “offered educational courses for staff, designing and spreading information booklets for clients, as well as offered training for on-site judgment of acoustics” (Meuwese-Jongeluegd, Harteloh, Verschuure, Nijs, Koot, & Evenhuis, 2005, pg. 66). Neighboring organizations that agreed to participate in this program eventually backed out, and the ARP attributes this lack of cohesion to organizational culture and unreliability. The program suggest that “obligatory building standards for special schools, homes, and day-care centers should include acoustics requirements” in order to accommodate all individuals with developmental disabilities. The ARP also suggests that “real involvement of the local care providers, which requires adequate management, is a factor that ultimately determining success or failure” and is necessary in order to provide specialized and consistent resources for this population (Meuwese-Jongeluegd, 2005, pg. 67).

Specialist Services

Adults with developmental disabilities have increased hospital visits, on average, when compared to the general population. An Australian study found that “adults with developmental disabilities presented to hospitals twice as frequently as patients from the general population” (Wallace & Beange, 2008, pg. 357). Specialized services need to be created in order to address this unique population’s needs, foster independence without sacrificing quality or access, and to continue ongoing treatment into adulthood. Due to the health disparities that this population experiences, adults with developmental disabilities are at risk for falling through the cracks, and “the biopsychosocial implications of cognitive impairment contribute to the vulnerability of adults patients with intellectual disabilities in any healthcare system” (Wallace & Beange, 2008, pg. 354).

A reason specialized services are not as prevalent could be due to the fact that “doctors may have had minimal formal training in the health, healthcare, and social implications of treating the adults patient with developmental disabilities” (Wallace & Beange, 2008, pg. 355). This lack of awareness limits the amount of doctors that could provide specialized services for this population. Training current healthcare professionals is needed in order to increase the possible healthcare practitioners that could provide specialized services for adults with developmental disabilities.

A new, specialized unit would “have the responsibility for ensuring that patients with intellectual disabilities are offered the same standards of healthcare that apply for the general population” (Wallace & Beange, 2008, pg. 357). A benefit of this suggested specialized unit is that “professionals can advise, treat specific medical problems, or take over a part of the medical care for people with intellectual disabilities” (Wallace & Beange, 2008, pg. 358).

Wallace and Beange created an outline for creating this new specialized unit. Roles of the unit include direct provision of secondary and tertiary outpatient services, facilitation of consultations with other providers, advocacy, adaptations to the standard organization of healthcare provision, participate in outpatient healthcare planning, teach medical students and colleagues, develop College-level accreditation standards, and establish a hospital mortality and adverse events register (Wallace & Beange, 2008, pg. 360)

Successful Strategies

Although several areas have been identified that need to be improved in order to meet the needs of adults with developmental disabilities, there are several approaches that have proved to be successful. These programs address the concerns associated with data collection, survey expansion, tracking and assessment, and employment opportunities for adults with developmental disabilities.

The Arkansas' Disability and Health Program adapted the Behavioral Risk Factor Surveillance System (BRFSS) to include pictures, abbreviated responses, and face-to-face interviews in order to collect more accurate health information on adults with developmental disabilities. Before the adaptation, the BRFSS relied on only telephone surveys to collect information, and "since people with developmental disabilities do not typically have the opportunity to participate in telephone surveys and most health surveys, their information is not captured" (Arkansas' Disability & Health Program, pg. 1). These telephone surveys overlook individuals who may not own phones, may not be able to physically answer phones, and may not have the cognitive ability to comprehend the telephone questions. This new adaptation and inclusion of face-to-face interviews ensures that the individuals with developmental disabilities

completing the survey comprehend the materials and that the information collected is accurate. This form could be adapted to all fifty states in order to better collect information about the health concerns associated with individuals with developmental disabilities.

The Rochester Health Status Survey (RHSS) is another method of survey expansion and adaptation that collected reliable and accurate information about the health needs of this population. The survey consists of 51 questions and takes approximately 45 minutes to complete. For the pilot survey, “a total of 21 nurses, 25 service coordinators, and 18 family members served as respondents” (Davidson, Henderson, Janicki, Robinson, Bishop, Wells, Garroway, & Wexler, 2008, pg. 13). Nurses were found to be the best resource for survey completion due to their familiarity with medical terms and patient history. The results found were reliable, and the RHSS “may provide a reliable means for obtaining a comprehensive and accurate snapshot of health status and health service utilization for groups of people with intellectual disabilities over age 21 when completed by a trained specialty health care personnel” (Davidson, et al., 2008, pg. 14). This survey could be expanded through the United States, so long as trained professionals were willing to collect information on their patients with developmental disabilities. Considering that the results were reliable and provided accurate and important information on the health concerns of this population, the RHSS could strength attempts to eliminate health disparities for adults with developmental disabilities.

With regards to assessment, Advanced Practice Nurses (APN) in a pilot program provided comprehensive geriatric assessments on the health status of adults with developmental disabilities. These assessments were conducted three times per year in the client’s home or community residential unit. APNs made individualized recommendations, identified needs relevant to their environment, and tracked the completion of referrals.

An APN is a “registered nurse who has undergone an advanced training as a nurse practitioner or clinical nurse specialist in a specialty area of nursing” (Hahn & Aronow, 2005, pg. 132). APNs used in this pilot program were specialized in the health needs of adults with developmental disabilities. Goals of the APNs were to include assessment of feasibility of enrollment and retention of participants with intellectual and developmental disabilities, adapt and simplify the assessment instrument and intervention so as to be understandable by persons with developmental and intellectual disabilities and their caregivers, and to assess baseline health status and evaluate the capacity of the assessment instrument to show change over time (Hahn & Aronow, 2005, pg. 132). Assessment components include medical history, physical examination, hearing screening, screening for gait and balance, review of preventive clinical services, screening for nutritional risks, functional assessment of daily living, review of prescribed and over-the-counter medications, psychosocial assessment including screening for depression, review of supports, assessment of mental status, and home safety evaluations (Hahn & Aronow, 2005, pg. 133). After the first assessment, “three quarterly, one hour follow-up home visits” were scheduled to “monitor health and to evaluate health problems for impact on function and survival” (Hahn & Aronow, 2005, pg. 133).

Recommendations made by the APN included “referral to primary care medical provider, referral to medical specialist, referral to other health professional, referral to community service, recommendations for self-care activity, or recommendations for participant to receive a clinical preventive service” (Hahn & Aronow, 2005, pg. 134). For the 70 adults with developmental disabilities who participated in this pilot program, over 1,000 recommendations were made by the APNs. This program was welcomed by adults with developmental disabilities, considering “The low attrition (11%) and refusal rates (5%) following enrollment, as well as anecdotal

reports by participants and caregivers, show that they were interested in participating in programs that provided individualized health interventions” (Hahn & Aronow, 2005, pg. 139). APNs could be utilized at any healthcare service provider for adults with developmental disabilities. APNs ensure that proactive measures and referrals are being applied to the health concerns of this population, which will decrease the level of health disparities adults with developmental disabilities experience.

As previously stated, more employment and income opportunities for adults with developmental disabilities would increase the health care options available for each individual. Instead of being limited to Medicaid and Medicare, which may not address the complex health concerns this population has, additional income would allow adults with developmental disabilities to purchase their own healthcare plans. Increased employment opportunities might also allow for adults with developmental disabilities to participate in their employer’s insurance plans and packages.

One program that attempts to employ individuals with developmental disabilities is the Vocational Rehabilitation Services program in Pennsylvania. Adults with autism spectrum disorders (ASD), mental retardation, specific learning disabilities, and other causes of impairment listed in a Pennsylvania database were approached to participate in this program. Subjects included 382,221 adults ages 18-65 (Lawer, Brusilovskiy, Salzer, & Mandell, 2009). The goals of this program were to “maximize employment outcomes by providing services such as assessment and diagnosis, counseling, job search assistance, assistive technology, and on-the-job training” (Lawer, et al., 2009, pg. 487). Their hypothesis was that “those with ASD would be more likely to be turned away from services because of the magnitude of their needs, would use

a greater amount of services, thereby resulting in greater costs, and would be less likely to be place in competitive work environments” (Lawer, et al., 2009, pg. 488).

Although individuals with ASD were more likely to be denied services and received a more expensive set of services, employment rates of individuals with ASD did not differ from the those with a specific learning disability or mental retardation, and were actually higher than those with other impairments (Lawer, et al., 2009, pg. 493). They also found that “individuals who use vocational rehabilitation services return the investment through taxes within 2-4 years, on average” (Lawer, et al., 2009, pg. 293). Implementing this program proves to be of low cost, and could even generate revue after four years. VRS state that “people with ASD would likely benefit from this program, and should be encouraged to participate” (Lawer, et al., 2009, pg 493). This program would provide additional sources of financial support, increased health care options, community integration, and vocational skill development for adults with developmental disabilities.

Implications

A universal method of data collection would allow for policy change to occur nationally, rather than by individual states. This would promote consistency across health care service providers, ensuring that the needs of adults with developmental disabilities nationally were being met. Accurate data collection would also identify unmet needs, allowing for organizations to decrease their health disparities by addressing those needs. Reliable surveys would provide a voice for adults with developmental disabilities to advocate their health concerns while collecting consistent and accurate information. This would decrease health disparities by identifying current health needs in order to generate possible policy and organizational solutions

to these concerns. A stronger tracking and surveillance system would ensure that the needs of this population are being met in a timely and non-discriminatory manner, and may proactively prevent the development of future chronic health concerns for adults with developmental disabilities. Vocational services promote independence whiles creating opportunities for adults with developmental disabilities to positively contribute to their community. This will allow members of this population to feel empowered, be self-determined, and learn new skills. Health disparities for adults with developmental disabilities would be decreased through the creation of strong, supportive community-based healthcare resources with trained professionals providing specialized services.

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