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## **A Blind Spot in Health Care Services: The Intellectual/Developmental Disabled Population and Training of Primary Care Providers**

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*Abstract: The intellectual and developmental disabled (I/DD) population is exposed to barriers that prevent access to quality healthcare. One of the main barriers is lack of training among primary care providers to treat the I/DD population. Because this population requires further devotion when addressing personal health needs, it is necessary to understand how lack of training and experience for primary care providers hinders the I/DD population's health. Primary healthcare providers need further training to obtain skills to provide adequate access for this population to reduce health disparities. Further training such as professionally facilitated courses on disability through lectures or seminars, discipline-specific training on I/DD population aspects, and exposure to working with this population throughout students' medical education will provide the additional experience and clinical skills needed for equity of care. As primary care providers gain these skills, they will be equipped to meet the unique health needs of people with I/DD.*

*Keywords: Training and experience, intellectual and developmental disabilities, service delivery, American's health care system, Medicaid, medically underserved population, and health disparities*

Over the past decade, steps have been taken to tackle healthcare needs of people with intellectual and developmental disabilities (I/DD) (Ervin, Hennen, Merrick & Morad, 2014). However, there are still barriers that prevent access to quality healthcare for this population, such as primary care providers lack of training to treat the I/DD population. According to the National Council on Disability (as cited in Krahn, Walker, & Correa-De-Araujo, 2015, p.S204) “the absence of professional training on disability competency issues for health care practitioners is one of the most significant barriers preventing people with disabilities from receiving appropriate and effective healthcare”. People with intellectual and developmental disabilities are a population that require further devotion, but primary healthcare

providers lack skills due to limited experience. Intellectual and developmental disabilities include but are not limited to cerebral palsy, language and learning disorders, down syndrome, autism spectrum disorders, vision impairment, and hearing loss (May Institute, 2010). The I/DD population has communication issues that pose a challenge when expressing personal health needs, a necessity for substantial personal support to ease health care access, and complex medical issues that require more care management (Harder + Company, 2008). Therefore, there is a need to explore this topic and gain understanding on how inadequate training and experience of primary care providers hinders the I/DD population's health. When health professionals understand the human rights, and needs of persons with I/DD, better quality of care will be provided for this population.

## **Literature Review**

There are between seven and eight million Americans that experience intellectual disabilities (Administration for Community Living, 2016). A recent study found on average in the United States, an individual with I/DD would have to call around fifty doctors before they found one with specific training and experience that would provide proper treatment (Kornblau, 2014). Since there is a lack of resources for the I/DD population, more specifically, qualified primary care providers that can deliver quality health services, this demonstrates a national issue of the need for additional education and training for primary care providers so that they can work with the I/DD population effectively. In addition, to further support the acknowledgment of this issue, Wilkinson, Dreyfus, Cerreto, and Bokhour (2012) conducted a study that included physicians' perspectives on providing care to the I/DD population. The study found that physicians were concerned about several barriers when attending to people with intellectual disabilities (ID), which included lack of accessible education about primary care, lack of confidence when interacting with the population, and no experience to guide visits. Also, patients with ID reported that the quality of the care received by physicians was poor (Wilkinson et al., 2012). Since both the physicians, as well as patients who have I/DD are faced with barriers regarding quality care, this issue should be of concern on a national level.

Because there is a lack of skills among health providers to deliver holistic care, the health disparities in the I/DD population continue to rise due to inadequate preparation. This issue can be observed from a macro perspective, but also from a micro perspective. Kornblau (2014) explains that barriers to care are experienced among the entire I/DD population in every state of America. Hence, primary care providers' lack of skills to provide care of the same quality to persons with I/DD begins within communities. To improve the healthcare quality of the I/DD population nationally, the development of further training and skills must first improve within primary care providers who work within communities across the United States.

According to Ervin and Merrick (2014), since a majority of the I/DD population relies on government programs, such as Medicaid, this creates problems within health care financing. Furthermore, since there is a low reimbursement rate for services and an absence of risk-based fee adjustment, there is a shortage of primary care physicians who will take patients that have Medicaid (Harder + Company, 2008). Consequently, for individuals who are considered a part of the I/DD population, they are additionally limited in receiving primary care provider's services because of the amount of time and skill that is needed to serve them (Harder + Company, 2008). Since providers are aware of the lack of reimbursement they get for their services regarding the I/DD population, many primary care providers avoid the net loss of treating Medicaid patients by rejecting the individuals. Not only does this result in barriers for individuals with I/DD in receiving care, but also results in higher cost of healthcare. Since primary care providers limit the access of preventative healthcare and health promotion resources, health problems are overlooked until there is a requirement for interventions that are more extensive and expensive (Ervin & Merrick, 2014). This extensive and expensive care requires the utilization of a specialist and increases long term expensive services that could be prevented by a primary care provider through screenings and health resources.

## **Research Questions**

The main question being presented to the United States health care system is what actions can be taken to increase primary health care provider's skills to provide the I/DD population adequate access to care to reduce disparities for this population. Through completion of an extensive literature search on this topic, many answers have been found and are discussed in this article. Also discussed within this paper is how primary care providers lack of experience with adults with I/DD population impacts the field of occupational therapy and how further developed skills of primary healthcare providers would change the American health care system.

## **Method**

### **Design and Procedure**

The purpose of this research project was to synthesize the discussion of primary healthcare providers' lack of experience with adults with I/DD from current literature to identify a solution that could be implemented to eliminate the I/DD's population poor health outcomes and increase their access to care. The following databases were searched: Academic Search Complete, Google Scholar, and Google. The following key words were used: lack of physician's skills, training and experience, intellectual and developmental disabilities, service delivery, American's health care system, Medicaid, medically underserved population, and health disparities. Each

article was carefully reviewed and selected based on appropriateness for the project's topic. The current lack of experience of primary healthcare providers with adults of the I/DD population in the United States was analyzed in relation to the national health care system, health care policies, occupational science and the field of occupational therapy.

## **Results**

### **Changes in Health Care Delivery**

Regarding current healthcare policies, the Affordable Care Act (ACA) is important for people with disabilities due to the expansion of Medicaid, as Americans who are disabled receive services that they previously lacked (Krahn, 2015). Furthermore, Medicaid provides spending for seventy-eight percent of individuals with developmental disabilities (National Council on Disability, 2011). However, even though ACA policies state that the reform of health insurance expands coverage and increases quality of care in all Americans, this is not always accurate for the I/DD population. Due to lack of providers that accept Medicaid because of low reimbursements, the limited primary care physician selection is lower quality than compared to the selection available to those with private insurance (Ne'eman, 2013). Due to Medicaid reimbursements policies, the I/DD population health is declining rapidly. Another policy that affects the I/DD population is the lack of inclusion in being a medically underserved population. According to Kornblau (2014), the designation of an underserved population is appointed due to shortages of services that results in declines for a specific population's health, which in turn, provides further access to government programs that promote quality health care. Among other services, these programs include training for primary care providers to enhance quality care to the specific underserved population (Kornblau, 2014). Since the federal government defines a 'medically underserved population' as a group that inhabits the same neighborhood, community, or geographic area, the I/DD population will never meet the medically underserved standard (Kornblau, 2014). If the federal government changed the medically underserved policies to focus on unmet needs instead of location, primary care providers would receive further education and resources and the I/DD population quality of health would increase.

### **Population Impacted**

The I/DD population is significantly impacted by the lack of primary care providers' experience and undeveloped skills regarding this population. As mentioned previously, since primary care providers are most often involved in caring for people with I/DD, their contribution is essential for disease prevention and coordination of care (Ervin et al., 2014). For healthcare providers that accept I/DD patients with Medicare, their lack of

knowledge on this population causes them to rarely focus on prevention and management of secondary conditions but instead the primary disability (Anderson et al., 2015). This leads to decreased screenings and healthcare prevention actions, which leads to a variety of negative health conditions. For example, there is an increased rate of people with I/DD experiencing sensory impairment, epilepsy, psychiatric disorders, as well as several chronic conditions and obesity related factors, such as high cholesterol, hypertension, and cardiovascular disease (Anderson et al., 2013). Specifically, in women with I/DD, there are health problems concerning contraception, menstrual issues, breast cancer screenings, cervical cancer screenings, as well as osteoporosis (Wilkinson & Cerreto, 2008). Another significant secondary condition that occurs in the I/DD population is a decline in oral health (Morgan et al., 2012).

People with types of I/DD are acknowledged as having obesity as a secondary condition, thus, other chronic conditions arise (Anderson et al., 2013). However, obesity and overweight prevalence is inaccurately diagnosed because physicians have a difficult time gathering accurate weight and height measurements from individuals with I/DD (Anderson et al., 2013). This inaccuracy leads to failing to address obesity related conditions or misdiagnosis, which further leads to extensive unneeded services. According to Wilkinson and Cerreto (2008), primary care physicians fail to focus on the gynecological needs of women with I/DD; in a survey, forty percent of women with I/DD noted that their primary care physician disregarded from asking about their gynecological needs. Since a majority of women are never examined, problems may occur in the future that could have been prevented. Wilkinson and Cerreto (2008) further discuss that women with I/DD have received less attention for breast cancer screenings, as well as a lack of screening for cervical cancer. The lack of screening for cervical cancer for women with I/DD is due to the experience of the examination being frightening and painful, which results in the examiner's unawareness of how to successfully address the situation (Wilkinson & Cerreto, 2008). In relation to the decline of oral health, a study by Morgan et al. (2012) found that the I/DD population has a wide variety of oral health issues, which includes untreated dental caries, periodontitis, gingivitis, and decayed/missing teeth. Since primary care providers have a lack of experience and skills with the I/DD population, the prevalence of oral health issues is often overlooked.

## **America's Health Care System and I/DD Population**

The three major cornerstones in America's health care system that are interrelated are cost, access, and quality (Shi & Singh, 2015). The cost aspect focuses on the price of how much America spends on health care. Access refers to the obtainment of convenient and effective health care services when needed. Lastly, quality is increased when health outcomes are reliable with up-to-date professional knowledge from health care

services (Shi & Singh, 2015). In regards to primary health providers' lack of experience and undeveloped skills in addressing the I/DD population's health, all three major cornerstones are observed. For instance, as previously mentioned, since people with I/DD rely mostly on Medicaid as well as require more time and skill from physicians to properly serve them, many primary healthcare providers deny services because of low reimbursements (Ervin et al., 2014). This forces people with I/DD to look for primary care providers that do accept Medicaid. However, Medicaid's access to limited providers are of lower quality than what is available to patients who have private insurance (Ne'eman, September 2013). This is due to lack of skills and experience with this population, which ultimately influences the primary care physician's decision to refer these clients to a specialist. Thus, this raises Medicaid's spending because the specialists' services are costlier and more tax dollars are needed to fund these expenses. Furthermore, living with an I/DD disability is associated with the likelihood of not having a high school education, which leads to lack of employment and low annual household income (Krahn et al., 2015). These factors lead to discrimination, disadvantage, and overall difficulties of accessing healthcare due to costs such as a possible copay. Overall, since health care is harder to access, people with I/DD end up living an unhealthier lifestyle and have poorer health because they cannot receive quality care that meets their health needs.

## **Connection to Occupational Science**

In occupational science, there is a strong focus on learning about the philosophy of client-centered practice to have respect for and partnership with people receiving services (Pierce, 2003). For the partnership to be successful, the patient must determine the priorities that need attention. However, in people with I/DD, there is a barrier to communicating about health needs due to verbal and cognitive limitations. Therefore, I/DD individuals "are commonly unable to identify pain, describe symptoms of illness, or articulate indicators of discomfort to physicians" (Harder + Company, 2008, September, p. 5). Even though there are barriers to successfully establishing a client-centered practice within this patient-practitioner relationship, skills can still be developed among practitioners to become aware of the patient's needs. For example, in the study of occupational science, the observable elements of performance skills are addressed to discover the underlying problem of participation in activities and occupations (AOTA, 2014). Similar skills that allow the physician to become aware of the client's need can be gained. When a behavioral issue arises in the patient with I/DD, this can be a sign of pain, which is a need that the patient desires to be addressed (Harder + Company, 2008). Since primary care providers are not given the opportunity to gain education on these unique skills, respect and beneficial partnerships are often not accomplished. As a result, the patient's quality of life declines and their health needs are continuously unaddressed.

## **Connection to Occupational Therapy**

For future occupational therapists (OTs), the lack of training in primary care providers for I/DD population applies to their role as healthcare providers; because OTs provide services to a diversity of populations, including I/DD individuals, they need to be aware of the importance of client-centered practice. According to the American Occupational Therapy Association (2013), there is a core belief that occupational therapists should enable participation in society, which is accomplished through specific services that focus on experiential knowledge and overall desire to improve quality of life for the individual. By OTs helping to enable participation in society, they are treating individuals of the I/DD population to increase independence with daily occupations. In addition, since the I/DD population is discriminated against, OT's can be advocates for this population so that equal healthcare services are provided. For individuals' improved quality of life to occur, the principle of autonomy must be established. Autonomy is one of the six principles in the occupational therapy code of ethics and can be defined as the duty of practitioners to treat the client based on the client's desires (AOTA, 2015). Through the experiential knowledge and practice of autonomy, not only can OTs accomplish client-centered practice with clients that have I/DD, but they can provide assistance to primary care providers so that individuals within this population can have quality of life increased in all areas.

## **Solution**

Since primary care providers lack experience with adults with intellectual and developmental disabilities, further training and experience is needed to provide adequate care to this population. According to Krahn (2015), training can be improved at many levels, such as basic disability awareness for all public health care providers and discipline-specific training on specific aspects. In addition, Krahn (2015) states that Healthy People 2020 includes an objective that focuses on increasing the number of public health programs with a course on disability. This course of disability could be completed through lectures or seminars, which would be facilitated by professionals that are experienced in working with the disabled population (Shakespeare & Kleine, 2013). This beneficial teaching experience would allow for an attitude shift among primary care providers and changes in their practices because they would feel more knowledgeable about the I/DD population. Furthermore, Harder + Company (2008), suggests a variety of recommended competencies to improve the delivery of health services for I/DD individuals. Suggested is medical knowledge specific to developmental disabilities, compassion and sensitivity, improvement of communication and observation skills, understanding of the health care system, and exposure to working with I/DD throughout students' medical education. Jurczyk and Kelly (2009) suggest that there should be training of developmental



disabilities incorporated into medical education, which would provide experience to this population, as well as an early development of clinical skills.

## **Discussion**

### **Relevance**

According to the Administration for Community Living (2016), there are between seven and eight million Americans that experience intellectual disabilities. In addition, in a conducted study, researchers found that in the United States an individual with I/DD would have to call around fifty doctors before they found one with specific experience and training that could provide beneficial treatment (Kornblau, 2014, April). Since a majority of I/DD patients rely on Medicaid, many doctors reject these specific patients because not only are they aware of the low reimbursements rates for their services, but due to their lack of experience with the I/DD population, they are hesitant to interact with this specific population (Wilkinson et al, 2012). Thus, patients of the I/DD population health problems are overlooked until utilization of a specialist is needed (Ervin & Merrick, 2014). This raises the cost of healthcare because more spending is used for extensive and expensive care. All of these factors will continue to impact the I/DD's population declining health. However, through primary care providers increasing their experience and skills with the I/DD population, adequate care is achievable for this population.

### **Implications and Consequences**

Primary care providers are the first contact that a patient makes with healthcare when having issues with their wellbeing. In addition, primary care providers' role is to protect patients from unnecessary procedures (Shi & Singh, 2015). However, since primary care providers have a lack of training with the I/DD population, they are unequipped with the resources and tools needed to meet the needs of clients with I/DD. Thus, this results in primary care providers unrecognizing, misdiagnosing, or undertreating an illness (Harder + Company, 2008).

According to Kornblau (2014), strengthening the workforce of health providers to beneficially treat the people of the I/DD population can be accomplished by implementation of training programs for primary care providers. Furthermore, primary care providers that are trained are more prepared to meet the unique health needs of people with I/DD (Kornblau, 2014). If primary care providers received training on working with the I/DD population, quality of health services would increase for this population, as well as result in decreases in health disparities. Correspondingly, the access to primary health care providers could potentially increase due to extensive training benefits. This would occur because primary health providers

would have hands on experience and develop educational knowledge on how to handle specific situations when providing their services to the I/DD population. As a result, they would be more comfortable and willing to care for people with I/DD (Harder + Company, 2008) Thus, the I/DD population would receive adequate health care and better health outcomes. Also, instead of primary care providers only focusing on acute medical conditions, they will be aware of chronic conditions that are far more likely to be present in patients with I/DD (Ervin et al., 2014). More screening would be provided to the I/DD population because health providers would be aware of secondary conditions that are prevalent.

## **Conclusion**

There are still barriers that prevent access to quality healthcare for the I/DD population, such as primary care providers lack of training to treat this population. Lack of training leads to lower quality of care for the I/DD population, as well as an increase of health disparities due to lack of knowledge about secondary conditions. Through intensive training programs that provide relevant criteria concerning the I/DD population's concerns of health quality, appropriate and effective healthcare can be established. Thus, the primary healthcare providers would gain experience and develop skills that would provide adequate access to care so that health disparities are reduced for the I/DD population.

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