


Health Care Access for Adults With Intellectual and Developmental Disabilities: A Scoping Review

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Abstract

Adults with intellectual and/or developmental disabilities (IDD) often experience health disparities. To address disparities, Healthy People 2020 includes specific disability and health goals focused on improving health care access. The study's purpose was to review the literature exploring health care access for adults with IDD to identify opportunities for occupational therapy research and practice. A scoping review was completed of articles discussing health care access among adults with IDD in the United States. Thirty-seven articles met the inclusion criteria. Results are framed using the ecology of human performance theory identifying person and environmental issues affecting health care access of adults with IDD. Opportunities exist for occupational therapy to improve participation and health of adults with IDD through engaging in research and practice efforts addressing health care access. Occupational therapy could develop interventions to establish skills and abilities and recommend changes to the health care environment.

Keywords

health, occupational performance, public health, scoping reviews, disability

Background

Society's concept of disability has evolved from the medical model to a social model with disability now seen as a natural part of the human condition and defined by the social and environmental context in which people with disabilities live (World Health Organization, 2011). Disability is separate from the concept of health, meaning people with disabilities can and should experience healthy lives (Krahn, Walker, & Correa-De-Araujo, 2015). People with disabilities, including individuals with intellectual and/or developmental disabilities (IDD), are now recognized as a population experiencing health disparities (Hensel, Rose, Kroese, & Banks-Smith, 2002; Krahn et al., 2015; Marks, Sisirak, & Hsieh, 2008). Healthy People 2020 (2016b) defined health disparities as health differences which are closely tied to environmental, social, and/or economic differences.

The American Association on Intellectual and Developmental Disabilities (AAIDD; 2013) defines intellectual disability as a disability occurring before age 18 in which the individual has difficulty with intellectual functioning and everyday practical and social skills. U.S. Federal law defines developmental disability as a severe, chronic disability of an individual attributable to mental or physical impairment or sometimes both, diagnosed before the age of 22 (Developmental Disabilities Act of 2000; PL 106-402). Adults with IDD are

now experiencing longer life expectancies and are more likely to experience comorbidities (Coppus, 2013; Janicki, Dalton, Henderson, & Davidson, 1999; Reichard, Stolze, & Fox, 2011; Thomas & Barnes, 2010). Adults with IDD have been found to have higher prevalence of coronary heart disease, diabetes, cardiovascular disease, and obesity (Bhaumik, Watson, Thorp, Tryer, & McGrother, 2008; Draheim, 2006; Peterson, Gordon, & Hurvitz, 2013; Reichard & Stolze, 2011). Adults with IDD are also more likely to have comorbid mental health conditions, in particular adults with Autism (ASD) have higher rates of depression, anxiety, and bipolar disorder (Centers for Disease Control and Prevention, 2009; Croen, Zerbo, Ouan, & Massolo, 2014). Women with IDD experience disparities in receiving cervical cancer and breast cancer screenings and have more adverse pregnancy outcomes (Parish et al., 2015; Parish & Saville, 2006; Parish, Swaine, Son, & Luken, 2013).

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Finally, adults with IDD have higher rates of poor oral health (Morgan et al., 2012).

Clearly, adults with IDD are a population experiencing health disparities. Health equity will only be achieved for adults with IDD if identified health disparities are reduced (Healthy People 2020, 2016b). The Social Determinants of Health (SDOH) identifies five categories that should be addressed to affect health disparities including neighborhood and built environment, economic stability, education, social and community context, and health and health care access (Healthy People 2020, 2016b). To address health care access, Healthy People 2020 includes an objective focused on reducing the proportion of adults with disabilities experiencing barriers to health care (Healthy People 2020, 2016a).

The last scoping review of the literature regarding health and health care access for adults with IDD was published in 2006 (Krahn, Hammond, & Turner, 2006). This review highlighted the existing disparities while pointing to opportunities for addressing access issues in obtaining health services. In particular, they point to two documents produced by the U.S. Department of Health and Human Services (2002, 2005) reviewing the health of individuals with IDD in the United States creating a call to action to systematically address health care access for individuals with IDD. However, no scoping review or systematic literature review has been completed since Krahn et al. (2006) to identify our current knowledge of health care access for this population.

In 2012, two national IDD groups, The Arc and the AAIDD, produced policy statements highlighting the need for policy and practice changes to address health care access and health disparities among individuals with IDD (AAIDD, 2012; The Arc, 2012). However, these recommendations have yet to be realized broadly in the United States. In addition, a report regarding the impact of the Patient Protection and Affordable Care Act (ACA) points to promising policy initiatives to improve health care access for individuals with disabilities, but highlights the need for more research on the impact of these policies and practices on improving health care access to address health disparities (National Council on Disability, 2016).

The purpose of the current study is to complete a scoping review of the literature regarding health care access for adults with IDD to identify opportunities for occupational therapy research and practice to improve accessibility of health care for adults with IDD. Systematic reviews include processes for assessing quality of studies to include in the final analysis, whereas scoping reviews allow for inclusion of all studies regardless of research quality (Classen & Alvarez, 2015). A scoping review was selected, instead of a systematic review, to encompass all evidence thereby fully exploring the breadth and depth of available knowledge (Arksey & O'Malley, 2005; Classen & Alvarez, 2015). To identify areas for action, the findings from the scoping review are framed using the ecology of human performance (EHP) theory. The EHP theory emphasizes the interdependent relationship between the person

(unique experiences, skills, and abilities) and the environment (cultural, physical, temporal, and social) (Cole & Tufano, 2008; Dunn, Brown, & McGuigan, 1994). This interaction affects task performance, in this case the adult with IDD accessing needed health care (Cole & Tufano, 2008; Dunn et al., 1994).

Method

This scoping review was completed using organizational strategies from Garrard's (2011) Matrix Method and followed the five-step process for scoping reviews outlined by Arksey and O'Malley (2005). The process consisted of identifying the research question, finding relevant research pertaining to the question, reviewing and selecting studies that best answer the question, charting the data, and synthesizing results. The research question guiding the scoping review was as follows:

Research Question 1: What are the facilitators and barriers to accessing health care services for adults with IDD in the United States?

Given the complexities of differing health care systems worldwide and to address Healthy People 2020's disability and health goal related to access to care, this study focused on studies available regarding health care experiences of adults with IDD solely in the United States.

Searches were completed by three members of the research team in three electronic databases: Pubmed, PsychINFO, and CINAHL. Search terms were combined as follows: "Healthcare," AND "Adult," AND population terms ("Developmental Disabilities," "Intellectual Disabilities," "Intellectual AND Developmental Disabilities," "Muscular Dystrophy," "Spina Bifida," "Autism Spectrum Disorder," "Autism," "Down Syndrome," "Cerebral Palsy," "Mental Retardation"). The searches in PsychINFO and CINAHL included a geographic subset filter of "USA." This was not available in Pubmed, thus, "United States" was included in the key terms used for all searches conducted in Pubmed. Inclusion criteria included articles published after 2006, English articles, studies conducted in the United States, articles that address health care access, and articles pertaining to adults with IDD. Exclusion criteria included articles published before 2006, non-English articles, studies conducted outside the United States, articles that address health promotion, articles not discussing health care access, and articles pertaining to pediatric and/or adolescent participation samples.

An initial search of all search term combinations yielded a total of 1,735 articles. Abstracts and titles were screened for relevance to the research question and 264 articles were pulled for further consideration. Ninety articles were removed due to duplication, leaving a total of 174 studies for full review by all members of the research team. After review of these studies, 34 articles were removed based on exclusion criteria, leaving

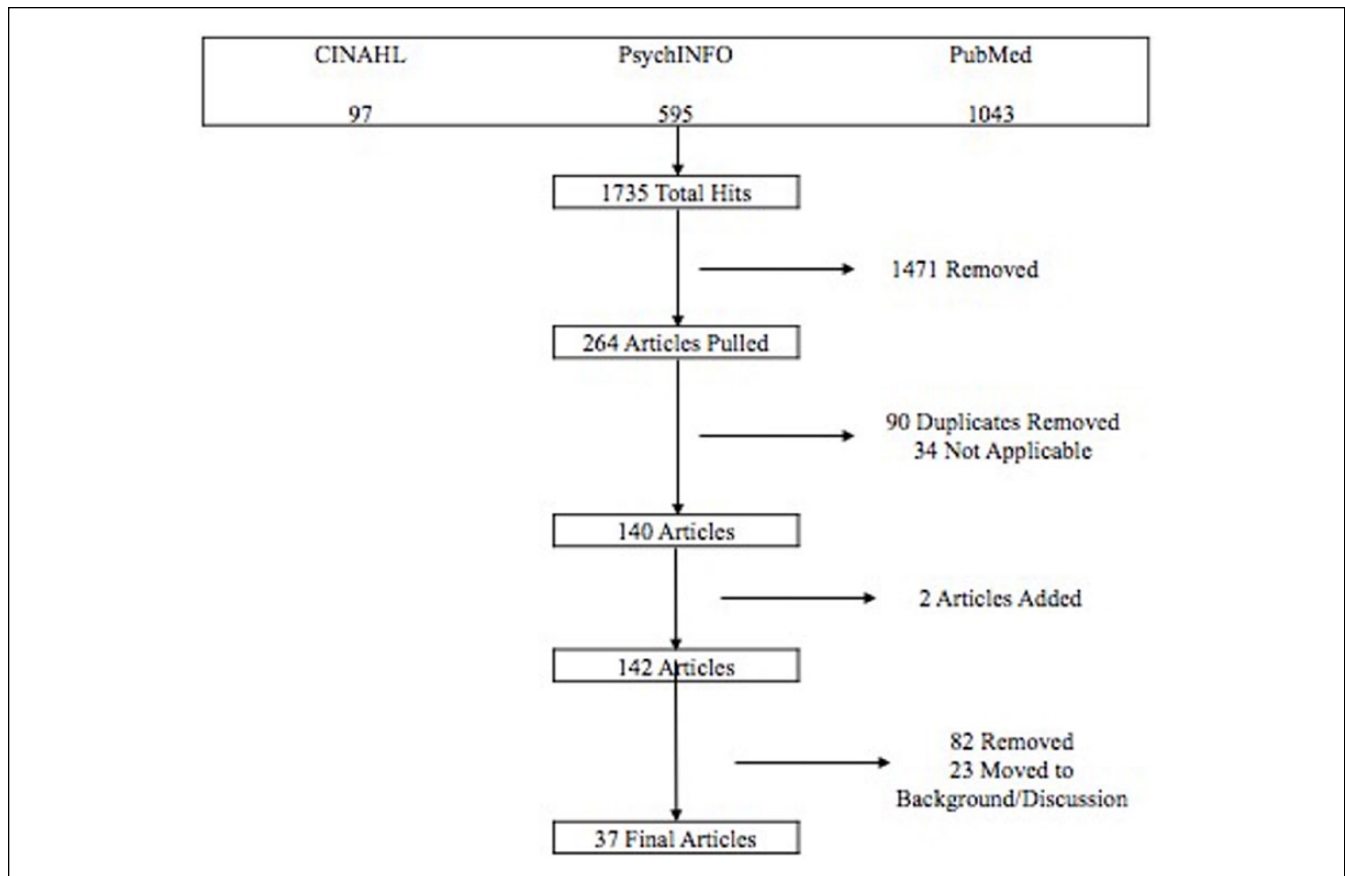


Figure 1. Summary of scoping review process.

a total of 140 studies. Two articles were added from an included study's reference list. Further review and discussion was done of these 142 studies by all members of the research team and an additional 82 articles were removed for not meeting all inclusion criteria. Additional review resulted in 23 articles being removed to be used in the background or discussion sections of this manuscript as they were not a study exploring health care access specifically, but instead reviewed broader health issues among adults with IDD. A total of 37 studies met full inclusion criteria (see Figure 1).

All members of the research team analyzed the selected studies in this scoping review using the EHP theory as a guiding framework to organize study results related to person and environmental factors. Within person and environmental factors, the study team identified common elements influencing health care access for adults with IDD in the United States. A summary of the 37 studies in this scoping review can be found in Supplemental Table 1, Summary of Studies.

Results

Person

Communication skills and abilities. Many individuals with IDD experience some difficulty both with expressive and receptive

communication skills. Several studies reported both expressive and receptive communication challenges experienced by adults with IDD as a barrier to accessing health care (Greenwood, Dreyfus, & Wilkinson, 2014; Kurre, 2014; Nicolaidis et al., 2015; Warfield, Crossman, Delahave, Deer Weerd, & Kuhlthau, 2015; Zerbo, Massolo, Qian, & Croen, 2015). Adults with IDD either had difficulty understanding the information from their provider or were not able to effectively communicate their thoughts, wants, or needs regarding their health or need for health services.

Communication barriers from the provider perspective include difficulty with calming patients, explaining hospital procedures, assessing pain levels, and preparing clients for discharge (Tyler, Schramm, Karafa, Tang, & Jain, 2010). Decreased communication can result in sedation for routine cancer and mammogram screenings (Tyler, Zyzanski, Panaite, & Council, 2010). There are also discrepancies with health care providers preferring to communicate with a caregiver versus the adult with IDD directly (J. Wilkinson, Dreyfus, Bowen, & Bokhour, 2013).

In addition, Greenwood, Dreyfus, & Wilkinson (2014) found that family members of individuals with IDD report having difficulty making medical decisions on someone else's behalf when that person is not able to communicate his

or her desires. This affects decisions to pursue or decline recommended preventive screenings and medical treatments. Individuals with ASD also report issues with emotional regulation resulting in fears or anxiety which influences their ability to effectively communicate their wishes for receiving health care (Raymaker, McDonald, Ashkenazy, & Nicolaidis, 2016).

Ability to adhere to health care recommendations. The ability to adhere to medical recommendations and follow through with instructions was identified as a barrier to health care access for adults with IDD. Mahmood, Dicianno, and Bellin (2011) reported that there was a correlation between ability to self-manage (i.e., self-catheterize, complete skin checks) and occurrence of secondary preventable condition in adults with spina bifida. In a survey of 346 primary care physicians (PCPs) who treat adults with ASD, 54.7% reported their patients with ASD had difficulty understanding or following medical recommendations, preventing the patient from being involved in an ongoing plan of care (Bruder, Kerins, Mazarrella, Sims, & Stein, 2012). Inability to follow through may also be related to organizational difficulties. Nicolaidis et al. (2015) reported some individuals with ASD have difficulty understanding how to schedule and follow through with different appointments and procedures. Vacek, Hunt, and Shireman (2013) identified that younger adults with IDD were more likely to adhere to medications than older adults.

Decreased knowledge about health care services. Decreased knowledge about health care was identified as a barrier to accessing health care. For instance, women with IDD were identified as being less likely to complete preventive screenings, such as mammograms, due to lack of knowledge or understanding of the purpose of mammograms compared with women without IDD (Greenwood, Dreyfus, & Wilkinson, 2014; Greenwood, Wang, Bowen, & Wilkinson, 2014; Parish, Swaine, Luken, Rose, & Dababnah, 2012; Swaine, Parish, Luken, Son, & Dickens, 2014; J. E. Wilkinson, Deis, Bowen, & Bokhour, 2011). Another study noted that adults with IDD may be less likely to utilize hospice services compared with the general public due to limited understanding of their diagnosis and/or limited knowledge about hospice services (Friedman, Helm, & Woodman, 2012).

Environment

Decreased health provider knowledge or education on treating adults with IDD. Many health care institutions are not always equipped or trained to work with the IDD population (Alexander, Bullock, & Maring, 2008; Bruder et al., 2012; Kurre, 2014; Levy et al., 2006; Ward, Nichols, & Freedman, 2010; Warfield et al., 2015). One survey of 1,500 physicians reported that approximately 10% of physicians felt uncomfortable treating individuals with Down Syndrome due to lack of knowledge, while 14.3% stated that they felt neutral

(Pace, Shin, & Rasmussen, 2011). It has also been shown that there are large gaps in dental care for individuals with IDD compared with those without IDD due to lack of trained dental providers (Parish, Moss, & Richman, 2008). In a survey of 75 members of the Special Care Dentistry Association, 47.7% reported that they did not feel like their education prepared them for treating patients with ASD (Weil, Bagramian, & Inglehart, 2011).

Providers have reported feeling uncomfortable with their level of training regarding patients with ASD, resulting in greater unmet health care needs, higher use of the emergency department, and lower utilization of preventive services (Nicolaidis et al., 2013). Individuals with ASD have reported hesitation to disclose their diagnosis to providers due to fear of discrimination related to provider misconceptions of ASD (Nicolaidis et al., 2015). (Ailey & Hart, 2010).

Health care provider knowledge also affects access to preventive care for adults with IDD. Decreased preventive care utilization in this population may be related to a lack of referrals or physician orders for preventive services (Greenwood et al., 2014). Jensen, Taylor, and Davis (2013) found inconsistent adherence by providers in following preventive care guidelines for individuals with Down Syndrome. Zerbo et al. (2015) found that although physicians report providing usual care when they suspect a patient has ASD, many do not ask about drug or alcohol use, or sexual health. This may influence referrals of preventive screenings.

Lack of preventive care opportunities. Adults with IDD are more likely to experience secondary conditions due to decreased mobility, lack of transportation options, and insufficient education on prevention opportunities (Liptak, Garver, & Dosa, 2013). Although adult women with IDD participate in tobacco use, substance use, and sexual activity, they have less education on HIV/AIDS, sexual health, and preventive health care services (Rurangirwa, Van Naardan Braun, Schendel, & Yeargin-Allsopp, 2006). Adults with IDD are also more likely to have preventable health care complications if they have a surgical procedure or have multiple chronic health conditions than adults without IDD (Ailey, Johnson, Fogg, & Friese, 2015). Finally, Mitra, Parish, Clements, Cui, and Diop (2015) found that women with IDD are in need of preventive care opportunities as they are more likely to smoke during pregnancy, less likely to receive prenatal care during the first trimester, and have a higher risk of adverse pregnancy outcomes.

Financial barriers. Financial barriers to health care access continue to exist. Carroll (2015) found that adults with cerebral palsy (CP) had difficulty with insurance companies approving needed services like physical therapy to maintain function. Kurre (2014) noted the complexities of providers staying up to date with Medicaid and Medicare regulations which affected care access. Adults with ASD identified employment challenges which resulted in poverty and/or

difficulty maintaining insurance coverage (Nicolaidis et al., 2015). Andrews, Davis, and Meaney (2014) found that individuals with Duchenne and Becker muscular dystrophy with lower incomes were less likely to utilize health services. In addition, providers report individuals with ASD require extra time to assess, treat, and collaborate with other professionals for quality care; however, the extra time is not reimbursable, creating financial disincentives for providers (Warfield et al., 2015).

Physical environment. The physical environment can be a barrier or facilitator to accessing health services. Loud, bright, over-stimulating waiting rooms were identified as a barrier to seeking care, whereas low, or natural lighting was identified as a facilitator (Nicolaidis et al., 2015; Zerbo et al., 2015). Providers have also reported noisy environments, and office locations that require use of stairs or elevators to be barriers to some individuals they work with who have ASD (Warfield et al., 2015).

Family context. The family context is an important consideration when addressing access to health care for individuals with IDD. Several studies found that adults with IDD who live with their families were less likely to receive services than those who live in more restrictive environments (Bershady, Hiersteiner, Fay, & Bradley, 2014; Scott & Haverkamp, 2014). Greenwood et al. (2014) conducted a study to gain perspectives of breast cancer screening of relatives of women with IDD. Families often perceive their loved one with IDD as being children rather than adults. Fears of a cancer diagnosis creating anxiety within the family and subsequent treatment-related decision making, and inaccurate cancer knowledge may affect decisions to pursue screenings/treatments. Family members, peers, and disability professionals, who can help participation in exams and support decision making, have been cited as important facilitators to accessing health care (Carroll, 2015; Nicolaidis et al., 2015). However, many individuals with IDD report having a lack of emotional support (Haverkamp & Scott, 2015).

Health care service transitions. Health care service transitions from pediatric services to adult-based services were reported to be difficult for both providers and individuals with IDD. Providers report a need for improvement with transitions (Zerbo et al., 2015). Carroll (2015) found individuals with CP report discomfort transitioning to adult care providers who are not as knowledgeable regarding their condition. In addition, there is limited availability of adult care providers competent in treating individuals with CP (Greenwood et al., 2014). Overall, there is a lack of adult care providers and services for adults with IDD (Greenwood et al., 2014; Warfield et al., 2015). K. M. Jensen and Davis (2013) found that over half of the adults in their longitudinal study had not fully transitioned into adult care services, and most adults receiving both pediatric and

adult services rather than solely adult services had complex cases of congenital heart disease.

Disparities related to race and ethnicity. Two studies investigated disparities among racial or ethnic minority groups of individuals with IDD. Scott and Haverkamp (2014) found that those in a racial or ethnic minority group were less likely to receive preventive health care than their Caucasian counterparts. However, Bershady et al. (2014) noted that race/ethnicity did not play a large role in preventive health care access patterns once the data were controlled for person-level factors, such as age, residence, and mobility level.

Health literate education efforts. Health literacy includes designing health care education materials in a manner that reflects the skills and abilities of its intended audience. Two studies looked at educational materials tailored to adults with IDD (Greenwood et al., 2014; Swaine et al., 2014). Results of both studies showed an increase of participant knowledge, which demonstrates the importance of presenting information in an appropriate manner given the intended audience. In another study, women with IDD demonstrated improved mammography preparedness after receiving mammography education tailored directly to their skills and abilities (Wang, Greenwood, White, & Wilkinson, 2015). Health providers have identified the need to establish procedures specifically designed for individuals with IDD including implementing different communication strategies for education about care procedures to improve health literacy (Ailey & Hart, 2010).

Discussion

Results of this scoping review identified both person and environmental factors that affect the task of adults with IDD effectively accessing both primary and preventive care services. The factors discussed in this scoping review provide opportunities to address the Healthy People 2020's (2016a) disability and health goals associated with reducing barriers to health care access among individuals with disabilities. The previous review by Krahn et al. (2006) promoted the conceptualization that individuals with IDD experience health disparities and pointed to broad strategies to address health care disparities. Given the complexity of care needs and approaches to promote care access among the adults with IDD, the current study used the EHP as a framework to provide specific strategies to address health care access among adults with IDD.

Occupational therapists can provide innovative approaches to improve access to health care for adults with IDD using the EHP theory's intervention strategies. The first EHP intervention strategy proposes to establish skills and abilities to improve task performance (Dunn et al., 1994). Adults with IDD have identified challenges with abilities related to knowledge and communication strategies necessary for accessing health care. Involving adults with IDD in the

process of health care decision making can build personal capacity for health care communication and knowledge, while also enhancing their self-determination (Anderson et al., 2013; Shogren, Wehmeyer, Reese, & O'Hara, 2006). Occupational therapists can work to develop and evaluate methods to promote communication in health care transactions among adults with IDD (e.g., adapting education materials for accessibility). In addition, adults with IDD should also be involved in the design of health programs to ensure their accessibility for a diverse group of individuals with varying communication and knowledge skill sets (Anderson et al., 2013). For example, through accessible evaluation effort, adults with IDD could provide feedback on education materials and the design of health care settings.

A second EHP intervention strategy involves modifying and adapting the context or the environment (Dunn et al., 1994). Lack of health care provider knowledge and skills required to effectively work with adults with IDD was identified as a barrier in this scoping review. One strategy to modify the context would be to include questions about the care of adults with IDD in clinical licensing exams (Nehring & Lindsey, 2016). While occupational therapy programs include in their curriculum how to effectively work with individuals with IDD, not all health professions yet require IDD specific education. Including IDD specific information on health provider licensing exams would encourage health care education programs across several disciplines to include information about working with adults with IDD in their curricula. Sisirak et al. (2016) also recommended adding disability specific questions in the Consumer Assessment of Healthcare Providers and Systems to evaluate satisfaction with services among individuals with IDD. In addition, providing and/or requiring education regarding working with diverse populations, including individuals with IDD, in mandatory continuing education requirements for licensure would also promote up-to-date knowledge on best practices for working with adults with IDD. Occupational therapists can work with primary care providers to identify approaches for modifying their physical and sensory environments to encourage the participation of adults with IDD in health care.

Finally, the EHP also identifies prevention of anticipated problems and creating opportunities for task performance as intervention strategies (Dunn et al., 1994). Adults with IDD are now experiencing longer life expectancies so it will be important to proactively plan for training providers on issues related to aging adults with IDD (Janicki et al., 1999; Perkins & Moran, 2010; Svien, Berg, & Stephenson, 2008; Tyler & Noritz, 2009). An integrated approach to primary care encompassing existing mental health care and other social services can produce enhanced access to health care (Ervin, Hennen, Merrick, & Morad, 2014). Occupational therapists can provide guidance on how to encourage participation of adults with IDD in coordinating their care and communicating their changing needs associated with aging.

To date, only one study from the perspective of occupational therapy points to a conceptual model of accessibility for environmental access among individuals with IDD (Yalon-Chamovitz, 2009). The *Occupational Therapy Practice Framework (OTPF)* identifies health management and maintenance as an occupation necessary to achieve health and wellness outcomes (American Occupational Therapy Association, 2014). Occupational therapists can use the *OTPF* as a guiding framework to inform both practice and research efforts targeting barriers and facilitators to health care access reviewed in this article. Interventions could be designed to influence client factors (i.e., sensory functions, mental functions), performance skills (i.e., process skills, social interaction skills), and context and environment factors (i.e., physical and social) influencing health care access among adults with IDD. Clearly, there is a need and opportunities for occupational therapy to contribute to knowledge in this field.

Fortunately, there are resources available to create opportunities for promoting health care access for adults with IDD. The Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (2016) has developed a free online resource titled *Healthcare for Adults With Intellectual and Developmental Disabilities: Toolkit for Primary Care Providers*. This toolkit includes education resources for providers as well as tools to address health and behavioral health needs of adults with IDD. *My Health Passport* is a health advocacy tool that adults with IDD can use to help reduce communication and knowledge barriers in health care interactions (Perkins, 2011).

Strengths and Limitation

This scoping review sought to address a broad research question related to health care access for adults with IDD in the United States. The study team did not evaluate the quality of the evidence included in this review to capture the full breadth of information available for consideration. Future reviews could systematically decide levels of evidence to include to provide a more refined approach to recommendations for research and practice (Classen & Alvarez, 2015). In addition, the broad focus of this review on adults with IDD did not allow for specific conditions or specific approaches to addressing health care utilization. Finally, any research endeavor includes a risk for potential bias in the design, implementation, and interpretation of the research. A more systematic approach to evaluating the quality of research studies included in a future systematic review or meta-analysis would allow for careful consideration of these biases in final analysis.

Implications

Occupational therapists have both practice and research opportunities for addressing Healthy People 2020 (2016a)

goals focused on disability and health. The lens of occupational therapy can prove critical in the development of education strategies focused on improving health care access for adults with IDD. Occupational therapists are trained to consider the larger ecological perspective to addressing task performance. Occupational therapists can provide education to health care professionals on strategies to modify treatment approaches to be more relevant and understandable for adults with IDD. In addition, occupational therapists can collaborate with primary care providers on strategies to address their perceptions of people with IDD. Finally, occupational therapists who regularly provide direct care or provide case management services for adults with IDD can work with adults with IDD on self-determination in their health care decision making and on strategies to improve communication. Ongoing advocacy is needed to promote the role of occupational therapy as service providers for this population.

Results of this review point to the need for more research on health care access for adults with IDD. In particular, research on effective health care provider readiness training will be vital to ensure a workforce prepared to treat adults with IDD. Additional research is also needed on promoting involvement of adults with IDD in their health care. A focus on self-determination and processes for informed consent in health care decision making will be particularly important for adults with IDD. This review identified environmental facilitators and barriers related to health care access including the physical environment, race/ethnicity, financial and family context issues which also could be explored in depth individually in future research.

Conclusion

Improving access to health care is a critical mechanism to address health disparities experienced by adults with IDD. This scoping review of health care access for adults with IDD in the United States identified personal factors of adults with IDD and environmental factors that influence health care utilization. Occupational therapy as a field can contribute to collective efforts to research and practice initiatives to address the Healthy People disability and health goals focused on improving health care access among individuals with disabilities.

Ethical Approval

The current study is a scoping review of the literature and is not research involving human subjects. Therefore, no IRB application was submitted to the Northern Arizona University IRB (FWA00000357).

Authors' Note

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Declaration of Conflicting Interests

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Supplementary Material

Supplementary material is available for this article online.

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