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Health Clinics and Adults with Physical Disabilities: An Inclusive Approach

Teresa Elizabeth Jones

A dissertation submitted to the faculty of Bethel University  
in partial fulfillment of the requirements for the degree of  
Doctor of Education

Saint Paul, MN

2018

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Reader: Dr. Steve Paulson

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## Abstract

There is evidence for health and education communities that call for disability curricula in care provider education. The purpose of this study was to explore what adults with physical disabilities (AWPD) experience in health clinics regarding access to care with physical environments, attitudes, and disability knowledge, and to construct a comprehensive survey for care providers asking about accessibility in their clinics. A transformative mixed methods approach included AWPD in research to provide an authentic representation of this population accessing care in health clinics. This study was conducted in two phases. Phase one collected qualitative data and documented AWPD perceptions, and developed a survey for care providers. Phase two collected quantitative perceptual data of care providers. Findings showed that AWPD reported concerns with accessing and maneuvering in clinic environments, absence of accessible medical equipment, discussing health-related issues with their provider, and other concerns about various aspects of their disability care. In some cases, not having adequate access resulted in undesirable outcomes and incomplete exams for AWPD. Findings also showed areas of accessibility. AWPD reported that clinic staff responded to their needs and providers gave suggestions to improve health. However, one-fourth of providers surveyed responded they were not knowledgeable in disability care, durable medical equipment, nonpharmaceutical alternatives for managing pain, secondary conditions, and communication techniques; nearly one-half were not knowledgeable in wellness activities and preventive screening. This suggests a disability knowledge gap exists among care providers working in health clinics. Education could be the key for improving physical environments, attitudes, and disability knowledge. The importance of this study is for providers and educators to have a better understanding of accessibility in health clinics so health services and outcomes for AWPD can be improved.

## Dedication

This research is dedicated to adults with physical disabilities as they navigate their way through health clinics and to the care providers who work tirelessly to serve them.

## Acknowledgements

I would like to thank my dissertation committee: advisor Dr. Diane Dahl, quantitative expert Dr. Steve Paulson, and qualitative expert Dr. Marta Shaw for their support and guidance throughout this dissertation process. Their actions radiated Christian values that help keep Bethel University strong. Dr. Dahl and I share a passion for disability-related issues and working under her knowledge and encouragement was such a joy for me. I would also like to thank Dr. Susanthi Fernando for granting me permission to conduct focus group sessions with adults with physical disabilities residing in her homes. Her graciousness and love of care-giving emanates through her actions. I would like to thank the seven focus group participants for their input on health clinic experiences from their perspective of accessing care in spite of physical disabilities; without them, development of an authentic care provider survey would not have been possible. In addition, I thank my family members, Daniel Jones, Anita Hoaglund, and Gretchen Hoaglund for assisting me with the multi-hour survey mailing project, and also Megan Hoaglund and Emily Jones who acted as stand-by assistants. Most of all, I want to thank God for giving me the desire, strength, and perseverance needed to do this important work.

## Preface

I worked in long-term care nursing for over 25 years. During that time, I wondered what kind of home settings the patients came from and where they were going to after discharge from care facilities. Then, an opportunity came about to work as a public health nurse. I was excited to make the connection between patients living in care facilities to living in the community. Most of my clients were young men who became physically disabled because of accidents or risky behaviors. I never expected to learn so much from working with this population. I was fortunate to see the continuum of care unfold and how essential community supports were for each individual person. However, I also witnessed many situations that made me question the effectiveness of certain facets of the U.S. health care system. Therefore, I was able to gain new insights on several complex aspects of the health care system, disability legislation, and most of all, my clients. A main theme still resonates with me today: People with disabilities want to be included.

“...inasmuch as you did *it* to one of the least of these My brethren, you did *it* to Me” (Matthew 25:40, New King James Version).

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## List of Abbreviations and Symbols

ABA: Architectural Barriers Act of 1968

ADA: Americans with Disabilities Act

ADAAG: Americans with Disabilities Act Accessibility Guidelines

ADL: Activities of Daily Living

AWPD: Adults with physical disabilities

CDC: Centers for Disease Control and Prevention

CP: Care provider

DHHS: Department of Health and Human Services

DOJ: Department of Justice

FGP: Focus group participant

IADL: Instrumental Activities of Daily Living

ICF: International Classification of Functioning, Disability and Health

ICT: Information and Communication Technology

OMB: Office of Management and Budget

SOFA: Statistics Open For All

TTY/TDD: Teletypewriter/telecommunications device for the deaf

WHO: World Health Organization

*n*: limited number of participants within the total sample

*N*: number of participants in the total population or sample

## **Chapter One: Introduction**

### **Introduction to the Problem**

According to the Centers for Disease Control and Prevention (CDC), up to 57 million people live with a disability in the United States (2016c). Furthermore, the national data suggests this number is expected to rise as the population ages. To ensure adults with physical disabilities (this group will be referred to as AWPDP) have a fluid transition into health care environments, health clinics may need to provide more specialized services that accommodate their unique needs. However, due to various issues with meeting mandates of the Americans with Disabilities Act (ADA), many health clinics are challenged in providing disability services or perhaps do not fully understand the law in regards to accessibility for people with disabilities (Lagu et al., 2013). To compound the situation, the World Health Organization (WHO) reported that people with disabilities had twice as much difficulty locating care providers adequately trained to “meet their needs,” were four times more likely to be “treated badly,” and were almost three times higher to be “denied care” compared to people without disabilities (2015, para. 17). Hence, AWPDP might not know which health clinics can accommodate their disability needs and have fewer recommended health screenings than people without disabilities (Drew & Short, 2010; Horner-Johnson, Dobbertin, Lee, & Andresen, 2014; Iezzoni, Park, & Kilbridge, 2011; Krahn, Klein Walker, & Correa-De-Araujo, 2015). Without appropriate access to health clinics and services, many AWPDP are encountering barriers that hinder adequate health exams and treatment of medical conditions.

Moreover, care professionals working in health clinics might face additional challenges when attempting to meet the health demands of the communities they practice in. The literature was mottled with examples of clinic resources lacking in funding, structural space, personnel

training (Burns & Gordon, 2010), adequate staffing, allotted time for patient visits (Lagu, Iezzoni, & Lindenauer, 2014), and a myriad of other constraints that stood in the way of care delivery. Thus, some health clinics struggle in meeting needs of AWPDP along with adopting certain mandates imposed by the ADA or other regulatory agencies. Accessibility in health clinics is vital for people with disabilities because they require specialized health-related services (McDoom, Koppelman, & Drainoni, 2014).

By contrast, health facilities committed to the early identification of patients' specialized needs may be more prepared to accommodate those needs (Lagu et al., 2014). One way to accommodate patients with physical disabilities is by adopting *universal access* in health clinics. The term "universal access" is a concept that means providing accessibility to all buildings and facilities for people with physical disabilities (Burns & Gordon, 2010). Lagu et al. (2014) added that universal access not only helps eliminate barriers, such as with equipment; it could be viewed as an investment. For example, a height-adjustable examination table could possibly serve an elderly adult with painful arthritis, a child with a long-bone fracture, or an adult with lower limb paralysis. Properly equipped clinics might be able to provide services supportive to disability populations that have difficulty with physical functioning, communication, sensory, and so on. In other words, health clinics that improve access for AWPDP might assist in serving the general public as well. Therefore, an inclusive approach does not mean to exclude other populations from participating in health services; rather, it offers availability of services for a variety of consumers.

Education plays a key role in accessing care for AWPDP. AWPDP reported that care providers did not fully understand their disability (U.S. Department of Health and Human Services [DHHS], 2005). However, accreditation agencies do not mandate disability knowledge



in medical schools (Wen, 2014). To provide adequate care for people with disabilities, Smeltzer, Blunt, Marozsan, and Wetzel-Effinger (2015) claimed that education for care providers is needed to improve disability knowledge, attitudes, and skills. Having disability knowledge will not only improve care for people with disabilities, it is needed because most health care practitioners will provide care for a patient with a disability sometime in their career (Smeltzer et al., 2015).

## **Background of the Study**

Historically, people with disabilities have been isolated from society and discriminated against in vital areas, such as health services (ADA, 1991a). For that reason, the U.S. Congress recognized the need to ensure equal opportunities in all aspects of society for persons with disabilities. Statutes by the ADA gave people with disabilities the right to fully participate in their communities by granting access to the same public entities and services that able-bodied individuals have access to. The following points represent a brief historical synopsis of disability-rights law enactment (Department of Justice [DOJ], 2010, pp. 1-8):

- Architectural Barriers Act (ABA) of 1968: provides “guidelines for facilities designed, constructed, altered, or leased with Federal dollars” (p. 1).
- Section 504 of the Rehabilitation Act of 1973: originally enacted to protect people with disabilities from discrimination in services, programs, and activities that received Federal funding. It was later amended with the enactment of the ADA of 1990 “...to all activities of State and local governments regardless of whether these entities receive Federal financial assistance” (p. 2).
- ADA, July 26, 1990: “...comprehensive civil rights law prohibiting discrimination on the basis of disability.” Title II “protects qualified individuals with disabilities from discrimination on the basis of disability in services, programs, and activities provided by

State and local government entities.” Title III “prohibits discrimination on the basis of disability in the activities of places of public accommodation” (p. 2).

- ADA Standards for Accessible Design, July 26, 1991: the ADA published standards regarding construction which were based on ADAAG 1991 guidelines.
- ADA Accessibility Guidelines (ADAAG), July 26, 1991: based on ADA 1991, Title III compliance of public accommodation and commercial facilities in regards to “newly constructed or altered facilities” (p. 3).
- Access Board republished 2004 ADAAG, July 23, 2004: combination of revised ADA and ABA guidelines in relation to federal, state, and local building codes to new and existing facilities, “including recreation facilities, play areas, and service animals (p. 5).
- ADA Amendments Act of 2008, September 25, 2008: “amended the ADA definition of disability to clarify its coverage of persons with disabilities and to provide guidance on the application of the definition” (p. 2).
- The 2010 Standards for Accessible Design: refers to “New Construction and Alterations” (p. 7).
- Access Board, September 14, 2016: approved rules on information and communication technology (ICT) which updates standards for “computer hardware and software, websites, multimedia such as video, phone systems, and copiers” and new accessibility standards regarding medical diagnostic equipment, “including examination tables and chairs, weight scales, radiological equipment, and mammography equipment” (United States Access Board, personal communication, September 14, 2016).

Despite the passage of the ADA which prohibits discrimination and prejudice toward people with disabilities, AWPD continue to face barriers in health clinic environments (Lagu et

al., 2013; Yankaskas et al., 2010). Only a few studies have attempted to quantify access to health clinics or subspecialties from the perspective of adult patients with physical disabilities and care providers. Still, researchers continue to examine barriers in health care and explore the experiences of people with disabilities. It appears reasonable there is enough evidence to take notice that a problem of access persists (Bachman, Vedrani, Drainoni, Tobias, & Maisels, 2006; Lagu et al., 2013; McDoom et al., 2014). Consequently, exclusion from accessing health care could be viewed as inequitable for those unable to utilize health services.

Availability of services is only one aspect of accessing health care. Accessibility is a multipart concept and means more than simply gaining entry to a facility structure. Access is the route to care (Lagu et al., 2014). For instance, navigating physical structures, and utilizing internal clinic processes and services are other major aspects to consider with accessibility (WHO, 2015). In addition, the WHO wrote having primary care providers trained in disability care is important for care coordination, continuity of care, and for building a trusting relationship with their patients. Without knowledgeable health clinic staff to assist in the processes involved in obtaining an examination, AWPB might not receive the medical care that corresponds with their intended health visit.

The peer reviewed literature was deficient in studies examining the accessibility of health clinic environments from the perspective of health clinic care providers. More research is needed in this area to inform policies and practices that will help deliver appropriate health services for individuals with physical disabilities. Furthermore, including AWPB in decision making processes in regards to health care service delivery is supported by the literature (Bachman et al., 2006; Eisenberg, Rimmer, Mehta, & Fox, 2015; McDonald, Williamson, Weiss, Adya, & Blanck, 2015; McDoom et al., 2014; Mertens, 1999; Rios, Magasi, Novak, & Hamiss,

2016; Suzuki, Krahn, Small, & Peterson-Besse, 2013). Thus, the importance of this study is for care providers and educators to better understand accessibility in health clinics so access to health services and outcomes for AWPDP can be improved.

### **Statement of the Problem**

The CDC reported 22% of adults in the U.S. live with a disability, 13% of which have difficulty with mobility (CDC, 2015a). In addition, disability trends showed a projected increase in disability prevalence as adults grow older (Brault, 2012; Burns & Gordon, 2010; Chen & Sloan, 2015; Darling & Heckert, 2010; Gu, Gomez-Redondo, & Dupre, 2015; Lee, 2010; Talih & Huang, 2016). In lieu of the trends, these aforementioned researchers predicted needing additional health services for aging individuals as well. However, AWPDP tend to receive fewer preventive health screenings than adults without disabilities (Drew & Short, 2010; Horner-Johnson et al., 2014; Suzuki et al., 2013). Without proper screening, people with disabilities are at risk for poor health outcomes (Krahn et al., 2015; Wang, 2012), become vulnerable to health problems (Drew & Short, 2010), and die at higher rates from conditions such as breast cancer (Iezzoni, Kilbridge, & Park, 2010; Iezzoni et al., 2011; Yankaskas et al., 2010). The problem identified in multiple studies was AWPDP continue to encounter inaccessible health facility environments, negative attitudes towards disability, and lack of provider knowledge in disability-related care.

Physical environments, care provider attitudes, and disability knowledge are factors in the environment to consider when accessing care in health clinics for people that need accommodations with a physical disability (WHO, 2001). For example, lack of accessible facilities (Suzuki et al., 2013), medical equipment and technologies (Drew & Short, 2010), provider training, and negative perceptions (Wen, 2014) are issues for many AWPDP because

without proper access to care, the quality of an examination could be compromised. The U.S. Department of Health and Human Services began an initiative over three decades ago with goals of improving access to health care services and eliminating disparities. This initiative is called *Healthy People* and monitors 26 national Leading Health Indicators (LHI) deemed as priority under 12 topics, two of which are Access to Health Services and Clinical Preventive Services. According to *Healthy People 2020*, none of the LHIs under these two topics have met their target percentages. In topic area Access to Health Services, individuals using a primary care provider were 76.3% in 2008 and are currently at 77.3%, showing little improvement towards the goal of 83.9%. In topic area Clinical Preventive Services, colorectal cancer screening, controlled high blood pressure, and childhood vaccination rates have improved since 2008; however, people with diabetes had little change in their blood glucose control, showing only a 3% improvement since 2008 (DHHS, 2014). It seems clear that accessing health services may be a continuing problem.

Another reason why accessibility to health services is so critical is the impact disability has on the nation in general. Studies showed that AWPD have more complex health needs than people without disabilities (Eisenberg et al., 2015). If these needs are not adequately met, the likelihood of medical conditions worsening increases and becomes more costly (Valderas, Starfield, Sibbald, Salisbury, & Roland, 2009). Treating chronic conditions absorbs over 75% of the \$2 trillion spent annually on U.S. health care (Iezzoni, 2010). In addition, disability currently carries a national cost of \$400 billion annually; affecting the overall stability of communities (CDC, 2015a). Therefore, health outcomes in the disability population is not only important for disabled individuals, it is vital for the health of the nation as a whole.

The issue of accessibility will become increasingly important as the U.S. population ages. According to the Pew Research Center (2010), 10,000 baby boomers will turn 65 years old every

day through 2030. Mobility limitations among older adults is common and affects roughly one-fourth of adults over age 70 and half of adults over age 80 (Ward et al., 2016). Ward et al. went on to say that mobility limitations precede disability, which will require an increase in health services. The influx of elderly people with mobility limitations along with AWPDP will place additional weight on the U.S. health system's supply and demand for services. This might prompt a call in the future from consumers to accommodate access to individuals with limited mobility functioning and physical disabilities. In addition, educational leaders may call for disability-related curricula that prepare care professionals to meet the present and growing health care needs of people with disabilities.

In summary, to improve the quality of health care for AWPDP, clinics could incorporate strategies that accommodate accessibility in their environments. For example, AWPDP may gain from adjustable examination equipment allowing for a thorough physical exam. However, studies conducted by Drew and Short (2010), Eisenberg et al. (2015), Lagu et al. (2013), Iezzoni et al. (2010), Suzuki et al. (2013), Wen (2014), and Yankaskas et al. (2010) suggested that AWPDP continue to struggle with various clinic barriers when they should have equal access and be included in the same health screening opportunities as their peers without physical disabilities. Consequently, there may be unfair differences in access to health care and quality of care received by providers. Krahn et al. (2015) and the CDC (2016b) reported people with disabilities are frequently excluded from fully participating in their communities because of limitations in the environment. It is important for providers and educators to understand access issues AWPDP have in clinics so environments can be improved to meet health needs. This study attempted to find out what those central issues are for AWPDP and ask providers what they are providing so as to inform health and education leaders about the need for disability curricula.

## **Theoretical Framework**

Transformative theory provides the framework for this study. A transformative paradigm centers on the lives and experiences of underrepresented groups, such as persons with disabilities (Mertens, 1999; Mertens, 2015, p. 21). Mertens (2009) added that because of conditions related to physical, historical, poverty, or other reasons, underrepresented group members have a higher probability of facing inequities in society. Furthermore, people in these groups tend to experience less access to resources and a poorer quality of life, such as with their health. The transformative paradigm evolved because people who have historically been driven to the margins of society “are finding a means to bring their voices into the world of research” (p. 3). The transformative paradigm supports those voices.

According to Mertens (2009), human rights are at the core of the transformative paradigm and reflect the 1948 United Nations Universal Declaration of Human Rights language. The declaration was updated in 1975 to include persons with disabilities as having the same rights as all citizens, regardless of the nature of their disability (pp. 12-13). Transformative theory can be applied to help connect research findings to creating positive change, as stated by Mertens (1999). However, researchers might not have the decision-making power to create that change. In that case, Mertens added that researchers can develop data collection tools that facilitate change by empowering those who do have the power to make positive changes. For example, data collection tools that were used in this current study included a question for both AWPD and care providers asking for ideas that improve clinic environments. Therefore, both groups were included, while care providers have the power to make changes if they choose to. In addition, findings from this study inform educational leaders that changes in health professional education are needed to include disability-related curricula.

Transformative theory focuses on two main facets. First, that friction can arise when issues of inequities are brought forward in what could be seen as an unyielding social problem (Mertens, 2009, p. 10). As mentioned, a problem of access in health clinics persists for AWPDP. For that reason, there was a potential for AWPDP to feel uncomfortable when they described their experiences with accessibility in health clinics. Likewise, there was a potential for care providers to feel uncomfortable responding to a survey about accessibility in their clinics, especially if they fear retaliation or perceive they provide adequate accommodations for AWPDP. Although the problem in this current study had the potential to create discomfort for both groups, there were conscious attempts to minimize discomfort; such as with a disclosure stating the topic is potentially sensitive in nature, which was noted in the consent process.

The second facet explained by Mertens (2009) is that strength can be found in underrepresented communities when respect is shown towards their human rights. Transformative paradigm is not about blaming the victim or fueling the problem. Instead, it concentrates on facilitating ways to create solutions for improvement (p. 10). In this current study, AWPDP and care providers were asked about access to health clinics as well as their ideas for creating an improved health clinic environment. Producing ideas for improvement might also serve to facilitate understandings of the problem, according to Mertens.

The transformative framework also demonstrates to the reader that AWPDP were represented in this research project. Mertens (2009) remarked that “An important aspect of the transformative paradigm is in the conscious inclusion of a broad range of people [such as people with disabilities] who are generally excluded from mainstream society” (p. 14). Accordingly, researchers and federal agencies are calling for more studies that include the perspective of people with disabilities to inform design of accessible environments, evaluation tools, and



curricula. Therefore, AWPDP were involved in this research project for data collection that could help to inform the disability community as well as health professionals and educators about accessibility in health clinics.

Researchers have shown that including AWPDP insights in disability research can be useful. For instance, inclusion of AWPDP allows for authentic disability representation when discussing their experiences with community health (Eisenberg et al., 2015). Eisenberg et al. asked people with disabilities how they accessed environments and utilized services in schools, health care facilities, food markets, and other community sites. Feedback was then used to identify main barriers and facilitators that affected access and participation by people with disabilities in those environments. The information not only served to create a community assessment tool, it could also be used to inform the public of accessible sites.

Inclusion also provides opportunities for AWPDP to address disparities in health care by participating in research and public health programs, which could lead to improved health (Krahn et al., 2015; Rios et al., 2016). For example, Krahn et al. (2015) suggested taking a closer look at differences in populations regarding preventive services involving mammography screening, obesity, and smoking to name a few. Moreover, inclusion offers “an equal partnership between those affected by an issue and researchers studying an issue” (McDonald et al., 2015, p. 351). This research project used an inclusive approach by partnering with AWPDP asking about their experiences in health clinics. Data from AWPDP focus group sessions were then used to formulate survey response choice items for providers about accessibility in their health clinics.

Finally, if an inclusive approach in research is not used, false ideas and incorrect conclusions about disability might be reached (Mertens, 1999). Mertens explained that including AWPDP in research will help acquire accurate information about disability and therefore improve

the research. In regards to this current study, not only were AWPB experiences in health clinics explored, AWPB also supplied the response choice items for the care provider survey. These items reflected components of clinic access that was important to measure from an AWPB perspective. Without this inclusive approach, a realistic depiction of a survey that asks what care providers are providing for AWPB would not have been possible.

### **Purpose of the Study**

The purpose of this study was to explore what AWPB experience in health clinics regarding access to care with physical environments, attitudes, and disability knowledge, and to construct a comprehensive survey for health clinic care providers. This study used a transformative approach by including AWPB in the development of a clinic survey tool asking care providers about accessibility in their health clinics. Results from both groups were examined in an attempt to inform health and educational leaders about the need for disability curricula in medical education.

### **Rationale**

There are few mixed methods studies that use transformative theory as its framework in relation to people with disabilities. Disability prevalence is expected to rise, especially as baby boomers age (Brault, 2012; Burns & Gordon, 2010; Chen & Sloan, 2015; Lee, 2010; Talih & Huang, 2016; Ward et al., 2016). Appropriate health care for people with disabilities is needed now and in the future, and must be addressed (Krahn et al., 2015). Therefore, input from AWPB was essential for gaining insight on accessing physical environments in health clinics, care provider attitudes, and care provider knowledge about disability. It was also important to know what care providers are providing in health clinics. Findings from care provider surveys could

help AWPB to understand provider perspectives, as well as help providers and educators to understand problems with AWPB accessing clinics.

This research project involved two different participant groups: AWPB and care providers. Perceptual data from both groups were collected and examined based on health clinic accessibility. Categorical areas of the clinic environment to study were chosen because this investigator observed AWPB in the literature, who reported problems with clinic physical environments also reported negative attitudes towards disability and providers that did not understand their care needs. Therefore, further exploration of environmental factors in clinics and ideas for improving health clinic environments was warranted. Findings can inform health and educational leaders of clinic accessibility reported by both groups, which has the potential to transform clinic environments by using genuine input from physically disabled consumers. In a health system which is predicted to experience high demands for disability services in the near future, an inclusive approach with AWPB was necessary for portraying a realistic account of what they experience in health clinics.

### **Research Questions**

This research project was designed with the intent to answer the following questions regarding accessibility in health clinics:

RQ 1. What is the experience of AWPB in health clinics regarding access to care that pertain to physical environments, attitudes, and disability knowledge?

RQ 2. What do health care providers say they are providing in their clinics regarding care for AWPB that pertain to physical environments, attitudes, and disability knowledge?

The research questions are directly linked to the problem and purpose of this study.

## Significance of the Study

As trends in disability prevalence increase, so will the need for disability-related health services. One-in-five adults have a disability, except for the Southeast United States where disability prevalence is even higher, in which one-in-three adults are disabled (CDC, 2015c). This representation denotes the importance to provide proper health care supports to a growing population who are already on the margins of society because of disability. Moreover, barriers to accessing health care services can negatively influence people from reaching their maximum potential and therefore, lead to unmet health care-related needs (DHHS, 2014; WHO, 2015). For that reason, it is important to recognize that barriers continue to exist in health clinics as reported by people with disabilities in several studies (Drew & Short, 2010; Eisenberg et al., 2015; Iezzoni et al., 2010; Iezzoni et al., 2011; McDoom et al., 2014; Suzuki et al., 2013; Wen, 2014; Yankaskas et al., 2010).

This study could aid health care providers in adopting a better understanding of what AWPD experience in health clinics so they can enhance systems and strive for providing ample access to disability care and services by improving physical environments, attitudes, and disability knowledge. *Healthy People 2020* (DHHS, 2014) claimed that access to care can impact the prevention of disease, ability to detect health conditions, and prevent death to name a few. *Healthy People* added, to improve services also means to increase accessibility to those services, such as with preventive screening. Yet, despite ADA mandates to comply with accessible environments, people with disabilities often receive care that is substandard (Lagu et al., 2014). For example, less than 10% of health facilities reported having a height-adjustable table (Krahn et al., 2015; Lagu et al. 2013; Lagu et al., 2014). Without access to care and preventive screening, people with disabilities become vulnerable to medical issues (Drew &

Short, 2010) and die from conditions like breast cancer at higher rates than people without disabilities (Iezzoni et al., 2010; Iezzoni et al., 2011; Yankaskas et al., 2010). Clinics that adapt their physical environment to improve accommodations for people with disabilities may be better prepared to meet their health needs as well as the growing needs of the disability population.

This study also informs health care providers that negative attitudes towards disability can be another type of environmental barrier to health care (WHO, 2002). Research showed that attitudes can vary from stereotyping and stigma (CDC, 2016a; Silverman & Cohen, 2014), to insensitivity and unprofessionalism (Lee, 2010), to negative perceptions (Wen, 2014), or being verbally abusive (Suzuki et al., 2013). For example, Suzuki et al.'s study findings indicated that attitudinal barriers created tensions and hampered patient-provider relationships, and in some cases, prevented an exam all together. Then again, some persons with disabilities may not always advocate for themselves (Bloustien & Wood, 2016; Nario-Redmond & Oleson, 2015). Nario-Redmond and Oleson explained that as a way of protecting one's identity, people with disabilities might attempt to hide or downplay the significance of their disability, whereas people without disabilities may detach themselves from groups with a perceived lower status. Providers and other health professionals knowledgeable in disability care could help to act as advocates for AWPDP in improving patient-provider relationships and service modalities overall. Therefore, adding to the literature base is valuable for increasing knowledge in regards to attitudinal barriers in health care clinics.

Furthermore, this study informs the field of education by increasing awareness in the need for training in disability care for health professionals. According to the Surgeon General, 25% of AWPDP reported having problems finding care providers who understood their needs (DHHS, 2005). However, health care providers may not necessarily be trained to care for people

with disabilities. To date, accreditation agencies do not require disability knowledge and therefore only 25% of medical schools have implemented such curricula (Wen, 2014) and only 13% of public health graduate schools offered a track in disabilities (Krahn et al., 2015). In addition, the Institute of Medicine (IOM) reported that out of 1,236 physicians surveyed in the U.S., almost two-thirds reported receiving inadequate training in chronic skills (p. 130), which is pertinent for the care of people with disabilities (p. 132). Disability knowledge is particularly vital for health care providers so they can identify how to serve and accommodate AWPDP during health clinic visits, such as with preventive screening services (WHO, 2015), assessing equipment needs, and implementing strategies that boost the potentials of their patients (IOM, 2007, p. 132). Otherwise, lack of provider training in disability care could act as a barrier to obtaining certain health services in clinic environments. Findings in this study inform health and educational leaders of the need to include disability-related curricula for health professionals.

Finally, this study lends importance to including AWPDP in research and development. In addition to researchers and federal agencies calling for the inclusion of people with disabilities in research, health policy, and programs (Krahn et al., 2015; WHO, 2015), physicians are also called to include this population in curriculum development (Wen, 2014). Moreover, people with disabilities want their voices to be heard (Mertens, 2009, p. 3). Inclusion in structural design, disability curricula, and disability-related health research is essential for incorporating insights by AWPDP for AWPDP. A transformative approach not only seeks to include the perspective of marginalized groups; their ideas and values could also be useful for the general public (Mertens, 1999). Thus, involvement of AWPDP in community domains, such as health care and education has the potential for including disability-centered outcomes.

In summary, health care environments that are knowledgeable in disability needs, work to eliminate structural and attitudinal barriers, and promote inclusion practices might be better prepared for increasing the quality and accessibility of services for AWPDP in health clinics. However, the peer reviewed literature was deficient in studies examining the accessibility of health clinic environments from the perspective of health care providers. This study was needed to: (1) examine health clinic experiences of AWPDP in regards to accessing physical environments, care provider attitudes, and provider disability knowledge; (2) examine provider perceptions of accessibility in their health clinics regarding physical environments, attitudes, and disability knowledge when providing care for AWPDP; and (3) provide evidence for health and education communities that call for disability curricula in health professional education.

### **Definition of Terms**

#### *Accessibility*

Accessibility is the “Extent to which a consumer or user can obtain a good or service at the time it is needed” (Business Dictionary, n.d.).

#### *Activities of Daily Living (ADL)*

ADLs are the ability to get around “inside the home, getting into/out of bed, bathing, dressing, eating, or toileting” (Brault, 2012, p. 9).

#### *Attitudinal Barriers*

The term attitudinal used in this research project encompasses negative attitudes, stereotype, stigma, prejudice, and discrimination associated with disability. Examples of attitudinal barriers as described by the CDC (2016a) are:

- Stereotyping: People sometimes stereotype those with disabilities, assuming their quality of life is poor or that they are unhealthy because of their impairments.

- Stigma, prejudice, and discrimination: Within society, these attitudes may come from people's ideas related to disability- People may see disability as a personal tragedy, as something that needs to be cured or prevented, as a punishment for wrongdoing, or as an indication of the lack of ability to behave as expected in society. (para. 2)

### *Co-Morbid Conditions*

Co-morbid conditions occur in addition to (and are unrelated to) a primary health condition associated with disability. For example the prevalence of diabetes in people with schizophrenia is around 15% compared to a rate of 2-3% for the general population. (WHO, 2015, para. 9).

### *Disability*

Disability is an “umbrella term for impairments, activity limitations and participation restrictions” (Brault, 2012, p. 70; WHO, 2002, p. 2; WHO, 2015, para. 2). Furthermore, “Disability is the interaction between individuals with a health condition (e.g. cerebral palsy, Down syndrome and depression) and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social supports)” (WHO, 2015, para. 2).

### *Disability Inclusion*

The CDC (2016b) wrote:

Disability inclusion means understanding the relationship between the way people function and how they participate in society, and making sure everybody has the same opportunities to participate in every aspect of life to the best of their abilities and desires. (para. 9)



### *Disability Knowledge*

Disability knowledge refers to care providers having knowledge and understandings about people with disabilities (CDC, 2016a). In addition, the WHO (2015) wrote:

People with disabilities were more than twice as likely to report finding health care provider skills inadequate to meet their needs, four times more likely to report being treated badly and nearly three times more likely to report being denied care. (para. 17)

### *Durable Medical Equipment (DME)*

“Certain medical equipment, like a walker, wheelchair, or hospital bed, that’s ordered by your doctor for use in the home” (Medicare.gov, n.d.).

### *Environmental Factor*

Environmental factors include “social attitudes, architectural characteristics, legal and social structures, as well as climate, terrain and so forth” (WHO, 2002, p. 10). The most common barriers in the environment to disability are related to negative attitudes, communication, physical environment, policy compliance, programmatic (disability knowledge), social, and transportation (CDC, 2016a).

### *Facility*

Facility is defined as “all or any portion of buildings, structures, sites, complexes, equipment, rolling stock or other conveyances, roads, walks, passageways, parking lots, or other real or personal property, including the site where the building, property, structure, or equipment is located” (DOJ, 2010, p. 31).

### *Functioning*

Functioning is referred as “all body functions, activities and participation” (WHO, 2002, p. 2). This research project mostly associates functioning with mobility, activities, and participation.

### *Impairment*

“Impairments are problems in body function or structure such as a significant deviation or loss” (WHO, 2002, p. 10).

### *Inequality*

Inequality is defined as “differences that can be measureable and observable” (Lee, 2010, p. 18)

### *Inequity*

Inequity is defined as “differences that are unnecessary, avoidable, unfair, and unjust” (Lee, 2010, p. 18).

### *Instrumental Activities of Daily Living (IADL)*

IADLs are the ability to get around “outside the home, managing money, preparing meals, doing housework, taking prescription medication, and using the phone” (Brault, 2012, p. 9).

### *Major Life Activities*

These pertain to “functions such as caring for one’s self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working” (DOJ, pp. 30-31). The ADA (1991b) included additional major life activities such as, “eating, sleeping, standing, lifting, bending, reading, concentrating, thinking, and communicating” (p. 7219).

### *Mobility*

Mobility is “moving and maintaining body positions, handling and moving objects, moving around in the environment, moving around using transportation” (CDC, 2015b, para. 11).

### *Participation*

Participation is defined as “involvement in a life situation” (WHO, 2002, p. 10).

### *Physical Barriers*

Physical barriers are described as “structural obstacles in natural or manmade environments that prevent or block mobility (moving around in the environment) or access” (CDC, 2016a, para. 7).

Examples of physical barriers as described by the CDC are:

- Steps and curbs that block a person with mobility impairment from entering a building or using a sidewalk;
- Mammography equipment that requires a woman with mobility impairment to stand; and
- Absence of a weight scale that accommodates wheelchairs or others who have difficulty stepping up. (para. 7)

### *Physical Disability*

“Conditions that substantially limit one of more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying” (U.S. Census Bureau, 2014, para. 2).

### *Physical Environment*

Accessible features in a clinic exam room allow patients with mobility disabilities to enter and maneuver around, including use of medical equipment (ADA, 2010). The ADA provides examples, including routes accessible to the exam room and within the room; accessible entry door; accessible medical equipment such as exam tables and chairs, patient lifts, scales, radiologic and mammography equipment, and adequate staff training to operate the equipment.

### *Program or Activity*

These terms cover multiple operational aspects and therefore, this research project will only refer to program or activity as a business engaged in “providing education, health care, housing, social services, or parks and recreation” (United States Department of Labor, n.d., para. b ii).

### *Secondary Condition*

“Secondary conditions occur in addition to (and are related to) a primary health condition, and are both predictable and therefore preventable” (WHO, 2015, para. 8).

### *Stereotype Threat*

“A concern that one could be viewed negatively in light of stereotypes about one’s group” (Silverman & Cohen, 2014, p. 1).

## **Assumptions and Limitations**

Many AWPDP may have encountered barriers in health clinics because of limitations in the environment (CDC, 2016b; Krahn et al., 2015). However, each individual is unique physically, mentally, socially, and spiritually, which also plays a role in how these characteristics interact with their disability. Therefore, it was not feasible to study or predict all barriers with accessibility in health clinics as it pertained to each of their personal experiences and perspectives. As for care providers and the vast number of health clinics and wide range of clinic types in Minnesota, not all were surveyed and clinic type was systematically selected. Systematic sampling included all clinic types despite the span of environmental factors associated with that particular clinic, e.g., orthopedic, psychiatry, dental, primary care clinic, and so on. Fear of retaliation or disclosing information that might be perceived as sensitive in nature was anticipated by this investigator. Attempts for reassurance were given in writing to AWPDP and care providers explaining the safeguards in place to protect their privacy and confidentiality.

There are also assumptions in regards to a mixed methods transformative framework: the presence of ethical issues with inclusion, the need to build trust and make goals transparent with the community of interest, and encouraging the use of study findings to improve human rights (Mertens, 2009, p. 5). This investigator was alert to these factors throughout the study.

## **Nature of the Study**

This mixed methods study used transformative theory framework to integrate genuine input from AWPDP into the development of a provider survey that collected data on care provider perspectives of accessibility in health clinics and the care they provide for AWPDP. A transformative paradigm centers on the lives and experiences of underrepresented groups, such as persons with disabilities (Mertens, 1999). In addition, Creswell (2014) advised using “an advocacy lens” in a transformative mixed methods study by involving AWPDP in research (p. 73). Other elements of this approach was included in a questionnaire which meant to empower AWPDP, such as providing ideas for improvements that advocate for change in health clinics. These data could benefit the disability community, according to Creswell.

For that reason, a qualitative research design was used to explore AWPDP experiences in health clinics regarding accessing the physical environment, care provider attitudes, and providers’ disability knowledge. During focus group sessions with AWPDP, their experiences aided in developing a survey tool for care providers asking what they are providing in their clinics regarding care for AWPDP; specifically with physical environments, attitudes, and disability knowledge. Care provider responses were collected and examined using a quantitative research design. A nominal measure of statistical analysis was utilized to measure frequencies of reported items of accessibility from both groups. A descriptive statistics approach summarized data so they could be comprehended by the reader without difficulty (Patten, 2014, p. 113). Moreover, this research was nonexperimental and did not infer causality from responses by either group, namely AWPDP and care providers. No direct comparisons were made between groups in this study. Findings from care provider surveys could help contribute to the body of literature regarding provider perceptions of accessibility in health clinics. This study also shows

readers that findings are applicable to educational leaders regarding potential gaps in education and the need for disability-related curricula for health professionals.

### **Organization of the Remainder of the Study**

1. Chapter Two provides a review of disability-related literature that discusses disability mandates, environmental barriers (physical, attitudinal, and disability knowledge) to physical disability in health clinics, provider perceptions of barriers, and transformative theory as it relates to inclusion of people with disabilities in research.
2. Chapter Three presents methodology of this mixed methods study: theoretical framework, limitations of methodology, field test of instrumentation, and ethical considerations.
3. Chapter Four presents results from focus group discussions and care provider surveys.
4. Chapter Five offers an overview of the study, discussion, conclusions, implications, and also provides recommendations for health practitioners and educational leaders.

## Chapter Two: Review of Literature

### Introduction

Empirical research revealed a surge of studies in 2010 relating to the structural environments of health facilities before sharply dropping off. There is a renewal of interest in this area, perhaps because the population is aging and acquiring more disabilities. The current research showed a modest number of studies identifying physical, attitudinal, and knowledge barriers to health care for AWPB. Yet, only two studies represented the perspective of health care providers and health clinic accessibility (Bachman et al., 2006; McDoom et al., 2014). In addition, two studies tested the relationship between human contact and disability bias (Crowson & Brandes, 2014; Pruett, Lee, Chan, Wang, & Lane, 2008). Lastly, the literature had scant offerings of recent studies in regards to transformative theory and disability (Mertens, 1999); however, there were authors who made reference to inequities in health care (Horner-Johnson et al., 2014; Krahn et al., 2015; Lee, 2010; Wang, 2010; Wen, 2014; Yankaskas et al., 2010).

The current research presented in this literature review revealed evidence supportive to the problem of accessing care in health clinic environments, mostly from the perspective of people with physical disabilities. Environmental factors include the physical environment, attitudes towards people with disabilities, and disability knowledge to name a few (CDC, 2016a; WHO, 2001). Environmental factors can be barriers and impede access to care (Lagu et al., 2014; WHO, 2001, p. 219). The WHO (2015) explained that “People with disabilities have less access to health care services and therefore experience unmet health care needs” (para. 1). Problems accessing care can have negative outcomes on the health of individuals and become more costly if medical conditions worsen (Valderas et al., 2016). The current research also showed that including people with disabilities in research is essential for improving their health

outcomes (Rios et al., 2016). Review of the literature demonstrated that other researchers supported the inclusion of people with disabilities in research. However, there was a gap in the literature examining care provider perspectives about clinic accessibility, as well as AWPD perspectives on disability knowledge vital for providers to know. The results of this current study helps contribute to the body of literature regarding provider perceptions of accessibility in health clinics and informs educational leaders about disability-related curricula considerations.

The review of the literature for this study was intended to identify central issues relevant to physically disabled adults and access to health clinics. Mainly, literature regarding AWPD and care provider reports of access to care with physical environments, attitudes, and disability knowledge was examined. The literature review included: (1) regulatory mandates by the Americans with Disabilities Act of 1990 and Section 504 of the Rehabilitation Act of 1973 regarding access to public entities and prohibiting discrimination; (2) environmental barriers for AWPD, care provider attitudes towards disability, and care provider knowledge about disability; (3) care provider perceptions of access to health care; and (4) transformative theory and inclusion of people with disabilities in research, evaluation, development, and implementation.

### **Overview of ADA and Section 504 of the Rehabilitation Act of 1973**

The Americans with Disabilities Act of 1990 was enacted due to findings that persons with disabilities were discriminated against in places of “employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services” (ADA, 1991a, p. 7218). The ADA reported that unfair practices denied persons with disabilities the same opportunities that able-bodied individuals enjoyed. As a result, the U.S. spent billions on dependency-related and productivity issues (ADA, 1991a).

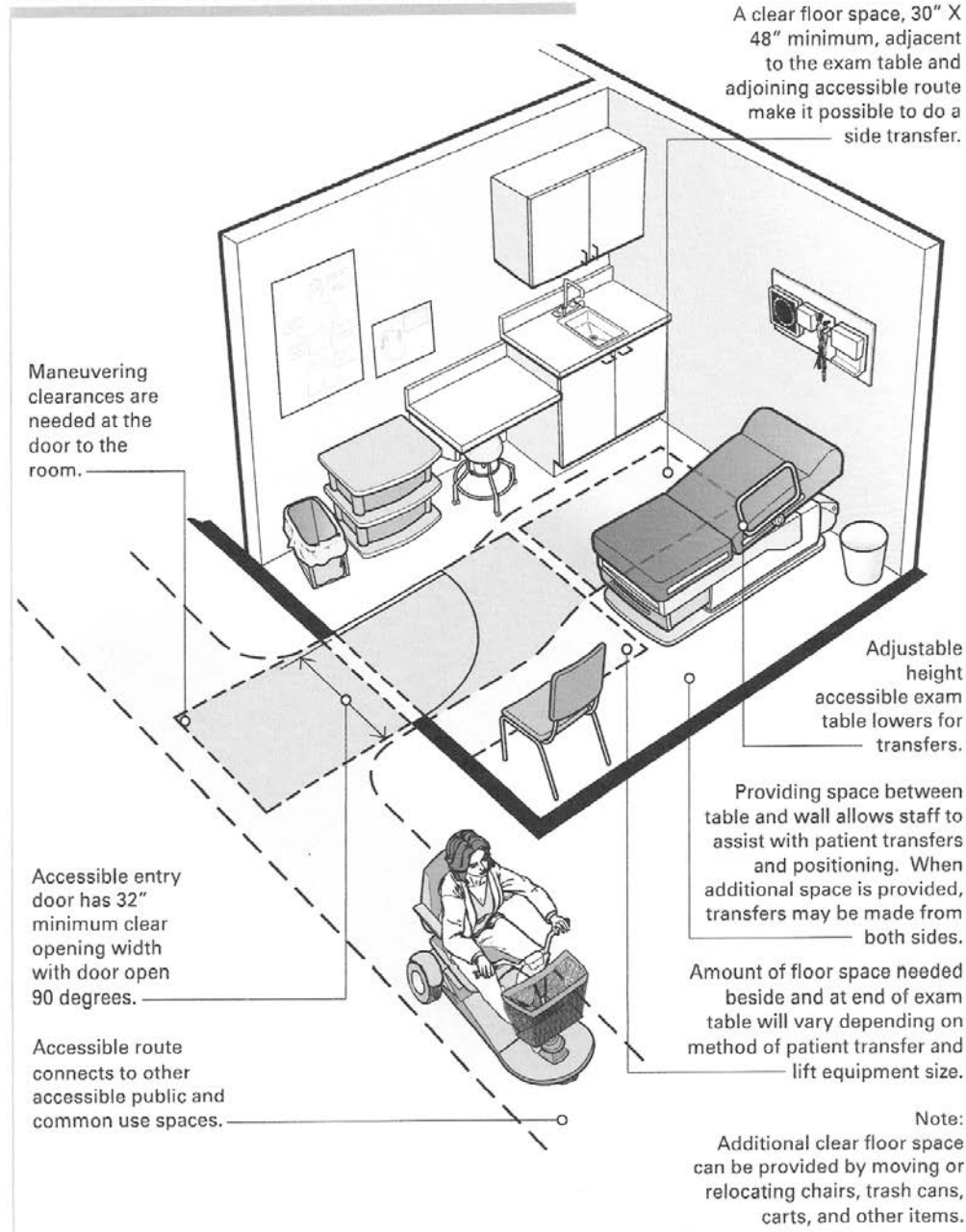


Exactly one year after the initial signing of the ADA on July 26, 1990, the ADA published Standards for Accessible Design and the Access Board published the Americans with Disabilities Act Accessibility Guidelines (ADAAG) (Department of Justice [DOJ], 2010). The DOJ further added the Americans with Disabilities Amendments Act of 2008, which clarified disability language. The ADA protects people with disabilities from discrimination and also calls for new construction and remodeling projects to comply with accessibility standards (DOJ, 2010). One example is the recent action taken by the Access Board. On September 14, 2016, the Access Board approved rules for information and communication technology (ICT) and historical new standards for medical diagnostic equipment (United States Access Board, personal communication, September 14, 2016). These two rules were submitted for review to the Office of Management and Budget (OMB) and must be cleared before the Access Board can publish them (United States Access Board, personal communication, October 24, 2016). According to the Access Board, review and clearance protocols is the last step in this rulemaking process, which includes several scheduled public hearings for the purpose of gathering input on how the two rules will be funded and enforced.

It is also important to note that ADA, Title II is an extension of section 504 of the Rehabilitation Act of 1973, which governs access to all activities provided by government entities whether or not they receive federal funding (DOJ, 2010, p. 2). While Title II of the ADA allows protection from discrimination in services, programs, and activities, Title III further protects people with disabilities from discrimination in public places, covering 12 business categories (p. 2). Doctors' offices fall into one of these categories. To assist health clinics in meeting accessibility, the ADA (2010) offers a guide outlining facility requirements. See Figure 1 for a graphic that shows features of an accessible examination room.

Section 504 of the Rehabilitation Act of 1973 mandated that persons with disabilities will not be discriminated against, denied benefits, or be excluded from participating in programs or activities receiving federal funding (United States Department of Labor, n.d.). This statute further described a “program or activity” as any corporation, partnership, private organization, or proprietorship that engages in providing health care. The statute also added that small providers are not expected to modify existing structures if they can supply alternative methods for providing services.

## Features of an Accessible Examination Room



*Figure 1.* Schematic graphic of an examination room setting that allows access to medical care for people that have mobility disabilities. Adapted from “Part 3: Accessible Examination Rooms” by the Americans with Disabilities Act. (2010). *Access to medical care for individuals with mobility disabilities*, p. 7. Copyright 2010 by the U.S. Department of Health and Human Services, Office for Civil Rights. Reproduction is encouraged by the ADA.

**Disability trends.** There are fundamental reasons why trends in the physically disabled population are important for the health care system. First, to understand causes in disability trends, Gu et al. (2015) explained it is necessary to also understand the conception of disability: disability usually starts with a chronic disease or illness, then leads to impairment, and then to limitations in functioning which bring about disability. Gu et al. went on to say that disability is not only a medical issue; it can be a social issue as well, in which certain factors in the environment prohibit a person from functioning. According to Gu et al., an example of disability created by factors in the social environment is the inability to access facilities and services. Studying disability that pertains to the environment in health clinics can help to inform care providers and educators about environmental barriers encountered by AWPDP.

Data on disability types and prevalence can also identify trends that help to project the need and cost for future health services (Chen & Sloan, 2015; Gu et al., 2015). For instance, Chen and Sloan (2015) explained that before long, the U.S. population of baby-boomers will be larger than all other populations. Gu et al. (2015) added the incidence of older adults with activities of daily living (ADL) limitations in the U.S. is expected to double by the year 2030. Furthermore, costs in healthcare related to ADL disability is currently about \$43 billion annually and could rise as high as \$87 billion in 2030. Gu et al. claimed that one-quarter of America's gross domestic product (GDP) will go to Medicare and Medicaid in 2080 if disability prevalence remains at a steady rate. Yet, a reduction in disability prevalence of just 1.5% annually could mean a savings of up to 14% of the GDP. Therefore, Gu et al. commented on the importance of focusing on improving disability trends such as these because the vast number of aging adults are predicted to produce even greater rates of severe disability in the future.

To build on the importance of disability trends, Chen and Sloan (2015) conducted a quantitative study in attempts to examine disability trends in near-elderly and elderly people. Using descriptive statistics and decomposition analysis, Chen and Sloan analyzed data from the Health and Retirement Study survey between the years 1996-2010 for the purpose of estimating contributors of changes in population demographics, chronic disease, and health behaviors. Trends in the disabling effects of these factors were also measured. Moreover, Chen and Sloan noted these measures are precursors of limitations in activities of daily living (ADL) and independent activities of daily living (IADL). Findings from Chen and Sloan showed rates of disability increasing for near-elderly people (from 55.91 in 1996 to 56.45 in 2010), and disability rates remaining stable in the elderly population (from 85.08 in 1996 to 85.26 in 2010). Surprisingly, overall ADL limitations declined in persons aged 83-88 (from 1.00 in 1996 to 0.87 in 2010) and significantly increased in persons aged 53-58 (from 0.19 in 1996 to 0.23 in 2010). Yet, lower body functioning for all ages between 53-88, showed significant increases in limitations with large muscle, gross motor function, and mobility categories. Chen and Sloan commented that lower body limitations also puts older people at risk for falls.

Another remarkable finding by Chen and Sloan (2015) was that obesity (health behavior) significantly increased for all ages from 1996 to 2010: ages 53-58 (0.26 to 0.38), 59-64 (0.24 to 0.38), 65-70 (0.20 to 0.36), 71-76 (0.16 to 0.31), 77-82 (0.13 to 0.25), and 83-88 (0.09 to 0.15). Chen and Sloan charged the increase in obesity rates as dramatic and was a leading contributor to decreased lower body functioning as well as arthritis. In fact, hip and knee replacement surgeries nearly doubled every year between the years 1990-2002, mostly due to arthritis. For this reason, Chen and Sloan anticipated higher demands for hip and knee surgeries in the future.

Trends such as this can aid health care and other officials in predicting and strategizing services such as rehabilitative therapy, in preparation for the wave of near-elderly and elderly needs.

This is consistent with findings from Gu et al. (2015) who cited several studies that showed physical therapy improved physical functioning in older adults. Gu et al conducted an exhaustive review of the literature for the purpose of studying disability trends, the causes of disability trends, and their consequences. Furthermore, Gu et al. proposed a framework for studying disability trends to better capture predictors of disability which included components of: a person's environment; behaviors and resources; disease, impairment, functional limitations, disability, and disability trends; interventions and technologies; and socioeconomic and ecological consequences. For example, behaviors such as lack of exercise, smoking, and obesity are risk factors linked to disability. In fact, Gu et al. found that obesity increased from 22% in Americans in 1988 to 38% in 2010. Similar to Chen and Sloan's (2015) findings, Gu et al. (2015) remarked that the trend in increased obesity posed concerns regarding physical functioning in the aging population.

However, interventions such as healthy diet and exercise can change risky health behaviors and are critical for reducing chronic conditions and disability, wrote Gu et al. (2015). In addition, Gu et al. revealed interventions such as physical therapy improved ADL and IADL function and therefore reduced ADL disability by up to 16% and IADL disability by roughly 18%. Moreover, Gu et al. found that people who had a higher socioeconomic status also had better physical functioning due to having exposure to health knowledge, social supports, and access to healthcare to name a few. Interestingly, education was the most attributed factor for improvements in late-life functioning; e.g., people with less than a high school graduation declined from an astonishing 72% in 1970 to 20.5% in 2010. Therefore, interventions supported

by the literature in Gu et al.'s study that helped improve physical functioning are known to reduce disease and impairments, and thus have a positive influence on disability trends.

**Disability terminology.** There are slight variations among government agencies for defining disability. Although the World Health Organization (WHO) offered the conceptual model of International Classification of Functioning, Disability and Health (ICF) to present standardized language for health and disability, it is slow in being integrated into tools that measure disability. For example, the ICF defined disability as an “umbrella term for impairments, activity limitations and participation restrictions” (Brault, 2012, p. 70; WHO, 2002, p. 2; WHO, 2015, para. 2). In another example, the CDC (2015b) stated “disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions)” (para. 1). A third example is the ADA (1991b) defined disability as “(A) a physical or mental impairment that substantially limits one or more major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment” (p. 7219). The ADA further described major life activities in general as “caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working” (p. 7219).

Krahn et al. (2015) revealed that just one decade ago there were at least 67 federal definitions for disability. Having uniform disability language bears importance for several reasons. For instance, Krahn et al. explained that a standardized definition for disability would be valuable for medical coding purposes, determining qualification of programs and benefits, and also for identifying health disparities. Furthermore, uniformity would assist disability

coordinators to efficiently collaborate services with other health clinicians about individuals' needs. Another reason why uniform language is important is for comparing the health of the U.S. population over time (Brault, 2012; Krahn et al., 2015). Brault (2012) cautioned about comparing data between varying sources because of differences in criteria when defining disability. Finally, having a universal disability and health language is significant in shaping policies for lawmakers (WHO, 2002). For the sake of consistency between defined disability criteria and reported disability prevalence, this current study based its physical disability definition and criteria on the physical domain of disability as defined by the U.S. Census Bureau (Brault, 2012). These criteria were also used to determine eligibility for AWPD focus group participation in this current study.

**Physical disability.** There is a multitude of conditions that can limit a person's physical activities. People with disabilities in the physical domain were characterized by having at least one of the following as described by Brault (2012), a leading expert for the U.S. Census Bureau. Brault (2012) wrote:

1. Used a wheelchair, cane, crutches, or a walker.
2. Had difficulty walking a quarter of a mile, climbing a flight of stairs, lifting something as heavy as a 10-pound bag of groceries, grasping objects, or getting in and out of bed.
3. Listed arthritis or rheumatism, back or spine problem, broken bone or fracture, cancer, cerebral palsy, diabetes, epilepsy, head or spinal cord injury, heart trouble or atherosclerosis, hernia or rupture, high blood pressure, kidney problems, lung or respiratory problem, missing limbs, paralysis, stiffness or deformity of limbs, stomach / digestive problems, stroke, thyroid problem, or tumor / cyst / growth as a condition contributing to a reported activity limitation. (p. 71)



Brault further explained disability has two levels of severity: non-severe and severe. A disability was classified as severe if personal assistance was needed with functioning associated with a particular disability. It is important to note that persons with a severe disability may also need assistance while at a health clinic (see Table 1 for Disability Prevalence and Needing Assist).

Table 1

*Disability Prevalence and Needing Assist*

| Age         | Any Disability % | Severe Disability % | Needing Assist % |
|-------------|------------------|---------------------|------------------|
| Under 15    | 8.4              | 4.2                 | 0.5              |
| 15 to 24    | 10.2             | 5.3                 | 1.4              |
| 25 to 44    | 11.0             | 7.3                 | 2.0              |
| 45 to 54    | 19.7             | 13.8                | 3.6              |
| 55 to 64    | 28.7             | 20.4                | 6.0              |
| 65 to 69    | 35.0             | 24.7                | 6.9              |
| 70 to 74    | 42.6             | 29.6                | 10.8             |
| 75 to 79    | 53.6             | 37.5                | 15.4             |
| 80 and over | 70.5             | 55.8                | 30.2             |

Adapted from the U.S. Census Bureau (2010).

**Secondary conditions.** Because AWPD typically have poorer health and tend to be inactive (DHHS, 2005; Eisenberg, et al., 2015; Wen, 2014), they are at risk for secondary conditions and co-morbidities (WHO, 2015). Secondary conditions are related to a primary health condition, are predictable, and thus can be prevented (CDC, 2015c; WHO, 2015). Common examples include pain, fatigue (Martin, 2013; Suzuki et al., 2013), obesity (Chen & Sloan, 2015; Gu et al., 2015; Martin, 2013; Rios et al., 2016; Wen, 2014), pressure-related wounds, urinary tract infections, and osteoporosis (WHO, 2015). Therefore, it is important for care providers to be knowledgeable in recognizing, treating, and preventing secondary conditions in AWPD. Without adequate access to health clinics and preventive services, AWPD become vulnerable to health problems (Drew & Short, 2010).

As disease leads to disability, disability can then lead to secondary conditions which may become chronic (Iezzoni, 2010; Rios et al., 2016). According to Iezzoni (2010), the three biggest causes of disability are chronic conditions, arthritis and back problems, and heart problems. However, health care needs of disabled populations are not always addressed adequately. In a literature review conducted by Iezzoni, goals were aimed at considering multiple chronic conditions (MCC) and disabilities in research, evaluating the quality of care, and developing performance measures to inform health care in regards to MCC or disability. Iezzoni explained that chronic conditions and disability increase with age. For example, 16.5% of people age 0-19 had one MCC, 3.7% had two MCC, and 1.2% had three MCC.

By contrast, 20.2% of people age 65-79 had one MCC, 21.5% had two MCC, and 45.3% had three or more MCC (Iezzoni, 2010). Yet, there is limited evidence-based information to steer treatment decisions because people with MCC and disabilities have generally been excluded from clinical trials, wrote Iezzoni. Furthermore, respective research studies rely on accurate data sources about MCC and disabilities. For that reason, Iezzoni called for improved health information technologies in gathering data that will help diagnose, treat, and measure effectiveness of care for people with MCC and disability. In turn, care providers will have availability of evidenced-based information and thus, gain knowledge in disability-related care.

***Co-morbidities.*** Co-morbidities are additional conditions not related to a primary health condition, yet linked with disability, such as diabetes and a psychiatric disability (WHO, 2015). Still, co-morbidities can develop due to other existing health conditions that have worsened or became chronic, effects of medical treatments (Valderas et al., 2009), or changes in mobility (Ward et al., 2016). Valderas et al. (2009) wrote one person can have many co-morbidities (also called co-occurring diseases), which become difficult to manage and have significant

implications on health-related outcomes. Outcomes noted by Valderas et al. included quality of life issues, quality of health care, increased care costs, effects on personal functioning, and death.

Valderas et al. (2009) set out to review the literature on the concept of co-morbidity and its implications for clinical care. Searching 25,000 records on the term co-morbidity, Valderas et al. found varying definitions in the literature, all stemming from the core concept of an individual having more than one medical condition. Strikingly, 80% of Medicare costs in the U.S. were spent on patients with four or more chronic conditions. Co-morbidities become even more challenging for health care professionals to manage patient care when disease factors interrelate with socioeconomic, environmental, and other factors. Thus, AWPD with multiple conditions or co-morbidities not only necessitate more intensive health resources, care providers need to be knowledgeable in the concept of co-morbidity and its inference for care.

***Accessibility.*** Accessibility is the “Extent to which a consumer or user can obtain a good or service at the time it is needed” (Business Dictionary, n.d.). The Surgeon General remarked that accessibility was one of the challenges people with disabilities encountered (DHHS, 2005). For that reason, the Surgeon General called to health care professionals to improve health and wellness for persons with disabilities. It was suggested to use an *Access Checklist* to ensure accessibility to parking, doorways, service areas, countertops, restrooms, and so on (p. 11). Being able to access health care clinics and utilize services are central, yet critical aspects of care for AWPD. The Surgeon General remarked that “People with disabilities must be able to get the care and services they need to help them be healthy” (p. 10). Yet, there are environmental factors that may facilitate or hinder accessibility of a resource (WHO, 2001). Therefore, to address accessibility as it pertains to environmental factors, this current study asked AWPD to describe their experiences when visiting a health clinic.

## **Environmental Factors and Barriers to Disability**

The extent to which an environmental factor acts as a facilitator or barrier comes “from the perspective of the person whose situation is being described” (WHO, 2001, p. 219). For instance, the WHO explained that curb cuts may be a facilitator for a person using a wheelchair, but act as a barrier to someone who is blind. Therefore, the environment can be “understood as involvement in a life situation or the lived experience of people in the actual context in which they live” (p. 214). This helps validate why including AWPD in research is important for an authentic representation of what they experience in health clinics. It seems environmental factors that facilitate or hinder access to care would be described best from the perspective of the person experiencing them and may differ, depending on the person’s situation. Furthermore, the WHO (2001) wrote:

It should also be kept in mind that an environmental factor can be a barrier either because of its presence (for example, negative attitudes towards people with disabilities) or its absence (for example, the unavailability of a needed service). (p. 219)

AWPD reported a variety of challenges when accessing health clinic facilities. Yet, there are multiple factors encompassing one’s environment besides gaining entry into a health clinic. Since the WHO’s guidelines for ICF has as a standard for disability language and is used by the U.S. Census Bureau, the ADA, and the CDC, it was applied to this research project as well. The ICF views *environmental* as pertaining to physical aspects in the environment, attitudinal, and social factors (WHO, 2002). Furthermore, the CDC (2016a) reported the most common barriers in the environment to disability are related to negative attitudes, communication, physical environment, policy compliance, programmatic (disability knowledge), social, and

transportation. Due to the large volume of environmental factors, this current study limited its environmental focus to physical environments, attitudes, and disability knowledge.

In a modest number of studies, AWPD consistently reported encountering more than one environmental barrier in health clinics. Many study participants who reported problematic experiences with the physical environment also reported attitudinal barriers and providers lacking in disability knowledge. Barriers in the environment impede the route to care (Lagu et al., 2014). Table 2 below demonstrates a compilation of current scholarly studies and their reported barriers in health clinics.

Table 2

*Studies Reporting Barriers in Health Clinics*

| Author(s) and Year      | Physical Barriers | Attitudinal | Disability Knowledge | *Other |
|-------------------------|-------------------|-------------|----------------------|--------|
| Bachman et al. (2006)   | √                 | √           | √                    | √      |
| Drew & Short (2010)     | √                 |             |                      | √      |
| Eisenberg et al. (2015) | √                 |             |                      |        |
| Hutch et al. (2011)     | √                 |             |                      | √      |
| Iezzoni et al. (2010)   | √                 | √           |                      |        |
| Iezzoni et al. (2011)   | √                 |             | √                    |        |
| Krahn et al. (2015)     | √                 |             |                      |        |
| Lagu et al. (2013)      | √                 |             | √                    |        |
| Lagu et al. (2014)      | √                 | √           |                      | √      |
| Lee (2010)              | √                 | √           | √                    | √      |
| McDoom et al. (2014)    | √                 | √           | √                    | √      |
| Suzuki et al. (2013)    | √                 | √           | √                    | √      |
| Wen (2014)              |                   | √           | √                    |        |
| Yankaskas et al. (2010) | √                 |             |                      | √      |

\*Other: medical insurance, co-pays, cultural, transportation, communication, or time constraints.

**Physical environment.** According to the CDC (2015c), one-in-eight adults have a mobility disability. This statistic is disturbing, especially if there are health clinic environments ill-prepared to accommodate physical access for AWPD. Physically accessible clinic environments means being free of physical barriers and allow access to doorways, examination tables, and weight scales to name a few (Lagu et al., 2014). Accessibility in clinics also includes

having access to medical equipment (United States Access Board, 2013). In contrast, Hutch, Bouye, Skillen, Lee, Whitehead, and Rashid (2011) reported that poorly designed built environments exacerbated health disparities and negative health outcomes. Hence, inability to properly access a clinic's physical environment can be a physical barrier to care for AWPDP (Lagu et al., 2014). Several studies reported AWPDP having difficulty getting through the clinic entrance (Eisenberg et al., 2015; Iezzoni et al., 2010; Lee, 2010), inability mounting exam tables (Drew & Short, 2010; Iezzoni et al., 2010; Iezzoni et al., 2011; Krahn et al., 2015; Lagu et al., 2013; Suzuki et al., 2013), not having accessible equipment (Lagu et al., 2014; McDoom et al., 2014; Yankaskas et al., 2010), or not being able to obtain a weight during their clinic visit (Iezzoni et al., 2010; Krahn et al., 2015). Yet, Bachman et al. (2006) argued that many health providers perceived they adequately accommodated AWPDP in their clinics. Consequently, there are discrepancies between what AWPDP and health care providers are reporting.

For example, the built environment was found to be a barrier to health care delivery in a study by Drew and Short (2010). Using data from National Health Interview Surveys, Drew and Short investigated the relationship between disability and obtaining a Pap smear among 20,907 women with and without disabilities. From this sample, 18% reported being disabled and 37% of these had mobility limitations. Multivariate findings showed that women with mobility limitations received Pap smears 35% less often than women without disabilities (0.7). Drew and Short suggested this finding is consistent with other studies arguing that environmental barriers are crucial for delivering care for people with disabilities. Without this recommended screening, Drew and Short wrote that women are at risk for developing cervical cancer.

In comparison, Iezzoni et al. (2010) conducted 20 interviews with women in nine states who had mobility impairments and diagnosed with breast cancer. Findings revealed physical

barriers in health facilities throughout their course of treatment. Participants identified problems, such as accessing mammogram equipment, exam tables, weigh scales, and entering the clinic door. For instance, one woman reported “hanging onto the machine” during a mammography exam, while another woman reported “I stand up and use one crutch and just lean” (p. 713). In addition, some participants remarked their clinics did not have exam tables that lowered for easy transfers. In these cases, women were examined in their wheelchair making them feel like they received “poor-quality care” (p. 714).

Another critical piece of clinic equipment described by Iezzoni et al. (2010) was weigh scales that were inaccessible. This is especially important because an accurate weight is needed to determine chemotherapy dosages. One woman reported her oncologist holding her in his arms to obtain a weight. This poses safety concerns for both clinic staff and patients, according to Iezzoni et al. Nonetheless, these barriers added tension to circumstances which were already stressful because of their cancer. Iezzoni et al. suggested solutions such as investing in accessible equipment could eliminate some of these physical barriers.

Iezzoni et al. (2011) set out again to interview another 20 women with mobility impairments and diagnosed with breast cancer. This time, the researchers wanted to learn how difficulties with mobility affected women’s course of cancer treatment. Findings not only showed that inaccessible equipment was the chief problem when receiving a mammogram, cancer treatments worsened mobility in some participants as well. Conversely, women’s mobility issues may have dictated the direction of treatment. One consideration was surgical treatment might affect arm mobility and the use of ambulation devices or propelling a wheelchair. Iezzoni et al. wrote seven of the interviewees based treatment decisions solely on concerns of arm mobility. For example, a left-handed woman had surgery on her left side

leaving her unable to use her walker and therefore resorted to using a wheelchair on a permanent basis. Another woman who used a scooter said “To have my left arm not usable would be a disaster for me” (p. 47). Because the prevalence of disability is expected to grow in the near future with baby boomers, Iezzoni et al. predicted rates of women with breast cancer and mobility impairments will also grow. Thus, recommendations were focused on installing accessible mammography equipment, adjustable exam tables, and also assessing mobility and other ADL needs prior to surgery.

Another study which found barriers in the environment was conducted by Eisenberg et al. (2015). In this mixed methods study, Eisenberg et al. performed a pilot test of the Community Health Inclusion Index (CHII) tool to identify barriers and facilitators in community settings. People with disabilities and professionals who work with people with disabilities were included in the development and testing of the CHII, which is also relevant to this writer’s study due to the nature of its inclusive approach with AWPDP. Five key areas were examined including the built environment, equipment, programs and services, staff, and policies at 164 sites; 32 of which were health facilities comprised of 22 health clinics and 10 hospitals. Data were collected through 20 focus groups and items analyzed using Cronbach’s alpha ranging from 0.700 to 0.965 by an expert panel, some who had a disability. Findings for these health facilities revealed barriers in accessibility in four waiting rooms (0.790), seven exam rooms (0.700), eight exam room’s equipment (0.759), and nine staff training (0.700). Furthermore, some sites feared repercussions from survey results and therefore declined to participate in Eisenberg et al.’s study. In those cases, Eisenberg et al. suggested accessibility was very low.

Lagu et al. (2013) also wanted to learn how people with mobility impairments accessed medical care. Lagu et al. commented that over three million adults in the U.S. use a wheelchair



for mobility so care providers must accommodate access to their care facilities under provisions by the ADA. Interestingly, these researchers used a deceptive technique to conduct their survey in attempts to illustrate real-life scenarios people with mobility difficulties encounter when scheduling medical appointments. From 256 practices in four states, subspecialties were randomly selected in five large cities. Lagu et al. found 56 (22%) of the practices surveyed could not accommodate their fictional, obese, wheelchair-bound patient in their health clinics. Reasons of inaccessibility included one or more issues with the physical building, transferring out of the wheelchair, and unavailable mechanical lift or height-adjustable exam table.

Lagu et al. (2013) further wrote that subspecialties possibly requiring transferring a patient (160 practices) included endocrinology, gynecology, orthopedic surgery, rheumatology, and urology. Of these, 42 (26%) were unable to accommodate the fictional patient. Further analysis revealed that 4 (2%) of these practices had an inaccessible building, 38 (24%) were unable to transfer the patient, and 88 (55%) planned on manually transferring the patient to a non-adjustable exam table. Only 14% of practices reported using a height-adjustable exam table or mechanical lift for transferring. More surprisingly, findings of practices unable to transfer the patient were: endocrinology 4 (13%), gynecology 13 (41%), orthopedic surgery 8 (25%), rheumatology 6 (19%), and urology 7 (22%). Furthermore, these practices would not examine the patient while in his wheelchair, with the exception of endocrinology where 8 (25%) would.

On the contrary, Lagu et al. (2013) showed there were 96 practices in three subspecialties that may not require transferring a patient including ophthalmology, otolaryngology, and psychiatry. Findings demonstrated that these practices could not transfer the fictional patient: ophthalmology 6 (19%), otolaryngology 3 (10%), and psychology 0 (0%). However, most would examine the patient while in his wheelchair: ophthalmology 21 (65%), otolaryngology 18

(56%), and psychiatry 28 (88%). Additionally, Lagu et al. found the issues with access were mostly associated with transferring a patient to an exam table; specifically, due to lack of equipment and clinic staff not knowledgeable in safe transfer methods of an obese patient. Consequently, Lagu et al. indicated the need to raise care provider awareness regarding ADA standards and mobility impaired patients.

There were also findings from a study showing multiple barriers, suggesting the importance in looking at several needs women with mobility limitations may have. Suzuki et al. (2013) conducted a two-part study with 47 female participants with mobility impairments and obtaining mammography exams. First, participants attended a workshop that concentrated on increasing preventive clinic services. Participants identified five barrier categories to obtaining a mammogram: patient knowledge, provider attitudes, physical environment, system barriers, and financial barriers. Participants were given assistance in locating care providers, accessible facilities, and creating six-month goals for obtaining a mammogram. Goals included scheduling a mammography appointment (55%), discussing test options with the doctor (13%), and attending an appointment that was already scheduled (7%).

The second part of Suzuki et al.'s (2013) study followed up with telephone interviews inquiring about their progress with mammogram screening. Because women had been given resources for getting a mammogram, the questions in part two focused more on health behaviors and reasons for not obtaining a mammogram. Data analysis revealed three themes: individual issues, issues with clinic systems, and negative attitudes by care providers. Using a socio-ecological framework, these themes were categorized as "*individual, interpersonal, and environmental barriers and facilitators*" (p. 713). Examples of *individual* issues reported were: other health conditions as barriers to getting their mammogram; having an infection; pain from

hip and knee surgeries; being in the hospital for fever, pneumonia, or knee surgery; not feeling well; responsibilities at home, with family, or self; other social responsibilities; death in the family; participants had insufficient knowledge about the mammography test; fear of mammography exam; and had breast implants. *Interpersonal* examples included women being unclear about provider instructions and negative experiences with providers. *Environmental* examples included: difficulty locating a primary care provider in their area, clinic was too far to travel, scheduling difficulties, were unclear about insurance coverage, and lack of funds to commute to the clinic. Some participants reported *facilitators* that would reduce barriers, such as getting a referral to a clinic closer to their home, finding a primary care provider, and having free mammography screenings.

The physical environment in health clinics is a critical environmental factor as shown by researchers for AWPB to: adequately enter a health facility and maneuver in examination rooms (Eisenberg et al., 2015), obtain preventive screenings (Drew & Short, 2010; Suzuki et al., 2013), utilize medical equipment (Iezzoni et al., 2010; Iezzoni et al., 2011), and safely transfer wheelchair-bound patients (Lagu et al., 2013). These studies indicated multiple barriers in the physical environment and the implications for AWPB. This current study asked AWPB and surveyed care providers about accessing the physical environment in health clinics, followed by an analysis of their responses.

**Attitudinal.** In addition to physical barriers, attitudinal factors are a barrier to access (Lagu et al., 2014). Several studies revealed that AWPB reported negative attitudes during a health clinic appointment. Attitudes towards people with disabilities can take several forms, some which can be harmful to relationship-building or interfere with care delivery. For example, Suzuki et al.'s (2013) qualitative study revealed findings from two women who did not obtain

mammograms because one “doctor’s attitude was abusive” (p. 715) during a past visit. The other woman reported receiving treatment options she could not understand and blamed herself for not being more assertive. As a result, Suzuki et al. claimed a number of participants reported that care provider attitudes were barriers to care.

By contrast, other studies claimed that negative attitudes did not always relate to a person’s medical condition. For example, researchers Bloustien and Wood (2016), Martin (2013), and Silverman and Cohen (2014), suggested some limits to disability were due to the psychological environment. These researchers, except for Silverman and Cohen, framed their studies using the social model of disability, deeming barriers were related to a social system and not impairment. For instance, people might stereotype individuals with disabilities by making assumptions that they have a low quality of life or are unhealthy due to their disability (CDC, 2016a). For that reason, people with physical disabilities could end up feeling inadequate in a variety of public and social settings, according to Silverman and Cohen (2014). Hence, these individuals “may worry about being seen as clumsy, incompetent, and not fully belonging” (p. 1330).

Furthermore, Silverman and Cohen (2014) found that a stereotype can develop into stereotype threat, which can limit achievement in persons with disabilities to the point where the environment is perceived as threatening. Silverman and Cohen surveyed 497 blind participants and assessed the correlation between stereotype threat and self-integrity, work achievement, challenge seeking, and well-being. All correlations were significant ( $p < .05$ ) except for threat and challenge seeking, which was ( $p = .056$ ). Significant correlations showed measures between threat and integrity ( $-.24, p < .01$ ), threat and unemployment ( $.10, p < .05$ ), threat and challenge ( $-.09, p < .06$ ), threat and satisfaction ( $-.19, p < .01$ ), and threat and stress ( $.35, p < .01$ ). Results

indicated that stereotype threat had negative effects and were “associated with higher unemployment, lower life satisfaction, higher stress, and less frequent challenge-seeking” (p. 1333). Silverman and Cohen also stated people with disabilities who perceived stereotype threat avoided public and social settings. Additionally, perceived threats could become chronic, according to Silverman and Cohen.

A second study by Silverman and Cohen (2014) examined if providing values-affirmations and supporting self-integrity encouraged learning while in a threatening environment. In this study, a controlled field experiment was conducted with 35 participating adult students from a rehabilitation center for the blind. Using computers, students were given written assignments to explain the importance of 11 values in their life such as relationships with family, friends, religion, and music (affirmation group), or explain the least important 11 values in someone else’s life (control group). Instructors were unaware of the differences in assignments, yet provided evaluations to all students one month following the intervention with a writing assignment. Findings revealed that the affirmation group advanced more in their courses (adj.  $M = .25$ ) versus the control group (adj.  $M = -.25$ ). Silverman and Cohen wrote that their findings were important for disability research and suggested values-affirmation could benefit people with disabilities in rehabilitation programs.

Findings from Silverman and Cohen (2014) were consistent with researchers Bloustien and Wood (2016), and Crowson and Brandes (2014), who also showed that study participants avoided threatening situations. Bloustien and Wood (2016) explored issues of disability identity and how participants chose to represent their disability while in a virtual world. This unique ethnographic research used a snowballing technique for recruiting participants through the online program Second Life, a 3D environment. Bloustien and Wood found that participants created

avatars capable of representing their inner-self and looking beyond their disability. This new start parse allowed participants to erase obstacles from the real world and form new online communities accepting of people with both disabilities and without. These virtual communities provided a “safe place” where people had the choice whether or not to divulge their real world identities (p. 104). In addition, people with physical disabilities found support and friendship among other avatars that also faced barriers to full participation in the real world.

Negative attitudes, stereotype towards disability, and feeling accepted in the community were important contributors of attitudinal barriers as shown by authors Bloustien and Wood (2016), Silverman and Cohen (2014), and Suzuki et al. (2013). It is important for AWPD to be supported by health care staff and feel a sense of belonging in a non-threatening clinic environment. Otherwise, AWPD might forego preventive screening or other essential health-related visits, as noted in Suzuki et al.’s study. Further research is needed to explore the relationship between negative health professionals’ attitudes and missed clinic patient appointments as it is beyond the scope of this research project. However, this current study addressed provider attitudes and asked AWPD to describe relationships with their care providers and vice versa.

***Intergroup contact.*** There were two quantitative studies that revealed findings of participants who interacted with persons with disabilities. For example, Crowson and Brandes (2014) surveyed 229 pre-service teachers, questioning how their attitudes about people with disabilities were shaped and maintained. Applying the hierarchal-based construct of social dominance orientation (SDO), Crowson and Brandes attempted to show how self-efficacy [pre-service teacher], negative stereotype, and intergroup anxiety played a role in predicting teachers’ attitudes, thus affecting inclusion of students with disabilities. Participants scoring higher on

SDO indicated a higher likelihood of stereotyping, intergroup anxiety, opposing inclusion, and lower scores in self-efficacy. By contrast, teachers scoring higher on self-efficacy had a lower probability for opposing inclusion.

Crowson and Brandes (2014) presented their correlation analysis and because higher SDO indicated higher scores of variables, only those scores are shown here: social dominance ( $M = 2.148, .429, p < .001$ ); intergroup anxiety ( $M = 3.023, .456, p < .001$ ); close contact ( $M = 1.581, -.241, p < .001$ ); self-efficacy ( $M = 5.116, -.374, p < .001$ ); opposition to inclusion ( $M = 2.237, .524, p < .001$ ); and negative stereotypes ( $M = 2.571, -p$ ). Overall, findings showed that the more contact an able-bodied person had with people with disabilities, prejudice was reduced and relations with them improved. Crowson and Brandes suggested teachers interacting with disabled persons may increase understanding about their students' needs and therefore feel more competent when working to meet those needs.

Improving relationships through increased contact with people with disabilities can also be applied to health care settings. For instance, Pruett et al. (2008) offered value from the perspective of contact as a way of reducing disability stereotype. Pruett et al. examined indexes of the Contact with Disabled Persons Scale (CDP) and added paths that improved the model to measure attitudes towards persons with disabilities. A sample of 552 post-secondary students from human service fields such as rehabilitation, nursing, special education, psychology, and counseling were randomly divided into two groups. The first group used exploratory factor analysis which generated factors of General Interpersonal Contacts, Positive Contact Experiences, and Negative Contact Experiences. The second group used confirmatory factor analysis to test validity for those three factors.

Pruett et al. (2014) categorized a total of 16 CDP survey items among the three factors; General Interpersonal Contacts, Positive Contact Experiences, and Negative Contact Experiences. CDP items were rated from *never* to *very often* on a 5-point time-frequency scale. Some examples included: (a) How often have you discussed your life or problems with a person with a disability? (b) How often have you met a person with a disability that you admire? (c) How often have you been annoyed or disturbed by the behavior of a person with a disability? (p. 214).

Pruett et al.'s (2014) findings for exploratory factor analysis found General Interpersonal Contacts revealed a coefficient alpha of .88 which was a high score indicating more frequent contacts; Positive Contact Experiences rated a high score of .86 indicating more frequent positive experiences; and Negative Contact Experiences rated .76 indicating an acceptable frequency of negative experiences. Scores from all three factors implied internal consistency of the CDP items. Therefore, Pruett et al. identified conditions of contact that can help reduce intergroup bias. Findings also supported that contact with disabled persons is important for educational leaders in shaping curriculum in disability-related fields. Reason being, it would offer students more general and positive contact with disabled persons and promote an increased awareness of their own attitudes, according to Pruett et al.

**Disability knowledge.** Educating care providers in disability-related care could be the key when addressing differences reported in care among variables in this research project: physical environments, attitudes, and disability knowledge. The sheer lack of disability curricula reinforces negative attitudes toward disability and the state of inaccessible environments in society ("The New Movement," 2013). Increasing disability prevalence in the United States coupled with accessibility issues in health clinic physical environments, attitudes, and disability



knowledge has implications for educational leaders. First, educational leaders could do with evidence that disability-related curricula for health professionals are warranted. Second, educational leaders need suggestions on what those curricula topics might include. This current study questioned AWPD regarding aspects of disability knowledge that is important to them and also surveyed care providers about their knowledge in disability-related care. Findings inform educational leaders that there is a place for disability-related curricula in health education.

To underscore, many AWPD who reported problems accessing health clinic environments also reported negative attitudes and care providers lacking disability knowledge. It is also important to note that most care practitioners will care for a patient with disability at some point in their career (Smeltzer et al., 2015; Wen, 2014). To meet the present and growing health care needs of people with disabilities, health professionals might be better prepared if they received education in disability-related care. For example, studies showed that disability has its own set of circumstances requiring advanced education and training in primary and secondary medical conditions, durable medical equipment, morbidity and mortality rates, disability sensitivity (Lee, 2010), and ADA infrastructure and accessibility mandates (Bachman et al., 2006; Burns & Gordon, 2010; Lagu et al., 2013). Therefore, lack of care provider knowledge in aspects of disability care such as these is yet another environmental barrier to care that people with disabilities face (CDC, 2016a).

There are differing views of what disability education and training should entail. For example, Couser (2011) believed disability studies have a lot to offer medical students; covering the life span from birth to death while framing curricula in both the medical and social models of disability can be complimentary. Couser's essay reflected on both models; the medical model which adheres to the physiological aspect of the person, whereas the social model suggests

constraints in society creates disability. Couser was supportive of people with disabilities' autonomy and noted the importance of medicine to be free of prejudice, stigma, and practices that devalue disabled persons. Furthermore, Couser cautioned that the quality of life for people with disabilities should not be underestimated, nor should physicians base life and death medical decisions on the assumption that disability means the person is suffering.

In comparison, Vanderbilt, Baugh, Hogue, Brennan, and Ali (2016) wrote that medical schools could close the health disparity gap by instituting facets of social medicine into their curricula. Because all patients have particular social conditions relating to medical care, it was suggested by Vanderbilt et al. that medical students receive training on how to apply social aspects to populations. For example, students exposed to underserved populations could gain a sense of social responsibility and an increased awareness of bias surrounding those populations, such as with people with physical disabilities. Vanderbilt et al. explained that medical education needs to do a better job in preparing physicians for caring for underserved populations. Thus, medical curricula that include student participation in service learning projects will prepare future physicians on reducing health inequities in the U.S. In addition, medical students training with underserved populations are more likely to go on to practice with the same population, strengthening the infrastructure of health care in that particular underserved community.

However, some researchers argued that medical education already has a saturated curriculum (McKenzie & Henzi, 2010; Smeltzer et al., 2015). To show a snapshot of medical curricula to the reader, the following study conducted by McKenzie and Henzi (2010) portrayed the first four years of medical school at one university. During the first two years, learning is primarily from lectures in preparation for competencies tested by Step 1 of the U.S. Medical Licensing Examination. In the last two years, students work with patients in a hospital and clinic

alongside interns, residents, and attending physicians. The third year is devoted to clinical rotations in primary care, such as internal medicine, surgery, obstetrics-gynecology, pediatrics, family and community medicine, and psychiatry. The fourth year is spent taking elective courses, usually in the student's area of interest. Medical students are also interviewing for residency programs during year four.

According to McKenzie and Henzi (2010), there are 131 medical schools in America with varying curricula. Although the purpose of their study was to explore knowledge of medical students and visual impairments, there is still much relevance regarding care provider knowledge in disability care. For example, McKenzie and Henzi stated that medical students received no training in visual impairments or disabilities. In addition, their sample of 152 medical students participated in a 3-point scale survey regarding their confidence level in performing eye examinations and understanding common eye conditions: 1 = not very confident, 2 = somewhat confident, and 3 = very confident. A brief overview of findings revealed confidence levels in performing eye exams ( $M = 2.09$ ); understanding common conditions of the eye, such as cataracts ( $M = 2.19$ ), diabetic retinopathy ( $M = 2.18$ ), and macular degeneration ( $M = 1.79$ ); and recognizing eye emergencies, such as sudden vision loss ( $M = 1.85$ ), corneal infection ( $M = 1.83$ ), and acute glaucoma ( $M = 1.55$ ). McKenzie and Henzi noted participants being the least confident in understanding macular degeneration, the largest cause of adult visual impairment in the U.S.

The low comfort level for recognizing eye emergencies in McKenzie and Henzi's (2010) study was worrisome because many participants planned to specialize in "gatekeeper" health care fields such as in family medicine (8.1%) (p. 712). This means needing to have knowledge about rehabilitation service referrals for patients, which a shocking 97.4% of participants were

unaware of such agencies. In addition, participants reported they planned to pursue residencies in gynecology (10.8%), psychiatry (7.4%), orthopedics and surgery (3.9%), ophthalmology (2%), ear, nose, and throat (1.3%), and urology (1.3%) among other specialties. This is relevant to disability care because these were the same subspecialty clinic types found in Lagu et al.'s (2013) study revealing a fictional patient could not be physically transferred onto an exam table. Therefore, medical students who participated in McKenzie and Henzi's (2010) study and plan to work in clinics will also need to be knowledgeable in disability-related care and accessing health clinics.

Disability education was also found to be sparse in nursing programs. According to Smeltzer et al. (2015), disability was least addressed in nursing undergraduate curricula in areas of health assessment, women's health, and health promotion. For that reason, Smeltzer et al. believed most nurses who entered nurse practitioner (NP) programs were ill-prepared to care for people with disabilities. Smeltzer et al. also emphasized that "disability is *not* an illness" and therefore, people with disabilities need preventive and wellness services just as people without disabilities need these services (p. 220). In a sample of 111 NP programs, descriptive statistics were used to analyze frequencies (responses in percent) for a 34-item survey regarding disability content in their curricula.

Smeltzer et al.'s (2015) study revealed 39 participants (35.1%) incorporated disability objectives in their NP programs. In addition, roughly half of participants ( $n = 58$ , 52.3%) responded that they discussed barriers to care and preventive screening. Yet, an astounding 82% of participants responded that curricula did not devote enough time to disability-related problems ( $n = 52$ , 49.5%) or far too little time to the topic of disability ( $n = 35$ , 33.3%). Interestingly, 22 participants (20.6%) responded that they assessed student attitudes towards people with

disabilities while in their NP program; however, only 2% used formal instruments to measure attitudes. Another interesting finding was participants ( $n = 81$ , 73%) used a combination of multiple models to teach about disability issues in their programs including the medical model ( $n = 94$ , 84.7%), social model ( $n = 58$ , 52.37%), rehabilitation model ( $n = 49$ , 44.5%), bio- psychosocial model ( $n = 36$ , 32.4%), dependency model ( $n = 26$ , 23.6%), and interface model ( $n = 24$ , 21.6%).

Of the 111 participants, Smeltzer et al. (2015) also showed rankings of disability content on a scale from 1-29, 29 being the lowest rank. Highlights from their findings include: Impact of Disability on Growth and Development ranked highest as the number one curricula content area ( $n = 62.5\%$ ), Identification of Barriers ranked three ( $n = 58.8\%$ ), Prevention of Secondary Disabilities ranked at 24.5 ( $n = 24\%$ ), and Parenting by Men with Disabilities ranked as the lowest content area at 29 ( $n = 5.8\%$ ). Another important ranking was for population groups on a scale of 1-18, 18 being the lowest rank. For example, the number one group addressed in NP programs was persons with dementia ( $n = 74.3\%$ ), number two rank was elderly persons with dementia ( $n = 56.5\%$ ), middle-aged adults with disabilities ranked 11 ( $n = 50.5\%$ ), young adults with disabilities ranked 13 ( $n = 47.7\%$ ), women with disabilities ranked 15 ( $n = 33.9\%$ ), and persons from minority ethnic groups with disabilities ranked last at 18 ( $n = 21.1\%$ ).

Smeltzer et al. (2015) commented that education for care professionals is needed to improve disability knowledge, attitudes, and skills in order to provide adequate care for people with disabilities. Besides asking AWPD about their clinic experiences with physical environments and provider relationships in this current study, they were also asked to describe examples of care provider knowledge in what they felt were important aspects of their disability care. In addition, care providers in this current study were surveyed about their knowledge in

disability-related care for AWPB. Based on findings in the literature, it was suspected that AWPB would report experiences regarding lack of provider disability knowledge in this study as well.

In fact, many AWPB reported that their disabilities were misunderstood and providers lacked disability-related knowledge to accurately diagnose and treat their conditions (Lee, 2010), recommend preventive screening (Yankaskas et al., 2010), or promote health and wellness activities (Martin, 2013). This is consistent with McDoom et al. (2014), Wen (2014), and the Surgeon General (DHHS, 2005), who claimed that doctors blamed patients' problems on their disability or did not fully understand the nature of their impairments. As a result, people with disabilities reported receiving inferior treatment by care professionals because disability was the focus instead of their medical symptoms. This can leave patients feeling dissatisfied and distrusting when their care provider cannot relate to their disability, as was the case with some women in Suzuki et al.'s (2013) study. However, misunderstandings in disability care by providers can also have implications when it comes to emergency medical care.

For example, in a hermeneutical study, Wen (2014) found that due to misconceptions of disability, some patients might be subjected to unnecessary medical tests. Per Wen's account, a young man with a stuttering disability presented to the emergency department with chest pain. Because the patient had difficulty speaking, the resident physician on duty did not take the time to adequately assess the patient and therefore ordered unwarranted diagnostic tests. In addition, the physician directed an intern in the room to talk to the patient stating "Oh, and make sure to say things sloooowly so he understands" (p. 1868). When alone with the intern, the tearful patient remarked, "I'm not stupid" (p. 1869).

Wen (2014) went on to say that the term “veterinary medicine” is used by health care professionals when patients are perceived as “slow” or “difficult” (p. 1869). This term is meant to mirror an animal which cannot speak and therefore tests are ordered instead of talking to the patient, according to Wen. Cases like this one have the opportunity for a teaching moment. At the end of the shift that night in the emergency department, the intern had a discussion with the physician regarding the hurtful comment. As a result, the physician apologized to the patient. The incident in the emergency department also led the patient to go on to mentor college students with stuttering disabilities, per Wen’s account. Hence, students and providers in health-related fields could gain insights from disability-specific education and therefore be more sensitive to this population’s needs and assessment (Crowson & Brandes, 2014; Wen, 2014).

On the other hand, lack of knowledge might be because of AWPD not understanding the importance of routine health screening or not knowing how to ask questions pertaining to screening. For example, some women did not think it was necessary to obtain routine mammograms, according to Yankaskas et al. (2010). In their quantitative study, 2,970 women over the age of 40, with and without disabilities, were surveyed to compare reasons why mammography screenings were not routinely scheduled. Of these, 1,055 women had a disability in which 679 had a physical disability. Overall, a fair amount of women reported not needing regular breast screening. Shockingly, the percentage of women from both groups with this belief significantly increased over the age of 65, especially for women with physical disabilities.

Using descriptive statistics, Yankaskas et al. (2010) found the following women did not think mammogram was necessary: without disabilities age 40-64 ( $n = 1569$ , 3.6%) and  $> 65$  ( $n = 346$ , 4.1%), with visual disabilities age 40-64 ( $n = 41$ , 0.0%) and  $> 65$  ( $n = 19$ , 12.5%), with hearing disabilities age 40-64 ( $n = 52$ , 2.0%) and  $> 65$  ( $n = 31$ , 13.3%), with physical disabilities

age 40-64 ( $n = 452$ , 2.5%) and  $> 65$  ( $n = 227$ , 3.9%), with multiple disabilities age 40-64 ( $n = 115$ , 2.8%) and  $> 65$  ( $n = 118$ , 12.6%). This is concerning because Yankaskas et al. commented that the risk for getting breast cancer increases with older age. However, these authors cited another study that showed physician recommendations can increase compliance in women's screening habits. Therefore, care providers knowledgeable in disability care could also educate patients on the importance of preventive screening measures to detect cancers, such as routine mammography.

This leads to the importance of including communication techniques with people with disabilities in disability curricula. Interestingly, in a study conducted by McDoom et al. (2014), care providers reported they addressed patient needs, even though consumers reported a communication barrier with their provider. In addition, findings showed that the older and more severe the disability, communication was less effective by people with disabilities. Therefore, McDoom et al. suggested some providers may lack training in communication approaches with people with disabilities. Regardless of how communication is perceived, interactions might improve between providers and patients if more providers were trained in disability-related knowledge. Expressing the right message and allowing sufficient time during a clinic visit could help both parties understand each other better (McDoom et al., 2014).

Another topic for disability curricula to consider might be to include end-of-life education and training for medical students. A cross-sectional study conducted by Valentino, Chervoneva, and Diemer (2016) investigated end-of-life preferences of residents, fellows, and medical students as they progressed through medical training. In a sample of 449 participants, six different clinic scenarios were presented in an online survey asking to identify specific interventions they would employ for each scenario. A brief description of the scenarios were,



Scenario 1: a patient with a critical illness could possibly recover if aggressive interventions were administered; Scenario 2: a patient with permanent physical disability who needs assist with ADLs acquires a serious acute illness; Scenario 3: a patient with a terminal illness lives independently and acquires a serious acute illness; Scenario 4: due to terminal illness, a patient has developed disability needing assistance and acquires a serious acute illness; Scenario 5: a patient with irreversible brain damage cannot work or care for self, does not recognize people, and acquires a serious acute illness; Scenario 6: a patient has major brain damage, is permanently unconscious, has no terminal illness, and acquires a serious acute illness.

Using logistic regression, Valentino et al. (2016) analyzed responses from three categories labeled Standard (patient would receive hospital care, intravenous fluids, or blood transfusion), Intermediate (patient would receive hemodialysis, invasive tests, or a feeding tube), and Aggressive (patient would receive cardio-pulmonary resuscitation [CPR], mechanical ventilation, or surgery). Results showed the more years of training that students received, medical interventions decreased for scenarios of terminally ill patients with cognitive or physical disability. For instance, over 96% of participants were in favor of aggressive and intermediate interventions for Scenario 1 (critical illness with possible full recovery) and almost all (>99%) responded that they would choose standard interventions. Years of medical training did not change the rate of refusing interventions. However, the odds ratio (OR) with participants who declined interventions versus their number of years of medical training significantly increased in Scenario 2. For example, participants in Scenario 2 (physical disability and acute illness) declined intermediate (OR = 1.14 [1.02-1.28],  $p = 0.02$ ) and aggressive (OR = 1.15 [1.03-1.28],  $p = 0.01$ ) interventions as years of medical training increased.

Valentino et al.'s (2016) findings for Scenario 3 (terminal illness, no physical disability, and acute illness) revealed a significant correlation in declining intermediate interventions and years of medical training (OR = 1.14 [1.03-1.25],  $p = 0.008$ ); whereas Scenario 4 (terminal illness, physical disability, and acute illness) showed a significant correlation between the rate of refusing interventions and higher number of years of medical training for intermediate (OR = 1.14 [1.04-1.26],  $p = 0.006$ ) and aggressive interventions (OR = 1.20 [1.08-1.34],  $p = 0.001$ ). Scenario 5 (irreversible brain damage and acute illness) indicated all interventions (standard, intermediate, and aggressive) declined as years of medical training increased. Last, Scenario 6 (major brain damage and acute illness) revealed no correlation between participants who declined interventions versus their number of years of medical training. Thus, approximately 87% of participants in Scenario 6 declined standard interventions and roughly 93% of participants declined both intermediate and aggressive interventions.

Valentino et al. (2016) commented that soaring health care costs are linked with a poor quality of death. About five percent of individuals that die every year incur 30% of Medicare costs, one-third of these expenses occurring in the person's last month of life. Hence, care providers focus on reducing medical interventions that are expensive and invasive towards the end of one's life, especially if there is no chance for recovery or if illness causes severe disability. Furthermore, Valentino et al. identified a trend toward declining aggressive interventions after two years of medical training and decline in intermediate interventions after three years of training. This is in contrast to individuals with lower health knowledge and education, where more aggressive treatment is typically chosen, according to Valentino et al. Overall, the study showed that preferences for interventions at end-of-life scenarios occurred

before medical students were experienced clinically. Therefore, Valentino et al. suggested medical knowledge had an influence on these students' swaying points of views.

In general, a common theme discovered in these studies was the shared interest in expanding health professionals' knowledge that could help provide a higher quality of care for people with disabilities. This research project collected and analyzed data regarding aspects of disability knowledge produced from AWPDP discussions and care provider surveys. Based on the literature and results from this current study, there are gaps in health curriculum design reflective of a lack in disability-related instruction. Lack of provider knowledge in disability care has implications for educational leaders. Inclusion of disability-related curricula could help bridge gaps in education by integrating instruction that improve access to care with physical environments, attitudes, and disability knowledge when caring for people with disabilities.

### **Disability-related Curricula**

Educational leadership is linked to disability-related curricula for improving access to care in health clinics for AWPDP. The need for disability education is becoming more apparent especially because the population is aging and trends showed a growing rate of disability in the United States (Chen & Sloan, 2015). Yet, articles related to disability curriculum content were sparse in the literature. Although education and training in disability care could help lay a foundation for disability knowledge, curricula design cannot be informed until evidence reveals an instructional need to health and education communities. Therefore, the results from this current study have implications for education leaders regarding gaps in education and also inform curriculum design to improve disability knowledge for present and future care providers. It was suspected that AWPDP would report issues with provider knowledge and aspects of disability care, which prompted suggestions for disability-related curricula items.

To emphasize the importance of care providers having disability knowledge, the WHO (2015) recommended that all health care professionals receive disability education in their undergraduate studies and beyond. Moreover, the WHO suggested the need to provide guidelines for assessing and treating people with disabilities so care professionals would be familiar with preventive health care measures. However, medical accreditation agencies do not require disability knowledge (Wen, 2014). For instance, medical education standards address clinical instruction that covers “all organ systems, and include the important aspects of preventive, acute, chronic, continuing, rehabilitative, and end-of-life care” (Standard ED-13); clinical experiences that “utilize both outpatient and inpatient settings” (ED-16); provide for educational opportunities “in multidisciplinary content areas, such as emergency medicine and geriatrics” (ED-17); provide instruction in communication skills with patients (ED-19); and “learn to recognize and appropriately address gender and cultural biases in themselves and others, and in the process of health care delivery” (ED-22) (International Association of Medical Colleges, n.d., Content section). Still, medical standards do not guide medical students to disability-related education or clinical experiences specific to disability settings.

To understand aspects of disability better, several researchers explained that care providers should be more informed about ADA standards and accessibility in health clinic environments (Bachman et al., 2006; Burns & Gordon, 2010; Lagu et al., 2013), trends in disability and associated health care costs (Chen & Sloan, 2015; Gu et al., 2015), disability terminology (Brault, 2012; Krahn et al., 2015), secondary conditions (Iezzoni, 2010), co-morbidities in disability (Valderas et al., 2009), and sensitivity towards disability (Crowson & Brandes, 2014; Wen, 2014). Other researchers shared varying ideas about what aspects of disability curricula could look like. For example, models of disability (Couser, 2011), health

assessment, promoting wellness activities and disease prevention measures (Smeltzer et al., 2015), exposure to people with disabilities (Pruett et al., 2014; Vanderbilt et al., 2016), communication techniques (McDoom et al., 2014), and end-of-life interventions for people with disabilities (Valentino et al., 2016) were some examples of how disability-related curriculum could prepare health care professionals to care for patients with disabilities. In addition, Wen (2014) remarked on the importance for including people with disabilities in curricula development. Developing disability-related curricula from the perspective of people with disabilities could “be a transformative model for patient-centered medical education” (p. 1870).

### **Disability Inclusion**

The CDC (2016b) noted disability inclusion as knowing how individuals function and take part in their communities, and ensuring equal opportunities for full participation. Although there has been movement to improve participation for AWPD, barriers still exist (Eisenberg et al., 2015; McDonald et al., 2015). For instance, a multi-phase study by Eisenberg et al. assigned people with disabilities in evaluating access to various community entities, such as schools and health care facilities, and then developed a community access evaluation tool. In comparison, researchers McDonald et al. involved people with disabilities in evaluating government buildings and services. Both studies revealed similar findings of some physical access improvement coupled with persisting barriers. Both studies also gained superior insights from people with disabilities by including them in the research process.

McDonald et al. (2015) used participatory action research (PAR) to examine perceptions of service providers. Sites from 60 southeast state and local government entities viewed as ADA priority, such as city halls, civic centers, parks, libraries, and police stations were visited by two groups: 50 PAR researchers with and without disabilities. PAR researchers set out to complete

48 prescribed activities at each site so they could gather data about accessibility. Using descriptive statistics, experiences of both groups were compared. McDonald et al.'s research identified problems with accessibility that may have otherwise gone unnoticed by people without disabilities. For example, there were significant differences in completing activities between PAR researchers with visual impairment (69%), compared to PAR researchers without disabilities (94%), hearing impairment (94%), or mobility disabilities (99%).

Results from McDonald et al.'s (2015) study also indicated improvement in some of the physical environment entities PAR researchers investigated, such as access to park benches and tables, screen readers, and staff who were sensitive to people with disabilities. In addition, features that were accessible at least 90% of the time included toilet seat height, door handle height, wheelchair ramps, width of aisles and pathways, and accessible entrances to entities. Other features with less accessibility included emergency intercom with voice and Braille communication (75%), accessible soap dispensers (70%), height of cashier counters (59%), companion seating for wheelchair users (46%), and signs to accessible restrooms (43%).

However, McDonald et al.'s (2015) findings showed barriers persisted in adaptive equipment, assistive technology, and staff knowledge with teletypewriter/telecommunication devices (TTY/TDD) for deaf persons to name a few. Some examples of accessibility included large print materials (22%), TTY/TDD (21%), Wi-fi (10%), closed-captioned TV (4%), and hand-held scanner (1%). There were also discrepancies between what consumers with disabilities and service providers reported. PAR researchers regularly encountered service providers or signage that was incorrect or missing altogether. Some PAR researchers even reported negative interactions with service providers. One of the researchers stated, "It is unfortunate that some public venues think they are providing adequate access to service but the

consumer's experience may be quite different" (p. 360). McDonald et al.'s study not only showed that barriers along with differing perceptions of barriers existed; it showed the importance for including people with disabilities in research for drawing accurate conclusions representative of this population.

Rios et al. (2016) also believed in the importance for including people with disabilities in research, specifically health research. Because adults with disabilities are recipients of health services amounting to approximately \$400 billion annually, Rios et al. commented that excluding them from research limits disability-related findings that could contribute to health care. For example, adults with disabilities have an increased risk for secondary conditions and have problems accessing health care services. Rios et al. claimed that representation of people with disabilities in research is needed for improving outcomes for this population. When people with disabilities are not included in health research, the validity and generalizability of a study could be questionable.

For those reasons, Rios et al. (2016) provided strategies for an accessible research design that allows inclusion for people with disabilities in health research. To accomplish this, Rios et al. expanded on the ideas of four large-scale design tools: Patient-Reported Outcomes Measurement Information System (PROMIS), National Institutes of Health Toolbox (NIH), National Children's Study, and National Health and Nutrition Examination Survey (NHANES). As a result, Rios et al. outlined strategies conducive for accessing research by people with disabilities. For instance, strategies addressed accommodating individuals with hearing, vision, speech, hand control, reading, and mobility impairments. These accommodations were applied to components of: recruiting participants (via large print, audio, internet, and training staff in TTY), obtaining consent to participate in research (sending participants a brief and concise

consent prior to the research, and allowing different modes of signatures), accessibility of the research facility (buildings, rooms, and equipment meet ADA standards), transporting participants to the research site (providing accessible and free transportation to and from the research site), measuring participants' responses (presentation of research information to participants through closed-captioning, large print, allowing ample time for TTY, accommodating for color-blindness, using surveys that provide multiple means of responding), and accessible technology (include multisensory options, such as talking watches, equipment with large displays, allowing for text or voice input).

Rios et al. (2016) also explained the importance of documenting any modifications that occurred during research because there could be validity concerns. For example, it must be documented if a proxy was used to record a response in a timed test. Otherwise, Rios et al. remarked that the use of a proxy rather than coming directly from the person with a disability could interfere with the speed of recall. Thus, correct documentation of modifications made to testing protocols are essential for interpreting results and identifying if it will make an impact on scoring attributes. Rios et al. indicated that pre-screening participants could help detect additional modifications that may be needed so investigators could be prepared to make further accommodations prior to conducting a study.

Finally, Rios et al. (2016) recommended researchers consult with someone with a respective disability if they do not understand how to include a person with disability in research. There may be a family member, caregiver, or the potential research candidate themselves who can give advice regarding accommodations. In this current study, AWPDP were provided with a handout listing the pre-constructed questions for care providers. This created a visual for AWPDP and aided in writing their response choice ideas for the provider survey. In addition, verbal



responses were audio-recorded for accuracy. Focus groups were conducted in participants' home settings, so transportation or building accessibility did not need further accommodations.

To summarize, research that includes the input from people with disabilities is vital to accurately represent disability for improving health outcomes. Several government agencies also identified the importance for including people with disabilities in research. The CDC, National Institute on Disability and Rehabilitation, and Agency for Healthcare Research and Quality were noted by Krahn et al. (2015) and added that inclusion in health practices can improve people with disabilities' health. Furthermore, Hutch et al. (2011) identified 14 federal departments prioritizing *smart growth* of the built environment to improve health in vulnerable communities. As Mertens (1999) stated, we all have a connection in society and problems that occur in one group, end up affecting everyone. Therefore, including people with disabilities in research and development is not only fundamental for designing and implementing practices; it is an ethical responsibility of society.

**Provider perceptions of barriers.** Although it is important to identify what AWPD experience in health care facilities, it is also necessary for providers to acknowledge said issues so proper actions can take place to resolve them. The literature was sparse in this area. However, there was one mixed methods studies (Bachman et al., 2006) and one quantitative study (McDoom et al., 2016) which found differences between what people with disabilities experienced regarding access barriers versus providers' perception of barriers. For example, Bachman et al. (2006) conducted focus groups with people ranging in disabilities along with other consumers and stakeholders, who identified chief barriers in a variety of health facilities. According to Bachman et al., barriers related to structural aspects, financial, and personal-cultural barriers. Using data from focus groups, a comprehensive 18-item survey for providers

was developed to gather data on their perceptions of access to care for people with disabilities. A total of 1,040 surveys were mailed to providers in Massachusetts with a response rate of 36%. The sample of 379 providers answered the survey about their experiences serving people with disabilities. Surprisingly, only 30% reported challenges when serving this population, mobility being one of the top issues.

Bachman et al. (2006) used a frequency scale of never, less than once per month, monthly, weekly, and daily regarding how often providers serve people with disabilities in six categorical conditions. Conditions included: mobility limitations, serious mental illness, cognitive impairments, communication impairments, visual impairments, and severe chronic illness that required ongoing medical monitoring. On a daily basis, 189 providers (51%) reported serving people with mobility limitations in their health facility, 218 (60%) served people with serious mental illness, 182 (50%) served people with cognitive impairments, 122 (33%) served people with communication impairments, 86 (24%) served people with visual impairments, and 161 (45%) served people with severe chronic illness on a daily basis. Less than 10% of providers never served these condition types.

Furthermore, Bachman et al. (2006) rated provider perceptions of barriers to caring for people with disabilities on a frequency scale of never, rarely, sometimes, frequently, and always. Barriers included: no insurance coverage, difficulty with transportation, difficulty getting into the building or exam rooms, difficulty using restrooms, difficulty using equipment (scales, chairs, exam tables, X-ray machines), difficulty making appointments, difficulty communicating needs to providers, and difficulty understanding providers or staff. Interestingly, results showed the rate of providers who perceived patients never faced the following barriers: no insurance coverage ( $n = 79$ , 23%), difficulty with transportation ( $n = 33$ , 9%), difficulty getting into the

building or exam rooms ( $n = 182$ , 51%), difficulty using restrooms ( $n = 200$ , 57%), difficulty using equipment ( $n = 108$ , 41%), difficulty making appointments ( $n = 121$ , 38%), difficulty communicating needs to providers ( $n = 74$ , 21%), and difficulty understanding providers or staff ( $n = 69$ , 20%). Three percent or less of providers reported people with disabilities always faced these barriers.

In addition, Bachman et al.'s (2006) survey asked providers if they had received disability-related training in the past year. Responses indicated that 56% had training about cognitive impairments, 55% severe psychiatric impairments, 53% severe chronic illness, 39% communication impairments, 33% disability sensitivity, 30% mobility impairments, 21% visual impairments. Also, 67% of providers reported making changes that improved physical access in their facilities to comply with ADA standards. Lastly, Bachman et al. remarked that a weakness in their study was that provider and consumer responses were not compared. Similar to this current study, AWPD and provider responses regarding clinic accessibility were not compared.

In another study, McDoom et al.'s (2014) quantitative research design utilized Bachman et al.'s (2006) findings to develop two additional surveys; one for providers and one for people with multiple disabilities. McDoom et al. (2014) examined both groups together using multivariate analysis. It was interesting to see that findings had similarities and differences in ranking of barriers and barrier types from those of Bachman et al.'s (2006) study. Although physical access to exam rooms, restrooms, and equipment was ranked as lower barriers in McDoom et al.'s (2014) study, these were still barriers for people with disabilities. Moreover, providers had differing perspectives on the rankings of some barriers in their clinics.

Findings by McDoom et al. (2014) showed that differences in perception of barriers between 379 providers and 540 people with disabilities were significant. People with disabilities

(PWD) reported experiencing the following eight barriers in percentage versus providers' perception of barriers for people with disabilities (also in percentage): insurance coverage (PWD  $n = 192$ , 26.48% versus provider  $n = 232$ , 71.38%), transportation (PWD  $n = 155$ , 28.70% versus provider  $n = 283$ , 87.08%), building infrastructure (PWD  $n = 32$ , 5.93% versus provider  $n = 162$ , 49.85%), restroom access (PWD  $n = 29$ , 5.37% versus provider  $n = 136$ , 41.85%), equipment (PWD  $n = 60$ , 11.11% versus provider  $n = 140$ , 43.08%), talking about needs (PWD  $n = 170$ , 31.48% versus provider  $n = 242$ , 74.46%), understanding the provider (PWD  $n = 116$ , 21.48% versus provider  $n = 247$ , 76.00%), and appointment making (PWD  $n = 156$ , 28.90% versus provider  $n = 185$ , 56.92%).

From the eight barriers ranking from highest (number one) to lowest (number eight), McDoom et al. (2014) revealed (1) transportation as the highest ranking barrier for both PWD and providers, (2) insurance (PWD) and understanding providers or staff (provider), (3) communicating needs for both PWD and providers, (4) making appointments (PWD) and insurance (providers), (5) understanding providers (PWD) and making appointments (providers), (6) using equipment for both PWD and providers. The seventh and eighth ranking was the lowest for both PWD and providers which included getting into the building, exam rooms, and restrooms. McDoom et al. suggested that the barriers reported by people with disabilities were likely to be a reflection of their disability type. Examples of disability characteristics from their study sample were mobility impairment, mental illness, cognitive problems, and visual impairment to name a few.

Nonetheless, McDoom et al. (2014) commented that as the trend of people with disabilities continues to rise, so will their needs and disability-related care costs rise. Therefore, it is important to provide equal access to care and the reduction of barriers for this population.

Finally, McDoom et al. recommended adding communicating needs and understanding providers in medical education as these were higher ranking barriers. Like these authors, this current study questioned two groups: AWPD and health clinic care providers. However, the AWPD sample in this research project was limited to criteria of physical disability characteristics.

**Health inequality and inequity.** Because several authors in this literature review remarked about inequities in health care, it is important to address it. Inequity is defined as “differences that are unnecessary, avoidable, unfair, and unjust” (Lee, 2010, p. 18). Having equity in health care refers to having equal access to health care, services, or outcomes (Wang, 2012). If AWPD are denied care (WHO, 2015), receive fewer preventive health screenings than adults without disabilities (Drew & Short, 2010; Horner-Johnson et al., 2014; Suzuki et al., 2013), and have higher mortality rates from certain medical conditions (Iezzoni et al., 2010 & 2011; Yankaskas et al., 2010) it would seem that there are differences between people with and without disabilities in health care. Nevertheless, agreement among health authorities regarding the existence of inequities needs to be accomplished first.

There has been much debate by researchers whether inequality and inequity in health care exist and if so, to what extent. It is important to determine various measures to establish standards (and enforce current ones) for purposes of allocating resources in appropriate development of policies and programs for people with disabilities and other marginalized groups. Three meta-synthesis studies set out to define health disparities (Lee, 2010), examine if health disparities exist, (Krahn et al., 2015), and to identify and eliminate health disparities (Hutch et al., 2011). Lee (2010) differentiated between inequality and inequity, stating that both were elements of health disparities. For instance, inequality towards persons with disabilities can be measured and observed with those without disabilities. Inequity on the other hand, was

described as unjust differences that can be avoided. Lee challenged that unless health disparities are conceptualized, they will continue being difficult to address and eliminate.

Furthermore, Krahn et al. (2015) argued that health disparities in the disabled population lacked recognition by federal agencies because the focus has been based more on race and ethnic differences. Therefore, without equal recognition, it was suggested that people with disabilities would continue to be at risk for inequitable health outcomes. Similar, Hutch et al. (2011) cited the Federal Collaboration on Health Disparities Research as identifying a poorly built environment playing a part in inferior health outcomes for the disadvantaged. Yet, the association between the environment and health necessitates a better understanding before disparities can be eliminated. Researchers agreed that investigating health disparities will help to verify best practices for improving health. In turn, practices that accommodate AWPD could increase their participation in other activities, such as health and wellness (CDC, 2015b). In this current study, responses from AWPD and care providers were examined to offer health and educational leaders a better understanding of clinic environments.

**Transforming social policy.** Mertens (1999) championed a pertinent meta-synthesis detailing how the transformative paradigm could bridge the gap between evaluation findings and social change. In addition, Mertens (1999) remarked that many adults with disabilities battle with predetermined public attitudes and thus need environments that advocate inclusion. Transformative researchers can use their study findings for stimulating change that advocate for the population of interest (Mertens, 2015, p. 461). Mertens went on to cite researchers that have shown in order to stimulate change in policies, transformation needs to occur in the general population (Mertens, 1999; Mertens, 2015). However, researchers might not have the power to make decisions that create positive change. In situations like this, Mertens (1999) suggested

researchers develop data collection tools that encourage decision-makers to make positive changes that advocate for marginalized groups.

Bloustien and Wood (2016) and Nario-Redmond and Oleson (2015) explored issues of identity as it relates to one's disability and self-advocacy. For instance, Bloustien and Wood (2016), who tested participants through a virtual gaming technique, suggested disabled persons who were able to self-advocate in a virtual world might have the potential to self-advocate in the actual world. In comparison, Nario-Redmond and Oleson (2015) found adults who positively identified with their disability were more likely to challenge the status-quo and advocate for disability rights as an individual. Therefore, it is imperative that AWPD viewpoints contribute to balancing the communities in which they have a right to participate.

Although there has been some progress made in compliance with disability policies (Burns & Gordon, 2010; McDonald et al., 2015), there is still more work to be accomplished in filling the gaps. Burns and Gordon (2010) conducted a meta-synthesis of the literature in regards to disability legislation to point out trends, gaps, and best practices. They argued that conventional measures of accessibility do not take all barriers or individual limitations into account. For example, Burns and Gordon found that follow-up to disability mandates was missing and cited several authors who supported education and training for public officials, health professionals, people with disabilities, and society in general so effective change in policy and services could take place. This is especially important as the population ages and the rate of people with disabilities is projected to increase, according to other cited authors. As Burns and Gordon noted, information gaps like these could hamper the forward motion for disability policy decision-making processes.

## Summary

The literature addressed central issues relevant to AWPB and access to care in health clinics. Researchers indicated that environmental factors can be barriers to disability and impede access to health care. Yet, in spite of the passage of ADA laws, inaccessible health clinics and services persist. Negative attitudes towards disability and lack of provider knowledge were also reported by many AWPB, resulting in fewer preventive screenings than people without disabilities. These differences in access to health services could be seen as inequitable. As disability trends increase, so will the need for additional health services. This is especially important because people with disabilities require specialized services and reported their disabilities were misunderstood by care providers. Educating health care providers in disability-related care could be the key to improving physical environments in clinics, patient-provider relationships, and overall disability knowledge. However, medical accreditation agencies do not require disability curricula in medical schools. Inclusion of people with disabilities in health research, structural design, and curricula development would be practical and worthwhile for improving health care delivery and outcomes for AWPB, and possibly for the general public as a whole.



## **Chapter Three: Methodology**

### **Philosophy and Justification**

A mixed methods design with a quantitative, inclusive, transformative emphasis was chosen in an attempt to capture the essence of AWPB experiences in health clinic environments and also the perspectives of health clinic care providers in regards to the care they are providing for AWPB. This study intended to use an inclusive approach which means to include AWPB input and illustrate a genuine representation of people with physical disabilities accessing care in health clinics. An inclusive approach was needed to highlight issues AWPB have in health clinics. A transformative framework was used because it allowed for authentic disability representation (Eisenberg et al., 2015) and offers findings that will heighten awareness in health professionals that might empower them to change their policies (Creswell, 2014, p. 71; Mertens, 2015, p. 21). In this current study, findings from AWPB focus group sessions and care provider surveys offer the fields of health and education a better understanding of accessibility in health clinics from the perspectives of AWPB and providers.

This study was conducted in two phases. Phase one collected qualitative data and documented AWPB perceptions, and developed a survey for care providers. A questionnaire was used during focus groups to verbally ask AWPB about access to care in health clinics that pertain to the physical environment, attitudes, disability knowledge, and ideas for improvement. Face to face focus groups with AWPB dictated and shaped survey response choice items for care providers, which were created during focus group sessions. Data collected from AWPB were transposed into response choice items for a uniquely crafted care provider survey. Phase two collected quantitative perceptual data of care providers. Surveys were distributed to care providers in metropolitan and greater Minnesota health clinics.

Focus groups and providers were asked five similar questions about accessing care in health clinics. Thus, the aim of this study was to explore what AWPB experience in health clinics regarding access to care with physical environments, attitudes, and disability knowledge, and to construct a comprehensive survey asking care providers about accessibility in their health clinics. To identify key issues with access, AWPB discussed aspects of environmental factors they perceived as important for their care and providers were asked about their clinic environments, relationships with their patients, and knowledge in disability-related care. Responses from focus group discussions and provider surveys were examined in an attempt to inform health and educational leaders about the need for disability curricula. A descriptive statistics strategy was applied to summarize given sets of data and provide evidence that warrants an instructional need.

### **Research Questions**

This research project was designed with the intent to answer the following questions regarding accessibility in health clinics:

RQ 1. What is the experience of AWPB in health clinics regarding access to care that pertain to physical environments, attitudes, and disability knowledge?

RQ 2. What do health care providers say they are providing in their clinics regarding care for AWPB that pertain to physical environments, attitudes, and disability knowledge?

### **Theoretical Framework**

Transformative theory adheres to central issues of underrepresented groups and that multiple points of view exist in relation to various social realities (Mertens, 1999). Mertens went on to explain that “we need to place those viewpoints within a political, cultural, and economic

value system to understand the basis for the differences” (p. 5). Although there are several populations considered as underrepresented, this current study addressed issues with health clinic access for AWP. This does not mean AWP perspectives are more important than the perspectives of other groups. Nor does it mean AWP perspectives are more important than the group who was surveyed, namely care providers. Rather, transformative theory observes all voices, emphasizing the inclusion of those who have historically been discriminated against and have traditionally been missing from research, such as people with disabilities, according to Mertens. Therefore, a mixed methods approach offered inclusive data from AWP reported experiences in health clinics along with their input for survey development for care providers.

Mertens (2003) categorized research steps that are congruent with transformative theory (pp. 142-155). The following steps were adapted from Mertens and helped to frame this study:

- Define the problem and conduct a search of the literature for issues related to health clinic accessibility for people with physical disabilities.
- Identify a research design that includes and respects the community of interest.
- Select participants who will accurately represent the physically disabled community.
- Construct data collection instruments and methods that will be useful to the community of interest and provide opportunity to participate in offering solutions that elicit change for improved health clinic environments.
- Data interpretation and analysis examine the differences between the community of interest and care providers with intent of contributing to the literature and raising awareness in the general health care professional community, as well as with educators.

Transformative theory emerged in part because traditional research paradigms limited responses from underrepresented groups who experienced issues with discrimination and

oppression, e.g., minority groups, feminists, LGBTQ community, and people with disabilities to name a few (Mertens, 2015). Moreover, exposure of these groups in research is changing how some professions are adapting practices. One example given by Mertens is the addition of more recent accreditation standards, which include issues of diversity for fields of psychology and education (p. 22). This current study addresses audiences from the disability community, health sciences, and educators. According to Creswell (2014), mixed methods research using transformative theory is growing in the literature in reference to community health and marginalized populations (p. 70). Creswell also wrote two main points of discussion in this area asks what transformative theory is and how researchers integrate transformative theory into a mixed methods study. The results of this current study will help contribute to the growing body of literature in mixed methods research and the transformative paradigm.

### **Two-phase Study**

**Phase one: Focus groups.** Phase one used a qualitative research approach to collect and document AWPD perceptions, and to develop a survey for care providers. The objective for phase one was to conduct focus groups exploring experiences of AWPD in health clinics and also to partner with this investigator in formulating a five-question provider survey based on those experiences.

**Phase two: Provider survey.** Phase two used a quantitative approach to collect perceptual data of care providers. Systematically sampling of health clinics in Minnesota was conducted. One care provider from each selected health clinic received a survey which asked about what they are providing in their health clinics regarding care for AWPD.

**Two groups:** AWPD and health clinic care providers.

## **Research Design Strategy**

A mixed methods approach was used for this study: Qualitative focus group sessions and a quantitative survey design framed the data collection. Descriptive statistics were used to describe simple features of data and provide a basic summary of the sample (Patten, 2014, p. 113). In this study, AWPDP were asked to describe their experiences in health clinics regarding access to care with physical environments, attitudes, and disability knowledge. Care providers were surveyed using similar questions, yet worded in a manner to fit their role as a provider. Due to the inclusive nature of this study, the survey tool for care providers was developed from the unique, individual responses of AWPDP. Therefore, existing tools, which are sparse in the literature, were not utilized.

## **Measures**

**Phase one: Focus groups.** The first part of this study used a qualitative approach to concentrate on gathering information from three focus groups consisting of one to five AWPDP per group. According to Merriam (2009), qualitative researchers need to respond and adapt during data collection and analysis; therefore, the researcher is the primary instrument in qualitative research. For that reason, qualitative researchers should be aware of how their biases could inadvertently shape data collection and interpretation (p. 15). This investigator has a history of working in health care. It was important for AWPDP to develop a survey for care providers from their own perspectives as individuals with physical disabilities instead of from the view of this health professional. Moreover, Patten (2014) explained that researchers act as facilitators and attempt to create a welcoming environment so participants can freely discuss the topic; which in this case relates to accessibility in health clinics. Patten claimed that the advantage of this method is to reveal “*the evolution of perceptions in a social context*” (p. 165).

Focus group data need to be checked for credibility and dependability of measures, which is equivalent to validity and reliability of measures in quantitative research (Orcher, 2014). One way to measure credibility is to see if study participants agree with the researcher's interpretation of data. For this study, if an agreement could not be reached between this researcher and AWPDP, interpretations were modified by this researcher. To measure dependability, a second person could code and translate the AWPDP question responses to compare results (pp. 68-69). However, no other person or coder besides this primary researcher checked focus group data for accuracy of interpretations. Therefore, dependability was noted as a study delimitation. Both credibility and dependability were based on AWPDP participants agreeing with the interpretation of data because together with this researcher, a survey tool was created during focus group sessions for phase two of this study.

***Focus group questionnaire.*** Questions for focus group sessions were constructed by this investigator based on the literature describing issues in health clinic environments faced by adults with physical disabilities (AWPDP). However, due to the large volume of environmental factors, this research has limited its environmental focus to physical environments (question 1), medical equipment (question 2), attitudinal (question 3), and disability knowledge (question 4). Participants were also asked if they had ideas for improvements (question 5). Their ideas were not statistically measured due to the nature of the question and individuality of responses. Rather, responses from question 5 were seen as unique to focus group participants and are summarized in Table 6.

Five open-ended questions were asked to allow maximization of responses in a one-hour time frame. The small number of questions was also intended to keep participant fatigue at a minimum. Focus groups were conducted by this author who is a Master's prepared registered

nurse with public health certification, licensed in the state of Minnesota. The definition of *environment* along with examples of environmental factors was provided with the questionnaire. Focus group questions were based on central issues extracted from the literature and reflect the following:

1. Describe your experiences of the physical environment when you visited a health clinic.
  - Prompts: Think about how you entered the building; checked in for your appointment; navigated in the wait area, examination room, and restroom.
2. Tell me about your experiences with medical equipment.
  - Prompts: How did you transfer to the examination table, weigh scale, mammography or other X-ray equipment?
3. Describe your relationship with your provider.
  - Prompts: Were you able to freely discuss any issues you had? Did you receive a referral to another provider? Were you satisfied with how the clinic staff responded to your needs? Would you have preferred a different outcome from your visit; if so, what would that have looked like?
4. Describe at least one example of how you think your care provider is knowledgeable in what you feel are important aspects of your disability care.
  - Prompts: Did he/she discuss durable equipment needs or updates with you? Did you receive recommendations for prevention of other health problems? Were ideas for wellness activities or preventive screening procedures discussed?
5. What are your ideas for creating an improved health clinic environment?
  - Prompts: What ideas would you give to your care provider? To educators?

*Survey development for care providers.* Near the end of each focus group session, development of survey response choice items for care providers were decided by participants based on their perceptions of health clinic environmental factors. All focus group participants were AWPB. Decisions made about selecting survey items were unanimous among participants. Because focus group participants had just finished discussing their experiences in health clinics, they readily verbalized items they wanted to include on the care provider survey. For example, when asked about the first category, physical environments in health clinics, participants recalled what they said about physical environments; which led them to offer six response choice items for that category of the care provider survey. When asked about categories medical equipment, attitudinal, and disability knowledge, participants readily provided items for those categories on the survey as well. This investigator took notes, verbalized-back participants' item selections, and provided minimal cues in constructing the formation of survey response items.

Furthermore, three additional response choice items for the care provider survey were developed in partnership between this investigator and focus group participants to allow care providers the opportunity to elaborate on information about their clinic and medical training. The following three response choice items were unique only to care providers:

- there are future plans to upgrade my clinic's physical environment
- there are future plans to upgrade my clinic's medical equipment to accommodate patients with physical disabilities
- I had no formal education in medical school regarding disability care

One week following the focus group sessions, this investigator returned to all seven participants and provided them with a copy of the finished care provider, 29-item survey titled CAMS and asked them to review it for any needed changes. No changes were requested.



**Phase two: Provider survey.** The second part of this study used a quantitative approach and involved mailing surveys to health clinic care providers. Surveys are another way to interview a population about their attitudes, beliefs, and behaviors (Patten, 2014, p. 9). In this study, health clinic care providers were surveyed in regards to their perspectives on accessibility in their clinics and the care they are providing for AWPDP. In comparison to measuring qualitative credibility and dependability of results, quantitative studies need to show validity (accuracy of measures) and reliability (consistency of measures) in their studies. To help ensure the survey was accurate and measure what it was supposed to be measuring (Orcher, 2014, p. 67), AWPDP were included in the survey's development. To determine reliability, test-retest for consistency a short time following the initial test could help see how much stability there is in the results (p. 128). Because the survey was developed in partnership with AWPDP, who are representative of the population of interest, a pilot test of the survey was not necessary (S. Paulson, personal communication, April 20, 2017).

Five survey questions were constructed by this investigator to mimic the same five questions asked of AWPDP focus group participants. In partnership with this investigator, focus group participants developed 29 response choice items for the care provider survey. The survey required approximately one minute to complete and addressed five areas: physical environment of health clinics, medical equipment that accommodates for physical disabilities, provider-patient relationships (attitudinal), disability knowledge, and ideas for improving clinic environments. In addition, this investigator collaborated with Jola Publications (Minnesota Medical Directory, 2016) for the most recent listing of 1,971 Minnesota clinics. A spread sheet of 640 health clinics was created by systematically selecting every third clinic in the directory, after removing known

satellite clinics. Satellite clinics do not see patients and were eliminated prior to constructing the list in order to maximize the care provider sample.

Another factor to consider when developing a survey is to give it a name. Orcher (2014) recommended naming a survey that points out the variables in a study (p. 205). For that reason, the survey for this research project was appropriately constructed and named *Clinic Access Minute Survey* (CAMS) in hopes that this title would be clear and prompt a higher return rate. After completing the focus group sessions and partnered development of the itemized survey with this investigator, the survey (CAMS) was mailed via systematic sampling of health clinics in Minnesota. CAMS comprised five similar questions asked of focus group participants, yet formatted to fit the care provider role. Survey response choice items depended on the input provided by AWPD during focus group sessions. The following reflects the finished survey:

Please check all items that apply and return CAMS in the envelope provided.

1. The physical environment of my clinic provides the following:
  - wheelchair-accessible building entrance
  - wheelchair-accessible push-buttons to open doors
  - wheelchair-accessible restrooms
  - grab bars in restrooms
  - wheelchair-accessible route to examination rooms
  - maneuvering clearance for wheelchairs to turn around in examination rooms
  - there are future plans to upgrade my clinic's physical environment
  
2. My clinic provides medical equipment that accommodates patients with physical disabilities:
  - wheelchair-accessible weigh scale
  - wheelchair-accessible mammography equipment
  - height-adjustable examination table
  - wheelchair-accessible laboratory equipment for blood draws
  - flexible x-ray equipment
  - flexible stirrups on examination table
  - mechanical lift
  - there are future plans to upgrade my clinic's medical equipment to accommodate patients with physical disabilities

3. Relationships with my patients with physical disabilities are:
  - I can freely discuss any health-related issue with my patients
  - I provide other clinic options if my clinic is unable to accommodate a patient with a physical disability
  - I listen to what my patients say about their health issues
  - I problem-solve with my patients about their care
  - my patients are satisfied with how clinic staff responds to their needs
  
4. I am knowledgeable in:
  - disability care for patients with physical disabilities
  - durable medical equipment
  - non-pharmaceutical alternatives to pain management
  - secondary conditions patients with physical disabilities are at risk for
  - communication techniques that prompt questions about a patient's condition
  - signs and symptoms of clinical depression
  - wellness activities for patients with physical disabilities.
  - preventive screening procedures for patients with physical disabilities.
  - I had no formal education in medical school regarding disability care.
  
5. I have ideas for improving my clinic's environment (write ideas in the space below):

This space is intended for care providers to write in their solutions.

Ideas for improvements (question 5) were not statistically measured due to the nature of the question and individuality of responses. Rather, responses from question 5 were seen as unique to care providers and are listed in Table 9.

**Clinic Access Minute Survey (CAMS).** For the purpose of investigating components of accessibility in health clinics, the *Clinic Access Minute Survey (CAMS)* was developed in partnership with AWPDP for this research project. There were few applicable survey tools in the literature that measured provider responses regarding clinic accessibility and disability. One example was found in Bachman et al.'s (2006) study, where a comprehensive, 18-item survey was developed and dispersed to 379 care providers in a variety of clinic settings. It was concluded that their tool asked questions beyond the scope of this research project's limited resources. However, due to the related nature of Bachman et al.'s study and this research

project, there were some similarities with the physical environment and equipment between their survey and CAMS.

In comparison, another survey tool discovered in the literature was one created by Lagu et al. (2013). These researchers conducted telephone interviews with 256 subspecialty clinics, asking specific questions about accommodating an obese patient with transferring needs. Their questionnaire also had similarities to CAMS in regards to the physical environment and equipment access. Lagu et al.'s tool focused more on subspecialty clinics and lacked potential areas of interest yet to be revealed by AWPDP and care providers in this current study. Hence, Lagu et al.'s tool was judged to be too restrictive for the purpose of this current study.

There were other survey tools established in the literature, such as the *Community Health Inclusion Index* (CHII) (Eisenberg et al., 2015), *ADA Checklist for Readily Available Barrier Removal* (McDonald et al., 2015), *Contact with Disabled Persons Scale* (CDP) (Pruett et al., 2008), and *Promoting Access to Health Service* (PATHS) (Suzuki et al., 2013). These tools and their respective findings have been supportive to the problem and content of this current study. In fact, they all met some aspects intended for this writer's study. Nonetheless, it was assessed that these tools did not fully align with this project's purpose or data collection plan.

### **Sampling Design**

The sample involved two different groups in this study: AWPDP and care providers. All focus group participants were AWPDP. Focus group is referred to as a face-to-face session with one or more AWPDP participants. Care providers are referred to as physicians working in health care clinics and are also referred to as providers.

**AWPDP.** Qualitative focus groups consisted of  $N =$  AWPDP living in a Midwestern state, aged 18-64 and met criterion of physical disability as defined by the U.S. Census Bureau (Brault,

2012). While the U.S. Census Bureau defined the adult age-range from age 15 to 64, there were no potential participants under the age of 18 residing at the designated disability organization setting for this current study. Three focus group sessions were conducted totaling seven focus group participants: three females and four males. The first session included one male who requested a one-on-one session. The second session included one male because the other housemates did not meet eligibility criteria. The third session included three females and two males. Participants resided at four separate assisted living homes and the third focus group session combined three of these locations due to the close proximity of home addresses. The third session was a non-segmented group and was documented as a study delimitation.

***Demographics and eligibility criteria.*** Out of five individuals excluded from the study, three were excluded because they were older than 64 years. According to the U.S. Census Bureau (2010), individuals over age 64 are classified as older adults and fall outside the age range of this study. Ages of qualifying participants ranged from 32 to 58 years with a mean age of 47.8 years. Physical disability types included cerebral palsy, stroke, lower limb amputee, arthritis, hernia, epilepsy, asthma, cancer of the thyroid and lungs, and spinal cord injury resulting in quadriplegia (see Table 4). Two participants had speech impairment; however they were able to verbally respond to questions. All seven participants used devices for mobility such as a wheelchair, cane, walker, or hemi-walker. All seven participants had at least one mobility limitation making it difficult to walk a quarter of a mile, climb a flight of stairs, lift more than 10 pounds, grasp objects, or get in and out of bed without assistance. Five participants (71.4%) had a severe disability requiring assist with mobility. Eligibility criteria qualifying participants for this study are shown in Table 3.

Table 3

*Eligibility Criteria of Focus Group Participants*

| Sample (N = 7) |                            |                         |                         |                                   |
|----------------|----------------------------|-------------------------|-------------------------|-----------------------------------|
| Age            | Uses a Mobility Device (n) | Mobility Limitation (n) | Physical Disability (n) | *Needing Assist with mobility (n) |
| 18 to 44       | 2                          | 2                       | 2                       | 2                                 |
| 45 to 54       | 3                          | 3                       | 3                       | 2                                 |
| 55 to 64       | 2                          | 2                       | 2                       | 1                                 |
| Percent        | 100%                       | 100%                    | 100%                    | 71.4%                             |

\*Indicates a severe physical disability requiring assistance with mobility in health clinics.

All seven participants reported having an escort to medical appointments by a personal care attendant or nurse working at the assisted living residence. For confidentiality and tracking purposes, focus group participants (FGP) were numbered using a code system FGP 1-7. FGP acronym is used in tables to conserve space. Table 4 shows FGP physical disability types.

Table 4

*Physical Disability Type of Focus Group Participants (FGP 1-7)*

| FGP 1              | FGP 2                                   | FGP 3                            | FGP 4          | FGP 5              | FGP 6              | FGP 7                                          |
|--------------------|-----------------------------------------|----------------------------------|----------------|--------------------|--------------------|------------------------------------------------|
| Lower limb amputee | Spinal cord injury, paralysis all limbs | Cerebral palsy, asthma, epilepsy | Cerebral palsy | Stroke, hemiplegic | Stroke, hemiplegic | Arthritis, hernia, cancer of thyroid and lungs |

**Care provider.** Quantitative surveys were mailed to one provider per selected health clinic throughout the state of Minnesota. Systematic sampling of  $n =$  every 3rd health clinic occurred due to the large volume of clinics and this investigator’s limited resources to collect and analyze data. There are currently 1,267 clinics in the Minnesota metropolitan area and 704 clinics in Greater Minnesota for a grand total of  $N = 1,971$  clinics. According to Orcher (2014), a population ( $N$ ) of 1,971 has a recommended sample size ( $n$ ) of 320 (p. 285).

Because mailed surveys typically have a low return rate, the rule for return rate for researchers with limited resources is roughly 50% (Pyrzczak, 2014, p. 58). However, Pyrczak claimed that confidence in generalizations can be increased if other researchers studying the same problem come to similar conclusions. For example, Bachman et al. (2006) and McDoom et al. (2014) studied the perspective of health care providers and health clinic accessibility. Results from their studies helped to bolster confidence in this current study and was noted in the discussion chapter accordingly. Incidentally, Bachman et al. (2006) mailed 1,040 surveys with a return rate of 379 (36%). This research project mailed 640 surveys to clinics with a return rate of 160 (25%).

**Setting.** Permission to conduct focus groups at a disability organization in the Midwest was obtained from the corresponding owner (see Appendix A). Recruitment for respondents followed, by hanging flyers (see Appendix B). Potential participants were sought out by this investigator based on their residing in assisted living and potentially needing disability-related services while at a health clinic. Consents and eligibility criteria (see Appendices C and D) were available with the flyers and were collected at the time of scheduled sessions. Focus groups took place on selected premises of the organization granting permission for use of their space for focus group activities. The disability organization is comprised of five viable homes licensed in the Midwest that provide assisted living services. Assisted Living is defined as providing “one or more regularly scheduled health-related services, and two or more regularly scheduled supportive services” (Golden Valley Assisted Living, 2017, “Assisted Living”). There was AWPD representation from four of these homes. Refreshments were provided as well as a \$25 gift card incentive for those who consented, were eligible, and joined one focus group session.

The setting for care providers involved mailing a survey to systematically selected health clinics in Minnesota. Care providers received CAMS and letter of explanation which also included a care provider consent to participate in the survey (see Appendix E). Focus groups with AWPDP took place and provider surveys were mailed after IRB approval of research with human participants was granted (see Appendices J and K).

### **Data Collection Procedures**

**Phase one: Focus groups.** After obtaining approval from Bethel University IRB to conduct research with human participants, qualitative semi-structured, open-ended questions were used to collect data from focus groups totaling seven AWPDP. Recruitment of AWPDP occurred by hanging a flyer inviting them to participate in a study that discusses their experiences in health clinics and also to assist in developing a survey for health clinic care providers. The flyer included a definition of *environment* along with contact information for this investigator. A letter of informed consent along with a form listing eligibility criteria of having at least one physical disability was provided with the recruitment flyer. Demographic data asking age, disability type, and gender was included on the eligibility form. Guardian consents were obtained prior to conducting focus groups.

At the beginning of each scheduled focus group session, the informed consent and eligibility criteria was explained by this investigator and participants were asked if there were any questions. It was emphasized that they were free to leave the session at any time without repercussions. Signed consents and eligibility forms were then collected. The purpose of the study and an overview of focus group activities were explained. It was discussed that a group consensus was needed if the session went past the allotted one-hour time frame due to disagreements or if participants wished to prolong the session. Each session lasted one hour.



The five-question focus group questionnaire was verbalized aloud along with prompts which addressed physical environments in health clinics, provider attitudes, provider disability knowledge, and ideas for improving clinic environments. All seven participants verbally responded to each question. In reply, this investigator asked if what they commented on was a concern or not, to provide uniformity of responses for future data analysis. Positioning of this investigator during sessions was deliberate to observe participant body language. Handwritten notes were taken along with audio recordings of sessions to help with accuracy (Orcher, 2014, p. 152; Patten, 2014, p. 167). However, the majority of note-taking occurred after sessions when listening back to audio recordings so this investigator could provide eye contact and pay attention to participant body language during sessions. Because there was no second coder helping to translate or interpret participant responses, a communication technique was used that repeats responses back to participants for clarity and verification of data. Sessions were conducted until saturation was reached in regards to reports of accessibility in health clinics.

It was unknown which health clinics or care providers AWPDP visited. Furthermore, AWPDP reported they had a primary provider and clinic, in addition to visiting other specialty clinics for care needs. Therefore, AWPDP responses cannot be linked to any specific care provider, nor can any care provider survey respondent be linked to any specific AWPDP patient. The fact that any direct relationships between AWPDP and care provider respondents in this study is unknown and was noted as a study limitation.

After answering the five focus group questions, participants developed response choice items for the care provider survey. There were no limitations on the amount of provider response items AWPDP chose to put on the survey. This investigator had a voice in creating the provider survey as well. Each participant received a list of the provider survey questions which

provided open spaces on the form so AWPD could use it as a visual guide to verbalize or write in response choice items adjacent to the corresponding question (see Appendix H). This tool also allowed AWPD the opportunity to provide input they might not wish to disclose verbally in a group setting. Private sessions with this investigator were also offered in addition to group sessions for those who requested it or had a physical disability that would otherwise prohibit them from sharing their input. Provider survey questions were pre-constructed by this investigator utilizing similar questions from the AWPD questionnaire. For example:

Focus group question #1 included:

1. Describe your experiences of the physical environment when you visited a health clinic.

Provider survey question #1 included:

1. The physical environment of my clinic provides the following:

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- and so on

Response choice items were formatted so providers could check all survey items that applied.

**Phase two: Provider survey.** After obtaining approval from Bethel University IRB to conduct research with human participants, collection of perceptual data from care providers began. Quantitative surveys and consents were mailed via systematic sampling of every 3rd health clinic throughout Minnesota. Clinics were identified from the 2016-2017 Minnesota Medical Directory (2016). Out of  $N = 1,971$  health clinics,  $n = 640$  surveys and consents were distributed by mail in a mass-mailing event. On October 25, 2017, surveys were mailed so that one care provider at each selected health clinic received a survey. Care providers received the survey that focus group participants created in partnership with this investigator.

As recommended by a colleague who is a physician's assistant working in a Minnesota clinic, *Attention Clinic Manager* was stamped on the front of each envelope to help direct the survey to a provider once it reached the clinic (A. Bronson, personal communication, July 27, 2016). Clinic return addresses were not required by this investigator in order to help alleviate fear of clinic recognition and in turn, boost return rate. Providers who voluntarily offered their clinic name and address shall remain confidential. Out of 640 mailed surveys, four were returned to sender unopened due to address issues or because the clinic had relocated.

Orcher (2014) remarked that surveys typically yield low response rates (p. 191). Therefore, this investigator predicted that a low response rate would occur with this research project. To increase the response rate of CAMS, Orcher suggested mailing a follow up postcard approximately two weeks after the initial survey mailing (p. 193). Another strategy recommended by Orcher to improve the response rate was to construct a brief, yet concise survey. Hence, the reason for the word *Minute* in the survey title *Clinic Access Minute Survey*.

In preparation for a potential low survey response rate, reminder postcards were designed and mailed November 14, 2017; 20 days following the initial mailing. Reminder postcards yielded 21 additional completed surveys. "Attention Clinic Manager" was also stated on the reminder postcards (see Appendix L). The final completed survey was received by this investigator on January 19, 2018. Table 5 shows clinic types systematically selected from the 2016-17 Minnesota Medical Directory (2016).

Table 5

*Clinic Types and Number of Surveys Mailed*

| Clinic Type                  | Surveys Mailed |
|------------------------------|----------------|
| Primary care                 | 309            |
| Dermatology                  | 24             |
| Allergy & Asthma             | 9              |
| Urgent care                  | 10             |
| Sleep center                 | 8              |
| Mental health/addiction care | 26             |
| Orthopedic and spine         | 29             |
| Wound/skin                   | 5              |
| Arthritis & Rheumatology     | 7              |
| Eye and eye surgery          | 36             |
| Urology/Nephrology           | 15             |
| Cosmetic/plastic surgery     | 15             |
| Cancer treatment center      | 32             |
| Diagnostic Imaging           | 4              |
| Pain                         | 10             |
| Ob/GYN and reproductive      | 24             |
| Gastroenterology             | 9              |
| Foot & Ankle                 | 4              |
| Heart, vascular, and lung    | 22             |
| ENT                          | 4              |
| Neurology                    | 12             |
| Infectious Disease           | 4              |
| Bariatric                    | 4              |
| Surgical clinic              | 10             |
| Occupational Medicine        | 5              |
| Endocrine/diabetes           | 3              |
| Total                        | 640            |

*Note.* It is not known which clinics returned a survey.

Out of 640 mailed surveys, 161 were returned for a 25% response rate. One survey was eliminated because the provider noted their clinic only saw patient tissue samples, not patients. This left a grand total of 160 surveys to be analyzed. For confidentiality and tracking purposes, each returned care provider (CP) survey was numbered using a coding system CP 8-167. CP acronym is used in tables to conserve space. Providers were asked to check all items that applied and return CAMS to this investigator. Checking an item on the survey indicated they provided

that item in their clinic. Leaving an item unchecked on the survey indicated the provider did not provide that item in their clinic. Data collected from CAMS were organized in one of five categories: Physical Environment, Medical Equipment, Attitudinal, Disability Knowledge, and Ideas for Improvement.

### **Field Test**

A field test was performed by emailing the focus group questionnaire and partially constructed survey to dissertation committee designees and one colleague in the fall of 2016. Feedback was positive and offered no adaptations. It was noted that the provider survey was preliminary and response choice items were only speculated to give the reader an illustration of what the survey might look like. Final response choice items were missing at that time because they were dependent on AWPD input, which had not occurred yet.

### **Data Analysis**

**Phase one: Focus groups.** Qualitative data collected from three focus group sessions with AWPD were hand sorted from notes and audio recordings, and then categorized per comment in one of the five categories: Physical Environment, Medical Equipment, Attitudinal, Disability Knowledge, and Ideas for Improvement. For example, this investigator listened to audio recordings of group sessions and transcribed participant comments onto paper. When participants discussed the physical environment of health clinics, this investigator wrote those comments on paper under the Physical Environment category. Handwritten notes taken during focus group sessions were also sorted and organized per comment under one of the five discussed categories. Notes were written in chronological order according to the flow of the questionnaire which made sorting comments into their respective categories manageable. Each of the five questions on the questionnaire signified a category. Common themes were discovered

during this process and synthesized for the reader in Table 6. Participant quotes and paraphrased statements are presented in the findings. No computer software was used to transcribe notes or audio recordings.

Common themes were further broken down into frequencies and itemized in one of four categories (see Table 7). The fifth category, Ideas for Improvement was excluded from Table 7 because participant ideas were not quantified. Handwritten notes taken from audio recordings and group sessions confirmed who and how many participants reported an issue as a concern or not. For example, when five participants ( $n = 5$ ) stated that entering a building in their wheelchair was a concern, this investigator consolidated those statements into the item titled *wheelchair-accessible building entrance* under the category Physical Environment. Thus, five participants reported wheelchair-accessible building entrance as a concern. The symbol  $n$  signifies the number of focus group participants within the total sample of seven. All seven participants agreed with how this investigator interpreted and assisted with the formation of the items they chose to include on the care provider survey. In all, 26 issues were consolidated into 26 items for the care provider survey. A rough draft of these items had already been discussed with participants and written down when developing the care provider survey during focus group sessions. Tables 6 and 7 were created after focus group sessions and content were reviewed for accuracy. Table 7 shows items that were central issues for focus group participants, which were then transposed into survey response choice items for care providers.

In addition, participant comments needed to be quantified into numerical data for purposes of tracking focus group responses and to calculate frequencies. The 26 issues that participants reported during focus group sessions coincided with response choice items they developed for the care provider survey. These 26 issues were entered as data into a spreadsheet

in Statistics Open For All (SOFA) (2017). The SOFA system is designed to work with raw data and “is recommended by Bethel University for statistical analysis of survey data” (S. Paulson, personal communication, March 21, 2018). The method used in this research project is as follows. The first column listed SOFA ID (participant identification number). The second column listed group name (group 1, Focus Group). The next 26 consecutive columns listed four categories as variables with corresponding items:

- Physical Environment (PE): PE 1 (wheelchair-accessible building entrance), PE 2 (wheelchair-accessible push-button door), PE 3 (wheelchair-accessible restroom), PE 4 (grab bars in restrooms), PE 5 (wheelchair-accessible route to exam room), PE 6 (wheelchair maneuverability in exam room);
- Medical Equipment (ME): ME 1 (wheelchair-accessible weigh scale), ME 2 (wheelchair-accessible mammography), ME 3 (height-adjustable exam table), ME 4 (wheelchair-accessible laboratory), ME 5 (flexible x-ray equipment), ME 6 (flexible stirrups on exam table), ME 7 (mechanical lift);
- Attitudinal (A): A 1 (discussing health-related issues), A 2 (referrals to other clinics), A 3 (listening to patients), A 4 (problem-solving with patients), A 5 (satisfaction with clinic staff); and
- Disability Knowledge (DK): DK 1 (disability care), DK 2 (durable medical equipment [DME]), DK 3 (pain management), DK 4 (secondary conditions), DK 5 (communication techniques), DK 6 (clinical depression), DK 7 (wellness activities), and DK 8 (preventive screening).

Category five, Ideas for Improvements, was discussed in focus groups and not entered into SOFA. Ideas were summarized from notes and audio recordings, and added to Table 6.

Next, the spreadsheet had rows in which the participant's assigned identification (ID) number, group, and response was entered. For example, under the first column, the number assigned to focus group participants was entered into seven consecutive rows to reflect the seven participants (1-7). Under the second column, the group name (group 1, Focus Group) corresponded with their designated SOFA ID numbers FGP 1-7. Moving from left to right across each participant row, participant responses were entered under the category columns and assigned with either 2.0 for *Concern* or 1.0 for *No Concern*. In all, 182 focus group responses were hand entered into the SOFA spreadsheet as either 2.0 or 1.0.

From the four categories and 26 corresponding items entered into the spreadsheet in SOFA (2017) software, frequencies were performed using SOFA Statistics version 1.4.6. Frequencies calculated sample percentages to summarize sets of data. No direct comparisons were made between AWPD and care provider results.

**Phase two: Provider survey.** Quantitative data from completed care provider surveys were categorized per item and entered by hand into SOFA (2017) software using the same spreadsheet that was constructed and used to enter focus group participants' numerical data. Care provider data entry began following a time lapse of roughly one week after the initial survey mailing and continued after postcard reminders were mailed. The care provider survey included 26 response choice items that were issues reported by focus group participants and developed for the survey. Care provider data were entered in the SOFA spreadsheet using the following method: The first column listed SOFA ID (provider identification number), which began with the number eight because it followed the seventh and last focus group participant ID entry. The second column (group name) continued from the last Focus Group entry, which now began with the new listed group name (group 2, Care Provider). The consecutive 26 columns



were already labeled with the four categories and corresponding items because they were used for focus group participant data entry: PE (Physical Environment) items 1-6, ME (Medical Equipment) items 1-7, A (Attitudinal) items 1-5, and DK (Disability Knowledge) items 1-8.

Although Ideas for Improvement was the fifth category and represented question 5 on the care provider survey, provider ideas were not entered in SOFA for statistical analysis due to the nature of the question and individuality of responses. Provider ideas for improvement were transcribed from written statements on surveys and are shown in Table 9. Furthermore, three additional items, PE 7, ME 8, and DK 9 that were developed by focus group participants and unique only to care providers, were not entered into the SOFA spreadsheet. The checked boxes of these items from each returned survey were hand counted and tracked on paper. A calculator computed the percentage of 160 providers who checked and did not check the boxes. Items PE 7, ME 8, and DK 9 were examined using descriptive analysis and are presented in the findings.

Next, data from care provider surveys were entered in the rows of the SOFA spreadsheet. Each survey that was returned was added under the first column (SOFA ID) in order to be assigned a number. This produced consecutive rows 8-167 to reflect all 160 care providers. Under the second column, the group name (group 2, Care Provider) corresponded with their designated SOFA ID numbers CP 8-167. Items checked on the survey indicated providers provide that item in their health clinic and were assigned number 2.0. Items that were not checked on the survey indicated providers did not provide that item and were assigned number 1.0. Therefore, moving left to right across each care provider row, care provider responses were entered under each categorical item and assigned with either 2.0 for *Provide* or 1.0 for *Not Provide*. In all, 4,160 response choice items were hand entered into the SOFA spreadsheet as either 2.0 or 1.0.

From the four categories and 26 corresponding response choice items entered into the spreadsheet in SOFA (2017) software, frequencies were performed using SOFA Statistics version 1.4.6. Frequencies calculated sample percentages to summarize sets of data. No direct comparisons were made between care provider and AWPDP results.

### **Limitations of Methodology**

This study has several limitations. First, this study did not represent people with disabilities under the age of 18 or over the age of 64. Second, the nature of disability was limited to the physical domain of disability and to focus group participants who could speak on their own behalf; hence, generalizability was not possible for all persons with disabilities or all disability types. Third, this study excluded people without disabilities and also excluded individuals residing in states other than Minnesota. Fourth, this study did not represent people with disabilities living in long-term care settings and prisons because these populations exist in different national data sources. Fifth, focus group and survey responses were from limited self reports and not from national governmental data sources. Sixth, data from AWPDP did not knowingly coincide with responses from any particular care provider or health clinic. Therefore, direct relationships cannot be made between the two groups or health clinics. Seventh, this investigator has bias towards AWPDP, primarily because of a previous working history in public health and observing a variety of obstacles that many people with disabilities encountered. Eighth, no direct comparisons were made with AWPDP and care provider results. Lastly, care providers working in long-term care facilities or hospitals did not receive a survey.

**Delimitations.** One delimitation is that focus groups were not segmented. However, it did not seem to hinder gender-specific responses because participants freely spoke about gender-specific items. Another delimitation is regarding dependable results of focus group data because

data were only interpreted by one researcher. However, this investigator used a communication technique that repeated information back to participants. In addition, the finished survey product was brought to each participant to review one week following the focus group sessions. No changes needed to be made according to participant feedback.

### **Ethical Considerations**

This study has ethical considerations because research was conducted with human subjects. One way to protect humans in research is to follow the three main ethical principles governed by *The Belmont Report* (DHHS, 1979). The first of these principles is *respect for persons*, meaning a researcher must respect the autonomy of others and protect participants who have weakened autonomy. This study involved adults with physical disabilities, which required approval from Bethel University's Institutional Review Board (IRB) prior to conducting focus group interviews. Likewise, a second IRB approval was required to mail surveys to health clinic care providers. All human subjects were provided a consent explaining that their participation was voluntary, and were informed of the study's subject matter and any risk involved.

Participants were free to discontinue the study at any time without repercussions.

The second ethical principle is *beneficence*, which means a researcher will not induce harm upon human subjects and that any potential benefits will be maximized (DHHS, 1979). Although this was not an experimental study, focus group participants were exposed to potentially sensitive information from other participants and therefore those responses could not be controlled by the researcher. A statement of this nature was included in the consent and the IRB was made aware during the study approval process. Individual health clinic care providers received the survey addressed to the clinic they worked in and had less risk of group think or exposure to other people's comments. However, it is unknown if they interpreted the survey

questions as offensive and therefore could review the consent and questions and opt out if they chose to. Additionally, data from care providers were protected in a secured office at the investigator's home with plans to be destroyed no later than October 1, 2018, approximately one year past the data analysis phase of the surveys.

The third ethical principle is *justice*, or "fairness in distribution" (DHHS, 1979, p. 6). Focus group sample sizes are typically small; however recruitment flyers invited any individual to attend the study that met inclusion criteria, and resided at the selected organization serving people with physical disabilities. Health clinic care providers were not targeted individually; rather, their clinic was systemically selected from the Minnesota Medical Directory (2016). All human subjects were treated equally and any possible benefits of the research are intended to serve individuals outside the physically disabled population as well.

### **Summary**

A transformative mixed methods approach provided the framework for this study. Few of these research designs exist in the literature; however, it is a growing body of literature partially to give underrepresented groups a voice about central issues that affect their lives. Thus, including AWPD in developing the care provider survey provided a genuine representation of a disability community in regards to accessibility of health clinics. Data collection involved conducting focus groups to explore AWPD experiences in health clinics, followed by surveying care providers about what they provide for AWPD. The 29-item survey CAMS completed by care providers was developed by AWPD in partnership with this investigator. A field test of these instruments produced positive feedback with no recommendations for improvement. A descriptive statistics research design strategy was used to summarize sets of data and provide evidence that warrants an instructional need for disability curricula in medical education.

## Chapter Four: Results

### Introduction

Providing evidence for health and education communities is essential to justify the need for disability content in health professional education. Before clinic environments and services can be improved to meet AWPB health needs, it would be prudent for care providers and educators to first understand access issues AWPB have in health clinics. Therefore, it was important to find out what the central issues are for AWPB regarding access to care and also to find out what care providers are providing in their clinics regarding care for AWPB. Data are intended to inform health and education leaders about gaps in education and the need for disability curricula. Findings in this study are presented in two phases. Phase one show qualitative findings from focus group sessions and highlights common themes in five categories. Common themes were further broken down into aggregate data to help guide the development of the provider survey, CAMS. Phase two show quantitative findings from providers who completed CAMS. No direct comparisons were made between the two groups.

### Findings

**Phase one: Focus groups.** Recruitment of focus group participants began September 14, 2017 with immediate response from 12 interested potential study prospects. Of these 12 prospects, five did not meet eligibility criteria or guardians did not return the informed consent. A total of seven candidates met eligibility criteria in which four guardian consents were required and obtained for these individuals. During focus group sessions, five questions were verbalized to participants that addressed environmental factors of physical environments, attitudes, disability knowledge, and asked for improvement ideas. All participants were AWPB.

***FGP Question 1: Physical environment.*** The first study question asked focus group participants to describe their experiences of the physical environment when they visited a health clinic. Prompts used by this investigator included asking how participants entered a building and navigated the wait area, examination room, and restroom. Common themes that emerged from participant discussions were concerns with building entrances ( $n = 5, 71.4\%$ ), push-buttons to open doors ( $n = 5, 71.4\%$ ), restroom accessibility ( $n = 5, 71.4\%$ ), grab bars in restrooms ( $n = 5, 71.4\%$ ), route to exam rooms ( $n = 5, 71.4\%$ ), and maneuverability in exam rooms ( $n = 5, 71.4\%$ ). All five participants who used a wheelchair for mobility commented that exam rooms are small and difficult to maneuver. Participants reported, “They don’t leave much room for wheelchairs at all” (FGP 3), and “They’re very narrow” (FGP 4). Three other participants (FGP 2, 5, 6) voiced they needed staff assistance to help navigate tight spaces by pushing their wheelchairs through the building entrance, through the wait area, and into the exam room.

Furthermore, FGP 3 reported that one of the clinics they visit on a regular basis does not have a push-button to open the door. Once inside the building, “Entry ways and hallways are very narrow. I can maneuver but it is very difficult” (FGP 3). In addition, several participants agreed that many clinics have push-buttons, yet they are not wheelchair accessible, and some suites had no push-buttons. Building entrances and navigating clinic spaces were reported as no concern for FGP 7 and FGP 1 said there is “plenty of room.”

Participants also voiced concerns with clinic restrooms. Most participants who used a mobility device agreed that not all restrooms are handicapped accessible. “They lie” (FGP 3 and FGP 4) about being accessible and there is “not even a grab bar,” “need two,” and placed in a user-unfriendly manner (FGP 3 and FGP 7). FGP 3 added, “The stall is so small it’s almost

pathetic.” In addition, FGP 3, 4, 5, and 6 who used a wheelchair for mobility stated they could not access the bathroom sink. Restrooms and grab bars were no concern for FGP 1 or FGP 2.

***FGP Question 2: Medical equipment.*** The second study question asked participants about their experiences with medical equipment. Prompts used by this investigator included how participants transferred to the examination table, weigh scale, and x-ray equipment. Common themes that emerged when discussing this category showed participants were concerned with the absence of wheelchair-accessible weigh scales ( $n = 5, 71.4\%$ ), mammography equipment ( $n = 4, 57.1\%$ ), height-adjustable exam table ( $n = 6, 85.7\%$ ), accessibility in laboratories ( $n = 2, 28.6\%$ ), flexibility of x-ray equipment ( $n = 6, 85.7\%$ ), flexible exam table stirrups ( $n = 3, 42.9\%$ ), and availability of a mechanical lift ( $n = 5, 71.4\%$ ). Although participants brought their own personal care staff to appointments, all participants who used wheelchairs for mobility reported having examinations while sitting in their wheelchair. In regards to getting on an examination table, one respondent reported, “That hardly ever happens” (FGP 2). FGP 3 stated there was a height adjustable table at the clinic, yet claimed clinic staff is not allowed to transfer patients.

Furthermore, the five wheelchair-bound participants reported there was no mechanical lift available for their accompanying personal care attendant to transfer them onto an exam table. FGP 5 replied that because there was no mechanical lift to transfer onto the examination table, the clinic provided a floor matt to lie on in order for the provider to check an alleged reddened area of the buttocks. Discussion about availability of height-adjustable exam tables revealed that six participants reported the absence of this equipment in the primary clinic they visit.

Availability of a height-adjustable exam table was reported as no concern by FGP 1.

Participants also voiced their concerns about weigh scales. One respondent said, “I haven’t been weighed in a long time” (FGP 2). This is especially important because a current

weight is required for obtaining certain durable medical equipment (DME) items and this individual is in the process of getting a new wheelchair. FGP 2 said, “I think my weight is around 200 but” an exact weight will be needed to attain the wheelchair. For this reason, FGP 2 further replied they will need to go to the hospital and use their wheelchair weigh scale. Even if someone is not in the process of obtaining DME, one participant said, “I want to know what I weigh” (FGP 3). FGP 3 added, “It drives me nuts. My primary physician only has a scale for ambulatory patients. I’m not the only wheelchair-bound patient you treat.” Availability of a weigh scale was reported as no concern for FGP 1 and FGP 7.

Participants went on to discuss x-ray equipment. FGP 3, 4, 5, and 7 reported needing wheelchair-accessible mammography equipment because of mobility limitations with standing. FGP 3 and FGP 4 reported they will not be able to get this screening procedure until they learn of a clinic that can accommodate mammograms for patients in wheelchairs. Another respondent needed a bone x-ray and reported needing to go to the hospital for accommodations saying, “They put me on a bed and wheeled me into the x-ray room” (FGP 2). Participants voiced x-ray tables should be larger because “they’re too narrow” (FGP 3 and FGP 4), and, clinics should “try and get more [financial] assistance with equipment that is easier not only for the doctors, but for the patients as well” (FGP 3). Participants also discussed needing flexible x-ray equipment to accommodate mobility limitations and limbs with deformities, flexible stirrups on exam tables to aid positioning for pap smears, and needing wheelchair accessibility to lab equipment for blood draws. FGP 1 reported having “no problems” with medical equipment in health clinics.

***FGP Question 3: Attitudinal.*** The third study question asked participants to describe their relationship with their care provider. Prompts used by this investigator included asking participants if they were able to freely discuss issues with their care provider, if they received



referrals to other providers, and if they were satisfied with how clinic staff responded to their needs. This investigator described clinic staff as staff other than providers, such as receptionists and nurses. The tone changed when this question was asked to participants from all three focus groups. Participants were lively and spirited throughout the first two questions and became more serious as the questions progressed. The first common theme that emerged from this category was an overwhelming response of concerns discussing health-related issues with providers ( $n = 7, 100\%$ ). Additional themes were discovered when participants also reported concerns with obtaining referrals to other clinics ( $n = 6, 85.7\%$ ), providers listening to patients ( $n = 5, 71.4\%$ ), and problem-solving with providers ( $n = 5, 71.4\%$ ). In addition, an overwhelming response was in favor of clinic staff meeting needs of participants and reported no concerns ( $n = 7, 100\%$ ).

All seven participants reported concerns discussing health-related issues with providers due to various reasons. Examples included responses from FGP 1 who said there was “not enough time” to discuss issues with the provider during appointments because “it’s pretty fast.” FGP 2 and FGP 5 said they could discuss any issue only if it was initiated by the nurse or personal care attendant who escorted them to the clinic. FGP 4 and FGP 6 are individuals with impaired speech who simply reported “No!” in response to being able to freely discuss issues with their care provider. Another participant reported that they “cannot discuss anything with their doctor” because the doctor “didn’t listen to a word I said” (FGP 3).

FGP 3, 4, 5, 6, and 7 reported that providers did not listen to them or problem-solve issues with them. Only one participant reported their primary provider includes them in patient care decisions and asks, “What’s your opinion on this?” (FGP 3). This same participant added that “others [providers] say here’s the pills, bye.” Other comments included, “many doctors don’t listen” (FGP 3), the “doctor is more focused on paperwork” (FGP 7), and “they make you

feel stupid” (FGP 4). FGP 3 reported, “Sometimes when I do ask the doctors questions, sometimes I get the feeling that they think that just because I’m disabled I’m stupid too.” This investigator asked the participant to further explain what made them feel stupid. The response was that FGP 3 was “wrongly diagnosed” and “it took 12 years to find someone [provider] who would listen to what I was saying.” FGP 7 added, “It’s [listening] very important. If you can’t discuss anything with your doctor then something’s up.” In a serious tone and facial expression, FGP 7 further stated, “They act like you’re a disease.” FGP 3 validated this statement by repeating it, “Yeah, they act like you’re a disease.”

Six participants could not recall being offered referrals by their care provider for other services, equipment, programs, or other clinic options unless it was addressed by the patient or care attendant. FGP 1 said there is “not enough time” to discuss referrals. Additionally, FGP 3 commented that referrals by providers would be helpful because “patients do not always know what resources are out there.” FGP 5 added that “Docs need to do a better job in asking questions” to help guide them in making appropriate referrals for patients. FGP 3, 4, and 5 further commented that they would like their doctor to talk to them more about clinical depression. FGP 3, 4, and 5 went on to say providers gave no referrals for psychiatry, nor discussed mental health with them. One participant stated it would be helpful to at least get a referral to a counselor. By contrast, one participant reported that if their primary care provider does not know the answer to something or cannot provide a service they will refer to someone who can.

Comments regarding depression were not anticipated by this investigator and surfaced without prompts during this study question. Interestingly, depression was brought up by two

separate focus group sessions when discussing referrals. One could speculate that the discussion about lack of referrals by providers was the trigger for comments about clinical depression.

Aside from what focus group participants said about discussing issues with providers, participants were asked if they were satisfied with how other clinic staff responded to their needs. Participants offered statements commending clinic staff. Responses included, “staff brings me coffee” (FGP 2), “no problems with staff” (FGP 1), and “staff is really good at clinics; they respond to needs” (FGP 7). FGP 4, 5, and 6 nodded their head in agreement that they were satisfied with clinic staff. Furthermore, one participant reported:

Staff are really nice at a lot of the clinics I go to. They’re really, really nice. At all the clinics I’ve gone to they’re really sweet. I go to [said clinic] and all the staff there are really nice. I like ‘em all. Yep, the receptionist, the nurses at the [said center] are really, really nice. And um, the physician assistants and everybody are really respectful. I like them a lot. (FGP 3)

All seven participants reported no concerns with how clinic staff responded to their needs while at a clinic visit. Furthermore, FGP 3, 4, 5, 6, and 7 voiced they had no concerns with environmental factors at a particular dentist office and disability center they visit, which will remain unnamed in this research project for the purpose of confidentiality.

***FGP Question 4: Disability knowledge.*** The fourth study question asked participants to describe at least one example of how they thought their care provider was knowledgeable in what they felt were important aspects of their disability care. Prompts used by this investigator included asking participants if providers discussed durable medical equipment (DME) needs, if providers gave recommendations for prevention of health problems, and if providers discussed wellness activities or preventive screening procedures during clinic visits. Common themes that

emerged when discussing this category showed participants perceived providers lacking knowledge in disability care ( $n = 5$ , 71.4%), DME ( $n = 6$ , 85.7%), non-medication alternatives for pain management ( $n = 2$ , 28.6%), secondary conditions in patients with physical disabilities ( $n = 6$ , 85.7%), communication skills ( $n = 6$ , 85.7%), recognizing clinical depression in patients ( $n = 3$ , 42.9%), and preventive screening procedures ( $n = 6$ , 85.7%). Participants overwhelmingly perceived provider knowledge in wellness activities as no concern ( $n = 7$ , 100%).

Out of seven participants, five reported their provider is not knowledgeable in their specific disability type. One participant said, “My physician is really nice but not knowledgeable in CP [cerebral palsy]” (FGP 3). FGP 4 agreed with FGP 3’s comment. This investigator asked participants if they have considered changing to a provider who specializes in their disability type. FGP 7 responded with, “It’s sticky to change providers because of your care plan and medical insurance. It’s the system.” By contrast, FGP 2 commented that a nurse from the assisted living residence escorts the participant to clinic visits prepared with a list of questions to assist the provider in addressing current needs of the participant. FGP 2 went on to say the “doctor is knowledgeable” in responding to needs that are addressed by the accompanying nurse regarding disability care. FGP 1 commented that there were no concerns with provider knowledge and their disability care.

Participants also discussed items of DME they perceived as important for their particular physical disability. For example, wheelchair, walker, oxygen, hemi-walker, cane, shower bench, and diabetic shoes were equipment reported as currently being used by participants. Six participants responded that DME was not addressed by their provider during clinic appointments. One participant voiced that by the time DME is brought to the provider’s attention, “it’s in need

of repair” (FGP 7). “Timing is important because equipment wears out and takes a long time to get new equipment” (FGP 3).

When asked about wellness activities, one participant reported their provider suggested ways to improve health, such as “quitting smoking” (FGP 7). Other participants’ responses for improving health included: “My doctor watches me for diabetes because it runs in my family” (FGP 2), “I am offered a flu shot” (FGP 2), “My doc encourages me to exercise” (FGP 3), “My clinic checks for cholesterol” (FGP 2 and FGP 5), and “He told me to do P.T. [physical therapy] at the [said center]” (FGP 5). In addition, FGP 3, 4, 5, 6, and 7 voiced they are offered yearly flu shots at their clinic. Six participants reported examples of wellness activities provided by their provider and one participant said wellness was “no problem” (FGP 1). Overall, all seven participants perceived provider recommendations for wellness activities as no concern.

By contrast, preventive screening for cancers was a concern for six participants, saying they did not know what it was, nor did their provider discuss this with them. This investigator gave examples, such as a colonoscopy and mammogram procedures. Four focus group participants were over the age of 50 and reported never having a colonoscopy. In regards to colonoscopy, FGP 2 said, “What’s that?” FGP 7 reported obtaining routine mammograms.

Another concern discussed by most participants was in regards to secondary conditions. “I don’t think my physician is knowledgeable in my unique needs and that kind of makes me a little disappointed” (FGP 3). FGP 4 nodded in agreement. When asked to expand on this statement, FGP 3 said, “My doctor does not talk to me about skin breakdown.” The participant went on to explain that a skin condition which was not looked at was prescribed a cream that did not work. The skin condition “got two times worse” and the participant had to return to the clinic. FGP 2 also reported that skin breakdown is not addressed during a clinic visit.

In addition to skin breakdown, other examples of secondary conditions not being addressed by providers according to six participants were pain, fatigue, and muscle atrophy. “They [providers] need to be more knowledgeable in secondary conditions” (FGP 3). FGP 3 and FGP 4 discussed having pain and did not want pharmaceuticals for relief. They reported providers being willing to prescribe “pills” versus offering non-medication alternatives to pain management. “They won’t give alternatives” (FGP 4). None of the participants elaborated on fatigue, however FGP 3 commented on muscle atrophy, “I’ve gone to him [provider] and said my muscles are atrophying and he looks at me like he’s a deer caught in the headlights like he has no clue.” Limb contractures were visibly noticeable in four other participants.

Participants also voiced they would like providers to be more knowledgeable in recognizing signs and symptoms of clinical depression. FGP 4 stated, “They don’t fix” and “I take meds.” FGP 3 said, “I do too.” FGP 5 said “I used to. I quit the meds. They don’t really help at all.” Furthermore, FGP 3 explained that the doctor did not provide information about how bad the depression would get and “I spiraled down so deep that I became suicidal twice. My new doctor said if you experience any depression symptoms I want you to come back and talk to me and I’ll refer you to a psychiatrist.” FGP 2 admitted not receiving referrals, however, “They check me for psychological.”

Out of seven participants, six commented on the need for providers to be more knowledgeable in communication skills. Examples of responses included: “They need to do a good job asking me questions” (FGP 5); “They need to be willing to listen” (FGP 3); and “Listening, that’s the biggest one” (FGP 7). FGP 7 further commented that although the provider stated at a clinic visit, “This is your time,” the participant felt that the provider’s focus was on paperwork. In addition, FGP 2 said they “wish staff would talk in short sentences” to

better understand the information being said during the visit. In lieu of these comments, participants developed a response choice item for the care provider survey regarding communication techniques that prompt questions about a patient's condition.

***FGP Question 5: Ideas for improvement.*** The fifth and final study question asked participants about ideas for creating an improved health clinic environment. Participants suggested that clinics update their physical environment and equipment to be “suitable” for patients with physical disabilities and mobility limitations (FGP 3 and FGP 7). Examples included widening the exam rooms for easier wheelchair maneuverability, providing height-adjustable tables to aid in examinations, and providing mammography equipment that can be lowered to accommodate patients in wheelchairs and with standing limitations. Participants also indicated mandatory education for providers in overall disability care principles; DME needs and process; pain management with alternative therapies to medication; secondary conditions people with disabilities are at risk for such as skin breakdown, pain, and muscle atrophy; clinical depression and recognition of signs and symptoms; and enhancing communication skills that prompt questions about a physically disabled patient's condition to help identify care needs.

Another suggestion discussed by participants was to add a referral component to clinic visits that addresses secondary conditions, mental health and psychiatry needs, and availability of community resources. Examples of community resources for people with physical disabilities included exercise programs, support groups, and recreational classes (e.g., art classes). Several participants also voiced that providers could offer suggestions regarding preventive screening for cancers, offer other clinic options if their primary clinic cannot accommodate for their physical disability, and make suggestions for additional services that could improve quality of life. One participant voiced that health clinics need to increase the appointment time allotted for visits.

**Common themes.** Common themes were identified among all three focus group sessions during qualitative data analysis. It was interesting to see that similar concerns with the physical environment and medical equipment often reflected a participant's mobility limitation or use of a mobility device; whereas concerns with attitudinal and disability knowledge often reflected participant disability type. Common themes aided in the development of survey response choice items because themes were further broken down into frequencies and itemized into four predetermined categories, and participant ideas for improvements in the fifth category. For example, AWPD reported six issues in the clinic physical environment, seven issues with medical equipment, five issues regarding provider attitudes, and eight issues regarding provider disability knowledge. In all, 26 main issues were summarized from qualitative findings and show the reader in Table 6. Itemization and frequencies of these 26 issues are shown in Table 7.



Table 6

*Common Themes Identified from Focus Group Sessions*

| Physical Environment                                                                      | Medical Equipment                                                                               | Attitudinal                                                                  | Disability Knowledge                                                                                                     | Ideas for Improvement                                                                                                                                         |
|-------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Wheelchair accessibility to building entrances, restrooms, and exam rooms is problematic. | Absence of wheelchair accessible: weigh scale, mammography equipment, and laboratory equipment. | Participants do not discuss issues with providers for various reasons.       | Providers lack knowledge in disability care, DME, pain management, secondary conditions, and clinical depression.        | Update clinic environment and equipment to be suitable for patients with physical limitations.                                                                |
| Clinics lack push-buttons to open doors or are not wheelchair accessible.                 | Absence of height-adjustable exam table.                                                        | Providers do not refer patients to other services, programs, or specialists. | Providers lack communication techniques in question-asking.                                                              | Mandate education for providers in disability care, DME, pain management, secondary conditions, communication, clinical depression, and preventive screening. |
| Clinics lack grab bars in restrooms.                                                      | Need flexible equipment, e.g., x-ray and stirrups on exam tables.                               | Providers do not listen to patients.                                         | Providers suggest ways to improve health, e.g., flu shot, quit smoking, exercise, and check cholesterol and blood sugar. | Add a referral component to clinic visits that addresses secondary conditions, psychiatry, and community resources.                                           |
| Wheelchair maneuverability is difficult in exam rooms; space is narrow.                   | No mechanical lift.                                                                             | Providers do not problem-solve issues with patients.                         | Providers do not address preventive screening measures.                                                                  | Offer suggestions for preventive screening, other clinic options, and services.                                                                               |
|                                                                                           |                                                                                                 | Participants are satisfied with how clinic staff responds to their needs.    |                                                                                                                          | Increase appointment time.                                                                                                                                    |

Table 7

*Itemized Focus Group Central Issues in Health Clinics and Frequency*

|                                                                                                                                                                                                                                       |                                             | Sample (N = 7)   |                     |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------|------------------|---------------------|
| Category                                                                                                                                                                                                                              | *Item                                       | Concern<br>n (%) | No Concern<br>n (%) |
| Physical<br>Environment (PE)<br><i>FGP question 1:<br/>Describe your experiences<br/>of the physical<br/>environment when you<br/>visited a health clinic.</i>                                                                        | 1. Wheelchair-accessible building entrance  | 5 (71.4%)        | 2 (28.6%)           |
|                                                                                                                                                                                                                                       | 2. Wheelchair-accessible push-button door   | 5 (71.4%)        | 2 (28.6%)           |
|                                                                                                                                                                                                                                       | 3. Wheelchair-accessible restroom           | 5 (71.4%)        | 2 (28.6%)           |
|                                                                                                                                                                                                                                       | 4. Grab bars in restrooms                   | 5 (71.4%)        | 2 (28.6%)           |
|                                                                                                                                                                                                                                       | 5. Wheelchair-accessible route to exam room | 5 (71.4%)        | 2 (28.6%)           |
|                                                                                                                                                                                                                                       | 6. Wheelchair maneuverability in exam room  | 5 (71.4%)        | 2 (28.6%)           |
| Medical<br>Equipment (ME)<br><i>FGP question 2:<br/>Tell me about your<br/>experiences with medical<br/>equipment.</i>                                                                                                                | 1. Wheelchair-accessible weigh scale        | 5 (71.4%)        | 2 (28.6%)           |
|                                                                                                                                                                                                                                       | 2. Wheelchair-accessible mammography        | 4 (57.1%)        | 3 (42.9%)           |
|                                                                                                                                                                                                                                       | 3. Height-adjustable exam table             | 6 (85.7%)        | 1 (14.3%)           |
|                                                                                                                                                                                                                                       | 4. Wheelchair-accessible laboratory         | 2 (28.6%)        | 5 (71.4%)           |
|                                                                                                                                                                                                                                       | 5. Flexible X-ray equipment                 | 6 (85.7%)        | 1 (14.3%)           |
|                                                                                                                                                                                                                                       | 6. Flexible stirrups on exam table          | 3 (42.9%)        | 4 (57.1%)           |
|                                                                                                                                                                                                                                       | 7. Mechanical lift                          | 5 (71.4%)        | 2 (28.6%)           |
| Attitudinal (A)<br><i>FGP question 3:<br/>Describe your relationship<br/>with your provider.</i>                                                                                                                                      | 1. Discussing health-related issues         | 7 (100%)         | 0                   |
|                                                                                                                                                                                                                                       | 2. Referrals to other clinics               | 6 (85.7%)        | 1 (14.3%)           |
|                                                                                                                                                                                                                                       | 3. Listening to patients                    | 5 (71.4%)        | 2 (28.6%)           |
|                                                                                                                                                                                                                                       | 4. Problem-solving with patients            | 5 (71.4%)        | 2 (28.6%)           |
|                                                                                                                                                                                                                                       | 5. Satisfaction with clinic staff           | 0                | 7 (100%)            |
| Disability<br>Knowledge (DK)<br><i>FGP question 4:<br/>Describe at least one<br/>example of how you think<br/>your care provider is<br/>knowledgeable in what<br/>you feel are important<br/>aspects of your disability<br/>care.</i> | 1. Disability care                          | 5 (71.4%)        | 2 (28.6%)           |
|                                                                                                                                                                                                                                       | 2. Durable medical equipment (DME)          | 6 (85.7%)        | 1 (14.3%)           |
|                                                                                                                                                                                                                                       | 3. Pain management                          | 2 (28.6%)        | 5 (71.4%)           |
|                                                                                                                                                                                                                                       | 4. Secondary conditions                     | 6 (85.7%)        | 1 (14.3%)           |
|                                                                                                                                                                                                                                       | 5. Communication techniques                 | 6 (85.7%)        | 1 (14.3%)           |
|                                                                                                                                                                                                                                       | 6. Clinical depression                      | 3 (42.9%)        | 4 (57.1%)           |
|                                                                                                                                                                                                                                       | 7. Wellness activities                      | 0                | 7 (100%)            |
|                                                                                                                                                                                                                                       | 8. Preventive screening                     | 6 (85.7%)        | 1 (14.3%)           |

\* Items were transposed into survey response choice items for care providers.

**Phase two: Provider survey.** Out of 640 surveys mailed to care providers, 160 surveys (25%) were completed and returned. Five survey questions addressed environmental factors of physical environments, attitudes, disability knowledge, and asked for improvement ideas.

***CP Question 1: Physical environment.*** The first survey question asked care providers about the physical environment of their clinic and included seven items. Most providers responded that they provide a wheelchair-accessible building entrance ( $n = 157, 98.1\%$ ), wheelchair-accessible restrooms ( $n = 153, 95.6\%$ ), grab bars in restrooms ( $n = 154, 96.3\%$ ), wheelchair-accessible route to examination rooms ( $n = 154, 96.3\%$ ), and wheelchair-accessible push-buttons to open doors ( $n = 136, 85\%$ ). Some providers added written notes about push-buttons: “only one door and not a convenient one” (CP 155), “only one door - monitored by receptionist and opened by her if need be” (CP 132), “push button at front doors - staff assist with non-electric doors” (CP 116), and “for building, but not for suite” (CP 93).

Roughly three-fourths of providers ( $n = 123, 76.9\%$ ) responded that their clinic provides maneuvering clearance for wheelchairs to turn around in examination rooms. Additionally, providers wrote that maneuvering clearance “could be better, we remove exam room chairs” (CP 116), and there is clearance for “manual w/c yes, but not electric w/c” (CP 75). Item seven was unique only to care providers and asked if there are future plans to upgrade their clinic’s physical environment. One provider wrote, “whenever a remodel or new build” (CP 46) and another provider wrote they were “Not ADA compliant - no steps - wide doors” (CP 165).

***CP Question 2: Medical equipment.*** The second survey question asked care providers if their clinic provides medical equipment that accommodates patients with physical disabilities. This section of CAMS included eight items. Approximately one-third of providers ( $n = 56, 35\%$ ) responded that they provide a wheelchair-accessible weigh scale. One provider wrote, “We support to stand” (CP 66). Less than one-fifth of providers ( $n = 29, 18.1\%$ ) provide wheelchair-accessible mammography equipment. One provider wrote, “Can lower equip if removable arm on w/c” (CP 29). Over half of the provider respondents ( $n = 107, 66.9\%$ ) provide

a height-adjustable examination table, and roughly half provide wheelchair-accessible laboratory equipment for blood draws ( $n = 79$ , 49.4%) and flexible x-ray equipment ( $n = 68$ , 42.5%). About one-third of providers provide flexible stirrups on examination tables ( $n = 60$ , 37.5%) and provide a mechanical lift in their clinic ( $n = 47$ , 29.4%). One provider wrote their mechanical lift is a “standing lift only” (CP 121). Another provider did not provide medical equipment stating, “none of these – but we manage ok w/procedures as is for the type of procedures I do” (CP 90). Item eight was unique only to care providers and asked if there are future plans to upgrade their clinic’s medical equipment to accommodate patients with physical disabilities. Examples written by providers included getting a wheelchair-accessible weigh scale (CP 20) and a height-adjustable exam table (CP 30).

Some providers made notations on their survey stating their services do not require use of medical equipment. For example, six providers indicated they were a mental health clinic (CP 13, 140, 143, 145, 155, 157) and two noted they were eye clinics (CP 17 and CP 110), which did not necessitate equipment items such as a weigh scale, mammography, height-adjustable exam table, access to blood draws or x-ray equipment, or mechanical lift. Six additional providers wrote that their clinic did not provide mammography services (CP 55, 89, 92, 126, 139, 153).

***CP Question 3: Attitudinal.*** The third survey question asked providers about relationships with their patients and included five items. Most providers responded that they can freely discuss any health-related issues with their patients ( $n = 151$ , 94.4%), listen to what their patients say about health issues ( $n = 151$ , 94.4%), problem-solve with patients about their care ( $n = 148$ , 92.5%), and patients are satisfied with how clinic staff responds to their needs ( $n = 144$ , 90%). One provider wrote their clinic rated a “98% pt satisfaction” (CP 80). Roughly two-thirds of providers ( $n = 109$ , 68.1%) reported they provide other clinic options if their clinic is unable

to accommodate a patient with a physical disability. Providers (CP 24, 52, 90) indicated there was no need to refer, and another provider wrote, “We are a rural clinic - we refer what we can’t see to a larger medical center” (CP 131).

***CP Question 4: Disability knowledge.*** The fourth survey question asked providers about disability-related knowledge and included nine items. Three-fourths of providers reported they are knowledgeable in disability care for patients with physical disabilities ( $n = 117, 73.1\%$ ), durable medical equipment (DME) ( $n = 117, 73.1\%$ ), non-pharmaceutical alternatives to pain management ( $n = 121, 75.6\%$ ), secondary conditions patients with physical disabilities are at risk for ( $n = 116, 72.5\%$ ), and communication techniques that prompt questions about a patient’s condition ( $n = 123, 76.9\%$ ). One provider wrote, “Medicare & Medicaid make it difficult” to pursue DME (CP 94) and another provider wrote non-pharmaceutical alternatives to pain management were, “not in practice scope” (CP 72).

Furthermore, most providers responded that they are knowledgeable in signs and symptoms of clinical depression ( $n = 138, 86.3\%$ ), while approximately one-half of providers surveyed responded that they are knowledgeable in wellness activities ( $n = 95, 59.4\%$ ) and preventive screening procedures ( $n = 91, 56.9\%$ ) for patients with physical disabilities. Item nine was unique only to care providers and asked if they had formal education in medical school regarding disability care. Comments about formal education written by providers included, “Can care for pts with HOH [hard of hearing]/blind/deaf” (CP 29), another provider wrote they went to school “35 years ago” (CP 80), and still another provider checked-off all areas of disability knowledge and wrote, “All or some of our providers have this knowledge or expertise” (CP 92). CP 80 commented that they “refer” patients who need disability care, DME, pain management, and preventive screening. Table 8 shows care provider survey responses and frequency.

Table 8

*Care Provider Survey Responses and Frequency*

| Sample (N = 160)                                                                                                                                   |                                                                                                              |                         |                             |
|----------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------|-------------------------|-----------------------------|
| Category                                                                                                                                           | Item                                                                                                         | Provide<br><i>n</i> (%) | Not Provide<br><i>n</i> (%) |
| Physical Environment (PE)<br><i>CP survey question 1: The physical environment of my clinic provides the following:</i>                            | 1. Wheelchair-accessible building entrance                                                                   | 157 (98.1%)             | 3 (1.9%)                    |
|                                                                                                                                                    | 2. Wheelchair-accessible push-button doors                                                                   | 136 (85%)               | 24 (15%)                    |
|                                                                                                                                                    | 3. Wheelchair-accessible restroom                                                                            | 153 (95.6%)             | 7 (4.4%)                    |
|                                                                                                                                                    | 4. Grab bars in restrooms                                                                                    | 154 (96.3%)             | 6 (3.8%)                    |
|                                                                                                                                                    | 5. Wheelchair-accessible route to exam room                                                                  | 154 (96.3%)             | 6 (3.8%)                    |
|                                                                                                                                                    | 6. Maneuvering clearance for wheelchairs to turn around in examination room                                  | 123 (76.9%)             | 37(23.1%)                   |
|                                                                                                                                                    | *7. Future plans to upgrade environment                                                                      | 21 (13.1%)              | 139 (86%)                   |
| Medical Equipment (ME)<br><i>CP survey question 2: My clinic provides medical equipment that accommodates patients with physical disabilities:</i> | 1. Wheelchair-accessible weigh scale                                                                         | 56 (35%)                | 104 (65%)                   |
|                                                                                                                                                    | 2. Wheelchair-accessible mammography                                                                         | 29 (18.1%)              | 131 (81.9%)                 |
|                                                                                                                                                    | 3. Height-adjustable examination table                                                                       | 107 (66.9%)             | 53 (33.1%)                  |
|                                                                                                                                                    | 4. Wheelchair-accessible laboratory                                                                          | 79 (49.4%)              | 81 (50.6%)                  |
|                                                                                                                                                    | 5. Flexible X-ray equipment                                                                                  | 68 (42.5%)              | 92 (57.5%)                  |
|                                                                                                                                                    | 6. Flexible stirrups on exam table                                                                           | 60 (37.5%)              | 100 (62.5%)                 |
|                                                                                                                                                    | 7. Mechanical lift                                                                                           | 47 (29.4%)              | 113 (70.6%)                 |
|                                                                                                                                                    | *8. Future plans to upgrade equipment                                                                        | 11 (7%)                 | 149 (93%)                   |
| Attitudinal (A)<br><i>CP survey question 3: Relationships with my patients with physical disabilities are:</i>                                     | 1. I can freely discuss any health-related issues with my patients                                           | 151 (94.4%)             | 9 (5.6%)                    |
|                                                                                                                                                    | 2. I provide other clinic options if my clinic is unable to accommodate a patient with a physical disability | 109 (68.1%)             | 51 (31.9%)                  |
|                                                                                                                                                    | 3. I listen to what patients say about health                                                                | 151 (94.4%)             | 9 (5.6%)                    |
|                                                                                                                                                    | 4. I problem-solve with patients about care                                                                  | 148 (92.5%)             | 12 (7.5%)                   |
|                                                                                                                                                    | 5. My patients are satisfied with how clinic staff responds to their needs                                   | 144 (90%)               | 16 (10%)                    |
| Disability Knowledge (DK)<br><i>CP survey question 4: I am knowledgeable in:</i>                                                                   | 1. Disability care for patients with physical disabilities                                                   | 117 (73.1%)             | 43 (26.9%)                  |
|                                                                                                                                                    | 2. Durable medical equipment (DME)                                                                           | 117 (73.1%)             | 43 (26.9%)                  |
|                                                                                                                                                    | 3. Non-pharmaceutical alternatives for pain                                                                  | 121 (75.6%)             | 39 (24.4%)                  |
|                                                                                                                                                    | 4. Secondary conditions patients with physical disabilities are at risk for                                  | 116 (72.5%)             | 44 (27.5%)                  |
|                                                                                                                                                    | 5. Communication techniques that prompt questions about a patient's condition                                | 123 (76.9%)             | 37 (23.1%)                  |
|                                                                                                                                                    | 6. Signs and symptoms of clinical depression                                                                 | 138 (86.3%)             | 22 (13.8%)                  |
|                                                                                                                                                    | 7. Wellness activities for patients with physical disabilities                                               | 95 (59.4%)              | 65 (40.6%)                  |
|                                                                                                                                                    | 8. Preventive screening procedures for patients with physical disabilities                                   | 91 (56.9%)              | 69 (43.1%)                  |
|                                                                                                                                                    | *9. Formal education in disability care                                                                      | 127 (79.4%)             | 33 (20.6%)                  |

\*Three additional response choice items PE 7, ME 8, and DK 9 were exclusive only to care providers.

***Three additional response choice items for care providers.*** Three supplementary survey items unique only to care providers were developed by focus group participants. Using descriptive analysis, items PE 7, ME 8, and DK 9 revealed provider responses in percentages as additional information for the reader and do not relate to items summarized in Table 7.

PE 7. *There are future plans to upgrade my clinic's physical environment.* Out of 160 care provider surveys, 21 providers (13.1%) responded that they had future plans to upgrade their environment compared to 139 providers (86.9%) who left this item blank on the survey. This finding suggests that most providers have no plans to upgrade the physical environment of their clinics because they already provide items of accessibility as shown in Table 8.

ME 8. *There are future plans to upgrade my clinic's medical equipment to accommodate patients with physical disabilities.* This item showed that 11 providers (7%) responded compared to 149 providers (93%) who left this item blank. This finding is disturbing because it suggests most providers have no plans to upgrade medical equipment in their clinics, even though many of them responded they do not have equipment that accommodates patients with physical disabilities (see Table 8).

DK 9. *I had no formal education in medical school regarding disability care.* This item showed that 33 providers (20.6%) responded compared to 127 providers (79.4%) who left this item blank on the survey. Analysis of the survey response rate from providers showed roughly three-fourths of providers have had formal education while in medical school. However, Table 8 shows approximately one-fourth of providers are not knowledgeable in disability care, DME, non-pharmaceutical alternatives for pain, secondary conditions, and communication techniques, and nearly one-half are not knowledgeable in wellness activities and preventive screening; suggesting a disability knowledge gap exists among providers working in health clinics.

**CP Question 5: Ideas for improvement.** The fifth and final survey question asked providers to write ideas for improving their clinic’s environment. The survey allowed space to write additional responses in which a total of 16 care providers wrote in their comments. Of these 16 providers, examples of ideas pertained to their clinic’s physical environment, medical equipment, or other. None of the providers reported ideas to improve provider-patient relationships or disability knowledge. Table 9 shows care provider ideas for improvement.

Table 9

*Care Provider Ideas for Improvement*

| Mechanical Lift                                                       | Building Entrance                           | Exam Table                                                    | Weigh Scale                                                            | Push Buttons                                                                                                     | Room Size                                                   | Other                                                                                                                    |
|-----------------------------------------------------------------------|---------------------------------------------|---------------------------------------------------------------|------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------|
| CP 89: “mechanical lift”                                              | CP 152: “Need disability access front door” | CP 63: “increasing our adjustable exam tables at each clinic” | CP 98: “w/c accessible scale”                                          | CP 69: “The [name of facility] needs push buttons for doors but unknown if admin would be willing to implement.” | CP 22: “Increased exam room size limited by physical space” | CP 9: “Grant funding needed to upgrade – clinic is an outreach site in an underserved community with limited resources.” |
| CP 99: “we don’t have a Hoyer lift – at times this would be helpful.” | CP 153: “easier access in winter”           | CP 152: “could benefit from power table in ONE room”          | CP 142: “we are adding a wheel-chair accessible scale next year. 2018” | CP 75: “wheelchair accessible push buttons to open doors”                                                        | CP 28: “larger exam rooms”                                  | CP 28: “better access to interpreters”                                                                                   |
| CP 143: “chair lift is needed / but costly & limited”                 |                                             |                                                               |                                                                        |                                                                                                                  | CP 30: “larger exam room size to accommodate wheelchairs”   | CP 87: “Have discussed”                                                                                                  |
| CP 153: “mech lift”                                                   |                                             |                                                               |                                                                        |                                                                                                                  |                                                             | CP 94: “Better coordination between waiver case management and clinic staff”                                             |

In addition, one provider wrote, “I see patients with physical disabilities at my hospital-ambulatory out-patient clinic at [name of care facility] – they have the ability to better meet the needs of these patients regarding accessibility & service. (versus my private clinic.)” (CP 16).



## Summary

Phase one of this study used a qualitative research approach to conduct focus groups with AWPDP. A total of seven participants voiced their experiences in health clinics and assisted in the development of a care provider survey with response choice items they deemed important for accessing care. Although findings from focus group sessions revealed concerns with the physical environment, medical equipment, provider attitudes, and provider disability knowledge, participants had no concerns when discussing satisfaction with clinic staff or wellness activities offered by providers. Reports from participants in this study are consistent with findings from previous studies where AWPDP reported barriers to care in health clinics. Participants also offered ideas for improving clinic environments along with suggestions for educational leaders.

Phase two of this study used a quantitative approach to survey care providers. A total of 160 providers responded to the survey, CAMS. Findings showed that most care providers provided access to the physical environment in their clinics; yet, far fewer providers provided accessible medical equipment. Many providers perceived that they discuss, listen, and problem-solve with their patients, and fewer still reported having knowledge in disability-related care. Providers also offered ideas for improving their clinic environments; however, none of their suggestions included ideas for improving provider-patient relationships or disability knowledge.

Additional results from provider surveys revealed 13% of providers plan to upgrade their clinic's physical environment, 7% plan to upgrade medical equipment, and 20% had no formal education in medical school regarding disability care. Findings also showed one-fourth of care providers are not knowledgeable in disability care, DME, non-pharmaceutical alternatives for pain, secondary conditions, and communication techniques, and nearly one-half of providers are not knowledgeable in wellness activities and preventive screening.

## **Chapter Five: Discussion, Conclusions, Implications, Recommendations**

### **Overview of the Study**

The problem identified in previous studies was adults with physical disabilities (AWPD) continue to encounter inaccessible health facility environments, negative attitudes towards disability, and lack of provider knowledge in disability-related care resulting in substandard exams. People with disabilities require specialized health-related services (McDoom et al., 2014) and without proper screening, AWPD are at risk for poor health outcomes (Krahn et al., 2015; Wang, 2012). Education for care providers could be the key to improving physical environments, attitudes, and disability knowledge. Furthermore, the need for disability education is becoming more pressing because trends showed that disability prevalence is expected to grow as the population ages (Chen & Sloan, 2015). However, disability knowledge in medical schools is not mandated by accreditation agencies (Wen, 2014). The literature is scarce in perspectives of health care providers and health clinic accessibility. The importance of this study is for care providers and educational leaders to better understand accessibility in health clinics so access to health services and outcomes for AWPD can be improved.

The purpose of this study was to explore what AWPD experience in health clinics regarding access to care with physical environments, attitudes, and disability knowledge, and to construct a comprehensive survey for health clinic care providers. Transformative theory provided the framework for this study by including AWPD in the development of a survey asking care providers about accessibility in their health clinics. An inclusive approach provided authentic representation of AWPD accessing care in health clinics. The survey CAMS was a valid instrument because it was developed in partnership with the population of interest. Generalizing findings is debatable due to the fact that focus group and care provider sample sizes

were small. However, it is likely that questions regarding accessibility in health clinics would yield similar results in these target populations.

Using a mixed methods research design, this study was conducted in two phases. Phase one collected qualitative data from seven focus group participants who were AWPDP residing in a Midwest assisted living setting. Focus group sessions consisted of five questions asking AWPDP what they experience in health clinics. Participants reported central issues with health clinic physical environments, care provider attitudes, and care provider disability knowledge. Participants also offered ideas to improve clinic environments. Common themes emerged from discussions and were itemized into five categories, guiding the design of 29 response choice items for the care provider survey, CAMS.

Phase two collected quantitative data from 160 completed care provider surveys asking what they provide for AWPDP in their clinics. Systematic sampling of every 3rd health clinic in Minnesota yielded a 25% response rate. Although the survey response rate was low, results from previous studies by Bachman et al. (2006) and McDoom et al. (2014) increased confidence in this current study's findings because of similar reports of AWPDP and care provider perspectives on health clinic physical environments and medical equipment. Data from surveys were organized into the same five categories as AWPDP and analyzed. Categories included Physical Environment, Medical Equipment, Attitudes, Disability Knowledge, and Ideas for Improvement.

This study achieved its intended purpose. Qualitative and quantitative data answered the research questions in phases one and two.

### **Research Questions**

This research project was designed with the intent to answer the following questions regarding accessibility in health clinics:

RQ 1. What is the experience of AWPDP in health clinics regarding access to care that pertain to physical environments, attitudes, and disability knowledge?

RQ 2. What do health care providers say they are providing in their clinics regarding care for AWPDP that pertain to physical environments, attitudes, and disability knowledge?

## **Discussion**

**Physical environment.** Results suggest that most AWPDP (71.4%) had concerns accessing care in the physical environment of health clinics whereas most care providers reported they provide access. Spaces in physical environments were narrow and difficult to navigate for AWPDP who used devices for mobility. Findings are consistent with other studies reporting AWPDP experiencing similar problems accessing clinic entrances (Eisenberg et al., 2015; Iezzoni et al., 2010; Lagu et al., 2013; Lee, 2010), access and maneuverability problems of waiting rooms and exam rooms (Eisenberg et al., 2015), and accessibility of restrooms (McDoom et al., 2014). Findings from these authors helped affirm what AWPDP reported in this current study. Furthermore, over half of the care providers in a prior study conducted by Bachman et al. (2006) perceived patients never faced problems accessing the building, exam rooms, and restrooms; similar to most providers in this current study who reported providing access to their clinic's building entrance (98.1%), exam rooms (96.3%), and restrooms (95.6%).

Moreover, 86.9% of care providers have no future plans to upgrade their clinic's physical environment. Perhaps this is because providers perceived they already provide access to their clinic's physical environment. Although roughly one-fourth (23.1%) of providers perceived wheelchairs did not have clearance to turn around in exam rooms, only a few providers wrote their idea for an improvement would be to have larger exam rooms. More space in exam rooms

might also alleviate the need to move furniture around to accommodate for a wheelchair, as one provider indicated. A variety of other comments written-in by providers including the lack of push-buttons to open doors (e.g., doors to suites or having push-buttons at inconvenient locations), not having space for electric wheelchairs to maneuver in exam rooms, and steps at the building entrance suggests these particular providers are not ADA compliant.

Strategic placement of push-buttons to open doors and grab bars in restrooms are important points of discussion as well. Access is the route to care (Lagu et al., 2014). Providers who reported providing push-buttons (85%) and grab bars (96.3%) does not necessarily mean AWPB in wheelchairs can access them, as some AWPB indicated. The 15% of providers who reported not having push-buttons at all not only suggests an ADA compliance issue; it suggests a physical barrier in the environment for AWPB attempting to access care. Reviewing ADA guidelines with medical students might also be a curriculum topic worth considering by health and educational leaders so students can be knowledgeable in current standards before they begin serving AWPB in health clinic facilities.

**Medical equipment.** Results suggest a wide range of variations in AWPB and care provider perceptions about medical equipment that accommodates patients with physical disabilities. Although there is no known relationship between AWPB and providers and their clinics in this study, the lack of accessible medical equipment in health clinics is consistent with what many AWPB reported in other studies. With the exception of a height-adjustable exam table, less than half of the providers surveyed in this current study provided accessible equipment in their health clinics.

Findings of medical equipment problematic for AWPB in this current study are consistent with AWPB in other studies who found similar issues with weigh scales (Iezzoni et

al., 2010), height-adjustable exam tables (Drew & Short, 2010; Iezzoni et al., 2010; Iezzoni et al., 2011; Krahn, 2015; Lagu et al., 2013; Lagu et al., 2014; Suzuki et al., 2013), wheelchair-accessible mammography (Iezzoni et al., 2010; Iezzoni et al., 2011; Suzuki et al., 2013), x-ray equipment (Bachman et al., 2006), and unavailability of mechanical lifts (Lagu et al., 2013). It was surprising that 66.9% of providers in this current study reported providing height-adjustable exam tables; especially in light of Lagu et al.'s (2013) study who found less than 10% of clinics provided this piece of equipment. The reason for the remarkable difference in findings between Lagu et al.'s study and this current study is unknown and one can only speculate why more providers in this current study were encouraged to provide a height-adjustable exam table. It is suspected that the response rate of various clinic types played a role in both studies.

In this current study, 33.1% of providers did not provide a height-adjustable exam table in their clinics, 65% of providers did not provide a wheelchair-accessible weigh scale, and 70.6% of providers did not provide a mechanical lift for transfers. Between 71.4% and 85.7% of AWPDP indicated a concern with the absence of, or inability to access this particular medical equipment. AWPDP received exams from their wheelchair; were not able to get a current weight necessary for purchasing new durable medical equipment; and even received an exam on the floor because there was no height-adjustable exam table and no mechanical lift to transfer to the existing exam table. In addition, one care provider reported their clinic staff physically supported patients to the standing position because there was no wheelchair-accessible weigh scale in the clinic. Similar to Lagu et al. (2013) and Iezzoni et al. (2010), reports in this current study indicated that unsafe transfers of wheelchair-bound patients to an exam table or weigh scale was an important finding and suggests the need for education and training of care providers and clinic staff in principles of safe transfer techniques.

Findings in this study also heightened awareness of exam-specific issues. The lack of wheelchair-accessible mammography was reported as a concern by all three female AWPDP and one male AWPDP (57.1%). Additionally, the lack of flexible stirrups on exam tables was reported as a concern by 42.9% of AWPDP, who were all female. This suggests gender differences may have an impact on being able to access certain medical equipment and thus obtain gender-specific health screening. This is consistent with the World Health Organization who reported females with disabilities receive fewer breast and cervical screenings for cancer than females without disabilities (WHO, 2015). Only 29 providers (18.1%) in this current study reported they provide wheelchair-accessible mammography and 60 providers (37.5%) reported they provide flexible stirrups on exam tables in their clinic. Lacking this equipment suggests a barrier to care for AWPDP, especially as indicated by female AWPDP seeking services and preventive screening for breast and cervical health needs. This study did not focus on gender-specific issues. However, the sheer lack of accessible medical equipment illustrates the importance of providing equipment conducive to serving patients with physical disabilities.

Further support for the findings in this study are consistent with results from prior surveys by Bachman et al. (2006) where 41% of care providers perceived disabled patients never had difficulties using equipment, and by McDoom et al. (2014) where care providers ranked medical equipment as lower barriers. Despite this supportive evidence from prior studies, it was still shocking to see that 93% of care providers surveyed in this current study had no future plans to upgrade their clinic equipment; especially since less than half of the providers surveyed reported they did not provide accessible medical equipment for AWPDP. Perhaps it is because several providers perceived their clinic type did not need to supply the equipment for the services they do. Regardless of clinic type, providing or not providing accessible medical equipment

demonstrates the importance of routinely assessing clinic equipment that ensures a safe and thorough exam for AWPB. Inability to identify clinic types responding to the survey is a weakness in this study and may have had an impact on results.

Wheelchair-accessible laboratory equipment for obtaining blood draws was discussed by 28.6% of AWPB and is unique to this study. AWPB reported getting routine blood draws for diabetes and cholesterol screening and laboratories inaccessible to wheelchairs suggest these patients receive lab services in a manner that is different from ambulatory patients. Almost one-half of providers surveyed responded they provide an accessible laboratory in their clinic. As with some of the other absent accessible medical equipment in this study, the remaining one-half of providers who did not provide an accessible laboratory may have perceived their clinic type did not need it, as with mental health and eye clinics. Overall, education and training on the indication and use of accessible medical equipment for providers and other health professionals may improve the quality of an exam for AWPB.

**Attitudinal.** Results suggest all AWPB had concerns discussing health-related issues with providers, whereas most providers (94.4%) perceived they discussed health-related issues with patients. This is consistent with results from a prior survey by McDoom et al. (2014) which found a significant difference in perceptions between providers and patients with disabilities talking about needs. Besides not having enough time during appointments, AWPB perceived they could not discuss issues because providers did not listen to them. AWPB reports of being misdiagnosed and feeling like a *disease* rather than a patient suggests an attitudinal phenomenon that cannot be explained here because it is beyond the scope of this study's findings. There might be several reasons why some providers focus on a patient's disability instead of their health problem; however, it often results in the wrong course of treatment for the patient (DHHS,



2005). Education efforts directed towards improving provider communication and disability-sensitivity could be beneficial for informing curricula design for medical students.

Further findings revealed 71.4% of AWPB had concerns with their provider listening and problem-solving with them, while most providers reported they listen to patients (94.4%) and problem-solve with patients (92.5%). Again, this inconsistency suggests a communication breakdown between AWPB and care providers and emphasizes a practical need for communication content in disability curricula. AWPB perceived the focus was not on them during clinic visits and reported feeling *stupid* when they asked questions. Lack of communication and feeling inferior could be blocks to delivering multiple aspects of disability care, as indicated by AWPB. Findings of attitudes concerning for AWPB in this current study are consistent with other studies where AWPB reported similar issues with care provider attitudes interfering with care delivery (Lagu et al., 2014; Suzuki et al., 2013), which is supportive to this study. A better understanding of how care providers perceive a patient's role as an active participant in their plan of care and including them in the decision-making process is vital for providers when prioritizing care for AWPB.

Despite having durable medical equipment needs for mobility, reporting secondary conditions to providers, and having preventive screening needs, 85.7% of AWPB in this current study had concerns with obtaining referrals to other clinics. This is particularly troublesome because AWPB have complex needs and require specialized services to meet their health needs (Eisenberg et al., 2015; McDoom et al., 2014). As indicated by AWPB in this current study, special needs necessitate specialists outside their primary clinic. However, only 68.1% of providers reported they provide referrals to other clinics. It is not fully understood why three out of 160 providers surveyed wrote that there was no need to refer patients to other clinics. To help

lead a healthy life it is important for people with disabilities to know what resources are available in their area that can meet their needs (DHHS, 2005). AWPDP reported they might not always know what is available and look to their providers for this information. Education for providers regarding accessible community resources might improve access to a variety of needed services and promote health-related outcomes for AWPDP.

Another surprising and unique finding in this study was that all focus group participants reported satisfaction with clinic staff to the point of them expressing complimentary statements. Evidence of accessibility was encouraging as AWPDP reported that they had no concerns with clinic staff from a variety of clinic types. Interestingly, 10% of care providers perceived patients were not satisfied with clinic staff. This inconsistency is important for informing care providers why this occurred and suggests there may be more data to explore within those particular clinics, such as with employee and patient satisfaction survey scores. One care provider indicated a 98% patient satisfaction score suggesting this clinic already conducts individual patient surveys.

**Disability knowledge.** Results suggest AWPDP and care providers have varying perceptions about care provider knowledge in aspects of disability care. Findings showed one-fourth of providers perceived they lacked knowledge in disability care, durable medical equipment (DME), pain management, secondary conditions, and communication techniques; nearly one-half of providers perceived they were not knowledgeable in wellness activities and preventive screening. This suggests a disability knowledge gap exists among providers surveyed working in health clinics. Additional findings indicated 79.4% of providers had formal education in medical school regarding disability care and 20.6% had no formal education. This is consistent with Wen (2014) who wrote that only 25% of medical schools in the U.S. include

some type of disability-related curriculum. This presents important implications for educational leaders as they consider balancing disability content into an already full medical curriculum.

From the perspective of AWPDP in these same areas of disability knowledge, 71.4% reported concerns about providers being knowledgeable in disability care, DME (85.7%), pain management (28.6%), secondary conditions (85.7%), and communication techniques (85.7%). Concerns posed by AWPDP suggest a reflection of their disability type. AWPDP perceived their provider was not knowledgeable in their specific disability care needs; nor was DME, alternatives to pain medications, or secondary conditions addressed during appointments. It was distressing for AWPDP to report that providers did not address secondary conditions with them; especially because secondary conditions are preventable (CDC, 2015c; WHO, 2015). The danger is once secondary conditions develop they can worsen and become more costly (Valderas et al., 2009), and become chronic (Iezzoni, 2010). Therefore, secondary conditions have serious implications for providers attempting to coordinate care for AWPDP.

Additionally, 76.9% of care providers indicated they were knowledgeable in communication techniques that prompt questions about a patient's condition. Yet, AWPDP reported that providers could do a better job asking questions; which rationalizes why they developed survey item DK 5, *communication techniques that prompt questions about a patient's condition*. It is possible that some providers are unaware of what types of questions to ask AWPDP if they have not had sufficient education in disability-related care. This further strengthens the argument that communication content in disability curricula is needed for care professionals. There were supportive results from other authors who also found people with disabilities reporting providers lacking in knowledge about understanding patient conditions

(McDoom et al., 2014; Wen, 2014), durable medical equipment (Lee, 2010), secondary conditions (Iezzoni, 2010), and communication techniques (McDoom et al., 2014).

Another study supportive to disability knowledge-related findings in this current study was conducted by Yankaskas et al. (2010). These authors found that patients did not think preventive screening was necessary as well as providers who did not recommend screening procedures. This is also similar to 85.6% of AWPDP in this current study, who reported not knowing what preventive screening measures were, nor were they discussed by their provider; yet over half of providers (56.9%) reported they were knowledgeable in preventive screening procedures for patients with physical disabilities. Although *Healthy People 2020* (DHHS, 2014) showed some improvement in the last 10 years towards their goal with Clinical Preventive Services and colorectal cancer screening, all AWPDP over the age of 50 in this current study reported never having a colonoscopy. Findings from this current study are important for informing health professionals and educators about training preventive screening measures and including it as part of the care regimen for AWPDP. To further emphasize the need for education in communication skills, Yankaskas et al. (2010) wrote that poor communication between patients and providers can lead to inadequate preventive care measures for people with disabilities.

Findings in this current study also revealed areas of accessibility for AWPDP. There were no concerns reported by AWPDP regarding wellness activities. AWPDP perceived wellness as ways to improve health and gave fitting examples of how their providers promoted this, such as quitting smoking and encouraging exercise. Findings are consistent with authors who wrote health promotion and physical activity is important for both people with and without disabilities to be healthy (DHHS, 2005; Smeltzer et al., 2015). Interestingly, 40.6% of providers in this

current study indicated they are not knowledgeable in wellness activities. This finding is curious because 100% of AWPB indicated no concerns. Perhaps providers promote wellness activities without realizing it or have misconceptions about what constitutes a wellness activity. On the other hand, some care professionals perceive that exercise has no benefit or may even be harmful to a person with a physical disability (Martin, 2013). Whatever the reason, nearly one-half of the providers in this study reported they are not knowledgeable in this area and suggests the need for education in promoting healthy lifestyle behaviors for AWPB.

Unique findings to the disability knowledge category in this study were AWPB concerns about providers lacking knowledge in nonpharmaceutical alternatives to pain management, and recognizing signs and symptoms of clinical depression. Roughly three-fourths of care providers surveyed reported being knowledgeable in both of these areas. It is noteworthy to mention that this study focused on physical disability, not mental health disorders and is documented as a limitation. By intention, there is no supportive literature included with this study to support findings regarding clinical depression. Because AWPB perceived managing pain and depression as important aspects of their care, findings from this study can help inform providers to consider modifying clinic policy that reflects addressing these needs during clinic visits. Moreover, educational leaders should consider developing curricula for providers in all eight areas of the Disability Knowledge category in this study based on findings from AWPB discussions and care provider surveys.

Data from AWPB did not coincide with responses from any particular care provider or health clinic. Therefore, direct relationships could not be made between the two groups or health clinics which is a weakness in this study and may have impacted the results in categories of Physical Environment, Medical Equipment, Attitudinal, and Disability Knowledge.

## Conclusions

AWPD reported concerns with accessing care while most care providers reported providing access to care for AWPDP. The results underscore the importance in understanding the unique needs that people with physical disabilities have so problematic environmental factors in health clinics can be improved. Problems accessing health clinics that remained unsolved for AWPDP were reflective of the survey items they developed for care providers. Findings also showed areas of accessibility. For example, AWPDP reported that clinic staff responded to their needs and providers gave suggestions to improve health. Findings in this study inform health and educational leaders of gaps in disability knowledge and the need for disability curricula.

**Physical environment.** Not being ADA compliant with the structural aspects of a health clinic facility continues to be a problem for some providers, which may necessitate structural updates in those respective clinics. Additionally, being ADA compliant can still leave room for improvement; especially since most AWPDP who used mobility devices perceived that spaces were too narrow, push-buttons to open doors and grab bars in restrooms were difficult to access or were nonexistent, and navigating restrooms and exam rooms was difficult. When AWPDP had difficulty navigating the physical environment, they required additional assist from other individuals. Providers who perceived they provided access to the physical environment should take into account challenges AWPDP reported with navigating the physical structures in their clinics. Even though most providers reported they had no future plans to upgrade their clinic environments, they should reconsider implementing upgrades that address AWPDP hurdles; particularly providers not in compliance with ADA standards. Thus, it could be beneficial for providers to include AWPDP when designing structural changes in health clinics to offer authentic representation of those affected by concerns in the physical environment.

**Medical equipment.** Not being able to access weigh scales, mammography and other flexible equipment, examination tables, laboratory equipment, and mechanical lift hampered the quality of AWPB exams, and in some cases, resulted in undesirable outcomes and incomplete exams for AWPB. Not having equipment that accommodates patients with physical disabilities also compromised safety and put AWPB at risk for falls and clinic staff at risk for injury. It seems reasonable that a mental health clinic or eye clinic are less likely to use a wheelchair-accessible weigh scale or height-adjustable exam table with their services; nor would clinics stating they do not offer mammography services provide mammography equipment. However, providers who reported not providing accessible equipment in their clinic because of resource constraints, improvised with the equipment they already had, or reported they had no future plans to upgrade their equipment should assess if their current equipment is conducive to performing a safe and thorough patient exam for AWPB; regardless of clinic type. It is becoming increasingly important for health and educational leaders to rethink equipment needs and training particularly in preparation for the new federal accessibility standards for medical diagnostic equipment, which are expected to be published by the United States Access Board in the near future.

**Attitudinal.** AWPB reported feelings of inadequacies during clinic visits even though care providers perceived they can freely discuss health-related issues, and listen and problem-solve with AWPB patients. Key connections were made between the Attitudinal and Disability Knowledge categories. Specifically, AWPB perceived that their concerns with discussing health-related issues, referrals to other clinics and services, listening to patients, and problem-solving with patients could be improved if providers had education in communication techniques that prompted questions about a patient's condition. AWPB reports of being misdiagnosed, feeling that their provider thinks they are stupid because they are disabled, and not knowing what

resources are available in the community is important evidence for health and educational leaders to take notice that education for providers is needed in communication and disability-sensitivity skills. Moreover, because AWPDP perceived satisfaction with how clinic staff responded to their needs does not assume that AWPDP are satisfied or dissatisfied with how care providers respond to their needs. Further exploration of patient satisfaction might offer additional understandings of disability-related health issues and internal needs of health clinics.

**Disability knowledge.** Findings suggest that a disability knowledge gap exists among providers surveyed working in health clinics. One-fourth of providers perceived they lacked knowledge in disability care, durable medical equipment (DME), pain management, secondary conditions, and communication techniques; nearly one-half perceived they were not knowledgeable in wellness activities and preventive screening (see Figure 2). AWPDP perceived secondary conditions and clinical depression could be improved if care providers had education in communication techniques and provided referrals to other clinics. Furthermore, improving skills in communication could aid care providers in providing multiple aspects of care for AWPDP. AWPDP who experienced conditions that worsened such as skin breakdown, thoughts of suicide, and limb atrophy emphasizes the importance for provider education in disability-related care. AWPDP perceived that mandating education for providers in aspects of disability care could improve overall access to health care.



## Disability Knowledge Gap

Care Providers (%) perceived they lack knowledge in aspects of disability care

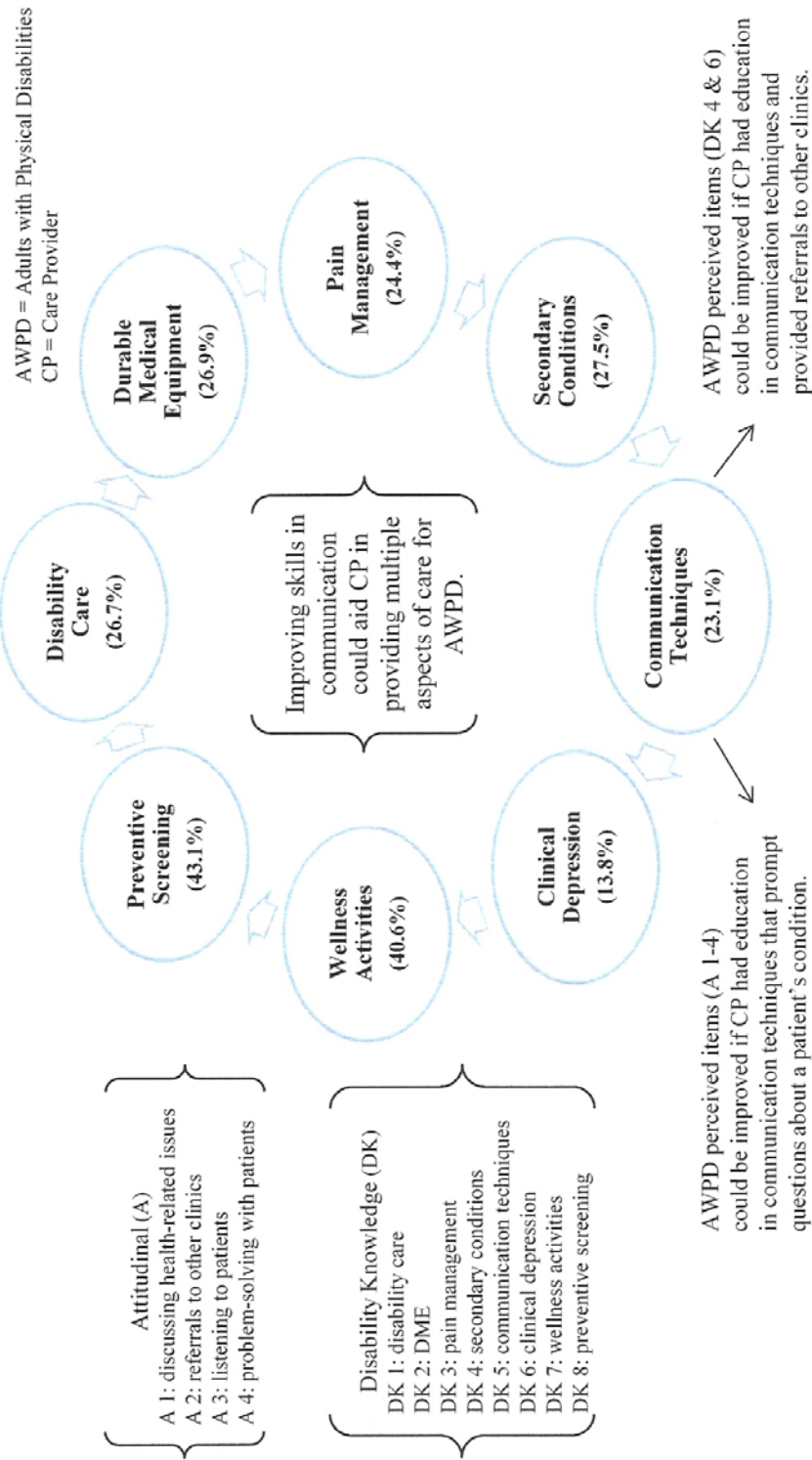


Figure 2. Findings suggest that a knowledge gap exists among care providers surveyed working in health clinics. Adults with physical disabilities perceived that care provider education in aspects of disability care could improve overall access to health care.

## **Implications**

**Theoretical.** There are theoretical implications for mixed methods research using the transformative paradigm. Transformative theory made an impact on the results of this study. Including AWPDP in the development of the care provider survey CAMS provided authentic representation of patients with physical disabilities. This inclusive approach offered real-world experiences of AWPDP and identified central issues they perceived as important for accessing care in health clinics. AWPDP input was valuable for gaining insight on physical environments, provider attitudes, and provider disability knowledge. Findings from AWPDP reports were intended to help care providers and educators understand problems with AWPDP accessing clinics. Moreover, findings from care provider surveys were presented and explained to AWPDP with the intent for AWPDP to better understand care provider perspectives. Historically, voices of people with disabilities have been missing from research (Mertens, 1999). Without AWPDP inclusion in this study, a realistic survey representative of their voices would not have been possible. Findings from this study have the potential for eliciting positive change in health clinic policies and inform health and educational leaders of the need for disability curricula.

**Clinical.** There are several clinical implications for care providers in this study. Results showed that AWPDP have concerns accessing and maneuvering in health clinic physical environments. Most providers indicated they provide accessible environments, whereas some did not provide certain aspects of the physical environment, and some providers reported that larger exam rooms would be an improvement. To help ensure equal accessibility for AWPDP in clinic facilities, providers must be in compliance with current ADA standards. It would also be beneficial for providers to pay attention to structural details in the environment, such as placing push-buttons and grab bars in strategic areas that are user-friendly to people operating a variety

of mobility devices. In turn, reducing physical barriers can aid in setting the stage for AWPDP to receive needed health services.

Accessible equipment in health clinics also plays a vital role in obtaining needed health care and services. Lack of accessible medical equipment has implications for providing safe and thorough exams and impedes care delivery as indicated by both AWPDP and care providers. Equipment that did not accommodate patients with physical disabilities fostered inappropriate use of existing equipment and can pose safety issues for both patient and clinic staff. Furthermore, not having accessible equipment prevented AWPDP from obtaining weights and health screenings. Less than one-half of care providers reported providing accessible equipment in their clinics. Providers could assess their clinic equipment needs and consider a best-practices approach to conducting a safe and complete exam for AWPDP.

There are implications with care provider attitudes and disability knowledge. AWPDP perceived educating providers in communication could play a role in improving: (a) discussing health-related issues, (b) referrals to other clinics, (c) listening to patients, (d) problem-solving with patients, (e) secondary conditions, and (f) clinical depression. Although the scope of care may vary from patient to patient, providers might consider advocating for education in disability-related care; especially if there is a possibility they may care for a physically disabled patient seeking services in their respective clinic. In addition, AWPDP perceived education could help care providers identify health issues, prepare for equipment needs, plan and refer care, and prevent new conditions from occurring or existing conditions from worsening. This supports the one-fourth of providers who perceived not being knowledgeable in disability care, DME, pain management, secondary conditions, and communication techniques, and the nearly one-half who perceived not being knowledgeable in wellness activities and preventive screening. Provider

education in disability-related care could strengthen the patient-provider dynamic as well as enhance the quality of care for AWPDP.

New problems that emerged chronologically from AWPDP reports were concerns with: (1) not being able to access or nonexistent push-buttons to open doors, (2) lack of or nonexistent grab bars in restrooms, (3) not having a wheelchair-accessible laboratory, (4) providers lacking knowledge in nonpharmaceutical alternatives for pain management, and (5) providers lacking knowledge in recognizing signs and symptoms of clinical depression. These areas would be important to explore further as AWPDP perceived them to be central issues for accessing care. Issues with environmental factors will not fade anytime soon as rates of disability grow in near-elderly and elderly populations (Chen & Sloan, 2015). Thus, understandings of AWPDP perspectives are important for care providers to consider for improving aspects of care for AWPDP. It might be useful to providers if they take AWPDP perspectives into consideration when evaluating clinic environmental factors to prioritize patient needs and inform policies.

**Practical.** There are practical implications for educational leaders. Findings in this study suggest a disability knowledge gap exists in a number of care providers working in health clinics. Providers reported not being knowledgeable in areas of disability care which has the potential for substandard exams, unmet needs, and medical conditions that worsen over time. Education such as improving skills in communication could aid care providers when providing multiple aspects of care for AWPDP. What this means for education efforts is taking the steps to initiate, develop, implement, and evaluate disability curricula in medical education. Until disability education in medical schools is in motion, the status quo in health clinics will persist.

Education in disability-related care would be beneficial for providers so they can better assist AWPDP with specialized needs and improve health services and outcomes. It is possible

that disability curriculum already exist in Minnesota, especially since 79.4% of providers surveyed reported having formal education in medical school regarding disability care. It is unknown which disability topics providers covered in school or other training. However, it would necessitate educational leaders to explore this area further as it could impact the design and implementation of disability curricula. Whether educational leaders are assessing existing disability curriculum or designing new curricula, they should consider including input from providers and other care professionals, and those impacted by services in clinics, namely AWPDP.

**Future research.** There are areas of interest in this study that merit further research. The literature regarding environmental barriers that was examined for this study was void of AWPDP perceptions of accessing laboratories for blood draws, nonpharmaceutical alternatives for pain management, and providers being knowledgeable in clinical depression. It would be worthwhile to see if these are issues for AWPDP in future studies as well. It would also be valuable to expand on the current literature addressing accessibility of push-buttons and grab bars in health clinics. Identifying obstacles that affect quality of life and care delivery would be important for directing efforts towards improvement. Researchers might consider exploring these items further when investigating physical environments of health clinics and evaluate how they affect care and outcomes for AWPDP.

Care provider attitudes also had an impact on care for AWPDP in this study. There is little understanding of why providers responded to the attitudinal survey items as they did because they were not instructed to explain their responses. Therefore, further research is needed to explore attitudinal perceptions of care providers more in depth. Further investigation in the area of patient satisfaction could also be useful to providers for improving patient-provider relationships and clinic services for AWPDP. Care providers and AWPDP may have very different

views about health clinic accessibility. Comparing responses between providers and AWPDP may offer deeper understandings of accessibility in health clinics and help to explain how care is impacted and delivered; findings could inform the transformation of clinic policies.

Another area worth researching is to examine disability curricula that already exist in medical schools. Educational leaders would need this vital information to compare and contrast topics of disability being taught as well as the effective teaching methods from various schools. There may be a rich data bank to explore which can help reduce redundancies in curricula design and possibly guide the development of uniform standards and skills competencies for medical students. Interviews with care providers, people with various disabilities, community members, and community leaders will also be necessary to gather input from those affected by a change in medical curriculum. These stakeholders would need to be involved throughout all stages of research, development, implementation, and evaluation processes to ensure an accurate depiction of disability topics and effective teaching strategies for medical students.

More research is also needed with the aging population to see if there are different issues with accessibility in health clinics. As trends in disability prevalence is projected to increase, additional health services will also increase (Brault, 2012; Burns & Gordon, 2010; Chen & Sloan, 2015; Darling & Heckert, 2010; Gu et al., 2015; Lee, 2010; Talih & Huang, 2016). Education leaders could think about adding content to curricula that reflects major practice considerations with physical disability and age-related differences. Health and education leaders must attempt to keep up with the evolving disability population demographics to properly meet health service needs of people with physical disabilities of all ages. Studying accessibility with the elderly would add to the body of literature supportive to observations in trends, which in turn might help leaders plan for future resources with this growing population of individuals.

## Recommendations for Health Practitioners

The following recommendations for care providers are based on the findings from focus group sessions consisting of AWPB and from providers who completed the survey CAMS.

- Review current ADA standards to ensure compliance with accessibility is being met in health clinics. For starters, this investigator recommends reading, *Access to Medical Care for Individuals with Mobility Disabilities* (ADA, 2010). This brief, yet concise publication provides general ADA requirements for health clinics and doctors' offices. The publication is available for viewing or downloading from the ADA website.
- Conduct a routine annual assessment of the medical equipment being used in health clinics. Evaluate if the equipment accommodates patients with physical disabilities and if modifications are needed to ensure a safe and thorough patient exam.
- Include input from people with disabilities when designing clinic structures.
- Provide staff training on safe patient transfer practices and follow manufacturer recommendations when using accessible medical equipment.
- Prepare for the near-future publication from the United States Access Board regarding new accessibility standards for medical diagnostic equipment.
- Add a referral component to clinic visits that addresses secondary conditions, psychiatry needs, and community resources for patients with physical disabilities.
- Offer suggestions for preventive screening; referrals for other services, equipment, programs, or clinics as needed to accommodate patients with physical disabilities.
- Advocate education and training for providers and clinic staff in disability-related care.
- Create and carry out a mock AWPB patient scenario navigating a clinic environment for provider and staff training purposes.

Health clinic environments did not always accommodate access to care for AWPDP as indicated by reports from focus group participants and care provider surveys. In part, it is essential for clinics to be in compliance with ADA standards to ensure AWPDP have access to health services. Even if there are clinics that do not provide services requiring certain medical equipment, it would be prudent for clinic leaders to conduct routine assessments of the physical environment and any equipment being used to make sure patients are receiving a safe and thorough exam. Also, conducting a mock scenario of a patient with a physical limitation or mobility device could offer new insights about a clinic's physical environment, attitudes, and provider disability knowledge that might otherwise be overlooked. Results from a mock scenario could provide valuable information for training providers and clinic staff. Providers may also benefit from AWPDP input when evaluating or modifying clinic environments and policies. One idea is to incorporate a referral component in health visits because many AWPDP need specialized care and may be uninformed about health screening and community resources.

### **Recommendations for Academics**

The following recommendations for educational leaders are based on the findings from focus group sessions consisting of AWPDP and from providers who completed the survey CAMS.

- Consult with medical accreditation agencies and other stakeholders regarding mandating disability curriculum in medical schools.
- Examine existing disability curriculum to identify current disability-related topics and teaching methods. Consider developing national standards and skills competencies for medical students.
- Interview persons with a variety of physical disabilities accessing a health clinic to gain new insights on how environmental barriers affect care services and provider education.



- Survey care providers to explore understandings of disability-related care, how often they treat patients with physical disabilities respective to their clinic type, and ideas for disability curricula topics.
- Design disability curricula to reflect principles and practices of:
  - ADA guidelines for health clinics and doctors' offices;
  - disability care;
  - durable medical equipment;
  - nonpharmaceutical alternatives to pain management;
  - secondary conditions patients with physical disabilities are at risk for;
  - communication techniques that prompt questions about a patient's condition;
  - signs and symptoms of clinical depression;
  - wellness activities for patients with physical disabilities;
  - preventive screening procedures for patients with physical disabilities;
  - training in disability sensitivity; and
  - major practice considerations with physical disability and age-related differences.
- Include input from AWPDP and care providers when designing disability curricula.

Although 25% of American medical schools already provide disability-related curriculum (Wen, 2014), a national curricula standard is needed to better prepare providers in meeting complex needs of people with physical disabilities. Leaders from the health care system and education system need to partner together to make necessary connections from the classroom to health clinics. Input from AWPDP and health professionals can help distinguish the particular underpinnings of disability-related knowledge to help make this major undertaking possible.

## **Concluding Comments**

This study highlighted AWPDP perceptions of accessing care in health clinics as well as care provider perceptions providing care for AWPDP. It is clear from the evidence that more work needs to be done in accommodating patients with physical disabilities in health clinic facilities. In some cases, not having adequate access to care resulted in undesirable outcomes and incomplete exams for AWPDP. It is important that care providers provide equal health services to people with and without physical disabilities. Moreover, providers that make available accommodations in their clinics for people with physical disabilities may be better prepared to meet their unique health needs as well as the growing needs of disability-related services in the aging population. Efforts from leaders in health and education fields could help by transforming clinic policies and disability curriculum that advocate for accessibility. Educating care providers and other health professionals in disability-related care could help bridge the gap between the research findings and improving health services and outcomes for AWPDP. In a health system which is predicted to experience high demands for disability services in the near future, an inclusive approach with AWPDP will be necessary for shaping and implementing structural designs and disability curricula.

The findings in this study will help (a) contribute to the literature regarding AWPDP and provider perceptions of accessibility in health clinics, (b) inform educational leaders of the need for disability-related curricula for health professionals that improve physical environments, attitudes, and disability knowledge when caring for patients with physical disabilities, and (c) contribute to the growing body of literature in mixed methods research and the transformative paradigm.

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## Appendix A

### Written Permission from Disability Organization to Conduct Focus Groups

I (print name), USANTHI FERNANDEZ

Give permission to Teresa Jones to conduct interviews with up to five separate focus groups comprised of current tenants who choose to participate in a study titled, *Health Clinics and Adults with Physical Disabilities: An Inclusive Approach*. Dates are tentative for spring 2017. Interview sessions will be scheduled from 4:00pm – 5:00pm and held at the participants' residential homes in Golden Valley, Minnesota.

I also give permission to Teresa Jones to post a flyer on the participating home premises recruiting tenants to participate in the study. Eligibility criteria and consent forms will be available for interested participants.

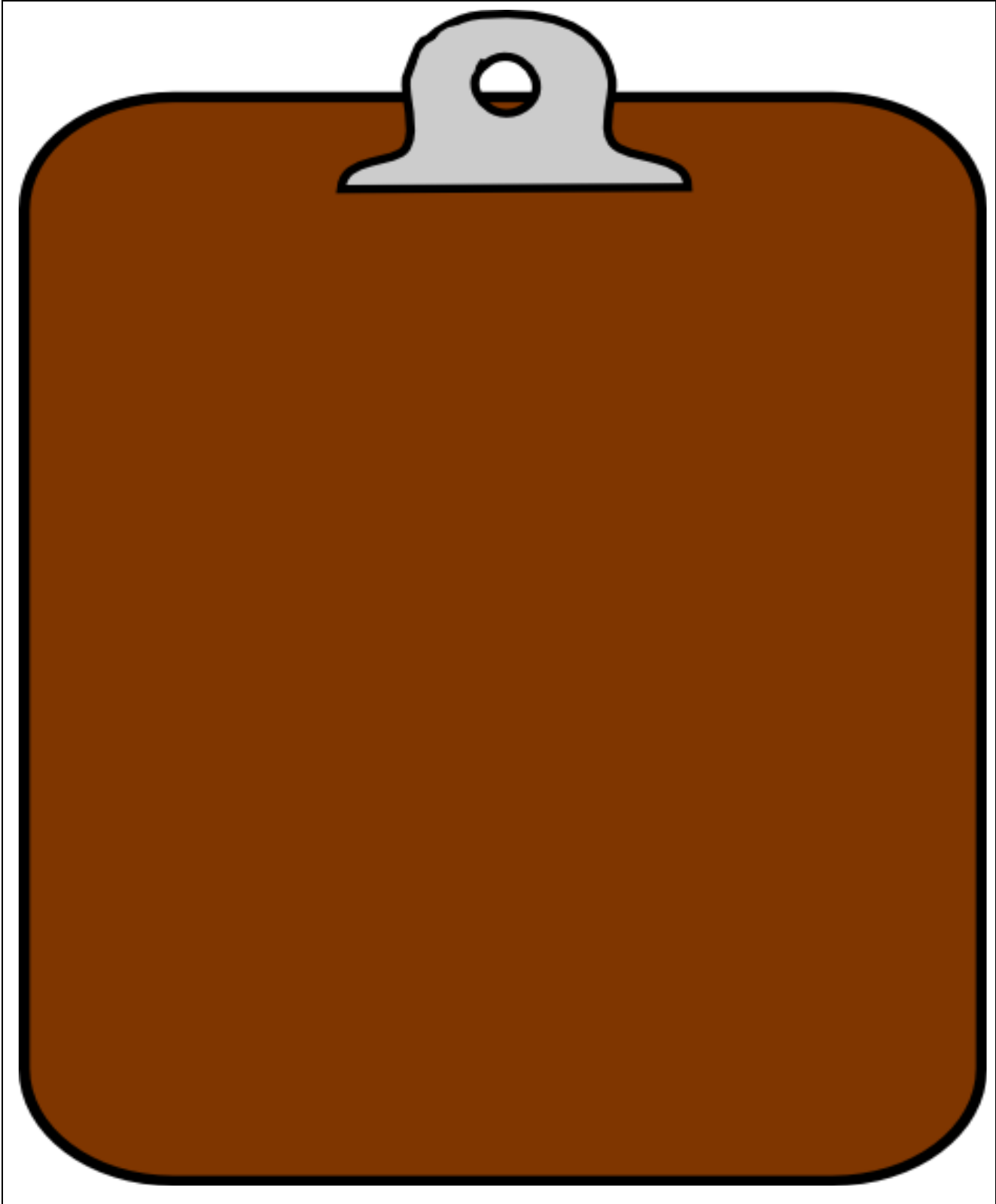
Name of Organization: HAWTHORNE HOUSE INC.

Authorized Signature: J.R. Fernandez Date: 12/29/2016

## Appendix B

### Focus Group Recruitment Flyer





## Appendix C

### Informed Consent: Focus Group Participants

You are invited to participate in a research project to:

- A. Voice your experiences in health clinics and share ideas on creative solutions for improving health clinic environments. Environmental factors include social attitudes, architectural characteristics, legal and social structures, climate, and terrain. The most common barriers in the environment to disability are related to negative attitudes, communication, physical environment, policy compliance, social, transportation, and programmatic (e.g. disability knowledge).

Your participation is voluntary and I, Teresa Jones will ask you the following questions:

1. Describe your experiences of the physical environment when you visited a health clinic.
  2. Tell me about your experiences with medical equipment.
  3. Describe your relationship with your provider.
  4. Describe at least one example of how you think your care provider is knowledgeable in what you feel are important aspects of your disability care.
  5. What are your ideas for creating an improved health clinic environment?
- B. Assist in developing a survey for health clinic care providers based on your experiences in health clinics. Surveys will then be mailed to systematically selected health clinics throughout Metropolitan and Greater Minnesota.

Your participation is voluntary and I, Teresa Jones will ask you to create response choice items for the following survey questions to care providers:

1. The physical environment of my clinic provides the following (check all that apply):  
 \_\_\_\_\_
2. My clinic provides medical equipment that accommodates persons with physical disabilities (check all that apply):  
 \_\_\_\_\_
3. Relationships with my patients with physical disabilities are (check all that apply):  
 \_\_\_\_\_
4. I am knowledgeable in (check all that apply):  
 \_\_\_\_\_
5. I have ideas for improving my clinic's environment (this is a fill-in-the-blank for the care provider to answer).

The purpose of this study will be to explore the differences between what adults with physical disabilities experience regarding access to care in health clinics versus what health care providers say they are providing in their clinics regarding care for adults with physical disabilities. The objective is to explore experiences of adults with physical disabilities in health clinics (A above) and then involve their input to formulate a five-question provider survey (B above) based on those experiences.

You were selected as a possible participant for this study because you reside in a home with assisted living licensure and may possibly have a limitation with physical mobility, requiring disability-related services while at a health clinic.

This research project is intended for use in a chosen dissertation project for Bethel University as part of my graduate studies fulfillment for the degree of Doctorate of Education. There are no funding agencies involved. Data will be collected through a group interview regarding your experiences in health clinics and ideas for improvement, and also the survey response choices you develop for providers.

The interview will be held in the common area of your home and could include up to eight participants. The group interview will be approximately one hour in length and will be audio recorded for accuracy. There are no physical risks or physical discomfort involved; however, some of the content discussed may be sensitive in nature. Due to open discussion amongst other individuals in the group, other group members will hear your remarks. I cannot control confidentiality amongst group members at times of open statements during the group interview. You may skip any question that you consider to be stressful or uncomfortable. You will also receive a list of the provider survey questions with space to write down your ideas or if you do not wish to disclose information verbally in a group setting. You may request a private, audio recorded session with me if you prefer to provide your input one-on-one. All recordings will be destroyed no later than one year past the interview date.

Your input in this research will help benefit the disability community, health professionals, and educators by gaining new insights on health clinic environments that advocate for clinic access improvements.

Refreshments will be provided during the interview.

Any information obtained in connection with this study that can be identified with you will remain confidential and disclosed only with your permission. In any written reports or publications, no participant will be identified or identifiable. Aggregate data will be presented using categories and number of responses and some participant responses may be presented in quotes. Interview data about health clinic experiences and improvement ideas, care provider survey items, eligibility criteria and participant demographics (age, gender, disability type, and physical disability) will be reviewed by Bethel University dissertation committee members Dr. Diane Dahl, Dr. Steve Paulson, and Dr. Marta Shaw for the purpose of partial fulfillment of the requirements for the degree of Doctor of Education.

Your decision whether or not to participate will not affect future relations with your care provider or the owner and proprietor of your current residence. If you decide to participate, you are free to discontinue participation at any time without affecting said relationships.

This research project has been approved by my dissertation advisor in accordance with Bethel's Levels of Review for Research with Humans. If you have any questions about the research, research participants' rights, or wish to report a research-related injury, please call Teresa Jones [REDACTED] or Bethel University dissertation advisor Dr. Diane Dahl [REDACTED].

You are making a decision whether or not to participate in this research. Your signature indicates that you have read the information provided and consent to participate. You may withdraw at any time without prejudice after signing this form should you choose to discontinue participation in this study. You will be offered a copy of this form to keep. RSVP to Teresa Jones [REDACTED] to join the study.

A \$25 gift card will be given to participants who qualify and join one group session.

Participant signature \_\_\_\_\_ Date \_\_\_\_/\_\_\_\_/\_\_\_\_  
Guardian signature (if applicable) \_\_\_\_\_ Date \_\_\_\_/\_\_\_\_/\_\_\_\_  
Guardian relationship to participant \_\_\_\_\_  
Investigator signature \_\_\_\_\_ Date \_\_\_\_/\_\_\_\_/\_\_\_\_

## Appendix D

### Eligibility Criteria to Participate in the Study and Participant Demographics

## Eligibility Criteria

Study participants must meet at least one of the following physical disability criteria.

Please check all that apply:

- Use a wheelchair, cane, crutches, or a walker.
- Have difficulty walking a quarter of a mile, climbing a flight of stairs, lifting something as heavy as a 10-pound bag of groceries, grasping objects, or getting in and out of bed.
- Have arthritis or rheumatism, back or spine problem, broken bone or fracture, cancer, cerebral palsy, diabetes, epilepsy, head or spinal cord injury, heart trouble or atherosclerosis, hernia or rupture, high blood pressure, kidney problems, lung or respiratory problem, missing limbs, paralysis, stiffness or deformity of limbs, stomach/digestive problems, stroke, thyroid problem, or tumor / cyst / growth as a condition contributing to a reported activity limitation.

*Source:* adapted from the U.S. Census Bureau (Brault, 2012, p. 71).

## Participant Demographics

1. Age \_\_\_\_\_

2.  Male     Female     Other

3. Disability type \_\_\_\_\_

## Appendix E

### Letter of Explanation and Consent for Care Providers

Valued Care Provider:

My name is Teresa Jones, Doctor of Education student at Bethel University in Saint Paul, MN.

You are invited to participate in a study regarding access to care for adults with physical disabilities in health clinics.

The purpose of this study will be to explore the differences between what adults with physical disabilities experience regarding access to care in health clinics versus what health care providers say they are providing in their clinics regarding care for adults with physical disabilities. This study uses a transformative approach by involving adults with physical disabilities in the development of a clinic survey tool asking providers about accessibility in their clinics.

You were selected as a possible participant for this study because you are a care provider currently working in a Metropolitan or Greater Minnesota health clinic. Your clinic was selected from the 2016-2017 Minnesota Medical Directory. A systematic sample of every 3<sup>rd</sup> clinic was chosen out of  $N = 1,971$  clinics in Minnesota.

This study is intended for use in a chosen dissertation project for Bethel University as part of my graduate studies fulfillment for the degree of Doctorate of Education. There are no funding agencies involved. Data will be collected from the attached survey named *Clinic Access Minute Survey* (CAMS). CAMS is a five-question survey which will take approximately one minute to complete. Returned surveys will be kept in a locked office and destroyed by October 1, 2018.

Your input in this research will help benefit the disability community, health professionals, and educators by gaining new insights on health clinic environments that advocate for clinic access improvements.

Any information obtained in connection with this study that can be identified with you will remain confidential and disclosed only with your permission. In any written reports or publications, no participant or clinic will be identified or identifiable. Aggregate data will be presented in categories, numerical values, and quotes. Survey data will be reviewed by Bethel University dissertation committee members Dr. Diane Dahl, Dr. Steve Paulson, and Dr. Marta Shaw for the purpose of partial fulfillment requirements for the degree of Doctor of Education.

There are no costs, no foreseeable risks, or no physical discomfort associated with this survey; however, some survey questions about accessibility in your clinic may be sensitive in nature and you may skip any item you consider to be stressful or uncomfortable. Your response to any question is on a voluntary basis only. Data will be collected without identifying information, therefore your decision whether or not to participate will not affect future relations with your patients, clinic staff, administration, or health system network.

This study has been approved by my dissertation advisor in accordance with Bethel's Levels of Review for Research with Humans. If you have any questions about the research, research participants' rights, or wish to report a research-related injury, please call Teresa Jones [REDACTED] or Bethel University dissertation advisor Dr. Diane Dahl [REDACTED].

Returning a completed survey means you provide consent to participating in this study.

I thank you in advance for considering to join the study.

Genuinely,  
Teresa Jones



## Clinic Access Minute Survey (CAMS)

Please check all items that apply and return CAMS in the envelope provided.

1. The physical environment of my clinic provides the following:
  - wheelchair-accessible building entrance
  - wheelchair-accessible push-buttons to open doors
  - wheelchair-accessible restrooms
  - grab bars in restrooms
  - wheelchair-accessible route to examination rooms
  - maneuvering clearance for wheelchairs to turn around in examination rooms
  - there are future plans to upgrade my clinic's physical environment
  
2. My clinic provides medical equipment that accommodates patients with physical disabilities:
  - wheelchair-accessible weigh scale
  - wheelchair-accessible mammography equipment
  - height-adjustable examination table
  - wheelchair-accessible laboratory equipment for blood draws
  - flexible x-ray equipment
  - flexible stirrups on examination table
  - mechanical lift
  - there are future plans to upgrade my clinic's medical equipment to accommodate patients with physical disabilities
  
3. Relationships with my patients with physical disabilities are:
  - I can freely discuss any health-related issue with my patients
  - I provide other clinic options if my clinic is unable to accommodate a patient with a physical disability
  - I listen to what my patients say about their health issues
  - I problem-solve with my patients about their care
  - my patients are satisfied with how clinic staff responds to their needs
  
4. I am knowledgeable in:
  - disability care for patients with physical disabilities
  - durable medical equipment
  - non-pharmaceutical alternatives to pain management
  - secondary conditions patients with physical disabilities are at risk for
  - communication techniques that prompt questions about a patient's condition
  - signs and symptoms of clinical depression
  - wellness activities for patients with physical disabilities
  - preventive screening procedures for patients with physical disabilities
  - I had no formal education in medical school regarding disability care
  
5. I have ideas for improving my clinic's environment (write ideas in the space below):

## Appendix F

Request for Approval of Research with Human Participants in Social and Behavioral Research:

Adults with Physical Disabilities Focus Groups

**For office use only:**

Code number \_\_\_\_\_ Action:

Date reviewed \_\_\_\_\_

## **Request for Approval of Research with Human Participants In Social and Behavioral Research**

**Institutional Review Board for Research with Humans  
Bethel University**

**P.O. Box 2322**

**3900 Bethel Drive  
St. Paul, MN 55112**

College and Federal policies require that each project involving studies on humans be reviewed to consider 1) the rights and welfare of the individuals involved; 2) the appropriateness of the methods used to secure informed consent; and 3) the risk and potential benefits of the investigation. Bethel has a three-level review structure, such that not all research proposals need to come to the IRB committee. The levels of review and their associated criteria may be viewed on Bethel's website. **Research may not be initiated prior to formal, written approval by the appropriate committee or person.**

The information on the following pages is necessary for review. Answer each item thoroughly, and put N/A for those that do not apply. Label each piece of information by section letter (A – G), item number (1, 2, etc.), and the boldface headers for each item. **Proposals lacking information will be returned without review.** Attach your typewritten pages to this cover sheet.

Submit the completed form to the committee, either at the above address or, if this is Bethel student research, to your research advisor. You *will not* receive this proposal back, so be sure you keep a copy of the materials you submit. You will be notified by letter of the committee's decision.

1/9/09

## A. Identifying Information

- 1) **Date** – July 12, 2017
- 2) **Principal Investigator** – Teresa E. Jones, Doctor of Education student, Bethel University; [REDACTED]  
[tjones3662@q.com](mailto:tjones3662@q.com)
- 3) **Co-investigators** – N/A
- 4) **Project Title** – Health Clinics and Adults with Physical Disabilities: An Inclusive Approach
- 5) **Key Words** – Physical Disability; Health Facilities; Health Services Accessibility; Transformative Theory; Disability Curriculum
- 6) **Inclusive Dates of Project** – Pending approval of IRB, Focus Group dates will be held between August 1<sup>st</sup> and August 31<sup>st</sup>, 2017. Reporting of the results will occur fall 2017.
- 7) **Research Advisor** – Bethel University, 3900 Bethel Drive, St. Paul, MN 55112-6999; Dissertation advisor Dr. Diane Dahl [REDACTED].
- 8) **Funding Agency** – N/A
- 9) **Investigational Agents** – N/A

## B. Participants

**Type of Participants** – Adults with physical disabilities between the ages of 18-64, who are able to speak on their own behalf.

- 1) **Institutional Affiliation** – All participants reside at Hawthorne House Inc., Assisted Living. Hawthorne House Inc., [REDACTED]. The owner is Dr. Susanthi Fernando [REDACTED].
- 2) **Approximate Number of Participants:** Up to four focus groups with an estimated 3-6 participants each. There are a total of seven homes in this organization. One group may have as many as 8 participants if two home sites are combined. For example, some of the homes are located next door to each other and therefore participants will join together at one home. A total number of study participants are estimated to be 10 – 20.
- 3) **How Participants are Chosen** – I am aware of this organization because of my past history of working as a public health nurse. No participant records will be used for this research project.
- 4) **How Participants are Contacted** – I plan to recruit participants by hanging a flyer at each home site. Written permission to hang flyers has been granted by Dr. Susanthi Fernando.
- 5) **Inducements** – Refreshments will be provided during focus groups. A \$25 gift card will be given immediately to participants who qualify and join one focus group session.
- 6) **Monetary Charges** – N/A

**C. Informed Consent** – Make an informed consent form that includes all the elements listed on the attached page, using the sample consent form and guidelines on the Bethel IRB website: <https://cas.bethel.edu/irb/Informedconsent>. Attach a copy of your informed consent form to the proposal. For research with minors or with vulnerable populations consent from parents or guardians is required in most cases.

- 1) During recruitment, I will ask potential participants if they have a guardian and for guardian contact information. Prior to the study, I will notify guardians and mail two consents: one for them to keep and one to sign and return to me.

#### D. Abstract and Protocol

- 1) **Hypothesis and Research Design** – RQ: What is the experience of adults with physical disabilities in health clinics regarding access to care that pertains to physical environments, attitudes, and disability knowledge? A mixed methods approach will be used to address the research question. Focus group interviews (qualitative) regarding experiences in health clinics and development of survey response items (quantitative) for care providers will frame the data collection. A causal-comparative strategy will be used to compare responses of both groups (adults with physical disabilities and care providers). Upon completion of the focus group data collection, a separate request for Approval of Research with Human Subjects will be given to the IRB for permission to survey health care providers. This research is nonexperimental.
- 2) **Protocol** – Focus group participants will not be asked about their experiences at Hawthorne House or any of its related facilities. I will ask and audio-record participants the following questions about their experiences in health clinics:
  1. Describe your experiences of the physical environment when you visited a health clinic.
  2. Tell me about your experiences with medical equipment.
  3. Describe your relationship with your provider.
  4. Describe at least one example of how you think your care provider is knowledgeable in what you feel are important aspects of your disability care.
  5. What are your ideas for creating an improved health clinic environment?

Prior to focus group sessions, participants will be asked to check the following physical disability criteria that apply:

- Use a wheelchair, cane, crutches, or a walker.
- Have difficulty walking a quarter of a mile, climbing a flight of stairs, lifting something as heavy as a 10-pound bag of groceries, grasping objects, or getting in and out of bed.
- Have arthritis or rheumatism, back or spine problem, broken bone or fracture, cancer, cerebral palsy, diabetes, epilepsy, head or spinal cord injury, heart trouble or atherosclerosis, hernia or rupture, high blood pressure, kidney problems, lung or respiratory problem, missing limbs, paralysis, stiffness or deformity of limbs, stomach/digestive problems, stroke, thyroid problem, or tumor / cyst / growth as a condition contributing to a reported activity limitation.

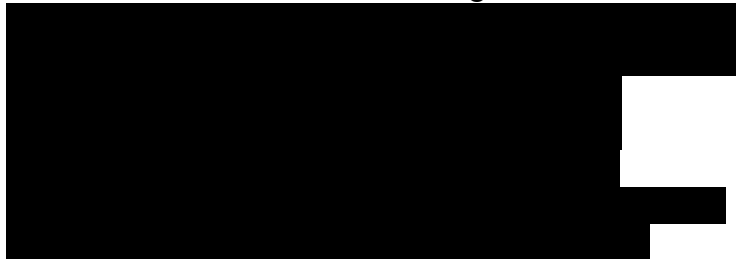
Prior to focus group sessions, participants will be asked to complete the following demographics:

1. Age \_\_\_\_\_
2.  Male     Female     Other
3. Disability type \_\_\_\_\_

The focus groups will also ask participants to assist in developing survey response choice items to the following pre-formulated questions for health care providers. Based on participants' experiences in health clinics, they will create response items asking care providers to select which items are provided in health clinics:

1. The physical environment of my clinic provides the following (check all that apply):  
 \_\_\_\_\_
2. My clinic provides medical equipment that accommodates persons with physical disabilities (check all that apply):  
 \_\_\_\_\_
3. Relationships with my patients with physical disabilities are (check all that apply):  
 \_\_\_\_\_
4. I am knowledgeable in (check all that apply):  
 \_\_\_\_\_
5. I have ideas for improving my clinic's environment (this is a fill-in-the-blank for the care provider to answer).

The focus group interview data will be collected from up to four focus groups via note-taking and audio-recording. Flyers will indicate to contact me if individuals wish to participate. At the time of contact, I will inform them of date, time, and location of focus groups so they are free to attend the focus group location of choice. Hawthorne House Inc. home addresses reflect the following locations:



Permission to conduct focus groups at these locations has been granted by the owner, Dr. Susanthi Fernando. In addition, when potential participants respond to the flyer by calling my posted phone number, I will inform them to complete the following two forms that will be hanging next to the flyers: 1) informed consent; 2) eligibility criteria and demographics (combined form). I will inform them that I will collect the informed consent and eligibility criteria/demographics form at the time of the focus group session if they choose to participate. I will also inform them that the consent lists the questions that will be asked during the focus group session if they wish to review them ahead of time. Eligibility and demographic information will not be shared with focus group participants. Participants will be debriefed regarding the purpose of the study prior to beginning all focus groups. To create a visual for participants, they will be given a list of provider survey questions with space to write down items during our time to develop the survey response choice items for health care providers. Private sessions will be offered for those who request it or have a physical disability that might otherwise limit them from sharing their input.

**E. Risks** – Evaluate the following items carefully to see which apply to your study. For those that do apply, state which one(s) and **what precautions will be taken to minimize risk to the participants**. If an item is not a risk for your study, please state “No known risk identified.” If, in the course of review, the committee finds evidence of possible risk that is not addressed, **the proposal will be immediately rejected**.

- 1) **Privacy** – Names of participants, their family members, their care providers, or names of clinics visited will not be recorded. Participants’ personal information gathered from eligibility criteria and demographics will be listed in my dissertation in Table or Figure format only. I will inform participants that any information obtained in connection with this study that can be identified with the participant will remain confidential and disclosed only with their permission. Aggregate data (numerical values; participant quotes) will be presented in written reports or publications, such as my dissertation, and as stated in the consent form and section F below. No participant health records will be used.
- 2) **Physical stimuli** – No known risk identified
- 3) **Deprivation** – No known risk identified
- 4) **Deception** – No known risk identified
- 5) **Sensitive information** – Participants will be asked to complete an eligibility criteria checklist regarding physical disability (use of mobility device; physical functioning ability; and if they have a physically disabling condition, such as arthritis, cerebral palsy, missing limbs, etc.); and participant demographics (age, gender, disability type). Some of the content discussed in focus groups may be sensitive in nature. For example, the investigator will ask participants to describe their experiences in health clinics pertaining to the physical environment, provider relationship, and provider knowledge in disability-related care. In the consent form and at the start of focus groups, I will inform participants that other group members will hear their remarks during the group interview and I cannot control confidentiality amongst group members at times of open statements. Participants will be informed they may skip any question they consider to be stressful or uncomfortable, or leave the group at any time without repercussions.
- 6) **Offensive materials** – No known risk identified
- 7) **Physical exertion** – No known risk identified

**F. Confidentiality** – Participant names or any names mentioned in focus groups will not be recorded. Any information obtained in connection with this study that can be identified with the participant will remain confidential and disclosed only with their permission. Aggregate data (numerical values; participant quotes) will be presented in written reports or publications, such as my dissertation. Audio-recordings and notes taken during focus group sessions will be placed and secured within a locked office in my home. The investigator is the only person who has access to the home office. Audio-recordings will be used only for study purposes and destroyed no later than one year past the interview date, by August 1, 2018. Data collected from focus groups, eligibility criteria, and demographics will be reviewed by Bethel University dissertation advisor, Dr. Diane Dahl and two second readers, Dr. Steve Paulson and Dr. Marta Shaw as part of my graduate studies fulfillment for the degree of Doctorate of Education. Data will not be reported in a way that violates participants’ confidentiality, nor become part of a participants’ permanent record. No third parties will be informed of anyone’s participation in the study.

A copy of the informed consent will be offered to participants.

**G. Signatures** – Type the following paragraph at the end of the proposal and have all investigators and the research advisor (if applicable) sign and date below it.

“I certify that the information furnished concerning the procedures to be taken for the protection of human participants is correct. I will seek and obtain prior approval for any substantive modification in the proposal and will report promptly any unexpected or otherwise significant adverse effects in the course of this study.”

1/9/09



## Appendix G

Request for Approval of Research with Human Participants in Social and Behavioral Research:

Health Clinic Care Provider Survey

**For office use only:**

Code number \_\_\_\_\_ Action:

Date reviewed \_\_\_\_\_

## **Request for Approval of Research with Human Participants In Social and Behavioral Research**

**Institutional Review Board for Research with Humans  
Bethel University**

**P.O. Box 2322**

**3900 Bethel Drive  
St. Paul, MN 55112**

College and Federal policies require that each project involving studies on humans be reviewed to consider 1) the rights and welfare of the individuals involved; 2) the appropriateness of the methods used to secure informed consent; and 3) the risk and potential benefits of the investigation. Bethel has a three-level review structure, such that not all research proposals need to come to the IRB committee. The levels of review and their associated criteria may be viewed on Bethel's website. **Research may not be initiated prior to formal, written approval by the appropriate committee or person.**

The information on the following pages is necessary for review. Answer each item thoroughly, and put N/A for those that do not apply. Label each piece of information by section letter (A – G), item number (1, 2, etc.), and the boldface headers for each item. **Proposals lacking information will be returned without review.** Attach your typewritten pages to this cover sheet.

Submit the completed form to the committee, either at the above address or, if this is Bethel student research, to your research advisor. You *will not* receive this proposal back, so be sure you keep a copy of the materials you submit. You will be notified by letter of the committee's decision.

1/9/09

## A. Identifying Information

- 1) **Date** – October 9, 2017
- 2) **Principal Investigator** – Teresa E. Jones, Doctor of Education student, Bethel University; [REDACTED]  
[tjones3662@q.com](mailto:tjones3662@q.com)
- 3) **Co-investigators** – N/A
- 4) **Project Title** – Health Clinics and Adults with physical Disabilities: An Inclusive Approach
- 5) **Key Words** – Physical Disability; Health Facilities; Health Services Accessibility; Transformative Theory; Disability Curriculum
- 6) **Inclusive Dates of Project** – Pending approval of IRB, Care Provider surveys will be mailed September of 2017. Reporting of the results will occur in fall 2017.
- 7) **Research Advisor** – Bethel University, 3900 Bethel Drive, St. Paul, MN 55112-6999; Dissertation advisor Dr. Diane Dahl [REDACTED].
- 8) **Funding Agency** – N/A
- 9) **Investigational Agents** – N/A

## B. Participants

- 1) **Type of Participants** – Health care providers in health clinics.
- 2) **Institutional Affiliation** – Health clinics are located in Metropolitan and Greater Minnesota and have been identified from the October 2016-October 2017 Minnesota Medical Directory.
- 3) **Approximate Number of Participants** – A systematic sample of every 3<sup>rd</sup> clinic will be chosen out of  $N = 1,971$  clinics in Minnesota. This accounts for 640 surveys being mailed with a desired return rate of 320 surveys.
- 4) **How Participants are Chosen** – One health care provider from each systematically selected health clinic via the Minnesota Medical Directory will be asked to participate. The front of each mailing envelope will state “Attention Clinic Manager” to help route the survey to a provider in the clinic.
- 5) **How Participants are Contacted** – Systematic sampling of every 3<sup>rd</sup> health clinic in Minnesota will receive a survey and letter of explanation which will include consent to participate in the survey.
- 6) **Inducements** – N/A
- 7) **Monetary Charges** – N/A

**C. Informed Consent** – Make an informed consent form that includes all the elements listed on the attached page, using the sample consent form and guidelines on the Bethel IRB website: <https://cas.bethel.edu/irb/Informedconsent>. Attach a copy of your informed consent form to the proposal. For research with minors or with vulnerable populations consent from parents or guardians is required in most cases.

## D. Abstract and Protocol

- 1) **Hypothesis and Research Design** – RQ: What do health care providers say they are providing in their clinics regarding care for adults with physical disabilities (AWPD) that pertain to physical environments, attitudes, and disability knowledge? A quantitative approach will be used to address the research question by conducting a survey. A quantitative approach will test the hypothesis by examining differences between AWPD and care providers on dependent variables. ( $H_1$ ): There is a significant difference between what health care providers say they are providing in their clinics regarding care for AWPD and the care reported by AWPD with physical environments, attitudes, and disability knowledge.  $H_1o$ : There is no significant difference between what health care providers say they are providing in their clinics regarding care for AWPD and the care reported by AWPD with physical environments, attitudes, and disability knowledge.

Prior to this IRB request, focus group interviews (qualitative) consisting of AWPD was approved by the Bethel IRB and conducted by this investigator. Focus group participants discussed their experiences in health clinics and assisted in the development of the survey response items (quantitative) for care providers. A causal-comparative strategy will be used to compare responses of both groups (AWPD and care providers). This mixed methods research is nonexperimental.

- 2) **Protocol** – I will mail a letter of explanation to care providers inviting them to participate in a study regarding access to care for adults with physical disabilities in health clinics. The letter will state the purpose of the study: to explore the differences between what adults with physical disabilities experience regarding access to care in health clinics versus what health care providers say they are providing in their clinics regarding care for adults with physical disabilities. The letter of explanation also states that data will be collected from the attached survey named *Clinic Access Minute Survey (CAMS)* and will take one minute to complete. A return envelope will be included to mail the survey back to the investigator. The letter states that returning a completed survey means the care provider consents to participating in the study. I will ask the following five questions and instruct the care provider to check all that apply:
  1. The physical environment of my clinic provides the following:
    - wheelchair-accessible building entrance
    - wheelchair-accessible push-buttons to open doors
    - wheelchair-accessible restrooms
    - grab bars in restrooms
    - wheelchair-accessible route to examination rooms
    - maneuvering clearance for wheelchairs to turn around in examination rooms
    - there are future plans to upgrade my clinic's physical environment
  2. My clinic provides medical equipment that accommodates patients with physical disabilities:
    - wheelchair-accessible weigh scale
    - wheelchair-accessible mammography equipment
    - height-adjustable examination table
    - wheelchair-accessible laboratory equipment for blood draws

- flexible x-ray equipment
  - flexible stirrups on examination table
  - mechanical lift
  - there are future plans to upgrade my clinic's medical equipment to accommodate patients with physical disabilities
3. Relationships with my patients with physical disabilities are:
- I can freely discuss any health-related issue with my patients
  - I provide other clinic options if my clinic is unable to accommodate a patient with a physical disability
  - I listen to what my patients say about their health issues
  - I problem-solve with my patients about their care
  - my patients are satisfied with how clinic staff responds to their needs
4. I am knowledgeable in:
- disability care for patients with physical disabilities
  - durable medical equipment
  - non-pharmaceutical alternatives to pain management
  - secondary conditions patients with physical disabilities are at risk for
  - communication techniques that prompt questions about a patient's condition
  - signs and symptoms of clinical depression
  - wellness activities for patients with physical disabilities
  - preventive screening procedures for patients with physical disabilities
  - I had no formal education in medical school regarding disability care
5. I have ideas for improving my clinic's environment (write ideas in the space below):

This space is intended for care providers to write in their solutions.

**E. Risks** – Evaluate the following items carefully to see which apply to your study. For those that do apply, state which one(s) and **what precautions will be taken to minimize risk to the participants**. If an item is not a risk for your study, please state “No known risk identified.” If, in the course of review, the committee finds evidence of possible risk that is not addressed, **the proposal will be immediately rejected**.

- 1) **Privacy** – No participant or clinic will be identified or identifiable in this study. I will inform participants that any information obtained in connection with this study that can be identified with them will remain confidential and disclosed only with their permission. Aggregate data (numerical values; participant quotes) will be presented in written reports or publications, such as my dissertation, and as stated in the letter of explanation and section F below. The letter of explanation is the informed consent. No participant records or clinic records will be used.
- 2) **Physical stimuli** – No known risk identified

- 3) **Deprivation** – No known risk identified
- 4) **Deception** – No known risk identified
- 5) **Sensitive information** – Providers will be informed that survey questions about accessibility in their clinics may be sensitive in nature and responding to any question is on a voluntary basis only.
- 6) **Offensive materials** – No known risk identified
- 7) **Physical exertion** – No known risk identified

**F. Confidentiality** – In any written reports or publications, no participant or clinic will be identified or identifiable and only aggregate data (numerical values; participant quotes) will be presented. Returned surveys will be kept in a locked office in my home and destroyed by October 1, 2018. The investigator is the only person who has access to the home office. Data collected from care provider surveys will be reviewed by Bethel University dissertation advisor Dr. Diane Dahl and two second readers, Dr. Steve Paulson and Dr. Marta Shaw as part of my graduate studies fulfillment for the degree of Doctorate of Education. Data will not be reported in a way that violates participants' confidentiality, nor become part of any care provider or health clinic's permanent records. No third parties will be informed of anyone's participation in the study.

Care providers may keep the mailed letter of explanation and return the survey.

**G. Signatures** – Type the following paragraph at the end of the proposal and have all investigators and the research advisor (if applicable) sign and date below it.

“I certify that the information furnished concerning the procedures to be taken for the protection of human participants is correct. I will seek and obtain prior approval for any substantive modification in the proposal and will report promptly any unexpected or otherwise significant adverse effects in the course of this study.”

1/9/09

## Appendix H

Response Choice Items for Care Provider Survey:

Tool for AWPD

## Response Choice Items for Care Provider Survey: Clinic Access Minute Survey (CAMS)

Please write in response choice items for the following survey questions to health care providers. Based on your experiences in health clinics, what items do you want care providers to say they are providing in their clinics? The survey will ask care providers to “check all that apply.”

1. The physical environment of my clinic provides the following:

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

2. My clinic provides medical equipment that accommodates persons with physical disabilities:

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

3. Relationships with my patients with physical disabilities are:

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

4. I am knowledgeable in:

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

5. I have ideas for improving my clinic’s environment (this is for the care provider only)



## Appendix I

Signatures:

Investigator and Research Advisor

**Signatures**

“I certify that the information furnished concerning the procedures to be taken for the protection of human participants is correct. I will seek and obtain prior approval for any substantive modification in the proposal and will report promptly any unexpected or otherwise significant adverse effects in the course of this study.”

Investigator signature *Teresa Jones* Date 7/12/17

Research advisor signature *Diane Doh* Date 7/12/17

## Appendix J

IRB Approval to Conduct Focus Groups:

Adults with Physical Disabilities



**BETHEL**  
UNIVERSITY

Institutional Review Board  
3900 Bethel Drive  
PO2322  
St. Paul, MN 55112

September 6, 2017

Teresa Jones  
Bethel University  
St. Paul, MN 55112

Re: Project SP-40-17 Health Clinics and Adults with Physical Disabilities: An Inclusive Approach

Dear Teresa,

On September 6, 2017, the Bethel University Institutional Review Board completed the review of your proposed study and approved the above referenced study.

Please note that this approval is limited to the project as described on the most recent Human Subjects Review Form, including email correspondence. Also, please be reminded that it is the responsibility of the investigator(s) to bring to the attention of the IRB any proposed changes in the project or activity plans, and to report to the IRB any unanticipated problems that may affect the welfare of human subjects. Last, the approval is valid until September 5, 2018.

Sincerely,

Peter Jankowski, Ph.D.  
Chair, Bethel University IRB

## Appendix K

IRB Approval to Conduct Clinic Access Minute Survey (CAMS):

Health Clinic Care Provider



**BETHEL**  
UNIVERSITY

Institutional Review Board  
3900 Bethel Drive  
PO2322  
St. Paul, MN 55112

October 16, 2017

Teresa Jones  
Bethel University  
St. Paul, MN 55112

Re: Project FA-16-17 Health Clinics and Adults with physical Disabilities: An Inclusive Approach

Dear Teresa,

On October 16, 2017, the Bethel University Institutional Review Board completed the review of your proposed study and approved the above referenced study.

Please note that this approval is limited to the project as described on the most recent Human Subjects Review Form, including email correspondence. Also, please be reminded that it is the responsibility of the investigator(s) to bring to the attention of the IRB any proposed changes in the project or activity plans, and to report to the IRB any unanticipated problems that may affect the welfare of human subjects. Last, the approval is valid until October 15, 2018.

Sincerely,

Peter Jankowski, Ph.D.  
Chair, Bethel University IRB

## Appendix L

Reminder Postcard to Complete CAMS:

Health Clinic Care Provider

# Reminder!

You recently received a survey titled:

*Clinic Access Minute Survey (CAMS)*

Please complete the survey and return it in the postmarked envelope provided to you earlier.

Thank You!

## Attention Clinic Manager

You recently received a survey titled:  
*Clinic Access Minute Survey (CAMS)*.

Any Care Provider in your clinic may complete the survey.  
Care Provider input in this research will help benefit:

- Disability Communities
- Health Professionals
- Educators

Please return the completed survey to:

Teresa Jones, Ed.D student

Note. Personal contact information for Teresa Jones was removed post-dissertation activities for confidentiality purposes.