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Barriers to Health Care Among Adults with Disabilities in Connecticut

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Plain Language Summary

Persons with disabilities are not as healthy as people without disabilities. There are reasons for this such as not being able to get to places that provide health care like offices and clinics. These places may have physical barriers to getting into the offices or clinics, or they may not have the right equipment for a person with disability. Health care providers may not be trained in the needs of persons with disabilities. The University of Connecticut (UConn) Center for Excellence in Developmental Disabilities (UCEDD) and Leadership Education in Neurodevelopmental and related Disabilities Program (UConn LEND) worked with self-advocates to ask adults with disabilities in CT about their medical care. The survey had 25 questions, was on the computer to fill out, and had a reading level of grade 5. The survey link was emailed from the UConn UCEDD mailing list and people were told they could share the email with others. The survey was filled out by a person with a disability or a family member or direct care support staff to a person with a disability. A total of 78 people did the survey. Most people had a physical disability. Over half of the people who did the survey said they needed an exam table that moves up and down, an office with no stairs to climb, and an office that can fit a wheelchair for them to have a successful health care visit. Others who filled out the survey said they have problems getting their provider to understand them, or they did not understand their provider. In CT and the rest of the country, there are many things that need to happen to have persons with disabilities get the health care they need and deserve.

Abstract

It is estimated that 25% of adults in the U.S. are living with one or more disabilities. Persons with disabilities (PWD) have unmet health care needs and experience health

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disparities compared to those without disabilities. Barriers to quality health care include structural barriers such as access to transportation, physical access to facilities, and lack of accessible medical equipment. Other barriers include the knowledge, skills, beliefs, and attitudes of health care providers to meet the needs of PWD. To examine the barriers to health care experienced by adults with disabilities in Connecticut, the University of Connecticut Center for Excellence in Developmental Disabilities and Leadership Education in Neurodevelopmental and related Disabilities program (UConn UCEDD; UConn LEND) worked with self-advocates to develop a 25-question online survey in plain language. Data from 78 PWD and/or family members and caregivers of a PWD living in Connecticut were analyzed. Respondents reported experiencing issues scheduling appointments because of a lack of availability, challenges with the scheduling system, or transportation difficulties (21%); using devices for telehealth visits (27%); and insurance coverage and cost (17%). More than half of respondents reported needing accessible buildings and exam rooms as well as accessible medical diagnostic equipment (MDE). Finally, 43% of respondents reported problems communicating with health care providers, 39% reported that providers demonstrated negative attitudes towards them during visits, and 61% reported that they did not think their health care providers had enough training about working with PWD. The results of this survey suggest that PWD living in Connecticut experience similar barriers to health care access as PWD across the country. Our findings support the need for federal enforcement of standards for accessible MDE, state-level compliance of the standards, and required training in disability competency for all health care training programs to ensure that providers can meet the needs of PWD.

Introduction

According to Behavioral Risk Factor Surveillance System (BRFSS) self-report data, an estimated 25% of adults in the U.S. are living with one or more disability, an increase from previous estimates (Iezzoni et al., 2014; Okoro et al., 2018; Reichard et al., 2011). For the BRFSS, disability is operationalized as a “yes” response to experiencing any of the six types or functional categories of disability as required by Section 4302 of the Patient Protection and Affordable Care Act (ACA) data collection standards on disability status and other demographic characteristics (Assistant Secretary for Planning and Evaluation, 2011; Okoro et al., 2018; see Table 1). These categories emanated from the World Health Organization’s (WHO) functional or biopsychosocial model of disability (WHO, 2001). Persons with disabilities will be referred PWD for the remainder of the paper.

One commonality among PWD is a a high probablility of need for ongoing and comprehensive support and care from health care providers (Lagu et al., 2022). This is not just because they have a disability, but also because of a need to prevent and treat co-occurring chronic conditions that PWD experience at significantly higher rates than those without disabilities. These include conditions such cardiac disease, diabetes, and obesity. Additionally, PWD are more likely to smoke, more likely to have unmet health care needs, less likely to receive preventative health care and health screenings, and less likely to have access to mental health services (Cree et al., 2020; Dixon-Ibarra & Horner-Johnson, 2014; Drum et al., 2005; Horner-Johnson et al., 2015; Iezzoni, Kurtz, & Rao, 2015; Krahn et al., 2015; Mahmoudi &

Table 1

Comparison of BRFSS Disability Items and UConn UCEDD Plain Language Disability Descriptions

	BRFSS			UConn UCEDD		
Category	Item	Grade level 1[a]	Grade level 2[b]	Item	Grade level 1[a]	Grade level 2[b]
Cognitive	Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?	18.3	12	It is hard for me to focus, or remember things, or make decisions.	5.8	4
Hearing	Are you deaf or do you have serious difficulty hearing?	7.1	5	I am deaf or can't hear very well.	0.8	1
Independent Living	Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?	14.9	10	It is hard to do errands like shopping alone.	3.6	4
Mobility 1	Do you have serious difficulty walking or climbing stairs?	8.8	7	I use a wheelchair, power chair, motorized scooter, walker, cane, or something else to help me get around.	9.1	7
Mobility 2	--	--	--	It is hard to walk or go up and down stairs.	0.5	1
Self-care	Do you have difficulty dressing or bathing?	7.3	6	It is hard to get dressed or take a bath or shower.	1.8	2
Vision	Are you blind or do you have serious difficulty seeing, even when wearing glasses?	9.2	7	I am blind or can't see well even with glasses.	2.4	2
Communication 1	--	--	--	I use a device like a phone or a table or communication or speech device to help me communicate with others.	10.5	6
Communication 2	--	--	--	I use [American] or other type of Sign Language or pictures to communicate with others.	7.5	7

[a] Microsoft Word (365): Flesch-Kincaid grade level.

[b] Hemingway app Readability.

Meade, 2015; Mitra et al., 2011; National Council on Disability [NCD], 2009; Reichard et al., 2011). These findings identify disparities for PWD in accessing and receiving quality physical and mental health care and disparities in health outcomes. When health care is not accessible nor available to PWD, their health is negatively impacted. COVID-19 exacerbated many of these health issues in PWD, leaving many with unmet health care needs (e.g., Assi et al., 2022;

Cochran, 2020; Lund et al., 2020; Nagarajan et al., 2022; Schwartz et al., 2021; Turk & Mitra, 2022b; D. Tyler et al., 2021). According to 2020 National Health Interview Survey data, a higher proportion of adults with disabilities reported delaying or not getting medical care for something other than COVID-19, compared to adults without disabilities (Akobirshoev et al., 2022).

To call attention to the medical needs of this diverse community, the NCD (2022) published a framework to achieve health equity for PWD with five core areas.

1. Designating PWD as a Special Medically Underserved Population (SMUP) under the Public Health Services Act.
2. Designating PWD as a Health Disparity Population under the Minority Health and Health Disparities Research and Education Act.
3. Requiring comprehensive clinical care curricula in healthcare professional schools; 4. Requiring the use of accessible medical and diagnostic equipment.
4. Improving data collection concerning healthcare for PWD across the lifespan. (pp. 2-3).

Unfortunately, this framework has not been implemented, contributing to the many barriers PWD experience in accessing the health care they need.

Barriers to Health Care for Persons with Disabilities

There are many structural barriers to health care access for PWD. These include a lack of accessible transportation (Chiu et al., 2017) and a lack of physical access to health care facilities and offices, such as lack of access to parking lots, exterior entrances, and restrooms (Frost et al., 2015; Grabois et al., 1999; Morris et al., 2017; Mudrick et al., 2012, 2019; Pharr et al., 2019). PWD also experience a lack of available and accessible medical diagnostic equipment (MDE) at health care facilities. This includes exam tables, weight scales, and diagnostic imaging technologies (Grabois et al., 1999; Iezzoni & Pendo, 2018; Iezzoni, Wint, et al., 2015; Lagu et al., 2013; Mudrick et al., 2012; Pharr et al., 2019).

These barriers are also evident in a study that revealed health care providers' concerns about the cost of providing physical accommodations for PWD (Lagu et al., 2022). Additional concerns identified by health care providers include the safety of accessible MDE, ease of use of accessible equipment, and issues related to space and size of equipment (Agaronnik et al., 2019; Maragh-Bass et al., 2018). Studies of medical office administrators and managers also indicated a lack of knowledge regarding accessible equipment and accommodations for PWD (Pharr, 2013, 2014; Pharr et al., 2019) and beliefs that use of accessible equipment can increase staff injury (Fragala et al., 2017; Morris et al., 2017).

While physical access to care and equipment remains a large contribution to health care inequities for PWD, an equally important barrier to appropriate care is insurance coverage. This includes a lack of insurance (Drainoni et al., 2006; Reichard et al., 2017), and inadequate insurance coverage as PWD may need more medical services and time from a health care provider than someone without a disability (Lagu et al., 2022). Low reimbursement rates for the care a PWD needs can impact the quality of a health care visit and the health care outcomes of the patient (Lagu et al., 2013, 2022).

Health Care Provider Attitudes, Knowledge, and Skills

In addition to the structural barriers to health care, there are also attitudinal barriers to health care access for PWD. It has been suggested that the explicit and implicit biases of health care providers toward PWD may impact the quality and quantity of the health care services they receive (Chapman et al., 2013; VanPuymbrouck et al., 2020). These biases include negative opinions about the quality of life of PWD (Albrecht & Devlieger, 1999; Gallegos, 2021; Lagu et al., 2022) as documented in a survey of 714 practicing physicians (Iezzoni, Rao, Ressalam, Bolcic-Jankovic, Agaronnik, et al., 2021). More than 80% of the physicians reported that persons with significant disabilities have a decreased quality of life than those without disabilities, thus suggesting a bias about providing aggressive medical care or treatment when needed to a PWD, compared to persons without disabilities.

More important findings from this study revealed that only 41% of respondents were very confident in their own ability to provide the same quality of care to PWD as to those without disabilities, and 36% reported knowing little or nothing about their legal responsibilities under the Americans with Disabilities Act (ADA). More than half reported feeling they were at risk of being sued under ADA (Iezzoni, Rao, Ressalam, Bolcic-Jankovic, Agaronnik, et al., 2021). These findings are supported by multiple studies that have reported that health care providers do refer PWD to other health care providers (Chiu et al., 2017; Frost et al., 2015; Grabois et al., 1999; Lagu et al., 2022), refuse treatment (Lagu et al., 2013, 2022; Pharr, 2014), ask patients to provide their own assistance for transfers (Frost et al., 2015; Iezzoni, Rao, Ressalam, Bolcic-Jankovic, Donelan, et al., 2021; Pharr, 2014), ask patients to provide their own weight (Iezzoni, Rao, Ressalam, Bolcic-Jankovic, Donelan, et al., 2021; Story et al., 2009) or perform physical exams with patients remaining in wheelchairs or mobility devices (Agaronnik et al., 2019; Mele et al., 2005; Morris et al., 2017; Pharr, 2013, 2014; Pharr et al., 2019). It has been suggested that many of these attitudes and beliefs emanate from a lack of knowledge and skill about PWD (Lagu et al.,2022*)*.

Last, the quality of communication between patient and provider has also been cited as a barrier to quality health care by PWD (Chiu et al., 2017; Marlow et al., 2019; Lagu et al., 2022). An analysis of patient-provider communication using data from the Health Information National Trends Survey (Marlow et al., 2019, p. 736) revealed that PWD were less likely to report their health care provider gave them a chance to ask questions, addressed their feelings, involved them in decisions, provided clear explanation, ensured they understood the next steps in their care and gave them enough time during the visit. PWD have reported delaying or forgoing medical care due to lack of disability competence, including communication, among health care providers (Krahn & Drum, 2007; NCD, 2009).

Purpose of the Study

Physical barriers, negative attitudes, and lack of knowledge about PWD among health care providers have direct implications for the health care provided to PWD and their subsequent health outcomes. According to 2021 BRFSS data as reported in the Disability and Health Data System, 23.9% of adults in Connecticut (CT) have at least one disability, and more PWD are obese, current smokers, have heart disease, and have diabetes compared to persons without disabilities. Additionally, fewer PWD can identify a personal health care provider, compared to those without disabilities (Centers for Disease Control and Prevention [CDC], 2021). The purpose of this study was to examine the barriers to health care experienced by PWD living in CT through a survey developed in collaboration with individuals with disabilities and disability advocates that could be completed by a PWD or a caregiver of a PWD. Findings from this study add support to the existing national data on disparities in health care access and quality of care for those with disabilities as well as the data for CT and echo the need for systems-level change.

Methods

Participant Characteristics

Survey invitations went out to PWD and families living in CT who were on a mailing list at the UConn UCEDD. Survey responses were received from 110 participants during a 3-month period in 2022 when the survey was open. Three individuals responded they did not want to take the survey, and 29 surveys were not complete. A total of 78 surveys were included in the final analysis. Forty-four percent of the respondents were 55 or older, 35% were 35-54 years old, and 19% were 18-34 years old (see Table 2). The sample was approximately equal in gender (53% male, 47% female). Most of the respondents' reported motor difficulties (58%). Descriptions of respondents' disability status are shown in Table 2.

Survey and Analysis

Graduate students from the UConn Leadership Education in Neurodevelopmental and related Disabilities (LEND) program participated in the survey design and piloting of questions. The students completed a literature review and interviewed seven informants for guidance on the development of plain language survey questions. The informants were PWD and active members of two disability advocacy organizations in CT. Table 1 provides a comparison of the BRFSS disability items and the adapted plain language items and additions to describe disability. Permission to adapt a publicly available measure, *Facility Site Review: Physical Accessibility Review Survey* by Mudrick et al. (2012, 2019) was also received. The survey questions were then reviewed by LEND students and LEND faculty and staff for readability, understandability, spelling, and grammar. Feedback was used to further revise the survey before it was uploaded into Qualtrics.

Table 2

Demographic Characteristics of Respondents

Variable	*n*	%
Age (*n* = 63)		
< 18 years old	1	1.6
18-24 years old	4	6.3
25-34 years old	8	12.7
35-44 years old	9	14.3
45-54 years old	13	20.6
55-64 years old	14	22.2
> 65 years old	14	22.2
Sex		
Male	41	52.6
Female	37	47.4
Description of disability		
It is hard to walk or go up and down stairs	45	57.7
Use a wheelchair, power chair, motorized scooter, walker, cane, or something else to help get around	43	55.1
It is hard to get dressed or take a bath or shower	37	47.4
It is hard to do errands like shopping alone	35	44.9
It is hard to focus, or remember things, or make decisions	17	21.8
Use a device like a phone or tablet or communication or speech device to help communicate with others	9	11.5
Blind, or can't see well even with glasses	8	10.3
Deaf or can't hear very well	8	10.3
Use American or other type of Sign Language, or pictures to communicate with others	5	6.4

The final survey instrument was comprised of 25 questions divided into 5 sections. These sections were (1) About you; (2) Your disability; (3) Your health care visits; (4) Your health care visits for x-rays or blood work; and (5) Your feedback and comments. The wording for survey items was altered depending on whether the PWD was taking the survey or if someone was completing the survey on behalf of a PWD (this is described in further detail below). An additional section contained questions for those who use mobility devices. Based on feedback during survey development, the survey took 15 minutes to complete. Most questions required respondents to click on a “yes,” “no,” or “I don’t know” as an answer. Some questions asked respondents for more information using a textbox for responses. These textboxes appeared on the survey page using display logic based on the “yes,” “no,” or “I don’t know” response. Some questions asked respondents to select all applicable answer options. The final survey instrument received the following overall scores on readability from Microsoft Word: 80.5 Flesch Reading Ease, 4.6 Flesch-Kincaid Grade Level, and 5.3% passive sentences (Microsoft Corp, 2022).

The study was approved by the UConn Health Institutional Review Board (IRB). A snowball recruitment method was used to distribute the survey (Morgan, 2008). The survey was distributed statewide via email with the survey link by the UConn UCEDD to PWD, caregivers, direct care staff, advocacy organizations, disability organizations and others to share the survey. The survey was also advertised on the UConn UCEDD social media sites. The email invitation was written using plain language and described the study, purpose, and procedures. If they wanted to continue, respondents clicked on the link to the survey embedded in the invitation. A choice was then given to the respondents to identify as having a disability, or being someone who was completing the survey on behalf of a PWD. If in the second category of respondent, they had to identify who they were from a list of choices that included parent, family, friend, unpaid caregiver for a person with a disability, staff member for a person with a disability, or other. Specifically, the invitation invited people who identified as having a disability, or someone who knew a PWD to complete the survey.

Data were collected using Qualtrics. Data collected from PWD (n = 62) and from respondents completing the survey on behalf of PWD (n = 16) were combined into one dataset in Excel and is presented in aggregate. For example, survey item 1 for PWD asks “how old are you?” and survey item 1 for respondents completing the survey on behalf of PWD asks “how old are they?” The data from these two items were combined to create the variable “age” in the final dataset.” Descriptive statistics were calculated using SPSS (IBM Corp, 2017).

Results

Health Care Access

Most respondents reported that they had a health care visit in the past year (73%). Most (74%) reported that they have a doctor who knows them that they can go to when they are sick or hurt, and 44% reported that they have a clinic they can go to where the staff knows them. A majority (73%) reported going to a doctor’s office in the community, 51% had doctors’ visits over the phone/computer. Half (47%) had also received care at a hospital or health center in the past year. In addition to the listed health care visits, 23% of respondents reported receiving health care in other places such as physical therapy centers, rehab centers, mental health centers, specialist visits, and at their residence (e.g., COVID vaccinations). A third of the respondents reported going to five or more doctors in the past year.

Many respondents (40%) reported attending health care visits alone, while others reported having others attend with them for assistance (37%). Some respondents (12%) reported other, with 6% reporting staff or a PCA assisting them and 5% reporting that it depended on the visit (e.g., sometimes they go alone, sometimes they go with a parent/staff). Most respondents (56%) take a taxi, uber, etc., or have parents or family member drive them to health care visits.

An additional 6% of respondents reported “other,” which included rides from other caregivers, personal vans, Sunshine Wheels (a CT accessible transportation company), or an ambulance.

Almost half of the respondents (47%) reported going to a health care provider when they were sick during the past year while 23% did not, even though they were sick. Reasons cited for not getting health care when sick were COVID 19, including fear of getting COVID or limited appointments because of COVID (9%), feeling that a visit to a health care provider would not be worth the trip or the hassle (8%). Most respondents (54%) reported that they did not have problems getting appointments to see health care providers when needed, but 21% reported issues getting needed appointments because of a lack of availability, challenges with offices phone/email scheduling systems, and transportation difficulties. Almost half of the respondents (42%) reported being able to use tablets or computers to access health care visits, but 27% reported problems using electronic devices. Reasons for these included challenges while using technology, general difficulties using computers or tablets for virtual visits, and not liking using tablets or computers for health care visits. More than half of the respondents (56%) reported that they did not have any problems with their insurance in the past year, and 17% reported deficits in coverage for needed services and insurance costs being unaffordable.

Barriers to Accessible Medical Diagnostic Equipment

Respondents reported barriers to needed MDE (see Table 3). Over half (54%) reported needing an exam table that moved up and down to get on and off it safely. Similarly, over half (54%) also reported needing an office that was accessible and did not require stairs to enter. Half (50%) also required an office that could accommodate a wheelchair. Other MDE reported as being needed by respondents included accessible scales (41%), electronic lifts (31%), and access to care in a quiet, uncrowded office (17%). Only a third of the respondents (33%) reported sometimes an exam table that moved up and down to accommodate them was available, and 21% reported that there was never a table available for them that moved up and down. A third of the respondents (32%) reported they needed others to help them on and off the table, and 21% reported that they needed a lift to get on an exam table; 18% stated there was no availability of an electronic lift to move them from their wheelchair or other chair on and off an exam table are never available for them when they needed it. A third (33%) reported that there was never a scale available to weigh them in their wheelchair, scooter, or walker.

Almost half (41%) of the sample reported having problems being able to use equipment or machines because of their disability, and a third of the respondents reported feeling anxious and unsafe using MDE such as X-ray machines, MRI machines, CT scan machines, and other MDE (32%). Reasons for this included the restrictions because of their disability, or having other medical issues that complicated the use of MDE (13%). The female PWDs (47%) reported that they needed a special mammogram machine that moves up and down (26%), and an additional 26% reported that they needed a special exam table for physical exams/Pap tests to be conducted. Lastly, 5% of the sample experienced untrained or unprepared staff who created barriers to the use of MDE. A third of the respondents (36%) reported not having a medical test done because of their disability.

Table 3

Issues with Health Care Visits

Variable	*n*	%
Barriers to Accessible Medical Diagnostic Equipment		
Problems being able to use MDE (equipment or machines) because of special needs	32	41.0
Felt scared and not safe using MDE such as X-ray machines, MRI machines, CT scan machines, and others	25	32.1
Not been able to have a test or X-ray image because PWD could not use the available machine	20	25.6
Health Care Provider Communication, Attitude and Knowledge		
Problems with the doctor or other health care provider showing a negative attitude about them	30	38.5
Problems having doctors understand medical concerns	24	30.8
Problems understanding doctor or health care provider	23	29.5
Problems when asked to use a computer or tablet to talk to a doctor or health care provider instead of seeing them in person	21	26.9
Other Issues Related to Health Care		
Decided not to go to a doctor/other health care provider when sick	18	23.1
Problems making an appointment with a doctor or other healthcare provider	16	20.5
Problems with their medical insurance	13	16.7

Of the 50% of PWD who reported using a mobility device such as a wheelchair, power chair, motorized scooter, walker, cane, or something else, 79% reported that they needed help to transfer to an exam table (e.g., from other people or from a lift). Further, 69% reported staying in their chairs for physical exams, 41% reported staying in their chairs for dental cleanings, 33% stayed in their chairs for medical procedures, and 41% stayed in their chairs for dental procedures. Over half of these respondents (54%) did not receive any explanation about why they were not transferred out of their chair to an exam table.

Health Care Provider Communication, Attitude and Knowledge

Almost half of the respondents (43%) reported problems with communicating with their health care providers (see Table 3). Approximately 31% reported their health care provider did not understand what they were telling them, with 15% reporting that their health care provider did not listen or understand them (e.g., health care provider not taking the time to listen, looking only to the caregiver for communication, or not understanding their disability). An additional 12% reported communication difficulties related to their disability as the cause of health care providers not understanding what they were telling them.

Some respondents (39%) reported that health care providers had a negative attitude toward them during visits, which was demonstrated by not listening to their concerns or being dismissive towards them (12%), not addressing them directly (6%), seeming nervous or uncomfortable with providing care (4%), and using offensive/outdated terminology when interacting with them (3%). A third of the respondents (31%) reported not being able to understand the health care provider's explanations for medical care.

Most respondents (61%) reported that they did not think that their health care providers and other staff have had training about PWD. Roughly 22% of respondents reported that their health care providers and staff did not seem to have knowledge about PWD and their health care needs, 10% reported negative experiences with health care providers, and 4% reported being treated as inferior. Most respondents (65%) felt health care providers and staff should have training about the needs of PWD, with 27% reporting that this would help health care providers provide better and more comprehensive care for PWD. Other respondents (15%) felt training would help their doctors become better providers, and 10% thought it would help to ensure PWD were treated as equals.

Discussion

Findings from this survey indicate that PWD in CT experience similar barriers to health care access as PWD across the US (Iezzoni, Rao, Ressalam, Bolcic-Jankovic, Donelan, et al., 2021; Lagu et al., 2022). Respondents who reported needing accessible medical equipment also reported that it was not always available, and some said it was never available to them, which is also consistent with national studies with PWD (Iezzoni et al., 2010, 2022; Mitra et al., 2017; Story et al., 2009). Further, the results from this study support national findings about the lack of accessible exam tables and lifts resulting in PWDs remaining in wheelchairs or other mobility devices during appointments and procedures, a possible deterrent to quality care (Agaronnik et al., 2019; Frost et al., 2015; Iezzoni, Rao, Ressalam, Bolcic-Jankovic, Donelan, et al., 2021).

The interpersonal barriers to care reported in this study are also like the findings of national studies with PWD (Chiu et al., 2017; Marlow et al., 2019). That is, PWD reported challenges in being understood by providers, and they also experienced challenges understanding their providers. Most respondents reported that their doctor, staff, and other health care providers should have training about the needs of PWD. These findings support those from national surveys on providers' knowledge and training in disability (Iezzoni, Rao, Ressalam, Bolcic-Jankovic, Agaronnik, et al., 2021; Iezzoni, Rao, Ressalam, Bolcic-Jankovic, Donelan, et al., 2021; Iezzoni et al., 2022; Lagu et al., 2022; Morris et al., 2017).

Recommendations to Improve Health Care Access

Accessible Medical Diagnostic Equipment

The ADA and Section 504 of the Rehabilitation Act of 1973 require accessible health care facilities and offices, including parking lots, exterior entrances, and restrooms for PWD (Iezzoni & Pendo, 2018). Additionally, Section 4203 of the ACA required the Architectural and Transportation Barriers Compliance Board, also known as the U.S. Access Board, to work with the FDA to develop accessibility standards for MDE, which went into effect February 8, 2017 (Standards for Accessible Medical Diagnostic Equipment, 2017). However, these standards have not yet been formalized by the Department of Justice (DOJ) and codified (Nondiscrimination on the Basis of Disability, 2017).

In response, many organizations and governmental agencies have developed and disseminated resources and checklists for providers, administrators, and staff to learn more about accessibility and accommodations for health care settings (ADA National Network, 2016; Office of Minority Health, 2021; Singer et al., 2017). While useful, these tools remain as guidelines and not as requirements and they are not currently legally enforceable. To assure compliance with the Accessibility Standards for MDE, the US DOJ must issue regulations to enforce the standards. It has further been suggested that banning the manufacturing and sale of inaccessible MDE could facilitate the purchase and use of accessible equipment, like the federal regulations for unsafe child safety seats (Lagu et al., 2015).

CT recently passed Public Act No. 22-58 (C.G.S. § 19a-490dd, 2022), which requires health care facilities to take into consideration the US Access Board's Accessibility Standards when purchasing MDE beginning January 1, 2023. While the Public Act is a positive step forward, it does not require existing equipment to be made accessible, nor does it require facilities to purchase new equipment that meets accessibility standards. Until this occurs, PWDs in CT will continue to report a lack of accessible MDE, which will negatively impact their health outcomes.

Communication to and from Health Care Providers

Electronic medical records (EMR) are one mechanism that can be used to improve the communication and other issues identified by PWD. EMRs can include information about a PWD's need for accommodations and modifications during a health care visit, as well as their preferred communication mode. Several studies have demonstrated that collecting disability status as part of new patient registration for primary and specialty care is an effective way to enhance communication for PWD, and PWD have reacted favorably to using this mechanism (Halkides et al., 2022; Morris et al., 2021; Mudrick et al., 2020; C. Tyler et al., 2010; Varadaraj et al., 2022). The Disability Equity Collaborative (2022) issued an implementation guide with training materials for frontline staff about how to systematically collect disability and accommodation status as part the EMR. This practice should be expanded and evaluated as a strategy to improve the quality of a health care visit for PWD.

Medical School Training about Persons with Disabilities

Calls for disability competence in health care training are numerous (e.g., Bowen et al., 2020; Havercamp et al., 2021; Stillman et al., 2022; Turk & Mitra, 2022a). Disability competence, sometimes referred to as "disability conscious" [medical] education, needs to address biases, address provider gaps in knowledge of the ADA, accommodations, and accessible medical equipment, include disability cultural competence and etiquette, increase provider comfort, and change the culture of clinical office visits (Agaronnik et al., 2019; Doebrich et al., 2020; Iezzoni, Rao, Ressalam, Bolcic-Jankovic, Agaronnik, et al., 2021; Iezzoni et al., 2022; Lagu et al., 2014). Quality, multi-modal, longitudinal education is needed for current and future health care providers on disability competence at all career stages (e.g., Amir et al., 2022; Griffen & Havercamp, 2020; NCD, 2022; Turk & Mitra, 2022a, 2022b). Section 5307 of the ACA requires the development and dissemination of model disability cultural competency curricula for health care training programs and continuing education; however, the curricula are not mandated (NCD, 2019b).

Revising accreditation standards for programs is one approach to requiring health care programs to embed disability competence into training. The Commission on Dental Accreditation (CODA), the accrediting body for dental, advanced dental, and allied dental education programs, now requires all U.S. dental schools to include patients with intellectual and developmental disabilities in their training curricula for predoctoral dental, orthodontics, dental hygiene, and dental assistant programs (NCD, 2019a). This model has not been adopted across education programs for other health care providers, most notably medical schools.

Despite the American Medical Association's adopted Resolution 428 to improve the care of PWD and the continued advocacy of disability groups, the Liaison Committee on Medical Education (LCME), the accrediting body of the Association of American Medical Colleges (AAMC), has not adopted any requirements for developmental disability content as part of accreditation standards, nor adopted any policy that specifically mandates education on developmental disability, similar to CODA dental programs (NCD, 2019b). Recently, the AAMC has developed competencies for diversity, equity and inclusion for learners entering residency, entering clinical practice, and faculty physicians as well as curricular models for undergraduate medical education (American Association of Medical Colleges, 2022), yet disability is not specifically stated as a competency.

Recent attempts to develop and revise curriculum for medical and dental students have been facilitated by the American Academy of Developmental Medicine and Dentistry's (AADMD) National Curriculum Initiative in Developmental Medicine. Medical schools may apply for grant funding to provide educational opportunities for medical students to develop disability competence (AADMD, 2021). Examples of practices used in the funded programs, as well as others who have embedded disability into health care education, include teaching with PWD as instructors or standardized patients (Alerte et al., 2021; Long-Bellil et al., 2011; Sheppard et al., 2017; Siebens et al., 2004; Woodard et al., 2012), providing opportunities for student participation on home visits/school observations, advocacy training and elevating and increasing the number and visibility of medical students and health care providers who have disabilities (Kaundinya & Schroth, 2022). Unfortunately, implementing disability content and competence into medical school curriculum is variable, and often voluntary. In addition, systemic barriers such as competing curricular requirements influence curricular enhancements on disability (Doebrich et al., 2020).

Continuing Education for Health Care Providers About Persons with Disabilities

In addition to training future providers, education is needed for community-based health care providers, office managers, and practice administrators about the need for accessible MDE and other interpersonal, knowledge, and skill-based barriers to quality care for PWD. Until continuing education requirements for health care providers mandates course work and credits about disabilities, PWD will continue to experience disparities in health care access and care.

Regarding accessible MDE, those who are responsible for purchasing equipment must be educated about the availability of such equipment, the importance of acquiring it, and opportunities for financial support for purchasing MDE (Pharr, 2013; Pharr et al., 2019). Further, the presence of accessible MDE itself is not enough to ensure it is used consistently and safely (Iezzoni et al., 2022; Morris et al., 2017); knowledge and skills are needed to use the equipment appropriately (Iezzoni, Rao, Ressalam, Bolcic-Jankovic, Donelan, et al., 2021; Pharr, 2013, 2014). Training on the use of accessible MDE could address provider concerns of about injuring patients, address patient concerns about their own safety, and benefit both as accessible MDE has been shown to reduce injury (Fragala, 2016; Fragala et al., 2017; Iezzoni et al., 2022; Lagu et al., 2022).

Limitations

This survey was developed with considerable input from PWD and assessed for accessibility. However, it is possible that PWD may not be represented in the data due to the survey language, survey distribution, or other barriers to access. For ethical and IRB purposes, we were not able to collect a respondent's geographic location (town, county, or voting jurisdiction). Geographic location would allow us to assess our statewide response and distribution. It would also allow us to work with local and community-based organizations, leaders, and policymakers to address the barriers reported through collaborative partnerships, advocacy, and policy change. Additionally, the use of snowball sampling as a method of convenience may limit the generalizability of the findings due to potential selection bias. Future research would benefit from the use of more probability-based sampling measures, as well as the collection of demographic characteristics and socioeconomic status variables (e.g., race/ ethnicity, education level, employment, income, or health insurance) that may be related to access and use of health care services.

Conclusion

The study indicated that PWD in CT experience barriers to health care including the accessibility of medical equipment and health care that are reported on the national level. The data described provides multiple directions to conduct further research, provide education and training, and advocate for systems change. Federal enforcement of the MDE standards, state level compliance of the standards, and requirements of health care training programs to educate providers in disability competency are needed. If the NCD (2022) framework was universally adopted and implemented, health care access and outcomes for PWD would improve.

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