Providing Primary to Adults with Disabilities:

Perspectives from Connecticut Primary Care Physicians

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Abstract

A survey was conducted to assess the knowledge, skills, and previous training of adult primary care physicians (PCPs) in Connecticut (CT) about the medical needs of persons with disabilities (PWD). A letter describing the purpose of the survey was sent to 6,556 eligible physicians, and a link to the online survey was provided to them. Ninety-one physicians responded. Fewer than half of the 91 participants (41%) reported feeling “knowledgeable” to provide care to PWD, and more than half (59.74%) reported professional experience as their only source of training in this area. Most participants reported an interest in additional training to provide care across disability types. Given the health disparities experienced by PWD and an identified lack of formal training, these results will inform future training and professional development opportunities for adult PCPs to increase their knowledge and skills.

Primary Care for Adults with Disabilities: Perspectives from Connecticut Primary Care Physicians

According to the latest estimates from the Centers for Disease Control and Prevention (CDC), 1 in 4 adults in the United States are living with a disability (Okoro et al., 2018). Compared to people without disabilities, persons with disabilities (PWD) are more likely to be unemployed, more likely to have less than a high school education, more likely to have a household income under $15,000, and are more likely to have inadequate transportation (Krahn et al., 2015). PWD also experience financial, environmental, physical barriers to receiving health services. One critical barrier to receiving health services includes a scarcity of adult care physicians who are knowledgeable and willing to provide medical care to PWD (Iezonni, 2011; National Council on Disability, 2009; Todd & Stuifbergen, 2012). According to the World Report on Disability (2011), physician lack of knowledge about disability can have a negative impact on quality of care of PWD. This is problematic as PWD are less likely to have access to primary care and are less likely to receive preventive services. PWD are also at a higher risk of developing secondary health conditions, such as obesity and hypertension and may engage in health risk behaviors at higher rates than people without disability, such as physical inactivity and smoking (CDC, 2001; CDC, 2015; Courtney-Long et al., 2014; Froehlich-Grobe, et al., 2016; Havercamp & Scott, 2015; Thompson, et al., 2012; WHO, 2018).

Living with Disability in Connecticut

Data from the 2013 Behavior Risk Factor Surveillance System (BRFSS) indicate that 18.2% of adults in CT have a disability (Courtney-Long, et al., 2015) and the estimated 56,752 individuals in CT have intellectual or developmental disabilities (IDD) (Braddock et al., 2016). Living with a disability is associated with a lesser likelihood of employment compared to individuals living without disability (Krahn et al., 2015). PWD are less likely to live independently than those without disabilities (DiGennaro Reed et al., 2014; National Core Indicators, 2016). According to the Annual Disability Statistics Compendium, only 39% of working age individuals with disabilities were employed in CT, compared to 78.8% of individuals without a disability. Moreover, this report found that CT has an employment gap of 39.8% between individuals with and without disabilities in 2016. Another study found that only 14% of Connecticut's young adults with disabilities were employed full-time for at least three months since leaving high school (Madaus, et al., 2016). Further, CT has a larger percentage of individuals with IDD living in settings with 16 or more residents (8%) in comparison to the national average (2%). CT has a larger percentage of individuals living in group homes with 4-6 residents than the national average (28% vs. 13%). CT has a smaller percentage of individuals with IDD who live in their own home or apartment compared to national average (16% vs. 20%) and a higher percentage that live in a parent or relatives home compared to the national average (36% vs. 35%) (National Core Indicators, 2016). According to the National Core Indicators 2015-2016 report, adults with intellectual disabilities experienced worse outcomes than the national average across several areas (National Core Indicators, 2016). CT has a higher percentage of individuals who have full guardianship status than the national average (78% vs. 41%). CT has a smaller percentage of individuals who chose or had input in choosing their home than the national average (45% vs. 57%). This absence of choice also applies to choosing roommates (39% vs. 47%) and jobs (74% vs. 86%). CT has a smaller percentage of individuals who can choose or request to change case manager/service coordinator (52% vs. 70%). CT has smaller numbers than average of individuals who have a job with publicly funded supports (22% vs. 39%) and who have an individual job without publicly funded supports (8% vs. 30%), but a higher number of individuals than average who have a group job with or without publicly funded supports (76% vs. 31%). CT has a higher percentage of individuals who want more help to make and keep in contact with friends when compared to the national average (53% vs. 44%). (National Core Indicators, 2016).

Primary Care

Primary care physicians (PCPs) have a unique opportunity to improve the health of all of their patients, including patients with disabilities. There is little published on the topic of primary care for adults with disabilities. A previous study of CT PCPs (n=346) and their patients with autism spectrum disorders (ASD) specifically revealed that the majority of participants cared for adult patients with ASD who did not live independently and only 18.4% reported their patients with ASD attending school (Bruder et al., 2012). Only 36% of the PCPS reported having received some training about caring for adults with ASD, about half of whom reported receiving the training during ongoing professional education and about half reported receiving training during formal continuing medical education (Bruder et al., 2012). Majority reported being interested in receiving more training in caring for adults with ASD and about half would like training on caring for people with other developmental disabilities. Their preferred mode of training was workshops/conferences (Bruder et al., 2012). A survey of nurses in the UK revealed that only 8% of participants had every received any training in how to communicate with people with IDD (Melville et al., 2005). A third reported receiving training in working with people with IDD as part of their initial nursing training (Melville et al., 2005). In Canada, Balogh and colleagues studied the effects of a continuing education course on five measures related to primary care of people with (I)DD for physicians, registered nurses, and nurse practitioners (2015). The five measures were frequency of use of developed guidelines, frequency of performing periodic health examinations, frequency of assessing patients who present with behavior changes, level of comfort while providing care, and knowledge of primary care related to adults with (I)DD. The intervention group showed significant increases in all but one measure, frequency of performing periodic health examinations, compared to the control group (Balogh et al., 2015).

Rationale

Given the health disparities experienced by PWD, the role of primary care physicians in the health of all people, including PWD, and previous literature indicating a lack of training to provide care to PWD, this study examined PCPs' experiences, knowledge, and skills in providing primary care for adults with disabilities in CT. Additionally, the amount of training that these physicians received over the course of their career and their self-reported knowledge and skills in providing primary care to PWD were examined. Finally, an exploratory analysis was conducted to examine whether the amount of training received in providing care to PWD was predictive of physician's self-reported level of knowledge in providing primary care to PWD.

Methods

Participants

Potential participants from the state of CT were recruited using a database of email addresses provided by the Department of Public Health (DPH), as well as a list of publicly available email addresses from a CT hospital website. The database provided by the CT DPH contained email addresses for 17,907 licensed physicians in the state. Information regarding each physician’s specialty (e.g., internal medicine, surgery, etc.) was also included in this database. In order to be eligible for recruitment into the study, the physician must have been listed as an actively licensed in either family medicine or internal medicine. This resulted in a list of 6,540 eligible physicians. The hospital website provided additional email addresses for 16 family and internal medicine physicians. The final compiled database included 6,556 email addresses of physicians with active licenses to practice the eligible specialties: family medicine (n=1,057) and internal medicine (n=5,499). In addition to not specializing in either family or internal medicine, physicians who reported that they were not licensed to practice, physicians whose license to practice is no longer active, and physicians not currently providing primary care to patients were also excluded. The University Institutional Review Board (IRB) approved these methods of recruitment as well as all other study procedures.

Procedure

The survey was initially emailed to the 6,556 physicians in early-March 2019, with two follow-up emails sent in mid-March 2019 and early-April 2019. After the initial email was sent, the researchers received returned emails from 121 contacts, 62 of which were automated “out of office” responses and 59 were “message delivery failure” responses. Emails that returned an automated “out of office” response were noted in the database, and those email addresses received the follow-up recruitment emails. Contacts that returned a “message delivery failure” response were not contacted during follow-up. Individuals who provided their email address to participate in follow-up and/or to receive a final report of findings were also noted in the database and were not contacted during follow-up (n=8).

With a response rate of 1% after two weeks, the first follow-up email was sent out to the list of 6,489 active emails. After this email was sent, the researchers received returned emails from 42 contacts, 18 of which were returned as a "message delivery failure". Because the overall response rate after the first follow-up email was still low (2%), an addendum to the IRB was submitted to send a second follow-up email two weeks after the first follow-up. Sixteen contacts were excluded from this second follow-up, as they had provided their contact information to participate in follow-up and/or to receive a final report of findings. The second follow-up emails were sent to the remaining list of 6,455 active emails. There were six emails returned as a "message delivery failure" after this second follow-up was sent.

The researchers also received several emails from physicians who did not meet inclusion criteria as they were currently retired and not seeing patients (initial email n=0, first follow-up email n=3, second follow-up email n=7). Therefore, the number of eligible physicians reliably contacted was 6,439, which was the number used to calculate the overall response rate. The survey closed in early-April 2019.

The initial emails sent to physicians contained a brief description of the nature of the study and details about participants, including an emphasis that participation was voluntary. These emails also contained a link to the survey for individuals interested in participating. Follow-up emails contained the same information as the initial email, but also included a statement thanking individuals who had already participated in the study.

Survey

Following the link sent in the initial and follow-up emails led potential participants to the first page of the Survey Monkey survey, the information sheet. This information sheet served as the consent to participate, as the IRB determined this study to be exempt and did not require a formal consent process. The information sheet provided information regarding the purpose of the survey, study procedures, potential risks and benefits, information protection, participant’s rights, and contact information regarding study content and rights. Participants were given the option to “accept” or “decline” participation in the survey.

The survey instrument consisted of 22 questions, 21 multiple-choice questions (seven of which had the option to type in a response if “other” is selected) and one open-ended question (age). Following the first two items, which assessed for eligibility, were questions related to physician’s medical practices and the PWD for whom they provide primary care. Three items were included to examine the exploratory aim of whether training received was predictive of self-reported knowledge in providing care to PWD. The first item asked about knowledge and skills in providing primary care to patients with the following disabilities: physical/motor disabilities, intellectual disabilities, Autism Spectrum Disorder (ASD), mental health related disabilities, deafness/hard of hearing, and blindness. Participants rated their knowledge and skills in providing primary care to patients with each disability on a four point scale, from not knowledgeable (0) to very knowledgeable (3). The second item asked about the different types of training participants received in the care of PWD, including training in medical school, residency/fellowship, continuing medical education (CME), and professional experience. Participants were instructed to select all the different types of training that they had received throughout their medical career. Finally, participants were asked how often they provided primary care to PWD in the past year, with responses ranging on a five point scale (0= never, 1= rarely, 2= sometimes, 3= often, 4= very often).

The survey concluded by asking participants about interest in receiving future training in providing primary care to PWD. While no identifying information was collected by this survey instrument, individuals interested in receiving future trainings were provided with a link to a separate survey in which they could provide their contact information. The survey for collecting contact information was not linked to the survey responses provided as part of the research study, maintaining privacy for participating physicians. Survey questions were developed based on literature on the topic of health care for adults with disabilities including Bruder et al. (2012) and Health Care Access Research and Developmental Disabilities (HCARDD, 2016).

Data Analysis

All data collected through Survey Monkey was downloaded into an excel file, cleaned, and imported into SPSS Statistics version 25 (IBM Corp, 2017) for analysis. Data cleaning involved the removal of cases that met the following criteria: 1) declined participation, 2) did not meet eligibility criteria, and 3) only responded to eligibility items/first item. Descriptive statistics were calculated for all included data.

Two exploratory analyses were conducted with these data. First, the relationship between the amount of training received and the level of knowledge and skills in providing primary care for PWD was examined. Prior to conducting this analysis, composite variables for training and knowledge/skills were created. To assess overall knowledge and skills in providing primary care to PWD, ratings for each disability type were summed, resulting in possible scores of 0-18, with zero being the lowest self-reported knowledge and skills and 18 being the highest self-reported knowledge and skills across disabilities. To assess amount of training in providing primary care to PWD, each type of training reported was recorded as one point, with possible scores ranging from one to four points (one point indicated receiving only one type of training (i.e., low amount of training), and four points indicated receiving all of the mentioned types of training (i.e., high amount of training). A linear regression was conducted with the overall amount of training as the independent variable and the overall level of knowledge and skills as the dependent variable. The second exploratory analysis examined the relationship between training and how often participants provided primary care for PWD in the past year using a linear regression.

Results

The total number of participants who opened the link in the recruitment email and at minimum started the survey was 177, which is equivalent to a 3% response rate. However, 79 individuals did not meet eligibility criteria, 12 only responded to eligibility items/the first item, and seven individuals were excluded from analysis for declining participation. Therefore, 79 individuals with complete data were included in the analysis. As displayed in Table 1, the mean number of years physicians had been practicing was 25.16 years (SD=12.04) and the majority of participating physicians specialized in internal medicine (75%). Almost all physicians reported that they have provided care for adults with physical and/or motor disabilities (99%) and mental health related disabilities (95%). The fewest number of physicians reported that they have provided primary care to adults with autism spectrum disorders (ASD; 62%). Over the past year, most physicians indicated that they have provided primary care to PWD sometimes (46%) or often (37%).

Table 1. *Physician Demographics*

	N	%
I am licensed to provide primary care within the specialty of:		
Family Medicine	20	25.3
Internal Medicine	59	74.7
I provide/have provided primary medical care to adults with the following:		
Patients with Physical/Motor Disabilities	78	98.7
Patients with Intellectual Disabilities	72	91.1
Patients with Autism Spectrum Disorders (ASD)	49	62.0
Patients with Mental Health Related Disabilities	75	94.9
Patients who are Deaf/Hard of Hearing	69	87.3
Patients who are Blind	56	70.9

Experiences Providing Primary Care to PWD

Both family and internal medicine physicians reported that the majority of their adult patients with disabilities live in a supervised or group home setting (55% and 31%, respectively, see Table 2). Family physicians reported that 20% of their adult patients with disabilities live independently (including with roommates) and 20% live with family. Similarly, internists reported that 27% of their adult patients with disabilities live independently, and 37% live with family. Only one physician (internist) reported that they do not inquire about their adult patients with disability’s living situation. Participants reported that the majority of their adult patients with disabilities were at least high school graduates (62%), with 18% having less than a high school degree. However, 16% reported that their adult patients with disabilities had some form of post-secondary education (e.g., some college, college degree, graduate coursework/degree). When asked about employment status of their adult patients with disabilities for whom they provide primary care, the majority of participants reported that they were unsure (family physicians = 65% and internists = 59%). The remainder reported that their patients were either employed part-time (23%) or full-time (6%). Three physicians (internists) reported that they do not ask their adult patients with disabilities about employment.

Participants were asked about their typical appointments with adult patients with disabilities. All family physicians reported that their patients were accompanied to appointments, while 27% of internists reported that their patients attended appointments on their own. Overall, the majority of participants reported that there was about equal participation between the patient and family member/guardian/personal care attendant at appointments (41%), followed by 27% reporting that the patient was the main participant in appointments, and family members/caregivers/personal care attendants were only involved in a supportive role. When asked about personal topics discussed during the appointments, most participants said that they talked about mental health (90%) and social activities (89%). Topics least often discussed included dental health (61%) and involvement in romantic/sexual relationships (46%).

Physicians were asked to report how often they utilized specific strategies to accommodate adult patients at their appointments. These strategies included scheduling appointments for times that are best for the patient and accommodating appointment environment, requesting that patients communicate back information to ensure comprehension throughout the appointment, providing written supplemental materials, providing a written or electronic appointment summary that included “next steps”, and providing contact information for community-based resources. As shown in Figure 1, most physicians reported that they utilized all of these strategies either “sometimes” or “often”.

Finally, when asked about the challenges associated with providing care to adult patients with disabilities (Table 2), both family physicians and internists agreed that not having enough time was the biggest challenge (42%), followed by a lack of knowledge of community resources (27%). Other challenges included lack of knowledge and skills about disabilities and comorbid health conditions (8%), lack of knowledge and skills about disabilities in general (6%), and lack of support from the physician’s medical practice (5%).

Table 2. *Primary Care Appointments with Patients with Disabilities Served (%)*

	Family Medicine (N=20)	**Internal Medicine (N=59)**
The majority of adults with disabilities that I care for attend their appointments:		
On their own	0.0	27.1
With a family member/guardian	50.0	33.9
With a personal care attendant	50.0	30.5
In general, I would describe the level of participation of most of my adult patients with disabilities in their primary care appointments as:		
Minimal participation	40.0	18.6
Equal participation	45.0	39.0
Majority participation	15.0	30.5
Full participation	0.0	10.2
During a typical primary care appointment with an adult with a disability, I ask about the following topics:		
Dental health/services received	65.0	59.3
Mental health/services received	95.0	88.1
Involvement in social activities	95.0	86.4
Involvement in romantic/sexual relationships	45.0	45.8
Transportation	70.0	69.5

	Family Medicine (N=20)	**Internal Medicine (N=59)**
In my experience, the biggest challenge to providing care to adult patients with disabilities is:		
Not enough time	45.0	40.7
Lack of knowledge and skills about disabilities	0.0	8.5
Lack of knowledge and skills about comorbidities	15.0	5.1
Lack of knowledge of community resources	25.0	27.1
Lack of support from my medical practice	0.0	6.8

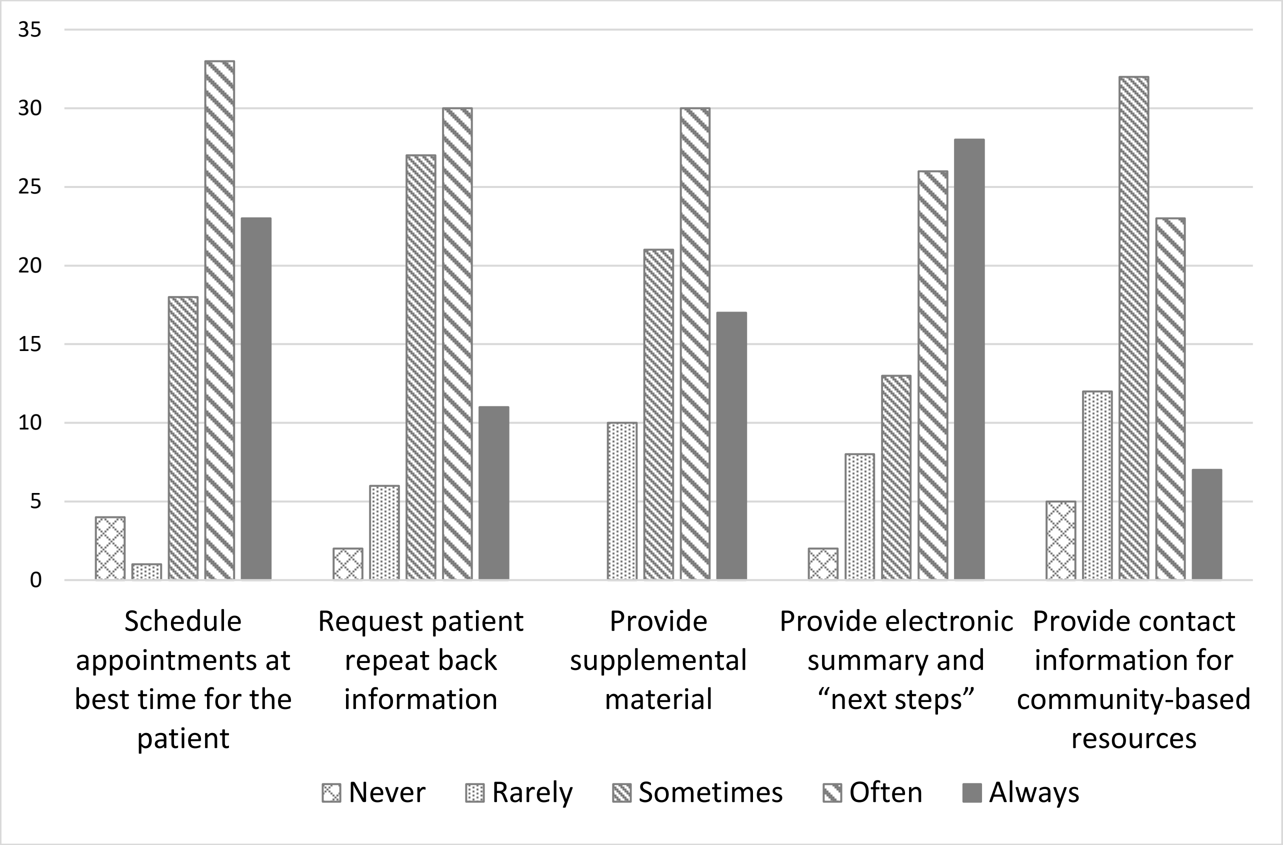

Figure 1. Strategies Used in Primary Care Appointments to Accommodate PWD

Training, Knowledge, and Skills in Providing Primary Care for PWD

Physicians were asked about how much training they received in providing care to PWD throughout the course of their career. The overall amount of training was derived from these responses (see Table 3) and showed that most participants received less than two of these training formats (M=1.39, SD=1.24).

Table 3. *Types of Training Received*

Type of Training	**N (%)**
Medical School	21 (26.6)
Residency	26 (32.9)
Continuing Medical Education	17 (21.5)
Experience	46 (58.2)

Physicians were also asked about their level of knowledge and skills in providing care for adults with physical/motor disabilities, intellectual disabilities, ASD, mental health related disabilities, adults who are deaf/hard of hearing, and adults who are blind (Figure 2). When these data were combined to create a measure of participant's overall level knowledge and skills, most participants rated themselves "somewhat knowledgeable" (M=8.64, SD=3.63).

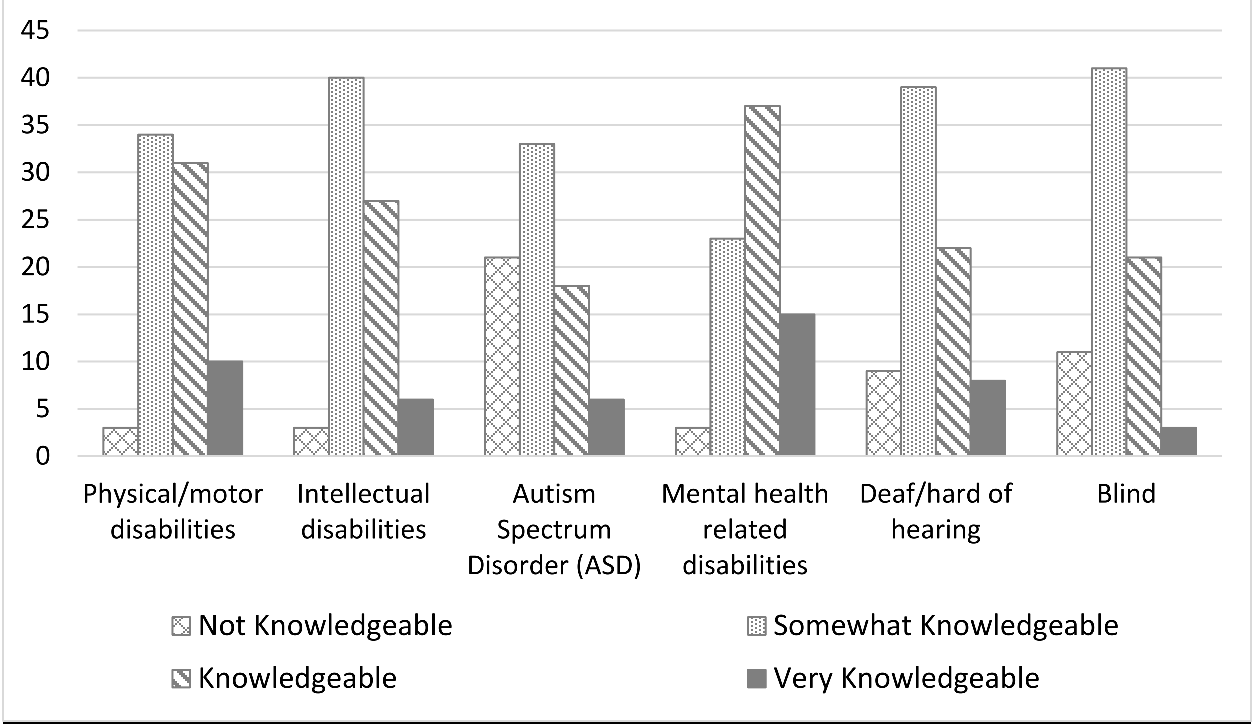

Figure 2. Knowledge and Skills in Providing Primary Care across Disability Types

The overall regression model found that the amount of training in providing care for PWD that physicians received significantly predicted their self-reported level of knowledge and skills in providing primary care for PWD, R^2= .13, *F*(1, 73) = 11.22, *p*= .001. Therefore, the amount of training in providing primary care to PWD accounted for about 13% of the variance in physician's level of knowledge and skills in providing care for PWD. The amount of training significantly predicted level of knowledge and skills, *b* = 1.06, 95% CI [.43, 1.69], *t*(73) = 3.35, *p* = .001. This suggests that for every increase of one type of training, there will be a 1.06 increase in physician's level of knowledge and skills in providing primary care for PWD (see Figure 3).

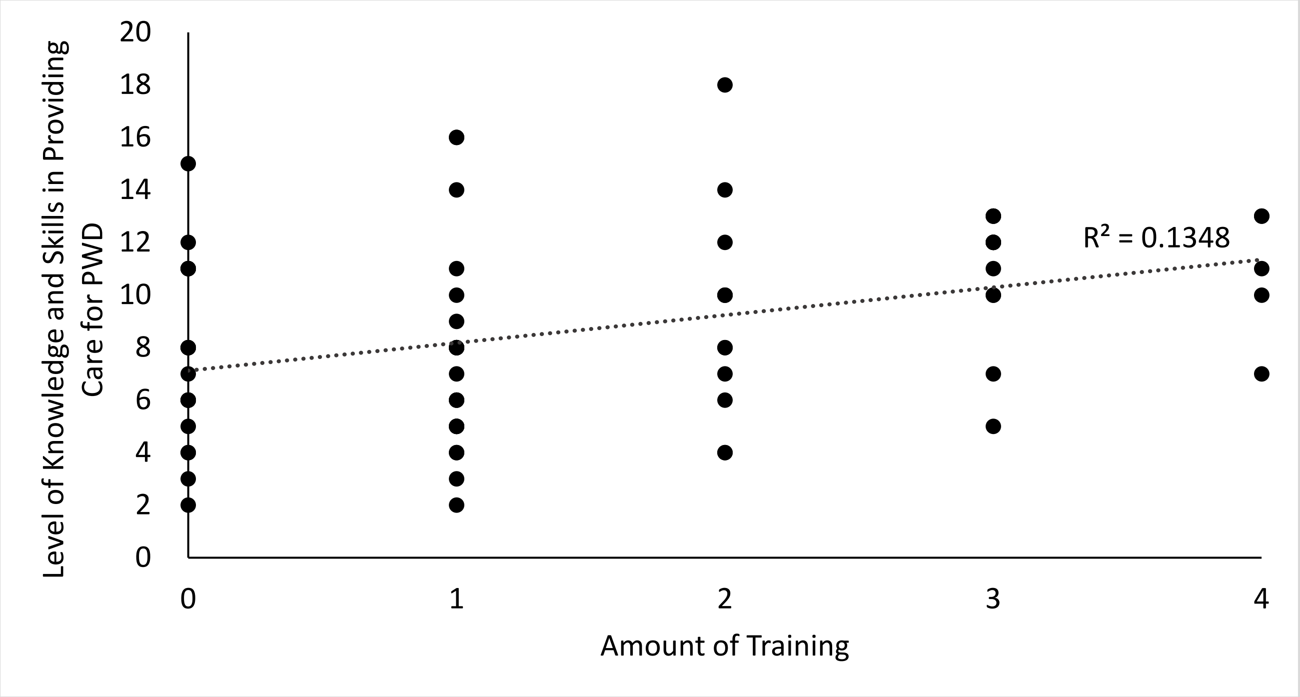

Figure 3. *Overall Knowledge and Skills in Providing Care for PWD by Amount of Training*

Physicians were also asked about how often they provided primary care to adults with disabilities in the past year (see Figure 4). The overall regression model found that the amount of training received did not significantly predict how often participants provided primary care for PWD in the past year, R^2= .05, F(1, 78) = 3.91, p= .052.

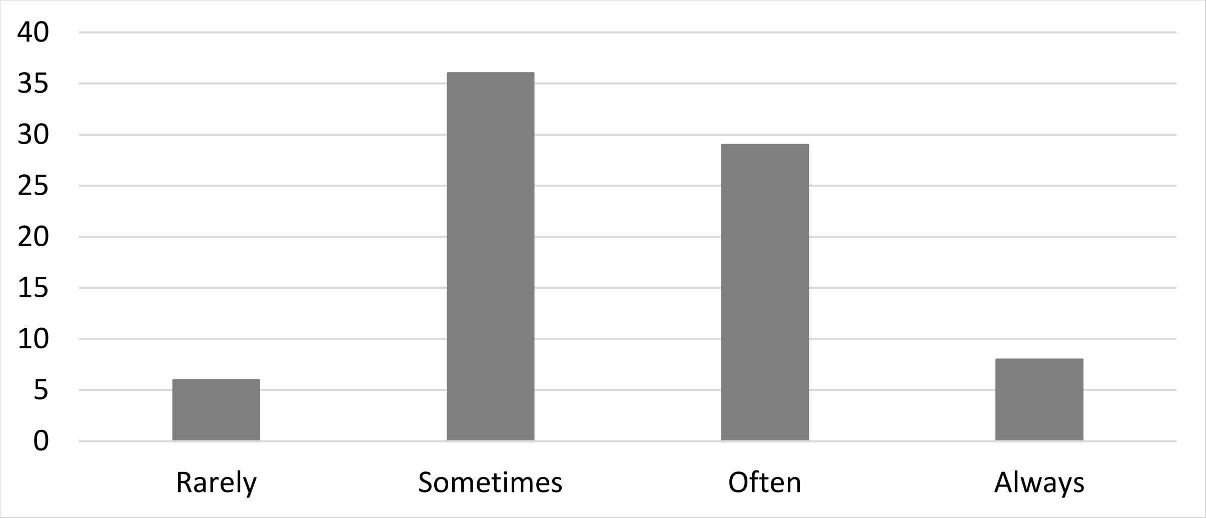

Figure 4. Frequency of Primary Care Provided to Adults with Disabilities in the Past Year

Finally, physicians were asked about their interest in receiving addition training in providing care for PWD. Roughly, two-thirds of the participants were interested in receiving training in providing care for specific disabilities (61%-67%; see Table 5). Physicians' preferred modes of trainings included web-based trainings (62%) and workshops and/or conferences (54%).

Table 4. *Training Needs of Primary Care Physicians in Providing Care for PWD*

	N	**%**
I would like training specific to providing quality care for adults with the following disabilities:		
Patients with Physical/Motor Disabilities	52	65.8
Patients with Intellectual Disabilities	50	63.3
Patients with Autism Spectrum Disorders (ASD)	53	67.1
Patients with Mental Health Related Disabilities	51	64.6
Patients who are Deaf/Hard of Hearing	48	60.8
Patients who are Blind	51	64.6
My preferred mode(s) of receiving training include:		
Workshops/conferences	43	54.4
Grand rounds	24	30.4
Web-based trainings	49	62.0
Detailed reading material	21	26.6

Discussion

The purpose of this study was to describe primary care for adults with disabilities in CT from the perspective of primary care physicians. A total of 79 primary care physicians participated in this online study, majority from internal medicine and mid to late career as the average number of years in practice was 25.16 (SD=12.04).

Most of both family and internal medicine physicians reported their adult patients with disabilities live in a supervised, group home setting. This is consistent with previous data from CT that indicates that more CT adults with disabilities live in group homes than the national average (National Core Indicators, 2016). This coupled with the fact that not all participants reported asking their adult patients with disabilities about their living situation, represents an opportunity for future training and continuing medical education opportunities for physicians about critical issues such as the status of housing for adults with disabilities in the state. Independent living, as stated in the Americans with Disabilities Act (1990) is a measure for quality of life and is indicative of a self-determined individual.

The majority of family physicians reported treating adults with disabilities who were accompanied to appointments with family members. Twenty-seven percent of internal medicine physicians reported treating adults with disabilities who attended their appointments on their own. These results may be related to factors such as the type of and severity of disabilities seen by family physicians compared to internal physicians, family support systems of those patients, and other components of health care access such as transportation. Similarly, both family medicine and internal medicine physicians reported that if another adult was present during an appointment, the adult with a disability either equally participated in the appointment or took the lead for their care during the appointment.

Even though participants may be unsure about some aspects of the quality of life of their adult patients with disabilities such as employment and independent living, majority of participants reported asking their patients about other topics such as mental health and social activities. However, participants were less likely to ask about other aspects of health such as dental and romantic/sexual relationships.

When asked about specific strategies used to accommodate patients with disabilities such as appointment time, active listening, supplemental materials, appointment summary, contact information for community-based resources, participants indicated that they use all of the strategies “sometimes or “often”. Participants also reported that the biggest challenge to providing care to adults with disabilities was not having enough time. Future research and training should reinforce use of specific strategies as well as introduce innovative ideas to address the time challenge. Participants also reported a lack of knowledge of community resources. Community resources may help address the lack of time challenge experienced by physicians as reported by participants.

Training and Future Learning Opportunities

While some participants reported receiving formal training during medical school, residency/fellowship or other CEU opportunities for caring for adults with disabilities, majority reported on-the-job experience as how they learned to provide care for these adults. Additionally, participants reported experiencing less than two types of these opportunities during their career. According to the regression model, the amount of training received significantly predicted self-reported level of knowledge and skills. This suggests that increasing the types of training received will result in increases in provider knowledge and skills.

The amount of training received did not predict how often participants provided primary care for PWD in the past year ($p= .052$). However, this is a practically significant finding that future research could explore the relationship between training received and the amount of adult patients with disabilities a physician treats, as well as the proportion of patients with disabilities a physician treats.

When data were combined to create a measure of participant’s overall knowledge and skills across types of disabilities (Figure 2), most participants rated themselves as “somewhat knowledgeable”. However, the smallest proportion of participants rated themselves “very knowledgeable” across all types of disabilities. The type of disability with the most participants rating themselves as “knowledgeable” and “very knowledgeable” were mental health related disabilities and the least participants rated themselves as “knowledgeable” or “very knowledgeable” for blindness. Majority of participants reported providing primary care to adults across types of disabilities (Table 1), and majority of participants reported that they would like training to provide quality care for adults across types of disabilities (Table 4). Further, participants would prefer to receive trainings as web-based trainings and workshops/conferences (Table 4). These results have identified a training need and have also identified the preferred method(s) through which this need can be met.

Results from this study indicate the need for learning opportunities throughout a physician’s career, starting with medical school and that physicians need to seek out these opportunities throughout their career as continuing education opportunities. The Association of American Medical Colleges (AAMC) provides professional development opportunities including strategies and resources to integrate disability into medical school curriculum (AAMC, 2019). These strategies can be incorporated into existing course and clinical experiences, rather than creating additional requirements and therefore may be attractive to medical schools. Another method to increase knowledge, especially during medical school, is to bring in advocates (adults with disabilities themselves) as faculty and guest lecturers as has been done through University Center for Excellence in Developmental Disabilities (UCEDD) connections in New York (Levitz, 2018) and Special Olympics in Connecticut (SOCT, 2019). In addition to these partnerships serving as learning opportunities for disability-specific content, it also represents opportunities to connect students and faculty with community resources related to serving PWD.

Limitations

There are several limitations to this study. First, the study collected self-reported data and contacted participants via email addresses. Therefore, results may not accurately reflect CT primary care physicians in general, rather just those who self-selected to participate. The response rate for this survey is within expectations for response rates for electronic surveys (Grand Canyon University, Center for Innovation in Research and Teaching, 2019). Future studies could employ other recruiting strategies such as offering incentives to increase participation and generalizability of findings. Several retention strategies identified in a systematic review by Robinson and colleagues (2015) include obtaining multiple contacts for each participant, including two who do not reside with the participant. These data would have to be systematically collected using partnerships with medical care groups or hospitals. There is literature that indicates that for academic research, invitations to participate in research that are personalized can increase the response rate (Heerwegh et al., 2005; Saleh & Bista, 2017). Saleh and Bista provide 11 recommendations for online studies and response rates (2017). This evaluation utilized most, but not all 11 recommendations as most are required by any institution’s IRB. Among the recommendations that could be adopted in the future include personalizing invitations to participate (9) and being aware of the time constraints related to the time of year (11) (Saleh & Bista, 2017). If conducted in the future, technology to personalize email invitations can be utilized.

Implications for the Field

Participants reported being interested in receiving additional training to provide care to adults with disabilities and preferred that these opportunities be either web-based or workshops/conferences. These findings are similar to findings from Bruder et al. specifically on providing care to adults with autism spectrum disorder (2012). This presents another opportunity for those responsible for medical education to make connections with organizations such as UCEDDs who serve as knowledge brokers between academia and the community. The CT Consumer Advisory Council (CAC), made up of consumers who represent individuals with IDD in the state and include advocates themselves play an active role in the development of the UCEDD's five year strategic plan (UConn UCEDD, 2019b). The CAC recognized the following as one of the UCEDD's four areas of emphasis for 2018-2023: promote accessible and equitable health care and medical management for persons with disabilities. The UConn UCEDD already has a long history of working with health care providers through various events and trainings on health-related topics including providing care for PWD, aging adults with IDD, and the medical home (UConn UCEDD, 2019b). UCEDD faculty members have appointments in the UConn School of Medicine and participate in curriculum implementation for medical students and residents. Recently, working with the UConn medical students interest group on disability, the UCEDD sponsored a panel for health care providers, "In our shoes: providing person-centered health care to persons with disabilities". This moderated panel included (self) advocates and family members (UConn UCEDD, 2019c). Based on positive evaluations, a second panel has been planned for fall 2019. UConn UCEDD faculty and staff have worked with other medical schools including Yale and Quinnipiac University to train current and future providers about improving health care for PWD. The UConn UCEDD also houses the UConn Leadership Education in Neurodevelopmental and related Disabilities (LEND) program, one of 52 programs across the country that trains graduate students from a variety of disciplines including medicine to improve the health and quality of life for people with disabilities and their families across the lifespan (AUCD, 2019). These projects complement ongoing partnerships between the UConn UCEDD with community organizations such as Special Olympics CT. Based on results from this survey, the UConn UCEDD will develop training and educational materials to provide to physicians that highlight community resources available for their patients with disabilities, as well as continue to provide learning opportunities for providers to enable them to provide better care to PWD in the state.

Data from several studies found that providing specific training to medical students as well as clinical skills learning opportunities to work with patients with disabilities yielded improved student attitude and comfort as well as increased knowledge and skills (Brown, et al., 2010, Karl et al., 2013; Long-Bellil et al., 2011; Warfield et al., 2015). As indicated by the results of this study, only 27% of participants received any training in medical school to provide care for PWD. This is an area for future development and is an opportunity for medical schools to work with organizations such as UCEDDs and other partners to provide opportunities to students.

Findings from this study support other data describing adults in CT living with a disability. While physicians are reporting utilizing accommodation strategies when providing care to these adults, they also are reporting a lack of formalized training and learning opportunities in this area. Future training opportunities, as indicated by these results, should address these needs and build on the knowledge and skills of physicians. Integrating disability content into already-exiting medical curriculum is as concrete first step for medical schools to improve the care of adults with disabilities by all of their future physicians, not just those with an interest in a specialty that is closely related to treating people with disabilities. Future research should assess the knowledge and skills of other clinical staff such as nurses, nurse practitioners, physician assistants, and nurse aides, as well as non-clinical staff such as front desk or administrative personnel to provide care to people with disabilities. Educational and learning opportunities for all those involved in the health care system including providing clinical and non-clinical services would improve the quality of health care provided to PWD (Balogh et al., 2015; Bruder et al., 2012; Melville et al., 2005). As disability is experienced by one in four adults in this country, it is imperative that those who are and who will provide direct services including medical care are knowledgeable, comfortable, confident, and skillful in providing care to all people.

References

Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 328 (1990). Retrieved from https://www.ada.gov/pubs/adastatute08.htm

Association of American Medical Colleges. (2019). *Integrating Disability into Medical School Curriculum: Practical Strategies and Resources.* https://www.aamc.org/members/gdi/pdopportunities/483048/integratingdisabilityintomedicalschoolcurriculumpracticalstrate.html

Association of University Centers on Disabilities [AUCD]. (2019). About LEND. https://www.aucd.org/template/page.cfm?id=473

Balogh, R., Wood, J., Lunsky, Y., Isaacs, B., Ouellette-Kuntz, H., & Sullivan, W. (2015). Care of adults with developmental disabilities: Effects of a continuing education course for primary care providers. *Canadian family physician Medecin de famille canadien*, *61*(7), e316–e323.

Braddock, D. L., Hemp, R. E., Rizzolo, M. K., Shea Tanis, E., Haffer, L., & Wu, J. (2016). *The state of the states in developmental disabilities*. http://stateofthestates.org/documents/Connecticut.pdf.

Brown, R., Grahamn, C. L., Richeson, N., Wu, J., & McDermott, S. (2010). Evaluation of medical student performance on objective structured clinical exams with standardized patients with and without disabilities. *Academic Medicine, 85*(11), 1766-1771. https://doi.org/10.1097/ACM.0b013e3181f849dc

Bruder, M. B., Kerins, G., Mazzarella, C., Sims, J., & Stein, N. (2012). Brief Report: The medical care of adults with Autism Spectrum Disorders—Identifying the needs. *Journal of Autism and Developmental Disorders, 42*(11), 2498-2504. https://doi.org/10.1007/s10803-012-1496-x

Centers for Disease Control and Prevention [CDC]. (2001). *Healthy People 2010, objectives report: Chapter 6: Disability and secondary conditions*. Atlanta, GA. https://www.cdc.gov/nchs/data/hpdata2010/hp2010_final_review_focus_area_06.pdf

Centers for Disease Control and Prevention [CDC]. (2015). *CDC Promoting the Health of People with Disabilities*. http://www.cdc.gov/ncbddd/disabilityandhealth/pdf/aboutdhprogram508.pdf

Courtney-Long, E. A., Carroll, D. D., Zhang, Q. C., Stevens, A. C., Griffin-Blake, S., Armour, B. S., & Campbell, V. A. (2015). Prevalence of disability and disability type among adults—United States, 2013. *Morbidity and Mortality Weekly Report, 64*(29). https://doi.org/10.15585/mmwr.mm6429a2

DiGennaro Reed, F. D., Strouse, M. C., Jenkins, S. R., Price, J., Henley, A. J., & Hirst, J. M. (2014). Barriers to independent living for individuals with disabilities and seniors. *Behavior Analysis Practice, 7,* 70-77. https://doi.org/10.1007/s40617-014-0011-6

Froehlich-Grobe, K., Jones, D., Businelle, M. S., Kendzor, D. E., & Balasubramanian, B. A. (2016). Impact of disability and chronic conditions on health. *Disability and Health Journal, 9*(4), 600-608. https://doi.org/10.1016/j.dhjo.2016.04.007

Grand Canyon University, Center for Innovation in Research and Teaching. (2019). *Survey Response Rates*.

https://cirt.gcu.edu/research/developmentresources/research_ready/designing_surveys/response_rates

Havercamp, S. M., & Scott, H. M. (2015). National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities. *Disability and Health Journal, 8*, 65-172. Doi:10.1016/j.dhjo.2014.11.002

Health Care Access Research and Developmental Disabilities (HCARDD). (2016). Improving Emergency Care for Adults with Developmental Disabilities: A Toolkit for Providers. https://www.porticonetwork.ca/documents/38160/99698/Emergency+Dept+Toolkit+FINAL.pdf

Heerweigh, D., Vanhove, T., Matthijs, K., & Looseveldt, G. (2005). The effect of personalization on response rates and data quality in web surveys. *International Journal of Social Research Methodology, 8*(2), 85-99. https://doi.org/10.1080/1364557042000203107

IBM Corp. (2017). *IBM SPSS statistics for windows, version 25.0*. Armonk, NY: IBM Corp.

Iezonni, L. I. (2011). Eliminating health and health care disparities among the growing population of people with disabilities. *Health Affairs, 20*(10), 1947-1954. https://doi.org/10.1377/hlthaff.2011.0613

Karl, R., McGuigan, D., Withiam-Leitch, M. L., Akl, E. A., & Symons, A. B. (2013). Reflective impressions of a precepted clinical experience caring for people with disabilities. *Intellectual and Developmental Disabilities, 51*(4), 237-245**.** https://doi.org/10.1352/1934-9556-51.4.237

Krahn, G., Walker, D., & Correa-De-Araujo, R., (2015). Persons with disabilities as a unrecognized health disparity population. *American Journal of Public Health,* 105,Suppl2, S198-206. https://doi.org/10.2105/AJPH.2014.302182

Levitz, M. (2018, November). *Session on caring for patients with disabilities for foundations of clinical medicine 1: Training for first year medical students.* Presented at the annual meeting of Association of University Centers on Disabilities, Washington, D.C. https://www.aucd.org/conference/detail/session_presentation.cfm?id=24771

Long-Bellil, L., Robey, K. L., Graham, C. L., Minihan, P. M., Smeltzer, S., & Kahn, P. (2011). Teaching medical students about disability: The use of standardized patients. *Academic Medicine, 86*(9), 1163-1170. https://doi.org/10.1097/ACM.0b013e318226b5dc

Madaus, J. W., Egan, C. M., & Lalor, A. R. (2016). Connecticut's post-school outcomes survey: 2013-2014 school year exiters of special education services. Final report, Department of Educational Psychology. Storrs, CT: University of Connecticut.

Melville, C. A., Finlayson, J., Cooper, S. A., Allan, L., Robinson, N., Burns, E., Martin, G., & Morrison, J. (2005). Enhancing primary health care services for adults with intellectual disabilities. *Journal of Intellectual Disability Research, 49*(Pt 3), 190–198. https://doi.org/10.1111/j.1365-2788.2005.00640.x

National Council on Disability. (2009). *The current state of health care fo rpeole with disabilities.* Washington, DC: National Council on Disability. https://www.ncd.gov/publications/2009/Sept302009

National Core Indicators. (2016). *National Core Indicators adult consumer survey: Connecticut report, 2015-2016 data*. https://www.nationalcoreindicators.org/upload/statereports/Connecticut_ACS_Report_2015.pdf

Okoro, C.A., Hollis, N. D., Cyrus, A.C., Griffin-Blake, S. (2018). Prevalence of disabilities and health care access by disability status and type among adults — United States, 2016. *Morbidity & Mortality Weekly Report,* 67:882–887. Doi: http://dx.doi.org/10.15585/mmwr.mm6732a3

Robinson, K. A., Dinglas, V. D., Sukrithan, V., Yalamanchilli, Mendez-Tellez, P. A., Dennison Himmelfarb, C., & Needham, D. M. (2015). Updated systematic review identifies substantial number of retention strategies: using more strategies retains more study participants. *Journal of Clinical Epidemiology, 68*(12), 1481-1487. http://dx.doi.org/10.1016/j.jclinepi.2015.04.013

Saleh, A. & Bista, K. (2017). Examining factors impacting online survey response rates in educational research: perceptions of graduate students. *Journal of Multidisciplinary Evaluation, 13*(29), 63-74.
http://journals.sfu.ca/jmde/index.php/jmde_1/article/view/487

Special Olympics Connecticut (SOCT). (2019). *Special Olympics Connecticut Recognized as a World Leader in Health*.
https://www.soct.org/files/9115/6078/3288/Healthy_Communities_Press_Release_-2019.pdf

Thompson, W., Zack, M. M., Krahn, G. L., Andresen, E. M., & Barile, J. P. (2012). Health related quality of life among older adults with and without functional limitations. *American Journal of Public Health, 102*(3), 496-502. https://doi.org/10.2105/AJPH.2011.300500

Todd, A. & Stuifbergen, A. (2012). Breast cancer screening barriers and disability. *Rehabilitation Nursing, 37*(2), 74-79. https://doi.org/10.1002/RNJ.00013

UConn University Center for Excellence in Developmental Disabilities (2019). About the Consumer Advisory Committee. https://uconnucedd.org/cac/

UConn University Center for Excellence in Developmental Disabilities. (2019). Completed projects. https://uconnucedd.org/completed-projects/

UConn University Center for Excellence in Developmental Disabilities. (2019). Event: Providing Person-Centered Healthcare for Persons with Disabilities. https://uconnucedd.org/2019/02/27/providing-person-centered-healthcare-for-persons-with-disabilities/

Warfield, M. E., Crossman, M. K., Delahaye, J., Der Weerd, E., Kuhlthau, K. A. (2015). Physician perspectives on providing primary medical care to adults with autism spectrum disorders (ASD). *Journal of Autism and Developmental Disorders, 45,* 2209-2217. https://doi.org/10.1007/s10803-015-2386-9

World Health Organization and The World Bank. World Report on Disability. (2011). Geneva: World Health Organization; pp. 77-79. https://www.who.int/publications/i/item/9789241564182

World Health Organization. (2018). *Disability and Health.* http://www.who.int/news-room/fact-sheets/detail/disability-and-health