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Research Paper

Health care experiences and perceptions among people with and without disabilities

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Abstract

Background: Little is known about health care experiences among people with and without disabilities.

Objective: We sought to explore perceptions of people with and without disabilities related to their health care experiences.

Methods: Nineteen persons with and without disabilities participated in one of four focus groups. Focus groups were conducted in the physical world in Milwaukee, WI and in the virtual world in Second Life® with Virtual Ability, a well-established community designed by and for people with a wide range of disabilities. A grounded theory methodology was employed to analyze focus group data. Inclusion of physical and virtual world focus groups enabled people with a wide range of disabilities to participate.

Results: While some participants described instances of receiving good care, many discussed numerous barriers. The main themes that emerged in focus groups among both persons with and without disabilities related to their health care experiences including poor coordination among providers; difficulties with insurance, finances, transportation and facilities; short duration of visits with physicians; inadequate information provision; feelings of being diminished and deflated; and self-advocacy as a tool. Transportation was a major concern for persons with disabilities influencing mobility. Persons with disabilities described particularly poignant experiences wherein they felt invisible or were viewed as incompetent.

Conclusions: Both persons with and without disabilities experienced challenges in obtaining high quality health care. However, persons with disabilities experienced specific challenges often related to their type of disability. Participants stressed the need for improving health care coordination and the importance of self-advocacy. © 2016 Elsevier Inc. All rights reserved.

Keywords: Disability; Access to care; Patient-provider communication; Barriers to health care; Online communities

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Conflicts of interest: None.

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A national agenda to “close the quality gap” in health care between those with and without disability has become a top priority for the U.S. Department of Health and Human Services.¹ Persons with disability experience access barriers, have unmet health care needs, and are more dissatisfied with care.² A careful literature review documents that disparities in health services related to disability are complex and inconsistent.^{3–8} Overall, persons with disability have been found to receive fewer preventive services such as dental care, mammograms, or fecal occult blood tests compared to persons without disability with the same chronic conditions.^{9–12} However, people with mild disabilities were more likely to receive influenza vaccines than persons without disability, while those with the most severe

disabilities who experienced the greatest need and access barriers were less likely to be vaccinated.^{11,13,14} The complex relationship between disability and receipt of services may be due to greater medical needs interacting with hampered abilities to obtain care. Other investigators reviewing the literature related to the quality of care for persons with disability identified several important issues related to the provision of health care services: physical barriers, transportation, communication, client and provider attitudes, and coordination.¹⁵

Studies utilizing qualitative methods have also been conducted among persons with disability recruited from community centers for independent living, resource and advocacy centers, agencies that provide services, informal social networks, as well as clinical settings.^{16–23} Most qualitative studies focus on specific groups of persons with disability, for example persons who are deaf,^{16,17} persons who are blind,^{18–20} rural residents with disabilities,²¹ persons with a psychiatric disability,²² or women with disabilities.²³ Participants in these studies discussed difficulties with effective physician-patient communication and obtaining adequate interpreter services, finding physicians who were knowledgeable about particular conditions, and overcoming physical and financial barriers to care. All of these studies have been performed in face-to-face settings, thus missing the input of persons with disability who are less able to participate due to disability-related access, travel, and communication barriers. Although website content has been analyzed to provide corroboration with focus group results,¹⁹ no study to date has been conducted with virtual world focus groups. Not all forms of internet-mediated communication are identical. Unlike websites, virtual worlds allow for an innovative kind of “face-to-face” setting that may have important implications for the access, travel, and communication barriers experienced by many persons with disability.

Our objective was to explore experiences and perceptions of persons with and without disability related to health care as provided in the physical world. We sought to assess perspectives through focus groups in the physical world in a community center as well as in the virtual world in an online community because persons with disability may face significant barriers to participation in either setting. Conducting groups in both the physical and virtual worlds enabled participation of persons with a wide range of disabilities.

Methods

Setting

Focus groups were conducted in the physical world at a community center in Milwaukee, WI and online in the Virtual Ability community in Second Life®. The purpose of recruiting from both the virtual and physical worlds was to ensure enrollment of persons from diverse

socioeconomic circumstances and across the broad spectrum of disability type and severity. Second Life is a free-to-access virtual world, an online, 3D environment in which residents create avatars and engage in a range of activities.²⁴ Virtual Ability, Inc. (VAI) is a well-established virtual community in Second Life that was designed by and for people with a wide range of disabilities. People come from many diverse cultures across the age spectrum, and frequently share innovative grassroots solutions to living autonomously, making the virtual world ideal for community-engaged research. However, access to VAI requires the ability to access and use a computer, as well as a broadband internet connection. Given that VAI is not available to a fully representative population of persons with disability, we also recruited from low income integrated supportive urban community housing projects run by a social service agency in Milwaukee, WI. This second cohort included a high proportion of ethnic minorities with educational challenges and low computer literacy.

Sample characteristics

Nineteen persons with and without disabilities participated in 1 of 4 focus groups in the virtual and physical worlds conducted between March and July 2014. Characteristics of study participants according to focus group location are presented in the Table 1. Participant's gender, age range, and focus group type (virtual or physical world) are shown in Table 2.

Sampling technique

Sampling was purposive to ensure enrollment of people from diverse socioeconomic circumstances and across the broad spectrum of disability type and severity. Inclusion criteria for both physical and virtual world focus groups were age 21 years old and older, living in a US community, and ability to communicate and participate in small group dialog online or in the physical world with or without an Americans with Disability Act (ADA) accommodation. Participants for the online VAI groups were recruited through membership of over 900 persons with disability, building on protocols established and applied extensively in Second Life®. Participants in the physical world focus groups were recruited by community newsletters and community meetings.

Data collection methods and procedure

The physical world focus group included 4 persons with disabilities and 1 without. All 4 people with disabilities in the physical world group had disabilities related to medical problems, 3 reported a psychiatric disability, 2 expressed a physical component, 2 had speech and language difficulties, 1 had blindness or low vision and 1 had a learning disability. The first virtual world group included 5 persons with disabilities. All 5 had contributing medical conditions,

Table 1

Characteristics of participants according to focus group location.

	Physical world with and without disabilities <i>n</i> = 5	Virtual world with disabilities <i>n</i> = 9	Virtual world without disabilities <i>n</i> = 5	Total sample <i>n</i> = 19
Age in years, <i>n</i> %				
21–40	0 (0%)	4 (44.4%)	3 (60.0%)	7 (36.8%)
41–60	4 (80.0%)	4 (44.4%)	2 (40.0%)	10 (52.6%)
61 or older	1 (20.0%)	1 (11.1%)	0 (0.0%)	2 (10.5%)
Gender, <i>n</i> %				
Female	5 (100.00%)	5 (55.6%)	2 (40.0%)	12 (63.2%)
Male	0 (0.0%)	4 (44.4%)	3 (60.0%)	7 (36.8%)
Ethnicity, <i>n</i> %				
White	2 (40.0%)	5 (55.6%)	4 (80.0%)	11 (57.9%)
Black/African American	3 (60.0%)	1 (11.1%)	0 (0.0%)	4 (21.1%)
Hispanic/Spanish	0 (0.0%)	2 (22.2%)	0 (0.0%)	2 (10.5%)
Other	0 (0.0%)	1 (11.1%)	1 (20.0%)	2 (10.5%)
Education, <i>n</i> %				
High school diploma or greater	5 (100.0%)	9 (100.0%)	4 (80.0%)	18 (94.7%)
Less than a high school education	0 (0.0%)	0 (0.0%)	1 (20.0%)	1 (5.3%)
Marital status, <i>n</i> %				
Married	2 (40.0%)	4 (44.4%)	2 (40.0%)	8 (42.1%)
Never married	1 (20.0%)	3 (33.3%)	2 (40.0%)	6 (31.6%)
Widowed, divorced or separated	2 (40.0%)	2 (22.2%)	1 (20.0%)	5 (26.3%)
Living arrangement, <i>n</i> %				
Lives alone	3 (60.0%)	3 (33.3%)	1 (20.0%)	8 (42.1%)
Lives with one or more people	2 (40.0%)	6 (66.7%)	4 (80.0%)	11 (57.9%)
Health care setting, <i>n</i> %				
Public clinic	0 (0.0%)	1 (11.1%)	1 (20.0%)	2 (10.5%)
Hospital-based clinic	4 (80.0%)	3 (33.3%)	1 (20.0%)	8 (42.1%)
Private physician office	1 (20.0%)	5 (55.6%)	3 (60.0%)	9 (47.4%)
Insurance coverage, <i>n</i> %				
Medicare	4 (80.0%)	3 (33.3%)	0 (0.0%)	7 (36.8%)
Medicaid	0 (0.0%)	1 (11.1%)	0 (0.0%)	1 (5.3%)
Medicare and Medicaid dual enrollee	0 (0.0%)	1 (11.1%)	0 (0.0%)	1 (5.3%)
Neither	1 (20.0%)	4 (44.4%)	5 (100.0%)	10 (52.6%)
Activities of daily living, <i>n</i> %				
Difficulty with 1 or more ADLs	3 (60.0%)	9 (100.0%)	0 (0.0%)	12 (63.2%)
No difficulty with ADLs	2 (40.0%)	0 (0.0%)	5 (100.0%)	5 (26.3%)
Instrumental activities of daily living, <i>n</i> %				
Difficulty with 1 or more IADLs	4 (80.0%)	9 (100.0%)	0 (0.0%)	13 (68.4%)
No difficulty with IADLS	1 (20.0%)	0 (0.0%)	5 (100.0%)	6 (31.6%)
Disabling condition(s), <i>n</i> %				
Mental disorder	3 (60.0%)	5 (55.6%)	0 (0.0%)	8 (42.1%)
Arthritis	3 (60.0%)	3 (33.3%)	0 (0.0%)	6 (31.6%)
Spinal cord injury	0 (0.0%)	2 (22.2%)	0 (0.0%)	2 (10.5%)
Diabetes	1 (20.0%)	1 (22.2%)	0 (0.0%)	2 (10.5%)
Respiratory condition	1 (20.0%)	1 (11.1%)	0 (0.0%)	2 (10.5%)
Multiple sclerosis	0 (0.0%)	1 (11.1%)	0 (0.0%)	1 (5.3%)
Cancer	0 (0.0%)	1 (11.1%)	0 (0.0%)	1 (5.3%)
Learning disability	1 (20.0%)	0 (0.0%)	0 (0.0%)	1 (5.3%)
Kidney failure	0 (0.0%)	1 (11.1%)	0 (0.0%)	1 (5.3%)
Other	2 (40.0%)	2 (22.2%)	0 (0.0%)	4 (21.1%)
None	0 (0.0%)	0 (0.0%)	5 (100.0%)	5 (26.3%)
Number of disabling conditions, <i>n</i> %				
None	1 (20.0%)	0 (0.0%)	5 (100.0%)	6 (31.6%)
1	0 (0.0%)	4 (44.4%)	0 (0.0%)	4 (21.1%)
More than 1	4 (80.0%)	5 (55.6%)	0 (0.0%)	9 (47.4%)
Disability onset, <i>n</i> %				
Present at birth	2 (40.0%)	3 (33.3%)	0 (0.0%)	5 (26.3%)
Present after birth	2 (40.0%)	6 (66.7%)	0 (0.0%)	8 (42.1%)
No disability	1 (20.0%)	0 (0.0%)	5 (100.0%)	6 (31.6%)
Visibility of disability, <i>n</i> %				
Visible	2 (40.0%)	5 (55.6%)	0 (0.0%)	7 (36.8%)
Not visible	1 (20.0%)	4 (44.4%)	0 (0.0%)	5 (26.3%)
No disability	1 (20.0%)	0 (0.0%)	5 (100.0%)	6 (31.6%)

ADLs, Activities of daily living; IADLS, Instrumental activities of daily living; PTSD, Post-traumatic stress disorder.

Percents are column percentages (*n* = 19).

Table 2

Participant gender, age range, and focus group type (virtual or physical world)

ID	Focus group type	Age range	Gender
1	Virtual world	21–30	Female
2	Virtual world	31–40	Male
3	Virtual world	70–74	Female
4	Virtual world	51–60	Female
5	Virtual world	21–30	Female
6	Virtual world	51–60	Female
7	Virtual world	41–50	Male
8	Virtual world	31–40	Male
9	Virtual world	51–60	Male
10	Virtual world	31–40	Male
11	Virtual world	21–30	Female
12	Virtual world	31–40	Male
13	Virtual world	41–50	Female
14	Virtual world	51–60	Male
15	Physical world	51–60	Female
16	Physical world	41–50	Female
17	Physical world	51–60	Female
18	Physical world	51–60	Female
19	Physical world	80+	Female

ID, Identification number.

3 had psychiatric disabilities, 1 had a physical disability, 1 was deaf or hard of hearing and 1 was blind or low vision. The second virtual world group included 4 persons with disabilities. Three of these individuals had physical disabilities, 3 had psychiatric disabilities and 2 had disabling medical conditions. The fourth virtual world focus group consisted of 5 individuals without disabilities. Focus groups were approximately 90 min. Assistance was provided for participants with special needs. Focus groups began by providing an explanation of the study and obtaining informed consent. The study protocol was approved by the Institutional Review Board of the University of Pennsylvania. All participants gave informed consent and had the right to withdraw from the study. The discussion centered on participants' experiences with the health care system. The research team included individuals with expertise in health services research, anthropology, qualitative methods, communication, health information technology, virtual world technology and primary care; some of which were from the disability community. The interview guides were developed based on a literature review of the health care experiences of persons with disabilities. Two similar standardized interview guides were created: one for persons with disability and one for persons without disability. Content across the two interview guides was similar. Focus group facilitators received task-specific training from the investigators using a standardized focus group handbook. The final steps in their training involved conducting focus groups with mock participants. Sociodemographic characteristics and functional status were obtained using a demographic form. All participants were provided with a small token of appreciation. The physical world focus group was transcribed using Communication Access Realtime

Translation (CART) remote captioning. Transcripts from virtual world focus groups were obtained from typed chat.

Data analysis and ethical considerations

A constructivist Grounded Theory approach was employed to analyze the data, which involves a constant comparative process in which theories were constructed about what was occurring in the data.^{25,26} Employing this approach we were concerned with developing themes that emerged “from the ground” based on participant responses to open-ended questions developed for this study.^{26,27} We used an approach in which many core categories emerged from the data concluding our theory development.²⁸ De-identified transcripts from both physical and virtual world focus groups were downloaded and entered into NVivo 10.0 QSR International qualitative software for analysis. The coding schema was developed through bi-weekly team meetings where text was explored line by line in order to reach consensus on topics, address identified discrepancies, collapse similar topics into broader categories, and define the preliminary codes for analysis.²⁹ The preliminary codebook was refined and finalized through the same consensus process. Individual team members coded transcripts independently, making notes of emerging topics. Team members met to develop a set of core categories and understand how themes related to one other. In our publication of results we were unable to indicate specific diagnoses of disability in order to maintain confidentiality. To ensure the trustworthiness of our findings we presented the themes to a sample of study participants for confirmation or modification, a process known as member checking.³⁰ There was strong support for the themes among participants. No new themes were raised during the member checking process.

Results

Summary of central themes

Some participants expressed instances of receiving good care but many described numerous barriers to receiving desired services. Core categories identified by persons with and without disability were poor coordination of care among providers; difficulties with insurance, finances, transportation and facilities; short duration of visits with physicians; inadequate information provision; feelings of being diminished and deflated; and self-advocacy as a tool for better services. Persons with disability described specific ways in which they perceived their disability affected their care. Participants discussed core categories exacerbating the negative impact of one another thus resulting in overall cumulative worsening of well-being and health. For example, lacking adequate insurance was discussed as resulting in poor coordination and information provision as well as the inability to obtain adequate transportation.

Persons often felt diminished and deflated and their overall health suffered. A discussion of the central themes and examples from the transcripts follows.

Coordination among providers

Many persons with and without disability described frustrating experiences within a multifaceted and fragmented health care system. One participant complained how no doctor treated every issue:

My biggest problem is that so many [of] my symptoms are interrelated and no doctor will put them all together. (participant 13, virtual world)

Additionally, many participants felt that communication among their various providers, even those within the same network, was poor despite the use of electronic health records (EHRs):

I know everything goes straight into a computer ... They don't read each other's information on me. (participant 17, physical world)

Insurance and finances

Several participants with and without disability discussed the amount of hard earned money paid for their health care in relation to the quality of services received:

I felt I was not getting proper health care with, with all of the insurance was coming out of my check, because I do work for a living, and they take quite a bit of money out a month. (participant 18, physical world)

Participants indicated that they faced a choice between paying for health care and daily living needs:

You have to go without food or other meds or you have to skip on the electric or rent. Not a good deal at all. (participant 17, physical world)

If I knew that I could, I'd go regularly (to see the doctor). As it is now, I don't because I take care of a family and I just don't have the money for it. (participant 10, virtual world)

You could be having chest pains and not go to the ER because you'd rather wait and see if it passes because you can't afford the \$300 co pay. (participant 11, virtual world)

Transportation and facilities

Coordination of transportation was a major concern, particularly for persons with disabilities influencing mobility. Participants described their experience in attempting to obtain transportation services to and from their providers' offices:

So, every time I had to go in for something, it involved hiring ambulance transport. Which never comes on time. And which one time left me laying there, waiting, at the entrance to the building ... (participant 8, virtual world)

I have to take the bus ... They can't find no other transportation or van service for me. That's the main thing I am having a problem with. If I am sick, too. (participant 15, physical world)

Another participant described an experience arriving at a health care facility and not being able to fit their wheelchair in the waiting area:

Minor gripe with facilities at all the medical offices I visit: make room for at least one wheelchair ... there is NO room for my wheelchair. (participant 6, virtual world)

Time with clinicians

Many persons with and without disability reported that providers rarely spent enough time discussing health issues:

It's almost like if you don't have something simple that the doctors can find and treat within ten minutes, they send you on your way ... (participant 1, virtual world)

One participant reported that their doctor liked them because they have fewer complaints, giving credence to the notion that patients are more well-liked by physicians if they have fewer health issues:

Well, I guess I'm kind of amazing to him, because I don't have any complaints. (participant 19, physical world)

Quality of information

Obtaining critical information related to medical conditions during rushed medical encounters was difficult for persons with and without disability. For instance, a participant said:

He mostly doesn't describe anything, he'll tell me to go home and look it up on Google or he'll refer me to a specialist saying they will explain things. (participant 4, virtual world)

Verbal communication was challenging in the context of short medical visits, particularly when persons with disability required additional assistance. One person who was deaf described their difficulties with communication:

For example, in an audiology clinic. I informed the desk I could not hear anything. The nurse forgot and if I hadn't looked up and seen a nurse checking everyone, I would have missed my appointment. (participant 3, virtual world)

Some participants reported that their physician made sure that the patient understood the information being conveyed during encounters. Most of this positive commentary focused on primary care physicians:

My main doctor who was on ER duty did an excellent job of facing me when talking, and when I indicated at times, I couldn't figure out what she was saying, she wrote it down. (participant 3, virtual world)

Diminished and deflated

Numerous persons with and without disability from every focus group reported feeling frustrated, confused, and even degraded by certain experiences within the health care system. Persons with disability described particularly poignant experiences wherein they felt invisible or were viewed as incompetent. A few persons with disability described incidents where they were treated as a disease or a body part, rather than as a person:

When I was in my 20s, once, I went to an urgent care because I broke my toes by ramming my foot between my chair and a sofa. A friend went with me. The nurse at the desk, and then the doc who did the exam as well as the x-ray person ... all talked only to him. Even though I was the one answering. And, I was and am perfectly capable of speaking for myself ... I was invisible or deemed incompetent. (participant 8, virtual world)

Some participants opined that health care providers and staff members have preconceived assumptions about patients:

I do not feel she (my doctor) is part of my community in the city nor does she understand my socioeconomic background or perspective. I think she is so accustomed to dealing with folks who are poorer or less educated, she can't gear up to talking to someone who could relate on a more educated level. (participant 13, virtual world)

Self-advocacy as a tool for better care

Some persons with and without disability felt that providers demonstrated a lack of knowledge and awareness. One participant stated:

They are so convinced sometimes that they have all the answers when they first meet you and they know nothing about the patient that has just walked through their door. (participant 1, virtual world)

A person with quadriplegia reported that doctors and other providers often times had no idea how to examine them:

I have had both extremes. The doc that sends a line-backer into the exam room who hauls me up and plops me on the exam table without asking ... to a

nurse that comes in, says "here, put this gown on and sit on that exam table" and then disappears ... and is upset when she returns and I am still sitting there, completely unable to self-transfer. (participant 8, virtual world)

Many participants from every focus group felt the need to be an assertive self-advocate. However, one participant recognized that while self-advocacy is important, it is something that not all persons can engage in:

There are people who are able to advocate for themselves, and there are people who are less able to advocate for themselves. (participant 17, physical world)

Participants also had suggestions about how persons could play an active role in promoting their own health. A participant mentioned:

... patients should also work with the doctor and let the doctor know, well, I am also taking this medicine from that doctor. Because certain prescriptions don't go together ... So I think it's on both ends; the doctor and the patient should have a lot of communication. (participant 18, physical world)

In summary, persons with and without disabilities described the numerous barriers faced and how they impacted experiences within the health care system. The barriers included poor coordination among providers; difficulties with insurance, finances, transportation and facilities; short duration of visits with physicians; inadequate information provision; and feelings of being diminished and deflated. Self-advocacy was identified as an important tool for navigating the health care system and interacting with providers.

Discussion

Participants' experiences and perceptions underscore many of the challenges both persons with and without disability have in obtaining high quality health care. Persons with and without disability discussed poor coordination among providers; difficulties with insurance, finances, transportation and facilities; short duration of visits with physicians; inadequate information provision; and feelings of being diminished and deflated. Several participants stressed a need for self-advocacy. Our investigation in both the physical and virtual worlds explores perceptions of persons with and without disability related to health care.

Narratives documented the difficulties persons with and without disabilities had in finding providers, especially providers who communicated with each other. Often providers, even in the same health system, were described as not reading each other's EHR records. Many participants also spoke about needs that influenced care coordination and quality, such as trouble with transportation to and from

health care visits, financial difficulties worsened by poor insurance coverage, and physical access to health care facilities. Disabilities were often multi-causal arising from the interactions of several medical or other types of conditions. Yet the presence of specific types was logically linked to distinct concerns. For example, persons with disabilities involving movement were particularly concerned with transportation difficulties and physical access to health care facilities. Our findings are consistent with other work in which poor care coordination has been identified as a significant impediment to high quality services.^{23,31,32}

Narrative content indicated that persons with and without disabilities may feel they burden providers if they discuss many medical concerns. Participants felt that providers viewed the ideal patient as someone who had few concerns and was able to concisely summarize them. Brief appointment times and rushed patient visits often left participants feeling their needs were unaddressed. Persons with disability, especially those with language/speech and/or auditory impairments, often required additional assistance in communicating with providers to obtain information. Communication barriers have been widely discussed and documented in the literature as substantial obstacles persons with disability must face in health care settings.^{18,22,32,33} Our findings place this issue within a larger systematic context of infrastructure constraints such as short patient visits.

Concepts expressed by persons with and without disabilities indicated feelings of being diminished and deflated and a lack of partnership with providers. Instead of feeling strong relationships with providers, participants felt weak and alone. Persons with disability described particularly poignant experiences wherein they felt invisible or were viewed as incompetent. Participants felt that they were treated as a disease or body part and not as a whole person. Several other qualitative studies have reported that participants expressed similar thematic content suggesting that this may be a widespread issue.³⁴ Because interactions between persons are shaped by our perceptions of others,³⁵ perceptions that consumers of health care lacked education, intelligence, and independence foster patronizing interactions. In contrast, the perception that consumers of health care are autonomous fosters interactions based on mutual respect and collaborative partnerships.

Narratives also indicated that persons with and without disability felt a need to advocate for themselves. Providing detailed medical histories and carrying instructions for specific care needs were strategies employed by some participants to enhance their care. There was a recognition that some people were able to advocate for themselves while some were not. Participants spoke about the need for education programs for providers to specifically address how best to provide care. They also discussed the importance of facilities and technologies that could accommodate persons with special needs. Our findings support a need for further research examining disability-specific barriers as

well as differences in perspectives between participants from virtual and physical worlds.

In this work the inclusion of virtual world focus groups enabled people with a wide range of disabilities to participate. Self-advocacy, an important construct reflecting empowerment, has brought about substantial health care reform. With increased usage of the internet, online communities have enabled people with minimal social and political power to unite and develop networks which help them to achieve a notable impact on the processes affecting their lives.^{36–40} The affordances allowed by the internet have enabled people to collaborate and overcome marginalized positions in society and bring about lasting changes.³⁶ The virtual world, particularly for persons with disabilities limiting participation in face to face interactions, offers opportunities for self-advocacy, empowerment and involvement in systemic change.

Several study limitations should be considered. First, the qualitative nature of this study does not provide insight for causal inferences. Second, the small number of participants limits this study. However, our sample included a broader range of persons with disability and without disability than previous samples. Third, persons who participated may have had different health care experiences from persons who chose not to participate. Our sample comes from two community centers and a world-wide online virtual community, which may limit generalizability. It should be noted that because of our use of virtual world settings persons did not need to physically travel to participate in a focus group. This gave people a voice that would not have been able to travel to participate in research. Fourth, interviewer and analytic team characteristics may potentially influence the nature of interviews and analysis. Thus, the role of the interviewer was clearly explained and the interview guides were closely followed. In addition, the analytic team had varied backgrounds and disciplinary expertise. Fifth, the results of this study do not suggest that care coordination, lengthy office visits with ample information, respectful patient–physician interactions, and appropriate care for persons with disability are uncommon; rather, our results highlight aspects and experiences of care that are of particular importance to persons with and without disability.

Conclusions

Findings from this study highlight the need for better coordination of care among health care providers as well as improving patient–physician interactions and perceptions related to persons with and without disability. While both persons with and without disabilities experienced challenges in obtaining high quality health care, persons with disabilities experienced challenges often related to their type of disability. Conceptualizing health care as a process rather than an entity or achievement may be a critical aspect of streamlining services. This may entail a shift from a focus

on acute services and treatment to one that adapts and tailors health care to the individual needs of patients. Education of providers needs to include views of health care consumers to ensure that policy initiatives and community outreach efforts address the most essential needs of all persons.⁴¹ There is broad support within the Affordable Care Act to systematically change curriculum development in order to train health care providers how to effectively provide care to persons with and without disability. Developing a national curriculum to train health care providers based on input from consumers of health care services may play a transformative role in improving care.⁴²

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