



Patient Centered Outcomes Research Priorities to Advance Disability Equity

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About the foundation: The Patient-Centered Outcomes Research Institute® (PCORI®) is an independent, nonprofit organization authorized by Congress in 2010. Its mission is to fund research that will provide patients, their caregivers, and clinicians with the evidence-based information needed to make better-informed health care decisions. PCORI is committed to continually seeking input from a broad range of stakeholders to guide its work.

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Approximately 1 in 4 people in the United States has a disability,¹ making people with disabilities (PWD) one of the largest minority groups in the country. Disability cuts across all identities of gender, sexual orientation, age, socioeconomic status, race, and ethnicity.² The Americans with Disabilities Act (ADA) defines disability as: “a physical or mental impairment that substantially limits one or more major life activities.”³ Included in this definition are persons “who have a history or record of such an impairment” and persons who are “perceived by others as having such an impairment.” Types of disabilities include but are not limited to physical, intellectual or developmental (IDD), communication, cognitive, and sensory disabilities.

For PWD to live full and active lives, they need to have equitable opportunities to achieve optimal health. Unfortunately, PWD experience significant health and health care disparities.⁴ Compared to non-disabled persons, PWD are more likely to have a greater number of chronic conditions and have higher rates of obesity, asthma, high blood pressure, high cholesterol, heart disease, diabetes, and smoking.⁵ PWD are more likely to rate the quality of their health as fair or poor as compared to non-disabled people.⁶⁻⁷ While a myriad of factors contribute to poor health outcomes for PWD, decreased access to timely, appropriate, and high-quality health care is a major contributor. For example, cervical and breast cancer screening rates for women with developmental and/or physical disabilities are significantly lower compared to the general population.⁸⁻⁹ Persons with communication disabilities are three times more likely to experience an adverse medical event when hospitalized.¹⁰ Finally, PWD are less likely to report satisfaction with their health care as compared to non-disabled people.

Health care organizations are mandated by Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 to provide accessible health care to PWD.¹¹⁻¹² The Patient Protection and Affordable Care Act (ACA) strengthens this mandate through Section 1557 by requiring organizations to: (1) provide effective communication, which includes provision of auxiliary aids and services such as hearing assistive devices; (2) establish accessibility standards for buildings and facilities, and health programs provided through electronic and information technology systems; and (3) make “reasonable modifications” to policies, procedures, and practices to provide PWD access to the organizations’ health programs and activities.¹³ While these laws are critical to ensuring access to equitable health care for PWD, they are primarily enforced reactively by lawsuits brought forward by PWD denied these accommodations. Additionally, no evidence exists that demonstrates that lawsuits change provider or health system behaviors or attitudes. Consequently, many health care organizations and clinics remain inaccessible and unaccommodating to PWD.

Research is needed to determine how to make meaningful changes to advancing equitable health care for PWD. To date, much of the research on disability health care disparities has focused on identification and understanding the disparities. While this literature is invaluable and foundational, significant gaps remain in the data needed to inform the provision of evidence-based equitable health care for PWD. Recognizing this need, we engaged researchers, policy makers, funders, payers, PWD, disability advocates and health care

organizations in key-informant interviews to identify critical research priorities to improve equitable health care for PWD. The following is a summary of the research priorities identified by the stakeholders. These findings should be used for setting patient-centered outcomes research agendas, providing funding agencies with priorities most in need of support, and informing policy makers of the gaps that need to be addressed, in order to assure equitable health care for PWD.

TABLE 1: ADVISORY COMMITTEE MEMBERS		
Name	Organization	Stakeholder Group
Zary Amirhosseini	Massachusetts General Hospital	Health care organization
Alex Bennewith	United Spinal Association	Advocate
Carol Bradley	Sutter Health	Health care organization
Mary Lou Breslin	Disability Rights Education & Defense Fund	Advocate and Researcher
Kelly Buckland	National Council on Independent Living	Advocate
Tricia Fingerle	National Jewish Health	Health care organization
Keri Gray	American Association of People with Disabilities	Advocate
Joan Griffin	Mayo Clinic	Researcher
Chanda Hinton	Chanda Plan Foundation	Advocate
Lisa Iezzoni	Harvard Medical School/Massachusetts General Hospital	Researcher
Kristi Kirschner	University of Illinois	Researcher and Provider
Tara Lagu	Northwestern Medicine	Researcher and Provider
Jen Longdon	State Representative, Arizona	Policy Maker
Liz Mahar	The Arc	Advocate
Michael McKee	University of Michigan	Researcher and Provider
Caitlin Powers	Northwestern Medicine	Health care organization
Carol Reagan	University of Colorado Health	Health care organization
Rylin Rodgers	Association of University Centers on Disability	Advocate
Wendy Sultzman	University of Colorado Health	Health care organization
Yomi Wrong	Sutter Health	Health care organization

METHODS

Advisory Committee Meetings

To oversee and guide the project, we recruited 20 stakeholders to serve on the Advisory Committee (see Table 1). Four Advisory Committee meetings were held via video conferencing throughout the 2-year project period. During the first Advisory Committee meeting, we established a meeting structure that allowed for equitable opportunities to contribute. The Advisory Committee members discussed the mission and values of the committee, confirmed terms and language to be used that were supportive of all members, and established processes for developing consensus for decisions. During subsequent meetings, the Advisory Committee identified stakeholders for interviews, helped develop interview guides, reviewed preliminary findings, and identified gaps to target recruitment efforts on specific key stakeholders for the remaining interviews.

Key-Informant Interviews

From May 2019 to August 2020, we conducted key-informant interviews with individuals representing the following groups: researchers, policy makers, funders, payers, disability advocates, professional societies and health care organizations (see Table 2). For health care organizations, we targeted individuals who lead disability initiatives at their organization. Their job titles varied, and included, but were not limited to ADA Coordinator, Section 1557 Coordinator, and Section 504 Coordinator. For the purposes of the project, we described these individuals as “Disability Accessibility Coordinators” or DACs. The DACs we interviewed represented community and academic hospitals and varied in size and geographic location in the United States. Policy makers included representatives from federal agencies and national policy organizations who create, recommend, and enforce health care and disability policies specific to PWD. Representatives from disability advocacy organizations ranged from regional and national organizations. Researchers represented academic institutions across the United States. Payers included representatives from non-profit and for-profit organizations who provide health insurance and coverage. Finally, we interviewed individuals from professional organizations. The Advisory Committee identified the list of stakeholders to interview. The Advisory Committee felt strongly that having input from individuals who represented different stakeholder groups provided a more comprehensive understanding around the research priorities needed to address equitable health care for PWD.

The interview guide was informed by an extensive literature review and then developed and refined by the Advisory Committee. The questions explored the stakeholders’ perceptions of priorities to address equitable health care for PWD and sought to better understand current or past initiatives and obstacles in ensuring equity for PWD in the health care setting.

TABLE 2: KEY STAKEHOLDER INTERVIEWS

Disability Accessibility Coordinators (DACs)	17
Researchers	9
Advocates	10
Policy Makers	7
Payers (2 also represent Policy Makers)	5
Professional Organization Representatives	2
Total	50



Understanding the Effects of COVID-19 Pandemic on Research Priorities

The majority of the interviews (49/50) were completed prior to the COVID-19 pandemic. It was unclear whether the priorities described by the stakeholders prior to the pandemic remained the priorities during and following the global health crisis. To explore this question, we received a COVID-19 Enhancement Award from PCORI. As a part of the Enhancement Award, we conducted four online focus groups with DACs and stakeholders who previously participated in interviews (Table 3). The focus groups occurred between August and September 2020, with two focus groups including just DACs and two focus groups including all other stakeholders. Focus group guide questions sought to understand changing priorities and new obstacles to providing equitable health care for PWD due to COVID-19. The findings from the focus groups are incorporated into the overall findings from the interviews.

TABLE 3: KEY STAKEHOLDER FOCUS GROUPS TO UNDERSTAND EFFECTS OF COVID-19 ON HEALTH CARE FOR PWD (N=4)

Disability Accessibility Coordinators (DACs)	16
Researchers	4
Advocates	4
Policy Makers	4
Payers	3
Total	31

Determining Priorities

The fourth Advisory Committee meeting focused on identifying a concise list of the research priorities. The meeting occurred in September of 2020 and lasted 4 hours. During the meeting, the Advisory Committee reviewed the research priorities identified from the key-informant interviews and then participated in a multiple round Nominal Group Technique process to discuss, further define and rank order each research priority. The Advisory Committee anonymously rank ordered the identified priorities on three characteristics: importance (how significant is this priority for advancing equitable health care for PWD), urgency (how critical is this priority right now), and feasibility (how practical is this priority to accomplish). For each of the priorities, the members assigned a ranking of high, medium, and low within each of the three characteristics. We used rank order analysis to calculate the frequencies of which each priority was voted the highest priority, second highest, third, etc. Once the frequencies of the rank order were determined, we categorized the priorities into thirds: highest priority (those which were ranked 1-5 most frequently), medium priority (those which were ranked 6-9 most frequently), and low priority (those which were ranked 10-14 most frequently) (Table 4).

Research Priorities

The Advisory Committee ranked the research priorities into three groups, “high,” “medium,” and “low” across three categories: feasibility, urgency, and importance. Those in the highest tier are highlighted in green, those in the middle tier are highlighted in blue, and finally the lowest tier in yellow. It should be noted that all of the identified priorities are important and needed. The ranking is intended to guide efforts of researchers, policy makers, funders, payers, patient advocates and health care organizations in the pursuit of health care equity for disability. In addition to the identified priorities, we present health and health care outcomes identified by the stakeholders as important to measure, as well as stakeholders’ perceptions of current barriers and challenges in conducting disability health care disparities research.

During the focus groups to understand the effects of COVID-19 on the health care of PWD, the stakeholders reported that not only did many of the research priorities remain the same, their urgency and need became more pronounced. As such, we have integrated the stakeholders’ perspectives from the COVID-19 focus groups throughout our findings. Telehealth accessibility and lack of preventative health care visits during COVID-19 for PWD emerged as new priorities, which were not distinguished as priorities prior to the pandemic.

TABLE 4: RESEARCH PRIORITIES RANKED BY CATEGORY			
	Importance	Urgency	Feasibility
Documenting Disability Status in the Health Record	Green	Green	Green
Implementation of Disability Accommodations	Green	Green	Green
Disability Competency Education for Providers and Staff	Green	Green	Green
Intersectionality of Disability and Other Demographics and Social Determinants of Health	Green	Green	Blue
Current Status of Accessibility in the US Health Care System	Blue	Blue	Green
Effectiveness of Accommodations in Improving Outcomes	Green	Blue	Yellow
Accessibility of Telehealth, Patient Portals and other Health Care Technology	Yellow	Green	Blue
Improved and Increased Use of Big Data	Blue	Blue	Blue
Inclusion of Disability Competency Training in Medical Education	Blue	Yellow	Blue
Engaging and Supporting Family Members, Caregivers, and Support Persons in the Health Care Setting	Blue	Yellow	Yellow
Cost Effectiveness of Health Care Accommodations	Yellow	Blue	Yellow
Educating Persons with Disabilities about their Rights to Disability Accommodations	Yellow	Yellow	Blue
Effectively Communicating Health Information to Patients with Cognitive or Intellectual and Developmental Disabilities (IDD)	Yellow	Yellow	Yellow
Effects of Gaps in Preventative Health Care During COVID-19	Yellow	Yellow	Yellow

The green shaded priorities represent the highest ranked priorities

The blue shaded priorities represent the priorities that fell into the mid-third ranked priorities

The yellow shaded priorities represent the lowest ranked priorities

HIGHEST RANKED PRIORITIES

Documenting Disability Status in the Health Record

IMPORTANCE	URGENCY	FEASIBILITY
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- **What is it?** Evidence is needed to inform the consistent and accurate documentation of patients’ disability status in health records.

- **Why is it important?** Documentation of patients' disability status within the health record is essential for health care organizations to identify PWD who may need accommodations and to track quality of health care delivered to PWD.

To advance equitable health care for PWD, health care organizations need to systematically collect and record patients' disability status within the electronic health record. Unfortunately, little evidence exists on how to implement collection and recording of disability status. This was the top research priority identified by our stakeholders in both the interviews and focus groups, as well as by our Advisory Committee. Documentation of disability status in the electronic health record allows health care organizations, hospitals, and clinics to track the quality of health care delivered to PWD within their organization and to identify patients who require health care accommodations. Without consistent documentation of patients' disability status, it is impossible to measure the effects of interventions aimed at improving health care equity. Health care organizations can also use disability status to guide decisions regarding investment in disability resources, aids, and services. Across the interviewed DACs, virtually all were actively working on collection and recording of patients' disability status to some degree within their organizations, but with little guidance on best practices.

During the COVID-19 focus groups, stakeholders stated that not only did documentation of disability status remain their top research priority, but it was even more important due to concerns that PWD were disproportionately negatively affected by COVID-19. The focus group stakeholders stated that systematic documentation of patients' disability status is necessary to understand the effects of the pandemic on health outcomes and health care delivered to PWD during COVID-19.

Data are needed to guide health care organizations in the collection of disability status. Specific areas that need to be addressed in order for disability to be accurately collected include: standardization of language and terms for documentation of disability in the electronic health record; development of staff training on how to ascertain disability status and accommodations; identification of touch points to collect disability information from patients, including frequency of collection; and the establishment of systems to visibly flag patients' health record if accommodations are needed so services can be provided in a timely manner.



"...I agree that without data on disability, it's very hard to know whether patients with disability are differentially affected by COVID. I think that's a huge problem and it goes beyond the COVID issue, of course, because we can't even document disparities in access to care or in outcomes because hospitals and health care systems are not required to collect data on disability. That's been a huge ongoing problem that limits our ability to understand how severe the disparity is. I think that is the defining question for disability researchers and will be until this is resolved." [Other Stakeholders Focus Group](#)

"...I think that's [documenting disability status] actually got to be the next frontier for us and for healthcare as a whole. It should be: 'if we can't document it, if we can't measure it, we can't improve it.' We need to be able to identify people with disabilities, develop clinical interventions for them as they present with complex medical needs, and then actually employ those interventions, and then be able to see how we're doing with that." DAC

Implementation of Disability Accommodations

IMPORTANCE

URGENCY

FEASIBILITY

- **What is it?** Evidence is needed to inform how to implement disability accommodations, auxiliary aids and services in the clinical setting.
- **Why is it important?** To ensure equitable access to healthcare for PWD, health care organizations need evidence-based methods to systematically implement accommodations.

Although some policy guidance exists on what types of disability accommodations should be provided, little evidence exists to inform how to determine patients' needed disability accommodations and then how to effectively and efficiently implement the accommodations into routine clinical and hospital care. Many health care organizations have policies stating what disability accommodations should be provided, such as effective communication policies, but there is little specificity on how to effectively implement these policies into practice, nor is there evidence to inform the implementation. Consequently, in our stakeholder interviews, DACs requested evidence-based toolkits with implementation guides for health care accommodations. These toolkits need to address the entire encounter from appointment scheduling through providing after-visit-summaries, as well as be developed for outpatient, inpatient, surgical, and emergency settings. Throughout the COVID-19 focus groups, stakeholders discussed the need for evidence demonstrating how to effectively implement accommodations during emergencies, such as the pandemic.



"... One thing that I've realized is that during all of this, one thing that we've learned is that there's a lot of policies that have been written and updated which look really good on paper, but when it comes to operationalizing it in a hospital setting, people are not really considering it. I think that when we write these things and when we suggest them, we need to be very comfortable within our own institutions on what we can and cannot realistically do." DAC Focus Group

*“I think where we’re lacking, that needs additional work, is training on how to use those [disability] questions appropriately. Once you have documentation of a [disability] or the screening for a disability, what’s the action after that? How do you actually move that information into the appropriate accommodation?” **Researcher***

Disability Competency Education for Providers and Staff

IMPORTANCE

URGENCY

FEASIBILITY

- **What is it?** Evidence-based training for staff and providers in providing disability-competent medical care is needed.
- **Why is it important?** Health care providers and staff are critical components in ensuring that PWD receive equitable health care.

Training providers and staff in disability competent health care is critical to achieving health care equity for PWD. Stakeholders recommended that evidence-based curriculum needs to be developed and should include instruction on self-awareness of implicit bias; disability stigma and how to address it when it appears; legal responsibilities for providing accessible health care and accommodations; how to implement disability accommodations; and how to communicate and interact with PWD. Training in cultural competency may be similar for providers and staff, but some trainings may need to be role-specific due to differing medical care responsibilities. To address staff and provider bias, these trainings should include a combination of experiential learning with didactic material. Participants in the focus groups emphasized that during COVID-19, disability implicit bias was more prominent in the health care setting; highlighting the continued need for training in disability competent health care.



*“I think that there are plenty of things that, through training – which is critical – all the way from just disability competent care, understanding disability, the social cycle components of everything, how to transfer a client...I think that the bottom line is training is required, should be required and taken.” **Advocate***

*“...Staff education and communication is the number one thing [challenge in position as DAC]. Because it’s not a matter of people don’t care. Everyone cares, which is amazing. It’s not an issue at all. It’s more of how to get information to people and in a way that they’ll be able to apply it to their job and know where to go to if they ever have any questions about resources, or training, or just guidance.” **DAC***

Intersectionality of Disability and Other Demographic Characteristics and Social Determinants of Health

IMPORTANCE

URGENCY

FEASIBILITY

- **What is it?** Research must explore how disability and other identities intersect and affect the health and health care outcomes of PWD.
- **Why is it important?** No significant research to date incorporates intersectionality of identities such as race/ethnicity and disability status or LGBTQ+ and disability status, and therefore we have inadequate data to accurately capture the experiences of PWD who have multiple identities.

Stakeholders reported that intersectionality was a timely and critical area in need of significantly more research. Stakeholders identified race and ethnicity, rurality, sexual orientation, and gender as significant identities that must be explored with disability due to the increased and unique disparities in health care outcomes. In addition to these identities, consideration is needed regarding the social context of the lives of PWD and how social determinants affect health and health care outcomes of PWD. Stakeholders thought that while this was a critical area of need, it was least developed amongst all of the identified research priorities.



"I think when we talk about this overarching conversation of what happens with people with disabilities in the medical arena, we have to think about: 'What are the advocates, the programs and things of that nature that are intentionally inclusive of people with disabilities that are also people of color, LGBTQ, women, etcetera?'. If we're not doing that, then we're actually missing a large piece of our community that is overly impacted by these disparities." [Advocate](#)

"...I think one of the challenges, a research opportunity is to try to parse out when there is an intersection between disability and another disparity or social determinants of health. If you have someone who's disabled, but also is low-income, and perhaps they are an ethnic minority, and language issues and all its parsing out what those challenges are, and where the intersection is. Then, also evaluating the interventions. It's challenging anytime you're talking about such complex issues that are layered on top of each other. I think more research on that is always helpful." [Policy Maker](#)

Current Status of Accessibility in the US Health Care System

IMPORTANCE

URGENCY

FEASIBILITY

- **What is it?** Research is needed to describe current gaps in practice as well as high performing health care organizations.
- **Why is it important?** A comprehensive and national review of health care organizations' accessibility will identify and describe the gaps in the provision of accessible health care, as well as identify important lessons and innovations that could be widely disseminated.

Stakeholders reported a need to evaluate the current state of accessibility in our health care system. This would identify health care organizations who are high performers and who could provide important lessons and innovations that should be disseminated. Additionally, an understanding of the current state will identify major gaps in accessibility across health care organizations that could be targeted in future research. Stakeholders reported interest in comparing organizations with different types of offered accommodations on common metrics and quality improvement goals, such as appointment access, wait times, preventative care, and readmissions. Finally, stakeholders believed that information about health care organizations' accessibility could be used to develop a directory for PWD to use to select providers and facilities that would meet their accommodation needs.



"I don't know what other [health care systems] do. I feel like this is an area that's relatively close to me. I don't have access to understand what best practices of a healthcare organization that addresses issues of accessibility and capabilities. I don't know what other people do, and I would benefit from knowing that." **DAC**

"For example, there isn't really any data out there on how many providers are physically accessible for people with disabilities. You're shopping around for a provider, you have to really do additional work to find someone and hope that the other person that says: 'yes we're physically accessible', is actually knowing what you mean by that. That lack of data makes it hard for the consumer to make an informed decision." **Advocate**

MEDIUM RANKED PRIORITIES

Effectiveness of Accommodations in Improving Outcomes

IMPORTANCE

URGENCY

FEASIBILITY

- **What is it?** Evidence is needed that demonstrates whether providing timely and appropriate accommodations improves health and health care outcomes.
- **Why is it important?** Health care organizations and policy makers need evidence to inform how to shape their disability accessibility initiatives and regulations.

Stakeholders reported that once accommodations are assured for each encounter, the effectiveness of those accommodations needs to be evaluated. This was viewed as only feasible in organizations with consistent documentation of patients' disability status. Tracking clinical outcomes, patient experience of care, and provider and staff comfort with caring for PWD were identified as important metrics to evaluate. (See Identified Outcomes on page 24 for more information.) DACs reported the need for research evidence on the effectiveness of accommodations, as well as evidence that *not* providing accommodations is detrimental to patient outcomes. During the Advisory Committee meeting, stakeholders debated the need for studies on the effectiveness of accommodations. Some argued that due to the legal mandate for accommodations, effectiveness data were not critical. Additionally, some accommodations were "obviously supportive of the needs of PWD" and therefore did not need to be evaluated in a research study. For example, women who use a wheelchair due to a mobility disability need mammography machines that can accommodate them while sitting. A study testing whether a mammography machine that is not accessible results in less mammograms for women who use wheelchairs is unnecessary. Despite this argument, DACs reported effectiveness data was critical for them to report to their leadership to support funding for disability initiatives and accommodations. Additionally, policy makers highlighted the need for evidence that accommodations improve patient safety and health care quality in order to develop practice guidelines.



"...we're not doing a very good job of this in our organization, documenting how much the need for disability accommodations is there in the healthcare sector. How often do we provide those accommodations? What difference did it make? Was it patient experience, or was it decreasing the rate of readmission? What was it? Because we need that level of evidence so that we can present it to our leadership in the area of evidenced-based practice so that we can convince people that not only is it important to provide disability-related

accommodations, but there's actually solid, high-quality evidence to support that." *DAC*

"...if we saw [research] that [provision of accommodations] really could improve quality, and safety for patients, that might be something that...would be an area that we would look at in terms of standards development. Any additional research supporting a positive impact on quality, and safety would definitely be something that would help us if we were to move in this direction for [standards] development." *Policy Maker*

Accessibility of Telehealth, Patient Portals and Other Health Care Technology

IMPORTANCE

URGENCY

FEASIBILITY

- **What is it?** Evidence is needed to ensure that patient portals, telehealth, virtual communication and other health care technology is accessible to PWD.
- **Why is it important?** Virtual forms of communication and telehealth are now a core component of health care both for patient visits and asynchronous communication, and therefore need to be accessible for PWD.

While technology advancements have improved the provision of health care, many advancements were not created with disability accessibility in mind. Research is needed to inform necessary adaptations of patient portals and other online tools to increase accessibility and ensure access to these tools for PWD. During the focus groups, stakeholders highlighted the importance of this topic area due to rapid adoption of telehealth and other remote technologies as a result of the COVID-19 pandemic. Many expressed that insufficient attention has been paid to ensure that these technologies are accessible for PWD. Telehealth has the potential to decrease health care disparities for PWD as it reduces transportation barriers, but it can also increase disparities if it is not accessible to those who have hearing, cognitive, vision or other communication disabilities. Evidence is needed to inform both the development and implementation of accessible telehealth and other health care technology.



"...I agree that the policy and research levers going forward need to be focused around 'how do we make this [telehealth] better? How do we decide the situations when it is appropriate and can be used and, in that sense, makes access to care easier for some patients with disability? How do we make sure that it accommodates all people, including people with communication disabilities? How do we make that happen?' The idea that it's going to go away feels impossible because it has been needed for so long."

Other Stakeholders Focus Group

“It’s a dream, but I think that the more that we can all move towards some levels of telehealth, so knowing that people with disabilities are absolutely going to have to see their physicians in person. We know that all of us will, but there are times where touchpoints need to occur for various things...There’s transportation barriers that exist, so why not have telehealth as a touchpoint for things that aren’t really critical to the moments in which you physically need to be in there?” [Advocate](#)

Improved and Increased Use of Big Data

IMPORTANCE

URGENCY

FEASIBILITY

- **What is it?** Research is needed to improve national surveillance of health care outcomes of PWD, as well as use of big data to track quality of health care.
- **Why is it important?** Using large scale data to track access to health care, quality of health care, and health outcomes for PWD is important for identifying disability health care disparities at a population-level.

Related to the first research priority of documenting disability status in the health care setting, stakeholders reported the need to increase national surveillance of disability health care disparities and improve methods for using big data to identify and describe disability-related disparities. While evidence of disparities in health care exists, many stakeholders reported that more research is needed to demonstrate these disparities. To do this, efforts should focus on creating improved national surveillance systems to track disparities in health care for PWD. This includes improved surveillance by public health agencies as well as including disability related questions in current hospital measures, such as H-CAHPS. Additionally, methods are needed to determine how PWD can be identified in claims data and other large data sets, which is currently challenging. This priority was reiterated in the focus groups. Participants reported that expanded and improved use of big data could be particularly impactful for understanding the implications of large-scale crises, in this case the COVID-19 pandemic, on access to equitable health care for PWD. The opportunities to study the impact of COVID-19 on health outcomes for PWD increases as more organizations adopt documentation of disability status.



“Unfortunately, some of the indicators for individuals with disabilities are incomplete in the claims and encounter data that are reported to us. I do think, though, being able to explore the data proactively to try to stratify the populations and better determine those at greater risk as well as being able to mine it retroactively to focus on following up with those who have been affected remains a very critical issue.”

[Other Stakeholders Focus Group](#)

“There's a dearth of evidence about the disparities in health for these populations, primarily because we don't have the ability to use claims data to identify the patients. In small populations, we know that patients with disabilities get screened for cancer less often. They get less preventative care. They have worse outcomes. We know all that stuff. The problem is that there's not a comparison group of similar patients who don't have disabilities, and that's because we don't have claims data to identify the patients. I think we desperately need more evidence of disparity.” [Researcher](#)

Inclusion of Disability Competency Training in Medical Education

IMPORTANCE

URGENCY

FEASIBILITY

- **What is it?** Create and implement evidence-based educational curriculum to develop disability cultural and clinical competency amongst medical trainees.
- **Why is it important?** Early introductions to disability cultural and clinical competency would ensure that future providers are prepared to provide disability-competent health care to PWD.

Stakeholders reported that developing and integrating evidence-based training in medical education was critical to providing equitable health care to PWD in the future. Data are needed about what training programs currently exist and their effectiveness. Ideally, all providers would graduate with a basic competency in delivering appropriate and accessible health care for PWD. Early introductions to these curricula would aim in part to address the implicit and explicit disability stigma and bias amongst providers, which is frequently cited by PWD as a reason for poorer care. It is important to note that we did not specifically seek out information on this topic during the interviews, but continued to hear unsolicited opinions from many of the stakeholders about why disability curricula for medical trainees played an important role when trying to decrease disparities for PWD in the health care setting.



“The biggest issue is that health care providers aren't being trained appropriately through professional medical education about disability, what disability competency really means.” [Advocate](#)

“The competencies or the expectations or the outcomes that we would expect of physicians – that would be incredibly helpful. Whether it's language to avoid, language to use, physical exam techniques or strategies. ‘How do you adapt your practice to meet the needs of patients?’ That would be very helpful if there was some guidance or strategies around that for medical educators.” [Professional Organization Representative](#)

LOWER RANKED PRIORITIES

Engaging and Supporting Family Members, Caregivers, and Support Persons in the Health Care Setting

IMPORTANCE

URGENCY

FEASIBILITY

- **What is it?** Evidence is needed on how to integrate family members, caregivers, and support persons of PWD into clinical visits and medical decision making.
- **Why is it important?** Providers need to know how to interact with both the patient and their caregiver or support person to ensure that equitable health care is provided.

Stakeholders reported that further evidence is needed on how to best integrate family members, caregivers and support persons into medical appointments and medical decisions. This was especially critical for patients with intellectual and developmental disabilities. They also desired specific research demonstrating how engagement with family members can improve patient care for PWD. Engaging and incorporating support persons in clinical encounters became even more challenging with restricted visitor policies due to the COVID-19 pandemic. Some stakeholders described a need for evidence-based training for providers on how to talk with family members, caregivers, and support persons.



“...I think having additional support people when someone needs a care attendant at the hospital and right now, everybody’s allowed to have one support person, but sometimes when you have someone with a disability, you have to have an additional, so making sure that everyone across the system is aware of that accommodation.” *DAC Focus Group*

“My experience is that they’re [support person] not really included at this point. They need to be, and I think that we require a lot of education around the concept, just even starting with the basics. You have a patient and a companion who comes, and the companion speaks another language or is hard of hearing. That needs to be as obvious to a healthcare provider as it is when someone who shows up and the patient is actually deaf and hard of hearing.” *DAC*

“Well, I think that they [support person] should be included if they need to be the voice of the individual, but I think the individual should always be the primary voice first because, again, we’re teaching through training that you don’t talk to the caregiver. You talk to the person with the disability.” *Advocate*

Cost Effectiveness of Health Care Accommodations

IMPORTANCE

URGENCY

FEASIBILITY

- **What is it?** Evidence is needed on the cost effectiveness of providing disability accommodations.
- **Why is it important?** Evidence demonstrating cost effectiveness and long-term savings would help incentivize health care organizations and leaders in investing and adopting disability accommodations.

Many disability accommodations include some level of financial commitment from the health care organization, whether it is hiring an employee to lead disability initiatives, purchasing height-adjustable examination tables, or covering time for employees to complete disability competency training. Stakeholders, especially the DACs, emphasized the need for evidence on the cost-effectiveness of accessible health care. Cost effectiveness analyses and demonstration of long-term cost savings would provide evidence to encourage health care organizations and leadership to adopt and invest in disability accommodations. This belief was reinforced in the focus groups as the types of accommodations changed with COVID-19 restrictions and new practice patterns.



“There's really a strong business case that even though accessible medical diagnostic equipment costs more than general equipment, it saves money and time and difficulty in other ways. Particularly by reducing injuries for nurses and nurse assistants, reducing workman's comp, lost wages, provider burnout. A lot of health providers are, in fact, dealing with workforce shortages, which can only be exacerbated by injuries.” [Policy Maker](#)

Educating Persons with Disabilities About Their Rights to Disability Accommodations

IMPORTANCE

URGENCY

FEASIBILITY

- **What is it?** Evidence-based strategies are needed to inform PWD regarding their rights, what accommodations they would benefit from, and how to request accommodations.
- **Why is it important?** PWD will likely not advocate for themselves and request accommodations if they are uninformed of their rights and unaware that health care organizations are legally responsible for providing accommodations at a visit.

Stakeholders reported believing that many PWD are not aware that health care organizations are legally responsible for providing accommodations during a visit. As such, they are likely to not advocate for themselves or know to request an accommodation. Similarly, stakeholders also described a knowledge gap for PWD about the types of available accommodations and the accommodations from which they would benefit. This is especially true for individuals with recently acquired disabilities. As such, there is a need for research to develop and implement evidence-based strategies to educate and empower PWD to request accommodations during their visits. DACs in the focus groups reported that PWD more regularly requested accommodations during the pandemic. They were uncertain as to whether this increased advocacy would continue following the pandemic.



“People don’t know where to go... ‘Where do you go for information? How do you find that?’ If it’s all cleared in one place, and if there’s an accessibility office at the hospital, people think, ‘Oh, maybe I can find it there and there’ll be some resources there.’” Advocate

“What can we do to make sure that [PWD feeling empowered] continues and that our patients feel empowered and feel like they can ask and receive the support that they need to be able to effectively engage in health care?” DAC Focus Group

Effectively Communicating Health Information to Patients with Cognitive or Intellectual and Developmental Disabilities (IDD)

IMPORTANCE

URGENCY

FEASIBILITY

- **What is it?** Evidence-based methods are needed for providers and staff to effectively communicate with patients with cognitive or IDD regarding their medical care.
- **Why is it important?** Health education and medical decision making is unique for people with cognitive disabilities or IDD, and efforts to improve their health care must incorporate interventions to ensure providers are communicating and educating their patients effectively.

People with cognitive or Intellectual and Developmental Disabilities (IDD) face challenges in equitable access to basic health and health care knowledge. Additionally, informed consent and engaging people with cognitive disabilities or IDD in medical decision making can be challenging and inadequate. Stakeholders discussed the need for research to determine effective methods for communicating health care information to people with cognitive

disabilities or IDD, as well as methods for obtaining informed consent. In order to do this, evidence-based trainings for health care providers and staff are needed.



*"I think that people with intellectual disabilities are really underserved in terms of access to partnering and being in determination in their own care. Being responsive and then providing access to everything they need in ways that makes sense." **Researcher***

*"There are just a number of providers who are either new to health care or had been involved in it for long and perhaps, maybe haven't remained current, with current practices that they're not comfortable or familiar with serving some of these individuals [persons with intellectual/developmental disabilities]. The need for cultural competence training becomes even more important than it is." **Payer***

Effects of Gaps in Preventative Health Care During COVID-19

IMPORTANCE

URGENCY

FEASIBILITY

- **What is it?** Access to preventative health care decreased during the COVID-19 pandemic, which may have disproportionately negatively impacted the long-term health and health care outcomes of PWD.
- **Why is it important?** Prior to the pandemic, decreased access to preventative health care contributed to poor health and health care outcomes experienced by PWD. With the pandemic, these disparities may have worsened.

Stakeholders reported that while there were numerous challenges related to COVID-19, one of their main research priorities was to understand how a lag in receiving preventative health care during the COVID-19 pandemic affects long-term health and health care of PWD. Regular preventative health care is imperative to one's health and while a great deal of the population was able to shift their preventative health care to telehealth without interruption during COVID-19, many PWD often experienced barriers to health care due to telehealth inaccessibility. Stakeholders were concerned that existing health care disparities in preventative health care were worsened by the COVID-19 pandemic.



"I know some individuals with disabilities who really needed preventative care, but they've struggled getting into their doctor because what they needed couldn't be done through telehealth. They had a sore that's not healing or something and they can't get to that doctor. It's been back, back, back, so care that they needed to have was not happening and so now hopefully, it's going to happen in September." [DAC Focus Group](#)

"There's also the issue of how much people are delaying or not getting non-COVID related health care. Are they getting their mammograms, their Pap smears, their colon screening, colon cancer screenings, all those kinds of things which were already problematic? Is it even worse?" [Other Stakeholders Focus Group](#)

RECOMMENDED OUTCOMES IDENTIFIED BY STAKEHOLDERS

The stakeholders identified the following outcomes as critical in patient-centered outcomes research to address disparities in health care for PWD. These outcomes are grouped into seven categories: patient outcomes, staff and provider outcomes, accommodation process outcomes, safety, cost, communication outcomes, and quality of health care outcomes. Importantly, the ability to measure these outcomes relies on the advancement of documenting disability status and the inclusion of PWD in big data (two aforementioned research priorities).

*(*Outcomes identified by DACs as important to their organizations' leaders)*

1. Patient-level outcomes

- a. Patient-reported outcomes
 - i. Experience of health care*
 - ii. Satisfaction of health care*
 - iii. Quality of Life and Health Related Quality of Life
 - iv. Met and unmet health care accommodation needs
 - v. Patient self-efficacy
- b. Patient's ability to identify a point of contact within a health care organization for accessibility inquiries
- c. Adherence to medical recommendations

2. Staff and provider-level outcomes

- a. Satisfaction and self-efficacy with providing health care for PWD*
- b. Attitudes towards PWD
- c. Burnout
- d. Comfort with caring for PWD

- e. Perceptions of adequate training and equipment
- f. Number of staff and providers with disabilities within the organization

3. Accommodation process outcomes

- a. Whether patients received requested accommodation
- b. Quality and efficiency of provided accommodations

4. Safety

- a. Patient injury or adverse medical events*
- b. Provider and staff injury*

5. Cost

- a. Cost effectiveness of providing accessible health care and accommodations*
- b. Cost savings and benefit of providing accessible health care and accommodations *

6. Communication

- a. Quality of patient-provider communication*

7. Quality of health care outcomes*

- a. Clinical outcomes
 - i. Prevalence and management of chronic health conditions
 - ii. Rate of progression of disease that contributes to disability (for example: does provision of equitable health care slow the progression of a disease such as Parkinson's disease or Multiple Sclerosis?)
 - iii. Clinical outcomes that are specific to patients' impairments (for example: do regular skin checks by providers reduce the incidence of pressure injuries for patients with spinal cord injuries?)
- b. Health care utilization
 - i. Preventative health care*
 - 1. Rate of cancer screening
 - 2. Rate of screening for chronic conditions
 - ii. 30-Day readmissions*
 - iii. Frequency of emergency department visits*
 - iv. Frequency and length of stay of hospitalizations
 - v. Behavioral health use
 - vi. Reduction of barriers to accessing health care
 - vii. Reduction of unnecessary health care
 - viii. Efficient access to health care (for example: can a woman in a wheelchair receive a mammogram in the same timeframe as a woman who is not in a wheelchair?)



BARRIERS TO HEALTH CARE DISPARITIES RESEARCH FOR PERSONS WITH DISABILITIES

Stakeholders highlighted key barriers and challenges when conducting research focused on improving disability health care disparities. These barriers and challenges are grouped into four categories: health care organization, funding, population, and outcome challenges.

1. Health care organization-level challenges:

- a. In order to carry out many of the identified research priorities, additional infrastructure is needed within the health care setting. Namely, health care systems need to consistently and accurately document patients' disability status in the Electronic Health Record (EHR). This requires an EHR that is equipped to track disability status and connect disability status to accommodations. This is critical to conducting interventions in the health care setting.
- b. Leadership, provider, and staff buy-in and commitment to advancing equitable health care for PWD is critical for not only the conduct of research, but also the dissemination of research. Many of the interventions to address disparities in health care require investment and integration into the health care setting. Without a stated priority for providing equitable health care to PWD, competing demands can easily overshadow disability interventions. Unfortunately, for the vast majority of health care systems, providing accessible health care to PWD is not a stated priority.

- c. DACs are key stakeholders and champions in their organizations for disability accessibility research and initiatives. While many expressed an interest in engaging in research, they reported limited time, resources, training, and support as barriers to their engagement.

2. Funding challenges:

- a. For some funding organizations, PWD are not considered a population that experiences health and health care disparities and therefore are excluded from equity and disparity funding opportunities. Consequently, this limits the availability of funds for research to address disparities in health care for PWD.
- b. Some funding organizations are focused on specific conditions that result in a disability (e.g., Multiple Sclerosis, Spinal Cord Injury) or body function (e.g., NIH Institutes are condition-specific). Researchers often then focus on one disability type, diagnosis, or subpopulation, rather than a range of disability types. While this is critical for the advancement of research for topics such as improving the functional outcomes of disability, this can create challenges for studying health care disparities across disability populations. For example, an intervention aimed at improving communication outcomes with patients with Autism might also be effective at improving communication outcomes with patients with other developmental or acquired cognitive disabilities. It can be challenging to find a funder willing to fund a project that includes participants with a range of etiologies. Additionally, health care systems can be hesitant to implement costly interventions focused only on a specific disability subpopulation. Consequently, this can limit the implementation of research findings into practice.
- c. Health care systems and advocates are eager for interventions to address disparities right now. Many of the funders, especially those who do not recognize disability as a disparity population, require more foundational work to identify and describe the disparity. Consequently, this creates a mismatch of priorities across stakeholders.

3. Population challenges:

- a. PWD tend to have high rates of chronic conditions, which causes challenges identifying a comparison group.
- b. PWD are often not identified or are underrepresented in national surveys.
- c. Including PWD in research can require offering accommodations to participate. For example, survey completion requires alternative and multiple response modalities to be accessible and inclusive of all PWD. Many researchers do not have the skills to adapt their methods to be inclusive of PWD.
- d. Interventions that broadly address disparities in health care for PWD should include sub analyses based on type and degree of disability, which can result in small sample sizes.
- e. Due to significant societal stigma, not all PWD are comfortable with or identify as living with a disability.

4. Outcomes:

- a. Measures of accessible and equitable health care for PWD do not exist. Patient-centered outcome measures for equitable health care for PWD need to be developed.
- b. Outcomes related to disability accessibility and satisfaction with health care interventions and disability accommodations need to be integrated into existing quality measures (e.g., H-CAHPS).



CONCLUSION

Persons with disabilities experience significant disparities in the receipt of equitable health care. In order to address these disparities, rigorously designed, patient-centered outcomes research is needed. Our diverse group of stakeholders identified 14 research priorities to advance research in this area. The top priorities include developing: 1) methods to collect patients' disability status in the health care setting; 2) training for staff and providers on how to deliver accessible, appropriate, and culturally competent health care to PWD; and 3) methods for providing timely disability accommodations during all health care interactions. To measure the effects of these studies, our stakeholders identified a range of priority outcomes that included patient-reported, clinical, processes of health care, and staff and provider-reported outcomes. Significant investment is needed in the identified research priority areas, as well as investment in addressing the methodological challenges associated with conducting high-quality, patient-centered research in this area. Persons with disabilities make up almost 25% of the population in the United States, which is expected to increase with the aging population. We urgently need evidence-based solutions to improve the health care for this marginalized population.

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