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## Perspectives of adults with disabilities on access to health care after the ACA: Qualitative findings

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### ABSTRACT

**Background:** Although health insurance gains are documented, little is known about personal experiences of adults with disabilities in accessing health care after coverage expansions of the Affordable Care Act (ACA) in 2014.

**Objective/Hypothesis:** We interviewed 22 adults across the U.S. with a variety of disabilities and health insurance types to document remaining barriers to health care after ACA coverage expansions.

**Methods:** Telephone interviews were conducted from May to August 2017. Participants were recruited via disability-related organizations and were demographically and geographically diverse. Content analysis of interview transcripts was used to identify major themes related to accessing health care.

**Results:** Five major themes emerged: 1) information and understanding of coverage; 2) out-of-pocket costs; 3) prescription medications; 4) provider networks; and 5) transportation. Barriers in these areas led participants to delay or forgo health care and interfered with their ability to participate in paid employment.

**Conclusions:** The ACA was intended to expand access to insurance coverage, not necessarily meet all health care related needs for people with disabilities. Many barriers remain to accessing needed care for this population, regardless of insurance status. Limited prescription coverage, limited provider networks and steep out-of-pocket costs may be addressed by policy makers at the state or national level. Similarly, having timely and accurate plan information is important in facilitating access to care and insurers should be aware that outdated information can result in missed care. Finally, transportation to appointments can be especially challenging for people with disabilities and insurers should consider options to address this issue.

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### Introduction

Access to health care services in the U.S. improved after passage of the Affordable Care Act (ACA) in 2010, which dramatically increased the number of Americans with health insurance coverage.<sup>1</sup> Likewise, for the more than 40 million working-age Americans reported as having a disability<sup>2</sup>, studies show that after implementation they are less likely to have access problems and more likely to have health insurance coverage.<sup>3</sup> Studies also show that increased access to coverage through Medicaid expansion under the ACA is associated with greater employment for people with disabilities.<sup>4,5</sup>

The ACA, however, was not specifically designed to address many of the difficulties in accessing care that adults with disabilities experienced prior its implementation.<sup>6–8</sup> Further, under the ACA, this population continues to encounter significantly more barriers to access than do people without disabilities.<sup>1,9,10</sup> This continuing disparity in barriers to access is important to understand because, for adults with disabilities, missed or delayed access to health care services can raise the risk of secondary conditions and hospitalizations, which lead to higher medical expenditures for adults with disabilities.<sup>8,11–13</sup> Exacerbations of health conditions due to access problems can, in turn, affect the ability to work for adults with disabilities. Thus, the noted gains brought about by the ACA could be attenuated if this population continues to face significant barriers to accessing medical care needed to maintain health and employment.

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The Institute of Medicine developed a conceptual framework for classifying barriers to accessing health care, including structural barriers such as transportation, financial barriers such as limitations in health insurance coverage, and personal barriers such as language or cultural factors that inhibit communication with providers.<sup>14,15</sup> Multiple studies indicate barriers in these three categories are more likely among adults with disabilities compared to adults without disabilities. For example, adults with disabilities are more likely to encounter various structural and environmental barriers to care, including transportation to medical appointments.<sup>16,17</sup> Adults with disabilities are more likely to face financial barriers to health care services than their non-disabled peers, at least partly due to their higher medical costs.<sup>6,8</sup> Similarly, studies have shown that a lack of clear communication with health care professionals and other providers can be a further impediment for people with disabilities when attempting to obtain needed health care services.<sup>6,18,19</sup> Few studies, however, have used qualitative methods to understand these barriers to health care access for Americans with disabilities after major coverage expansions and marketplace provisions of the ACA took effect.

The purpose of this study was to understand the recent experiences and perspectives of working-age Americans with disabilities with various types of insurance—or no insurance—in accessing health care services. The study sought to document barriers to timely and adequate health care that participants experienced in the years after coverage expansions under the ACA, and to better understand how these barriers affected this population's ability to work. Understanding the various barriers experienced by adults with disabilities from their perspectives and in their own words is a critical first step in developing policy solutions and improving practices to address the issues.

## Methods

Data for this study came from interviews with 22 adults with disabilities from across the United States conducted between May and August of 2017. The purpose of the interviews was to obtain an in-depth understanding of consumer experiences and perspectives on access to health care and other services. Study procedures, protocols and consent documents were approved by the institutional review board (IRB) at the University of Kansas.

**Table 1**  
Interview protocol items and probes.

Items	Probes
<ul style="list-style-type: none"> <li>Please tell me about your current health insurance coverage.</li> </ul>	For each type of coverage: How long have you had this type of coverage? Describe the process for getting this health insurance coverage What are the co-pay, deductible, co-insurance, and out-of-pocket costs for your coverage? For those without any type of coverage: How long have you been without insurance? Why do you have no coverage? How do you access needed health care services without coverage?
<ul style="list-style-type: none"> <li>Please tell me about any challenges or barriers you have encountered in getting the health care that you need.</li> </ul>	Limits on number of visits? Is provider network adequate to meet all your needs? If you needed, have you been able to get prescription drugs, personal attendant services (PAS), other services? How have you dealt with or what have been the consequences of these challenges or barriers?
<ul style="list-style-type: none"> <li>Have your employment or decisions about working been affected by your health insurance or access to care? If so, please explain.</li> <li>What one service is most important/crucial for you to have to maintain or improve your health and why?</li> <li>What information do you need regarding health insurance options?</li> <li>What would you like to tell policy-makers about access to health insurance and health care services for people with disabilities?</li> </ul>	n/a n/a What sources have you used to get needed information? n/a

## Study sample

A nationwide convenience sample of participants between the ages of 18 and 64 (working-age) was recruited through national disability organizations and at national disability conferences. Recruitment took place via print flyers, organization newsletters (electronic and print), websites, and email. Those interested in participating in an interview were directed to either call a toll-free telephone number or access a secure website. Recruitment through these channels provided a pool of nearly 600 individuals from all 50 states and Washington DC, a large national convenience sample from which to draw a study sample with diverse representation across disability types, geographic location, gender, age, race/ethnicity, employment, educational level, and type of insurance coverage.

## Interview protocol and procedures

Telephone interviews were conducted with each individual participant and two researchers. One researcher facilitated the discussion by using a semi-structured interview protocol of open-ended questions (Table 1). A second researcher took notes and asked clarifying questions as needed. After obtaining the consent of each individual participant, interviews were audio-recorded and then written transcripts were produced. The semi-structured interview protocol was designed to guide the topics for discussion and elicit information from participants about their experiences with health insurance coverage, barriers to accessing care, and decisions related to health and employment. Questions were developed and reviewed by the study team as well as other health policy and disability experts. The interviews did not have set time limits, ranged in length from 15 to 45 minutes ( $M = 26$  minutes;  $SD = 7.6$  minutes), and concluded when the discussion was ended by the participant. The shortest interviews were those in which participants experienced barriers in one specific area (such as accessing prosthetics) but otherwise were generally content with their coverage; the longest interviews were those in which the participants experienced numerous and varied barriers. Participants received a \$40 gift card for their participation in the interview. Data saturation was achieved after conducting 22 interviews, at which time no substantively new

themes or issues emerged.

A multi-disciplinary research team conducted the qualitative analysis of the written transcripts. The team consisted of four researchers and included two disability policy experts who conducted the telephone interviews, a health economist, and a sociologist. The team analyzed the transcripts using conventional content analysis, a methodology in which the researchers immerse themselves in the data to allow codes and themes to emerge.<sup>20,21</sup>

Each written transcript was coded by two independent researchers.

Results were arbitrated by a review process to verify that codes were applied consistently across researchers. A kappa value of 0.4 or greater was used to determine inter-rater reliability, and the research team met to reconcile individual cases below this threshold. Codes were subsequently grouped into larger categories of parent nodes and themes, using NVivo software.<sup>22</sup> Finally, the team met several times to discuss preliminary findings and additional themes before concurring with a final set of themes.

## Results

The demographic characteristics of the study sample are provided in Table 2; participants ranged in age from 25 to 62 years old, 59.1% were female and 63.6% were non-Hispanic white. More than two-thirds (68.2%) reported having multiple disabilities or chronic conditions and slightly more than half (59.1%) were employed. Participants lived in all census regions of the country and had a wide range of insurance types.

Five major themes related to accessing health care emerged from the qualitative analysis of interview transcripts: 1) information and understanding of coverage; 2) out-of-pocket costs; 3) prescription medications; 4) provider networks; and 5) transportation. These five major themes are discussed below, with representative quotations provided in Table 3.

### Information and understanding of coverage

Many respondents, across all types of public and private insurance, expressed frustration and even anger about the difficulty of obtaining accurate and consistent information about their health coverage. Often, lack of timely access to needed information resulted in delays in accessing care and/or increased out-of-pocket costs. One individual reported multiple instances of using her entire lunch break, while being placed on hold and waiting to talk with an insurance representative on the phone. Once she was able to talk with a person, the information provided was often not helpful or understandable. Other participants reported that the provider network directories that were furnished by their insurers were often out-of-date and that they wasted a considerable amount of time in contacting multiple providers by phone before finding one who actually accepted their insurance plan.

Some participants noted that access to coverage information was needed in real-time when a primary care provider referred them to a specialist or other follow-up service as part of an appointment. Rather than holding up the process of accessing specialists for needed care, some just expressed hope that specialist visits or follow-up services would be covered. One respondent suggested the need for an online database for consumers that would provide up-to-date information on covered providers and services. Because of the difficulty in obtaining coverage information from insurers, many respondents shared that they often had to consult informal online networks, such as Facebook groups, or disability service providers for needed information and advice.

**Table 2**

Participant characteristics (n = 22).

Item	n	% of sample
Age		
25–34 years	7	31.8
35–44 years	4	18.2
45–54 years	5	22.7
55–62 years	6	27.3
Female	13	59.1
Race/ethnicity		
Non-Hispanic white	14	63.6
Hispanic	2	9.1
Native American/Hawaiian	2	9.1
Black	2	9.1
Multi-racial	2	9.1
Employment Status		
Full-time (at least 40 h/week)	7	31.8
Part-time	6	27.3
Not working	9	40.9
Disability type <sup>a</sup>		
Chronic illness <sup>b</sup>	10	45.5
Physical <sup>c</sup>	10	45.5
Mental illness <sup>d</sup>	7	31.8
Autism Spectrum Disorder	5	22.7
Traumatic Brain Injury	1	4.5
Blindness	1	4.5
Multiple disability types	15	68.2
Health insurance coverage		
Private, employer-sponsored	6	27.3
Medicare & Medicaid	4	18.2
Uninsured	3	13.6
Medicaid only	3	13.6
Medicare only	2	9.1
Private, Marketplace purchased	2	9.1
Medicare & private employer-sponsored	1	4.5
Medicaid & private employer-sponsored	1	4.5
Population Density		
Urban or metropolitan <sup>e</sup>	18	81.8
Rural <sup>f</sup>	4	18.2
Geographical Region		
West <sup>g</sup>	9	40.9
South <sup>h</sup>	5	22.7
Northeast <sup>i</sup>	4	18.2
Midwest <sup>j</sup>	4	18.2
Gained coverage due to ACA	4	18.2
Medicaid expansion	2	9.1
Marketplace coverage	2	9.1

<sup>a</sup> Total percentage is greater than 100 due to participants reporting more than one disability type.

<sup>b</sup> Includes conditions such as, cancer, hepatitis, heart disease, kidney disease and chronic fatigue syndrome.

<sup>c</sup> Includes conditions such as, paraplegia, quadriplegia, limb loss/difference, and spinal cord injury.

<sup>d</sup> Includes conditions such as, bi-polar disorder, schizophrenia, and depression.

<sup>e</sup> ≥ 150 persons/square mile.

<sup>f</sup> < 40 persons/square mile.

<sup>g</sup> Includes Alaska, California, Colorado, Hawaii, Idaho, Montana, Oregon, Utah and Washington.

<sup>h</sup> Includes Missouri, North Carolina, Tennessee, Texas and Virginia.

<sup>i</sup> Includes Connecticut, Massachusetts, New Jersey, and New York.

<sup>j</sup> Includes Illinois, Indiana, Kansas, and Minnesota.

### Out-of-pocket costs

Out-of-pocket health care costs were problematic for respondents with all types of insurance as well as those who were uninsured. These out-of-pocket costs included the cost of coverage itself (i.e., premiums) as well as deductibles, copayments, or other cost-sharing requirements. One person without insurance reported that, despite having multiple chronic conditions, she had to skip medical care visits due to financial barriers. This uninsured person checks the Marketplace coverage available in her state each year, yet cannot find an affordable plan due to her husband's income.

**Table 3**  
Key themes and representative quotations from study participants.

Themes	Representative quotations	Participant Demographics
Information and Understanding of Coverage <sup>a</sup>	<ul style="list-style-type: none"> <li>“I usually go and speak with whichever service provider that I'm trying to get assistance through and ask them questions ... and, in parallel, I'll go and contact both my insurance providers and on top of that, I'll go speak with the individual who is my health care coordinator, in order to see what dots line up, so to speak, and make sure that I have the most accurate information so I can make the best judgement call for my health. I wish there was one central online database that had all my insurances, with different tabs and what-not, that had [information] for eye, dental—like a one-stop, so to speak—for my service letters, for anything that I might want to do in the future, instead of having to go through three different people in order to get a list and that list [has] a warning saying it's three months out of date. I've actually gotten this list and at least 75% of service providers on the list have canceled and no longer accept the insurance.”</li> <li>“I'm put on hold for a long time. I've spent so many lunch breaks calling about things that I don't understand, and it will use my entire lunch break being on hold and when I finally talk to somebody, it's like they're in a boiler room or something. It's hard to understand them and they're very repetitive. When you ask them a question and you're not understanding, they just say the same thing over and over and it doesn't make it any easier to understand what they're saying.”</li> <li>“I feel like when I ask a healthcare provider they'll say they don't know if something is covered or they think it should be covered. But there's usually not a lot of time, I'm at a doctor appointment [and I need] to consent to something to be like 'Let's hold up and let me look at my insurance and call them and wait and find out answers.' It's more something you have to consent to on the spot as it happens and then [if it's not covered] I'm stuck.”</li> <li>“They do provide you with a book ... but a lot of providers drop out pretty quickly because of the problems they have, but they won't take their names off the list so you're searching the entire book and you might find one. Or you go online, and they have a bunch but, once again, they don't take it [Medicaid] any longer. You can call them [insurance company] and they'll give you a few numbers, but there is no guarantee [doctors] will be accepting patients. So it's a little bit of research you've got to do. It used to be if your doctor gave you a referral, you would go do the thing your doctor wanted you to do. Now they have to approve it and they typically don't approve or you don't know when it's approved. Once [I] didn't get approved, I had to appeal it. Nothing could be done until it was appealed and it's like they made a mistake on it and I can't get another referral until it was straightened out ... I get [a notice] 'Your information has been approved!' but it will be after you did the services and you're 'Whew, I'm glad it was approved!' ... I normally just hold off until I know it's approved for sure.”</li> </ul>	<p>35 year old black male with autism and Medicare &amp; Medicaid coverage</p> <p>26 year old white female with chronic illness and private insurance purchased through the Marketplace</p> <p>32 year old white male with autism and employer-sponsored insurance</p> <p>44 year old Hispanic female with traumatic brain injury and Medicaid coverage</p>
Out-of-Pocket Costs <sup>b</sup>	<ul style="list-style-type: none"> <li>“I'm paying for them [specialist visits] out of pocket. It's \$675 just for the visit. My prescriptions run me about \$1,800 out of my pocket every month, and I'm just burning through my savings. At this rate, I've got seven months before my savings is gone. And that's just medical, that's if nothing goes wrong. That's with my parents paying for my food, that's my parents not charging me rent, that's nothing going wrong with my dog, you know, that's seven months of just paying for medical.”</li> <li>“I'm on Medicare, which I got when I was on disability and, of course, they only pay 80% so when things get any kind of expense, my 20% is difficult to come up with. It's just horrible to be in a situation where I can't afford the surgeries that I need and the fact that I can't get all the prescription medications that I need. These are two things that never crossed my mind that would happen to me and the fact that I can't afford food—those three things are just blowing my mind.”</li> <li>“I still do have unpaid medical bills from before. I have \$18,000 in medical bills from 2009 when I was hit by a car that I'm never going to be able to pay off. I've had some other medical bills that have come up since then from X-rays, MRIs, that kind of thing. There was one that I got in the past year that was for an MRI my doctor ordered and then I got a surprise \$3–4,000 bill that I wasn't expecting. I have not paid that.”</li> <li>“We cannot pay out of pocket for anything. I have basically gone untreated, even though every year we keep checking back to the Marketplace to see if perhaps there is a provider that's offering lower options, something. But out of pocket for visits is just too expensive, and then we look at the insurance, and that's too expensive and so we're just kind of in this hinterland, where no option gives us affordable care.”</li> <li>“The only real health care that I've needed recently was getting a crown and it was considered cosmetic, even if you get a note from a physician, as well as my primary dental provider, even if I had a note from both of them to cover the cost of the crown, in order for my tooth not to split into four in my mouth and cause me to have to go into surgery to have the tooth yanked out completely. The insurance company stated that it's still a cosmetic procedure, even if you have all that information. So, they said 'well you'll just have to go through surgery or have to pay out-of-pocket to get the crown in.' The surgery would have also come out-of-pocket, as well, and that would have been several thousands of dollars and so I decided to spend less than a thousand to get the crown instead of having to spend several thousand to have the tooth completely removed. So that's the barrier and the solution was I have to set up for a medical credit card in order to cover the cost and make payments like a regular credit card, so that way I can keep my tooth safe and not have to have the tooth completely ripped out of my mouth.”</li> </ul>	<p>37 year old white female with chronic illness and no insurance coverage</p> <p>59 year old white female with chronic illness and a psychiatric disability and Medicare coverage</p> <p>32 year old white male with autism and employer-sponsored insurance</p> <p>30 year old white female with chronic illness and physical disabilities with no insurance coverage</p> <p>35 year old black male with autism and Medicare &amp; Medicaid coverage</p>

Table 3 (continued)

Themes	Representative quotations	Participant Demographics
Prescription Medications <sup>c</sup>	<ul style="list-style-type: none"> <li>• “The drug that helps me absorb phosphorus and calcium into my bones is [drug name]. Without that, I would be stuck in my chair for the rest of my life. And insurance has never wanted to pay for that. But, they’ll pay for pain meds. And [drug name] has gotten harder and harder to find, because there’s no money in my disease, because it’s not like a penis or hair loss or whatever.”</li> <li>• “If I don’t take my thyroid medicine, my depression gets worse. Sometimes, I’ve tried asking the pharmacy to see if they could void the copays, because I don’t have the money at the time. And some pharmacists give me a hard time as if I’m paying them the money. So, sometimes since they refuse, I just leave it. I just started a medication for depression that I have been able to get, but the thyroid medication which I have been taking longer, sometimes I don’t have the co-pay to cover it.”</li> <li>• “I do have a couple of other different conditions and also I have to take asthma medication. Because the asthma medicine increases my heart rate and I have arrhythmia problems, there’s only one kind I can take. For some reason, they no longer cover that particular one and I can’t afford it. Some medications aren’t covered that you really need so I have to ignore my asthma, because the only one that’s available to me that I can afford makes me skip my heart beat, so it risks your health.”</li> <li>• “I do have a shot that I’m supposed to have, but I usually have to go without from July through January, because I can’t afford the shot ... There’s quite a few of my meds that I don’t get every month because I can’t afford all of them. July and August are usually my worst because my insurance year starts then, it goes from July 1st to June 30th .... Once, they [insurance company] made me try a different shot which made things even worse. And then it took four months of using the [previous drug that worked] to overcome the three months of the other. And I really need a rheumatologist, because my regular doctor was prescribing [the medication] and now my insurance is saying it has to be [prescribed by] a rheumatologist or a dermatologist .....I work and I get paid. I don’t get paid a lot as I’m in a rural area. If the insurance companies want me to stay healthy and not use their services so much, they’ve got to make it to where I can afford the meds and stay working.”</li> </ul>	<p>37 year old white female with chronic illness and no insurance coverage (speaking about previous coverage)</p> <p>31 year old Hispanic female with mental illness and Medicaid coverage</p> <p>44 year old Hispanic female with traumatic brain injury and Medicaid coverage</p> <p>50 year old white female with chronic illness and psychiatric disability and employer-sponsored insurance</p>
Provider Networks <sup>d</sup>	<ul style="list-style-type: none"> <li>• “If you need to have surgery they only will cover it if you go to their specific doctors and they’re all out of state, they’re not in Alaska. Most all doctors are out of network in Alaska. You can only now see doctors that they’ve been able to negotiate these rates. They now fly, not only me but everyone in this plan, they fly them out of state to go have surgery and it’s actually cheaper for them to have surgery there, put people up for a couple weeks in another state, than it is to pay somebody here. But then the problem is that there isn’t a doctor up here willing to see you because they don’t want to deal with taking on another doctor’s surgery. So now getting care after surgery is becoming an issue for people.”</li> <li>• “With my mental health, I have been going to this one provider for many years now, ever since I got sick, but for my physical health it’s been a problem finding good doctors that take Medicaid and Medicare.”</li> <li>• “I understand providers aren’t being paid for up to a year at a time and they can’t really afford to continue to take Medicaid if they want to pay their staff. So, because of that, anybody in this county (and that includes a lot of very populated areas) goes over 50 miles to specialists. I recently lost function in my left hand and when I went in [to PCP] there wasn’t any ‘Ok, let’s get you to a specialist’ or any physical therapy because providers are far away. It was just ‘Ok, we’ll put it in your chart that you’ve lost function’ because there’s no nearby treatment for that.”</li> <li>• “But in my network, there’s only so many service providers that actually still take my insurance and that number is dwindling due to the number of services that are provided to me that have to be written off, because of the proportion of the amount that the service provider asks from the insurance company that gets denied. And, from what I was told, the insurance company will only reimburse between 15 and 25% of the total cost and so the rest of the cost has to be written off, so the number of providers in my network is very small.”</li> </ul>	<p>49 year old white female with physical disabilities and chronic illness with employer-sponsored insurance</p> <p>49 year old black female with mental illness and Medicare &amp; Medicaid coverage</p> <p>44 year old Hispanic female with traumatic brain injury and Medicaid coverage</p> <p>35 year old black male with autism and Medicare &amp; Medicaid coverage</p>
Transportation <sup>e</sup>	<ul style="list-style-type: none"> <li>• “It’s very difficult to get healthcare and even when you have access it doesn’t mean that you can actually afford them or reach them. I have healthcare [coverage], but if I have to go 2 h away in order to get it, that may not be possible, especially if I am working. So it’s just not very accessible and I don’t think that’s a problem for policymakers, it’s a feature.”</li> <li>• “Gas and the parking, I have to go [to doctors] pretty frequently ... seven times this month and parking is \$4 [each visit], but I’m on disability and that cost actually adds up for me.”</li> <li>• “They assign you to a healthcare provider and my healthcare provider is really far away from my home. And I have transportation issues sometimes, so sometimes I have to cancel that appointment that I waited 6–8 weeks for, at the last minute because of transportation issues. I can’t ride the bus because it’s too far to walk to the bus stop, and I really don’t have a support system here. So, the distance is way across town and hard to get to.”</li> <li>• “There are things I need to have done at a hospital where you’re required to have a driver and I don’t have anybody to drive me to the hospital so I don’t get things done that I need to do. Because of my [disease name] I need to have a colonoscopy more frequently than normal because you’re more prone to cancer, and I haven’t had one. I</li> </ul>	<p>32 year old white male with autism and employer-sponsored insurance</p> <p>44 year old Hispanic female with a traumatic brain injury and Medicaid coverage</p> <p>55 year old white female with a physical disability and Medicaid &amp; Medicare coverage</p> <p>59 year old white female with chronic illness and a psychiatric disability and Medicare coverage</p>

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Table 3 (continued)

Themes	Representative quotations	Participant Demographics
	used to hire a nurse that would drive me there and back and wait in the waiting room with me, but now I can't afford to hire a nurse." <ul style="list-style-type: none"> <li>"They [insurance] don't pay for me to get transportation and they don't pay for me to get para-transit to the hospital. I don't know if that was because I live in the middle of nowhere. I lived with my sister when I first got out of the hospital initially and so I was able to get para-transit through [the city], but they didn't offer or cover any kind of individual driving services or driver rehab, so I could get a chance to get better at driving, or equipment for that."</li> </ul>	25 year old white male with limb loss and Medicare coverage and employer-sponsored insurance
<p><sup>a</sup> Includes any mention of communication between consumer and payer (private or public/state) and communication between consumers and their health care providers.</p> <p><sup>b</sup> Includes any mention of costs paid by the consumer, including but not limited to co-pays, deductibles, cost-sharing, premiums, etc.</p> <p><sup>c</sup> Includes any mention of supply-side restrictions on prescription medications such as generic substitutions, dosage issues, formularies, uncovered medications, etc.</p> <p><sup>d</sup> Includes any mention of barriers or facilitators to care specifically in relation to provider network.</p> <p><sup>e</sup> Includes any mention of public or private transportation.</p>		

Another person without insurance reported having to spend \$1,800 out of pocket every month just for prescription medications and \$675 per visit with her medical providers. She anticipated that all of her savings would be exhausted within a few months, despite receiving some financial assistance from her parents to help pay for housing and food expenses.

Even among respondents with health insurance, cost-sharing requirements were often a major financial burden. One respondent with Medicare coverage noted that the 20% coinsurance associated with that program was beyond her means and resulted in skipped medications and surgeries because of the limited budget she had to purchase food. In several cases, the inability to pay for cost-sharing requirements (e.g., deductibles, copayments) occurred due to the accumulation of medical debt that some respondents felt they would never be able to pay off.

### Prescription medications

Interview participants reported multiple barriers to accessing prescription medications, including out-of-pocket costs as well as insurance exclusions or formulary restrictions. In some cases, participants reported that insurance companies did not seem to understand or take into consideration the complexities of an individual's health conditions and medication needs. For example, one individual reported having heart arrhythmias as well as asthma. Only one asthma medication did not exacerbate the arrhythmia, but the insurance company refused to cover it because it was not on the formulary list of approved medications. Other participants reported that insurance exclusions seemed short-sighted, such as not covering antibiotics for an infection or thyroid medications that could prevent depression. Some individuals were able to go through an appeals process to obtain access to a needed medication, but such actions required a great deal of time, hassle, and resources that imposed insurmountable barriers for many.

Other issues that participants mentioned included the difficulty of getting their prescription medications covered when they were out of state for specialty care, unexpected changes by insurance companies in which previously covered medications were later determined to be experimental and therefore no longer covered, and the difficulty of accessing medications for relatively rare conditions due to limited choice and affordability. Some participants emphasized that delayed access to prescription medications would result in the worsening of their health conditions and the need for additional medical appointments, which would take more time away from work.

### Provider networks

As with out-of-pocket costs, limited provider networks also interfered with timely access to care for interview participants with all types of conditions and insurance sources. For some respondents, limited provider networks necessitated long travel times to in-network providers, which contributed to transportation-related barriers and problems with missing work. One person living in a populous area reported that he had to travel more than 50 miles for medical visits because none of the local physicians in his county were on the list of in-network providers. Another person living in Alaska had to travel out of state to access some health care services, including surgeries.

Other respondents described challenges in finding local providers who would accept Medicaid, or both Medicare and Medicaid. In some instances, this inability to find any local providers accepting one's insurance plan led to individuals forgoing care completely. A few respondents also talked about the difficulty of switching from one insurance plan to another. One individual noted that he could no longer see the doctors who knew his personal history and understood his health condition as a result of obtaining new health insurance, even though he was living in the same place. Several respondents talked about the difficulty of transitioning from children's health insurance programs to adult coverage and losing access to the comprehensive benefits they had used and providers they previously visited.

### Transportation

Although the interview questionnaire did not focus on transportation, the vast majority of participants (17 of the 22 respondents) mentioned transportation-related issues during the interviews. Distance to in-network providers was a widespread concern even though 81.8% of the sample lived in urban or metropolitan areas. In some instances, limited provider networks resulted in increased distances to the nearest available provider, creating substantial difficulties for many respondents who could not drive or relied on others for a ride. Longer travel times and distances to an in-network provider also interfered with respondents' ability to work. In other instances, respondents' multiple health conditions required frequent medical appointments. One individual reported having to drive 50 miles one-way for appointments with a specialist whom she needed to see up to seven times per month. In addition to the cost of gas, the \$4 charge for parking at each visit also created a financial hardship and barrier to accessing needed care. Another participant reported needing frequent colonoscopies to monitor for colon cancer, which required having another person drive her to and from the appointment and wait during the procedure. She did not have family members

nearby and could not afford to pay someone to assist her, meaning that she often did not meet the screening schedule that her doctors recommended.

Several participants who lived in areas where public transportation was available reported that the nearest bus stop was too far away to walk or that getting to the bus stop was not safe or accessible for wheelchair users. One respondent with multiple amputations reported that his insurance company would not pay for any driver's rehabilitation program services, which would have helped him learn how to drive independently with his prostheses and empower him to drive by himself to needed medical appointments.

## Discussion

This study sought to understand the personal experiences and perspectives on health care access of American adults with disabilities and the barriers that continue even with increased access and coverage afforded by the ACA. Analysis revealed several major themes on barriers to care. Specifically, we found that a lack of timely and accurate information about insurance plan coverage, out-of-pocket costs, limits on prescription drug coverage, limited provider networks, and transportation issues all created barriers to accessing health care for this population. Although these barriers are not entirely unique to people with disabilities, people in this population often experience a smaller margin of health,<sup>23,24</sup> meaning that even small gaps in accessing care can result in adverse outcomes. Moreover, social determinants of health, such as lower income and educational levels, less access to technology, and inadequate transportation in addition to higher rates of co-morbid health conditions, may exacerbate the effects of these barriers for people with disabilities.<sup>8,10</sup> For example, lack of internet access can severely limit access to information, and co-morbid health conditions can limit stamina and make lengthy appeals processes or long-distance travel to appointments especially challenging. Thus, these findings are especially important to policy makers, insurers and other stakeholders who continue to refine and improve ACA and other social support systems for people with disabilities.

The interviews for this study were conducted during the summer of 2017, more than three years after implementation of most parts of the ACA. While many of the ACA's provisions have the potential to improve access to coverage and care for people with disabilities, numerous barriers to timely access remain. In fact, many concerns that were voiced by participants in this study were similar to concerns raised before passage of the ACA. For example, a 2003 survey of Americans with disabilities conducted by the Kaiser Family Foundation found that out-of-pocket costs and limited provider networks created substantial barriers to accessing care and that improving prescription drug coverage and transportation services were among the top issues respondents felt that government needed to address.<sup>25</sup> More recent research shows that, while people with disabilities continue to experience substantially higher out-of-pocket medical costs than their non-disabled peers, these costs have decreased after implementation of the ACA.<sup>3</sup> Similarly, the percentage of adults with disabilities who reported delaying or forgoing care due to costs decreased post-ACA. The same study found that prescription drug costs for people with disabilities average almost seven times those of people without disabilities. It is not surprising, then, that prescription drug coverage was cited as a major concern in surveys from both 2003<sup>25</sup> and 2017.<sup>3</sup> Structural issues with insurance coverage, including out-of-pocket costs, limited provider networks, and prescription drug coverage are all policy issues that can be addressed via federal- or state-level insurance regulations. Examples include lower deductibles and co-pays for prescriptions and stronger requirements for provider

network adequacy.

Two other problems identified in this study were lack of timely access to accurate plan information and issues with transportation. As participants noted, a lack of accurate information about health plan coverage and network providers can result in unanticipated costs that lead to foregone care and substantial delays in following up on provider referrals. A recent report from the Centers for Medicare and Medicaid Services (CMS) finding deficiencies in more than half of online provider listings from Medicare Advantage organizations affirms the informational problems identified by participants.<sup>26</sup> CMS notes that "inaccuracies can create barriers for members to receive services critical for their health and well-being" and, in addition to warnings and fines of insurers, is considering ways that CMS may be able to assist insurers in keeping their directories more current. Public and private insurers must both make stronger efforts to ensure that beneficiaries have timely access to coverage information; such efforts can result in lower costs to insurers, better access to care for consumers, and, over time, better outcomes.

While the ACA was not specifically designed to improve transportation access (except perhaps through state Medicaid expansions in which non-emergency medical transportation is a mandatory benefit) and most private insurers do not cover routine medical transportation services, many respondents noted that a major barrier to accessing care was a lack of local in-network providers, which necessitated long-distance trips to covered providers. Some participants reported that the time required for these long-distance trips interfered with their ability to work, which potentially threatened their access to private health insurance. Therefore, broadening provider networks would be an important step in addressing transportation issues. In addition, people with disabilities may need personal care attendants and other individuals to assist them in driving or accompanying them at medical appointments, resulting in an extra cost that can disproportionately affect this population and its access to care. Insurers should consider allowances for drivers or vouchers for transportation services to address this issue for people with documented transportation barriers or for those undergoing procedures that require a driver to be present during and after the appointment.

Several limitations of this study should be noted. First, the sample was recruited from individuals engaged with various disability or disease-specific organizations and therefore may over-represent the experiences of people who are more active in disability- and health-related issues and exclude those who are less engaged in such activities. The sample also did not include people living in institutional settings. Second, the study design allowed for the identification of a range of issues experienced by responding participants, but these findings cannot be generalized to the experiences of all Americans with disabilities. Third, while the diversity in our sample allowed for a broad range of experiences to be reported, the limited sample did not allow us to gauge the relative impact of these issues for sub-groups such as those with a specific type of disability. Finally, respondents varied in the volume and range of information they shared about their experiences, despite receiving similar interview prompts. Moreover, those who shared more information tended to have had more extreme positive or negative experiences, perhaps skewing the results.

Further research is needed to explore and quantify these findings and themes. Building upon what was learned from these interviews, the research team conducted a national survey of more than 1,200 individuals in 2018. Survey findings will allow for a more detailed understanding of the relative prevalence of the barriers identified here and how different groups are affected by each. Such work will lay the foundation for developing specific policy recommendations to meaningfully address identified issues.

## Conclusion

Implementation of the ACA, including the establishment of health insurance marketplaces and, in some states, expansion of Medicaid, has resulted in increased access to coverage and care for Americans with disabilities.<sup>1,3,10</sup> The importance of these ACA-related increases in coverage cannot be overstated and, over time, may result in reduction of long-standing health disparities for this population. Moreover, in states expanding Medicaid eligibility, employment rates for people with disabilities have shown steady gains.<sup>4</sup> Indeed, as one participant noted, “People with disabilities are in desperate need for the subsidized health care from the Affordable Care Act....Preserving many of the important aspects of the Affordable Care Act will save millions of lives.”

Nevertheless, people with disabilities continue to report numerous barriers to care, regardless of insurance status. Many of the issues reported in this study, such as limited prescription drug coverage, limited provider networks, and steep out-of-pocket costs are also problematic for Americans without disabilities.<sup>27</sup> However, because people with disabilities often have a smaller margin of health, and because their health care costs are 3 to 7 times those of people without disabilities,<sup>3</sup> limited coverage, limited networks, and steep out-of-pocket costs can have disproportionately large impacts on their access to care, health outcomes, and ability to work. As one participant noted, “If the insurance companies want me to stay healthy and not use their services so much, they have to make it so I can afford the meds, and stay working ... If I don't get the medication, I can't work, then I'm back on the state paying for everything.”

As efforts to improve the American health care system continue, and the great majority of Americans now believe that people with pre-existing conditions should have access to affordable and adequate health insurance,<sup>28</sup> these issues can and should be addressed by policy makers at the state and national level. In addition to increasing access to local providers, ensuring broader provider networks could also decrease transportation barriers for many people with disabilities and, at the same time, support or increase their ability to work. Finally, by facilitating access to physician-referred services and decreasing uncertainty about coverage, timely and accurate plan information could improve access to care and outcomes for people with disabilities. This study suggests that, in many ways, people with disabilities continue to act as “canaries in the coal mine.”<sup>29,30</sup> The problems they identified with accessing the health care system affect many Americans but are more likely to have immediate adverse effects on their own health and quality of life. As with the coal mine analogy, however, correcting these issues to improve health care access would be beneficial for all in the long run.

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