Barriers and experiences of people with disabilities engaging with health services: An analysis of focus group findings

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Executive summary

This report provides a summary of focus groups conducted with people with disabilities and caregivers throughout Utah. The Disability and Health team at the Utah Department of Health and Human Services (DHHS) worked with the Utah Developmental Disabilities Council (UDDC) and local health departments to learn about experiences participating in health promotion programs, barriers to participation, experiences accessing and receiving preventive healthcare, and barriers to receiving preventive healthcare.

These focus groups provided people the opportunity to share their frustrations and recommendations for improvements to create more inclusive spaces that meet the needs of people with disabilities. Five themes were also identified from the experiences shared, highlighting specific barriers to participating in health promotion programs and to receiving needed healthcare. Overall, the most common barriers shared included:

- **Awareness**: Participants were generally unaware of available health promotion programs in their communities as well as the recommended preventive screenings and services they should be receiving.
- **Programming**: Participants felt excluded from programs because recruitment and program materials were not accessible, lacked information about available accommodations to participate, or were not tailored to include people with disabilities.
- **Transportation**: Many participants did not have a form of personal transportation to attend programs or receive care and public transportation options within the communities was often insufficient or inconvenient.
- **Healthcare provider interactions**: Providers are not commonly trained to communicate with and treat people with disabilities, which caused participants to have poor experiences with providers and unmet healthcare needs.

- **Systems**: Participants noted gaps in available programs and the need to leave their communities to receive needed care and services. Additionally, participants shared frustrations working with insurance providers and a priority to first meet other needs before considering participating in health programs or seeking preventive care.

Recommendations

Public health professionals, healthcare providers, and these systems should work to repair and build trust with the disability community from years of poor treatment and past experiences. A focus should be given to improving standard practices by incorporating trauma-informed approaches, increasing competence through appropriate trainings, and revising or creating policies to better support people with disabilities in our work. The focus group findings specifically identified the following recommendations:

Increase the accessibility of information and program materials in both print and digital formats. Additionally, promote inclusion through advertising and registration procedures.

Train staff on topics such as disability awareness, disability-competent care, and communication best practices.

Work with insurance providers to standardize communication practices to make sure accurate information is given to clients. Provide resources about covered preventive care and proactively provide to clients.

Improve healthcare records data through collecting demographic disability data and documenting needed accommodations in the health records.

Background

The Disability and Health grant is funded to improve the health and well-being of adults with disabilities throughout the state. A needs assessment was first conducted to identify the health differences experienced by Utah adults with disabilities.[1] This needs assessment identified a gap in available data documenting barriers experienced while engaging health promotion programs and preventive healthcare services by people with disabilities.

To address this gap in information and better understand these experiences, focus groups were designed and conducted. This report summarizes the focus group findings conducted as part of this larger statewide needs assessment. Findings are based on focus groups that were conducted around the state of Utah during an 8-month period in 2024. Focus groups were conducted with people with disabilities and caregivers of people with disabilities and explored:

- Awareness of health promotion programs and preventive care
- Experiences and barriers enrolling and participating in health promotion programs
- Experiences and barriers receiving preventive care, and
- Needed support to more fully participate.

Findings from this report will be used to create resources that support accessible, inclusive programs and services.

Methods

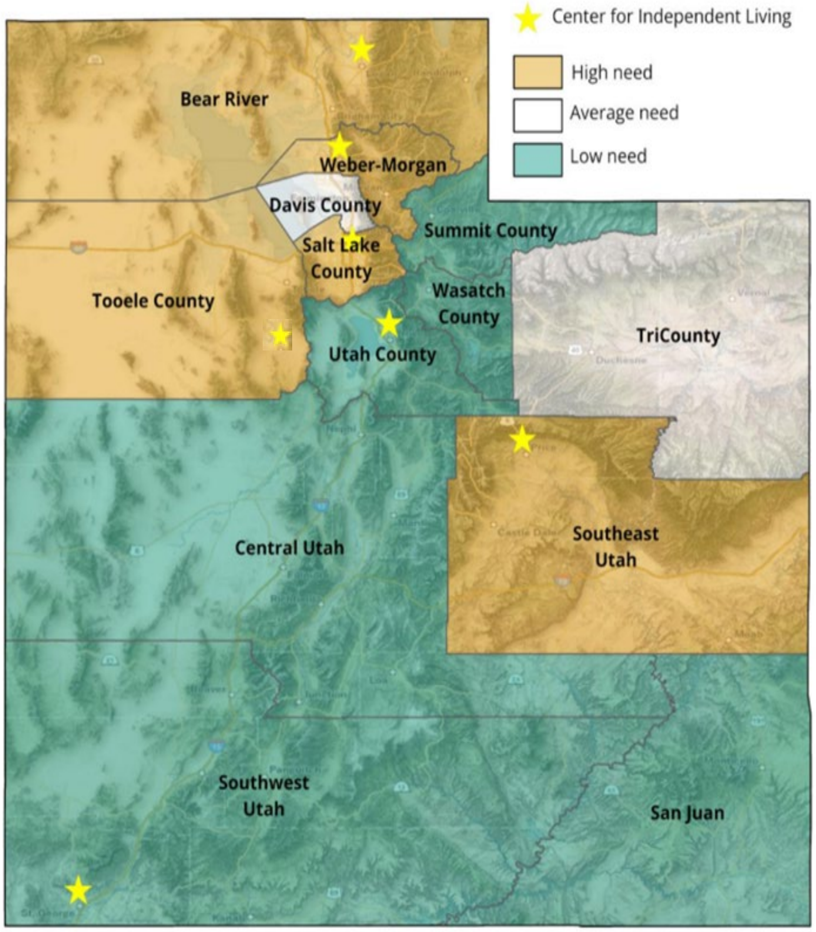
Selecting focus group areas

To get perspectives from across the state, data was used to select specific communities. Three factors were used to select these areas.

1. Index score based on need: Data from the Behavioral Risk Factor Surveillance System (BRFSS) was used to assess overall disability prevalence, healthcare access, and health status measures for each of the 13 local health districts. An overall score was then produced where higher scores indicated greater need.
2. Locations of Centers for Independent Living (CIL): Centers for Independent Living were used to recruit participants. Buildings were also used to hold the focus groups as they are well known throughout the disability community and typically have accessible facilities. Local health districts that had a Center for Independent Living in the area were prioritized.
3. Local health district interest: The Disability and Health grant contracts with certain local health departments on other grant strategies to create policy, systems, and environmental changes. These local health departments were considered primed to collaborate with on the focus groups and to use the results. The local health districts identified using criteria 1 and 2 above, were contacted to determine interest in and capacity for this project. Local health department involvement was flexible and included support with logistics, material development, and analysis.

The index score and CIL location are mapped in Figure 1. Ultimately, 5 local health districts were identified and selected to hold focus groups. These areas included Bear River, Weber-Morgan, Davis County, Southeast Utah, and Tooele County.

Figure 1. Local health districts and disability needs



Conducting the focus groups

The Disability and Health team partnered with the Utah Development Disabilities Council (UDDC) to conduct the focus groups. The UDDC took lead with the logistics, organizing and coordinating the focus group schedules and facilitating the focus groups. The Centers for Independent Living and local health departments supported recruitment. The Disability and Health team transcribed focus group recordings and analyzed the data.

A total of 4 focus groups were held. Due to scheduling conflicts, the focus group in Davis County was not held. Focus groups were 1-2 hours in length and were recorded then transcribed verbatim. Each focus group participant was invited to complete a questionnaire. The questionnaire asked about demographics, healthcare status, tobacco us, and cancer screening. See Appendix B for the full focus group discussion guide.

Results

Qualitative data analysis revealed 5 overarching themes (Table 1). These themes represent the common barriers described that prevent people with disabilities from seeking out or engaging with health programs and services. Within each of the major themes, a number of sub-themes were identified. Sub-themes will be discussed within the presentation of each theme.

Table 1. Overarching focus group themes
1. Lack of awareness
2. Programming barriers
3. Transportation
4. Interactions with and competence of healthcare providers
5. System barriers

Theme 1: Lack of awareness

Across all focus groups, participants shared being unaware in general about both health promotion programs available in their communities as well as recommended preventive care screenings. Additionally, participants expressed being unaware or unsure of covered care and screenings by their insurance.

Unaware of available health programs or recommended preventive care

Across all focus groups, participants were generally unaware or didn't know about available health promotion programs available in their communities. When asked about health programs available in their communities, common responses included, "*No, I don't know what you offer here*." and *"Yeah, same. I don't know what programs are available."* The lack of awareness was not a result of a lack of effort by participants. For example, one respondent reported finding available programs by luck or accident:

> *"I feel like sometimes the programs aren't readily, like they're not announced … some of the programs that we've participated in we've discovered clearly by accident."*

This lack of awareness also extended to preventive care. Participants shared not engaging with or receiving recommended preventive screenings because they simply weren't aware of them. Similarly, participants expressed trying to learn this information but wasn't able, as expressed by one participant:

> *"I didn't know that. I've been involved in a lot of different things trying to educate myself, but I didn't know."*

Some participants shared learning about recommended preventive care screenings by filling out the "participant information sheet" before starting the focus group. One participant noted:

> *"I just found out from that questionnaire that my daughter needs a pap smear from the paper today."*

Unsure of covered care and screenings by insurance

Many respondents talked about wanting to receive preventive care and screenings, but not doing so because they didn't know if they were covered through their insurance. In response to questions about preventive care received, feedback such as *"I don't know if Medicaid covers it."* was common. Participants expressed frustrations with insurance providers and preventive care, as shared by one participant:

> *"I wish Medicaid would let you know what they cover and how. That's always been a pain in the butt to know what they cover and not cover."*

Theme 2: Programming barriers

Many barriers to participating specifically in health promotion programs were identified through the shared experiences. These were identified as programming barriers as they relate to public health and community health professionals and how they develop and implement programs, and in turn how they may prevent people with disabilities from participating.

Lack of inclusive advertising

Many respondents shared experiences of seeing advertisements for health promotion programs but choosing not to enroll or participate because they didn't see themselves represented on the promotional materials which led to feelings of not being welcomed. As noted by one respondent:

> *"I've lived here for 8 years, and I've never once seen anything advertised for inclusivity."*

Similarly, another respondent shared:

> *"The problem that I find when I see things advertised is that I'm not sure of the inclusivity. I open the headings and look for disabilities."*

Accessibility of information or program

In addition to not being aware of available health promotion programs, participants described not being able to access program information when looking for it, saying *"finding out about these things is sometimes the stumbling block"*. This included not being able to find program information in general as well as issues with the accessibility of available program information. This was expressed by one participant:

> *"it seems like I've heard about programs offered by [LHD], but they're not right there. I have to search and search to find it ... navigation is not the best, of the website ... you have to know what you're looking for and hunt for it."*

Similarly, another participant noted:

> *"[We] don't know about these programs because it is not accessible in any shape or form. You have to search for it, and deeply search for it in, in order to find what you're looking for. And half the time, it's not accessible to our disabilities."*

Program participation

Participants described various barriers to participate in offered programs. These barriers ranged from lacking accessible equipment to program instruction. For participants who use a wheelchair, wheelchair-accessible equipment such as pool and gym equipment was noted. For example,

> *"They don't even have a proper Hoyer lift at our swimming pool. You can't even get into the pool safely if you're in a wheelchair."*

In regard to receiving and understanding program information, people with disabilities have various communication needs. Program instruction may prevent people with disabilities from participating and understanding program materials. Comprehension needs were shared by participants:

> *"For me, I would recommend doing a recorded video feed and then post it somewhere where the people that are taking the class can access it. That way, those that have comprehension issues, or those that feel overwhelmed can come back and say oh what was that I missed. And they can watch it three more times and get the information that they need to get out of it. Rather than, oh here's the one class and they think, 'what the heck did I miss'."*

These needs were further highlighted:

> *"For me, if you just hand me a packet of paper, that you know, in and out. It's gone. Even if I can read it 100 times later, it's just gone. If you're making me write down the recipe or you know, write things down, it's going to help me remember or be part of it. Instead of just, here, you know. I would want to participate more."*

Perceptions about program cost and eligibility

When asked about participating in health programs, some participants expressed concerns about the cost and whether they would be eligible to participate. Participants' concerns for eligibility were primarily focused on health insurance coverage:

> *"If there's a cost, I probably can't afford it."*
>
> *"More low-budget options would be great too."*
>
> *"Wouldn't that be great? But they cost money, right? And you probably have to have health insurance."*

Lack of understanding about the lives of people with disabilities

Some respondents shared experiences participating or wanting to participate in health promotion programs but were prevented because of daily living limitations. In response to a shared experience about participating in a nutrition class, one participant noted:

> *“More discussion [to] see what disability people could get involved with, and disability people would like to have a taste of food. A lot of disability people here have dietary problems and some food they can’t eat.”*

Additionally, a few participants shared about barriers to attending programs due to schedules. Some program schedules were felt to be a burden due to the time commitment required to participate. Others shared how they couldn’t attend the program because they use public transportation and services would end before the program ended, leaving the person unable to get home:

> *“Depends on where the actual class is. Because some, let’s say that you don’t have a license, and you would need – the class would have to be over by 6 o’clock because that’s the time the last bus heads out on the extended route … because they shut down the bus … at 6.”*

Theme 3: Transportation barriers

Participants frequently shared about numerous transportation-related barriers that prevented them from attending health programs and receiving healthcare. These barriers ranged from personal barriers such as not having a form of transportation or not being able to drive to barriers introduced from public transportation and paratransit services.

Lack of personal transportation

Many participants shared how they were limited in where they were able to go and when because they relied on others to drive them. This required coordinating multiple schedules and limited when programs could be attended or appointments scheduled, as shared by participants:

> *"But its sometimes hard for me cause ... I have to ask people to take me to get my appointment."*
>
> *"Sometimes I ask somebody if they have days off if they can get me. To take me to my doctor's appointment."*

Insufficient or inconvenient public transportation

Public transportation options were also listed as a barrier. Certain areas lacked public transportation altogether, where other areas had extremely limited routes and options. For example:

> *"Well and things like public transportation, it's, it doesn't exist [in place]."*

"They do have a bus that goes in a circle, and if you're lucky enough to have your stop where you need to go in that circle."

These frustrations with limited transportation options were shared by many participants and summed up as:

"I wish there was more transportation here so we can get places and go where we need."

Participants also shared other inconveniences of using public transportation in their communities. Public transportation services often end before an appointment, potentially leaving people stranded or unable to attend in the first place. As reported by one participant:

"UTA on demand, only services [place]. So, if you need to go to Salt Lake, they'll take you where the bus will pick you up. But there again, even if you used UTA On Demand, they start at 8, they end at 7. What happens if you gotta be somewhere and you can't get out until 6 or 7. You're stuck. You don't have a place to go. And it is frustrating to me to see that happen to a lot of people who, you know, if you want to go somewhere, you can't get back home."

For some participants who experienced being stranded because of public transportation or were not able to coordinate a ride with paratransit services, this meant they needed someone to come and pick them up.

Discussing this, one participant said:

> *"Last week I was at the grocery store … and the guy on the phone told me he couldn't get me a ride. So, my mom had to use her gas to come all the way to [place] to come pick me up cause they couldn't get me a ride."*

Additionally, using public transportation and paratransit services often require taking multiple rides and coordinating routes and schedules to get to the intended destination. This can be inconvenient and time-consuming, as shared by the following experience:

> *"I finally got on the bus to go down to the hospital in Salt Lake. You have to sit in a parking lot in Bountiful for a good half hour at least while you're waiting for the next paratransit bus to meet up. And you get off that bus, and you get on the next bus so that you can go the rest of the way. And then they don't even drop you off at the front of the hospital, they drop you off at the parking garage. [and then getting back] And if you're not right out there, because your appointment ran long and you can't get out there on time, they'll leave you."*

The time-consuming frustrations of using public transportation and paratransit services was repeated. One participant shared:

> *"I used to go to a place in here, and it gets out at about 2:30 and I don't get home until about 8 or something."*

Similarly, another participant noted:

> *"You're there almost all day, just for an hour appointment. Because it takes time for them to reach you, it takes time to get over there, and there's so many steps you have to do."*

A less commonly shared barrier included learning how to navigate and use public transportation. Although resources are available to help people learn and use routes, people may be uncomfortable taking public transportation on their own. Discussing these issues, one participant said:

> *"The route to me is so confusing, like how you get somewhere." I've always struggled with the bus ... for me it's terrifying."*

Poor past experiences with public transportation

Some participants shared past experiences with using public transportation that made them hesitant to use it again. These experiences included interactions with operators and lead to feelings such as embarrassment and potentially harmful situations. The following is an example of one of these experiences:

> *"I've been left on the platform in Farmington because I wasn't right inside the little blue box on the concrete and the Frontrunner just blew past. And it was another hour and a half before the next one would come. It took me a while to want to get back on the Frontrunner, let alone UTA. I was down in Salt Lake going up to the hospital and the Trax train driver just suddenly decided to put on the breaks and flip my wheelchair backwards. And it was just kind of you know just scrape yourself back up and head out cause there wasn't anyone that was going to say or do anything to help."*

The interactions between people with disabilities and operators was also witnessed and impacted the opinions of using public transportation. One such interaction was shared:

> *"I saw a guy on the bus, and the driver got mad at the person in the wheelchair. He couldn't move and the driver had to attach him, his wheelchair, to the bus. Didn't get it done correctly. This poor guy was trying to keep himself from going all over. And it was just frustrating."*

Theme 4: Interactions with and competence of healthcare providers

Participants shared many experiences interacting with healthcare providers while receiving or trying to receive care. These experiences illustrated provider skills and competence that affected how people with disabilities were treated. These experiences often acted as barriers to receiving care.

Lack of disability competent care

Many participants shared how providers in their areas lacked the knowledge about disabilities and how to appropriately assess and provide needed care. This applied to people seeking a provider and receiving care. Some of these experiences included:

> *"It's hard to find somebody [a healthcare provider] that even knows about disability."*
>
> *"Even finding a doctor here in [place] that understands and knows about spina bifida. That's rare."*

The lack of trained providers in disability care impacted the quality of care received. Some participants felt providers focused on the disability itself while other symptoms were overlooked. One participant shared:

> *"I went 8 years [without seeing a doctor]. Because I needed to find someone who knew CP [cerebral palsy]. Because they don't know CP, and they don't know how extensive it is. [After the 8 years and finding a new provider] She actually diagnosed me [with asthma], which is something that none of the other doctors ever caught. I'd get sick and no one ever knew why. So, there's some stuff that falls through the gaps.*

Some participants felt their symptoms were also overlooked because their disability was not visible, as shared by one participant:

> *"I had 5 doctors refer me to rheumatology before they accepted me. And that's over 10 years. Because I had hidden disabilities, and not outright in your face disabilities."*

Provider attitudes and perceptions

The attitudes and assumptions providers bring to their interactions with people with disabilities also affected how and if needed care was received. For example, some participants felt their providers didn't want to treat them because of their disabilities. One participant shared their experience with trying to find a provider for their child with a disability:

> *(Respondent 1) "It was like oh, she has a disability, therefore I'm going to …"*
>
> *(Respondent 2) "Freak out?"*
>
> *(Respondent 1) "Yeah, freak out. And they don't want to deal with it, so send her to someone else was the kind of attitude."*

Similarly, other caregivers shared how providers appear to treat people with disabilities differently or appear uncomfortable to treat them:

> *"The doctors are afraid of them ... I've taken people to the doctor, and they don't even look at them or talk to them."*

The assumptions of providers about the lives of people with disabilities also affected receiving care. Some caregivers described the struggle to get providers to treat the needs of their children related to sexual health. When caregivers requested a pap smear for their children, providers said it was not needed because they assumed they were not sexually active. These interactions were noted by one participant:

> *"I've been told several times that people without a sex life don't need to get one [a pap smear]. And my question is, how do you know they don't need to get a pap smear? I've never had a physician agree to pap smear anyone that I've taken."*

Communication

The communication skills of a provider also impacted the quality of care received. Participants shared examples of how providers usually communicate with them compared to how they best communicate and comprehend. Frustrations were shared about providers lacking the time needed to effectively communicate and the lack of skills needed to communicate with people with disabilities. Participants shared these communication experiences and needs noting:

> *"I do notice that doctors and ERs and such have comprehension issues. I have anxiety. I just need you to slow down and let me reiterate what you said so I can understand it and they get so impatient with me. And then I have people saying, oh you possibly advocate for your own health. And I'm like how do I do that without them getting impatient with me? When I tell them hey, I need to understand this. And what you said, it might take me a minute to repeat it. They're upset with me. Well, how do I advocate then if I'm telling you what I need and you're still pushing me out the door?"*

Similarly, another respondent said:

> *"For me, it's being able to repeat it back. They don't want to take the time to hear me figure out my way of saying it so I understand it. And then by then, I forget my other questions. And the doctor is like ok you're done, goodbye. Get out of here. Don't ask anything else, you need to go. And then I get home and remember half the things and am like, you know I really needed to know that information."*

Communication skills among providers are also needed for nonverbal people. One participant shared the perceived assumptions of providers about people who are nonverbal:

> *"[Providers] don't talk to them. And you know if you're nonverbal, you can't possibly have important things to say. Just because you're not verbal doesn't mean you're not able to understand."*

Poor past experiences with healthcare providers

Some participants also shared about previous experiences receiving healthcare or communicating with providers that negatively impacted them and made them not seek out care after. Because of these experiences. Some participants noted going years without receiving healthcare services because of these experiences. One participant shared:

> *"Some GPs [general practitioners] make fun of their patients. Some of them to their face. Which is why I didn't have a GP for 7, 8 years. I mean I just barely got a new one."*

Another participant said:

> *"I had one of my doctors on my team actually yell at me cause I thought I'd be funny ... I was trying to make it funny, but he took it the wrong way. And he yelled at me ... so, I haven't gone back to him since then."*

Theme 5: System barriers

System challenges and barriers were brought up in all focus groups. Participants discussed a range of experiences that they felt prevented them from being able to participate in health promotion programs and receive healthcare services. These included gaps in programs available, issues with insurance, and healthcare system barriers such as wait times and services available within communities.

Gap in needed care or available programs

Many participants observed a gap in both health promotion programs and healthcare services available for certain age groups in their communities. Participants felt programs were available and directed to youth and senior groups, but adults were not eligible to participate. One participant said:

> *"It was like I didn't fit. It's like if I needed the class on balancing, it was for seniors. And I'm not a senior. Or you know, it's just I wasn't going to fit into the category that the class was for."*

Similarly, another participant noted:

> *"There are a lot of youth classes that I would be interested in as an adult. Not to be hanging out with the youth, that's too much for me … cause we're not seniors yet. So yeah, just that gap. You hit that adult age and you're just out of luck."*

The gap was also discussed in terms of healthcare, moving from pediatric care but before someone qualified for Medicare. Participants noted less care coordination and support available to navigate and receive healthcare. This shift was described by one participant:

> *"Being born with a birth defect, like growing up I had no problem [receiving care]. My parents took me to Primary Children's twice a year for checkups and for anything that I needed done. And they had a clinic that I went to, so I saw all the doctors I needed at one time. And then you get older and it's like the door closes. It's like there's no adult support."*

Need care not available in the community

Many participants shared the need to travel long distances because the needed care wasn't available within their communities. Some participants felt there was an overall shortage of healthcare providers in their area:

> *"I don't think there's enough doctors in [place] that take Medicare. You have to go clear to [place] to get an appointment."*

This perception was also shared by others:

> *"I usually have to go outside of [place] to find those services I need."*

Additionally, many participants had to leave their community to find a provider who is knowledgeable about and welcome to treating people with disabilities. This was noted by one participant:

> *"[Place] is not accessible for many people with disabilities. To the point where a lot of us have to go to Salt Lake just to cater to our disabilities. And have accessible access to things."*

Participants also shared the need to leave the community for specialized care. While some participants were able to find a general practitioner in their community, many shared the need to travel for services such as cancer screenings, imaging, mental health services, and more. One participant shared their experience as:

> *"Discovering I had breast cancer; they didn't have the right technology in the hospital here because it was outdated. So, I had to go into Salt Lake. When I had to get my biopsy, the didn't have the right technology, so I had to go into Salt Lake. And with my arthritis stuff that has been coming up and my herniated disk, they don't have the right technology."*

Some participants shared the time burden experienced from continually traveling for various healthcare appointments. Especially in families with multiple people with special healthcare needs. This was described by one participant:

> *"It's like we're going into Sale Lake four days a week for different appointment between the four of us."*

Wait times to receive care

Another barrier to receiving care participants discussed was the long wait times to get appointments for various services. These barriers included waiting months to years to get an appointment and getting turned away because providers were not accepting new patients. These barriers were encountered while trying to receive a range of care such as mental health services, cancer screenings, and other specialty care. Discussing this, one respondent shared:

> *"I had to wait 6 weeks for the ultrasound and the biopsy. Six weeks later I had the mastectomy."*

Similarly, another said:

> *"It is a two, three-month wait for mammograms."*

Finally, one participant stated:

> *"I'm finally getting into the specialist I need after 10 years."*

Insurance barriers

Participants detailed many barriers experienced because of insurance coverage and benefits. Specifically, participants shared many experiences navigating public insurance programs such as Medicare and Medicaid, jumping through hoops to get and maintain coverage. These obstacles included spending a lot of time on the phone speaking to representatives to try and understand the process and qualifications. For example:

> *"[It's] very frustrating. It's very confusing ... being on the phone for six hours and being completely confused. I wasn't able to get a medication for about a week and a half. And I had to sit on the phone with them [Medicare] for six hours."*

One source of confusion from calling the insurance provider help lines that participants commonly stated was talking to a different representative each time. And often, the representative would relay different and often opposite information than a previous representative. An example of this experience was shared by one participation:

> *"I feel like every time I call, I get a different representative and it's some new piece of information ... It would be helpful if I know that when I call, I'm going to get the same information. I can go to McDonald's and know that the hamburger is being made the same every time. But with Medicaid, there's a good chance you might get someone that doesn't know as much or tells you one thing and another one's saying oh no, that's not correct. But oh yeah, you almost lost this [coverage]."*

Another insurance barrier participants shared that limited their ability to receive care was insurance providers removing transportation benefits from policies. This was highlighted by a participant:

> *"Transportation [is] the only thing I have problems with. Cause we used to have transportation people, but my insurance didn't want to pay for it no more."*

For those who still had transportation benefits, participants shared it took a lot of time and effort to learn about these resources and to actually use them. This was described by one participant:

> *"They charge you [for paratransit services]. And there are resources and help for that through Medicaid. But you have to kind of navigate getting to those resources. Which is kind of, it's difficult."*

Participants also shared that some providers in their communities did not take their insurance. This included for services outside of general care such as for hearing aid repairs. This was highlighted by a participant:

> *"I have hearing problems, and I wear hearing aids. A while back I had to find a place to see if they can do something about my hearing aids. And those places here in [place], they would not take my insurance. Or if they did, I'd have to pay a lot of money."*

Stigma was also a less common barrier discussed. For participants who use public insurance programs, they felt stigmatized against, both my providers and insurance representatives. Some participants shared they felt providers didn't want to take them on as patients because of their insurance type. For example, one participant shared:

> *"I think there's a stigma that's passed down from the people that have been there a long time that we're all a bunch of lazy [people]. And they probably don't want to help us as much next time cause they don't know where they're going to get paid or not."*

Worried about other needs

Many respondents discussed not participating in health promotion programs or receiving preventive care because they were busy trying to meet more immediate needs. When asked whether preventive care had been received, one participant stated:

> *"A lot of people don't have time … they're too busy trying to make sure they have food, trying to turn in verification [to receive health insurance].*

Other needs participants discussed as being more important were finding a job and a place to live. Participants shared more accessible and affordable living options are needed in their communities. Additionally, participants discussed obstacles to finding employment within the community. This difficulty was shared by one participant:

> *"It was really hard to find a job because a lot of people at these jobs wouldn't accept me because of my disability ... or people tell you they don't want to hire you because you have a disability."*

Discussion and recommendations

The findings from these focus groups highlight numerous barriers that people with disabilities experience when accessing health promotion programs and healthcare. Five overarching themes are discussed which summarize the common barriers and experiences shared. Many of these barriers are not new or unknown. However, the experiences discussed in this report represent an important call to action.

The Americans with Disabilities Act (ADA) was originally passed in 1990 to make sure people with disabilities can participate in their communities.[2] Under Title II, all state and local government programs are required to give people with disabilities an equal opportunity to benefit from and participate in all programs, services, and activities.[3] Despite including topics such as communication, program accessibility, and physical accessibility, barriers continue to limit the ability of people with disabilities to fully participate. Further, a recent federal ruling was made because barriers continue to exist.[4] Under this final ruling, any program or activity funded by the Department of Health and Human Services is required to meet standards related to medical treatment, community integration, accessibility of medical equipment, web, mobile app, and kiosk accessibility, and value assessment methods.[4]

The combination of the experiences discussed in this report and federal mandates require our attention. Action is needed to address these barriers to prevent the further widening of health disparities experienced by people with disabilities. Making health promotion programs and healthcare systems more inclusive and accessible to people with disabilities can promote the health and well-being of people with disabilities.

Recommendations to address barriers were identified indirectly through focus group discussions as well as during analysis. These include:

1. **Create accessible and inclusive advertising and promotional materials.** This may include:
    - Including people with disabilities in pictures on materials.
    - Asking about needed accommodations to participate.
    - Providing and delivery materials in multiple formats.
    - Making websites and digital content accessible.
2. **Offer education and training opportunities for public health professionals and healthcare providers.** Training topics may include:
    - Disability 101 training for all staff.
    - Communication best practices for disabilities.
    - Disability-competent care and trauma-informed approaches.
3. **Improved communication practices among insurance providers.** To clarify experiences, insurers could:
    - Create resources that document preventive care that is covered, and any eligibility required.
    - Standardize customer experience interactions to make sure similar information is given, no matter the representative.
    - Train staff on communication best practices.
4. **Better documentation within healthcare records and improved systems communication.** Patient experiences with providers and healthcare systems could be improved by:
    - Documenting disability status in the patient health records.
    - Documenting needed accommodations in the patient health records.
    - Increasing system capacity to coordinate care for individuals with co-occurring disabilities.

Available resources

The Disability and Health grant provides resources to address some of these barriers and is working with organizations such as the Utah Disabilities Advisory Committee to develop additional resources. Resources include:

- ❑ Healthcare provider trainings. To increase competency in disability-specific care and communication practices, 2 trainings are available. Free continuing education credits are available for completing each training.
  - ▪ Providing health care and screenings to individuals with disabilities
  - ▪ Accessible and adaptive communication
- ❑ The Linkage Project was created to connect people with disabilities to unmet healthcare needs.[5] Individuals may self-enroll or be referred. Linkage Coordinators work to connect people to needed services.
- ❑ Disability 101 training for staff. This training is offered in partnership with the Utah State University Institute for Disability Research, Policy & Practice.[6] The training covers the basics of working with and including individuals with disabilities in workplaces and programs.
- ❑ Living Well with a Disability program. This is an evidence-based program developed to support persons with disabilities manage their health.[7] The curriculum supports self-management of qualify-of-life goals to make health behavior changes.

Conclusion

These focus groups indicated that people with disabilities throughout Utah experiences barriers to participate in health promotion programs and while accessing healthcare services. The findings highlight areas needed to improve in both public health and healthcare sectors. There are multiple opportunities to train the workforces to better support people with disabilities and create more inclusive settings. Addressing these barriers is important to improve the health and well-being of people with disabilities.

References

1. Utah Department of Health and Human Services. Health disparities among Utah adults with Disparities. https://healthyaging.utah.gov/wp-content/uploads/Disability-and-Health-Needs-Assessment-Report.pdf
2. U.S. Department of Justice Civil Rights Division. Americans with Disabilities Act of 1990, As Amended. https://www.ada.gov/law-and-regs/ada/
3. U.S. Department of Justice Civil Rights Division. State and Local Governments. https://www.ada.gov/topics/title-ii/
4. U.S. Department of Health and Human Services. HHS Finalizes Rule Strengthening Protections Against Disability Discrimination. https://www.hhs.gov/about/news/2024/05/01/hhs-finalizes-rule-strengthening-protections-against-disability-discrimination.html
5. Utah Health Policy Project. Linkage Coordinator Project. https://takecareutah.org/linkage-coordinator-project/
6. Utah State University Institute for Disability Research, Policy & Practice. Disability 101. https://noncredit.learn.usu.edu/browse/idrpp/courses/disability-101
7. Healthy Community Living. Living Well in the Community. https://healthycommunityliving.com/hcl/lwc-session/home/

Appendix A: Definitions and acronyms

Accessible: Refers to a site, facility, work environment, services, or program that is easy to approach, enter, operate, and/or use safely and with dignity by a person with a disability.

In the case of an in-person health promotion program, an accessible location would allow for someone with a disability to independently enter the building, navigate to a room where the program is held, enter the room, and have a place in the room where they could participate equally with peers. This also applies to virtual environments.

Health promotion program: Any program designed to empower individuals to choose healthy behaviors and make changes that reduce the risk of developing chronic diseases or other health conditions (e.g., Walk with Ease, Chronic Disease Self-Management Program, etc.).

Healthy Aging Program: A program within the Utah Department of Health and Human Services Office of Health Promotion and Prevention. It aims to empower adults to age well through evidence-based programming and resource sharing. The Disability and Health grant is included under the Healthy Aging Program. It works to support the health and well-being of people with disabilities throughout Utah.

Inclusion: Inclusion is when all community members

a) Are presumed competent,

b) Are recruited and welcomed as valued members of their community,

c) Fully participate and learn with their peers, and

d) Experience reciprocal relationships

Independent living center: Also called centers for independent living. A non-profit organization that provides services to help people with disabilities live independently.

Preventive healthcare: Refers to medical services and interventions that try to prevent disease and maintain good health. It focuses on identifying and addressing potential health risks early on, before they develop into serious conditions. It may include things like regular check-ups, cancer and chronic disease screenings, genetic testing, and immunizations.

Utah Disability Advisory Committee (UDAC): The purpose of the Advisory Committee is to improve the health of Utahns with disabilities. Partners meet to build support, leverage resources, educate, and encourage community engagement. The aim is to promote practices and resources for people with disabilities to achieve optimal health and well-being.

Utah Developmental Disabilities Council (UDDC): “The Council supports and empowers people with intellectual and developmental disabilities to achieve inclusive, meaningful, and self-determined lives in their communities through its ongoing support of leadership, education, policy, and advocacy actions.”

Appendix B: Focus group discussion guide

The first thing we're going to talk about is health promotion programs. Health promotion programs focus on keeping people healthy. They empower people to choose healthy behaviors. They encourage changes that reduce the risk of developing chronic diseases. There are a lot of health promotion programs. Nutrition classes, physical activity promotion, quitting smoking, and safe sleep for babies are examples.

1. What health promotion programs are you aware of in your community?

2. How would you find out about a health promotion program in your community?

3. What has been your experience enrolling in or attending health promotion programs?

4. What has prevented you from attending or joining in these programs?

[Question 5 only asked if participants selected currently using a tobacco product on the participant information sheet]

5. What has prevented you from using waytoquit or the Utah Tobacco Quit Line?

6. What support did you need to participate in health promotion programs?

7. How well do you feel health promotion programs in your community meet your needs? Why do you say this?

The next thing we're going to talk about is preventive healthcare. We'll define preventive healthcare as the stuff you do (before you get sick) to stay healthy. Preventive care can also help find health problems earlier, when they're most treatable. Examples of preventive care include annual checkups, and checking your blood pressure and cholesterol. It can also be checking for diabetes and cancer, and getting shots and vaccines.

8. What has been your experience receiving or trying to receive preventive healthcare?

9. What makes it hard scheduling healthcare appointments?

10. What makes it hard getting to healthcare appointments?

11. What makes it hard for you to access preventive care or healthcare in general?

12. What are the barriers that keep you from staying up-to-date on your cancer screenings?

13. How do you learn about preventive healthcare?

14. What support do you need to maintain your health?

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