

# Enrolled Medicaid Member

## Focus Group Report

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Prepared for

# Utah Department of Health



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## TABLE OF CONTENTS

<b>Introduction</b>	<b>1</b>
<b>Executive Summary</b>	<b>5</b>
<b>Detailed Results</b>	<b>7</b>
<b>Appendix A: Participant Screener</b>	<b>A1</b>
<b>Appendix B: Moderator's Discussion Guide</b>	<b>A5</b>

## Introduction

Lighthouse Research & Development, Inc. was contracted by Utah Department of Health to conduct urban, rural, and Spanish-speaking focus groups with the following segments of individuals who are enrolled in Medicaid:

- 1) Adults
- 2) Parents (including pregnant women)
- 3) Individuals with disabilities or blindness
- 4) Seniors age 65 or older

## Objectives

The main objective of this research project was to gather feedback from Medicaid-enrolled participants in four different segments. To accomplish the project objectives, participants were guided through a discussion that encompassed the following topics and themes:

### **Explore the Application and Eligibility Determination Process**

- Discover how participants first learned about Medicaid
- Determine the methods participants used to apply for Medicaid
- Explore the barriers participants encountered with applying for Medicaid
- Determine if the application process was timely
- Gather feedback regarding DWS interactions
- Determine how the application process could be improved

### **Explore Medicaid Coverage and Benefits**

- Determine if participants and/or their families are currently enrolled in Medicaid
- Determine how long participants have been enrolled in Medicaid
- Explore overall satisfaction with their Medicaid experience
- Determine how their experiences could be improved while enrolled in Medicaid
- Identify gaps participants wish Medicaid covered that currently aren't covered
- Explore affordability of copays
- Determine if participants have a particular health plan, and how that plan was selected
- Explore participants' satisfaction with their current health plans
- Evaluate Medicaid interactions

### **Explore Community-based Services (Segment 3)**

- Determine how participants learned of home- and community-based services
- Explore satisfaction with home- and community-based services
- Identify barriers to accessing services
- Determine how utilizing services could be made easier
- Determine how such services could be improved
- Determine if there are gaps in services that should be provided but aren't
- Identify aspects that are most important in creating a waiver

## **Project Overview**

The specific scope of work for this research project is described below:

- Recruitment of participants for each group
- Confirmation emails and reminder calls/text messages to each participant
- Development of a moderator's guide, including specific discussion topics, questions, and ratings
- Facilitation of the virtual focus groups via Zoom and in-person groups
- Development of a written report of results

## **Research Methodology**

The research methods used to complete the project are outlined in detail below.

### **Screener Design and Development**

Lighthouse Research, in consultation with Utah Department of Health personnel, prepared the participant screener. The information collected during the screening process was used to verify participant eligibility and gather demographic information.

### **Sampling Procedures**

Recruiting for the focus groups was conducted using sample provided by Utah Department of Health.

### **Recruiting**

Experienced executive recruiters conducted the recruiting. Recruiters were briefed thoroughly on the screener before proceeding. Calling hours for this recruit were between 9:00 a.m. and 9:00 p.m. on weekdays. Each participant received personal emails, phone calls, and text messages confirming their invitation to participate in the focus group and reminding them of their appointment.

### **Development of Moderator's Guide**

Lighthouse Research, through consultation with the client, designed the moderator's guide for the focus groups. The guide encompassed the following topic areas:

- Explore the Application and Eligibility Determination Process
- Explore Medicaid Coverage and Benefits
- Explore Community-based Services

## **Focus Group Fulfillment**

A total of 13 focus groups were facilitated by Lighthouse Research. Christie Leake facilitated the English-speaking groups, while Eve Halterman facilitated the Spanish-speaking groups. Moderators guided participants through the topic areas outlined in the discussion guide. The focus groups were held between June 1<sup>st</sup> and June 5<sup>th</sup>, 2021. All but one of the groups were held virtually via Zoom. The urban adult group was held at the office of Lighthouse Research & Development, Inc. in Salt Lake City, Utah.

The scope of work for this research included three focus groups for each segment (one rural, one urban, and one Spanish-speaking), with the exception of the 65 and older segment, which included four focus groups (one rural, one urban, one male Spanish-speaking, and one female Spanish-speaking).

## **Organization of the Report**

Data collected during the focus groups was analyzed for reporting. The results were compiled and are presented in this report, organized by the following areas:

- Introduction
- Executive Summary
- Detailed Results
- Appendices

The Executive Summary section of this report provides a summary of the most pertinent findings of the focus groups.

The Detailed Results portion of this report presents the complete findings of the research organized by topic.

The Appendices section provides a copy of the participant screener and of the moderator's discussion guide.

This report represents the deliverable for this contract and is presented respectfully to the project sponsors.



## Executive Summary

The following summary represents the most pertinent findings of the focus group research.

English- and Spanish-speaking focus groups were conducted with four segments of Medicaid users:

- 1) Adults
- 2) Parents (including pregnant women)
- 3) Individuals with disabilities or blindness
- 4) Seniors age 65 or older

Participants most frequently said they heard about Medicaid 1) when seeking medical care at a hospital or from a healthcare provider, 2) from friends, coworkers, or family members—especially their mothers, and 3) Department of Workforce Services.

Most participants reported completing the Medicaid application online. Participants with disabilities, seniors, and Spanish-speaking participants more frequently visited a DWS office or had a medical professional complete their application at the time they sought medical care.



### Perceptions of the DWS Website

Participants overwhelmingly reported that the DWS website is in need of improvements, as:

- The website is outdated and needs updating
- The website is not user-friendly
- The website is not usable in a mobile format
- Uploading documentation is a challenge, doesn't work
- The chat feature is not useful
- Website navigation does not allow users to “go back”
- The site has poor Spanish-to-English translation



### Perceptions of the Application Process

Participants made the following observations about the application process:

- The process is discouraging
- It is not intuitive to apply for Medicaid through DWS
- The application is confusing
- The application requires assistance
- Collecting and providing documentation is an issue
- The process takes too long to approve
- Participants are fearful of disqualifying due to exceeding the asset limit
- Spanish-speaking participants are concerned about submitting personal data



## Perceptions of DWS Interaction

Participants offered the following thoughts on their interactions with DWS:

- Telephone wait times are too long
- It is difficult to access caseworkers
- Users would prefer having designated caseworkers
- Caseworkers are “a mixed bag,” some helpful and some not
- Some staff are courteous, others are not
- Some staff are knowledgeable, others are not



## Perceptions of myCase Portal

Participants offered the following thoughts on the myCase portal:

- Upload confirmation is not provided
- Notifications are unnecessary and complicated
- Notifications are easy to miss
- Notifications require follow-up to learn why coverage is denied



## Perceptions of Medicaid Coverage and Benefits

When discussing Medicaid coverage, participants commented on the following:

- Medicaid is helpful, members are grateful
- Medicaid provides adequate access to care
- It is difficult to find out what coverage benefits are
- Lack of coverage knowledge yields lack of medical care
- Providers are limited and difficult to see
- It is difficult to pick a plan
- Copays are reasonable for most, but not for some
- Medicaid does not cover important medications
- Medicaid should provide more benefits—especially dental and vision coverage



## Evaluation of Mental and Behavioral Health Services

Participants mentioned the following regarding Medicaid’s mental and behavioral services:

- Members are unaware of mental and behavioral health benefits
- Medicaid’s mental and behavioral health resources are limited
- Some mental and behavioral healthcare providers are excellent, others are not



## Detailed Results

English- and Spanish-speaking focus groups were conducted with four segments of Medicaid users:

- 1) Adults
- 2) Parents (including pregnant women)
- 3) Individuals with disabilities or blindness
- 4) Seniors age 65 or older

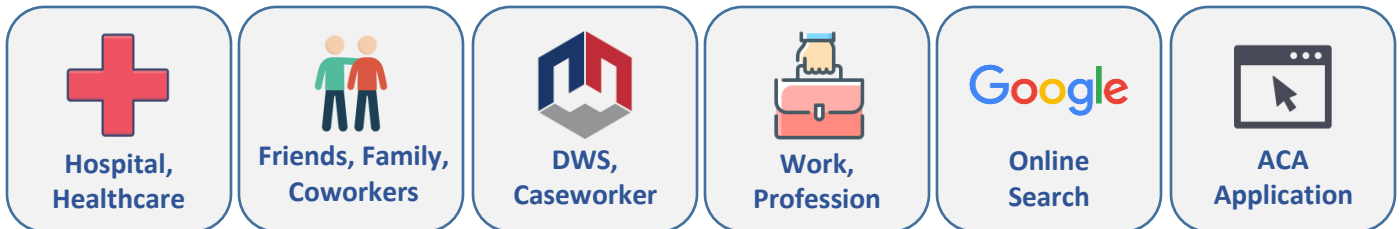
Though participants were categorized by segment, it was evident there was a great deal of overlap among segments. For example, mothers of young children were not unique to Segment 2, and individuals with disabilities were not exclusive to Segment 3. For this reason, results are presented in aggregate, with differences noted when applicable.

## Awareness of Medicaid

Participants most frequently said they heard about Medicaid 1) **when seeking medical care** at a hospital or from a healthcare provider, or 2) **from friends, coworkers, or family members**—especially their mothers, and 3) **Department of Workforce Services**.

- Multiple participants each reported hearing about Medicaid through their professions, an online search, or the ACA application.
- A couple of participants reported learning about Medicaid through their families, as their parents themselves were on Medicaid.
- Among Spanish-speaking participants, the majority of mothers learned about Medicaid when visiting a clinic or hospital when pregnant or in labor, and participants with disabilities learned about Medicaid when receiving a diagnosis.
- Spanish-speaking participants indicated that many individuals in their communities are unaware of Medicaid, and that outreach should be made to inform them of the existence of these services.

### How did you first hear about Medicaid?



Most participants reported completing the Medicaid application **online**.

- However, participants who heard about Medicaid through a hospital or healthcare provider indicated their application was completed for them by a medical professional when they sought care.
- Multiple participants—particularly those with disabilities, seniors, and Spanish-speaking participants—reported going to a DWS office to complete their applications.

Many participants needed assistance in completing their applications.

- Participants with disabilities and seniors sought assistance from friends, family, or DWS staff.
- Spanish-speaking participants sought assistance from English-speaking relatives and DWS.



## Perceptions of the DWS Website

**The Website is Outdated and Needs Updating** – Participants overwhelmingly described the DWS website as “clunky,” “janky,” and in need of updating.

- *“It looks like it was designed 20 years ago.” (Adults, Urban)*
- *“At DWS: This is the 1990s, they want their HTML back.” (Disability, Rural)*
- *“I think a lot of the calls could be mitigated with a better website.” (Parents, Urban)*
- *“Modernize the website, update it. We all get on hundreds of website every day. You can tell when you get on a website how it used to be back in 2005, and that’s how DWS is.” (Parents, Urban)*
- *“I dread having to get on. It’s terrible. Words cannot describe how poorly designed the website is. Nothing’s intuitive, nothing is easy to find. I’m always trying to dig if I have a notice I need to find, and uploading is terrible. It does feel clunky and super dated. I just dread anytime I have a review online.” (Parents, Urban)*

**The Website is Not User-friendly** – Multiple participants felt the website was difficult to navigate, difficult to use, and not user-friendly.

- *“I feel like it wasn’t straightforward.” (Adult, Urban)*
- *“I just don’t feel like it’s user friendly. I’m trying to imagine someone who doesn’t sit on a computer a lot and can see how they would be very confused. There’s probably a better way to design it.” (Adults, Urban)*
- *“The process wasn’t as intuitive as I would have liked it to be. I had to do it twice. I would like the process to be a little more streamlined.” (Disability, Urban)*
- *“It was confusing. What I wanted was to log into the website and choose a plan, and it wasn’t giving me that option.” (Adult, Urban)*

**The Website is Not Usable in a Mobile Format** – Multiple participants indicated that they have experienced challenges with using the DWS website on a mobile device. This is particularly problematic for individuals who only have access to a mobile device.

- *“The mobile version is atrocious. It’s not even worth trying. It doesn’t scroll. It’s the worst.” (Parents, Urban)*
- *“I do wish it was a little easier to navigate on a phone.” (Adults, Rural)*
- *“Seeing as I only have a phone, it’s very tough. I still have a hard time navigating it.” (Disability, Rural)*
- *“Checking notices is not really possible on mobile – you need a full laptop screen to do that. They need to improve that, their mobile coding. It really needs a redesign.” (Disability, Rural)*
- *“Sometimes I have trouble getting the [notifications] they send out, trying to pull them up to read them. I just have an iPad.” (65+, Rural)*

**Uploading Documentation is a Challenge, Doesn't Work** – Multiple participants expressed frustrations with uploading documentation on the website. While some participants reported having difficulty with the uploads, others reported that their documentation wasn't received after they had, in fact, submitted it.

- *"When I would submit papers online through their website, half the time they wouldn't get them." (Disability, Urban)*
- *"Two or three times I submitted it, but it didn't get recorded." (Parents, Rural)*
- *"Sometimes it won't upload. I'll try multiple times and it just won't upload. There have been times when it will say it has uploaded, and then days later it's still saying it needs to be received." (Disability, Urban)*
- *"When you have to upload extra documents, you have to click 'save' two or three times in different places, otherwise it doesn't upload, which is not easy to recognize the first time you do it. It was frustrating thinking I had uploaded all of these things, and then when I called to check, they would say they didn't get anything because I didn't hit the right button." (Parents, Rural)*
- *"I always had a problem figuring out where to upload it on their website. Every time I have to do a review, it's the most annoying thing to have to submit any forms to them online. At first, it's not obvious and it doesn't tell you if your document uploaded – it just disappears." (Parents, Urban)*
- *"The uploading thing; there aren't enough files that are accepted. I know when I save things to my phone it's a PNG, and I think that's one of the ones they don't accept. So then I have to find a way to convert it into a PDF." (Disability, Urban)*
- *"When I do have to go and provide a pay stub or something, I have to call and tell them to open a spot to upload. There isn't a spot to upload documents; I have to call them to provide a place." (Adults, Urban)*
- *"I've never been able to get the upload to work. I've always had to go to Workforce Services and do the images there. Every time I tried to image something in it wouldn't even show up on the system when I tried to access the download." (Adults, Rural)*

**The Chat Feature is Not Useful** – Participants who have used the website's live chat feature felt it is generally unhelpful. In fact, multiple participants reported calling and speaking with a DWS caseworker, when they felt the website and a better chat feature could eliminate a phone call and a long wait time.

- *"They do have live chat; the live chat doesn't work though." (Adults, Urban)*
- *"Sometimes I just had to call a caseworker to see what it meant, and sometimes the wait time was at least 20 minutes if not 45. I wished I could use the chat for basics like that, but the chat was just for technical stuff." (Parents, Rural)*
- *"I would make a chat available with a real person, not a chat robot. I ran into so much trouble online trying to get everything uploaded and finding the right form. If there was a chat feature that could help you right then, that would be helpful." (Adults, Rural)*
- *"The chat isn't really beneficial; they can't answer anything specific to your case. Pretty much every question I've ever had was specific to my scenario. Having a generic chat isn't helpful." (Adults, Rural)*

**Website Navigation Does Not Allow Users to “Go Back”** – A couple of participants had experiences where they made mistakes in the application process, but were unable to fix them with the current design of the website.

- *“I made a mistake because I thought we’d gotten a raise and we hadn’t, so I put it in and went one page and tried to go back, but it wouldn’t let me change it. Once I had changed it, it was like locked in stone even though I hadn’t submitted it.” (Parents, Rural)*
- *“I remember getting halfway through inputting information and realized something was wrong. I tried to go back to change it and it was just locked in. There was no way for me to change it, and I just had to restart the application. I was already 20 to 30 minutes in!” (Parents, Urban)*

**The Site Has Poor Spanish-to-English Translation** – Participants indicated that the site needs improvement in terms of Spanish translation.

- *“They don’t do the best translation and they use words that confuse me.” (Adults, Spanish)*
- *“I almost always have to ask questions because the questions that are in Spanish are a little confusing.” (Adults, Spanish)*
- *“I’m a Spanish-English interpreter so I take time to read how things are translated into Spanish, so I saw some discrepancies in there that weren’t quite accurate. I don’t know how they do the translation and stuff, but I feel like it could be done better for people who have English as a second language if they’re going on there to access it in Spanish to make sure wording is correct.” (Disability, Rural)*
- *“When I said, ‘I didn’t understand the questions in the application,’ they said ‘Why not? It’s in your language.’ And I say ‘Yes, but they’re not translated well.’ It’s like they are offended or bothered.” (Adults, Spanish)*



## Perceptions of the Application Process

**The Process is Discouraging** – Multiple participants expressed frustration with the application process and indicated that the process discourages individuals from applying for Medicaid.

- *“I tried several times on my own and ended up in tears. I just gave up.” (65+, Rural)*
- *“I ended up just not even getting Medicaid even though I tried really hard to get it.” (Parents, Urban)*
- *“Navigating was very imposing and difficult to jump through all those hoops. I felt if they made it hard enough to apply, I would just give up.” (Adults, Urban)*
- *“Unfortunately, a lot of people fall off Medicaid that need it because they don’t know the right questions to ask.” (Adults, Rural)*

**It is Not Intuitive to Apply for Medicaid through DWS** – Participants, in general, felt it was confusing and not intuitive to apply for Medicaid through DWS.

- *“It’s not intuitive to me that applying for social services would be through Workforce Services. You have to go through jobs.Utah.gov.” (Parents, Rural)*
- *“I used Google and then questioned if it was [at the right place].” (Parents, Urban)*
- *“It’s so confusing that DWS and Medicaid are connected. All of my dealings with Medicaid was at a DWS office, they always have me go to DWS.” (Parents, Urban)*
- *“At first, trying to find everything is a little confusing because you have to log in to Utah.gov, and then that same login, you go from there to myCase, and then you are on your account with Medicaid. That was a little confusing.” (Parents, Rural)*

**The Application is Confusing** – Participants with disabilities and Spanish-speaking participants were among those who felt the questions in the application were particularly confusing.

- *“Going onto the site, I had to pause and read the language a couple of times. It was a little bit confusing.” (Disability, Rural)*
- *“When you’re dealing with mental or physical disabilities, it’s just an extra challenge. That’s part of having a mental or physical disability; any extra thing can just bring the house of cards down and ruin your motivation or just be too much for that day.” (Disability, Urban)*
- *“There are some questions that are confusing. There are some you don’t know if you should put ‘yes’ or ‘no.’” (Parents, Spanish)*
- *“If I didn’t understand, so I didn’t make a mistake, I left it blank. Then, when they called me to ask ‘Why is this blank?’ I’d tell them I didn’t understand it.” (Parents, Spanish)*

**The Application Requires Assistance** – Participants overwhelmingly commented on the difficulty in applying for Medicaid. Many participants—particularly those in the senior groups and groups with disabilities—needed assistance in completing the application.

- *“I needed my daughter-in-law to go through the application with me. She helped me fill out the application. I didn’t understand what they were asking me.” (Adult, Rural)*
- *“Because of my disability, I could’ve used more assistance. I’m not dumb, but I have a hard time processing information. It felt really overwhelming as far as the information that I was trying to gather – the stamina and diligence it took to be able to get it. I think I was denied because I didn’t finish it the first time. I think it was like the third time I applied that I was approved for it.” (Disability, Urban)*
- *“My neighbor, who’s a good friend, helped me complete the application. It may have just been me and my processing, but I had to clarify with her what it was that they were asking for. It was more the structuring of the sentences. I had to think about it for a moment.” (Disability, Urban)*
- *“I got stuck a couple of times on some questions. On some, you get confused, but I took the form to Workforce Services and they helped me.” (Adults, Spanish)*
- *“My daughter helped me and filled everything out so I could have the right [coverage].” (Parents, Spanish)*

**Collecting and Providing Documentation is an Issue** – For some participants, collecting and submitting the required paperwork is a challenge. Participants who are self-employed or not traditionally employed found this to be particularly challenging for them. Other participants reported being in situations where it is difficult to obtain such documentation.

- *“I had a problem with getting the paperwork and everything I needed. I was working on a traveling carnival show, and I just left and came here with my husband. I didn’t have a birth certificate, I didn’t have a Social Security card, and I had to get all those things to prove who I was.” (Disability, Urban)*
- *“I’m not fully employed. I’m part-time, temporary, I get laid off every semester, and I also do contract work on the side. They wanted proof of everything. The application was okay, but the proving of it was a problem. They wanted copies of three months of check stubs, which I had electronically. But at one university, I only had a couple of months. My contract work, I didn’t have anything, so I just had to estimate, and they didn’t like the estimate. They wanted something more substantial. I gave them my tax returns and that wasn’t good enough. If you’re self-employed or a gig worker, they don’t really know how to handle it.” (Adults, Rural)*
- *“I had just barely moved from Utah to Minnesota and so they wanted proof I wasn’t working. I did have my check stubs from the job I had in Utah. I was trying to explain to them that I had just moved and was looking for work but hadn’t found any. That wasn’t good enough. I didn’t know what to give them to prove that I didn’t have a job.” (Adults, Rural)*
- *“I have my son 50/50, and in order to qualify, I have to have him 51% of the time, which, due to life, varies all of the time. Verifying 51% of the time with an ex isn’t easy, especially because the divorce was not amiable. Having to get a letter from him saying that I had my son 51% of the time when it’s 50/50 in the court order was a major, major problem for me for years.” (Parents, Rural)*
- *“It was embarrassing asking my employer to fill out verification forms over and over. It’s just embarrassing to go back to my employer and have them fill them out again, sometimes I feel like I’m asking for not only their time, but I feel very vulnerable.” (Parents, Rural)*
- *“I think some people have problems because they don’t have the information they are being asked to provide.” (65+, Spanish)*

**The Process Takes Too Long to Approve** – Participants indicated that it took anywhere from two weeks to six months to be approved for Medicaid, with the majority of participants saying it took **one month or less** or **three to six months**. The focus groups comprised of English-speaking participants with disabilities were among those who received approval quickest, while Spanish-speaking participants with disabilities indicated their approval took longer for them than participants in other Spanish-speaking segments. Regardless, most participants felt it took far too long to receive approval.

- *“I have to be on some really important medications, so the time limit of approval, due to my medical needs, made me very anxious. It was worrisome because I was in between doctors, and when I had moved from California to here, they could only do a 30-day supply, and I was within a window. I had to wait 30 days before I would qualify.” (Disability, Urban)*
- *“Having to go into the ER when in limbo is not conducive to continuity of care. It's unfortunate the process to be approved takes so long.” (Parents, Rural)*

**Participants are Fearful of Disqualifying Due to Exceeding the Asset Limit** – Multiple participants—particularly those with disabilities and seniors—expressed concerns about exceeding the asset limit and potentially being disqualified themselves from Medicaid.

- *“There's this fear that if you have an asset anywhere, that you're going to be disapproved. I find myself living with my life without assets because I can't rock the boat, otherwise I'll be out on the street with this and other benefits.” (Disability, Rural)*
- *“I've been with Medicaid for four years now, but the \$2,000 asset limit is tough for me. I like to have a little more cushion than that. I thought the head gasket just went out on my car. That would have blown me out of the water if it had! You need more than \$2,000 in the bank to deal with that.” (65+, Rural)*
- *“That \$2,000 cushion is ridiculous. I save money because I have to. I am so frugal, I do things that people laugh at me for, like using paper towels twice. I don't throw anything away. I'm very careful about my food budget. I don't buy expensive food. I don't go out to eat. I don't spend money on entertainment, so I'm able to save money. It's absolutely stupid that a responsible person can find a way to live more cheaply and save some money for an emergency. If my car broke down, \$2,000 wouldn't do anything!” (65+, Rural)*

**Spanish-speaking Participants are Concerned about Submitting Personal Data** – English-speaking participants indicated that they have no concerns with submitting personal data to DWS, as they are already familiar with doing things such as taxes and banking online. However, Spanish-speaking participants expressed some concerns over submitting personal information online.

- *“I had to provide the residency and Social Security numbers for me and my daughter. I was afraid to send it, but I had to. In fact, I talked to the gal and said, ‘This is important information and I'm afraid to send it,’ and she told me where the fax arrives and how it's all confidential.” (Parents, Spanish)*
- *“Do you remember when Medicaid case information was stolen? We got a notification and they said my sons' ID numbers had been stolen.” (Adults, Spanish)*
- *“When I call, I hear about that [myCase] option on the phone recording, but I haven't tried it. I don't have much experience with technology, and I'm afraid to get online and make a mistake.” (Adults, Spanish)*



## Perceptions of DWS Interaction

**Telephone Wait times are Too Long** – Participants overwhelmingly expressed frustration with the long wait times when calling DWS.

- *“I have had to call quite a few times, and I feel like I always wait on hold for so long to get through to someone.” (Adult, Urban)*
- *“You’re on hold for so long. With most working people, they call on their lunch break so everyone’s calling on their lunch break, so you wait one to two hours on hold. Less of a hold time would make it easier to call in.” (Parents, Urban)*
- *“If I called in the morning or the evening, it was a two hour wait. Most people don’t have two hours to wait. (Parents, Urban)*
- *“More often than not, I’m looking at least a half an hour [wait when I call].” (Adults, Rural)*
- *“It is very difficult to call into DWS. You call and you wait on hold for a half an hour or more every single stinkin’ time!” (Disability, Rural)*
- *“I had a prolonged period where I was waiting for approval. I had to call many times. I probably spent 10 hours with different hold times. It was a call and plan on literally one hour each time.” (Adult, Urban)*
- *“It’s always kind of long waiting. Especially during COVID, [the wait time] maybe doubled or tripled.” (Parents, Rural)*
- *“The hard part is that you wait an hour, half an hour, 15 minutes, until someone answers.” (Adults, Spanish)*
- *“We have the option [for Spanish phone service], but they make us wait a long time.” (Adults, Spanish)*
- *“It’s a lot faster if you call to speak in English. When you select to wait to speak to someone in Spanish it’s a longer wait.” (Parents, Spanish)*
- *“I called once ... and I was on hold so long that the call dropped.” (65+, Spanish)*

**It is Difficult to Access Caseworkers** – Multiple participants expressed frustration with being unable to access their caseworkers when needed.

- *“When I had questions, I would call and I get put on hold for 30 or 40 minutes. And then when someone does talk to me, it’s not my caseworker, it’s someone else. I could have solved my issue on income verification a month earlier if I had been able to talk to my caseworker.” (Adults, Rural)*
- *“The first person I talked to was helpful or courteous, but they weren’t the caseworker or the decision maker. The only person who could make the decision was your caseworker, but you can’t ever talk to your caseworker.” (Adults, Rural)*
- *“I was having problems contacting people and then finally I got a caseworker who gave me her direct number, and I had never had better help ever. Now, I’ve gone through two caseworkers like that, and now with this caseworker, I can call and don’t get anything back, no calls back.” (Disability, Rural)*
- *“I put in my case number and get transferred to Marta, who is my case manager, but she doesn’t always answer – that’s where the misinformation happens, when someone else answers.” (Disability, Spanish)*



**Users Would Prefer Having Designated Caseworkers** – In some instances, participants indicated they would prefer to have one designated caseworker who understood their case and who would not require them to explain their situations over and over again.

- *“It was much easier in my case when they assigned me an agent and so only one person helps me, and that person knows my case and I direct everything to him.” (Disability, Spanish)*
- *“I call Workforce Service and put in my case number and every time ‘Mark’ takes my call. Always! There is nobody else who takes my calls. For me, that helped A LOT!” (Disability, Spanish)*
- *“Why don’t we just have one caseworker that manages our case consistently? I don’t feel as though they’re consistent across the board enough. If I had that one caseworker, it would make a huge difference because they would know my story and I wouldn’t have to make my case to whomever answered the phone on that particular day.” (Parents, Rural)*
- *“Having one caseworker assigned instead of talking to four or five different people would be a big help.” (65+, Rural)*

**Caseworkers are “A Mixed Bag,” Some Helpful and Some Not** – When asked if the staff answering their calls are courteous, helpful, and knowledgeable, participants indicated that “it depends” or “it’s a roll of the dice,” that “some are and some are not.”

- *“For myself it’s been all across the board. I have had probably two or three in the past seven years that I was really like, ‘Wow, they were really helpful and understanding of my plight.’ I’ve had like 10 people and they were like, ‘Let me just get through this call.’ More often than not the customer service isn’t anything to brag about.” (Adults, Rural)*
- *“I would say 70% of the time the person was helpful, and 30% of the time it was somebody who just put up walls to getting the information I needed.” (Disability, Urban)*
- *“Honestly, it depends on the day and who I talk to. I’ve had some people that were absolutely amazing. They took the time to answer all my questions, they didn’t speak to me like I was dumb. And then I’ve had others that have literally put up roadblocks to where they wouldn’t answer my questions.” (Disability, Urban)*
- *“It’s the luck of the draw. I have gone in person and been totally shutdown, but I could go in the next week and they are the nicest and most helpful human on the planet—a different person. It is night and day, luck of the draw, day of the week, run of the gambit.” (Parents, Urban)*
- *“It really depends on the caseworker. When I first applied and was denied, when she was interviewing me it felt very condescending. It was almost like she didn’t believe me. The second time, when I got this caseworker, she was super nice and she worked really well with my caseworker here at Bear River. That was a lot better than the first time I applied.” (Disability, Rural)*
- *“I’ve been on disability for a mental illness, but now that I’m several years into having Medicaid, I currently have stage four breast cancer, and it feels like as soon as your diagnosis changes somebody starts treating you better. They are more cordial, they ask me questions, and I felt like they cared. I feel like the experience has gotten better with the customer service and accessibility to help. I hope it’s not just because I have cancer.” (Disability, Rural)*
- *“It’s 50/50, some of them are really nice, polite, and friendly and don’t mind answering your questions. The other half of the time, your questions annoy them, it’s not their job, they don’t know, or they tell me to use the website. It doesn’t seem like they’re trying to help you, it just seems like they want the call to be over already.” (Parents, Urban)*

**Some Staff are Courteous, Others are Not** – Participants were mixed in their perceptions of whether or not staff members were courteous and kind. While some participants reported receiving exceptional treatment, others reported the opposite. Participants with disabilities were among those who felt they had received particularly rude or condescending treatment.

Courteous, Kind	Rude, Condescending
<ul style="list-style-type: none"> <li>• <i>“They were always nice to me.” (Adults, Urban)</i></li> <li>• <i>“When I applied and talked to someone on the phone, she was very helpful and very compassionate.” (Adults, Rural)</i></li> <li>• <i>“We are a small community. I really feel it’s more personal, one-on-one when you go in there. I’ve always been treated really well.” (65+, Rural)</i></li> <li>• <i>“I’ve been very fortunate and have had a positive experience. Sometimes it takes a while waiting on the phone to get to the right person, but I am able to find someone to listen and answer my questions.” (65+, Rural)</i></li> <li>• <i>“They’ve always been really respectful.” (Parents, Rural)</i></li> <li>• <i>“There must be thousands of people who call and ask the same question I did, but they still answer with kindness.” (Parents, Spanish)</i></li> <li>• <i>“Even when they reject your claim, they do it with class!” (65+, Spanish)</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>“There has been the assumption that you’re there to game the system.” (Disability, Rural)</i></li> <li>• <i>“It always feels like they’re looking down on you, like you’re less than they are. A lot of people assume if you’re disabled that you’re just lazy.” (Disability, Urban)</i></li> <li>• <i>“Quite often I would feel like they were condescending and just overlooked what my priorities were or my interest in having the conversation.” (Disability, Rural)</i></li> <li>• <i>“I think the main thing is that we’re human beings. We may present as low-income and maybe have multiple health issues, and that’s why we’re on Medicaid, but have compassion and understanding and not be so quick to judge. Sometimes our situations are handed to us and it’s not something we would have chosen ourselves, and it’s beyond our control.” (Disability, Urban)</i></li> <li>• <i>“With the Medicaid and DWS, I feel like I always have to preface and tell them I’m not dumb, I’m just having a hard time processing information. That seems to soften the experience that I have with them; but I shouldn’t have to explain to them that this is not a choice. If I could be independent and on my own, I would be independent and on my own.” (Disability, Urban)</i></li> <li>• <i>“They hold a certain amount of power over you and your life, so you just kind of have to take it because you don’t want to piss them off since it could affect you and your application negatively.” (Parents, Urban)</i></li> <li>• <i>“I experienced racism once with [a DWS staff member] when they found out that my place of birth was outside the country.” (Disability, Rural)</i></li> <li>• <i>“One thing I don’t like is how they end the conversation. Usually, people end a conversation with ‘God bless you,’ or ‘Have a good day’ or ‘Good afternoon,’ but these guys just hang up! I find it odd.” (65+, Spanish)</i></li> </ul>

**Some Staff are Knowledgeable, Others are Not** – Similarly, participants were mixed in their perceptions of whether or not DWS staff members are knowledgeable and able to answer their questions.

Knowledgeable or Helpful	Not Knowledgeable or Helpful
<ul style="list-style-type: none"><li>• <i>“I had a really good case management worker who helped answer any of the questions I had.” (65+, Rural)</i></li><li>• <i>“I have found quite a bit of help through the caseworkers. I haven’t had any difficulty through the years.” (65+, Rural)</i></li><li>• <i>“For me it’s been great. I’ve been lucky with the caseworkers and I’ve been very fortunate to find people who knew the regulations to help me.” (65+, Rural)</i></li></ul>	<ul style="list-style-type: none"><li>• <i>“I just don’t get the most knowledgeable people whenever I call. I’ve asked detailed questions and they’re like, ‘I’m going to have to go ask someone else.’ They’ll take my number and say, ‘I’ll call you back,’ but they don’t.” (Adults, Urban)</i></li><li>• <i>“It’s frustrating. A lot of the time it sounds as though they’re reading from a script and they don’t have a lot of knowledge.” (Parents, Rural)</i></li><li>• <i>“I have been told one thing by one worker and another thing from another worker.” (Adults, Urban)</i></li><li>• <i>“I’ve called in to talk to different people, and one person will tell me something so I’ll call in to double check it, and someone else will tell me it’s absolutely wrong.” (Parents, Rural)</i></li><li>• <i>“They use a lot of terms that, as a first time applicant, I didn’t understand. A lot of forms they would just name off, but what was that form supposed to do? Where do I get it? I just didn’t know because it was the first time I applied.” (Adults, Rural)</i></li></ul>

## Perceptions of myCase Portal

Most participants had experience with the myCase portal, though participants with disabilities and seniors were less familiar and less likely to have used the myCase portal.

**Upload Confirmation is not Provided** – One of the biggest concerns myCase users face is that there is no confirmation or indication that they have been successful in uploading a document. As a result, users have uploaded documentation multiple times or been left wondering if their documentation was received.

- *“When I upload a form, it doesn’t say that it was uploaded or received. So, when I first was applying, I kept pushing the button and thinking they didn’t get it. Then I called, and the girl was like, ‘You uploaded it like five times.’” (Adults, Rural)*
- *“I probably uploaded my payroll stubs 10 times because I couldn’t get verification that it accepted it.” (Adults, Rural)*
- *“I uploaded one file over 15 times because they couldn’t find it. They finally came in weeks later, and now my files have the same document a bunch of times.” (Parents, Rural)*
- *“I eventually found the place to see where it said ‘documents received,’ it’s just when it says ‘document received’ it sometimes takes half an hour or up to 24 hours. That’s a little hard. Even when it says what you sent, it’s just pretty generic, so if you look at it later, you might not know exactly what you sent.” (Parents, Rural)*
- *“I have a little confusion when I upload any documents. I can’t really tell if it was processed or not. I can’t really tell, so I don’t know if it’s uploaded since I didn’t get a notification or a note. I have to do it multiple times sometimes just to make sure.” (Parents, Rural)*
- *“When I had to upload my documents in MyCase, there was nothing that said ‘It’s been uploaded.’ So I did it 15 times, and when I called, the guy said, ‘Lady, you’ve done it about 15 times.’ It was very embarrassing.” (Parents, Spanish)*

**Notifications are Unnecessary and Complicated** – When commenting on the frequent notifications they receive, multiple participants indicated that some notifications are unnecessary or overly complicated.

- *“I keep getting notifications, so I open them up and it’s nothing.” (Adult, Urban)*
- *“When you go into myCase to look at documents, you have to download a PDF every time. I’d rather just view it on the browser than have to download the document.” (Adults, Urban)*
- *“All of your notifications are a PDF, and I feel like they say in the first line what the PDF is, and then there’s like four pages of stuff and I’m not sure if it’s pertinent. It stresses me out reading them. I feel like I’m reading a legal document every time I’m reading these notifications.” (Adults, Urban)*
- *“When you get an email saying you have a notification, your heart kind of jumps in your chest because you’re worried it’s a review or something. When you get there, it’s one of those stupid letters telling you there’s this thing called myCase and you should really use it. They send those out a lot.” (Disability, Rural)*
- *“You go to all the trouble of finding your password, getting in there, doing all that rubbish, only to find out it’s some stupid notification I don’t need to know about. So I stopped reading them; then I missed one that was really important.” (65+, Rural)*
- *“I got a notice online that I had a message and it said my coverage was terminated. I called them and they were like, ‘Oh no, you’re fine.’ To do that to someone is scary.” (Adult, Rural)*

**Notifications are Easy to Miss** – Unfortunately, some participants indicated that they use myCase on an infrequent basis, and therefore, miss notices that may be of importance.

- *“I don’t always get on the computer. I’m not a computer freak, and sometimes I can’t afford the service, so it goes down and I cannot check my emails. If you don’t see it, and it’s within a very short period of time [that you have to respond], you’ll miss that [important] one. I’ve had my food stamps shut off, and I don’t think it’s fair that they can’t send both physical mail and [email notifications].” (Disability, Urban)*

**Notifications Require Follow-up to Learn Why Coverage is Denied** – Multiple participants said they experienced a lapse in coverage or a denial of coverage at some point of enrollment. Participants, in general, indicated that the notifications are not specific or clear in explaining why coverage has been denied; however, some participants indicated that after speaking with a caseworker, they were able to understand why such decisions were made.

- *“The doctor referred me to get an echocardiogram, but I was denied. But they didn’t tell me why. They didn’t tell me ‘You don’t qualify,’ ‘You don’t need it,’ nothing. I didn’t receive anything.” (65+, Spanish)*
- *“In the letter it’s not very specific, but it had to do with a form that was uploaded or something. It just said ‘Documentation not received.’ Once I called, I was able to understand which document they didn’t see and I let them know I had uploaded it. The clarification comes if you’re willing to sit on hold and get a hold of them. From time to time, you might be able to work with them.” (Adults, Rural)*
- *“My kids were taken off because we made \$52 too much per month. Another time, my husband was working as a painter during the summer. One month they forgot to pay him, so they paid him [double] the next month; so then he made too much. The letter just said ‘Too much income,’ so then I had to call. I kind of assumed that’s why, but I had to ask them.” (Adults, Rural)*
- *“More clarity around what it is that’s missing or what it is that’s needed. When they say something is missing, what was missing and why? I couldn’t talk to anyone about that to find out. The communication on the website is not very clear.” (Adults, Rural)*
- *“When I would call in and talk with somebody they were pretty clear about why it was denied and what was needed.” (Parents, Rural)*



## Perceptions Medicaid Coverage and Benefits

**Medicaid is Helpful, Members are Grateful** – Overwhelmingly participants expressed sentiments of gratitude for Medicaid coverage and felt that Medicaid contributes positively to their quality of life.

- *“They’re awesome. They take care of not just your medical, but your prescriptions, too.” (Adults, Urban)*
- *“I feel like Medicaid is the best thing ever. How can you not be grateful for that?” (Adults, Urban)*
- *“We are very satisfied. Medicaid came in very perfect timing for us, me being pregnant, not having a lot of income during COVID, and giving birth during COVID. It was wonderful.” (Parents, Rural)*
- *“I’ve been very satisfied. My first child was born with multiple birth defects so he had six surgeries in his first two years of life. We didn’t pay anything because we’re on Medicaid.” (Parents, Urban)*
- *“I feel like it’s given me a lot of peace of mind. My husband had this lump in his arm that’s been growing and been giving me so much stress. I thought, ‘He has cancer and he’s going to die, and we really can’t afford to have it checked out.’ We finally had it checked out and he’s fine, but I’m so glad we were able to just find that out. Even though we’ve talked a lot about what a hassle it can be, it’s totally worth it to have the peace of mind. Otherwise, we just absolutely can’t afford it.” (Parents, Urban)*
- *“I’ve been going through chemotherapy for three years, and I know that I wouldn’t be able to pay for that if I didn’t have the Medicare and Medicaid together.” (Disability, Rural)*
- *“I’m very satisfied with medical coverage, it has done amazing things for me. Thank you to the Lord and to the system for saving my life many times over.” (Parents, Rural)*
- *“It’s a blessing to be here in this country and have this coverage for my sons [with disabilities]. I wouldn’t be able to cover the expenses that they have.” (Adults, Spanish)*
- *“Treatment here in the States is very expensive and you have to have a lot of money. But having Medicaid, it helps you a lot. The best thing for you is to get Medicaid.” (65+, Spanish)*
- *“Having Medicaid makes your life easier. You feel so different from having worries, especially if you’re over 60.” (65+, Spanish)*

**Medicaid Provides Adequate Access to Care** – Participants, in general, indicated that they have been able to access providers and the medical care they need.

- *“I can’t go to anybody I want, but I can find a doctor or a specialist or all sorts of things they have covered.” (Adults, Rural)*
- *“We’ve always found providers nearby. I like that there are a lot of providers that seem to accept it here.” (Parents, Rural)*
- *“I’ve always been able to get the care from a doctor that I need.” (Disability, Urban)*
- *“I was able to stay with my current provider.” (Adults, Rural)*

**It is Difficult to Find Out What Coverage Benefits Are** – Participants, in general, indicated that they have found it challenging to learn what benefits are covered on their Medicaid plan.

- *“I called to find out who I could go to for a vaccine, but I didn’t think they were knowledgeable. Three that she gave me, two of them were for in-patient treatments. I didn’t think she had a very good handle on places that would take Medicaid.” (Adults, Urban)*
- *“It’s been a little confusing since I went from traditional Medicaid to disability Medicaid because I know they pay for more, but utilizing the ‘more’ of things has been confusing because I don’t know what all they cover.” (Disability, Urban)*
- *“A recent worry that made me lose sleep and that still makes me anxious is that I had to see an ophthalmologist two weeks ago. When you talk to the staff, they don’t know what Medicare is going to pay. There are so many unknowns. I live in fear of getting that bill. I had to go, otherwise, I would rot away.” (65+, Rural)*
- *“They’re not as helpful as they could be when you’re asking about specific services covered. A couple months ago, one of the doctors recommended I get a panel of blood tests. She told me to check with Medicaid and make sure it’s covered. When I called, they said they didn’t know.” (Adults, Rural)*
- *“I found that the only way you can ever find out if something is covered, you have to have the specific code for everything. A lot of times, you have to call them with every code. I had to call my doctor and ask for every code in the panel. My daughter had bloodwork done, and I had 25 codes. It was tedious. Even if you say an MRI for you knee, they won’t tell you. You have to give them your specific insurance information and the specific code for what they’re going to bill.” (Adults, Rural)*
- *“I find that it’s easier to just call the doctor. The doctors can tell you who takes Medicaid.” (Disability, Spanish)*

**Lack of Coverage Knowledge Yields Lack of Medical Care** – Some participants indicated that because they were unsure of the benefits that are covered on Medicaid, they have avoided seeking medical care.

- *“I was supposed to get a mammogram. They told me any hospital, I could go to the Davis Hospital, so I tried to make an appointment and they said they don’t take Medicaid. So I asked the nurses, ‘Where do I go to get a mammogram?’ I am now 54 and I’ve never had a mammogram. I don’t know where to go with my Medicaid card to get one.” (Disability, Urban)*
- *“I just quit and I stopped going to see doctors. It was too frightening to think of what I could be charged. I’m still afraid to go to a hospital. I live on \$950 a month. It would be devastating to me. I’m afraid of the government and Medicare and Medicaid.” (65+, Rural)*

**Providers are Limited and Difficult to See** – Some participants—particularly those in rural areas—have had issues accessing healthcare providers, as providers accepting Medicaid are limited, and as some providers only accept a limited number of Medicaid patients per month.

- *“It took a while to find a doctor that would accept both Medicare and Medicaid.” (65+, Rural)*
- *“It’s been hard because coming from Minnesota, most of my doctors accepted Medicaid, so when I came to Utah, not every doctor accepts Medicaid here in Utah.” (Adults, Rural)*
- *“A lot of doctors have limits on how many they’ll take. I was looking for a dermatologist, and there were only six on there, and the ones that would still take it would only take two per month, so they had to schedule me out.” (Adults, Rural)*
- *“When we were on Medicaid and trying to find providers, availability wasn’t there. We were in waiting lines for several months knowing that by the time we were able to get an appointment, we would have a job and better insurance, so we just went without when we were on Medicaid.” (Parents, Urban)*

**It is Difficult to Pick a Plan** – Many participants reported that they chose their Medicaid plan, while others reported being assigned a plan. Participants who had little or no difficulty choosing a plan typically chose a plan based on the providers available in each plan. Participants who had difficulty in selecting a plan mentioned that the process was “confusing” and challenging.

- *“I don’t feel like I got enough information [to choose a plan].” (Adults, Urban)*
- *“I remember getting a letter saying there were Select Choice, Molina, etc. If you don’t do anything they pick one for you, but it didn’t explain how you choose, so I just let them choose. I don’t really know what the difference is; they’re all about the same. I don’t know the benefit of one versus the other. I don’t remember them ever explaining that.” (Parents, Rural)*
- *“My experience with the different plans is that it’s very confusing. They don’t provide enough information and to have them choose for me. There are differences, but it’s not really clear. We don’t have time to go reading through these different plans in order to choose one. If it could just be simplified and clarified for us so we could choose appropriately...” (Parents, Rural)*
- *“I chose because you have to choose a plan; but you don’t know which one helps the most.” (Disability, Spanish)*
- *“They tell you to choose a plan, but when you ask, ‘What are the differences between plans?’ they don’t know what to tell you the plan differences are. What I wanted was to choose one that is best adapted to my illness, that benefits me the most with my disease.” (Disability, Spanish)*

**Copays are Reasonable for Most, but Not for Some** – Participants who reported having a copay indicated that their copay is \$4. Most participants felt that this is a reasonable amount to pay, though a handful of participants—particularly those in rural groups or with disabilities—stated it is often a challenge to provide a copay.

- *“It’s only \$4, but when you’re broke, you’re broke.” (Disability, Urban)*
- *“My copay is only \$4, but when I have to put gas in my car, buy diapers, the basic necessities to make your family get by every day, \$4 can be a lot. It can add up quite fast.” (Parents, Rural)*
- *“Because of my medical issues I’m in and out of the hospital and the doctor’s office constantly. I don’t have anything. I have nothing, and I’m helpless, and hopeless and there’s nothing I can do. I’ll just opt out of going to the doctor [instead of paying the copay].” (Parents, Rural)*



**Medicaid Does Not Cover Important Medications** – Multiple participants expressed frustration with the fact that their medicines are not covered by Medicaid.

- *“If you have a set maintenance medication you’re on, they try to change it. I’m not happy with that.” (Adults, Urban)*
- *“Medicaid won’t cover that medicine. When I was in California, I was on something called Celebrex for my arthritis. They did cover it here when I first moved here, but then all the sudden they decided they weren’t going to cover it anymore. With my doctor, we went through the process you’re supposed to go through to try the generics. We went through all of that, and Celebrex was the only thing that worked. They still wouldn’t cover it. They won’t cover anything I need.” (Disability, Urban)*
- *“I have actually had an experience fairly recently where Medicaid was covering a prescription Vitamin E, and it covered it just fine, and then all of the sudden it wasn’t covering it, so I was having \$10 copays when normally I wouldn’t even have a copay at all.” (Disability, Rural)*
- *“Compound medications; when I lived in Hawaii, they were covered by their Medicaid. That would be so helpful. They’re so expensive. Those are things that I could use and take that would eliminate other stuff that is covered.” (Disability, Urban)*
- *“Something that I had to deal with that kind of baffles me, I can’t understand how they can have this policy. I travel between Utah and Ohio frequently, and I needed to get my prescriptions for my vacation. I called Medicaid and told them I needed them, and they were like, ‘We don’t do that.’ It was unbelievable to me. I just don’t understand how they can do that.” (Adults, Rural)*

**Medicaid Should Provide More Benefits** – Multiple participants indicated that their quality of life would be improved with expanded Medicaid benefits. When asked to identify the benefits they wish Medicaid offered that they don’t currently offer, participants most frequently mentioned dental and vision care, but mentioned the following as well:

- **Chiropractic health**
- **Dermatological care**
- **EMDR therapy**
- **Eye care**
- **Hormone therapy**
- **Mammograms**
- **Massage therapy**
- **Mental healthcare**
- **Orthodontia**
- **Oxygen therapy**
- **Prosthetics**
- **Respite care**
- **Surgery aftercare**
- **Therapeutic yoga**
- **Vitamins, supplements**

Participants offered the following comments about their desire to receive additional Medicaid benefits:

- *“My husband just wanted to see a chiropractor instead of a surgeon, but they don’t cover that.” (Adults, Rural)*
- *“Dental work is really expensive, so we just aren’t going to go do what we need to get done and that’s pretty tough.” (Parents, Rural)*
- *“When I first had my heart attacks they didn’t cover my aftercare, and that’s a huge problem. My physical health has gone down so bad now that I feel like I’m not going to wake up the next morning, it’s gotten really scary.” (Disability, Rural)*
- *“I also have some chronic problems that would benefit and help me to not be on medicine if I could get yoga or something like that with a trainer that helps and knows disability. A therapeutic type of yoga should be part of a preventative health.” (Disability, Rural)*
- *“With fibromyalgia, it’s been shown that if someone is able to get massages – and I’m not trying to be a princess or special – but there was a time when my mom was able to pay for these once a week and I was functioning a lot better. There are illnesses that require this type of care and treatment.” (Disability, Rural)*
- *“What would be better is that Medicaid cover mammograms for women at a younger age for preventative care. I was denied a mammogram because I was too young; I came back two years later and, boom, metastatic breast cancer. I think women’s preventative health should be taken more seriously.” (Disability, Rural)*
- *“I have been without vision coverage for quite a while. The glasses I’m wearing now are just reading glasses, and I’m supposed to have prescription. Not being able to see properly definitely affects my work performance, and my ability to provide for my family.” (Parents, Rural)*
- *“I wish Medicaid would cover glasses.” (Disability, Rural)*
- *“I would like to have a better prosthetic. Medicare is pretty strict about what I can or can’t have. But I could probably get closer to what I want if Medicaid would help pay some of it for my prosthetics.” (65+, Rural)*
- *“A therapist here said I would benefit from EMDR treatment, but it’s not covered by insurance.” (Disability, Rural)*
- *“I only have Emergency Medicaid and I had to have prostate surgery and it was rejected. I went to the emergency room because I was in a lot of pain and the diagnosis was the need for surgery but they denied coverage of the surgery. They alleged that it wasn’t an emergency surgery and that it wasn’t life threatening. For them it wasn’t life threatening, but for ME it was!” (65+, Spanish)*
- *“I wear glasses and I haven’t changed them for two years. Medicaid only covers the exam. They don’t cover the frames.” (Disability, Spanish)*

Participants in rural areas indicated that though their benefits offer certain coverage options, there are no providers in their area that accept Medicaid, which prohibits them from getting the care they need.

- *“No way can I get dental care here in Moab. I’ve called DWS and the dentist locally, and there is nobody. They just won’t deal.” (65+, Rural)*



## Evaluation of Mental and Behavioral Health Services

**Members are Unaware of Mental and Behavioral Health Benefits** – Some participants were not aware of mental and behavioral health services provided by Medicaid, but felt that such benefits would be of value.

- *“I feel I don’t know about mental health or counseling opportunities. It feels too daunting to figure out what options are available, so I just don’t feel like I do know what services I could be getting.” (Parents, Rural)*
- *“I kind of assumed that I couldn’t really get any mental health help. There’s stuff on the letters that addresses behavioral health, but I don’t know what kind of mental health stuff is covered. There’s not information on it.” (Parents, Urban)*

**Medicaid’s Mental and Behavioral Health Resources are Limited** – Overwhelmingly, participants throughout all segments commented that Medicaid’s mental and behavioral health services are limited and lacking—particularly in rural areas.

- *“I don’t feel like there’s a lot of options, first off. I think the behavioral health should match the medical health coverage. We just don’t get the same access to behavioral health as we do the medical.” (Parents, Rural)*
- *“I think it would be really nice to be able to have the mental health open up a little bit more, and not have to just go to one certain facility in the county. It’s hard to not have a choice with mental health.” (Disability, Rural)*
- *“I wish that there was more expansion with mental health providers. I was going to Valley for a long time, and now I’m at Southwest and it’s very limited.” (Disability, Rural)*
- *“I was pleased that there was coverage hospital-based, but when I went to outpatient, the options were much more limited.” (Adults, Urban)*
- *“There’s very limited providers. There are certain specific needs that I’m looking for, and I don’t have providers that are available to me that are specialized in those areas.” (Parents, Rural)*
- *“There’s only a select few psychiatrists and mental health doctors that I’ve come into contact with that will accept my insurance. We make a big deal about suicide prevention and things like that; well, mental health is just as big as that is. It’s very important for people’s sanity. We should have the availability to be seen by someone of our choice.” (Parents, Rural)*
- *“I had my daughter tested for autism and it was not the easiest to find a provider, and there was like one in the area. I would not have picked to go to him if I didn’t have to.” (Parents, Urban)*
- *“My psychiatrist is listed as a provider, but she’s having problems getting paid. Because of that, we’ve had to drop my therapy and just do prescription appointments. I have yet to be able to find another therapist that specializes in what I need.” (Disability, Urban)*
- *“It seems like if you have both Medicare and Medicaid, I learned that you’re in the situation where you’re limited as far as who you can see and who you cannot see.” (Disability, Rural)*
- *“I wish there were more providers, but more than anything I wish there were more specialized services that were approved.” (Disability, Rural)*
- *“In my area, I have one choice: Wasatch Mental Health. That’s pretty much it. They’re okay, but it would be nice to have a choice.” (Disability, Rural)*
- *“I had some psychological help because my husband committed suicide. I needed help right away. I was confused, out of it, I didn’t know what to do. They took about three weeks to find someone to help me. Then I only got one therapy session; they didn’t give me more.” (Disability, Spanish)*

**Some Mental and Behavioral Healthcare Providers Are Excellent, Others are Not –** Unfortunately, while some participants reported receiving exceptional mental and behavioral healthcare, others reported having negative experiences.

Excellent Care	Poor Care
<ul style="list-style-type: none"> <li>• <i>“For the most part, I actually feel pretty fortunate that I’m able to have therapy twice a week and Medicaid will cover it.” (Disability, Rural)</i></li> <li>• <i>“I have been so grateful for Medicaid for mental health services. I needed emergency care a year ago and got right in. From there, they took my file, what I needed, and I didn’t even have to worry about it anymore. They just passed it on to the people I needed to see.” (Adults, Rural)</i></li> <li>• <i>“I’ve been with the same person for eight years and he’s fabulous and I wouldn’t change it for the world. It’s been a very positive experience.” (65+, Rural)</i></li> <li>• <i>“I just had a talk with my psychiatrist yesterday and I had a talk with my therapist the day before. I’m very satisfied with the services that have been provided so far. My therapist comes out every week to my home, and I’m glad that’s covered by Medicaid.” (Disability, Urban)</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>“I used it for years until I had to switch. I was seeing a new lady. She asked me some real personal questions that made me sound like an idiot. I told her, ‘Well you’re the one that went to school for it!’ I walked out of the room. I went out to get my daughter, and the ladies behind the counter were laughing about some lady that had just left and how stupid she was. I’ve never gone back. I just handle it with my primary care provider through Wasatch Mental Health.” (65+, Rural)</i></li> <li>• <i>“I’ve had an issue with the providers I’ve found. Davis Behavioral Health, only one time did I have a therapist that knew her beans. All the other ones that I qualified to go see didn’t know what they were doing. I was misdiagnosed, I was put on medication I shouldn’t have been on.” (Disability, Urban)</i></li> <li>• <i>“My appointments are so far and few between, and the only way that I can get any frequency is with maybe an intern, and not really a professional. It makes it really hard.” (Disability, Rural)</i></li> <li>• <i>“They definitely seemed more like second tier services, just in the ease of getting in and the doctors that were there.” (Parents, Urban)</i></li> </ul>



## Exploring Community-based Services for Individuals with Disabilities

This section summarizes conversations with only the focus groups comprised of participants with disabilities, though most participants were unaware of such services, and urban participants were unable to speak to this subject entirely.

A handful of participants reported using community-based services. Specifically, participants mentioned the following:

- *“At Bear River Mental Health they have groups in the morning or afternoon at Bear River House. For the longest time, I was actually living in the group home. Medicaid didn’t cover it, it was \$10 a night.” (Disability, Rural)*
- *“I’ve had a nurse come over to just check on me and help set up a diet plan that’s healthy to help with my chronic illness. They have offered an open door for me to be able to reach out and ask for help to move things that are too heavy for me.” (Disability, Rural)*
- *“I started going to a place called The Clubhouse where you’d get out every day, have lunch, and work on projects with people in different departments of the place. It really did me a lot of good. It got me over fears of leaving the house, it got me feeling more valuable, and it got me feeling like I have more to offer. It was a preparatory step for me going back to school and a couple other things, getting involved with church, and now I have a life and feel like I’ve advanced a long way in my recovery.” (Disability, Rural)*
- *“I started volunteering my time at a place called Families Feeding Families. They also have the Cache Pantry where you can go get food and stuff like that, and that helps out a whole lot, too.” (Disability, Rural)*
- *“I’m affiliated with Ability First Utah, it’s an independent living center here in Provo. They do all they can to help people with whatever disability they have. They do transitional services, they help you find work, they help you with vocational rehabilitation, and they’re just wonderful. If you have an independent living center in your area, they could be a help to you. They could really be a big help.” (Disability, Rural)*

When asked how they learned of community-based services, one participant said, *“I realize that a lot of the stuff that I did learn about that I could use came in my first grade child’s folder in a flyer sent home to parents. A lot of times people are embarrassed of their situation or feel shame because of stigma and we don’t want to seek those services out. If someone slips me a flyer saying they can help with rent or food or I see it in there without feeling singled out for whatever reason, I’m more likely to go investigate. I’m more likely to go on a website and learn about it or send an email. If the information is put out toward you, you’re more likely to investigate it and want to choose an option for yourself and be interested without feeling shamed or criticized.” (Disability, Rural)*

When asked about the community-based services they would like access to, participants mentioned the following: housing, caregiving, housecleaning, home health, and hands-on training for the blind (rather than videos or printed information). One participant said, *“In California, I have a sister-in-law who does that – takes care of her husband and gets paid.” (Disability, Spanish)* Another said, *“Pay even just a little salary through Workforce or Medicaid to someone to be a housekeeper to take care of people in their homes.” (Disability, Spanish)*

## APPENDIX A: PARTICIPANT SCREENER

Hello, this is \_\_\_\_\_ calling on behalf of the Utah Department of Health. We are conducting focus groups with individuals enrolled in Medicaid, to learn more about your experience with the program. The focus group will last approximately [90 minutes for English / 2 hours for Spanish] and are held [via Zoom / in – person]. At the conclusion of the focus group, we will mail you a \$100 incentive check [**\$150 for Spanish Speaking groups**] as a thank-you for participating. We are not selling anything; we are only interested in your opinions. Is this something you would be interested in participating in?

I just have to confirm a few things.

1. [If Urban/Rural] In which county do you live?

- |                                       |   |                                       |
|---------------------------------------|---|---------------------------------------|
| <input type="checkbox"/> Beaver       | <input type="checkbox"/> Iron             | <input type="checkbox"/> Sevier       |
| <input type="checkbox"/> Box Elder    | <input type="checkbox"/> Juab             | <input type="checkbox"/> Summit       |
| <input type="checkbox"/> Cache        | <input type="checkbox"/> Kane             | <input type="checkbox"/> Tooele       |
| <input type="checkbox"/> Carbon       | <input type="checkbox"/> Millard          | <input type="checkbox"/> Uintah       |
| <input type="checkbox"/> Daggett      | <input type="checkbox"/> Morgan           | <input type="checkbox"/> Utah         |
| <input type="checkbox"/> <u>Davis</u> | <input type="checkbox"/> Piute            | <input type="checkbox"/> Wasatch      |
| <input type="checkbox"/> Duchesne     | <input type="checkbox"/> Rich             | <input type="checkbox"/> Washington   |
| <input type="checkbox"/> Emery        | <input type="checkbox"/> <u>Salt Lake</u> | <input type="checkbox"/> Wayne        |
| <input type="checkbox"/> Garfield     | <input type="checkbox"/> San Juan         | <input type="checkbox"/> <u>Weber</u> |
| <input type="checkbox"/> Grand        | <input type="checkbox"/> Sanpete          |                                       |

***Bold Counties = Rural; Max 2 per county for Rural***

Underlined Counties = Urban

2. [If Segment 1] My records show you are enrolled in a Medicaid Expansion program. Is this correct?

- Yes  
 No → **Thank & Terminate**

3. [If Segment 2] Are you currently pregnant or do you have children?

- Yes, pregnant  
 Yes, children  
 No, neither pregnant nor children → **Thank & Terminate**

4. [If Segment 3] My records show you have a disability, are blind, or are enrolled in a home and community-based services waiver—or that you are a guardian of someone enrolled in these waivers. Is this correct?

- Yes, I am enrolled  
 Yes, I am a guardian of someone enrolled  
 No, neither → **Thank & Terminate**

5. *[If Segment 4]* My records show you are age 65 or older. Is this correct?
- Yes
  - No → Thank & Terminate
6. *[If Spanish]* Do you speak Spanish, English, or both?
- Spanish only
  - English only → **Thank & Terminate**
  - Both → **Screen for Spanish Fluency**
7. *[If Spanish]* In what country did you live before you came to the United States?
- 

### **Virtual Group Invite**

We would like to invite you to participate in an online group discussion that will take place on **[Date] at [TIME], via Zoom**. We will send you a link to participate in the group; all you have to do is click the link we send you from your desktop or laptop (If your computer is an Apple/Mac you will be required to download the Zoom app). We ask that you participate in a quiet area, away from noise and distractions. We also ask that you keep your video on and your microphone muted unless you are speaking. One or Two days prior to your meeting we will be conducting reminder calls, during which time we will ask that you test the link on the computer you will be using to participate in the meeting. As I mentioned, you will receive **\$100 [\$150 for Spanish Speaking groups]** for participating in the group, and your check will be mailed the day after the discussion.

8. Have you participated in an online meeting using Zoom, Google Meet, Microsoft Teams, or another virtual platform?
- Yes
  - No → **Thank & Terminate**
9. Do you have a desktop computer, laptop, or tablet with a camera and microphone you can use to participate in an online focus group (not a Smartphone)?
- Yes
  - No → **Thank & Terminate**

**In-person Group Invite**

We would like to invite you to participate in a focus group discussion that will take place on **Monday, June 1 at 3:00 PM**. The focus group will be held at the office of Lighthouse Research & Development, located at 375 East 500 South in Salt Lake City. You may park on the street or in the parking lot to the west of the building. As I mentioned, you will receive **\$100 cash [There are no Spanish groups in-person]** at the conclusion of the **90-minute** discussion group.

**Enrolled Group Segments**

<b><u>Segment 1</u></b> <i>Adults</i>	<b><u>Segment 2</u></b> <i>Pregnant Women + Parents</i>	<b><u>Segment 3</u></b> <i>Disability + Blindness</i>	<b><u>Segment 4</u></b> <i>65+</i>
<input type="checkbox"/> 6/1 @ 3:00 PM <b>Urban</b> <i>(In-person)</i> <input type="checkbox"/> 6/1 @ 5:00 PM <b>Rural</b> <i>(Zoom)</i> <input type="checkbox"/> 6/1 @ 6:00 PM <b>Spanish</b> <i>(Zoom)</i>	<input type="checkbox"/> 6/2 @ 9:00 AM <b>Spanish</b> <i>(Zoom)</i> <input type="checkbox"/> 6/2 @ 3:00 PM <b>Rural</b> <i>(Zoom)</i> <input type="checkbox"/> 6/2 @ 5:00 PM <b>Urban</b> <i>(Zoom)</i>	<input type="checkbox"/> 6/2 @ 1:00 PM <b>Urban</b> <i>(Zoom)</i> <input type="checkbox"/> 6/2 @ 6:00 PM <b>Spanish</b> <i>(Zoom)</i> <input type="checkbox"/> 6/3 @ 1:00 PM <b>Rural</b> <i>(Zoom)</i>	<input type="checkbox"/> 6/4 @ 12:00 PM <b>Spanish Women</b> <i>(Zoom)</i> <input type="checkbox"/> 6/4 @ 1:00 PM <b>Urban</b> <i>(Zoom)</i> <input type="checkbox"/> 6/4 @ 3:00 PM <b>Rural</b> <i>(Zoom)</i> <input type="checkbox"/> 6/5 @ 10:00 AM <b>Spanish Men</b> <i>(Zoom)</i>

We would like to be able to send you directions and a reminder before the group. Can you please confirm your name, address, and contact information?

NAME \_\_\_\_\_

MAILING ADDRESS \_\_\_\_\_

CITY \_\_\_\_\_ ZIPCODE \_\_\_\_\_

HOME PHONE \_\_\_\_\_ ALT. PHONE \_\_\_\_\_

EMAIL ADDRESS \_\_\_\_\_

RECRUITED BY \_\_\_\_\_ DATE RECRUITED \_\_\_\_\_

SOURCE OF RECRUIT \_\_\_\_\_

If you have any questions or find that you can't attend, please call us right away at 801-446-4000 so we can find a replacement. We will be giving you a reminder call prior to the group. Thank you for your help.





## APPENDIX B: MODERATOR'S DISCUSSION GUIDE

### Objectives

The main objective of this research project is to gather feedback from Medicaid-enrolled participants in four different segments:

- 1) Adults enrolled
- 2) Parents enrolled (including pregnant women)
- 3) Enrolled individuals with disabilities or blindness
- 4) Seniors age 65 or older enrolled

To accomplish the project objectives, participants will be guided through a discussion that encompasses the following topics and themes:

#### **Explore the Application and Eligibility Determination Process**

- Discover how participants first learned about Medicaid
- Determine the method participants used to apply for Medicaid
- Explore the barriers participants encountered with applying for Medicaid
- Determine if the application process was timely
- Gather feedback regarding DWS interactions
- Determine how the application process could be improved

#### **Explore Medicaid Coverage and Benefits**

- Determine if participants and/or their families are currently enrolled in Medicaid
- Determine how long participants have been enrolled in Medicaid
- Explore overall satisfaction with their Medicaid experience
- Determine how their experiences could be improved while enrolled in Medicaid
- Identify gaps participants wish Medicaid covered that currently aren't covered
- Explore affordability of co-pays
- Determine if participants have a particular health plan
- Explore participants' satisfaction with their current health plans
- Evaluate Medicaid interactions

#### **Explore Community-based Services (Segment 3)**

- Determine how participants learned of home- and community-based services
- Explore satisfaction with home- and community-based services
- Identify barriers to accessing services
- Determine how utilizing services could be made easier
- Determine how such services could be improved
- Determine if there are gaps in services that should be provided that aren't
- Identify aspects that are most important in creating a waiver

## Part One: Introduction and Greeting

10 Minutes

### **Moderator Introduction**

- Moderator introduction
- Ask participants to turn off cell phones
- *[Zoom Groups]* Ask participants to seclude themselves in a quiet spot/room
  - Ask participants to mute themselves when not talking (if necessary)
- Observers are present to take notes and ensure participant ideas and opinions are recorded correctly
- Advise participants of recording

### **Purpose of Focus Group**

“The reason we are here today is to gather your impressions about your experience with Medicaid. I will be leading you through some discussion questions and activities to help us learn more about what you think. We are very interested in each of your personal thoughts and opinions. Please try not to let the comments of others in the group influence what you share during the discussion.”

### **Moderator Role**

- To introduce the discussion topics, ask probing questions, and guide the discussion through each of the relevant issues
- The moderator is not to guide the participants’ responses or give advice

### **Discussion Rules**

- Speak one at a time; we want to hear all of your ideas.
- Everyone needs to participate; we need everyone’s ideas and comments.
- There are no wrong or right answers; we invited each of you here so we could understand what you know and how you feel about these topics.
- It is likely that your opinions will differ from someone else’s in the room; as such, please be respectful of others and their opinions.

### **Participant Icebreaker**

Participants will be asked to introduce themselves, including the following in their introductions.

### **General Public Groups**

- Name
- City of residence
- Occupation
- Number of people in their families

## Part Two: Explore the Application and Eligibility Determination Process

30 Minutes

As I mentioned before, each of you have been invited to participate, as you are currently enrolled in Medicaid. (Confirm before proceeding.)

**Q1.** How did you first learn about Medicaid?

### Application Process

**Q2.** How did you apply for Medicaid?

- **Prompt:** Online, paper application, via telephone?

**Q3.** Using a one-to-five rating scale where one is “very difficult” and five is “very easy,” please rate how difficult or easy the application was for you to complete. Explain.

**Q4.** What challenges did you have in completing the application?

- **Prompts**
  - Was the application easy to find? Explain
  - Was the application easy to understand? Explain
  - Did you need help from someone in completing the application? Explain.

**Q5.** What could be done to improve the application process?

**Q6.** By show of hands: Were you required to complete an interview with DWS prior to being approved for Medicaid coverage?

- **Prompt:** Was your interview scheduled in a timely manner? Explain.

**Q7.** Were you required to provide additional information after your application was submitted?

- **Prompt:** What were you asked to provide?
- **Prompt:** Was it easy or difficult to provide this information? Explain.

**Q8.** Using a one-to-five rating scale where one is “not at all satisfied” and five is “very satisfied,” how satisfied are you with how long it took to get approval once your application was submitted? Explain.

- **Prompt:** How long did the process take?
- **Prompt:** How long did it take after approval to receive your Medicaid card?

**Q9.** Have you ever been denied coverage or lost coverage? Why?

- **Prompt:** Did you understand why coverage was denied/lost?
- **Prompt:** Were you able to have your questions answered to your satisfaction?

## DWS Interaction

- Q10.** By show of hands: Was your case assigned to a single DWS worker or a team?
- Q11.** How do you typically interact with DWS?
- Q12.** Using a one-to-five rating scale where one is “not at satisfied” and five is “very satisfied,” how satisfied are you with your interaction with DWS? Explain.
- **Prompt:** Were your calls answered in a timely manner?
  - **Prompt:** Were you treated with kindness and courtesy?
  - **Prompt:** Were DWS workers helpful?
  - **Prompt:** Were your questions answered to your satisfaction?
- Q13.** By show of hands: Have you ever used myCase or the DWS website?
- **Prompt:** Using a one-to-five rating scale where one is “not at all satisfied” and five is “very satisfied,” how satisfied are you with myCase or the DWS website? Explain.
  - **Prompt:** Do you have concerns with using myCase/DWS website? Explain.
  - **Prompt:** What information should be included on myCase/DWS website that isn’t currently there?

## Part Three: Explore Medicaid Coverage and Benefits

30 minutes

### Medicaid Experience

- Q14.** Who in your household is currently enrolled in Medicaid?
- Q15.** How long have you/your household been enrolled in Medicaid?
- Q16.** Using a one-to-five rating scale where one is “not at all satisfied” and five is “very satisfied,” please rate how satisfied you are with your experience as a Medicaid member? Explain.
- **Prompt:** Have you/your family been able to get the care you need through Medicaid?
- Q17.** How could your experience with Medicaid be improved?
- Q18.** Are there benefits you wish Medicaid covered that are not currently covered? Explain.
- Q19.** Do you feel your copay is a reasonable amount? Explain.
- **Prompt:** What is your copay amount?
  - **Prompt:** Have you ever chosen not to go to the doctor/ER/pharmacy because of the cost of your copay amount?

### Health Plans

- Q20.** Are you enrolled in a specific health plan?
- **Prompt:** Which health plan are you enrolled in?
    - Health Choice Utah
    - Molina Healthcare
    - Healthy U
    - Select Health Community Care
- Q21.** Using a one-to-five rating scale where one is “not at all satisfied” and five is “very satisfied,” how satisfied are you with your current health plan? Explain.
- Q22.** Did you choose your current health plan?
- Q23.** Did you have difficulty selecting a plan? Explain.
- Q24.** Do you know how to change your plan if you wanted?
- Q25.** Has it been easy or difficult to find providers that you need, whether it be a general practitioner, a specialist, dentist, etc.? Explain.

### **Mental Health**

- Q26.** By show of hands: Have you used Medicaid’s behavioral health services (i.e. mental health, substance abuse, medication, etc.)?
- Q27.** Using a one-to-five rating scale where one is “not at all satisfied” and five is “very satisfied,” how satisfied have you been with Medicaid’s mental and behavioral health services? Explain.
- Q28.** Have you been able to find a provider through Medicaid’s mental and behavioral health services?
- Q29.** What could improve your experience with Medicaid’s mental and behavioral health services?

### **Medicaid Interaction**

- Q30.** Have you contacted Medicaid about your benefits or to find a provider? (i.e. Medicaid hotline or a Health Program Representative)
- Q31.** Using a one-to-five rating scale where one is “not at all satisfied” and five is “very satisfied,” how satisfied were you with your interaction with a Medicaid representative? Explain.
- Q32.** Was the representative helpful?
- Q33.** Were your questions answered to your satisfaction?

**Part Four:**  
**Explore Community-based Services (Segment 3)**

*10 Minutes*

*Currently, you use home- and community-based services.*

- Q34.** What home- and community-based services do you utilize?
- Q35.** How did you learn of these home- and community-based services?
- Q36.** Using a one-to-five rating scale where one is “not at all satisfied” and five is “very satisfied,” how satisfied are you with your experience using home- and community-based services?
- Q37.** What challenges have you experienced accessing these service?
- Q38.** How could it be easier to access these services?
- Q39.** What could be done to improve the home- and community-based services?
- Q40.** Are there services you would like to be available that aren’t currently?
- Q41.** If you could create a waiver, what would be most important to you?

**Part Five:**  
**Conclusion**

*10 Minutes*

- Q42.** Do you have additional comments you would like to provide about your experience, or suggestions for improvement, that haven’t already been mentioned?

The moderator will thank participants for their time and dismiss the group.