

# State Medicaid Member Experience Qualitative Data Scan



The State Health Access Data Assistance Center (SHADAC), with support from the Robert Wood Johnson Foundation (RWJF), and in collaboration with partner organizations is in a second planning phase to assess whether a data tool to track indicators of health equity in state Medicaid programs can be designed, developed, and maintained to provide information and opportunities for structural change to improve health for people enrolled. At the end of the first project phase, a high-level conceptualization wireframe of a potential tool was developed. In this second planning phase, the project team will now create a series of resources to shed light on the opportunities and gaps in populating sections of a first iteration data tool that aligns with the wireframe created in phase one. Information in this specific resource is foundational for the section of the wireframe labeled “State Medicaid Member Experience.” This section of the tool (shown in green in the image below) would present qualitative information about member experience for various subgroups and how experiences are changing over time.

State Medicaid Member Experience			Health Outcomes			Underlying Factors
Measures describing how equitable a Medicaid member's journey is through the program at each stage.			Measures describing how equitable member health outcomes are.			Information about factors in the Medicaid system that perpetuate health inequities for people of color and other communities that have been historically marginalized and how they can be addressed.
Seeking and Keeping Coverage	Satisfaction with Services and Providers		Mortality	Chronic Disease Prevalence	Clinical Quality Measures	
Accessing Needed Services	Member-reported Health and Well Being					
Medicaid Program Actions			Demographics			Root Causes (e.g., racism, ableism, classism)
Measures describing actions state Medicaid programs are taking to address health equity and what we know about what's working.			Measures describing who does/should Medicaid serve.			Vital Community Conditions (e.g., access to food, housing)
Program Structure	Coverage and Benefits	ACO/MCO Contracting and Provider Payment	Medicaid as Percent of Population	Medicaid Members	Medicaid Providers	Glossary of Terms
Community Engagement	Investments in Community Supports and SDOH	Medicaid Expenditures				Sources and Methods

## Background

In May 2021, SHADAC embarked on a multi-phased project to assess the feasibility of developing a national Medicaid Equity Monitoring Tool that would be useful to state Medicaid programs, policymakers, advocates, and other organizations. The goal of this tool would be assisting with access to Medicaid and care, along with aiding efforts to advance health equity. Visit the SHADAC website for an [overview of the project](#).

## Summary of Key Takeaways

- The State Health Access Data Assistance Center (SHADAC) with support from the Robert Wood Johnson Foundation (RWJF) finished the first phase of our Medicaid Health Equity Monitoring Tool project with the creation of a **high-level conceptual wireframe** of a potential tool.
- Phase two requires **identifying both opportunities and gaps in populating sections** of that wireframe. This resource focuses specifically on **qualitative research studies related to Medicaid member experience**.
- We **identified 15 subpopulations of particular interest** to keep centered in equity work and limited the review for this brief to sources that focused on Medicaid experiences in these populations.
- SHADAC found that **there are few qualitative sources** available that explore the experiences of Medicaid enrollees, and even fewer that focus specifically on the populations of interest.
- **Discrimination, Accessing Services, and Care Experience/Satisfaction** were the most common domains with which member experiences were associated. **Most experiences reported were negative**.
- Of the 21 studies reviewed, **only two surveys were longitudinal**, representing a substantial gap in the availability of sustained qualitative data collection on the Medicaid member experience.

In the initial phase, SHADAC recruited an Advisory Committee of experts, including state Medicaid agency staff, policymakers, researchers, and representatives of marginalized communities that have an interest in tracking health equity in Medicaid, and conducted key informant interviews, to explore whether there is a need for a data tool. The Committee confirmed the need for a tool and agreed on a broad purpose: to serve as an accessible, flexible, member-centered data resource that allows users to monitor health equity-related activities and outcomes and hold Medicaid accountable for actionable solutions that improve access to care and advance equity, health and well-being in communities. The Committee also set high-level goals for future project phases, including that the tool must also include information on the root causes of health inequities in the Medicaid program, including [structural racism and resulting social determinants of health](#). The hope is that a Medicaid Equity Monitoring Tool will provide information and opportunities for structural change to improve health equity for people enrolled in Medicaid.

Measurement concepts that consistently rose to the top of the Advisory Committee’s priority list were those related to understanding the Medicaid member’s experience. The Advisory Committee was interested in assessing member experiences not only after they have received care, but also earlier in their journey through the Medicaid program related to seeking and enrolling in coverage and accessing services. Findings from a scan of quantitative data sources related to Medicaid member experience is available [here](#).

This brief summarizes findings related to a targeted, qualitative data scan focused on member experience measures as well as subpopulations identified by the Advisory Committee. After a description of our methods, we present the results of our scan of both peer-reviewed and grey literature in terms of characteristics of sources identified as well as what was learned about the experiences of Medicaid members. Additional detail about each source is provided in the Appendix.

## Methods

The Advisory Committee recommended focusing the Medicaid Equity Monitoring Tool on people who are “at the margins” in order to keep the perspective of the communities that are most marginalized and impacted by Medicaid program inequities at the center of this work. The Committee identified 15 populations of interest:

- Black/African American people
- American Indian/Alaska Native people
- Hispanic people
- Asian/Pacific Islander people
- Non-English-speaking people
- People living in rural areas
- Adults (18-65) with very low income (under 50 percent Federal Poverty Level)
- Adults living with disabilities
- Dually eligible (Medicare and Medicaid) people
- Adults with mental illness and/or substance use disorder (SUD)
- Justice-involved people
- Persons who identify as LGBTQ+
- Pregnant/birthing people
- Infants (0-1 years)
- Children (>1-18 years)

Along with centering certain marginalized and impacted communities, the Advisory Committee also recommended consideration of several measurement concepts of Medicaid member experience, which we “bucketed” into five high-level domains: **accessing services; experience/satisfaction; discrimination within the health care system; member reported health and well-being; and seeking and keeping coverage.**

This data scan focused on qualitative sources, including Medicaid member focus groups, interviews, stories, committees, surveys, and other similar information gathering methods. Resources were identified through searches on Google Scholar and the University of Minnesota library database. Search strings included variations

of “Medicaid experience [population of interest]”, “Medicaid enrollee experience [population of interest] equity interview”, and “Medicaid member experience [population of interest] inequity”, searching for each population of interest and interchanging “interview” with other forms of qualitative data collection (e.g., focus groups, committees, etc.).

Factors for inclusion were sources that focused specifically on Medicaid enrollees in the population of interest or described Medicaid enrollees’ experiences in the context of the population of interest. SHADAC also only included products published between 2017 and 2023 to ensure timely information, greatest relevance, and the inclusion of foundational projects; sources from before 2017 were excluded. Sources that described the population of interest’s health care experiences were excluded unless they specifically referenced Medicaid. Sources that referenced Medicaid and/or a population of interest without discussing health experiences or connecting Medicaid coverage and health experience were excluded (e.g., one person in a rural focus group discusses grocery stores in their area and happens to be on Medicaid). Sources using only quantitative methods were also excluded.

## Findings

Based on the methods above, SHADAC found that there are few qualitative sources available that explore the experiences of Medicaid enrollees, and even fewer that focus specifically on the populations of interest identified by the Committee. A total of 21 sources were found to fit the inclusion criteria. All but two of the member experience data sources found were collected at a single point in time. The most common forms of qualitative data collection were interviews (including semi-structured interviews, telephone and in-person interviews, and interviews using a biographical narrative interpretive method) and focus groups. Just two surveys were longitudinal, representing a substantial gap in the availability of sustained qualitative data collection on the Medicaid member experience.

Most products included data collection at the state level. Products assessed member experiences from states across the US as well as a few geographic regions and one Gulf Coast tribe. There were more California-specific resources than any other state. No resources assessed member experience at the national level, though a few resources identified participants at a program or local level.

Questions and prompts were similar to the following (extracted from sources when available):

- Are discrimination and unfair judgement the same or different? (McDaniel et al.)
- What were some positive aspects of interacting with your Managed Care Organization (MCO)? (Arora et al.)
- What were some negative experiences that you’ve had when interacting with your MCO? (Arora et al.)
- How does experiencing discrimination and/or unfair judgment affect how people may view and use the health care system? (McDaniel et al.)
- During your recent hospital stay when you had your baby, how often were you treated unfairly because of your race or ethnicity? (Sakala et al.)
- During your recent hospital stay when you had your baby, how often were you treated unfairly because of the type of health insurance you had or because of your lack of insurance? (Sakala et al.)

## Findings by Measurement Domain

Using the information gained from the 21 included qualitative sources, we found that Medicaid enrollees in the identified populations of interest largely described negative experiences related both to their coverage and to

how they felt their identity or identities affected that coverage. All member observations fit into the five high-level measurement domains identified by the Committee. The most common domains that are associated with the qualitative member experience data we found during this scan were *Discrimination, Accessing Services, and Care Experience/Satisfaction*.

The following section presents findings by measurement domain from the included qualitative resources identified during this data scan. Each measurement domain includes a domain-relevant quote from members of the populations of interest. For more information on the source geographies, populations of interest, sponsor, and quote examples, see the appendix.

### ***Seeking and Keeping Coverage***

**“The hardest part was applying for it. It was a lot of paperwork.”** – Pregnant Medicaid Member

- Members from multiple populations of interest described health plans not having sufficient coverage, experiencing a denial of requests for additional coverage, having to use multiple forms of insurance to ensure coverage, making care decisions based on expected coverage loss, and more
- Members from multiple populations of interest struggled with obstacles to enrollment and redetermination, finding requirements for different programs confusing
- Members from multiple populations of interest noted some Medicaid policies can exacerbate issues with healthcare navigation (e.g., difficulties with proof of program, coverage, address, etc.)
- Members from multiple populations of interest described concerns about losing coverage if they receive additional pay or experience changes in employment status
- Some members reported administrative difficulties related to their Medicaid coverage

### ***Accessing Services***

**“Although Lia needs 24/7 care, her plan only covers 34 hours of personal care assistance. The plan has denied three requests for an additional 64 hours of personal care service.”** – Interview with sister of Medicaid Member living with a disability

- Members from multiple populations of interest described issues with accessibility including difficulties with assistive technology, lack of internet access, issues with using online accounts, and difficulties contracting with transportation vendors in rural areas
- Members with primary languages other than English experienced difficulty with language barriers on Medicaid applications and lack of translators for interactions with agency staff
- Pregnant members noted having limited choices and access for doctors and birth services; they also described delayed access to resources
- Members from multiple populations of interest described limited access to services including birth services and doctors, and home health services
- Some elder American Indian members described difficulty finding and receiving needed services due to confusion and complexities related to health insurance, which was exacerbated by inconsistent outreach by insurance providers and government agencies

### ***Care Experience/Satisfaction***

**“[Treatment centers would say] ‘You’re doing this, you’re doing that, you’re not complying’, and [...] the ACS [Administration for Children’s Services] worker will say, ‘Oh yes, she’s not complying and she doesn’t want her kids.’ No, that’s not it. You’re putting me in a place that I’m not comfortable with, that I don’t feel like I’m getting what I need.”** – Medicaid Member with SUD

- Adult members described poor experiences that lead to delaying medical care
- Pregnant members described dissatisfaction with care communication and pressure from providers in making care choices
- Some members had positive experiences, reporting gratitude for Medicaid’s role in them and their children’s care experiences, positive feedback from working with care teams, and working with responsive providers
- One member described difficulties with care for her autistic child – providers stopped working with the child for the very behaviors the parent was seeking care to treat

### ***Member-Reported Health and Well-Being***

**“Another participant felt that without Medicaid she wouldn’t have been able to pay for all the healthcare she needed while pregnant: ‘I was able to access, I had good health care. I had great, I qualified for Medicaid....I went to all my prenatal visits...I had it good.’”** – Pregnant Medicaid Member

- One member in two different sources noted that their access to medication due to their insurance was important for maintaining their physical and mental health
- An analysis of interviews conducted with people with Limited English proficiency status found that postponed or canceled care visits were associated with mental stress and poor overall health and well-being

### ***Discrimination***

**“I just had my baby a few weeks ago, and I feel like the doctors treated me differently because I was black. Especially when asked for an epidural or pain medication.”** – Black Medicaid Member

- Members experienced discrimination, dismissal, mistreatment, and disrespect from providers, receptionists, and others related to the care experience based on race, ability, public insurance status, etc.
- Black, Indigenous, and People of Color (BIPOC) members described welfare stigma when interacting with agency representatives
- Members noted lesser quality of care and unfair/different treatment for both women of color and those with state Medicaid coverage
- Gender-expansive members described structural stigma-related barriers in routine care and insurance policy communications

## **Conclusion**

Our goal with this resource was to compile recent evidence about equitable or inequitable experiences in the Medicaid program for each subpopulation of interest for a future Medicaid Equity Monitoring Tool. This will help to inform member engagement that will take place during this project phase, which will be led by Health Leads. Including a representation of qualitative data in the tool could also provide a more nuanced understanding of member experiences across states, which would otherwise be unmeasured by quantitative data collection methods. The appendix table includes additional quotes and findings from these sources.

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**Appendix Table: Excerpts of Key Findings from Qualitative Resources Describing Medicaid Member Experiences**

Author(s), Date, Sponsor(s), and Population of Interest	Measurement Domains	Excerpts from Qualitative Resources	State/Geography
<p><b>Author(s):</b> Allen et al.  <b>Date:</b> 2022  <b>Sponsor(s):</b> Kate B. Reynolds Charitable Trust (Urban Institute contractor)  <b>Population of Interest:</b> People living in rural areas</p>	<i>Seeking and keeping coverage</i>		NC
	<i>Accessing Services</i>	<p>These informants noted that provider shortages were most common in behavioral health care, pediatric specialties, and therapies such as occupational and speech therapy and for most provider types in rural areas. However, key informants also acknowledged that shortages in these specialties and rural areas existed even before the managed-care transition. There were also challenges with contracting transportation vendors in rural areas, which tend to have limited public transportation options and fewer providers. These challenges required residents to travel longer distances to access care.</p>	
	<i>Care Experience/satisfaction</i>		
	<i>Member reported health and well being</i>		
<p><b>Author(s):</b> Arkansas Advocates for Children &amp; Families  <b>Date:</b> 2022  <b>Sponsor(s):</b> Arkansas Advocates for Children &amp; Families (AACF)  <b>Population of Interest:</b> Black/African American people, Pregnant/birthing people, Children, People living with disabilities, Infants</p>	<i>Seeking and keeping coverage</i>	<p>“The hardest part was applying for it. It was a lot of paperwork.” Lauren says the paperwork process is slow and difficult: “just frustrating the red tape parents have to work through to keep their services, rates correct, etc.”</p>	AR
	<i>Accessing Services</i>	<p>Lauren also notes that there are some therapies that are beneficial to her son with special needs that are not covered by Medicaid. Chiropractor services and alternative therapies, for example, do not tend to be covered under Medicaid.</p>	
	<i>Care Experience/satisfaction</i>	<p>“It has helped us tremendously as far as paying all medical costs and providing transportation when I was pregnant. I absolutely love it.” “I have always went to the doctors when needed... They have taken care of me and my baby.” “It was like a miracle. I was able to go to the doctor, be seen by any doctor.”</p>	
	<i>Member reported health and well being</i>	<p>Although Celeste has been able to receive coverage, she struggles with taking care of her physical health.</p>	
	<i>Discrimination</i>	<p>When SS was in the hospital for the birth of her child she felt discriminated against by the medical providers. “I just had my baby a few weeks ago, and I feel like the doctors treated me differently because I was black. Especially when asked for an epidural or pain medication.” SS stated that she was not given an epidural after asking multiple times. However, she did receive some pain medicine eventually. SS also feels that there has been mistreatment from medical providers due to having Medicaid coverage. “I do feel that I have been given some wrong information, I do not think they would have given me that information if I had better insurance, like private insurance.” MD: “I have been treated unfairly because I feel doctors treat you differently if you have Medicaid, especially if you are Black. I feel you are seen as uneducated.”</p>	
<p><b>Author(s):</b> Arora et al.  <b>Date:</b> Jan. 2020  <b>Sponsor(s):</b> No funding organization  <b>Population of Interest:</b> People living with disabilities, Older adults</p>	<i>Seeking and keeping coverage</i>	<p>Findings indicate serious concerns among LTSS beneficiaries in Iowa’s MMC, including cuts and delays in service approvals, challenges with care coordination and delayed provider payments. Several waiver beneficiaries experienced impediments in navigating the new system as well as in getting recourse when the above challenges arose, whether through MCO customer service or the state’s MCOP office. The perception that MCO practices were “deliberately” designed to cause such issues was common across multiple themes.</p>	IA
	<i>Accessing Services</i>		
	<i>Care Experience/satisfaction</i>	<p>Many respondents described situations in which the MCOP was responsive and led to positive outcomes: “They were extremely helpful in getting his supplies,” and “They jumped in right away and they would update me through the process. They did a fantastic job.”</p>	
	<i>Member reported health and well being</i>		
	<i>Discrimination</i>		
<p><b>Author(s):</b> Beaver et al.  <b>Date:</b> Feb. 2023  <b>Sponsor(s):</b> Centers for Medicare and Medicaid Services and Massachusetts (Mathematica contractor)  <b>Population of Interest:</b> Dually eligible people, People living with disabilities</p>	<i>Seeking and keeping coverage</i>		MA
	<i>Accessing Services</i>	<p>Beneficiaries in the blind or low vision group reported more difficulty reaching their MMP and receiving educational materials on member protections than those in the other two subgroups. A few of these commented that their MMP’s automated phone system and mailed materials were inaccessible.</p>	
	<i>Care Experience/satisfaction</i>	<p>Interviewees generally shared positive feedback about working with health teams, especially how providers, coordinators and informal supports communicated with one another to facilitate their care. Those with a recent in-patient hospitalization were satisfied with the after-care experiences facilitated by their MMP.</p>	
	<i>Member reported health and well being</i>	<p>Discrimination</p> <p>Despite those in the blind and low vision group reporting highly positive MMP experiences overall, those in the Spanish-speaking blind or low vision group reported less communication, care coordination, HCBS and NEMT use than that reported by English-speaking participants.</p>	



Author(s), Date, Sponsor(s), and Population of Interest	Measurement Domains	Excerpts from Qualitative Resources	State/Geography
<b>Author(s):</b> Cummings <b>Date:</b> Jan. 2022 <b>Sponsor(s):</b> California Health Care Foundation (CHCF) <b>Population of Interest:</b> Black/African American people	<i>Seeking and keeping coverage</i>		CA
	<i>Accessing Services</i>		
	<i>Care Experience/satisfaction</i>		
	<i>Member reported health and well being</i>		
	<i>Discrimination</i>	“The clinics in, let’s say, a Black neighborhood, for Black and brown people . . . the facilities and the equipment will be substandard as well....” — 55-year-old Black man, Los Angeles “[The hospital where my wife gave birth] did a good job. A reason I know this through my wife’s two best friends . . . I heard about the stuff my wife’s friends went through and their experience during childbirth. I couldn’t imagine the [expletive] they went through. But both of them had their children through Medi-Cal, through the state, through the system, whereas we have private insurance and a private doctor, and we picked the hospital. We picked everything.” — 31-year-old Black man, Los Angeles	
<b>Author(s):</b> Cummings <b>Date:</b> Oct. 2022 <b>Sponsor(s):</b> California Health Care Foundation (CHCF) <b>Population of Interest:</b> Black/African American people	<i>Seeking and keeping coverage</i>	[A] lot of people want to do something and you feel like, “Well, we can pay you to do that thing,” but then just even five dollars over their limit that they get from their other programs cuts them off and so they would rather not get money or do it. . . . This one lady . . . wanted to be helpful and wanted to work and just giving her a stipend to help her with her gas, if she reports that then it already goes like five dollars over the amount that she’s allowed to have as an income. . . . Then they cut her off on everything and it’s like, “No, I’d rather not,” so that’s really frustrating.	CA
	<i>Accessing Services</i>		
	<i>Care Experience/satisfaction</i>	Women with Medi-Cal coverage (52%) report inadequate treatment for pain.	
	<i>Member reported health and well being</i>		
	<i>Discrimination</i>	Reports of mistreatment are high for respondents with a disability (40%) and for Medi-Cal enrollees (37%). More than one in three Medi-Cal enrollees report avoiding care due to concerns about being treated fairly.	
<b>Author(s):</b> Florida Health Justice Project <b>Date:</b> 2022 <b>Sponsor(s):</b> The Florida Bar Foundation, Health Foundation of South Florida <b>Population of Interest:</b> People living with disabilities, Children	<i>Seeking and keeping coverage</i>		FL
	<i>Accessing Services</i>	Lia’s sister, Linda, said, “If you don’t have an advocate, you fall through the cracks.” Her managed care plan has also failed to provide her with a nurse despite Lia’s use of a catheter and recurrent UTI’s. Although Lia needs 24/7 care, her plan only covers 34 hours of personal care assistance. The plan has denied three requests for an additional 64 hours of personal care service.	
	<i>Care Experience/satisfaction</i>	In spite of ongoing challenges with the managed care plan, Alene is grateful for the Medicaid home health services she receives. “This program is what keeps people like me going. It’s our lifeline. Without Medicaid paying for my home health services, I would be on a nursing home or assisted living. Like most people, I want to live independently in my own place.” “It would have been terrible if my kids did not have coverage under Medicaid. I thank Medicaid for taking care of my kids,” Miriam says.	
	<i>Member reported health and well being</i>		
	<i>Discrimination</i>		
<b>Author(s):</b> Greene et al. <b>Date:</b> Apr. 2022 <b>Sponsor(s):</b> Robert Wood Johnson Foundation (RWJF) <b>Population of Interest:</b> 20 grantees focused on immigrants, people of color, Children	<i>Seeking and keeping coverage</i>	Immigrant People with Medicaid Experience (PME) often struggled with language barriers on Medicaid applications, lack of translators when interacting with agency staff, and correspondence with “wording used above their comprehension level.”	ID, UT, AZ, AK, TX, OK, MO, AR, LA, IL, KY, TN, MS, FL SC, NC WV, VA, DE, DC, NY, NH, MA
	<i>Accessing Services</i>		
	<i>Care Experience/satisfaction</i>		
	<i>Member reported health and well being</i>		
	<i>Discrimination</i>	“BIPOC PME reported that it “depends on the people’ they interact with at the agency, but they sometimes feel ‘stigma...when interacting with agents of DHS,’ ‘slighted by the attitudes of representatives,’ or ‘greater scrutiny when applying.’”“Most folks are responding that they ... have not felt racism or discrimination in the Medicaid process or even really the access to care portion of their Medicaid experience. I think one person identified ... the lack of providers that accept Medicaid in her area. She was like I feel this is a result of ... racism and discrimination that there’s not more available to me in ... the part of town I live in.”	

Author(s), Date, Sponsor(s), and Population of Interest	Measurement Domains	Excerpts from Qualitative Resources	State/Geography
<p><b>Author(s):</b> Jaramillo et al.  <b>Date:</b> 2022  <b>Sponsor(s):</b> Unknown  <b>Population of Interest:</b> American Indian people</p>	<i>Seeking and keeping coverage</i>	One elder recounted receiving a letter from his Medicaid provider that said, “You were late [in recertifying] and were dropped”; when asked if he had followed up to reenroll, he joked, “I don't think so. I'll wait. I'll just quit getting sick.” An elder lamented the case of an acquaintance who refused the opportunity to make a little extra money because she was afraid even a few dollars would cause her to lose health and social programs on which she relied	2 southwest states
	<i>Accessing Services</i>		
	<i>Care Experience/satisfaction</i>		
	<i>Member reported health and well being</i>	Elder and professional interviewees agreed that the complexities, ambiguities, and shortcomings associated with health insurance took a significant toll on elders. These problems were aggravated by inconsistent or unreliable outreach on the part of government agencies and health insurance providers.	
<p><b>Author(s):</b> LeBlanc et al.  <b>Date:</b> 2022  <b>Sponsor(s):</b> Patient-Centered Research Outcomes Institute (PCORI); dissemination supported by National Institute of Allergy and Infectious Diseases  <b>Population of Interest:</b> Persons who identify as LGBTQ+</p>	<i>Seeking and keeping coverage</i>		MA, NY
	<i>Accessing Services</i>		
	<i>Care Experience/satisfaction</i>		
	<i>Member reported health and well being</i>	<i>Discrimination</i> <p>"One FG [focus group] participant described an experience with structural discrimination in utilizing Medicaid and the lag time and discrepancy due to the process of legal name changes. Additionally, TGD participants shared that they had faced further structural stigma-related barriers with health insurance. One participant offered a personal example in utilizing their Medicaid policy and noted a discrepancy in communication due to their name change. '[an] experience dealing with insurance is that they're not sensitive to the name change because you can go by the name you want but that doesn't mean legally that your name has changed yet. And then when your medical insurance like Medicaid wants to give you a phone call they call you by that name. And it's like no' (New York Focus Group)."</p>	
<p><b>Author(s):</b> Liddell and Lilly  <b>Date:</b> 2022  <b>Sponsor(s):</b> Tulane School of Liberal Arts, New Orleans Center for the Gulf South at Tulane University  <b>Population of Interest:</b> American Indian people, Pregnant/birthing people</p>	<i>Seeking and keeping coverage</i>	Many participants described how they used multiple forms of insurance to ensure adequate coverage, especially during pregnancy and youth. One participant was able to use Medicaid as supplemental insurance to offset costs associated with pregnancy, but she notes that this coverage only extended a few months after the pregnancy ended.	Gulf Coast Area
	<i>Accessing Services</i>	One participant discussed the need for tribal members to learn about Medicaid enrollment to increase low-income people's ability to access healthcare - increasing awareness about and access to Medicaid coverage might go a long way in helping people to access healthcare who might not otherwise be able to afford it.	
	<i>Care Experience/satisfaction</i>	<i>Member reported health and well being</i> <p>Another participant felt that without Medicaid she wouldn't have been able to pay for all the healthcare she needed while pregnant: “I was able to access, I had good health care. I had great, I qualified for Medicaid....I went to all my prenatal visits...I had it good.”</p>	
	<i>Discrimination</i>		
<p><b>Author(s):</b> MACPAC  <b>Date:</b> Jan. 2022  <b>Sponsor(s):</b> Medicaid and CHIP Payment and Access Commission  <b>Population of Interest:</b> People living in rural areas, People with disabilities</p>	<i>Seeking and keeping coverage</i>		FL, KY, LA, MI, MO, TX
	<i>Accessing Services</i>	One advocacy organization representing individuals with disabilities noted that they have received complaints from beneficiaries who use assistive technology, such as screen readers, about use of state online systems. Beneficiaries, particularly those in rural areas, may not have adequate broadband access. Affordability of devices and internet service is also an issue.	
	<i>Care Experience/satisfaction</i>		
	<i>Member reported health and well being</i>	<i>Discrimination</i>	

Author(s), Date, Sponsor(s), and Population of Interest	Measurement Domains	Excerpts from Qualitative Resources	State/Geography
<p><b>Author(s):</b> Manivannan et al.  <b>Date:</b> 2020  <b>Sponsor(s):</b> The Commonwealth Fund; participation of Dr. Vickery was supported by the National Institute of Diabetes and Digestive and Kidney Diseases of the National Institutes of Health  <b>Population of Interest:</b> Very low -income people</p>	<i>Seeking and keeping coverage</i>	Participants described the instability of income-based health insurance coverage, given their shifting employment status. Available formal work often did not include insurance coverage, leaving participants with the potential loss of coverage if their income exceeded Medicaid eligibility thresholds. Results reinforce literature documenting that people with very low income (< 75% federal poverty) already face substantial administrative burdens and confusion about their Medicaid coverage.	MN
	<i>Accessing Services</i>		
	<i>Care Experience/satisfaction</i>		
	<i>Member reported health and well being</i>		
<p><b>Author(s):</b> McDaniel et al.  <b>Date:</b> Aug. 2021  <b>Sponsor(s):</b> Urban Institute (funded by RWJF)  <b>Population of Interest:</b> Black/African American people</p>	<i>Seeking and keeping coverage</i>		Nearly half of the people interviewed were from the South, and a quarter were from the Midwest.
	<i>Accessing Services</i>		
	<i>Care Experience/satisfaction</i>		
	<i>Member reported health and well being</i>		
<p><b>Author(s):</b> Mirza et al.  <b>Date:</b> March 2021  <b>Sponsor(s):</b> Sociological Initiatives Foundation and UIC Institute for Research on Race and Public Policy  <b>Population of Interest:</b> Limited English Proficiency people</p>	<i>Seeking and keeping coverage</i>	All interviewees had reached out at some point to their ethnic community organization to help them navigate the redetermination process. Findings suggest that language barriers hinder Medicaid redetermination and play a role in cancellation of benefits. Interviewees who had never lost their benefits had developed ingenious strategies and cultivated support networks to help them navigate the redetermination process.	IL
	<i>Accessing Services</i>	Interviewees described financial difficulties from paying for services and medications out of pocket. essential healthcare appointments were cancelled or postponed, worsening underlying health conditions. Loss of Medicaid benefits also created barriers for other public services.	
	<i>Care Experience/satisfaction</i>		
	<i>Member reported health and well being</i>	Qualitative findings highlight the negative health impact of losing benefits as a result of postponing or cancelling healthcare visits and prolonged mental stress.	
<p><b>Author(s):</b> Roman et al.  <b>Date:</b> Dec. 2017  <b>Sponsor(s):</b> Agency for Healthcare Research and Quality, the Strong Beginnings Federal Healthy Start program (HRSA/ MCH and W.K. Kellogg Foundation)  <b>Population of Interest:</b> Pregnant/birthing people, Black/African American people</p>	<i>Seeking and keeping coverage</i>		MI
	<i>Accessing Services</i>	While all Medicaid-insured women in Michigan can get help from Strong Beginnings or EPC to enroll in PNC, most women did not know about the assistance before PNC was initiated. For most women, PNC and additional resources were delayed until the second trimester.	
	<i>Care Experience/satisfaction</i>		
	<i>Member reported health and well being</i>	Most women felt like they were being treated differently because of Medicaid insurance; and some women felt their treatment was influenced by their race. They described perceived provider judgmental attitudes and stereotypes of pregnant women who are Black and poor. They also perceived unsaid things: extended waiting, Medicaid labels on their files, and non-verbal facial expressions from staff.	

Author(s), Date, Sponsor(s), and Population of Interest	Measurement Domains	Excerpts from Qualitative Resources	State/Geography
<b>Author(s):</b> Sakala et al. <b>Date:</b> 2018 <b>Sponsor(s):</b> California Health Care Foundation, Yellow Chair Foundation (National Partnership for Women & Families contractor) <b>Population of Interest:</b> Pregnant/birthing people	<i>Seeking and keeping coverage</i>		CA
	<i>Accessing Services</i>	"I loved that I could choose my doctor and he listened. ... With my other 3 babies I was on Medi-Cal. I had VERY limited choices of doctors."	
	<i>Care Experience/satisfaction</i>	Medi-Cal beneficiaries had less decision-making autonomy than women with private insurance. Medi-Cal beneficiaries rated communication worse than women with private insurance.	
	<i>Member reported health and well being</i>		
<b>Author(s):</b> Thigpen <b>Date:</b> Feb. 2022 <b>Sponsor(s):</b> California Health Care Foundation (CHCF) <b>Population of Interest:</b> Black/African American people	<i>Seeking and keeping coverage</i>		CA
	<i>Accessing Services</i>		
	<i>Care Experience/satisfaction</i>	White entered the ER at 3 PM but was not treated until nearly 8 PM. "To be honest, I didn't know if it was racism or just sh*t service," he says. Although he'll eventually need surgery to remove a cyst near his spine, this ordeal has led White to put off medical care if possible. "I've developed a bad habit of avoiding doctors," he says. "It just becomes a task."	
	<i>Member reported health and well being</i>		
<b>Author(s):</b> Thomason, S., & Vitulli, E. <b>Date:</b> 2023 <b>Sponsor(s):</b> The Center for Popular Democracy (CPD), People's Action Institute, Make The Road, funded by RWJF <b>Population of Interest:</b> Medicaid applicants or enrollees since Jan 2020, across many identified groups of interest--qualitative findings were excerpted only from specifically identifiable populations of interest.	<i>Seeking and keeping coverage</i>	"My income level has fluctuated over the past few years while I've been on Medicaid and it's always stressful trying to renew my coverage. It's also a dehumanizing process because now they require not just bank statements, but Venmo and PayPal statements, and I always feel like I'm under a huge amount of financial surveillance, when my average annual income is about \$10,000 a year."	From highest to lowest participation: NJ, NY, NV, CT, WV, OH, IN, CA, PA, VT, MI, MO, DE, DC. Minimal participation from AR, AK, MD, NH, CO, FL, AL, HI, NC, TX, ME, MA, WI
	<i>Accessing Services</i>		
	<i>Care Experience/satisfaction</i>	[Translated from Spanish] "I did not renew my coverage because the insurance did not cover the specialists, treatments, and medications that I need after my accident so I did not want to go through the whole process again if I am not going to be able to use it for what I need."	
	<i>Member reported health and well being</i>	"Currently my physical and mental health is very stable and I owe that to Medicaid. It has allowed me to get diagnosed with ADHD, dramatically improving my quality of life"	
	<i>Discrimination</i>	"I would say being discriminated against by healthcare providers was due to being gay, and not necessarily because I was on Medicaid. That said, the discrimination at times has been horrific. Lots of inappropriate behavior and things said, sometimes not directly to me but in vicinity. I've had to change my primary care doctor three times because of it. I'm running out of Medicaid options. I guess I'm lucky to have a primary care doctor at all, but it is extremely stressful getting care because of these issues."	

Author(s), Date, Sponsor(s), and Population of Interest	Measurement Domains	Excerpts from Qualitative Resources	State/Geography
<b>Author(s):</b> Yates et al. <b>Date:</b> Dec. 2022 <b>Sponsor(s):</b> Society of Family Planning Research Fund <b>Population of Interest:</b> Pregnant/birthing people	<i>Seeking and keeping coverage</i>	A few women experienced coverage challenges with Medicaid. For example, two women knew that Medicaid for Pregnant Women ends 60-days postpartum, which impacted their contraception decision-making.	NC
	<i>Accessing Services</i>	About half of the women reported that the cost of contraception under Medicaid contributed to their choice of contraception. Limits on Medicaid coverage for pregnant women diminish women’s access to comprehensive postpartum contraception counseling and options	
	<i>Care Experience/satisfaction</i>	Three Black women reported receiving unsupportive/coercive counseling and feeling forced to make contraceptive choices they did not want.	
	<i>Member reported health and well being</i>		
	<i>Discrimination</i>	Findings suggest that there are racial differences within the Medicaid program affecting Black women’s and White women’s experiences with prenatal and immediate postpartum contraception counseling. Postpartum contraception counseling can help some Medicaid beneficiaries choose methods consistent with their reproductive goals; however, counseling that fails to consider women’s reproductive goals may be less helpful and potentially harmful, especially for Black women.	
<b>Author(s):</b> Zhen-Duan et al. <b>Date:</b> May 2021 <b>Sponsor(s):</b> National Institute on Drug Abuse (NIDA) <b>Population of Interest:</b> People with SUD	<i>Seeking and keeping coverage</i>	“I was already in treatment. So, they [Medicaid] were asking me for proof of address, if I was taking money and proof of the program. So, I came and told [name of clinician] ‘Hey, they are asking me for proof of the program,’ so she made me the letter. Then I brought the letter to them [Medicaid] and finally I have it [insurance]. [I lost insurance for] about two weeks”	NY
	<i>Accessing Services</i>	Some patients stated they liked the “old Medicaid” better because they could go to any clinic that accepted Medicaid without restrictions.	
	<i>Care Experience/satisfaction</i>	[Treatment centers would say] “You’re doing this, you’re doing that, you’re not complying” and then they’d go back to the court and say this and this and that, and then the ACS worker will say “Oh yes, she’s not complying and she doesn’t want her kids.” No, that’s not it. You’re putting me in a place that I’m not comfortable with, that I don’t feel like I’m getting what I need. But they don’t care about that, they just want you to go to the program and complete what you’ve got to do.”	
	<i>Member reported health and well being</i>		
	<i>Discrimination</i>	Many programs have strict requirements for daily check-ins as a condition of receiving medication, with consequences for missing visits including inability to see their families. Patients described that these leverages exacerbated the stigma, shame, and punitive nature of SUD treatment, hindered their ability to stay engaged, and therefore reduced the perceived quality of SUD care.	

Source: SHADAC review of resources, 2023.

Note: Positive experiences/quotes are highlighted by green text.

## About the Robert Wood Johnson Foundation

The Robert Wood Johnson Foundation (RWJF) is committed to improving health and health equity in the United States. In partnership with others, we are working to develop a Culture of Health rooted in equity that provides every individual with a fair and just opportunity to thrive, no matter who they are, where they live, or how much money they have.

Health is more than an absence of disease. It is a state of physical, mental, and emotional wellbeing. It reflects what takes place in our communities, where we live and work, where our children learn and play, and where we gather to worship. That is why RWJF focuses on identifying, illuminating, and addressing the barriers to health caused by structural racism and other forms of discrimination, including sexism, ableism, and prejudice based on sexual orientation.

We utilize evidence to advance health equity. We cultivate leaders who work individually and collectively across sectors to address health equity. We promote policies, practices, and systems-change to dismantle the structural barriers to wellbeing created by racism. And we work to amplify voices to shift national conversations and attitudes about health and health equity.

Through our efforts alongside the efforts of others, we will continue to strive toward a Culture of Health that benefits all. It is our legacy, it is our calling, and it is our honor.

For more information, visit [www.rwjf.org](http://www.rwjf.org).

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## About SHADAC

This resource was prepared by former State Health Access Data Assistance Center (SHADAC) Graduate Research Assistant Maya Benedict. SHADAC is an independent, multi-disciplinary health policy research center housed in the School of Public Health at the University of Minnesota with a focus on state policy. SHADAC produces rigorous, policy-driven analyses and translates its complex research findings into actionable information for states.

For more information, visit [www.shadac.org](http://www.shadac.org).

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## About the Medicaid Equity Monitoring Tool Project

The Medicaid Equity Monitoring Project is a multi-phased effort to explore whether a new national data tool could increase accountability for making actualized progress toward improving population health while also supporting state Medicaid programs in advancing health equity. The Robert Wood Johnson Foundation (RWJF) contracted with the State Health Access Data Assistance Center (SHADAC) and its subcontractor RACE for Equity to assess both tool need and feasibility. RWJF contracted with Health Leads to work collaboratively with the SHADAC team to engage community members in discussions of a potential monitoring tool. At the end of the current phase, SHADAC, RACE for Equity, and Health Leads will make recommendations about the feasibility of moving forward with designing and developing a Medicaid equity monitoring tool.

Resources developed throughout the multi-year project are available here: <https://www.shadac.org/Medicaid-Equity-Monitoring-Tool>

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