Monitoring Medicaid Using Lived Experience

Interim Report

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Acknowledgements

About the Interim Report

This report is being issued at the mid-point of the *Monitoring Medicaid Using Lived Experiences* project. Therefore, some of project findings may change and nuance will be added when the final report is released in the spring of 2023.

The findings presented here are based on data collected in 2021, which included 32 interviews with lead grantees and subgrantees, 2 rounds of surveys with subgrantees, and transcripts from 2 Virtual Learning Sessions attended by lead grantees and subgrantees.

Participants were promised confidentiality when sharing their project experiences; therefore, we do not attribute quotes to particular individuals or organizations. There was one exception: organizations' approaches to collecting lived experiences were not confidential and are in some cases identified.

Throughout the report we use the following terminology:
- **PME** is people (or person) with Medicaid experience. This includes applicants and enrollees, their families, and those left out of the program.
- **Subgrantees** are the state and locally-based organizations that received grants from one of the four **lead grantees**.
- **Advocates** is the term we used for staff and leaders of lead and subgrantee organizations.
- **Partnering organizations** are organizations that worked with subgrantees to recruit PME. They included community health centers, faith-based organizations, and other advocacy and community-based organizations.

Finally, the report makes extensive use of advocates' quotes so that their experiences are expressed in their own words. In order to render the quotes more readable, we have removed verbal pauses such as "you know, "like" and "kind of."

If you have comments or suggestions related to the Interim Report, please contact Jessica Greene, Ph.D. (Jessica.greene@baruch.cuny.edu), who leads the Learning Team.

Executive Summary

In late 2020, four organizations received funding support from the Robert Wood Johnson Foundation (RWJF) to explore and test approaches for monitoring Medicaid by learning directly from people with Medicaid experiences (PME), including applicants and their families, enrollees, and people left out of the Medicaid program. The goal of the projects was for Medicaid advocacy to be informed by on-the-ground experiences with the Medicaid program. The *Monitoring Medicaid Using Lived Experience* project sought to learn how technology could be used to collect PME's stories and how racism is manifested in Medicaid.

In the first year of the project, the four lead grantees contracted with 28 subgrantees located in 22 different states and the District of Columbia. The key first year project findings are described below:

Recruiting PME. Recruiting PME was an essential first step for learning about Medicaid lived experiences. All subgrantees used multiple approaches to recruit PME, yet still found recruiting PME to be challenging.

- Partnering with trusted community organizations, like health centers and advocacy organizations, to recruit PME was considered very effective, particularly when staff provided a "warm handoff." Many subgrantees also found recruiting from their own organization's clients and members to be effective.

- Regardless of recruitment approach, trust, gained through "human interactions," was viewed as critical for getting PME to share their experiences.

  - Recruitment approaches without direct human connections, like social media solicitations and posting flyers, were rarely effective.

- Compensating PME for sharing their lived experience not only motivated PME to participate but honored their expertise and time.

Capturing Lived Experience. Subgrantees captured Medicaid lived experience using a wide range of approaches. All subgrantees learned directly from PME, and many additionally learned from people who work directly with PME, like doctors and navigators.

- In-depth interviews, which were the most common approach, were viewed very positively. PME were able to "tell their story authentically" and advocates "were able to ask follow up questions when [PME] highlighted something new."

- Surveys were used to cast a wide net and learn about a large number of Medicaid experiences, and some subgrantees used them as an entry point for recruiting people for interviews.

- Videos were considered emotionally compelling, but subgrantees largely found it "really, really hard to get people to make a video." The challenges related primarily to technology difficulties and reluctance among some PME to share their experiences publicly.

- Less common though effective approaches included using an advisory council with PME members, having PME share experiences directly with lawmakers, and having navigators document their experiences enrolling PME in Medicaid.

Identifying Key Learnings. Most of the approaches to capturing lived experiences generated data that subgrantees had to manage and analyze. Many subgrantees were just beginning data analysis as this report was written.

- Some subgrantees felt their approach to storing the lived experiences data worked well. However, many expressed a desire to improve data management: "A more streamlined and efficient way of storing data is needed."

- Many subgrantees informally identified key issues from the interviews and focus groups. One advocate explained, "...if I have two or three stories in a row, where the families [are] essentially saying the exact same thing, it's worthy of noting."

- Coding or tagging transcripts from interviews and focus groups to identify key themes was a new skill for many subgrantees. One lead grantee provided training on coding transcripts to subgrantees, and these organizations found it very helpful for identifying key themes: "[Coding] makes everything feel a lot more manageable when you have hundreds of pages of transcripts or…hours of audio."

- Subgrantees who collected surveys of PME cautioned that care would need to be taken in interpreting survey results since the PME who completed surveys were not representative of all PME in the state.

Learnings from the First Year. Almost all subgrantees reported learning about new Medicaid issues as a result of this project and having "a richer understanding of the Medicaid program."

- PME highlighted that Medicaid is "a really valuable program." Parents in particular, emphasized that Medicaid coverage "helped them and their babies get a healthy start in life."

- There were commonly reported Medicaid challenges, which included applying for Medicaid, maintaining coverage, finding providers who accept Medicaid, and language access for people who did not speak English.

- Some PME described experiencing racism in the Medicaid program ("slighted by the attitudes of representatives" and "greater scrutiny when applying"). It was not uncommon for immigrants to describe feeling that Medicaid agency staff discriminated against them for not speaking English.

Using the Lived Experiences. Making sure that the lived experiences captured during this project were put to use, and did not "just sit on a shelf," was very important to subgrantees.

- Half of the subgrantees informed their state Medicaid agency about the barriers that PME reported. Many agencies were "responsive on a case-by-case basis" though fewer made systematic changes to address the issues.
  - A few subgrantees additionally arranged for meetings between PME and the state

Medicaid agency or recruited PME to serve on Medicaid agency committees.

- Advocates felt bringing lived experiences to the Medicaid agency's attention was important, as few agencies' monitoring efforts capture the breadth of the Medicaid user experience.

- Twelve subgrantees informed state lawmakers about PME's concerns and half of them arranged for meetings for PME to share experiences directly.

  - A PME from Florida testified to the federal Senate Committee on Aging about the importance to her of having home care.

- Approximately one third of subgrantees received media coverage or published op/ed articles related to the lived experiences, including coverage in The New York Times and The Washington Post.

- Almost all of the subgrantees who used lived experience in advocacy with government leaders or received media coverage during the first year of the project had substantial prior experience in these activities.

- Many subgrantees posted PME's stories on their websites or on social media to raise awareness of specific issues with the Medicaid program or to highlight how the program helped members of the community. The lived experiences influenced several grantees' policy reports and informational materials.

Organizational Impact. Lived Medicaid experiences provided subgrantees with new context about the Medicaid program and individual stories that made their advocacy more effective ("The human storytelling piece is always far more compelling than a policy wonk").

- Learning directly from PME, though, was considered a resource intensive endeavor, requiring team members with a wide range of expertise. Components of the project were new to many subgrantees, and subgrantees recommended flexibility and having clear goals for the use of lived experiences.

- For some subgrantees, the project was an opportunity to focus their organization's advocacy priorities based on "what is being experienced by beneficiaries." One advocate described it as shifting "the [organization's] paradigm from top down to bottom up."

- The project also enabled some subgrantees to focus on developing PME's leadership skills so PME could be "their own advocates to create change."

Introduction

In late 2020, four organizations received funding support from the Robert Wood Johnson Foundation (RWJF) to explore and test monitoring Medicaid by learning directly from people with Medicaid experiences (PME), including applicants and their families, enrollees, and those left out of the program. The goal was for Medicaid advocacy to be informed by people's on-the- ground experiences. The *Monitoring Medicaid Using Lived Experience* project sought to learn how technology could be used to collect PME's stories and how racism is manifested in Medicaid.

In the first year of the project, the four lead grantees were:
- [Center on Budget and Policy Priorities](#)
- [Georgetown University's Center for Children and Families](#)
- [National Health Law Program](#)
- [The Center for Popular Democracy](#)

The four lead grantees each subcontracted with 6 to 8 state or local organizations in their networks, for a total of 28 subgrantees. All subgrantees had worked with their lead grantee prior to this project. Lead grantees made this choice both to leverage prior existing connections and because the project's initial one year time frame was too short for developing new connections. Appendix 1 lists each lead grantee and its subgrantees.

Subgrantee Organizations

The subgrantees were located across the country, in 22 states and in the District of Columbia (Appendix 2 shows the states where the subgrantees worked). Thirteen of the subgrantees were state policy or advocacy nonprofits (Figure 1).   Seven were legal services organizations and another 6 were grassroots or community organizations.

The subgrantees ranged considerably in how much prior relevant experience they had related to this project (Figure 2). Twenty subgrantees had a moderate or a lot of prior experience collecting lived experiences, though only 9 subgrantees reported that level of prior experience using video or audio to collect stories or lived experiences.

Figure 1. Types of Subgrantee Organizations

The vast majority of subgrantees (20) reported a lot of prior experience advocating for Medicaid policies with state lawmakers. Fewer subgrantees (14) had a lot of experience working closely with their state Medicaid agency, and 5 subgrantees reported having no such experience.

Subgrantee Objectives

Subgrantees embraced learning from PME for a range of reasons— including informing their Medicaid advocacy, developing their organizations' expertise in gathering lived
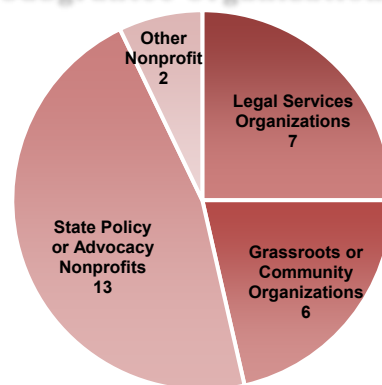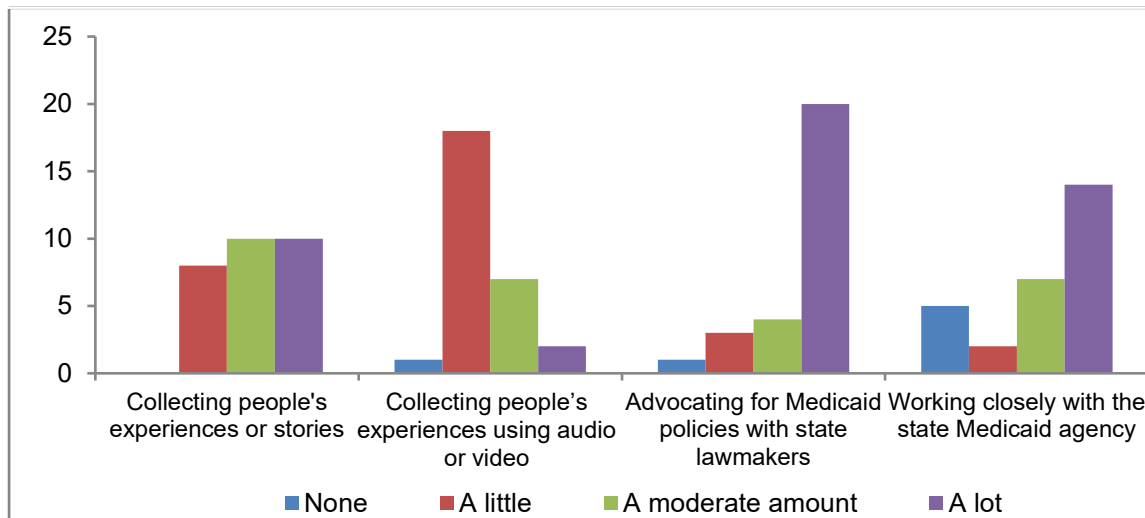
Figure 2. Number of Subgrantees with Lived Experience and Medicaid Advocacy Prior Experience

experiences, and integrating PME more intentionally into their work. Below, the project objectives are listed in order of how frequently subgrantees highlighted them as their top project objectives.

Identifying new Medicaid issues for advocacy was described by over half of subgrantees (16) as a key project objective. One advocate explained that the project enabled her organization to make "sure that what we are pursuing on a systems change level ...[is] really being determined through what is being experienced by beneficiaries." A few subgrantees described identifying advocacy priorities "through what is being experienced by beneficiaries" being part of a current shift in their organization's orientation, from a "top down to bottom-up" paradigm.

Identifying examples of known Medicaid issues was described as a key goal by about half (13) of the organizations. Advocates felt there was real power in being able to share individuals' experiences while advocating for specific policy issues. "You know the issue exists, and then you tell the story [of] one family or one child...and it brings it home in a different way," explained one advocate. Another expressed:

> *"The human storytelling piece is always far more compelling than a policy wonk coming in front of [Medicaid staff] and saying we need to move this, this, and this around."*

Developing organizational capacity to capture people's lived experiences was also described as a key project purpose by approximately half of the subgrantees (13). One leader said, "This project has really allowed us to expand and re-examine story sharing as an organization," while another explained that it enabled her organization to "to be much more thoughtful and intentional about our engagement [with PME]." The emphasis on testing out video and audio technology also enabled organizations to build capacity in new

areas:

> *"It allowed us to try out a new technology that we probably would have never considered in terms of doing our story collecting work."*

Getting people in the community more involved in health advocacy was a key goal of over a third of the subgrantees (10). For these subgrantees, getting PME to share their Medicaid experiences was considered a first step. The next step was following up with the PME to "build a base for a campaign" or provide PME with "the opportunity and the power to engage and be part of… the advocacy work— to make changes to the Medicaid program." Another advocate explained:

> *"[This project] helps us build our network of advocates, but also advocates with lived experience, which I think is so much more powerful."*

Developing PME's Medicaid advocacy skills was a key objective of the effort for 5 subgrantees. One advocate who worked with an advisory council explained:

> *"We're not just focusing on these short-term policy goals, we are helping to really develop people's advocacy skills and their knowledge."*

Another advocate explained that this grant had enabled partnering with their advisory council in a more thoughtful way:

> *"It gave us some space to sit down and really think about how we could be engaging with [advisory council] members in an even more intentional way and really kind of growing their capacity as advocates."*

Steps in Capturing Lived Experiences in Advocacy
Capturing lived experience for Medicaid advocacy involved a series of actions, which are described in depth in the following chapters:
- Recruiting PME
- Capturing PME's lived experiences
- Identifying common issues
- Using Medicaid lived experience in advocacy

There are two additional chapters:
- Preliminary learnings about Medicaid from lived experiences, and
- Key reflections on collecting Medicaid lived experiences

Recruiting PME

Recruiting PME to participate in interviews, surveys, and other activities was an essential first step for learning about PME's Medicaid experiences. Recruiting PME, however, was often described as a major challenge. Advocates felt that PME were sometimes reluctant to share their Medicaid lived experiences because their lives were busy and complex; they often lacked smart phones, computer technology, or adequate data plans; they had concerns about immigration status; and some had poor prior experiences sharing their stories. The COVID-19 pandemic was also described as a "formidable obstacle" to recruitment since staff were largely not able to go into the community, for instance to health fairs, food banks, and health centers, the way they typically would.

Most subgrantees (20) were interested in recruiting a particular group of PME, like immigrants, people of color, children, or people in the Medicaid coverage gap. However, only 3 subgrantees limited their recruitment only to specific types of PME.

In this chapter, we first describe the ways that subgrantees identified PME to participate in the project, and then we describe strategies subgrantees recommended to encourage PME to share their lived experiences.

Identifying PME to Share Lived Experiences

Subgrantees used a variety of methods to identify PME for this project, and these approaches varied in how effective subgrantees found them to be. Appendix 3 has additional quantitative detail about how frequently subgrantees' used recruitment approaches and their effectiveness.

A key project takeaway was that all of the subgrantees used multiple recruitment approaches and universally recommended the use of multiple approaches for recruiting PME: "I think that having more than just one approach, it's also a good strategy for trying to cast the widest net." Another advocate explained:

> "[We have] a menu of entry points to get people … to share their stories. … the survey … is just … an entry point. For us to…be able to have a more in-depth conversation on the phone."

More Effective Approaches. **Partnering with community-based organizations** was the most common main approach subgrantees used to recruit PME and was used in some capacity by all but 4 subgrantees. Many of the partnering organizations were community health centers, legal aid organizations, or faith-based organizations, and one subgrantee partnered with barbershops and hair salons. In almost all cases the subgrantees had a pre-existing relationship with the partnering organizations they worked with, though for many this project formalized the relationship. Ten subgrantees reimbursed the community partners for their role.

Using community partners trusted by PME was viewed as a very effective recruiting

approach by most subgrantees. One advocate explained, "We're grateful to have strong relationships with partner organizations who are seen as trusted messengers in the communities we're trying to reach." Another explained:

> *"Working with the partners who work directly with individuals and families has been by far the most successful because [these partners] built the rapport with the individuals … they've been really good at helping [PME] feel comfortable to speak to us and help them understand that we are working to create change in a positive way."*

When recruiting PME for focus groups and interviews, staff at partner organizations often directly referred specific individuals. One advocate described the most effective approach being a "referral from [a] trusted person who has an established relationship with PME."

Partnering organizations were also considered very effective for encouraging people to complete surveys. In some cases the partner posted flyers with QR codes for clients to access the survey, in other cases they shared a survey web link, and still others provided paper surveys.

One advocate explained that partnering with community organizations for recruiting had the benefit of developing deeper trust with those organizations:

> *"It was really useful for us in establishing a kind of chain of trust between us and the intermediaries as well. That relationship went in both directions - it helped us to engage interviewees, but it also made us more of a trusted resource for groups to turn to when they wanted data or analysis."*

Another commonly used recruitment approach, which also was generally considered effective, was for subgrantees to **reach out to their organization's members or supporters**. This was typically done by email or texting the organization's supporters.

Subgrantees providing direct services to PME reported that **recruiting their own clients** was also a generally effective approach:

> *"Our navigators [have] the day-to-day contact with the people that we're trying to get the stories from. … We've established the trust there."*

However, for some of these subgrantees, particularly legal services organizations, there was a desire to hear from PME who were not their own clients. "There are reasons that some people are going to end up getting legal services help and other people are not" and they wanted to hear from a wider variety of PME so they could learn about Medicaid issues they were not already familiar with. One legal services organization reached out to community organizations representing immigrants, organizations in rural areas, and smaller BIPOC-led grassroot partners, which "fostered new relationships with the community and expanded the diversity of the voices we heard from in our storytelling project."

A few subgrantees asked **advisory council members (sometimes including PME) to reach out to their personal networks** to recruit PME to share their experiences, and the approach was effective for organizations that used it.

Most organizations tried recruitment at virtual **advocacy events,** and there were mixed experiences on how effective a strategy it was. One subgrantee hosted Facebook live forums in Spanish with Latino radio hosts explaining why people sharing their experiences is important.

Less Effective Approaches. Recruitment approaches that involved less human interaction were generally considered less effective by subgrantees. For example, **social media** was repeatedly described as not very successful at getting PME to share their experiences. One advocate said, "[It] doesn't seem to garner a lot of …success," while another explained:

> "*Social media was probably least effective based on the number of people it moved to take action, but it will still be an important tool we use to get the word out and get reminders to our networks.*"

Similarly, **posting a survey link** on an organization's website was not, on its own, an effective way to get PME to complete surveys. "People aren't just going to stumble on our website and submit their story," an advocate explained, "traffic needs to be driven to it somehow." **Texting to the voter database** also was less effective than had been hoped, as were posting **flyers in neighborhoods**. One subgrantee, however, had a very positive experience recruiting with flyers in public libraries:

> "*One component of the flyering that we found to be very successful, particularly in finding respondents from rural areas, was placing flyers in public libraries. … I think probably like half of our respondents. Most of them go there to use the printer and the fax machine … all of that kind of stuff for their day to day lives, and that's how they saw our flyers.*"

Ways to Encourage PME to Participate

Subgrantees recommended several ways that helped encourage PME to share their Medicaid experiences once they had been initially contacted.

Building or Using Trusted Relationships. Subgrantees emphasized that trust, gained through "human interactions," was critical for PME to share their experiences.   One advocate described PME being much more willing to share their experiences when she recruited at a vaccine clinic in person, whereas without the human connection, she found recruitment very challenging. Another advocate explained:

> "*Meeting people where they are and in settings they trust and in which they feel comfortable. People were much more willing to share under this approach and it helped build trust when we could meet face-to-face, answer questions, and be a real person and real face behind the project.*"

A referral from a trusted partner organizations often helped establish trust with the subgrantee. One advocate described the effective way one partner connected PME with her organization:

> *"[They used] a warm handoff where they're saying …my colleagues are engaged in this project…here are the parameters around it and, if you're comfortable, I'll connect you with another colleague of mine who will actually do an interview."*

Several subgrantees found building on trusted relationships with PME to connect with others in the PME's network to be very effective. "As always, word of mouth is king," one advocate said, while another explained:

> *"I think our biggest success [is] from people who are in our network, taking the survey and then sharing it with people that they know and encouraging them to take it."*

A few subgrantees additionally suggested that having staff who shared some background in common with PME, like having received Medicaid, was very effective for building trust.

Compensating PME. Most subgrantees compensated PME for sharing their Medicaid experiences, and compensation was widely viewed as essential both for recruiting PME and appropriately reimbursing people for sharing their Medicaid stories. For recruiting, a number of subgrantees believed compensation was "a motivating factor" to get PME to participate: "Without the compensation, this would be 1,000 times harder." Compensation also encouraged partner organizations to emphasize the opportunity:

> *"The hundred-dollar incentives … played a large part in caseworkers reaching out to their clients immediately and just being like, 'Hey, this is going to be a great opportunity.'"*

Several subgrantees stressed that "adequate and respectful compensation for people's time is critical," since PME were "opening up their lives and experiences to us in this very personal way." One advocate elaborated:

> *"Compensation … for their time is critically important to getting people to do this. It's also critically important to us. We are no longer going to extract information from community without compensation."*

Compensation generally ranged from $25-$100 for participating in an interview, and some organizations had more complex arrangements: "If we interview them, they get $50 guaranteed and then, if they post [a video] on Soapboxx there's a raffle for [a] $100 gift card." Since many interviews were done remotely, sometimes the logistics of compensating PME was complicated:

> *"What we finally found … worked was [getting] their name and address and then*

sending a cash card like [a] visa card or something in a secure way. Because otherwise it was just sort of hard to figure out ... do they have to pick it up, do you do it by text or email which didn't seem secure and safe. So there was a little logistics."

Linking Participation to Improving Medicaid. Many subgrantees emphasized the importance of clearly explaining to PME that the end goal of learning about Medicaid experiences was to improve the Medicaid program. One advocate explained:

> "*The main thing as far as enticing them to do it, is that they're helping other people. By telling their story in the media...or to legislators, or to policymakers, they're putting a face on the program, they're telling people what they like or don't like or what happened or didn't happen, and it can lead to change.*"

Several advocates highlighted that some people have had negative story sharing experiences in the past, so explaining the purpose was particularly important:

> "*We don't want them to think this is just another one of those song and dance routines that is not gonna lead to anything.*"

Capturing Lived Experience

The 28 subgrantees used a variety of approaches to gather lived experience once PME were recruited. As is described below, these included in-depth interviews, surveys, focus groups, integrating stories into template letters, creating PME advisory councils and more. Appendix 4 presents a table showing how subgrantees captured lived experience and perceptions of effectiveness.

Almost half (13) of the subgrantees captured lived experience in languages other than English.

In-depth Interviews

In-depth interviews with PME were the most common approach used to learn about Medicaid lived experiences. It was the main approach for 20 subgrantees and was used by an additional 5 subgrantees.

Most subgrantees found in-depth interviews very effective. Interviews enabled PME to "tell their story authentically" and have a "platform to be heard." In-depth interviews also created connections with PME and enabled advocates to probe and learn more about topics they were not aware of:

> "*It was extremely helpful because we were able to ask follow up questions when they highlighted something new that we never heard before. It also helped us build a connection with the interviewee and let us really engage in the conversation to get more information regarding their experiences.*"

Many subgrantees interviewed people working directly with PME, like physicians and navigators, in addition to PME. These interviews contributed to a broader perspective on what they were learning from individual PME and enabled them to "reach even more people." One advocate explained:

> "*Hearing from providers is important too as they can not only validate patient stories, but they can talk about systems.*"

Interview Approach. In part due to COVID, many of the in-depth interviews were conducted over the phone or by Zoom. One advocate emphasized the importance of making PME comfortable during the interview by giving them choices of modality:

> "*I gave people the options when they signed up like, would you want to speak in person… over the phone, or over video call on Zoom. And almost everybody chose just the phone call option.*"

Although the interviews typically used an interview guide with open-ended questions, most interviewers aimed for an experience that felt "like just having a normal conversation" or for the PME to "tell [their] story as if [they] were talking to a friend or a

relative." Interviewers routinely followed up on interesting issues raised by the PME that were not part of the interview guide, and throughout sought to make sure the PME was comfortable:

> *"You actually have to engage with people as they're talking and show…so even though like it's on the phone and I can't see them face to face, you know you can still convey interest in people through the tone of your voice and the little reassurances as they're going along that you're listening."*

This type of conversational approach to interviewing was new to a number of subgrantees. One advocate described it as requiring "interview skills that might differ from law office client intakes," and that legal aid staff likely needed interview training or that "social work staff might be a natural fit for the project."

While most subgrantees had one or two staff who were responsible for conducting the interviews, the Louisiana Budget Project (LPB) had one staff member lead all the interviews, and other staff members took turns either taking notes or providing technical assistance during the interviews. LBP staff explained:

> *"We want to have as broad participation from within LBP on at least one interview to meet our own internal goals of understanding how folks with lived experience expressed their experiences with Medicaid."*

LBP found this approach enabled many staff to learn from PME and "it's an approach that we're likely to continue."

Consent. Prior to interviews, PME were asked to document their consent to participate. For remote interviews, consent was verbal, while in-person interviews used written consent forms that were signed. Consent forms often provided a list of options that PME could select for how their experiences could be shared, like on social media or with legislators, and some allowed the PME to revoke consent in the future. Subgrantees emphasized the goal of ensuring PME were in control of how much personal information would be shared:

> *"They can be anonymous. They can be super anonymous, and I can even change every single [personally identifiable] fact and make it totally untraceable to them in every way if they like…and they can change their mind at any time."*

Some organizations reached back out to the PME to get consent again before the story was shared publicly. An advocate explained:

> *"Once we decide we're going to use the story, we like to take that extra step of getting their consent [again] to make sure that it is in context and true to the spirit of their experience."*

In-Depth Interview Guide. Most questions in subgrantees' interview guides focused on the Medicaid enrollment process, getting medical services, and the overall impact of having

Medicaid, as can be seen in Figure 3 on the following page. In addition to identifying problems, many subgrantees sought to identify "the good stuff" about Medicaid too, to help build support for the program and let the Medicaid agency know what was working well.

Figure 3. Examples of In-Depth Interview Questions

Medicaid Enrollment Questions
- Can you explain what the Medicaid enrollment process was like for you?
- If you could help someone else apply for Medicaid, what advice would you give them?
- How helpful were the customer service representatives who assisted you during the initial Medicaid enrollment process?
- When interacting with the Medicaid enrollment/renewal process, have you ever felt like you were treated with less respect than other people? [If yes: What do you think is the main reason for this experience?]
- How does the Medicaid program communicate with you? What do you like or not like about it?

Health Care Access Questions
- Once you got Medicaid coverage, did you have any issues being able to find a doctor?
- Did you experience difficulty getting medical services or was it easy?
- Are there any barriers in accessing health care for you or your child/children? [If yes: What are the barriers?]
- How do you feel you are treated when you seek health care?
- Have you encountered barriers based on race, ethnicity, language, disability, LGBTQ+, sex, or any other factors?
- Do you have any health-related expenses that you have to pay for that Medicaid doesn't cover? [If yes: Are they reasonable or are they creating financial difficulties?]

Overall Medicaid Questions
- What kind of impact has Medicaid had on your life and your health?
- What would you like to see changed to improve your experience with Medicaid?
- If you could talk to our state lawmakers, what would you want them to know about how Medicaid has impacted you?

Interview guides also typically included questions about PME's demographic characteristics and some also included questions about how the PME would like to engage with the subgrantee's organization in the future.

Exploring Racism. Seven subgrantees used their interviews to explore whether PME had experienced racism as part of their Medicaid experience. They typically approached this in one of two ways. One was to ask directly about experiencing racism. One subgrantee did this by asking: Have you encountered barriers based on race, ethnicity, language, disability, LGBTQ+, sex, or any other factors?

The other approach was less direct. PME were asked, for example, if they felt that they were treated with less respect than other people when enrolling in Medicaid. For those who responded "yes," there were follow up questions to explore what the PME thought was the main reason for being treated with less respect.

There was also interest in exploring whether people experienced structural racism— or whether the policies, practices, and norms of the Medicaid program were discriminatory. Subgrantees, however, considered this much harder to examine through interviews than interpersonal racism.   "How do you identify when something is due to structural racism, when you're an individual?" one advocate asked. One subgrantee that worked with Native American PME was able to effectively ask about structural racism, though, by exploring whether PME felt that the U.S. Government was fulfilling its treaties to provide health care to indigenous people at no cost.

Surveys

Just over half of the subgrantees surveyed PME. The Center for Popular Democracy's seven subgrantees used the same survey, which focused on applying for and renewing Medicaid coverage (results are published [here](#)). Their survey asked about PME's level of satisfaction with their recent Medicaid application process as well as whether they faced any of 18 challenges, including there being no nearby office, not having transportation, the phone representative not being helpful, and feeling stigma or shame in applying.

There were three, often overlapping purposes of the surveys for subgrantees: learning about PME's Medicaid experiences, recruiting PME to participate in interviews, and as a first step in engaging PME in the subgrantees' advocacy efforts.

Learning about PME's Medicaid Experiences. A number of subgrantees reported that the survey results were used to quantify how often specific Medicaid barriers were experienced by PME. This type of quantitative data was viewed as a powerful tool for identifying which issues to advocate for and persuasive when presented to Medicaid administrators.

Surveys also enabled subgrantees to explore whether Medicaid barriers were equally reported by PME from different racial and ethnic backgrounds. However, a difficulty is that sufficient numbers of respondents from different racial and ethnic backgrounds are needed in order to draw statistically sound conclusions. This, for example, proved to be a challenge for the subgrantee that collected the largest number of surveys, almost 300, because almost all of their respondents were Black PME and they had there were only a handful of respondents who were White and Latino PME. This made racial/ethnic comparisons of Medicaid experiences unreliable.

Notably, subgrantees did not attempt to collect surveys from a random, representative sample of PME. As a result, the findings cannot be inferred to apply to all PME in the state, and several advocates highlighted that the results had to be interpreted with caution. One explained, "The organizations are reaching out to [their] members, and so…. it's not representative." However, the survey results from these non-representative samples of

PME likely provide a signal about issues to be further explored.

Surveys for Interview Recruitment. A number of subgrantees used the surveys as a mechanism to identify people as potential candidates for subsequent in-depth interviews. One advocate explained, "Surveys are great for collecting stories on barriers to coverage, care, or potential threats to the Medicaid program, but not so great for general 'tell us about your experience with Medicaid' stories." Thus, her organization's survey included a question about whether the PME "would be willing to talk to us and share more information."

Engaging New Advocates. Subgrantees with more of a grassroots organizational focus also viewed surveys as a way to engage new advocates from the PME community. One advocate explained:

> *"I think the survey is a useful tool, particularly for engaging folks and… it's sort of multi-purpose. You're gathering information but also ultimately its purpose is for base building."*

Survey Challenges. One of the key challenges of surveys was that it was **difficult to get PME to share detailed lived experience**. Subgrantees tried a few approaches to get more detailed lived experiences from PME who completed a survey. The most successful was for advocates to talk PME through the survey over the telephone (or Zoom), which provided "that human connection." Using this approach, the survey questions effectively served as an interview guide. Advocates who used this approach felt that PME shared their broader experiences and were more likely to answer all the survey questions.

A less successful approach was to include open ended questions in the survey where PME could elaborate on their Medicaid experiences. An advocate explained, **"…**people are not choosing to just sit there and [write] about the many barriers to Medicaid without being egged on a little bit." Nor did many people upload videos or audio recordings at the end of surveys, as is discussed in the Video/Audio section.

Subgrantees also reported **technology-related challenges** with online surveys, since some PME, particularly those in rural areas, often had limited access to data. Some organizations created paper versions of the surveys to distribute to people without broadband access and one organization invested in cell phones so that staff could input the responses directly on the phone when working in rural areas.

Focus Groups

Eleven subgrantees used focus groups to collect lived experiences, though only one used it as their principal approach.   Focus groups were done in person and virtually. While some organizations hosted focus groups with PME, they were more often held with people who work directly with PME. An example consent form is included in Appendix 5.

Subgrantees were mixed in terms of how successful they found focus groups for collecting lived experience. One advocate described the differences between focus groups and in-

depth interviews:

> *"I think the disadvantage to [the focus group] approach is that you're not getting as much intimate biographical detail, but I think the tradeoff there is that people kind of feed off of each other and they they're like, 'Oh yeah, I've had that same experience' or you see people relating to each other and helping each other remember similar experiences there."*

Integrating Stories in Comment Forms or Letter Template

Several organizations created the opportunity for PME to provide letters or comments on specific policy issues like 1115 Medicaid waivers or the need for Medicaid expansion. One advocate explained:

> *"While you think public comments don't really sound like stories, when you're collecting … comments from consumers, they are their stories. And we asked the question in such a way that they are telling us their story."*

Subgrantees used Google Forms or Phone2Action to collect individual's comments and incorporated them into a letter template that included their organization's "key ask." To do this effectively, subgrantees simplified the policy issue into language that the PME could understand, relate to, and provide their thoughts on. One advocate explained:

> *"We try to simplify things into plain language, make it accessible, distill complicated policy down to something that people understand and can relate to, they understand how it would impact themselves, their families or their communities."*

Advisory Councils that Include PME Members

Only a handful of subgrantees used an advisory council that included PME members for learning about Medicaid lived experiences, but these organizations largely viewed it as an effective approach. Several groups leveraged existing advisory councils and four groups created new councils.

For Kentucky Voices for Health, creating an advisory council was the principal focus of the Medicaid lived experience project. Staff viewed creating the council as a meaningful way to formalize a network of PME and people who work directly with PME, many of whom they had existing relationships with. Additionally, the structure allowed council members to be compensated for their contributions.

Kentucky's council members were introduced to the key policy issues the organization was working on, including postpartum coverage extension and access to benefits for immigrants, and members selected an issue to become involved with. The organization was investing in its council members. "We're really trying to invest and help develop leadership and stronger advocacy skills," an advocate explained. She further explained:

> *"Next month, for instance, we're going to do a Medicaid 101 training, and the month after that an Advocacy 101. We'll do some media training, and then we're doing individual*

technical assistance and just support."

North Carolina Child, which had an existing parent council, used their council to direct their Medicaid lived experience project. Council members were provided with background on the project as well as training on story collection and advocacy, and then members decided whether they personally would like to be paid to collect Medicaid lived experiences from people in their networks. North Carolina Child staff felt that the council members had taken ownership of the process:

> *"This is their work, that they see themselves as the conduits of change through this work and that this is not just collecting information to feed off to other systems or organizations…. I think it's incredibly valuable for their communities that they are really able to see how they can own their own narratives."*

The next step will be for North Carolina Child's council members to work with an evaluator to synthesize the lived experience findings and develop policy recommendations.

Sharing Experiences Directly with Decision-Makers

The Children's Defense Fund of Texas (CDF Texas) organized virtual meetings with state lawmakers and invited PME and other advocates to join. Staff described this approach as "our favorite" because it provided PME "with direct access to decision makers." The organization provided talking points and other tips for sharing their story to PME in advance of the meetings, although "we don't really obsess over the shape of the story, or how the story is told." A CDF Texas advocate described creating the advocacy opportunities as powerful:

> *"It's a more comfortable setting, and we find that people are more direct, more vulnerable, and more comfortable sharing their experiences. Plus, [legislative] staffers must directly face their real constituents, rather than reading their story off a page. We are also able to connect with advocates afterwards to check in and deepen our relationships with them."*

Capturing Medicaid Experiences from People Who Work Directly with PME

A few subgrantees used employees who work directly with PME to systematically document Medicaid experiences. One example was the Virginia Poverty Law Center, which has a team of 24 health insurance navigators on staff who enroll community members in Medicaid and marketplace health plans. The navigators completed a 10 question Google Form after working with each PME with questions that "reflect [on] the experience of the process of the application, what were the bumps along the way, what were the successes." The form also asked about "feeling welcome in the process." This approach provided a broad overview of PME' application experiences:

> *"As not all community members were willing to interview, the collected data was vital in helping us identify early on problematic areas that needed to be addressed so that the community member could be successfully enrolled. Without this data, we would not*

have been able to resolve issues and help our community members as effectively."

Video/Audio Technology

The *Monitoring Medicaid Using Lived Experience* project tested whether using video and/or audio technology enhanced collecting and making use of Medicaid lived experiences. Almost all of the subgrantees made use of video or audio recordings, with the exception of three subgrantees that were focused on learning from PME who were immigrants.

Technology Benefits. Subgrantees described the key benefit of recording Medicaid lived experiences was that recordings made the policy issue emotionally compelling, which was very helpful when advocating for related changes. "Videos are always the most powerful storytelling," said one advocate, and another explained:

> *"We use video…when the story is so compelling, so raw, so real that only their real voice truly captures the feelings that they're actually experiencing."*

Recordings were viewed as very useful during the pandemic since videos recorded remotely could show "this is a real person who is experiencing this issue." One advocate also stressed that having recordings was also useful for rulemaking or legislative hearings:

> *"It's often just convenient to have a Zoom recording with their permission to use because they may not be available at the time and place, [and] we generally have no control over when it [the hearing] will be."*

Technology Challenges. Most subgrantees reported that it was quite challenging to record PME's lived experience. One explained, "It is still really, really hard to get people to record a video. It's a pretty big lift." Getting PME comfortable to make a recording was the biggest challenge: "There are a fair number of people who aren't necessarily comfortable being on camera," explained one advocate. Another advocate highlighted that "video is hard, especially for immigrant communities" and several advocates described that it was particularly challenging in "red states where there's so much stigma in even revealing that you're on Medicaid."

In addition to the comfort level, the technology itself was often a barrier for PME. Some PME did not have access to broadband, others were not as savvy with technology and needed extensive support to make recordings.

Technology Used. Over half of the subgrantees used **Soapboxx**, which is an online platform that enables people to record short videos, usually under 3 minutes. It has been used for high profile public messaging campaigns, including recent presidential campaigns.

Most subgrantees using Soapboxx said they would "moderately recommend" it. A subgrantee noted, "I think that people like [it], it's very user friendly, it's very easy to record a video …and I think people like to see it polished." Another subgrantee explained, "It helps people learn how to be precise and say powerful things with just a few words."

The fact that Soapboxx provides a project webpage, where videos for a subgrantee can be recorded and posted for viewing, was also a benefit.

However, the three-minute limit on Soapboxx recordings was viewed by some grantees as a disadvantage because it was difficult to get an effective short version of a story, especially when PME "have three different [issues with Medicaid] going on." Additional reservations about using Soapboxx for work with PME was its cost to the organization and that it was very hard to get some PME to use it. One advocate described her organization's PME council members as being very used to giving interviews about their Medicaid lived experience, but "no one has been interested in Soapboxx." Another advocate described Soapboxx working best for "engaged users of smartphones."

Five subgrantees used **Zoom** as their primary platform and others subgrantees used it in addition to Soapboxx or other platforms. Subgrantees were quite positive about Zoom, largely because of people's familiarity with it. "We're all comfortable with Zoom at this point," one advocate said. It also enabled PME to have the option of being video or audio recorded. One advocate explained:

> *"Zoom has been very effective for our interviews because it allows the caller to call in or use their camera. It also is helpful because it allows the translator to join the call and translate in an effective manner."*

The key challenge subgrantees described with Zoom was that recordings needed to be edited when subgrantees wanted to create an effective video for advocacy. One advocate explained, "We want it [the video] to be concise and short and you don't want to lose the audience's attention." That required a skillset that was new for many advocates. One explained, "What the challenge is right now is just that we have a lot of raw footage that we need to edit."

Eleven subgrantees created videos with clips from different recordings. Some advocates learned to video edit as part of the project while a few hired video editors or had their communications team "edit those down into really short snippets that can be shared on social media or on our website."

Other approaches to recording PME included:

- Use of **Memria** by one subgrantee. Memria is a platform for collecting audio recordings, and staff particularly liked that the platform allows people who use it to revoke consent at any time without contacting their organization or the person who helped collect their story.

- Two subgrantees with prior video experience had videographers record and edit videos for the project.

Effective Video and Audio Strategies

Subgrantees recommended several strategies for recording Medicaid lived experiences:

Recording in Conjunction with In-Depth Interviews. A number of advocates described that it worked well to record PME during in-depth interviews both because trust is built during the conversations and staff can help support PME with the technology. Some described asking the PME at the end of the interview if they would speak on camera about a particular issue that they discussed earlier. Other advocates recorded an entire conversation over Zoom and then edited short clips from the interview.

Recording During Advocacy Events. Both in person and virtual advocacy events provided opportunities for staff to connect directly with PME and to provide them with the training and support needed to make recordings. One subgrantee reported that the majority of the Soapboxx videos they collected were from virtual advocacy days. Not only were PME there having "already committed their time to our cause" but staff could "walk users through the Soapboxx recording process" and that made it "feel a lot more manageable."

Providing Audio Option. Some PME were more comfortable with audio rather than video recordings, so many subgrantees felt that giving PME a choice about how they would like to be recorded was a helpful approach:

> *"Videos... can be intimidating for folks but they're a little bit more open to sharing their stories using just their voice, especially for the stories that are being collected from marginalized groups who for different reasons are justifiably distrustful of some of these systems."*

Recording Only Particularly Unique Stories. Rather than video recording all interviews, some subgrantees identified particularly compelling stories for video recording. One advocate explained:

> *"Persuading people to record video remains a big ask. We reserve this for stories that we know will make a powerful impact."*

Recording People who Work Directly with PME. A number of subgrantees found that while it was challenging to record PME, those who work directly with PME were much easier to video or audio record. One advocate explained:

> *"It's been easier to get recordings from people who are closer within our networks like from people from partner organizations who might have a relevant experience, people speaking to the experience of their community rather than individual grassroots activists."*

Less Effective Video and Audio Strategy

Subgrantees that invited PME to record and upload brief videos or audios at the end of a survey or onto the organization's website found the approach resulted in few recordings,

often fewer than 5. "No one has taken the initiative to record a video without [a personal] prompt," explained one advocate. "It hasn't taken off," said another. Another advocate explained:

> *"The tool requires planning and support from our end to get people to use it. We'd have to plan an event to show people and encourage them to be comfortable with the technology."*

Identifying Key Learnings from Lived Experiences

Most of the approaches to capturing lived experiences generated data that subgrantees had to manage and analyze. Many subgrantees were just beginning data analysis as this report was being written.

Data Storage

While some approaches to the project involved the direct sharing of PME stories with elected officials and program administrators, for the vast majority of subgrantees, the lived experience was stored for future use. One advocate stressed:

> "*Make sure you develop a comprehensive structure for collecting stories and storing them, as well as protecting the privacy of those you speak to.*"

Some subgrantees wrote a summary after an interview was over, while others typed notes during the interviews. One advocate explained her organization's approach:

> "*Throughout the interview process, each question is answered on the form and a final summary is written after the call is over. The summary is then stored in a shared file where we exclusively hold stories. These summaries serve as a reminder of the PME characteristics and as a transcript for what was said during the conversations.*"

Subgrantees that audio or video recorded PME often had the recordings transcribed, which was very useful for finding important quotes and identifying key themes in experiences. Some subgrantees used the transcription available as a part of the Zoom or Memria packages, others paid for separate transcription services, and several reported using Rev.com for transcribing. Several advocates mentioned that it was difficult to have transcripts in languages other than English translated. One advocate explained:

> "*As someone who doesn't speak Spanish fluently or read Spanish well … logistically it's been challenging to … work with a third-party translator and kind of navigate that process.*"

Most subgrantees stored project-related documents and files in shared folders on cloud-based storage sites (e.g., Google Drive, SharePoint, OneDrive, OneNote, Microsoft Forms or Dropbox), though others used flash drives or local hard drives.   Subgrantees that used Soapboxx or Memria to collect audio or video recordings typically used these platforms to store recordings. One subgrantee noted Memria's additional functionality: "Memria has made it easy to archive images, recordings, and consent forms for participants within its online portal." Airtable was used to store the results of surveys collected by CPD subgrantees and was used by some subgrantees for keeping track of coded/tagged information.

Some subgrantees felt their approaches to storing the lived experiences data worked well: "We are currently utilizing google drive … it has definitely been beneficial throughout this

process, "one advocate said, and another explained, "We store content and findings on Airtable, which has worked quite well." However, many expressed a desire to improve data management. As one subgrantee wrote, "The system is clunky and not user friendly. A more streamlined and efficient way of storing data is needed." Another subgrantee explained:

> *"The success of the project did reveal the need for a data management infrastructure to ensure that the stories are being used to amplify the voices of those who courageously shared their stories."*

Identifying Key Issues

At the end of the first year of the project, slightly over half of subgrantees (15) reported that they had started to identify key issues or themes from the Medicaid lived experiences that were collected, and the remainder of subgrantees planned to identify key issues or themes in the future.

Analysis of Qualitative Data. Almost all subgrantees (26) reported they were using, or planned to use, informal approaches for identifying the major issues raised from the Medicaid lived experiences. One advocate described his process:

> *"There's no process where I go through it and identify recurring themes. Typically, I'll just have a conversation…about it if I find something interesting, like if I have two or three stories in a row, where the family's essentially saying the exact same thing, it's worthy of noting… I'll talk…about that just for us to keep in mind, moving forward with our advocacy."*

More than three-quarters of subgrantees (23) reported they were, or planned to have, staff members more formally "code" or "tag" the key issues in documents such as interview transcripts. Few subgrantees, though, had experience with coding transcripts prior to this project. One advocate said, "Honestly it's … the first type of project that we've had where we're pulling out themes and then reporting them."

The subgrantees that used coding/tagging found it to be very helpful for identifying themes in Medicaid lived experiences. As one advocate explained, "[Coding] makes everything feel a lot more manageable when you have hundreds of pages of transcripts."

Subgrantees also reported that coding/tagging made it easier to make use of project findings: "Having the related transcriptions and quotes in one document is also very helpful." Another advocate explained:

> *"One of the things that's really appealing … to me about [coding] and I think [to] the other members of the staff as well, is that it allows us when we're writing about something that we may have a quote [about] … it makes it much, much easier … for staff, who [are] not intimately familiar with the interviews themselves to either take a look, or …to ask [staff involved in coding] 'Do you have anything relating to SNAP*

access?', for example, and then, if something's coded with SNAP, she can pull up a list and send that over."

To prepare subgrantees to conduct coding, the lead grantee CBPP contracted with the nonprofit Code for America to provide training on coding transcripts to CBPP's 8 subgrantees. CBPP subgrantees reported that this training was extremely helpful:

"It was a new process for us to learn, especially using Airtable, but one that I found very helpful in identifying quotes from our interviews and identifying main themes and key issues."

The 8 subgrantees that coded transcripts of Medicaid lived experiences during the first year of the project used codes to identify recurring issues related to the Medicaid agency (e.g. application, call center, red tape, eligibility), access to medical care (e.g. dental care, behavioral health, language barriers), and other safety net programs.   They also frequently coded the PME's type of eligibility and demographic characteristics.   Appendix 6 contains sample codes used by subgrantees.

Subgrantees reported using spreadsheet programs (Airtable, Excel), Microsoft Word, and digital collaboration software (Mural) to organize coded quotes. Airtable users reported that while it took some time to learn to use it, the program (free version) was viewed as "a really great way to keep track of and organize data."

Quantitative Analysis of Survey Data. Ten subgrantees reported that they or their lead grantee had analyzed quantitative data collected from surveys of PME in the first year of the project. The quantitative data were typically used to generate descriptive information about PME who had shared Medicaid lived experiences and what barriers they experienced. Some subgrantees used cross tabulations to examine issues such as whether the Medicaid challenges experienced by PME differed by the demographic characteristics, like race/ethnicity.

Learnings from the First Year

At the end of the first year, all subgrantees reported having obtained useful information from the Medicaid lived experiences that had been collected. "As a result, we have a richer understanding of the Medicaid program," said one advocate. The vast majority of subgrantees (21) reported learning about new Medicaid issues through this grant project. New problems were identified by 18 subgrantees while new benefits were identified by 12 subgrantees.

Identifying useful examples of known Medicaid issues was even more common. All but one subgrantee reported that they had identified useful examples of known Medicaid-related problems, while 20 subgrantees reported identifying useful examples of Medicaid benefits they were already aware of.

Several subgrantees mentioned the adage, "If you've seen one Medicaid program, you've seen one Medicaid program." However, despite differences between states in Medicaid programs and differences between subgrantees in approaches for collecting experiences and advocacy goals, common Medicaid themes did emerge. The following sections focus on Medicaid barriers, including how the issue of racism was raised, and positive aspects of Medicaid and highlight issues that were mentioned by multiple subgrantees based upon formal or informal analysis.

Medicaid Barriers

Getting and Keeping Medicaid. Difficulties related to applying for Medicaid or maintaining coverage were often reported. Over a thousand PME were surveyed by the Center for Popular Democracy's seven grantees and over a third reported dissatisfaction with the Medicaid application process.   Concerns from the surveys and interviews included confusing and missing notices, extensive documentation requirements, long call center wait times, the Medicaid website being difficult to navigate, and PME's lack of internet access. The application process was described by advocates as "too cumbersome for those with mental disabilities" and changes in the renewal process seemed "to really impact families who have kids with disabilities the hardest."

PME misunderstandings about whether they were covered by Medicaid were common, "People often do not know that they have been cut off a Medicaid program and find out only when they go to the doctor."

> *"I mean we don't even give people [insurance] cards anymore. They just go to the doctor and … they're supposed to be able to look them up and that's how they know that they have Medicaid. … I've heard people [say] 'Oh, I didn't get a card, so I didn't know whether or not I qualified.'"*

Access to Medical Care. PME challenges with access to healthcare and problems with healthcare providers were also common. These issues included lack of Medicaid coverage for dental and vision care; enrollees not knowing when services available through Medicaid

had been changed or expanded; trouble finding providers who accepted Medicaid insurance, particularly for mental health care; lack of access to Medicaid transportation services; and concerns about differential treatment by health care providers.

> *"A few [PME] mentioned that they felt their doctors were not treating them equally in comparison to patients with "regular" health coverage, things like getting necessary tests or medications, not getting approved for some things, or not being believed or experiences not being respected."*

Medicaid Coverage Gap. Problems for PME in the Medicaid coverage gap were raised repeatedly in states that had not expanded Medicaid. The central issue was that "people in the coverage gap have no access to affordable health care" and this was particularly concerning for those with mental health issues and "parents who are struggling to care for their children while sick." One advocate explained:

> *"Lots of [parents] wishing that they … had access to Medicaid so that they could be more present at times … in caring for their kids because it's hard – raising kids is hard anyway, but it's really hard when you're not feeling great; when you have to be on all the time because kids … don't necessarily understand … when parents are having … chronic health conditions. That can be really challenging."*

Racism and Discrimination in Medicaid. Several subgrantees reported that some PME they interviewed mentioned experiencing racism when interacting with Medicaid agency staff. These subgrantees found that Black, indigenous, and people of color (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."

Discrimination related to language issues was commonly reported. "We learned that immigrants feel that they are discriminated against by Medicaid personnel because they do not speak English," one advocate explained. Immigrant 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." The Immigration Research Initiative's brief report quotes an immigrant from Mexico living in New York who described prior interactions with staff who "just have a way of answering you that just isn't nice" and as a result, she was scared to ask for a translator:

> *"I speak about 60 percent English so I try to speak with them in English because I'm afraid if I ask for a translator, they might get more angry and who knows how they might talk to me."*

Not all subgrantees heard from PME that they had experienced racism, though for some subgrantees, this may have been because they did not directly ask about racism or discrimination. One advocate, who did explore the topic, described hearing about structural racism but not interpersonal racism:

"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."

Several subgrantees who did not explicitly hear about discrimination from PME identified patterns in the experiences of PME that they felt were consistent with racism. For example, one advocate said that most of the people who "talked to me about workers giving them attitude….were Black and immigrant folks." Another advocate described a pattern of immigrants having more trouble being approved for Medicaid coverage:

"We tend to see more ... immigrants going in and being told erroneously that they're not eligible when they actually are, because the immigrant eligibility is so confusing and challenging, but I think it also evidence of a bias or prejudice [by] some of the caseworkers assuming that somebody of a certain nationality or ethnicity is not eligible. I definitely think there's some racial discrimination in that pattern."

Some subgrantees also heard from PME about discrimination and racism by health providers. One advocate explained, "BIPOC participants raised many examples of bias and discrimination against them from providers especially the double 'stigma' of being BIPOC and on Medicaid." Additionally issues of cultural insensitivity from providers were repeatedly described:

"We have heard some things in terms of ... just a general lack of cultural awareness and sensitivity with providers coming into homes and not necessarily understanding some of the ... cultural beliefs and things like that and responding in a way that is disrespectful to families, quite frankly, and harmful."

Medicaid Benefits

Importance for health and well-being. The importance of Medicaid for the health and well-being of children and adults was a common theme identified across the country. "Parents have talked about how Medicaid has literally saved their child's lives," and, "We're hearing lots of reinforcement that Medicaid is a really valuable program and ... that parents ... are aware of how valuable it is to their families' well-being." Medicaid's role in providing access to pre-natal, pregnancy, and post-natal care to low-income women "helped them and their babies get a healthy start in life."

Additional positive aspects of the Medicaid program that were shared by PME from multiple subgrantees included Medicaid's contribution to the financial well-being of families, the benefits of automatic renewals, positive enrollment experiences when facilitated by a navigator, and positive experiences with health care providers.

Use of Lived Experiences

Medicaid lived experiences collected for this project were used in five main ways: adapting an organization's own Medicaid advocacy, informing government leaders of PME's concerns, in media coverage, for broad public dissemination, and to identify and help resolve problems faced by specific PME. Appendix 7 details the number of subgrantees that used PME's lived experiences in each way.

Adapting Organization's Own Medicaid Advocacy

Half of subgrantees (14) reported that their organization's Medicaid advocacy was adapted to include new focus areas based upon what they had learned from PME. One advocate described ensuring that her organization's "2022 legislative priorities reflect [the] frequent needs, challenges, barriers identified by PME," and another described her organization launching a new educational campaign in response Medicaid lived experiences:

> *"Due to this project, we quickly realized that the 'public charge' fear was a major hindrance and in response we launched a campaign to dispel the fear and to help immigrant communities feel comfortable in allowing us to advocate on their behalf."*

Informing Government Leaders of PME's Concerns

Informing state Medicaid agency. Half of the subgrantees (14) informed state Medicaid agency staff of the barriers to Medicaid access that PME had reported. These included barriers people faced in the Medicaid home and community based services program, the loss of coverage for children due to monthly premiums, citizenship requirements, barriers to reentry experienced by people leaving prison, and "access and enrollment barriers [the Medicaid agency] were unaware of."   One advocate explained:

> *"We learned about the problems foster and special needs adoptive children were facing, took the issue for individual help to the agency, but then went further to work a systemic fix."*

A handful of subgrantees connected PME directly with their state Medicaid agency. Six arranged for meetings between PME and the state Medicaid agency. Three subgrantees recruited PME to serve on Medicaid agency committees or working groups. One advocate described:

> *"Some policy issues lend themselves better to story banking than others. On more administrative issues related to enrollment or recertification, we have found that facilitating meetings between policymakers and consumers, or having consumers serve on advisory councils, can be a better way to influence policy."*

Most subgrantees described Medicaid agencies being responsive to learning about the issues raised by PME.   One advocate described the agency being "receptive to the issues, but not especially responsive, [they were] slow to act." More commonly, advocates

described the Medicaid agency addressing individual PME's issues, but not necessarily addressing the problematic policy or procedure:

> *"The agency has been very responsive on a case-by-case basis. It is more challenging to see where larger scale systemic changes have been incorporated to address challenges on a more macro level."*

The advocates who brought lived experiences to the Medicaid agency's attention believed doing so was very important, as few state agencies have monitoring efforts that capture the breadth of the Medicaid user experience. One advocate explained:

> *"State agencies are very focused on the federal accountability aspect and just trying to keep their heads above water with basic functioning and ... there's not a lot of awareness of how their decisions and policies translate to on the ground."*

Advocates reported that having individual stories was crucial for being taken seriously by the Medicaid agency:

> *"In the past ... when we've tried to advance policy changes [the agency is] like well, where is the issue, like, who's having issues? We've had to connect stories to get them to listen to us and hear us and hear why it's needed."*

A few subgrantees described efforts "to push our Medicaid agency to more formally take PME's input on policies," including one who is advocating "for creation of an advisory group of people with lived experience and advocates."

The 14 subgrantees that did not inform the Medicaid agency of the issues they identified from PME fell into two groups. For some, the agency was not responsive to the advocacy group's outreach. "In the past year we have had a challenging relationship with our state's Medicaid agency," explained one advocate. Other subgrantees did not have prior experience working closely with the Medicaid agency. Notably all 14 subgrantees that informed their Medicaid agency about barriers reported having a lot or a moderate amount of prior experience working with their Medicaid agency.

Informing state lawmakers. Twelve subgrantees reported informing state lawmakers about issues PME raised through this project, including the benefits of Medicaid. Educating lawmakers, as distinct from lobbying for specific legislation, was typically done through press releases, testimony at public hearings, and showing video clips of PME at legislative briefings. Some subgrantees noted that social media was an effective approach for informing legislators:

> *"Our legislators are... on social media all the time, even in committee hearings, even when we're presenting to them, so we know that how we engage with them and how we lift up these stories is really important, how we're able to catch their attention."*

Six subgrantees arranged for PME to meet with lawmakers and share their experiences directly either by phone or video conference. Advocates found doing so "incredibly important." An advocate explained, "It has been rewarding in multiple ways and made some of our meetings with legislators or their staff much more powerful." Another said:

> *"I would encourage others to also engage in this work but also go a step further in empowering decision makers to take steps to develop a feedback loop with PMEs."*

Yet some state political environments were described as not being hospitable to PME. As one advocate pointed out, in some circumstances the PME would need a very thick skin to interact with legislators "because [of] the hostility and just the sort of denigration of people on public benefits."

There were 16 subgrantees that did not inform state lawmakers about the issues that PME raised in this project. For some, the project timeline did not correspond with the legislative session. Others had little prior experience working with state legislators, and still others sought to do other forms of advocacy that were not limited by lobbying rules. Of the 12 subgrantees that reported informing state lawmakers about the issues raised by PME, all but 2 had "a lot" of prior experience working with state lawmakers. Others did not think they could influence lawmakers in their state:

> *"We have a legislature that is kind of past the changing of hearts and minds. Our stories are not effective in that level of advocacy. They have heard everything under the sun for decades and they're really easy at turning that part of their brain off."*

Informing federal lawmakers. Subgrantees mostly worked at the state legislative level, but five shared PME lived experiences with lawmakers at the national level. For example, the Florida Health Law Project reached out to federal lawmakers about the importance of home and community based services, providing them with links to published PME stories. This was done prior to the introduction of legislation in this area, so it was not lobbying. Additionally, early in 2022, a PME they worked with Aleen Shaheed, testified to the Senate Committee on Aging about the importance of having home care. In her testimony she said, "the aides are the lifeline to my independence."

Another subgrantee worked to impress upon President Biden the importance of Build Back Better legislation:

> *"We organized these handwritten letters to President Biden … a very quick turnaround project based on the information we were hearing about what key decisions are being made."*

Media Coverage

Approximately one third of subgrantees (9) received media coverage or published an op/ed article related to PME's lived experiences. A few subgrantees were particularly successful getting the PME's stories into national news outlets, including The New York

Times, The Washington Post, and National Public Radio (Figure 4). Almost all the organizations who received coverage had a lot of prior experience working with the media.

One subgrantee cautioned that effective stories for reporters need to be very timely:

> *I think there's an incredibly wrong perception that once you … collect a story, then that's a good person for [future] media. And that's rarely true because … that person's life has already changed. Their story is already different …You need to find someone right then in that moment.*

Figure 4. Examples of News Coverage

Abelson R. Biden Promised to Fix Home Care for Seniors. Much More Help May Be Needed. New York Times. 11/1/2021.

Abelson R, Kliff S, Sanger-Katz M, Gay Stolberg S. Democrats' Bill Would Go Far Toward 'Patching the Holes' in Health Coverage. New York Times. 12/1/2021.

Brooks Harper K. How One Grandmother Fell Into the Health Insurance Gap- and Why the Build Back Better Plan Could Help Cover Texans Like Her. The Texas Tribune. 11/16/2021.

Goldstein A. The Uninsured are Eager for Congress to Fill a Coverage Gap — Even for a Few Years. The Washington Post. 12/8/2021.

Lopez A. A Death in Dallas: What's at Stake as Congress Weights a Medicaid Fix for the Uninsured. National Public Radio. 9/29/2021.

Schencker L. New Illinois Law Aims to Improve Medicaid, Slash Costs for Some Families. Chicago Tribune. 7/6/2021.

Tareen S. Health Care for Older Immigrants Sees Momentum Among States. US News and World Report. 7/24/2021.

Broad Public Dissemination

Many subgrantees posted PME's stories on their websites (15) or on social media (12) to raise awareness of specific issues in the Medicaid program or to highlight how the program benefits members of the community. The Florida Health Justice Project website, for example, has videos on Medicaid lived experience by the type of PME: children, former foster care children, pregnant women, low-income parents, and seniors and people with disabilities.

Some advocates intended this dissemination to spark their supporters to inform their policymakers:

> *"We're going to be sharing [our videos] constantly on our Instagram and Twitter, as well as Facebook so during our legislative session so we can bug people…so they can call their representative."*

The lived experiences were highlighted in a number of subgrantees' research and policy reports; for example, by the Shriver Center and the Immigration Research Initiative. A few subgrantees hosted virtual meetings over Zoom or Facebook to discuss learnings from the project with the community and others used stories to update their informational materials for PME. One subgrantee, after learning about the fear immigrants had about "public charge" created an information campaign directed to inform PME that receipt of Medicaid would not impact immigration:

> *"We had to kind of switch gears … as we discovered [immigrant fears about claiming benefits] and started running campaigns really focused on getting the word out that 'public charge' is no longer being enforced-- having the benefit of Medicaid is not going to affect you and your immigration status."*

Identify and Help Resolve Individuals' Problems

Most subgrantees (19) felt that, as they collected lived experiences, they needed to provide assistance with the PME's problems either directly or by referral:

> *"If we interview somebody, it's our commitment to them to not just pay them $50 but to help them with whatever we can help them with. So that's like another thing that builds a relationship, but also is like our commitment to them."*

Notably, PME's problems were not always confined to the Medicaid program. Subgrantees heard about problems related to transportation, lack of family leave, issues with SNAP, housing insecurity or lives being derailed by COVID. This often complicated how and where assistance could be provided and also how subgrantees could best allocate their bandwidth.

Key Reflections

Subgrantees described learning a tremendous amount in the first year of this project, and they shared key reflections for other organizations considering this work:

Be Ready for a Challenge. Subgrantees described capturing lived experience as work that was very important, but challenging. "You know storytelling sounds….easy and fun, but it's really incredibly hard," said one advocate. Another explained, "It is hard work, however, it must be done to improve access to care in our states."

A Wide Range of Expertise is Needed. Capturing Medicaid lived experiences and using the learnings effectively requires staff expertise in a wide variety of areas, ranging from working with partner organizations, conducting in-depth interviews, recording and editing video, and analyzing transcripts for recurring themes, to using the findings in advocacy. Several subgrantees suggested that organizations seriously consider their organizational strengths and think through:

> "[whether] this is something your organization takes on [by itself], or are there partner organizations with the staff expertise, tools and infrastructure that you might subcontract with."

Have a Clear Purpose for Using the Lived Experiences. A number of subgrantees underscored the importance of having a clear plan for how the organization will use the lived experiences. PME are sharing deeply personal experiences and, to be respectful to those sharing, advocates strongly believed the information should be used to improve the Medicaid program, and not "just sit on a shelf":

> "I feel a sense of responsibility to them to get their stories shared in a useful and productive way, because they took the time and the mental energy and emotional energy to tell me these stories and I want to make sure that I'm a good conveyor of this information."

Relatedly, advocates highlighted that capturing a large number of lived experiences should not necessarily be the goal of the project. It should depend on the organization's goals for the lived experiences. Subgrantees that were interested in highlighting specific policy issues found that a small number of well-produced videos could be very effective, whereas organizations seeking to identify Medicaid barriers they were not aware of previously often needed to reach out to many more people.

Be Flexible. Aspects of this work were new for many subgrantees, and allowing the process to evolve was important. One advocate said, "I think that's something to plan for from the beginning - learn, adapt, evolve." Another advocate explained:

> "I would advise an organization just starting out doing this work to remember to be flexible, as you must adapt to changes that are identified in the process and to be ready

to think outside of the box in finding solutions in an ever-changing climate and pandemic world."

Maximize Usability of Learnings Within the Organization. Several subgrantees stressed the benefit of making sure that staff throughout the organization were aware of and could access the lived experience learnings. That way, the learnings could be widely integrated into the organization's advocacy work. One example of this was rotating different staff to take notes during interviews with PME. Additionally, having a "comprehensive structure" for collecting and storing lived experiences increased the usability of lived experiences and was considered essential in case of staff turnover, which was not uncommon.

Use the Opportunity to Have PME Priorities Drive Organization's Advocacy. Several subgrantees used this project as an opportunity to ensure their organizations' priorities were determined "through what is being experienced by beneficiaries." An advocate described integrating PME priorities into her organization's advocacy as an important organizational shift that will continue beyond the grant:

> *"I think it takes a full year to lay the groundwork for integrating PME into an advocacy organization's work, and even then, there is still a lot to learn and do differently."*

Other advocates recommended hiring PME to capture lived experiences or to "start by having representation of people with lived experience of poverty as part of its tables, committees, or advisory boards." For organizations taking smaller steps towards integrating PME priorities, one advocate recommended to "make sure to make time to cultivate relationships with your storytellers that will continue over time."

Use the Opportunity to Empower PME to Advocate for their Community. Several subgrantees used this project as an opportunity to build leadership skills among PME. An advocate explained:

> *"[We want to] really develop individuals into being their own advocates to create change—to empower them to know that they have the ability to be heard. They have the ability to create changes that not only will positively impact their families, but also impact other families in the state."*

Another advocate explained that her organization's approach to building leaders is meeting PME where they are and getting them to engage on their terms. She described asking:

> *"'How do you want to engage? What time do you have and what ways? Is it just us asking you what's going on and running ideas by you and you giving us your wisdom and feedback? Is there more?' So just making sure that in any interaction asking folks how they want to be engaged, but also providing a menu is helpful."*
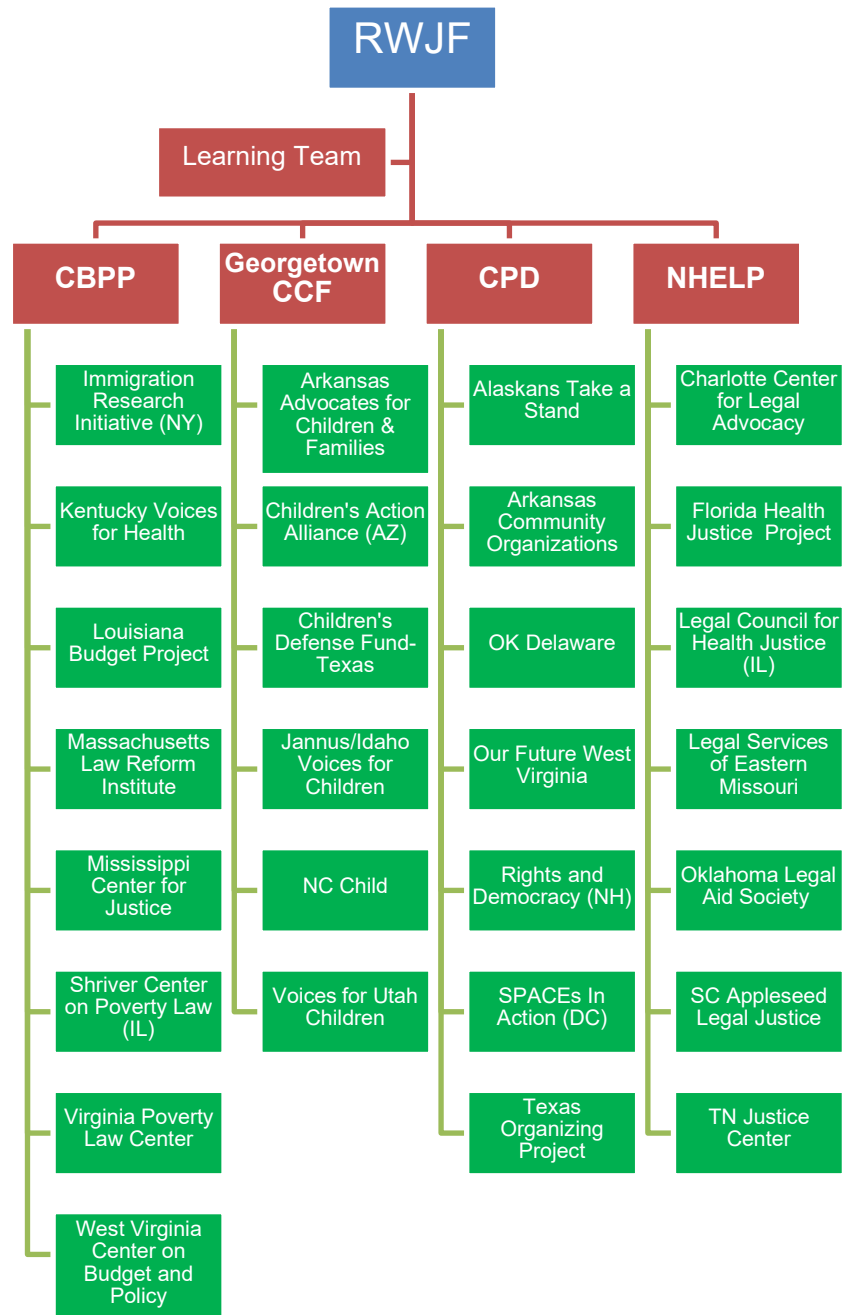
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Appendices

Appendix 1. Funding Streat to Support Monitoring Medicaid Using Lived Experience Project 2021

Appendix 2. Location of the 28 Subgrantees

States with Organizations Participating in the RWJF Monitoring Medicaid Grant Program

Appendix 3. Recruitment Approaches and Perceptions of Effectiveness in 2021

	Use of Approach			Effectiveness of Approach (Among Those Using it)		
	Main Approach	Additional Approach	Not Using	Very Effective	Moderately Effective	Slightly or Not Effective
Clients referred from partner organization	12	12	4	6	11	7
Reaching out to your organization's members/supporters	9	16	3	7	7	6
Clients of your organization	8	11	9	2	12	5
Recruitment at advocacy events	5	16	7	4	3	9
Social media solicitations	5	15	8	0	4	15
Posting survey or comment form on website	5	13	10	1	3	10
Advisory council outreach to network	4	4	20	3	2	3
Door to door canvassing	2	6	20	0	3	4
Posting flyers in neighborhoods	2	7	19	1	1	7
Direct outreach to voter roles	1	4	23	0	0	5

Source: August 2021 survey of subgrantees

Appendix 4. Approaches to Capturing Lived Experiences and Perceptions of Effectiveness in 2021

	Use of Approach			Effectiveness of Approach (Among Those Using it)		
	Main Approach	Additional Approach	Not Using	Very Effective	Moderately Effective	Slightly or Not Effective
In-Depth Interview	20	4	4	14	6	3
Online Survey or Comment Form	8	9	11	2	6	9
Focus Groups	1	10	17	2	1	5
Creating a PME advisory council	2	2	24	2	1	1
Staff Recording Video or Audio of PME	8	13	7	4	8	8
Inviting PME to Record and Post Video or Audio	3	14	11	1	2	14

Source: August 2021 survey of subgrantees

Appendix 5: Sample Consent Form

Oral Health Access Focus Groups—Consent Form

Purpose: We are interested in understanding challenges families face when getting children the dental care they need. We hope to use what we learn today to educate policymakers, providers, and advocates working to improve Illinois families' dental health care system.

Voluntary Participation: Participation in this focus group is **completely voluntary.** You may choose not to participate, and you can stop participation at any point in time during the focus group without penalty.

Time and Compensation: This focus group will take 1 hour and 30 minutes. Everyone who completes the focus group will receive a $20 Visa Gift Card and dinner for your time.

Confidentiality: Everything you say today will be **completely confidential.** This means we will not tell anyone outside of our organizations that you participated in this focus group. We will keep all records and notes from this focus group in a secure location. If any information from this focus group is published or shared, **we will not use any identifying details** about you (like your name or where you work) and we will use fake names with any direct quotes.

Audio Recording: We will be recording this focus group to make sure we have correct quotes and notes about what you tell us today. This recording will be stored on a password protected computer and will never be shared with anyone outside of our organizations. The recording will be deleted after one year.

Benefits and Risks: Your participation in this focus group may help create policies that will make it easier for Illinois families and children to get the dental care they need. The risks for participating in this focus group are minimal. You may feel emotional distress when talking about challenges with going to the dentist. We will be sharing resources for finding dental care, health insurance, and other social services with all of our focus group participants today.

Questions and Concerns: You will be given a copy of this consent form for your records. If you have any questions or concerns after the focus group, please contact:

Name/Organization/Email/Phone

Please sign below if you agree to participate in this focus group:

Name (Print): _____
Signature: _____
Date: _____

Appendix 6: Examples of Codes Used to Tag Interview and Focus Group Transcripts

Medicaid Agency:
- Application
- Call Center
- Communication
- Loss of Coverage
- Language Access
- Eligibility
- Online Accessibility
- Racism/Discrimination
- Red tape
- Renewals
- Verification Documents

Access to Medical Care:
- Behavioral health
- Culture barriers
- Dental care
- Discrimination
- Financial Hardship
- Language barriers
- Prenatal/postpartum care
- Transportation
- Vision care

Type of PME:
- Children
- Disability
- Foster/kinship caregiver
- Immigrants
- Rural

Other Program Codes:
- ACA Marketplace
- Paid Leave
- SNAP
- Unemployment Benefits

Appendix 7. Use of Lived Experiences by Subgrantees in 2021

Use of Lived Experiences	Number of Subgrantees
Adapted organization's Medicaid advocacy to include new focus areas based upon what was learned	14
Informing Public Servants	
Informed state Medicaid agency of issues raised	14
Arranged meetings between PME and the state Medicaid agency	6
Connected PME with state Medicaid agency to serve on Medicaid committees or working groups	3
Informed state lawmakers of issues raised	12
Arranged meetings for PME to share experiences with lawmakers	6
Informed federal lawmakers of issues raised	5
Published OP/Eds or received media coverage related to this project	9
Connected PME with reporters	11
Disseminating Learnings from Lived Experience	
Posted stories, quotes, videos or other lived experience on organization's website	15
Posted stories, quotes, videos or other lived experience on social media	12
Created a video with clips from different recorded interviews	11
Wrote a report that used stories or quotes collected for this project	9
Hosted Facebook live/Zoom meetings to discuss learnings from project	5
Problem Resolution	
Connected PME with resources to address their specific Medicaid problems	19

Source: December 2021 survey of subgrantees