



A GUIDE TO

# Monitoring Medicaid Using Lived Experience



## 100% KIDS COVERAGE

Storybook

Why health coverage matters for Utah children & families



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# Contents

Executive summary	3
Introduction	6
Why Medicaid lived experience is so important	6
Getting started	8
Recruiting PME	10
Recruiting people who work directly with PME	14
Sharing Medicaid lived experience	16
In-depth interviews	17
Videos	19
Surveys	22
PME sharing directly with Medicaid decision-makers	24
Other approaches	26
Using lived experience in advocacy	28
Working with the Medicaid agency	29
Educating lawmakers	31
Media coverage	33
Broad public dissemination	35
Additional advocacy approaches	36
Conclusion	37
About the authors	38
Appendix: Participating nonprofit organizations	39

# Executive Summary

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This guide highlights the key learnings from over 50 nonprofit organizations that have been directly engaging with people with Medicaid experience (PME) with the goal of grounding Medicaid advocacy in lived experience. The recommendations in the guide were developed by synthesizing learnings from interviews, surveys, and virtual learning sessions with the nonprofits participating in this Robert Wood Johnson Foundation-funded initiative over the last two and a half years. The key recommendations are described below, along with illustrative supporting quotes from nonprofit staff members.

## Why lived experience is so important

**Reveals Medicaid issues.** “Often the issues identified through PME’s stories were issues that both we and our agency were unaware of.”

**Focuses advocacy on PME priorities.** It makes “sure that the voices of the people that we represent are ingrained in what we’re doing.”

**Persuades Medicaid decision-makers and the public.** “We have definitely felt that decision-makers were influenced by stories in a way that they simply were not by policy advocates.”

**Empowers PME.** “Just having their voices heard has been powerful for many of the storytellers.”

## Getting started

**Have a clear purpose for using lived experience.** PME share deeply personal experiences. To be respectful to those sharing, the information should be used to improve the Medicaid program.

**It’s about relationships.** “Start by building relationships....Don’t expect people to volunteer without trust and reciprocity.”

**Planning is essential.** “Before launching this work, organizations need to be clear about their goals and objectives,” and consider staffing, technology, and the organization and storage of data.

**Be flexible.** “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.”

## Recruiting PME

**Use trusted connections.** Trust is essential for recruiting PME to share their Medicaid experience: recruit using existing relationships, partner organizations, and in settings that PME trust.

**Use multiple recruiting approaches.** Using multiple approaches is “a good strategy for trying to cast the widest net.”

**Give PME choices and control.** PME are more likely to participate if they are given choices of how they share their experiences and if “they maintain full control of when and how their advocacy story is shared.”

**Compensate PME.** “Adequate and respectful compensation for people’s time is critical,” since PME are “opening up their lives and experiences to us in this very personal way.”

**Highlight that the purpose is to improve Medicaid.** “The main thing as far as enticing them to [share experiences], is that they’re helping other people... and it can lead to change.”

## Sharing Medicaid lived experience

PME can share their experiences in a variety of ways, including through in-depth interviews, videos, surveys, and having PME share directly with Medicaid decision-makers. Regardless of the approach, the following strategies are essential:

**Listen to and value PME.** Help PME “feel that their voice is important,” be “willing to meet them where they are,” and offer “no judgement.”

**Be culturally responsive and allow sharing in PME’s native language.** “Conducting interviews and providing surveys in a participant’s native language is essential and is also very doable.”

**Be prepared to help PME.** “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.”

**Develop ongoing relationships.** With an ongoing relationship, PME know where to reach out for help if needed, can become more involved in advocacy, and can learn how their lived experience has made an impact.

## Using lived experience in advocacy

Medicaid lived experience should be used to address issues raised and not “sit on a shelf.”

## The following are the key ways to put Medicaid lived experience to work:

**Working with the Medicaid agency.** “When we can bring specific stories to their attention, it has allowed the state agency to follow the situation and determine where a breakdown may have occurred. When we have multiple stories with the same issues that they can investigate, it leads to systemic change or correction.”

**Educating lawmakers.** “Some of them really don’t understand the program or what people face, so it often is really educational, especially with new legislators.”

**Media coverage.** “Getting these stories in the press is a key strategy to advocate for change.”

**Broad public dissemination.** “The best way to build public support is sharing stories of PME.”

**Developing PME advocacy leaders.** When PME gain advocacy skills it provides “renewed purpose,” “builds self-worth,” and “facilitates them understanding how much power they have.”

The experiences of the participating nonprofits highlight the benefits of using lived experience for monitoring Medicaid. “Any organization can benefit from incorporating the knowledge of those with lived experience, no matter the issue or policy,” emphasized a nonprofit staff member.

# Introduction

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In late 2020, the Robert Wood Johnson Foundation (RWJF) began funding nonprofit organizations to monitor Medicaid by directly engaging with people with Medicaid experience (PME), including applicants and their families, enrollees, and people left out of the Medicaid program. The project goal is to use a variety of methods to learn directly from PME about the effects of Medicaid policies and practices so that Medicaid advocacy is grounded in actual lived experience. Over the initial two and a half years of the project, RWJF funded 8 national advocacy organizations, which in turn funded 57 on-the-ground nonprofits to monitor Medicaid using lived experience. These organizations have been engaged in this work in 33 states and the District of Columbia.

Staff from these organizations unanimously agree that lived experience is important for monitoring Medicaid. However, they also found the work to be challenging. This guide highlights the nonprofits' key learnings for effectively working with PME to have them share their lived experience and then use the learnings to advocate for Medicaid program improvements.

This guide is only possible because the participating nonprofits' staff have been extraordinarily generous in sharing their experiences with us. Over the course of the project, we surveyed participating organizations at three different times, conducted 53 in-depth interviews with nonprofit staff, and hosted three virtual learning sessions. Recommendations made in this guide reflect approaches that were repeatedly raised as being effective by staff. In several places, the guide highlights innovative ideas that were used by only a few organizations. The guide makes extensive use of quotes from staff members so that their experiences and perspectives are expressed in their own words.

We hope that this guide will enable organizations that are getting started using lived experience or that are looking for strategies to enhance their use of lived experience to benefit from the learnings from the many nonprofits involved in this work.

*~ Jessica Greene, Diane Gibson, Lynn Quincy, and Jonathan Rapoport  
June 2023*

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The views expressed here do not necessarily reflect the views of the Foundation.*

# Why Medicaid lived experience is so important

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“No one is more expert on the Medicaid program than enrollees,” said a nonprofit staff member explaining why she feels Medicaid lived experience is essential for monitoring Medicaid. Lived experience, which is defined by Oxford Reference as “personal knowledge about the world gained through direct, first-hand involvement,” was described by another staff member as “the only real way to know how Medicaid is or isn't working.”

**Staff identified four key reasons why Medicaid lived experience is so important:**

## **Reveals Medicaid issues**

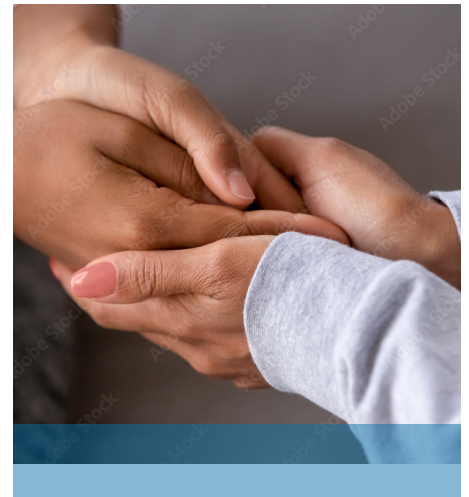
A key benefit of lived experience is that it provides both advocates and Medicaid program administrators with information about the Medicaid program that they were not previously aware of. “[Lived experience] is the only way to monitor Medicaid,” said a nonprofit staff member, as “no one knows the challenges or benefits better than those most directly impacted by the program.” Another explained,

“There is sometimes a difference between what is supposed to happen and what happens in real life. Lived experience shows the real life.”

For example, a staff member explained, “One of the most compelling and over-arching issues we learned from this project was how shockingly bad our agency's customer service performance and general consumer interaction is.” Other examples of learnings from lived experience include learning that Medicaid dental coverage “was not sufficient to take care of a substantial amount of dental work,” learning about permanent closures of Medicaid offices in rural areas, and the “unreliability” of Medicaid-provided transportation.

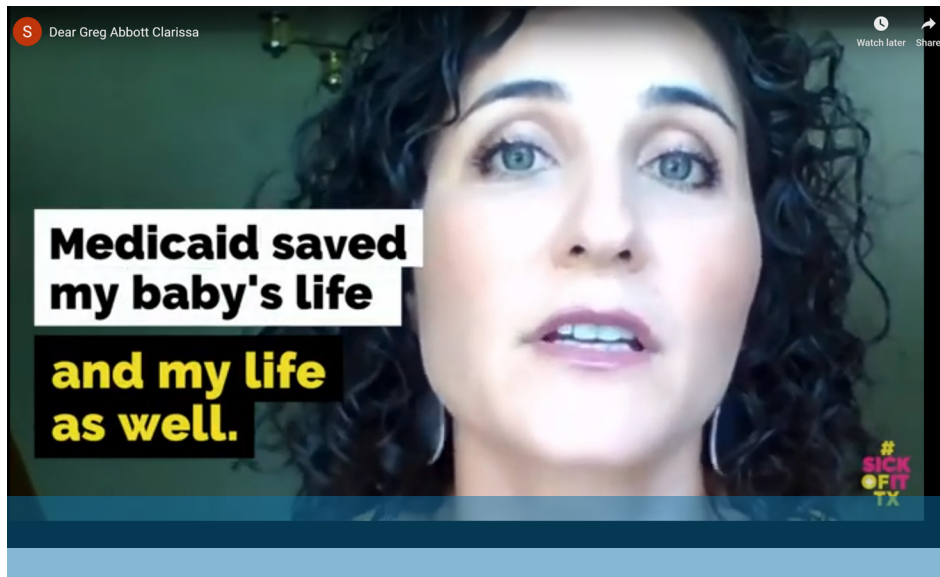
## **Focuses advocacy on PME priorities**

Knowledge of Medicaid lived experience helps nonprofits focus their advocacy efforts on issues that PME experience and view as important.



***“The biggest benefit for the organization has been making sure that the voices of the people that we represent are ingrained in what we're doing... It's those stories that are leading, and we're following.”***

## Why Medicaid lived experience is so important



Furthermore, as one staff member noted, “An added benefit is that communities are more likely to buy into a solution that they have helped shape.”

### **Persuades Medicaid decision-makers and the public**

Medicaid lived experience is very forceful and persuasive to lawmakers and Medicaid agency staff. A nonprofit staff member explained, “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.” As another put it, “We have definitely felt that decision-makers were influenced by stories in a way that they simply were not by policy advocates.”

Advocacy is even more effective

when PME share their stories directly with decision-makers. “Nobody tells the story like the person who is living it. We can be interpreters and messengers, but we just don't have the same credibility or impact,” said a staff member. Another said:

“I think that’s what moves the needle. I won’t name names, but I go before a committee in the state house [and] the senator is on his phone, and he's having other conversations. But the other day I was there [with] a mom. She has a young son with Down Syndrome, and she got up and shared her story, and he was paying attention.”

### **Empowers PME**

“Just having their voices heard has been powerful for many of the storytellers,” said one staff member. When PME are

supported with opportunities to build skills and directly engage in advocacy, that power is further reinforced. Another staff member put it this way: “We're not just focusing on these short-term policy goals, we are helping to really develop people's advocacy skills and their knowledge.”

In addition to advocacy skills, helping PME gain a deeper understanding of the healthcare system and the Medicaid program is highly valuable. As a nonprofit staff member explained, “This [enables] community members to understand how to do a Medicaid renewal, find a doctor who speaks their language, push to be respected if they are being discriminated against and to understand their rights.”

***“[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.”***

# Getting started

**“You know storytelling sounds...easy and fun, but it’s really incredibly hard,” said a nonprofit staff member. Another explained, “Working with PME and community groups is time-consuming. It takes time to build trust and to really listen to the community. But it’s worth it.”**

**There are four key recommendations for getting started monitoring Medicaid using lived experience:**

## **Have a clear purpose for using the lived experience**

It is important to have a clear plan for how Medicaid lived experience will be used. PME are sharing deeply personal experiences. To be respectful to those sharing, the information should be used to improve the Medicaid program:

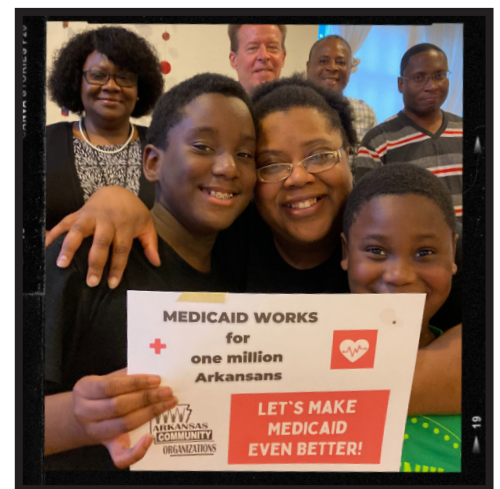
"I feel a sense of responsibility to them to get their stories shared in a useful and productive way, because they took the time and the mental energy and emotional energy to tell me these stories and I want to make sure that I'm a good conveyor of this information."

## **It’s about relationships**

Start by building relationships," said a nonprofit staff member. Another advised, "Don't expect people to volunteer without trust and reciprocity. This is not one and done but ongoing with the individuals we are working with, trust is essential as is ensuring the individuals feel their value to the work."

## **Planning is essential**

"Spend a good amount of time on preparation," said a staff member, echoing advice offered by staff at many nonprofits. "Before launching this work, organizations need to be clear about their goals and objectives," said another, and will need to "Identify what is needed to implement and sustain this effort in terms of personnel, expertise, tools, and referral sources."



***“Ensure that the people doing this work understand it is as much about relationship building as it is about story gathering.”***



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## Getting started

**Staffing.** Effectively collecting Medicaid lived experience and using the learnings requires staff expertise in a wide variety of areas, potentially including working with partner organizations, conducting in-depth interviews, recording and editing video, analyzing transcripts for recurring themes, and using the findings in advocacy. Therefore, it is necessary to consider 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.”

For the parts of the process that are done in-house, it is important to take the time to consider what type of training is needed to help staff succeed and for PME to be valued and protected in the process. Given that staff turnover is common, one staff member advised, “Create a clear story collection and story promotion process that can stay with your organization, regardless of employee turnover.”

**Technology and equipment.** Making choices about what technology and equipment to use and to what extent to go “high-tech” is a key part of planning for collecting lived experience and organizing the data collected. Factors to consider include cost, the difficulty of access and use for both PME and staff, training and support needs, and how technology-related incidents such as online surveys being spammed will be handled.

Demonstrating issues with access and potential solutions, one nonprofit staff member explained,

“Reliable internet access in rural areas and user error with technology can be problematic. Some solutions that worked well included visiting the person in their home/community with items needed (e.g., hotspot, laptop, etc.) and helping record video as needed.”

**Organization and storage of data.** Carefully choosing an approach for organizing and securely storing lived experience-related data is essential so that others within the organization can use the information, “protecting the privacy of those you speak to,” and so that data can be easily located if there is staff turnover.

“Creating a robust master database to manage all our story collection data and content has been incredibly helpful. The system... is helping us keep better track and make better use of a huge and growing library of stories,” explained a staff member.

## Be flexible

Allowing the process to evolve is important. One nonprofit staff member said, “I think that's something to plan for from the beginning — learn, adapt, evolve.” Another 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.”

# Recruiting PME

Recruiting PME is an essential first step to having PME share their lived experience. Recruiting PME can be very challenging, and a nonprofit staff member offered the following words of general advice and encouragement:

“Ultimately people are very hard to reach and it's a very sensitive topic. People may not want to talk about it, especially with a stranger or in a group of strangers. So, just be patient with yourself around your ability to recruit, and also the process in general, and be open-minded to trying various methods.”

## Effective strategies

**Use trusted connections.** Trust is an essential component of the most effective strategies for recruiting PME to share their Medicaid experience, ranging from using trusted personal or organizational relationships to recruiting in trusted community settings.

### Here are several strategies for working with trusted connections:

**Reach out to known PME.** Reaching out personally to PME who already have a trusted relationship with your organization, including current clients, is a very effective strategy for recruiting PME. As a nonprofit staff member explained, “By in large, it's been personal phone calls to folks to say we know you have a story to tell. We want to make sure we capture this, and so it's been a very targeted approach that, I think, has been the most helpful.”



A further benefit of “starting with folks you know well” said a nonprofit staff member, is that “they'll lead you to people who are not currently within your circle to get you more people with more diverse experiences.” “As always, word of mouth is king,” said another staff member.

**Partner with trusted community organizations.** Having trusted community partners recruit PME to share their lived experience is also an effective strategy, particularly for nonprofits that are not direct service providers. “We learned just how important it is to work closely with partner organizations who have strong relationships with the individuals and communities we are trying to reach,” said a nonprofit staff member.

## Recruiting PME

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.”

Working with partners also offers the opportunity to connect with PME from a wider range of backgrounds than might otherwise be possible. For example, one nonprofit reached out to community organizations representing immigrants, organizations in rural areas, and smaller BIPOC-led grassroots partners, which “fostered new relationships with the community and expanded the diversity of the voices we heard from in our storytelling project.”

An additional benefit of asking community partners to recruit PME to share their experience is that “people who came to us through partners were often the most prepared to engage in advocacy, speak to reporters, and more. They are often pre-vetted and trusted us with their experiences because of our partnership.”

**Go where PME are.** In-person approaches for recruiting PME to share their experience such as hosting events in the community to recruit PME, recruiting at community events hosted by other organizations, door-to-door recruiting, or street canvassing are often effective.

One nonprofit staff member advised, “Meet 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.”

**Human interaction matters.** Recruitment approaches without direct human interaction are generally less effective. For example, attempting to recruit PME through social media campaigns, posting recruitment invitations on nonprofit websites, and network email blasts were described by nonprofits as minimally effective. “Social media was probably least effective based on the number of people it moved to take action,” explained a staff member, while another said, “Digital, it just didn't work.”

**Use multiple recruiting approaches.** A common refrain from nonprofit staff is that it is necessary to use multiple approaches for recruiting PME. Using multiple approaches was described as “a good strategy for trying to cast the widest net.”

For example, a staff member 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.”

**Give PME choices.** PME are more likely to share their lived experience if they are given choices about the way to share their experience. As a nonprofit staff member explained, “We found it's really important to ask the interviewee how they feel comfortable sharing, whether it's a written statement, an actual recorded interview, or just an audio file. That's been really key for us as well to be able to build trust, is asking them 'Hey, how are you comfortable sharing?'”

**Give PME control.** In order for PME to choose to share their experience, it is important to “make sure they maintain full control of when and how their advocacy story is shared” since “they are the ones that may have to deal with negative feedback.”

## Recruiting PME

Consent forms can provide a list of options for PME to select how their experiences can be shared, like on social media or with legislators, and if personally identifiable information, like name or image, can be used. As one nonprofit staff member explained, "When it comes to the actual collection of stories, just recognize that everybody comes from a different space...Just acknowledge that maybe they're not comfortable in sharing their story publicly, maybe they want to stay anonymous, that's okay."

This is especially important for recruiting PME who are undocumented or have undocumented family members. Another staff member shared, "Talking about mixed-status families ... they were more open to speaking after learning that it was confidential and learning that it was for their own benefit and for the community's benefit."

**Compensate PME.** Compensating PME for sharing their Medicaid experiences is essential both for recruiting PME and appropriately recognizing the value of their lived experience. As one nonprofit staff member explained, "Adequate and respectful compensation for people's time is critical," since PME are "opening up their lives and experiences to us in this very personal way." Another shared, "Without the compensation, [recruiting PME] would be 1,000 times harder."

Another staff member elaborated, "I think being able to say like, 'Hey, your time and your story is valuable, and it's so valuable that we're actually going to pay you for it at a market rate or a little bit higher because we know that you are important.' [It is] an important power shift, right?"

Non-monetary compensation can also be very effective. "I've been taking people for like coffee and stuff, just to treat them to something, and let them know that somebody cares about them in this process ... because I find that that is really very important when you have that one-to-one conversation," shared a staff member.



## Dylan

AGE: 21  
LEE COUNTY, FL

*Dylan, who suffered a stroke at birth which left him permanently disabled, has relied on Medicaid for his entire life. His Mom has managed to raise him at home, but she just got a notice that his Medicaid was ending.*

Compensating PME is not without difficulties, as the logistics of compensating PME may be complicated given nonprofit policies. Additionally, it is important to be on the lookout for potential scams related to compensation. For example, a few nonprofits that were offering gift cards for completing surveys received several hundred "spam submissions" in a day.

### **Explain that the purpose is to improve Medicaid.**

"The main thing as far as enticing them to [share their Medicaid experience], is that they're helping other people...and it can lead to change," said one nonprofit staff member.

Another explained, "I think that people want to be involved with helping to make programs better. ....So we definitely leaned into that. We saw a good kind of response from people being like, 'Okay, it won't take me that long. And I actually could make a difference. So sure, why not?'"

## Challenges

**It's time consuming.** "Allow more time than you think is necessary to recruit PME," a nonprofit staff member said since building relationships takes time. "This work is labor and time intensive. It can take many hours of work to secure a single story or interview. But it is worth the effort," explained another staff member.

## Recruiting PME

**Hesitation to participate.** A nonprofit staff member explained that some PME are afraid to share lived experience, “A lot of people were afraid. Especially if they were undocumented. They were afraid of giving their names out. They were afraid of giving their numbers out, afraid of giving their emails. They were afraid of everything.”

Leveraging relationships with trusted community partners, providing interpreters, and giving PME the opportunity to be anonymous when they share their experience can help PME overcome their hesitancy.

**PME may undervalue their own experience.**

“People may be scared to share because they think their stories are unimportant,” explained a staff member. Making a similar point, another staff member described some PME having applied multiple times and being denied: “So, we want to gather that, but their story doesn't feel big to them because they haven't been able to use [Medicaid].”

Offering a suggestion for helping PME overcome these concerns, a staff member explained, “You have to know when it is best to step back and give the storyteller time/space to digest and think about the opportunity.”

**Mistaken for Medicaid agency staff.** Several nonprofits found that it was important to highlight that they were not Medicaid agency staff so that PME would share honestly about their experiences. A staff member elaborated, “At first [PME] just wanted to tell us how great [Medicaid] was because they thought we were with the state. And so, we've had to kind of like distance and say we want your real experiences. We are not here to gloss over your reality.”

***“We found out we had to say we're not with the state, and we're not with Medicaid.”***

**Access to and comfort with technology.**

Some PME have limited access to and varying levels of comfort with technology that affect their ability and willingness to share their lived experience. For example, as a staff member explained, “Access to broadband and reliable cell service remain limited in many parts of the state. ...Additionally, [our] partners in Tribal, immigrant, and Latinx communities felt that parents and caregivers of children may be unlikely to participate freely with an unknown and thereby untrusted technology platform.”

As a result, this organization chose not to use any new technologies in collecting lived experiences. As illustrated here and discussed in the “Getting started” section, careful planning about what technology to use and making a range of options available for sharing experiences, including some that are low-tech, can reduce barriers to participation.



# Recruiting people who work directly with PME



In a Kentucky Voices for Health video posted on YouTube, Christina Libby shared:

***"I am able to go and speak with legislators and take those first hand experiences of my clients and hopefully impact the policy that is going to have a much broader effect on all Kentuckians."***

In addition to having PME share their lived experience, another impactful option is to recruit people who work directly with PME, such as health care navigators, assisters, social workers, and physicians to share their first-hand knowledge of what PME are experiencing.

## Benefits

**Broad perspective.** "These individuals can point out themes or direct experiences of their clients to give you a better understanding of Medicaid in that community," said a nonprofit staff member.

As another explained, "These folks often possess the technical knowledge of systems, and empathy for their clients that give them unique insight into policies that serve or do not serve clients well. They also have multiple experiences to report and can do so in a manner that carries weight with policymakers."

**Reinforce PME experience.** As one nonprofit staff member explained, "If [people who work with PME] are already known and respected by your target audience, it's helpful to share their voices as third-party validators for the PME sharing their stories directly." Similarly, another staff member said, "People take it very seriously when it's coming from a health care professional, and I think it's [useful] in addition to [hearing from] folks with lived experience. It's just another branch of what people need to hear."

**Often more comfortable sharing.** "These individuals didn't have the fears and trauma that PME do, making them easier to recruit," said a staff member. Others explained, "They tend to be highly motivated to help advocate for changes by sharing their knowledge" and "they are often more comfortable identifying and speaking on the issues."

### Effective strategies

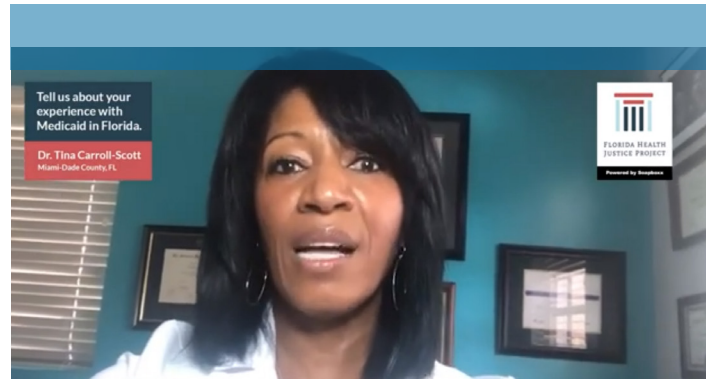
**Draw on existing relationships.** Reaching out to people who are already a part of your organization’s network or to trusted community partners for help recruiting people who work with PME are very effective strategies. “Again, it is all about relationship building,” said a staff member

**Personalized outreach.** “[Ask] the individuals personally,” advised a nonprofit staff member. Similarly, another suggested, “contact them directly and send personalized messages [that explain] the importance and purpose of the project.”

**Ask for referrals.** “Asking those recruited to reach out to others in their field or departments for participation,” was a very successful approach. Similarly, another staff member explained, “We started with people we knew who had worked with [our organization] to identify others and as our group grew, members suggested others to join us.”

### Challenges

**Time constraints.** “They are all so busy doing much-needed work like enrolling families and children into Medicaid/CHIP,” said a nonprofit staff member. Another explained, “We worked with doctors/residents who are really busy, so it took some time to get the videos.” A staff member offered these words of advice for dealing with the time constraints of people who work with PME: “Be patient. Set deadlines/timelines that are reachable. Check in often.”



Dr. Tina Carroll-Scott shared the following in a video posted on the Florida Health Justice Project website:

***“I’m just so happy that many of my patients are on Medicaid and are able to receive the necessary care that they not only need but that they deserve.”***

# Sharing Medicaid lived experience

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Several effective approaches for having PME share their Medicaid experiences are described in this chapter including in-depth interviews, videos, surveys, and sharing directly with Medicaid decision-makers. Regardless of the approach used, four strategies are crucial for creating an environment where PME feel comfortable sharing their experience and for maintaining longer-term connections.

**Listen to and value PME.** Be patient, empathetic, and appreciative when listening to what PME have to say. PME should be “treated as the experts in their own story,” said a nonprofit staff member. Others emphasized “making them feel that their voice is important,” “being willing to meet them where they are,” and offering “no judgment.”

**Be culturally responsive and allow sharing in PME’s native language.** “It’s important to be respectful of people’s culture [and] language” when PME are sharing their experience said a staff member. This includes the need to “be mindful of cultural variations and traditions. For example, wear appropriate clothing if visiting religious community centers.”

Nonprofit staff also emphasized the importance of providing an option for PME to share their experience “in their own language is helpful and respectful to the participant. This way they [don’t] have to try to navigate a language barrier while trying to talk with you.”

**Be prepared to help PME.** For PME to share their lived experience in a way that does not seem extractive, be prepared to help PME with the issues they raise. “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,” explained one staff member. For nonprofits that do not provide direct services, PME can be referred to appropriate organizations in the community. For organizations that provide direct services, addressing PME issues is often straightforward, though PME whose issues are outside of an organization’s scope may need to be referred elsewhere.

**Develop ongoing relationships.** Trust is built through the process of PME sharing their Medicaid experience, which creates an opportunity to develop longer-lasting relationships with PME. With an ongoing relationship, PME know where to reach out for help if needed and can learn how their lived experience has been used. PME can also become more involved in Medicaid advocacy. Several nonprofits described moving PME up a “ladder of engagement,” in which nonprofits continue to reach out to PME to offer them opportunities to take the next step in advocacy, like being interviewed by a journalist or meeting with lawmakers. Ongoing relationships also benefit the nonprofit: “We stay grounded in their lived experience.”



# In-depth interviews

## Benefits

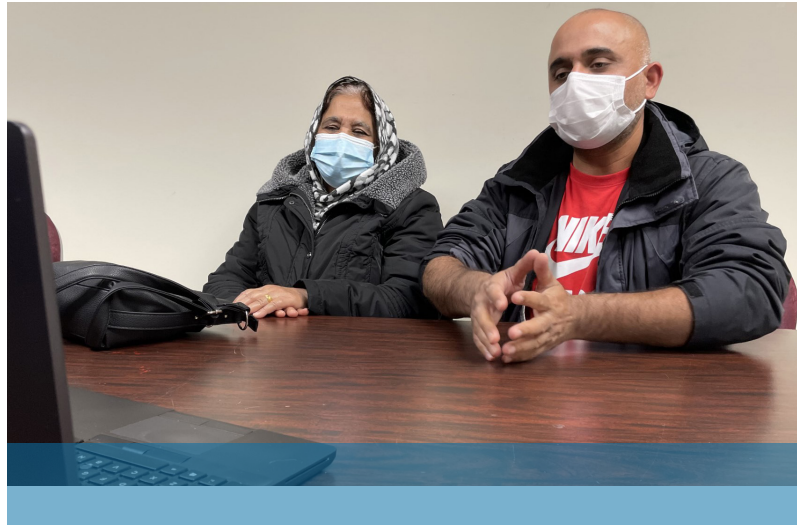
**In-depth learning.** One-on-one interviews that use open-ended questions provide nuanced information about the Medicaid issues that PME face. “Storytellers have the space to share as much as they want,” explained a nonprofit staff member, and PME can focus the conversation on issues that really matter to them. Interviewers have the flexibility to “dig deep” and explore topics raised by PME that they might not have known to ask about. “The back and forth allows follow-up questions which tease out more information than we’d otherwise get,” explained a staff member.

**PME feel heard.** Interviews enable PME voices to be truly listened to by an interviewer, regardless of whether the interview is in person, over the phone, or like the interview to the right, over Zoom.

A nonprofit staff member described how she showed that she was actively listening, “You actually have to engage with people as they’re talking...so even though 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.”

Another staff member highlighted how meaningful it is for PME when they feel heard with empathy and curiosity. “When done correctly, it is a very positive experience for the storyteller — even if their story is a sad one.”

**Learning about non-Medicaid issues.** PME often raise concerns during interviews that are not related to Medicaid but are relevant to the nonprofit. Staff at several nonprofits described colleagues in other parts of their organization being able to use these



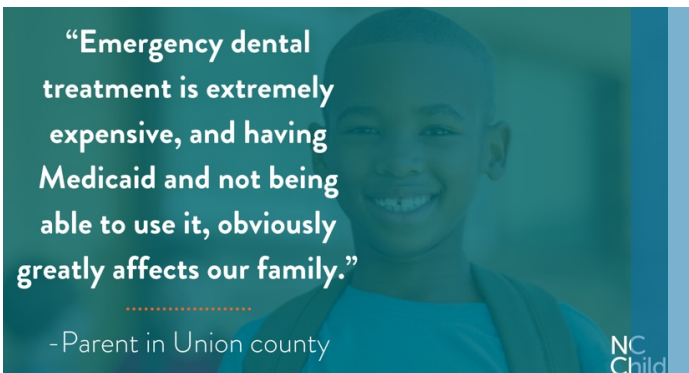
stories in briefs and reports. “If another person on our team was wondering what folks thought about the child tax credit, we would be able to pull up quotes that were relevant to the child tax credits,” explained a staff member.

## Effective strategies

**Start with warm-up questions.** When starting an in-depth interview, it is helpful to begin with getting-to-know-you questions before exploring their Medicaid experience. A nonprofit staff member explained, “The person being interviewed [can] become comfortable with the interviewer over the course of warm-up questions.”

**Make it conversational.** While an interview guide with open-ended questions is needed to ensure key questions are asked, a nonprofit staff member explained that it is important to “make these interviews not feel like interviews - but rather conversations.” Approaches to make the interview flow include asking follow-up questions on

## In-depth interviews



interesting comments PME make, and asking the interview questions in an order that is responsive to PME comments rather than how they are listed in the interview guide. "Don't be afraid to let the person being interviewed lead the conversation," suggested a staff member. Additionally, it can help to avoid language that reinforces that the discussion is an interview. For example, an interviewer can say, "I'm interested in hearing about your experience..." rather than saying, "The next question is about..."

**Get draft transcripts.** If using Zoom to conduct interviews, the program will generate a draft transcript—either by recording a session or enabling closed captioning. Recordings made on phones or other devices can be transcribed by online software, like Otter.ai. While these transcripts can be made quickly and are often free, they can be quite rough and additional editing will likely be needed to make sure they accurately capture exactly what was said by PME.

**Have an analysis plan.** Identifying the key issues that emerge from the interviews is essential, and there are a wide range of ways to do so. One effective approach is to use word processing software. A nonprofit staff member explained, "I kept a Word document organized by themes and would copy and paste the quote to the appropriate theme[...]. This helped when writing because all the quotes related to one theme were in one place."

Other nonprofits found specialized database programs like Airtable and Taguette to be very

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."

## Additional strategies

**Avoid asking about "Medicaid barriers".** A staff member explained that she had to reframe questions about Medicaid from "tell me about the barriers that you're experiencing" to "tell me about the experiences that you're having." She explained, "We learned that many Medicaid recipients do not see administrative barriers as barriers at all. Medicaid-eligible folks seem to see these hurdles as the price of admission."

**Include trusted partners.** PME may feel more comfortable if someone they already trust is with them during the interview. One nonprofit found "the PME feel more secure" when the navigator who had previously assisted them in applying for Medicaid sat in on the interview.

## Challenges

**Interviews are time intensive.** A staff member explained, "Interviews usually take about an hour and could be hard to schedule if a storyteller is super busy with their job, family, or responsibilities." Another shared: "Storytellers are usually not in a stable place so there are often a few appointments made before we actually get the story."

**This work is new to many nonprofits.** The process of reviewing transcripts and notes to identify recurring themes was new to many nonprofits. "Honestly it's ... the first type of project that we've had where we're pulling out themes and then reporting them," a nonprofit staff member said. Interviewing PME to learn about their experiences was also new to some nonprofits. Staff from a law nonprofit highlighted that "interview skills...differ from law office client intakes."

# Videos

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In a video posted on The Arc's Youtube page, Ray highlights how hard it is to hire support workers for his son because Medicaid pay is so low:

***"No worker is more essential than direct support workers, and we need to treat them, respect them, and pay them to reflect that fact."***

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## Benefits

### **Videos are humanizing and emotionally compelling.**

Video recordings enable Medicaid decision-makers and the general public to “hear the story as told by the PME, in the PME’s voice,” which can “put humanity to what can sometimes be a partisan issue.” Compelling videos can be “useful as a community education resource” and can have a lasting impact.

### **Sharing videos is less burdensome for PME than directly speaking with decision-makers.**

As an alternative to sharing their story directly with Medicaid decision-makers, video recordings can be easier for PME. Videos eliminate the need for PME to be in a potentially uncomfortable situation with Medicaid decision-makers, and videos do not require PME to travel or accommodate the schedules of others: 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 [the hearing] will be.

## Effective strategies

Since an effective approach to video recording is to record during in-depth interviews, much of the guidance from the in-depth interview section is also relevant for videos. This section highlights information that is specific to using videos for capturing lived experience.

### **Relationships are extremely important.**

“We only use video with people that we have a pretty established relationship with,” explained a nonprofit staff member.

When recording someone unknown to your organization, another staff member recommended, “Build a relationship with the PME first by asking about their experience off camera.

Consistent with the importance of relationships, very few PME chose to create videos when there was no human interaction during the process, such as when PME were given a link to record a video at the end of a survey or on a website.

“No one has taken the initiative to record a video without [a personal] prompt,” explained a staff member.

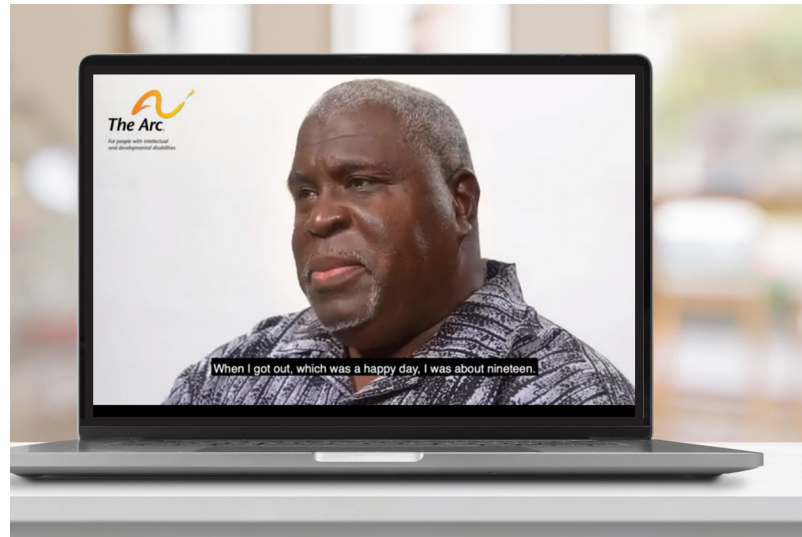
**Select compelling stories.** Since recording a video can be “a big ask” for PME, not all lived experience needs to be video recorded. Videos can be reserved for stories that are particularly powerful. A staff member explained, “[What] we use video for is when that story is so compelling, so raw, so real that only their real voice truly captures the feelings that they’re actually experiencing when they are trying to either stay on Medicaid, reapply for Medicaid, or talk about just their shared experiences of relying on Medicaid.”

**Help PME feel at ease.** Being in a video can be intimidating for PME. “The whole point is I want them to feel comfortable,” a nonprofit staff member explained. Ways to do so include providing PME interview questions ahead of time, practicing with PME beforehand, and encouraging PME to have family or friends close by for support. One staff member recommended, “If possible, have two storytellers prepare together – they can bounce ideas and learn with each other.”

***“By the time we work up to doing a video, I know that person’s story pretty well. So it’s more like a conversation between friends and not like a big looming scary thing.”***

### **Consider pros and cons of different video technology approaches.**

**Zoom.** “We’re all comfortable with Zoom at this point,” said a nonprofit staff member, “and it has other useful features. 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. Zoom will also create a transcript with time stamps, which can be used for identifying themes and the video sections to be edited.”



The quality of recordings, however, can vary a lot “depending on the PME’s internet connection and other circumstances.” Many PME in rural areas, and elsewhere, do not have reliable internet access. Additionally, Zoom recordings usually need to be edited. A staff member who recorded a number of compelling interviews over Zoom explained, “What the challenge is right now is just that we have a lot of raw footage that we need to edit.”

### **Online platforms for making short videos.**

Online platforms, like Soapboxx, that enable people to record very short (~3 minute) videos, can help people “be precise and say powerful things with just a few words.” Soapboxx also provides a project webpage where videos for a nonprofit can be recorded and posted for viewing.

The three-minute limit on recordings, however, was viewed by some nonprofits as a disadvantage because it was difficult to get an effective version of a story, especially when PME “have three different [issues with Medicaid] going on.” Additionally, it was very hard to get some PME to use it. One nonprofit staff member 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 described Soapboxx working best for “engaged users of smartphones.”

**Videographer.** For organizations that do not have good-quality recording equipment or experience shooting and editing film, hiring a videographer is a very effective approach. “They can capture very professional recordings with great video and sound,” explained a nonprofit staff member. It can, though, be expensive and is more challenging when PME need to reschedule. A staff member explained, “Only having so many contracted dates from the videographer can limit the amount of stories we can gather with quality audio and video.”

***“We want [our videos] to be concise and short. You don’t want to lose the audience’s attention.”***

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**Short videos are impactful.** Short “snippets” can be shared on social media and websites. A staff member described how she and her team edited down videos to create a short video, “We listen to interviews and also pull the transcripts in a team of two and then identify key themes. From these themes, we group quotes from different interviews with their time stamps and write a script for the video we want to put together so that it is easier to send to the video editor.”

## Challenges

**PME may be reluctant to be recorded.** “There are a fair number of people who aren’t necessarily comfortable being on camera,” explained one staff member. Another highlighted that “video is hard, especially for immigrant communities” and several

others described that it was particularly challenging in “red states where there’s so much stigma in even revealing that you’re on Medicaid.”

If PME do not feel comfortable being on camera, offering an anonymous audio option can be less intimidating. A staff member explained, “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.”

Another alternative is to record videos of those who work directly with PME, who are typically less likely to be uncomfortable on video, “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.”

**Editing video is challenging.** Making short, impactful videos usually requires significant editing, which is often a new skill for many nonprofit staff. One described it as “time-consuming to find all of the time stamps for the final video, but worth it.”

Another highlighted how writing a script for the video using the transcripts was not as straightforward as she initially thought it would be “When you’re looking and reading a transcript, you see those words on a page and read smoothly. But then when you actually play the video clip it’s like there’s a lot of ‘ums’ and ‘ahs’ and pauses and weird inflections and it just doesn’t piece together as cleanly as you might think it would.”

# Surveys

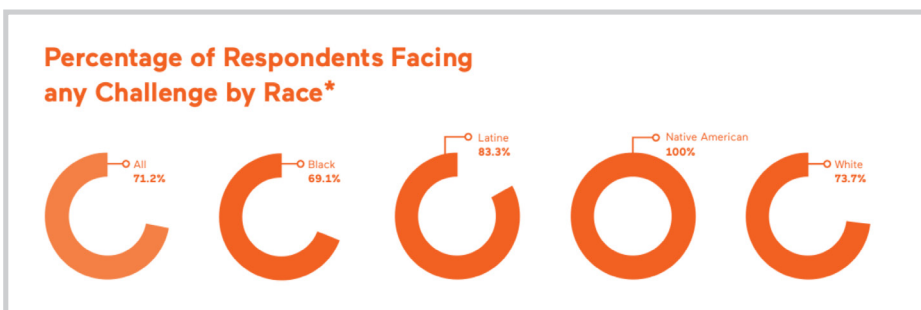
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## Benefits

**Easy for PME.** “Multiple choice surveys are accessible and quick to complete,” explained a nonprofit staff member. Not only are surveys “low touch”, but they are “less personally intense” than interviews.

**Quantitative data is powerful.** Surveys enable nonprofits to gather responses to the same questions from a large number of PME. “Quantitative data was viewed as a powerful tool for identifying which issues to advocate for and persuasive when presented to Medicaid administrators,” explained a nonprofit staff member. Other staff highlighted that “numbers are easy to understand” and take less time for government officials to process than stories.

**Reveal Medicaid equity issues.** Survey data can be analyzed to look at differences by PME race and ethnicity, gender, and other characteristics to examine whether there are subgroups of PME disproportionately experiencing barriers with Medicaid, as the image below from a Center for Popular Democracy report shows.



**Initial connection with PME.** Since surveys are quick to complete and number of nonprofits used a survey to identify respondents who were willing to participate in a longer interview or video. Community organizing-focused nonprofits view surveys as “a tool to get to know our people and bring them into the work.”

## Effective strategies

**Create an easy to complete survey.** Nonprofit staff recommended that surveys be short: “no more than 20 questions” and “less than 5 minutes.” Additionally, the language in surveys needs to be clear and jargon-free: “The language should be simple, straightforward and easy for people from a variety of backgrounds to understand the questions.”

Pre-testing the survey, for example, by having several PME react to the survey out loud as they answer the questions, is a helpful way to make sure that the questions are understood as intended.

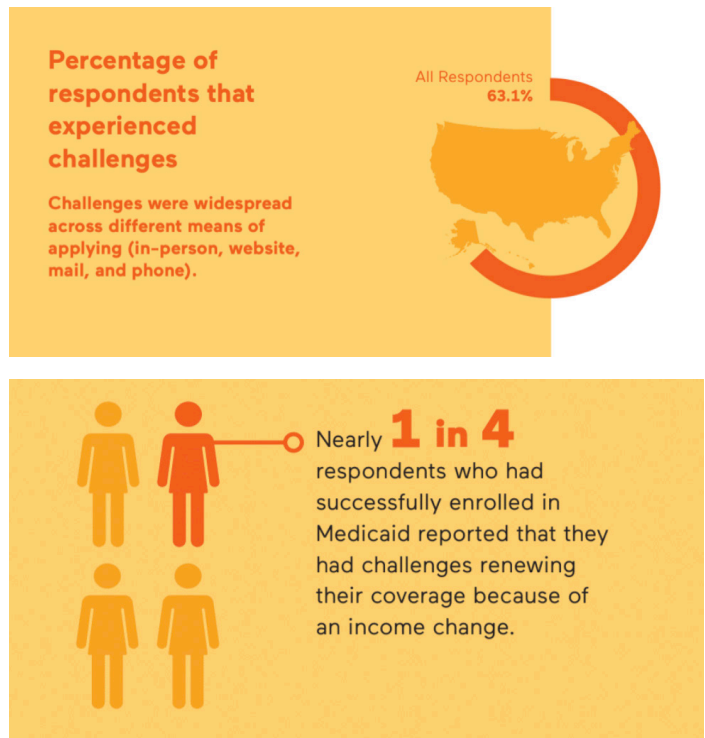
**Support PME during survey completion.** Having staff guide PME through completing the survey provides a “human connection,” enables PME to ask clarifying questions, and results in “a higher chance of them actually doing the full survey.” Assistance was particularly important for open-ended questions—both to engage PME in conversation on the topic and to document their responses.

A nonprofit staff member explained, “What we found is that people were uncomfortable about writing their response because they were worried about their handwriting or whether or not they were spelling words correctly, and it created a whole new layer of anxiety with folks that I never considered.”

However, something to consider is that several nonprofits found that helping PME with survey completion required more staff time than anticipated.

**Provide the survey in written and electronic formats.** Having multiple modalities enables PME to complete the survey regardless of their access to, or comfort with, technology.

**Have an analysis plan.** Most nonprofits that used a survey did not analyze the quantitative data themselves. They either worked with their lead national advocacy organization or hired a consultant to analyze the data. There were a few nonprofits



that used programs like Qualtrics Stats IQ that simplify the analysis of survey data.

## Challenges

**Results can lack depth.** There is often limited context and detail in the results from brief surveys. A staff member explained, “Each PME is different, and the survey did not provide the nuances of personal stories.” Even when surveys include open-ended questions, responses are often “short and very vague.” Another explained, “People are not choosing to just sit there and [write] about the many barriers to Medicaid without being egged on a little bit.”

**Interpreting data.** Caution is needed when interpreting survey results since PME who complete surveys are likely not representative of all PME in the state. The results may reflect the experience of certain demographic subgroups of PME and may not capture the experience of other groups.

# PME sharing their experiences directly with Medicaid decision-makers

**Nonprofits do not need to be the only ones to convey PME’s lived experience to Medicaid decision-makers. Having PME directly share their experiences with Medicaid agency staff and lawmakers can be very compelling.**

## Benefits

**Humanizes Medicaid and PME.** When Medicaid decision-makers hear directly from PME about their Medicaid experiences, “It forces them to look at the humanity of people. These are not numbers, these are people,” explained a nonprofit staff member. “It is harder to deny someone’s experiences than it is to ignore data,” described another staff member, and hearing from individuals can “start to break down some of those harmful assumptions and barriers” that some agency staff and lawmakers may have about PME.

“We [can] talk about network adequacy, and being able to find providers within the network. We can say, ‘The network has adequacy challenges....’ And then, if a mom comes and goes, ‘I made 27 phone calls, and I can’t find myself a doctor.’ If they’re hearing that directly from them, it’s a lot harder to push back on,” explained another staff member.

**PME feel their own power.** For PME, being listened to by Medicaid decision-makers can be empowering. “Learning to tell [their] story unapologetically moves people to understand their own power,” explained a nonprofit staff member. Other staff highlighted that it “empowers our storytellers because they begin to understand how our legislators work for us” and “once you kind of understand how a process works, you’re more able to participate in it.”

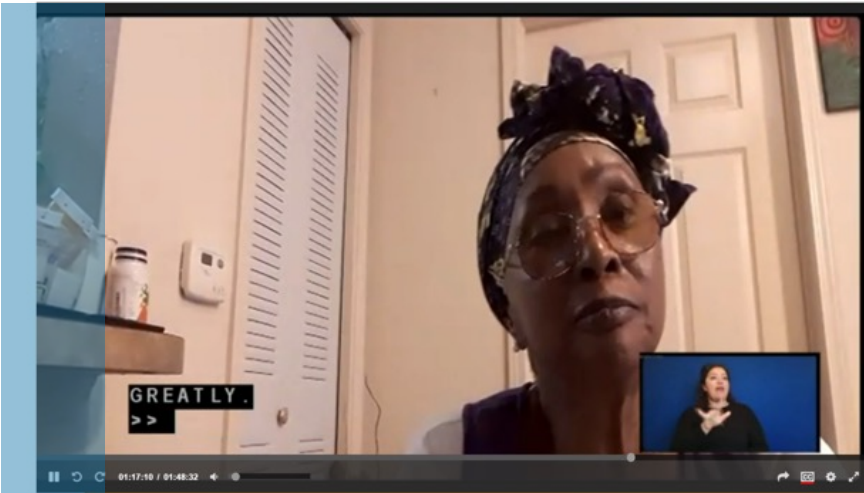
## Effective strategies

**Prepare PME.** Speaking to Medicaid decision-makers can be very stressful for PME, so helping them practice and know what to expect is essential. A staff member explained, “There are a ton of nerves and doubt from storytellers. It is often their first time engaging in advocacy and talking to legislators, so providing coaching and a space for questions to be asked for the storyteller is needed.”

Effective approaches to help PME feel comfortable and confident speaking to Medicaid decision-makers include “help[ing] them understand how to be strategic with what they share,” creating tip sheets, and offering to help them draft their testimony. One nonprofit staff member explained that when a PME is initially unsure of what to say when testifying to the legislature, her organization will create a draft for PME to edit: “We have a draft of their story... and we know what messaging works.”

**Offer another way for PME to share.** If PME have compelling lived experience but are not comfortable sharing directly with Medicaid decision-makers, making a video recording can be a less intense alternative, as is having PME share a written story.





Alene Shaheed, who relies on Medicaid home health care workers, testified to the Senate Committee on Aging:

***"Not having the help affects every aspect of my life, because the aides are my lifeline to remaining independent. I absolutely do not want to go into the nursing home."***

## Challenges

**PME fear retaliation.** Speaking to Medicaid decision-makers can be intimidating to PME. "They are afraid to complain — for fear of retaliation or losing their coverage," a nonprofit staff member explained.

**Scheduling.** It is not easy to schedule a time for PME to meet with Medicaid decision-makers. "Time and availability to advocate is a luxury that is not always available to PME," shared a staff member.

**PME are not always welcome.** In some states, nonprofit staff report that Medicaid decision-makers are hesitant about meeting with or even unwelcoming towards PME. The Medicaid agency in one state was described as "skittish about opening themselves up to these conversations." Legislators in another state were described as "not always receptive or do not always appreciate PME, which can...push them away from further participation."

# Other approaches to sharing lived experience

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## PME advisory boards

PME advisory boards for nonprofits can be used in different ways to gather Medicaid lived experience, including learning directly from members and having the board members gather lived experience from within their communities. Regardless of the approach, a key benefit is that PME develop new skills: “I feel like people are becoming stronger, more outspoken advocates, because they feel a little bit more capable and informed,” explained a staff member.

To effectively work with a PME advisory board, “give the group some power” and “have dedicated staff to support the council.” A staff member describes, “The biggest challenge is that this work can be time and labor-intensive. There is a significant return on your investment; however, ensuring adequate funding to support this work can be a challenge.”

## Focus groups

Focus groups typically have 6-10 participants, and they are conducted with open-ended questions, like in-depth interviews. Benefits of focus groups are that PME’s comments can “resonate with others” who are participating and spark interesting discussion, and focus groups “help...people understand they are not alone in their issues.”

To be effective, a nonprofit staff member recommended, “Be very intentional with questions.

Set specific time limits. Don't be scared to call on [participants] to speak.”

The biggest challenge of conducting focus groups is getting multiple PME to gather at the same time and place. “Finding an appropriate location has also been a challenge,” explained a nonprofit staff member, though others found Zoom to work well. Hosting focus groups with people who work directly with PME rather than PME themselves is also an effective strategy for hearing first-hand knowledge of what PME are experiencing.

## Written stories

“Written stories allow individuals to express themselves with the added benefit of careful editing,” explained a staff member. They enable PME to stay anonymous if they prefer and to write at their own pace. One staff member said, “If the written stories are public, they can be very effective. Our organization worked with PMEs to develop an editorial that appeared in our state's largest newspaper.”

Relatedly, a key challenge to written stories is “there are not a lot of PMEs who write the stories without help.” Without support, stories may not get completed. A nonprofit staff member explained, “It is time consuming to work with PME in developing a well-crafted narrative that uses their voice and language.”

## Comment letters

When states apply to the federal government to make specific changes to Medicaid, there is a public comment process. While nonprofit staff often submit comments, it is far less common for PME to do so. Bringing the voices of PME into the public comment process is Kentucky Voices for Health's "secret sauce." The nonprofit simplifies the policy issues into language that PME can understand and relate to and provides an online letter template, like the one to the right, where PME can share their thoughts. The nonprofit submits the stories that PME share verbatim to the public comment website.

## People who work directly with PME complete a form after interacting with PME

A few direct service nonprofits have navigators within their organization or staff at partner organizations complete a brief form or survey after working with PME, an approach they found to be very effective. As a staff member at one of these organizations explained, "It takes the burden off of the PME to take additional time to fill it out and it [covers] all of the key areas we are looking to track and gain feedback on."

### Medicaid Dental, Hearing, and Vision, Services Comment Collector

Please tell us how these additional services would affect you, your family, or your community.

**Dental Services**  
This regulation covers 2 cleanings per year, fillings, dentures, root canals, crowns, extractions, restorations, some implants, and periodontics. Previously, adults were only eligible for one annual cleaning, extractions, and limited fillings.

Your answer \_\_\_\_\_

**Vision Services**  
This regulation covers glasses and contacts for the first time. Previously, adults could receive a vision screening or exam.

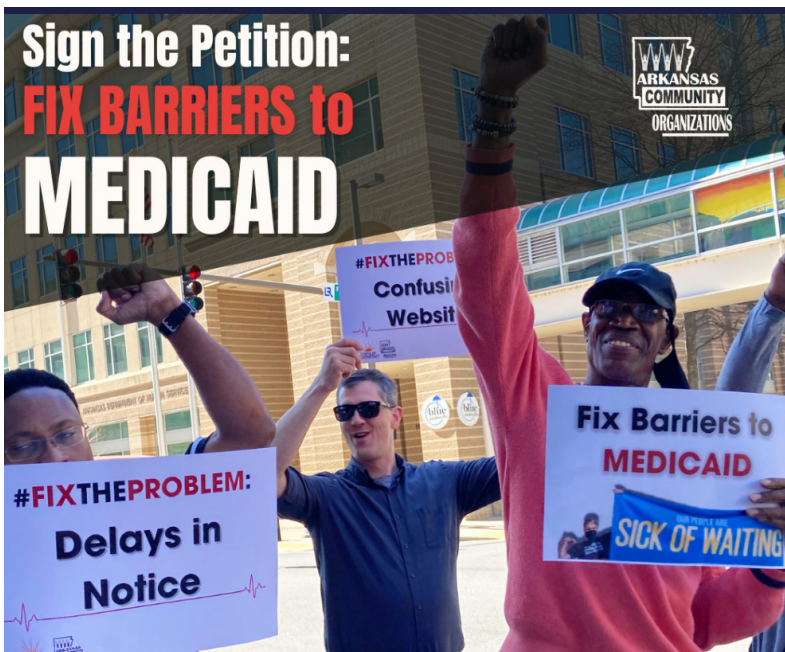
Your answer \_\_\_\_\_

# Using lived experience in advocacy

Medicaid lived experience should not “sit on a shelf.” Lived experience should be used to take action and address issues that PME highlight. There are multiple, mutually-reinforcing pathways to advocating for change, including informing Medicaid agency staff and lawmakers, raising awareness through traditional media, and broadly disseminating PME stories to build support for Medicaid.



The **family glitch** has given us a lot of hard time during my wife's pregnancy, despite my job as a science teacher at a charter school. **It was too hard to find a doctor without proper insurance, other than admission through the ER.**



# Working with the Medicaid agency

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## Benefits

### **The Medicaid agency can address problems.**

“Often the issues identified through PME’s stories were issues that both we and our agency were unaware of,” explained a nonprofit staff member. By bringing these issues to the attention of agency staff, improvements in Medicaid can be made:

“When we can bring specific stories to their attention, it has allowed the state agency to follow the situation and determine where a breakdown may have occurred. When we have multiple stories with the same issues that they can investigate, it leads to systemic change or correction.”

The types of changes that Medicaid agencies, in both red and blue states, have made in response to lived experience advocacy through this RWJF project include:

- **Retraining agency staff on immigrant eligibility rules and cultural sensitivity.**
- **Adopting the term ‘non-citizen’ rather than ‘illegal alien’ in all of the agency’s materials.**
- **Increasing the pay of Medicaid home health workers.**

In addition to structural changes, many Medicaid agencies addressed issues individual PME were facing like reversing “arbitrary cuts in personal care attendant hours when specific cases were brought to the attention of managerial staff.”

### **Sharing lived experience can foster a relationship with the Medicaid agency.**

For nonprofits that do not have strong connections with their state Medicaid agency, sharing PME lived experience can help build or strengthen relationships. One nonprofit provided a report of their lived experience findings to their state Medicaid agency staff, which a staff member credited for helping establish ongoing interactions between the nonprofit and the agency: “I think that softened the ground... That’s how we got [the Medicaid director] to come meet with us.”

## Effective strategies

**Work collaboratively with the agency.** Creating a positive relationship with the Medicaid agency is important for getting the agency to be responsive to problems brought to their attention. A nonprofit staff member recommended: “Try to begin things on a positive note—we are looking to work together, not attack each other, and you will get farther.” Additional recommendations are to “engage with the agency often” and “maintain an open line of communication.”

**Provide specific examples.** Concrete examples of problems people experience with Medicaid are needed so that agency staff “can independently look up a case....and they can see where something broke down.” Having more than one example of an issue is helpful to demonstrate the problem did not just impact one person.

### **Let agency staff hear directly from PME.**

“Ensure that state Medicaid agencies hear about the issues from directly impacted people,” advised a nonprofit staff member. “The impact of PME sharing their experiences firsthand are far more powerful than organizational policy staff sharing the same information,” said another. As noted in the prior chapter, nonprofits need to support PME to share their lived experience directly with Medicaid agency staff to ensure that they feel comfortable and prepared to interact with agency staff.

## Challenges

### **Problems may be treated as isolated incidents.**

Many Medicaid agencies are willing to “resolve an individual case,” but less likely to view problems as systemic. A nonprofit staff member explained, “Often, our agency just wants to write the issue off as a glitch, correct the error for the one person, and call it [a] day.” Another staff member explained that the more families “we can point to, the greater the impact of the lived experience.”

**Agency action may be constrained.** Administrative, legal, political, or staffing constraints may prevent Medicaid agencies from acting on the issues being raised. One nonprofit staff member highlighted: “Much of the process is entrenched in statutory law or CMS guidelines. Neither of which allow for a tremendous amount of flexibility.”

**Not all agencies are interested.** While some states welcome working with nonprofits to improve Medicaid, not all states do. In some states, there is no tradition of interacting with PME or nonprofits and success requires “breaking down longstanding agency fear about interaction.”

***“The more stories you can bring, the better. It helps establish a trend and makes it more difficult for the agency to deny the systemic nature of the issue.”***



June 8, 2021

Ann Dalton  
Deputy Secretary  
Division of Medicaid  
Florida Agency for Healthcare Administration

via email: Ann.Dalton@ahca.myflorida.com

Re: Urgent Suggestions for Use of FMAP bump for HCBS

Dear Ann,

Again, we greatly appreciate that you and your team are working on a plan for the \$ 320 million FMAP bump available to Florida under the American Rescue Plan for certain Medicaid HCBS expenditures. If there has been any change in the Agency's intent to submit a plan, please let me know immediately.

These comments are in followup to our [May 21, 2020 public comment letter](#) and our May 28, 2021 email requesting that the newly available funds be utilized in ways that will assist enrollees who are currently suffering from the lack of funding. We included links to our website describing the dire situation of 3 such clients, [Alene](#), [Shirley](#) and [Hortense](#) (mother of Thelma).

The Florida Health Justice Project is part of a broad community of stakeholders, including participants in HCBS programs, HCBS providers, caregivers, and other advocates who can contribute valuable insight, ideas, and feedback to develop a plan under section 9817 of the ARP.

As you likely know, CMS is encouraging states to utilize stakeholder engagement in order to ensure varied perspectives on how to expand, enhance, and strengthen HCBS, and they have allowed states a 30 day

# Educating lawmakers\*

## Benefits

**Increase lawmakers' understanding of Medicaid.** A key use of Medicaid lived experience is to inform legislators about Medicaid and its role in people's lives. "Some of them really don't understand the program or what people face, so it often is really educational, especially with new legislators," explained one nonprofit staff member.

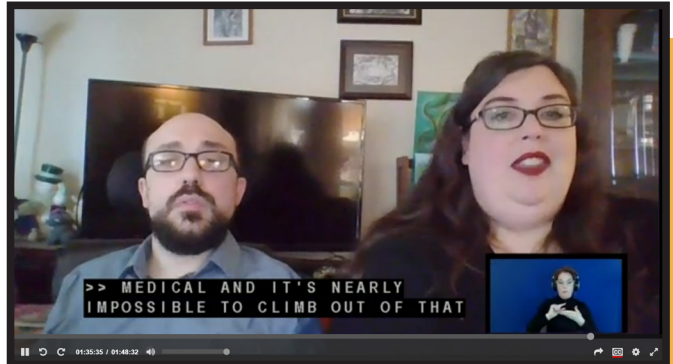
*"It has humanized Medicaid. It has helped [legislators] see that individuals on Medicaid are responsible individuals who are not trying to 'game the system,' but rather are seeking basic services. It has also helped them see the impact of Medicaid on everyday life, including employment, education, and seeing the positive fiscal impact."*

**PME stories are useful for lawmakers.** Stories from lived experience give lawmakers concrete examples that they can use in committee debates and floor sessions. It also "primes them for identifying additional issues when talking with their constituents," explained a nonprofit staff member.

**Builds relationships between nonprofit and lawmakers.** For a nonprofit, serving as a source of information and a conduit to the lived experience of PME leads "lawmakers [to consider] us as [a] trusted source," said a staff member.

## Effective strategies

**PME share directly with lawmakers.** It is very effective for PME to share their experience directly with lawmakers. A nonprofit staff member advised, "When possible, have [PME] share their experiences



directly rather than having a [nonprofit] staff person share on their behalf. It is far more effective and makes it much harder for the lawmakers to dismiss them."

Hearing from "PME who are constituents of lawmakers has the biggest impact," said a staff member. The prior section entitled, "PME sharing their experiences directly with Medicaid decision-makers" offers strategies for supporting and empowering PME in this process.

**Share videos of PME with lawmakers.** A short compilation video of PME sharing their experiences can be a "really powerful tool to show to lawmakers, legislators, policymakers...to say hey, no matter what you think your program is doing, this is how people are experiencing it." One nonprofit staff member explained the impact of a video featuring a PME named Vicki: "We had some legislators that referred to Vicki's video during the session ... it was really short, but it was really powerful, and it was a real person... and she just became a person that we could reference."

\*Due to federal law, no lobbying to influence specific legislation was done as part of this project. However, given how effective lived experience is for educating lawmakers, it can likely be used for lobbying when the funding permits.

### **Share stories that resonate with lawmakers.**

“Strategically connect the stories to lawmakers' interests and constituencies,” advised a nonprofit staff member. As another put it, “If we can make it something smaller and more specific to [a lawmaker's] constituents, then maybe it's something [they will] invest in solving.”

**Take a non-partisan approach.** To reach as many lawmakers as possible, “Try to approach things in a non-partisan manner,” advised one nonprofit staff member. “[Health] is an issue that all people care about, no matter what their political party.”

**Be concise.** Lawmakers are busy and may not be familiar with all of the nuances of Medicaid. “Talk to lawmakers in a way that make[s] it digestible. Be concise and have PME stories clearly connected to [the] advocacy issue,” advised a nonprofit staff member.

## **Challenges**

PME fear of retaliation, scheduling complications, and PME feeling that they are not welcome to share their experiences were noted earlier in the guide as challenges to PME sharing their experiences directly with Medicaid decision-makers.

### **Some additional challenges are unique to informing lawmakers:**

**Other items on lawmakers' agendas.** Getting attention for Medicaid and the experience of PME is difficult because there are a “number of legitimate issues in addition to ours that will occupy legislators.” Relatedly, many lawmakers have “philosophical differences” about Medicaid, since “Medicaid is a highly polarizing political issue among lawmakers.”

**Story saturation.** While most nonprofit staff reported that lived experience was very effective with lawmakers, a small number described lawmakers responding negatively, “While important and often impactful, lawmakers have become inundated with stories and shared lived experiences, making them numb to the effects of the human experience within these systems... ultimately resulting in their dismissal in favor of more evidence-based, quantitative, data-driven arguments.”



# Media coverage

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## Benefits

**Educate the public.** Media coverage of Medicaid lived experience “amplifies stories,” “educates the public,” and “raises the profile of issues.” “The community is aware of what is taking place through the media coverage,” explained a nonprofit staff member, and coverage can “increase awareness to shift harmful narratives around poverty.” Another shared, “Getting these stories in the press is a key strategy to advocate for change.”

**Put pressure on Medicaid decision-makers.** Press coverage “can get people to call their legislators and then this brings attention to issues that people really want change on,” explained a nonprofit staff member. Media coverage on Medicaid, “has also caught the attention of agency officials.”

**PME more willing to share.** “[PME] are more willing to share when they hear others’ stories” in the media, explained a nonprofit staff member.

## Effective strategies

**Cultivate relationships with journalists.** “If you know that the journalist has an interest in health care, and you have compelling information about PME, don't hesitate to reach out to one or more journalists,” recommended a nonprofit staff member. Another explained, “They need to know that you have both subject matter expertise and are able to educate them on intricacies of [the] state's Medicaid program and [can] connect them with PME.”

## Keep an updated list of PME for sharing stories.

Stories of interest to reporters typically need to be very recent and timely. To address this need, one nonprofit staff member advised, “Have an established system of media contacts who can be called to connect with journalists quickly. [A] PME hotline if you will.”

***“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. Like their story's already different...You need to find someone right then in that moment.”***

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**Prepare storytellers.** Before PME speak with journalists, it is advisable to “spend time with PME deciding how to shape their stories and how much personal health information to share,” said a nonprofit staff member. Another suggested that it is helpful to “identify succinct sound bites” for PME to share. Additionally, to put PME at ease as they are getting ready to share their experience, it can be helpful to assure them that “they don't have to be experts in anything other than their story.”

**Put out press releases.** As one nonprofit staff member explained, “Sending out press releases [is] a good way [to show], Oh, this organization is working on this. It gets [us] on different reporter's radars.” Another advised, “Make sure that in your press advisory/release you quote PMEs.”

HEALTH

## New report highlights Medicaid access challenges, offers recommendations

BY ANNMARIE TIMPINS - FEBRUARY 1, 2022 4:46 PM

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The report released Tuesday made several recommendations for lawmakers and state agencies. (Lizeth Moore | New Hampshire Bulletin)

## Challenges

**Journalists have tight deadlines.** Journalists often work under fast turnaround times, and it may be difficult to quickly coordinate schedules with PME. Additionally, because of the time pressure, journalists can “show little care for the storyteller.”

**Hard to keep issues newsworthy.** It may be difficult to generate and sustain news coverage related to Medicaid issues. A nonprofit staff member explained, “These stories are not always as exciting as other, more immediate issues.”

Another explained, “Due to the need for fresh news, we find it difficult to obtain continued exposure — for example on the workforce issue and the lack of day services.”

**PME fear of retribution.** Fear of retribution or discrimination may prevent PME from sharing their experience with the media. As a nonprofit staff member explained, “People are worried, and somewhat fairly, about backlash once they have gone public.” One staff member, in fact, reported that a PME “faced discrimination at work due to media coverage.”

# Broad public dissemination

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## Benefits

**Creates broader understanding of and support for Medicaid.** “The best way to build public support is sharing stories of PME,” explained a nonprofit staff member. Efforts aimed at informing individuals who are not very familiar with Medicaid “can help non-Medicaid recipients to identify with people on Medicaid” and build “sympathy or empathy among the public.”

Sharing lived experience with supporters and other nonprofits enables organizations “to bring awareness to current issues that are occurring within Medicaid and present it in a manner that is easy to understand and connect with.” Reports, social media, and other broad dissemination approaches also have the potential to reach Medicaid decision-makers.

**Encourages public interaction with policymakers.** Communications featuring PME stories can educate people on “the issues that [PME] are facing” and help inspire them to “act and advocate.” One staff member described using social media to encourage supporters to reach out to policymakers:

“We’re going to be sharing [our videos featuring PME] constantly on our Instagram and Twitter, as well as Facebook...during our legislative session. We can bug people...so they can call their representative.”

**Counter misleading Medicaid narratives.** “Medicaid can be viewed in a negative light” and there are “harmful narratives around poverty.” Lived experience can help humanize PME and provide educational information on how Medicaid “truly works.”

**Increase nonprofit’s visibility.** Sharing lived experience with the general public reinforces the existence and mission of the nonprofit. It can help “build trusting relationships with the community” and let community members know “that they can reach out with questions or for help.”

## Effective strategies

**Tailor message to the audience.** “Messaging to the public is not the same as messaging to other audiences such as lawmakers, constituents, and donors,” explained a nonprofit staff member, “All require different messaging approaches and content.” Another advised, “If possible develop a consistent message which can be adapted to different audiences and develop a cadence that fits the audience targeted.”

**Disseminate PME stories in multiple ways.** “[W]e have this story bank that goes back for years. But ... you don’t get a whole lot of people like clicking and reading those stories.” Nonprofits find that combining multiple approaches for distributing information is important. For example, one nonprofit staff member explained her organization’s multipronged approach:

“We will put stories on our website and also send individual stories to state leaders via electronic communications and also do social media blasts to share the full campaign or Soapboxx ‘question page’ with stories.”

## Challenges

**Changing minds.** While lived experience can humanize Medicaid, there are some people who “are just in their world....and don’t want to listen” or “have such ingrained preconceived notions of Medicaid recipients that they don’t hear the message.” The biggest challenge, according to one staff member was “the reluctance of some people to accept data that is counter to long-held beliefs.”

**Getting attention.** “It can be difficult to direct attention away” from other “urgent needs,” and get them to focus on Medicaid lived experience, explained a nonprofit staff member. Another noted, “I don’t know [if] people have time to actually go to the website or read people’s experiences.”

# Additional advocacy approaches

## Develop PME advocacy leaders

Some nonprofits are committed to using lived experience as a pathway for developing PME’s advocacy skills. This is done in a range of ways including organizing regular community meetings, creating a PME advisory council, having a leadership academy, and by developing long term relationships with individual PME and providing them with a range of options for how they can become increasingly involved in advocacy.

When PME gain advocacy skills, it provides “renewed purpose,” “builds self-worth,” and “facilitates them understanding how much power they have.” It also improves PME’s understanding of Medicaid and they can “apply advocacy skills in their personal goals and needs.” Staff highlighted that developing PME advocacy leaders, however, is not easy work.

***“It takes a lot of time and the right staff to know how to build the advocacy skills of a directly impacted individual.”***

## Create educational materials for PME

Learnings from lived experience can enable nonprofit organizations to develop educational materials that are targeted to help PME with

specific Medicaid-related issues. A nonprofit staff member described developing an educational campaign for PME in response to learning that immigrants in her state were not enrolling in Medicaid for fear that it would impact their immigration status:

“We discovered [immigrant fears] 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.”

To communicate effectively with PME, a staff member recommended making sure to “use plain language and break it down into small pieces so that it is not overwhelming.”



# Conclusion

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The experiences of over 50 nonprofits across the country that worked to learn directly from PME about the effects of Medicaid policies and practices show the benefits of using lived experience for monitoring Medicaid. Learning from PME can reorient nonprofits' advocacy priorities so they are aligned with the community and bring emerging issues to the attention of the Medicaid agency. "There is no other way to know what is really happening without talking to the folks who are directly impacted," shared a nonprofit staff member.

Lived experience humanizes complex policy issues, which makes it an effective way to educate people, including Medicaid decision-makers, about how Medicaid is operating on the ground. It puts "a face to the fact" and can be shared in "a manner that is easy to understand." In addition, lived experience empowers the people who share their own experiences to "use their experience to

make a difference" and to help them understand "that they are important, and their experiences are not shameful."

Because of the power of lived experience, many of the nonprofits involved in this RWJF funded project have begun using it throughout their organizations, not only for Medicaid advocacy. A staff member shared, "We now use stories in every policy advocacy area of our work. Not just health care advocacy."

While impactful, using lived experience is not easy. A nonprofit staff member offered these final words of advice:

**"Use the resources and insights provided by other partners that have been doing this work. Try others' ideas, see what works best for you, and make it your own."**

***"Any organization can benefit from incorporating the knowledge of those with lived experience, no matter the issue or policy."***

# About the authors

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### SPACEs in Action

(cover, bottom left)

### Voices for Utah Children

(cover, bottom right)

### Children's Defense Fund Texas

(pages 7 & 28)

### Arkansas Community Organizations

(pages 8, 28 & 36)

### Florida Health Justice Project

(pages 11, 15, 25, 28 & 30)

### NC Child

(pages 12 & 18)

### Kentucky Voices for Health

(pages 14 & 27)

### Virginia Poverty Law Center

(page 17)

### The Arc

(pages 19 & 20)

### The Arc of North Carolina

(page 19)

### The Center for Popular Democracy

(pages 22, 23 & 28)

### Rights & Democracy NH

(page 34)

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## Appendix: Participating nonprofit organizations

<b>Center on Budget and Policy Priorities</b>	<b>Georgetown University Center for Children and Families</b>	<b>The Center for Popular Democracy</b>	<b>National Health Law Program</b>	<b>Feeding America</b>	<b>Make the Road</b>	<b>The Arc</b>	<b>People's Action Institute</b>
Immigration Research Initiative	Arkansas Advocates for Children and Families	Alaskans Take a Stand	Atlanta Legal Aid Society	Arizona Food Bank Network	Make the Road Connecticut	The Arc of California	Connecticut Citizen Research Group
Kentucky Voices for Health	Children's Action Alliance	Arkansas Community Organizations	Charlotte Center for Legal Advocacy	Federation of Virginia Food Banks	Make the Road Nevada	The Arc of Colorado	Hoosier Action
Louisiana Budget Project	Children's Defense Fund – Texas	OK Delaware	Florida Health Justice Project	Feeding Illinois	Make the Road New Jersey	The Arc of Indiana	Michigan United
Massachusetts Law Reform Institute	Idaho Voices for Children	Our Future West Virginia	Legal Aid of Arkansas	Feeding Texas	Make the Road New York	The Arc of Massachusetts	Missouri Jobs with Justice
Mississippi Center for Justice	NC Child	Rights & Democracy (NH)	Legal Aid of North Carolina	Feeding the Carolinas	Make the Road Pennsylvania	The Arc of New Jersey	New Jersey Citizen Action
Shriver Center on Poverty Law	Voices For Utah Children	SpACES in Action	Legal Counsel for Health Justice	Ohio Association of Foodbanks		The Arc of North Carolina	Power California
Virginia Poverty Law Center		Texas Organizing Project	Legal Services of Eastern Missouri			The Arc of Texas	Rights & Democracy (VT)
West Virginia Center on Budget and Policy			Legal Aid Services of Oklahoma				River Valley Organizing
			South Carolina Appleseed Legal Justice Center				
			Tennessee Justice Center				