The CMS Innovation Center's Person-Centered Listening Session: Leveraging Relationships with Community-Based Organizations to Meet Health-Related Social Needs
April 24, 2024

>> Alexis Malfesi, CMS: As we are seeing the number of participants climb, we are going to go ahead and get started. So good afternoon, everyone and welcome to The CMS Innovation Center's Person-Centered Listening Session: Leveraging Relationships with Community-Based Organizations to Meet Health-Related Social Needs. Next slide, please.

Before we get started, we have a few administrative items to address. First, I want to let you know that this session is being recorded. Second, closed captioning is available for this event by clicking the CC button at the bottom of the screen. Third, we have a Q&A function available to use during this meeting, and I would encourage you all to use it. Due to the size of the event, we may not be able to respond to everyone's questions, however, we will be monitoring the Q&A closely and capturing any follow-ups there. Lastly, if there are any press on this call, please submit questions through the CMS Media Inquiries Portal. That link is going to be shared now. Next slide, please.

We are grateful to have you here, and are looking forward to hearing your thoughts and perspectives in discussions today. For our agenda, Dr. Liz Fowler, Deputy Administrator and Director of the CMS Innovation Center will provide a few welcoming remarks. Next, Ellen Lukens, Deputy Director of the CMS Innovation Center, will provide a brief update on the Innovation Center's progress toward integrating family perspectives across our models. Later, Dr. Purva Rawal, Chief Strategy Officer of the Innovation Center and Kate Davidson, Director of the Innovation Center's Learning and Diffusion Group, will facilitate a panel discussion focused on partnerships with community-based organizations. Last, we'll close by reflecting on what we've heard and cover other ways that you can engage with the Innovation Center. So with that, I'll now hand things over to Dr. Fowler. Next slide, please.

>> Dr. Liz Fowler, CMS: Thanks, trying to get my video on. There we go. Thanks Alexis, and thanks to everyone who joined us today.

I think as many of you may know, in 2021, the Center laid out a vision and a new strategy. The vision is a health care system that achieves equitable outcomes through high quality, affordable, person-centered care. We are grounding our vision in five strategic objectives.

First, drive accountable care that promotes delivery of whole-person, integrated care. For beneficiaries in Traditional Medicare, who aren't in a Medicare Advantage plan, we want them to have integrated, coordinated care and patient navigation that leads to better outcomes and improved quality. We set a goal that 100% Medicare beneficiaries are in a relationship with a trusted provider, who is responsible for their total cost of care and quality by 2030.

Second, we are focused on advancing health equity. We are committed to embedding equity into every aspect of our work. A few examples include screenings for social drivers of health, or health-related social needs, engaging safety net providers, and requiring participants in all our new models to develop health equity plans.

Third, we are focused on supporting innovation that enables the delivery of person-centered, integrated care. What more can we do to help model participants be successful? Providers need tools, data, resources, and flexibility to deliver care that is consistent with people's goals and preferences.

Fourth, we are focused on affordability by addressing health care prices and reducing duplicative or unnecessary care. That means addressing out-of-pocket costs for patients, not just savings for Medicare and Medicaid programs. One recent example is the $35 per month insulin model that became part of the Inflation Reduction Act.

And then finally, we need to partner to truly achieve health system transformation. Medicare and CMS can't do this alone. We need to be working with other payers in the system, that's Medicare, Medicaid, and commercial payers. But it also means hearing from others, like all of you joining us today, so thanks again for being here. Next slide, please.

In partnering to achieve health system transformation, we aim to align priorities and policies across all audiences and develop closer engagement with beneficiaries to make sure we're meeting their needs. We know we can't expect our participants in models or pilots to provide seamless, accountable care if we continue to pay them in a fragmented way across fee-for-service, Medicare, Medicare Advantage, Medicaid and commercial coverage. And for this reason the Innovation Center is committed to working closely with payers to drive directional, multi-payer alignment and reduce provider burden for model participants. Next slide, please.

The Innovation Center is also using Patient-Reported Outcome Measures, or PROMs to elevate patient care experience and patient outcomes across our models and support our model, our partnership aim in delivering whole-person care that puts patients at the center. This strategy supports a more person-centered quality strategy in Innovation Center models by measuring what really matters most to patients. It aims to have two or more patient-reported measures in most accountable care models. Of note, nearly all models announced since our Strategy Refresh have incentives to collect Patient-Reported Outcome Measures. It recognizes the importance of capturing the caregiver experience, and makes the beneficiary perspective a key dimension of quality by advancing the use of patient-reported measures the voice of patients as data that drives improvement. Next slide, please.

To achieve aims in this area, we need to make sure that we understand patient and caregiver perspectives and then build those perspectives into the foundation of the models at the outset. The Innovation Center is soliciting feedback from patient and caregiver representatives and organizations across model development, implementation and evaluation. We want to be thoughtful about what kind of information patients want to know about an Innovation Center model test, and how we can communicate what the model might mean for improving care, for the experience of care. As models are launched and patient care is impacted, we need to be able to understand how patients are experiencing these changes in care delivery, quality of life and experience. And last, we need to consider how scaling of the model affects patients, and how can we ensure that the benefits patients have gained are built into new programs after a model ends.

With all of this in mind, I'm going to hand it over to Ellen Lukens, Deputy Director for Policy at the Innovation Center, to take it from there. Thank you.

>> Ellen Lukens, CMS: Hi, everyone, thank you for being with us today. Next slide, please.

I wanted to dig in a little bit more on the Center's vision for our models, and that they are first and foremost, patient-centered. We can ensure that they are patient-centered by being systematic, and making sure that we're soliciting feedback from patients and families, and incorporating that information into all the models across our portfolio. In doing so, we're embedding a person-centered mindset deeply within each of our models.

We do this by integrating patient feedback during each step of the model lifecycle, as Liz walked through on the last slide. We're building ongoing partnerships, understanding family perspectives, and experiences. We can't do this alone or in a vacuum, we have to be out there talking with you. This involves two-way communication, with the Innovation Center sharing updates, asking for input, listening, and using that feedback we've received to strengthen our models and promote continuous improvement.

Our partnerships are meaningful when we're taking an inclusive, big tent approach to these relationships. We need to ensure that we are capturing the diverse range of patient and caregiver perspectives that reflect what is happening in the real world. Ultimately, this will advance health equity. Without health equity, we cannot achieve improved experience and outcomes that matter to families. Next slide, please.

Before we get into our panel discussion, we want to share a couple of examples of how the Innovation Center is moving this forward. The Center recently launched the Value-Based Care Spotlight webpage, which I hope many of you have seen, to help people really better understand value-based care and it's role in improving health care and the patient experience. We know that outside of health policy experts and our model participants, value-based care is an unfamiliar concept, and may even be misinterpreted as meaning cheap or bargain basement care. What's more, some providers are hesitant to move away from fee-for-service for value-based care because of perceived or anticipated obstacles.

The Value-Based Care Spotlight addresses this knowledge gap, using language directly informed by our conversations with patients, caregivers, and providers. For the general public, we describe what value-based care is, what it looks like for a patient, how it contributes to better coordination and full-person care, and how it addresses health equity. For providers, we explain what they can expect by participating in value-based care, and how the CMS Innovation Center will support their success, as well as includes links to other helpful resources. Next slide, please.

The site also features a section, which is actually my personal favorite section, called Patient and Provider Voices, which showcases different aspects of value- based care, as told through the personal experiences of CMS Innovation Center model participants, health care providers and patients. For example, and you see it here on the left, we have an article and video about Lamont Mitchell, whose primary care doctor is part of the ACO REACH Model and took time to understand Lamont's health goals and help support lifestyle changes so that he could avoid taking medication when he was diagnosed with diabetes. You'll see if you see this video, that Lamont even started a step challenge to encourage others to be more active.

We also have a video and article about Connor Samuel, which is another really compelling story, who gets home dialysis through the Kidney Care Choices Model. He wanted to continue working, and this has enabled him to continue teaching students who are at higher risk of failing out of school. These are just a few examples of the narratives on the site to help people learn what value-based care looks like in real

life, and how it helped transform care experiences. We plan to continue adding content and hope that people will find the information useful. Some of this content is also available in Spanish. The web address will be dropped in the chat shortly. Next slide, please.

We also want to highlight the Health Care Payment Learning and Action Network, what we call the HCP-LAN for short, and they have a health equity advisory team which produced a guidance document that provides payment model recommendations for engaging community-based organizations, or CBOs, to address health-related social needs, like transportation, caregiver support or food and housing security. As defined in the report, CBOs are non-profit organizations whose members represent a local community and focus on addressing the community's socio-cultural conditions and lived experiences. We recognize that those closest to their communities have the best insight on their needs. This report, which is linked in the chat, organizes guidance for engaging community-based organizations and social service providers around four key themes.

The first is collaboration and partnership. To ensure marginalized populations have a role in decision-making and governance of health care organizations, like through advisory groups that include diverse community members, provide info on ideas. And also, really thinking through programs and how those same populations can really help promote ideas for programs and how the programs should be implemented.

The second is using hubs and neutral conveners. Community care hubs are community-focused bodies that organize and support a network of community-based organizations that provide social support services. These hubs and conveners can lessen burden on under-resourced and understaffed CBOs, and improve communication by serving as a single point of contact for both community-based organizations and health care entities.

The third theme is related to community-based organization capacity and infrastructure. Like care coordinators, financing, referral workflows, technical assistance and technology platforms with data transparency. Health care entities and conveners could offer resources for CBOs to develop the infrastructure needed to participate in alternative payment models.

The final component is funding. Sometimes, the available resources and payment rates for CBOs do not reflect the true costs of addressing social needs or providing the services desired by their communities. Health care entities could provide pre-funding support or infrastructure grants to help community-based organizations meet the necessary startup and operational needs to partner with health systems and provide social service needs. Next slide, please.

Finally, I want to tell you a little bit about some of the models that we've recently launched that really leverage community-based organizations, or CBOs, to meet health-related social needs. So to highlight some examples, I know we have many acronyms, but we recently announced a voluntary Cell and Gene Therapy Access Model in June of this year. This model aims to improve the lives of people with Medicaid, living with rare and severe diseases by increasing access to potentially transformative cell and gene therapies. The model will initially focus on beneficiaries with sickle cell disease. The model includes opportunities for states to partner with CBOs to address potential pain points that beneficiaries may face related to knowledge about gene therapy to treat sickle cell disease, access to gene therapy and other specialty care, social support services, and navigating and coordinating their care.

Commented [LA1]: Deloitte: She said June, but that is not correct. The model was announced this winter.

Another model is a voluntary model in behavioral health that we're calling the Innovation in Behavioral Health Model. It was also announced this past January, and is focused on improving quality of care and outcomes for Medicaid and Medicare beneficiaries with moderate to severe mental health conditions and substance use disorders. Participating behavioral health practices will screen beneficiaries for health-related social needs, and refer them to community-based organizations to provide services based on the results of these screenings.

We also, late last year, announced the Transforming Maternal Health Model, which is designed to focus exclusively on improving maternal health for people enrolled in Medicaid and the Children's Health Insurance Program. The model will support participating state Medicaid agencies to develop whole-person approaches to pregnancy, childbirth, and postpartum care. The model will use payments to support providers to identify local organizations that provide social support and behavioral health services, integrate those organizations into the screening, referral, and follow-up process, and support communication and coordination through data sharing and integration.

Another model that will be launching later this year, the Making Care Primary Model, participants will research, plan, and implement approaches to advance primary care, such as conducting health-related social needs screening and referral, partnering with CBOs and social service providers to address those needs, and deepening connections to community resources. This includes identifying ways to incentivize community health workers, improving navigation and supporting bi-directional data sharing between primary care practices and CBOs.

Last, but certainly not least, is the AHEAD Model, or the All-Payer Health Equity Approaches and Development Model, which is a state-based transformation model with the goal of improving population health, curbing health care cost growth and advancing health equity. Aspects of this model include requiring the state governance structure include CBOs and beneficiaries, providing payments to primary care practices, support better coordination with CBOs and specialists, and incorporating more onsite staff for better resource coordination.

Thank you again for being here today, and I will now pass it over to Purva and Kate for today's panel discussion.

>>Dr. Purva Rawal, CMS: Thank you so much, Ellen. That was a great intro, and really appreciate you and Liz opening up today's webinar.

We want to shift gears now and speak with our panel of experts, which includes families, community representatives and advocates on a few priority areas for the Center. Our discussion is going to feature two community-based organizations, and families who are going to share their experience with receiving services from those organizations.

We're really thrilled to welcome Cindy Causey (Caregiver), Nancy Walsh (the Director of Community for Life), and Leigh Ann Eagle (the Director of Health and Wellness Program and the Chief Operating Officer) of the MAC Living Well Center of Excellence. Also, like to welcome Jamal Brown, a Camden Coalition Housing First Program Participant and Advocate, and Mary Pelak, Senior Program Manager of the Housing First Program. And finally, Gwen Darien, the Executive Vice President of Patient Advocacy, Engagement, and Education for the National Patient Advocate Foundation, who's going to close us out with some reflections and insights.

And before we dive in, we want to open up a poll to hear from all of you. Next slide, please.

We'd love to hear your response to the following: What are the greatest challenges that patients experience, related to connecting with and receiving services from community-based organizations? If you could take a moment to select your top two choices. We'll give you a moment before we show the poll results.

Think we're just, we have some more coming in. So, we're going to give it just another minute. Thank you all. Okay, so thank you all for your responses. It looks like the top two, pretty clearly were, some of the top greatest challenges that folks are reporting are, lack of information about services from community-based organizations, and a lack of transport, transportation to receive services. So, thank you so much for your responses. And out-of-pocket costs actually came in at 27% as well.

So with that I am going to hand things over to Kate to kick off our discussion. Next slide, please.

>>Kate Davidson, CMS: Thanks so much, Purva. And thanks everybody for being here today, and especially to our panelists.

As we kick off the, in hearing directly from our panelists, I want to turn my first question to Leigh Ann and Nancy from the MAC Living Well Center of Excellence. I'm wondering, Leigh Ann, if you could tell us a little bit about your organization, and, Nancy, if you could tell us a little bit about the Community for Life Program. So, I'll turn it over to you guys to give us a little bit of background on the work that you guys are doing.

>> Leigh Ann Eagle, MAC Living Well Center of Excellence: Okay, thank you so much for having us here today. I look at this as really a pleasure to share what we've been doing in Maryland, because we know that on my Maryland's very different in our payment models.

So we actually established the Maryland Living Well Center of Excellence in 2015 as a state, the State Department on Aging, as a plan to sustain all of the evidence-based, you know, programs. When 2020 came, we were one of the first hubs you were talking about, community-based organizations and a lot of what you had discussed. We became one of the first hubs, where we took part in all of the ACL Learning Collaboratives, to become that CBO, to become that hub. So we feel very privileged to have been involved in that in the very beginning. And as we're rolling into this now, we look at the Maryland, the Maryland Longevity Plan, which we work with, Wes Moore, and Secretary Roques, Maryland Primary Care. We work very closely with all of those to make sure that we are aligned.

So really, this Community for Life Program came out of that Maryland vision of maintaining people at home. So that's a lot of what we do. And we are also launching the Maryland coding project, which is a minor project, where we're actually building out that dashboard for social determinants of health as a model for the country.

So I want to turn this over to Nancy so she can tell you about our Community for Life Program and the role it plays in maintaining people at home. Nancy.

>> Nancy Walsh, MAC Living Well Center of Excellence: Thank you, Leigh Ann, and thanks everyone for this opportunity.

Community for Life, here in Wicomico County, it provides our seniors the ability to maintain their independence and stay at home. And that's what our goal is. And the way I've been able to

kind of change it, a little bit, is I've worked with doctors' offices personally, gotten contracts with them. So, they just, they support us through what their HEART funds, so they pay for the clients to be a part of the Community for Life Program, which has been incredible.

I recently was in a home where the daughter couldn't reach their father, and he was actually having a stroke. I called the doctor's office. The doctor actually talked to him on the phone personally. But we didn't know, of course, he was having a stroke, but was able to convince him to get to the hospital. So that's kind of how I work really closely with that doctor's office.

But the client that I'd like to talk about today, oh and about Community for Life, what we do is we do provide transportation. And I was a little bit limited to my transportation availability at the beginning when I started. But I've gotten nine volunteers who graciously have helped, and it all came out of one client who needed extra transportation because of cancer. And I just made it happen. So I have all these wonderful volunteers that actually not only go to the doctor's office, but take them there, but sit with them, and wait till they're done, and take them home.

So the client I'd like to talk about today, is her name is Jeanette, we'll call her Jeanette. She came to Community for Life through TidalHealth, Regional Hospital in Maryland. And her needs are mainly transportation, my services navigating whatever. She was subject to fraud through mail, so we put an end to that, I helped her do that. I also helped her with, we have a pharmacist on staff that went to the house and went through all her medications to make sure she understood them and so we and we put them in our home med system.

She called me because she was going into the hospital for heart stent surgery, and while she was in the hospital, she called me multiple times. I was glad that we had that relationship. You know, speaking of parts of this, is really acquiring that relationship where they trust you, and they depend upon you. So I went to see her a couple of times in the hospital, and she said to me that she could not go home unless she had a caregiver, she would have had to go into a facility. So, I was able to check my resources and I had a list of providers, and fortunately I had one was available, so I was able to reach out and see if she could help with Jeanette. So, fortunately it all worked out. The family was able to contact Cindy and they were so happy with her services, and she was able to stay home. And because she was able to stay home, she was then able to get onto Community First Choice, so she didn't have to go anywhere in the interim.

So that's basically what I have. Do you have any questions?

>>Leigh Ann Eagle, MAC Living Well Center of Excellence: Another part about this is that we were able to implement the HEART funds that are in Maryland, which has played a very intricate role on how, that we can help our patients and make it very patient-centered.

>> Dr. Purva Rawal, CMS: This has been really helpful. I think that number one, Leigh Ann you really described kind of from the state perspective, how you positioned your organization to align with the, with the initiatives that are happening currently in Maryland. But then, also, Nancy, you really described what happens at the local level with such clarity. And how important it is for organizations to be really connected to your communities in the local context.

Oh, you know we also have Cindy here who is a caregiver with your organization. I wondered if you could tell us a little bit, Cindy, about how you connected with Community for Life Program. I know that

Nancy gave us a little bit of that background, but also what happens once you are connected and what, what are the kind of supports that you receive and provide, as well.

>>Cindy Causey, MAC Living Well Center of Excellence: Well hello. Thank you, Nancy and thank you everyone.

I was with Jeanette from the time she got home from the hospital. And kind of sat down, talked to her about her family, and she asked me questions about my family and my background, my experiences with other clients and tried to get closer to her, and we became friends. And I encouraged her to, I brought a piece of paper with me, encouraged her to go ahead and write everything down on the paper and put it on the counter; her daily breakfast, lunch dinner. Since she's diabetic and needs to eat at certain times. Just reminders to her to eat at certain times, also, have her medication lined up in a pill reminder. So she had one of those. And reminders to use her walker, because she was definitely a fall risk, and she would try and walk without the walker. And I said, that's definitely not a good idea, and that's something very important, you need to remind yourself.

And also, I felt it was wonderful that she wanted to be home. Most seniors do want to be in their own home because it's familiar, and they know where things are, and they have certain things, certain ways. And if they weren't a facility, all that would be gone. And they feel very comfortable being in their own home.

And I stayed with her several nights in the beginning, to make sure she stayed in bed. She was comfortable, well taken care of, and she felt the safety issue of me, having me there, laying on the sofa if she needed anything during the night. And that worked out very well for her, and after that, I kind of weaned her off of me staying there at night, and checked on her during in the morning. I gave her a call, and she answered and said it went very well. So I knew that was something that she didn't need anymore, someone staying at night and so that I just talked to her about it, and said, I know that you're kind of weaning off having someone here. But you know that her your daughter, is just a phone call away. If you need her, she'll be right here.

And she wanted that independence, and she wanted me to sit in in the morning. I weaned my hours down to where I was just there in the morning to help her get a shower, and she also enjoyed reading the Bible in the morning, and we sit there and read the Bible together. And it's just a matter of giving the client, some, she felt very good about being home by herself, that's what it is. They just have to feel that confidence that they can do it. And I felt like just being with her and having to write things down and making sure that certain times a day, certain things were being done. So that's about it.

>> Nancy Walsh, MAC Living Well Center of Excellence: And to address your question about how we connected? Yeah, I can. We have a caregiver list here at MAC and Cindy was in position to help another client of mine, and they didn't need her. So it just so happens, because I come from a caregiving background, I did it for multiple years, and that's why I've known Cindy in the past for that, too. But, you have to be available. That's the hugest part of getting a caregiver, because most of the time you're already signed up, or you're with someone. And so that availability of Cindy being available, I knew that she was because she was said she was going to be with one person that couldn't be, didn't need her. So does that help?

>>Kate Davidson, CMS: It's very, it's tremendously helpful. And, Cindy, thank you so much for all that you do. You can tell just from the way you described the work that you did with Jeanette, about how

much you care, and how important it is for you to ensure that people remain independent, and in the community, and in their homes, and self-directed. So I think that's really helpful. Thanks for providing that story, and also for Nancy and Leigh Ann, for the work that you do.

I'm going to move us on to our next poll. And the last poll was really centered in on connecting patients to community-based organizations, but wanted to ask the question about: What are the greatest challenges that community-based organizations experience related to navigation and coordination with health systems? There's a couple of choices here down below, workforce issues, IT infrastructure to collect and share data, or lack of funding and reimbursement streams for CBOs. Or, feel free to enter into the chat, much like you did last time, if there are some things that we didn't put as a potential answer that you would like us to know about. So, we'll give folks a second to answer that question.

Looks like things are still coming in. So we'll give just folks one more minute. Okay, so the results are in. So again, the question is: What are the greatest challenges that community-based organizations experience related to navigation and coordination with health systems?

And it looks like far and away at 72% that there's a lack of funding and reimbursement streams for those CBOs. We hear that a lot. And I think that Nancy and Leigh Ann gave us a really good background on kind of how they've established their organization in Maryland. But I think that there, that is still a major issue that we're hearing. But then we also are hearing that there's workforce issues as well as IT infrastructure to collect and share data. I'm going to go to the Q&A to see if there's anything that I missed here. So navigating eligibility requirements, so many, too many systems, complex, complexity of accessing services. So definitely hearing some of the challenges of navigating the system, as well as wait lists and resourcing.

So this has been really helpful. We're going to collect all of that information and continue to use that to inform our thinking at the Center. So, thank you. And with that, Purva, I'm going to hand this back over to you, to do some conversation with the Camden Coalition. Purva.

>> Dr. Purva Rawal, CMS: Thanks, Kate. We've got Mary and Jamal up next. Mary, I was going to start with you, and then Jamal will come to you next. But, Mary, I was hoping that you could tell us a little bit about the Housing First Program to start.

>>Mary Pelak, Camden Coalition: Sure. And I'm going to even go a little bit broader first and just tell about our organization, and then how we got into the housing space.

So The Coalition is a multidisciplinary non-profit based in Camden, New Jersey. And we implement various person-centered programs and do a lot of piloting of new models to address chronic illness and social barriers to health and wellbeing. We're really focused on building cross-sector partnerships and coordinated ecosystems of care here in Camden, in the South Jersey region, and across the country through our National Center. I just wanted to highlight a few of those, some examples of those.

So The Coalition serves, and we help design a unique model in New Jersey, called the Regional Health Hub, and this is the successor to the Medicaid ACO demonstration project here. And in this role we can ensure better alignment between the state's priorities and what we and other community partners see on the ground. So that there's community feedback and input given to state and local decision makers.

Just this morning some of my colleagues hosted the Camden Care Management Meeting. It's a monthly convening with Camden area community-based organizations to relationship-build and refine referral

processes. And then getting closer to just our day-to-day work here, we're out in the field doing home visits, attending appointments with our clients, and those home and community visits are so key to learning more about someone and building relationships.

I heard Nancy mentioned relationships in her section. I think relationship building functions on all of those levels. So with our participant-facing work, we use a model we developed called the Coach Model. It's so many of those principles in the Coach Model applies to building community partnerships as well.

And the Housing First Program, that I manage and Jamal is a participant in, was launched in 2015. Because our, again, our staff members out in the community we're really seeing the challenges of chronic homelessness in our community, and not being able to help people work towards their goals for themselves without stable housing. And so, we have this originally started as a pilot to bring the Housing First philosophy into New Jersey.

We now have 50 project-based vouchers from the Department of Community Affairs to provide, in a scattered site model, housing to folks who have experienced chronic homelessness in our city. And we also receive funding from the state to provide support of services, so that they're able to work on those goals with the stability of housing. And you know, just that need to, once you have housing, you want to be able to maintain it, and so that requires often some support from case management, and again, having strong and trusting relationships with our participants.

>> Dr. Purva Rawal, CMS: Thank you, Mary. I'll just say, just even listening, I appreciated that you took a step back and gave a little bit more, little context on the Camden Coalition itself. Because I know many of us have been reading about Camden Coalition's work for many, many years, and it's almost a mini CMMI on the ground, that I know many of us are learning from.

And I think before we transition to Jamal, I'll just say, I think, the Housing First Program, you are talking about how you all came up with it is a really great example of how a program started in response to the needs that you all saw on the ground. And so it's, you know, it's something that you guys are doing with the community. And really again, building those relationships and trust I felt that's another theme that's already coming through in our discussion today.

So with that, Jamal, I'll pivot to asking you just a couple of questions, and hearing from you. And as a program participant and an advocate, can you talk a little bit about how you were first introduced to Housing First, the way that it's impacted you, and then, if it's possible, also love to hear a little bit about the challenges that you know you've encountered. That was one of the themes that came out in the Q&A, that a lot of people are citing, just a number of challenges in even navigating all of these different supports and services.

>> Jamal Brown, Camden Coalition: Okay, I'm going to start off, in 2016, I suffered a stroke that partially paralyzed my right side of my body. And I am blessed enough to say that Camden Coalition came to my bedside, and they assisted me with getting on social security, getting to healthier living, and building me to where I'm at today.

The barriers that I faced was, not having, it was hard for me at first to get my social security, not having the ability to be able to maneuver without the proper identification. Like, if you don't have your social security card, birth certificate, or ID, it's very hard, especially if you're coming from a dysfunctional background. When it comes to the health and the way you live, you're living, it's very, very difficult to

get the proper help, the proper healthy traits, if they don't have the proper identification. And when it comes to the identification, it's very, it's very hard.

Like in Jersey I'd see every day, every day I see things that are needed. When I say things that are needed, things that are needed, that that that everyone needs, that that not that don't have the proper health care. They are cutting like stuff that the people, that don't have everything, they're cutting the things that people need. And how do you expect people to get healthy? How do you expect people to raise up in life, if you're taking away the one thing that is helping them get to the proper goals?

>>Dr. Purva Rawal, CMS: Jamal, I just want to ask you a follow up question. I think this example about the social security card identification, right? It's like the ability to work with, you know people like Mary and the Camden Coalition, the Housing First Program, means you really have to go back to the sort of have to take things step-by-step, and really understand all of the different pieces that people need to have, and to be in place, to have you know their needs gotten to be to be healthy. Can you talk a little bit about how some of your needs, or the ways that you've worked with Housing First, how has that changed over time? And none of us ever stay the same, so how, how has some of that changed over time?

>> Jamal Brown, Camden Coalition: I can confidently say that some of the things, like every part of me has changed. There, I would, I've been part of Camden Coalition, believe it or not, in December will be nine years. And I would say in nine years, and this is not tooting my horn, in nine years I've seen myself accomplish way more than I expected with the help with Camden Coalition, compared to if I didn't have that type of support.

It's important for me ,because when you have that type of support, you're more motivated, and you have someone on your tail telling you, like, stop slacking. And we need that, and so and like for me, like now I'm going to say now, I'm not going to say then, but now I'm more responsible. But back then I didn't have that same desire, but to have that support, and like, "hey, Jamal" I can honestly say they don't, they don't have to call my phone every three days to make sure that I'm taking my medicine because I know I got to take my medicine.

And it's very important, and I say this heavily, it's very important to always express what you're going through, because it deals with your mental health, physical health, emotional health, and if you, if you don't attend to one and only the other ones, you whole body gets affected. So, if I go to you and say, I need help in a certain area, I also will go to her and tell you the same thing because we are in the same field. So sometimes, when you want ,what I don't, I'm thinking, "want" is too demanding, when you are pushing towards trying to better yourself, it's good that you be supported, around that type of atmosphere, because it motivates you to be more healthier and to activate and to live a healthier life, because a healthier life changes lives.

>>Dr. Purva Rawal, CMS: I don't think anyone could say it better Jamal. But I think the thing that's coming out is that that long term relationship, right? Where people really get to know each other, understand each other, understand what you need, really allows everyone to be able to grow and to be healthier.

Before we, so thank you for that Jamal, and before we pivot to back to Kate and Gwen, I was wondering, Mary, if you could just there any kind of reactions or insights that you would add from your perspective,

based on what Jamal shared? And maybe even talk just for a second about some of the opportunities and the challenges that you've observed in working with health care providers in particular.

>>Mary Pelak, Camden Coalition: Yeah, I think, so when Jamal spoke to us, coming to his bedside when he had his stroke many years ago and was hospitalized, that was due to some targeted outreach we were doing using our Health Information Exchange that we administer here in Camden. So able to see people using the hospital system frequently, who's struggling with health and complex health and social needs, and that's how we originally met. And it has been such a journey, I think, to get that stability first through having a safe place to live, then through connecting to primary care and specialists.

And I would say, like Jamal, you said "a want", and I think, Jamal, through building that trusting relationship with Jamal and our care team, you started to express that you wanted to bring your voice into these kind of spaces, various other spaces. Jamal is really active with our Community Advisory Council here in Camden, our community engagement team, and able to share in this way, and that's like something that we want to be able to help him continue to develop.

But it's all layered in through that kind of like, he said, I can, I'm maintaining my stability here, taking my medications, doing all that that allows me to then pursue these goals I have for myself. I think our relationships with health systems and providers here in Camden, that are so effective. It's the education we've done with providers, that they see the value of not just seeing, like, Jamal said, not just seeing the clinical piece, but understanding his life outside of that exam room, understanding who he is and what he wants for himself. I think that's a really big part. And again, that's that relationship building on the more like the systems level.

>> Jamal Brown, Camden Coalition: And you know, one, one thing I want to ask, I mean, add real quick. Its very important when it comes to health clinics, health care providers, interacting with people, it is very important, cause I heard it a few times, it's very, very important to have a healthy relationship. That's a must.

>>Dr. Purva Rawal, CMS: Thank you, Jamal. I don't. I will say I am for one very grateful that you brought your voice to us today and to others as well, through your through your own journey and all the work that you've done. So with that, Mary and Jamal, thank you. And I'm going to turn it back to Kate.

>>Kate Davidson, CMS: Thanks so much, Purva. And yeah, I think that as I was listening, I was hearing so much, both in the first example in Maryland, but also then at Camden Coalition, just how important and central relationships are across the board, both like in an acute situation where someone is having a health issue. And then longitudinally, as they're developing that relationship with the community-based organization. So thank you for those examples.

I'd like to move to talk with Gwen. I think that you really bring this national perspective in your work. And wondering if you could reflect back on both what you heard as MAC was presenting, as Camden Coalition were presenting, and what some of your reactions were. Are there other examples that you see from your national perspective of CBOs and providers that are integrating together to make a difference for patients and to improve their own care delivery experience? And what are some of the challenges that we need to be considering, to try to mitigate, that are addressed to improve, not only for screening for social supports, but following through on those needs to ensure that they're addressed?

>> Gwen Darien, National Patient Advocacy Foundation: Thank you Kate, and thank you to the other panelists as such. I love doing these, I love participating in these kind of listening sessions, because I learned so much.

And I think that everybody there, so many themes, and that come together in so many different ways from so many different perspectives. And one of the things I, one of the ways that I like to describe our organization, because we're the patient advocate foundation, or the National Patient Advocate Foundation. Didn't have room on that slide with my long, but we are, I like to describe us as a learning patient advocacy organization, because we really work at the intersection of learning from people and helping people with direct patient services and system change activity.

So, I think some of the things that were highlighted and one of the things I wrote I mean, I wrote down a lot of notes here, but everybody talked about trust, trustworthiness, and relationships. And everybody talked about a kind of sustained and long-term relationship. And I think there's so many ways that our systems, because we have such a fragmented system, work against a lot of those, work against a lot of that.

You know, for example, we're doing a project now in with three different communities in the Mississippi Delta, Richmond, Virginia, and LA County. And in LA County and South-Central LA and in the Mississippi Delta, the problem is not just affordability, but it's also accessibility. So, we started out looking at how we elevated people's voices, and we're learning from our communities. And we talk, we started looking at shared decision making, and how we support people being very, very much involved in their care.

But if you can't, if there are health, if there are health care provider shortages, if there are both from the primary care to the specialist shortages, you can't, you actually can't have accessibility. So I would strongly advocate for CMS to add in not simply affordability, because that is significant issue, but also accessibility. And you can't build those relationships if you don't have any care providers, or if you have or if you go to clinics where you see somebody different in each time. I mean, I've known the work of the Camden Coalition for a long time, and they've done extra, they've really done extraordinary work.

I also wanted to say that I, one of the things that I found so heartening about this panel in the, in the opening presentation that Dr. Fowler gave, was the extent to which CMS has really integrated learning from communities and learning from people. And the other lens that I come to this, this conversation with is that of a, is that of a very, a long-term cancer survivor and a long-term patient advocate. So I've been I've been, I've had three cancers, and I've been a cancer survivor for 30 years, and I've been working in advocacy for 27.

And when I started working in advocacy, all we really wanted was a seat at the table. We were very, we were grateful to be invited to the table. And we've gotten to the point, I've gotten to the point, where I don't want to be invited, I don't want to come to the table when the when the menu is already set and the dinner is half consumed. I want to be there as we build the table. And I think many of my, many patients, family members and advocates see that.

So, learning from communities is one of the kind of principles of how you are doing this work is so critically important, and that's why it was so, it was so great to hear from Jamal and Cindy, the work that they were doing in their communities. So I could, I could go on for a long time. But I'm going to let, yeah, I will turn it back to you for my next question. Thank you.

>>Kate Davidson, CMS: No, I think that's fantastic, Gwen, thank you so much for sharing. And I had a lot of the same reflections as well, in terms of relationship, trust, accessibility, and I think that that you laid that out so nicely. Is there anything that you think that we should know or be thinking about at CMS in terms of our own policy decisions in in making that beyond just accessibility, that you would like to have kind of a final thought on from your, from your perspective?

>> Gwen Darien, National Patient Advocacy Foundation: I think that, I think that one of the underlying things to really consider is, just going back to something that I was talking about before, which is that, it is we focus very much on building long standing, trustworthy relationships, that takes time. From a CBO perspective, or a national perspective, a lot of times we don't have, people don't fund the building of relationships. And so in the Mississippi Delta we are with, this is an 8-year relationship. Another, another friend and colleague is, you know, 20-year relationship, and we don't fund that. And then we also assume that there's somebody to have to have a relationship with, whom we can have a relationship, an organization, a health care provider, patient advocates, a community activist. And I think that we have to really focus, and that's one of the areas of policy focus I would really consider, is making sure that there's somebody with whom or with which, we can have a relationship.

And I think, lastly, which is which was the other, you know, one of the other reflections I had. I remember the first panel I did on value, which was probably about 20 years ago. I was the patient perspective, and I felt a little bit like Flat Stanley. I don't know, if you may have remembered the little, the little cut out paper doll that people would, you know, I did it for my nephew. I put, I put Flat Gwen in all these different situations, so I felt a little bit like Flat Gwen. I was a, I was a two-dimensional object that people responded to rather than a three-dimensional person that has that is much, was much more than her diagnosis, or much more than this one subject.

So one of the things that that I find it really heartening and also fulfilling after all these years of advocacy work on, I would say, on behalf of all, a lot of my friends and colleagues who are patient and caregiver advocates, is that we are looking at who is defining value. So in the beginning, value is very much defined from an economic model. And now you're really talking about value as assigned, as defined, by the people who are, who are, who deserve, need and deserve the health care that we are, that you are helping to provide for them.

>> Kate Davidson, CMS: Thank you, Gwen. That was beautifully said, I could not agree more. And I think you picked up on all of the themes that we heard over the course of this hour.

Whether it was for MAC, hearing about kind of the and specifically, I'm thinking about your comments on both relationship, but also on kind of the longitudinal aspect of all of this and the fact that the relationships and trust really take time. And so MAC described for us, you know what that has been like in terms of the relationship with the State, and thinking about how to align with their initiatives and having relationships with the caregivers that are so important to be able to work with the patients. And to, and then, certainly, with the Camden Coalition. Jamal's like really poignant description of how he's evolved over the last nine years. And, Gwen, you know the work that you've been doing in the Delta, but in other communities, you know that you've really described that that takes a commitment. And it takes something that that is about really being in a community for a period of time and really kind of working towards shared goals.

So lots of themes that we're hearing throughout the presentations today. Thank you so so much. Appreciate your advocacy, and appreciate you being here and sharing your thoughts with us today. With that, I'm going to hand it over to Purva to close us out.

>>Dr. Purva Rawal, CMS: Thank you so much, Kate. And for you know, bringing out, I think, some really important themes from today's conversation discussion. And we, it's so important that we continue to have these so that we at the Innovation Center can think about what we're testing, identifying what's best at supporting the work that many of you are out there doing every day.

So first, I just want to thank everyone on this call for joining today's listening session. We look forward to continuing in future dialogue. The Innovation Center is going to be synthesizing today's conversation to curate key insights and feedback, and so we really hope that you can participate in the survey for today's event by clicking on the link in the chat window. Also, want to take note of some of the following actions that you all can take to stay engaged and to learn more. First, sign up to receive regular email updates from the Innovation Center. Please visit our website and model specific web pages, and follow us @CMSinnovates.

So this concludes today's listening session, right on time. Thank you for joining, and I hope you all have a great rest of your day. And thank you so much again to our panelists today for joining us.

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