

Transcript

And welcome to the Ohio Department of Health's presentation on family engagement, what people think versus what is.

We are excited to be here, guys, today.

My name is Melissa Jackson.

And my name is Kim Matthews. Thank you for joining us today.

And we are the Ohio Department of Health's Parent Consultants and the Maternal Child and Family Health Bureau. Our presentation today is a play on the trending social media topic, what people think versus what is or expectation versus reality. We know that in life, often our expectations can be high and reality can tend to fall short. In fact, this happens so often that we tend to expect reality to always be worse.

But when it comes to family engagement, we have learned that often reality is better

So what our parent consultants, often people think parent consultants or individuals with similar titles are simply parents, not professionals. That they are volunteers, not state employees that are part time are not available to help very often.

We also hear the parent consultants are those that can only speak to their own families struggles and should only be brought to the table for certain topics.

On the contrary, sometimes we hear the parent consultants are just trained professionals in public health and are not parents of children with special medical needs that parent consultants have the educational experience not the lived experience. The reality for Kim and I is we are parents of children with special medical needs and professionals with years of experience prior to coming on board at ODH, we needed both to obtain our jobs. We are lucky to be full time employees and we are welcome at any seat at the table at any time. In fact, we support the 40 plus programs and the Maternal Child and Family Health Bureau and the two of us lead numerous work groups and title five block groups.

We are always encouraged to work with the community and external teams and gather live experiences. We aren't here just to share our own stories.

We're here to be a bridge between the communities and the state. You might be thinking, Wow, that is unique and perhaps our roles are the people like us or not. Every state has tons of parents that could hold this title and make these partnerships.

So why are there not more of us across the nation?

Perhaps the following myths or misconceptions are partly to blame

So some common struggles you may have heard or experienced in your work as a professional or a parent might be. We have shared our work and opportunities on our website and social media pages, but we haven't had any engagement.

Often it feels like families don't want to be involved. I think that's a very common sentiment, or it can lead us to feel that way in some cases.

Another one is now more than ever. Families are going through so much they're likely to be too busy to work or contract their time.

We don't want to add more onto their plate. Some families have endured a lot emotionally, and we know this to be true.

We don't want our questions or our conversations to upset or anger them.

We would never want to make their struggles worse. We often hear as well many lived experience or don't have backgrounds in their content areas or degrees in public health.

How do we balance lived experience and educational experience?

And we're going to talk about that as well.

This might be one that many of you are familiar with.

We have tried to diversify our teams.

We can't seem to reach the minority communities. And lastly, another myth we're going to address today is teens and youth can sometimes be harder to reach.

Their busy school and extracurricular schedules make planning meetings difficult. We also can get the teens that are struggling to come to the table. Often the teams we speak to don't have the issues we are trying to address in the communities. So all of these are the myths and misconceptions that we are going to talk about today and kind of share how we as a department in a bureau have addressed a lot of these and are trying to make things better in our community, in our state. So our first one, what people think as I shared before. Often we hear we have shared our work and our opportunities on our website, on our social media pages, and we've tried to push out the info, but we haven't had any engagement.

Often it feels like families don't want to be involved.

The reality is if they aren't using it, they don't really know about it.

Perhaps they don't understand.

Trusted or your message, just not in the right language for them.

Make sure that when you're communicate, you communicate the same message to them in a variety of ways and offer them even more ways to engage back. Use social media, use your website, use blogs, use externals, and we're going to talk about a lot of the different ways that we can also do that on the next slide.

But another topic that you can do is get trusted individuals

in the community to post those fires or speak with families directly. Let them know about your different opportunities and then let those in individuals as they're communicating and working with the community, determine who might be a good fit and pass on the resource. Make sure your materials are both culturally and linguistically tailored to each audience.

Use supportive images.

They need to be able to see themselves in the messaging Often we take our materials and we get them translated, but then we don't really finesse the wording or change the images to really match.

So make sure that when you're doing that, each is tailored. And then a huge point that we've noticed with our families is demonstrate or explain how their voice and perspective will be heard.

Respected and utilized in decision making.

So when you're putting out those ads, be very clear about what the outcome will be, and then make sure, as always, that you're using common language and wording. This is an example here on the corner of this slide is one of the promotional materials that we put out about parent consultants We shared a little bit about ourselves. We talked about what we do, and then we shared exactly what we can do for each of them and how to get a hold of us.

When looking at communicating.

I know many of you have utilized various

amount of these different communication outlets and so today I'm just going to briefly kind of mention them and just know that for each myth and misconception that we're going to go over, we tend to do a mix of these different communication outlets throughout. So we do what you would have internally run social media platforms for a variety of the different bureaus as well as the department itself.

And then some service and program areas have their own social media pages as well.

And we definitely are able to utilize those and push out materials through them.

But we have also found great traction in our external social media groups. So being able to go on to those certain social media platforms that might address the target audience. For instance, there's an Ohio special needs family page.

There is a medical mamas page. There's all sorts of Facebook pages out there where families will share their concerns and you can be a listening ear and offer your contact information. We also utilize social media polls and surveys because it's very quick and easy for families just to click and engage and share that information, and it's very meaningful for us.

We also definitely work because many of you do.

I'm sure, with nonprofits and externals, and we definitely try to make sure that we keep them abreast with all of the things that we're doing so that they can push those out in their newsletters.

And throughout their platforms as well.

We also run a variety of newsletters.

Our Children with Medical Handicaps program has a wonderful newsletter where we share stories of families, and we allow individuals to share their updates with us from across the bureaus to get those out in one place. We also have website and YouTube webinars that we have.

We have Lifeforce learning tools that we utilize with our families, as well as promote throughout the different services we have. We have a parent advisory committee and a medical advisory council that Kim will talk about later today, and we're building a youth advisory committee, so we're very excited about that. And then, of course, the typical things, you know, the email blasts and the SurveyMonkey and Eventbrite really using all the tools that are out there. Another one that we're trying to start heavily using more in some of our areas is the WhatsApp. And so having that collaboration to be able to linguistically and culturally tailor the information and put it out on the website,

and now

knowing that it can even link with Facebook so that we're able to put our social media posts on WhatsApp as well. And we know there's a big, broad internal international reach with WhatsApp so, so deep,

dove deep, even deeper is this family focused social media platform. As I mentioned, the parent consultants Kim and myself, we utilize a variety of social media platforms to connect with families and discover pain points. Many families publicly share their concerns and ask for help on the parent run groups. And now more than ever, families are finding their voices to advocate for their children.

And so we have to go where they're advocating, which is on social media We also share our poll surveys and obtain lived experiences with permission via those channels as well. And it's been a wonderful way to offer the services such as the Children's Medical Handicap Program, Work, Save our site, and many others through social media by just posting the fliers or our contact information when we see a parent or a family member asking for help. As I mentioned as well, we also have that parent to parent newsletter that's there on the side for you to see and we make sure that the very essence of the newsletter is very family friendly and engaging.

And we write to families and we share stories.

We have families write and send messages of hope. It's just a very loving and community building resource for those that are in our children's medical handicaps.

Program, which goes to the 40 plus thousand families.

We also do a lot of our surveys online, and so as you can see, we we've also gathering formation for our needs assessment. We by sharing surveys with the CMH families, external partners and on those public social media platforms.

We asked real Ohio families to share their opinions, insight and needs. And so we definitely try to use a mix in a variety of different areas.

And a really good example of a perfect mix here is our infant hearing program. The infant hearing program collaborates with the Child Coalition for Education of Children with Disabilities, the Ohio Hands and Voices and the Ohio School for the Deaf to provide family to family support and community engagement. So we partner with all of these wonderful services and programs, and some examples of some of the work that we've been able to do together is the Ohio hands and Voices is an organization that is comprised of parents and families of children with hearing loss. So we're able to have that lived experience and that really rich good experience that they can bring to the table by being a part of that group. That same group needs a private Facebook group to provide various supports to families, including direct parent to parent support, information education, training, and referrals to other community resources.

Additionally, they host quarterly events to enhance family to family support opportunities and build connections so they have that online component as well as having the in-person and virtual webinars and events as well. And the Ohio Coalition for the Education of Children with Disabilities also hosts an annual statewide parent to parent event for families of children with hearing loss to build connections and share resources.

So families have a variety of ways they engage.

They can sit at some of these councils and have their voice heard.

They can engage on facial social media.

They can attend these hosted quarterly events and then they can also come to a very large statewide event later as well.

And it really has led to us having a lot of great input and feedback from those families that has directly impacted the way that we run and provide our services So another myth about engaging, which will be your second one, is now more than ever, families are going through so much, they're likely too busy to volunteer or contract their time.

We don't want to add more to their plate.

And I think all of us can say families, including our own, are busy and just like us, everybody has a lot on their plates, yet they still want to be involved.

They want to make a difference for their family and another like theirs.

Can only tell you how important it is for a family that has gone through something to be able to then take that and turn it into something positive and help others is very therapeutic.

So we urge you to offer shorter, less demanding opportunities to engage or contribute. If you're worried about timing, be flexible, hold meeting times outside of the typical work hours, create shorter surveys and bowls for individuals to engage with on the go So, like I said, with social media being able just to click on a poll or fill out a quick survey is key.

You should also offer opportunities in social media groups, on community boards and online support groups for a lived experience or to engage. And then, as we mentioned before, get trusted individuals in the community to post a flier, speak with families.

That would be a good fit.

We've had a variety of different scenarios that have come up with the Somali population here in Ohio. And how we were able to reach out to some trusted individuals to share information about COVID within that population. And had we not had those trusted individuals that were able to then give that information, it would have been very hard at times to reach. And so offering all those unique ways for them to share their voice and get information and really share their story is very important.

And it leads to such rich work that you end up doing An example of this is something that I'm extremely proud of is in 2020, a team of childhood cancer patients, parents, advocates and supporting hospitals state non-employees nonprofit employees were assembled through this. How partners for cancer control to develop state goals surrounding childhood cancer for the first time in Ohio history, three objectives and nine strategies focusing on childhood cancer were included in the state's cancer plan. Because of this amazing, robust group of individuals with so much lived experience and passion through this work.

The first annual Childhood Cancer Summit 2021 was planned and I am very pleased to say that over 100 children and childhood cancer families in Ohio were surveyed to determine

the topics and speakers. There was 11 more than 11 Facebook polls and threads that were conducted and existing pediatric cancer support groups here in Ohio to really allow the families to submit questions for the panelists and speakers. We then compiled that information provided into the panels and speakers and so everything was really crafted by the families.

We did have all six of Ohio's children's hospitals and several adult hospitals come to the table.

They were consulted and involved in the work, and many of them were asked to speak at the event. We also, during that time, collected 113 photos of Ohio's childhood cancer warriors. And shared them throughout the presentations and throughout the two days of the summit. This allowed families to both see and feel representation and it was really engaging and meaningful to have their own child's be a part of such a momentous occasion.

We also had a video from several of our legislators, and we also had several sessions focusing just on brave supports and palliative care. We made sure that we were supporting families across the spectrum when it came to childhood cancer.

So individuals that were just starting their journey to individuals that were in survivorship, as well as individuals that unfortunately lost their child. The end result, and I am very pleased to say this as a pediatric cancer mom myself.

The end result was that 761 participants were registered, 36 speakers spoke, and we had 27 sessions conducted answering questions shared by the community. This was truly an event that was planned for her and by the pediatric cancer community.

And we are just so glad that this work is going to continue

and is getting stronger as we continue to add more lived experiences to our workgroup.

So another one of these misconceptions that we often hear, our families have endured a lot emotionally and I can honestly say as a parent that has gone through a lot with my child is that, you know, this is very true.

We don't want our questions or conversations to upset or anger them.

We would never want to make their struggles worse. And I absolutely understand that and often feel that way myself when engaging with lived experiences, because families have been through a lot.

Yet they still need to be heard. Let families decide if sharing is too much, do not decide for them.

Every family might be in a different space.

And a lot of times families reach a point where they are ready to share.

Families don't need the perfect answer.

A response from you.

That is one thing that I often struggle with, and you just need to know that.

They just need people to listen and understand their lived experience.

They just need to feel heard.

You don't have to have the perfect response or be able to make things better right then and there.

Emotion and passion drives change.

You don't need to fear their sadness or their anger.

You just need to find a way to help it drive change.

And so really harnessing that passion and embracing it. It leads to so many incredible things, and we know heart is everything.

And so if people that are behind the work are feeling that work and are definitely dedicated to pushing it forward, only great is going to come from it.

And so we here in Ohio are so glad that we have our Infant Mortality Task Force. It is such a heavy topic and something that is very difficult to talk about at times.

But we're very thankful for the work that is taking place here in Ohio. And so the Infant Mortality Task Force, it works with local, state and national leaders to identify needed changes to address racial disparities in infant mortality.

A kickoff meeting was held in March 2021. This is still fairly new, with 30 members representing multiple organizations across the state.

There have been six monthly meetings and a supplemental information session occurring.

And so we've definitely hit the ground running with that work. The task force was intentional about engaging black women, families and communities throughout the process.

More than 30 family listening sessions and 11 partner listening sessions were held in the 11 counties that account for a large portion of all infant deaths in the state. Nearly 300 families participated in the initial family listening session and a follow up session to review draft recommendations And I just think that is an extremely powerful number because that not only represents all of those families with lived

experience, but all of those people coming to the table happy to be at the table to share and advocate for their loved ones. And we're very also pleased with the number that more than 200 community members completed surveys on key concepts and ideas for recommendations.

So you can tell that this is something that was very needed here in Ohio. And I think the fact that we had so many individuals in the community come out and want to be a part of this, and we allowed them to be a part of this, and we're so excited to have them at the table.

It has just been a wonderful task force, and we look forward to all the work that can be done here. So another myth that we have many lived experience was don't have backgrounds in their content areas or degrees in public health.

How do we balance lived experience and educational experience?

And that is a difficult one.

Everyone including staff, comes to the table with different levels of education and experience.

So try to keep an open mind.

Try not to compare people's background

There is a time and a place for everyone's insights.

Lived experience is extremely valuable.

So definitely make sure that when you're thinking about that background and what they have, know that every project should include a lived experience.

And make sure that you know about combining your education and professional experience with their lived experience to create a powerful team. So not everybody has to have or check every single box, but on every team that you have, you should definitely have someone with that professional experience and with that live experience. So making sure that you really have both perspectives coming to the table and then fostering a good relationship for them to work together And so we definitely are going to go ahead and have Kim Matthews share some of the slides coming up forward as she is a wonderful, intricate part of our parent advisory committee. Ken.

Thank you, Melissa.

So one of the things that we do is as masses shared in several slides is we heavily engage the lived experience voice And so on the screen, you will see the first bullet point is the Parent Advisory Committee, otherwise known as PAC, AC.

And this is a committee that serves under our Ohio CMH program, children with medical handicaps. And we bring parents from different cultures diagnoses, regions and races from all across Ohio to come together to share, to advocate and support other families serving on this committee.

It's a volunteer committee. And we are very grateful for the parents that are involved on this team.

We completed a health equity and an implicit bias training with this team. And we do provide resources to anyone that would come on board since that training. And we also have a selective recruiting method that's being utilized to strengthen their efforts.

We offer remote meetings.

And this allows anyone to engage in this team as a member of the team. And it allows them to grow within their region and find a stronger voice.

That's one of the things that COVID taught us was that having virtual meetings actually strengthens the team rather than having people drive for three or more hours to get to one single location and to meet together in person.

Our next team is our Medical Advisory Council, otherwise known as M.A.C. or Mac.

This is a team of medical providers from Ohio's children's hospitals who come together to share.

They consult on Bureau Matters, and they also support the CMH program. They are providers who are treating children who are enrolled in that CMH program.

And we've taken many steps to contract a provider to help weigh in on medical issues within the Bureau of Maternal Child and Family Health. So one of our medical providers who serves on the MAC is doing some contract work for us.

And it's been a wonderful collaborative relationship. So the next question is, are you not able to convene a new committee?

That's okay if you're not. So find ways to partner with existing nonprofits in your state, join their groups and bring their voices back into your space to help support the work and the things that are happening to support families that your programs are ultimately serving.

Our next thing that we want to share is how we further our engaging families is through our Ohio Council to Advance Maternal Health, otherwise, known as OH-CAMH, we like our acronyms here in Ohio. So the OH-CAMH was established in the spring of 2020 to convene stakeholders working on maternal health issues.

So you can see four bullet points on this screen and I'll sort of run through these rather quickly.

But I do want to highlight them because they are important. So our Kim team currently consists of almost 200 individuals across 84 organizations

And you can see that they include state agencies, community-based organizations, social service organizations, clinical organizations, public health agencies, advocacy organizations, and most importantly, individuals with lived experience. And then we did complete an initial needs assessment process that included over 55 hours of one on one meetings. And so those meetings then set the stage for tell us what you need.

Tell us what's working.

Tell us what's not working, etc. And then we also had interactive tools to use during those meetings to further engage members such as live polling surveys and other interactive measures. And then a draft of the strategic plan was developed based on that feedback and discussion with those members about what the future of maternal health in Ohio should look like. And the draft plan included 11 strategy areas that are actively being led and implemented by all members, all implementation teams are led by volunteer members.

With some of them being led by individuals with lived experience. Many teams include at least one person that has experienced maternal morbidity personally as a family or friend or someone who died from pregnancy related causes.

I'm sorry, as a family friend of someone who died from pregnancy related causes.

So again, we're highlighting that lived experience.

Either family or friend experience because we know that is most important in this work.

Next slide.

So our next myth is what people think.

We've tried to diversify our teams and we can't seem to reach the minority communities.

And so some of the things that we have discovered in this space is that families of every color and ethnicity have something to say and something to share.

They all want and they most importantly, deserve a seat at the table.

Families from every culture and ethnicity are on social media.

So we use social media platforms to reach families.

We do that intentionally as well as to share.

Previously, we find trusted individuals within communities that can help translate materials or share them within those communities. We also utilize nonprofits, churches, schools, libraries, and even small businesses to share content

and engage families because every family matters. And so here's some ideas of what we have been able to experience through this work.

And we wanted to share this with you today. Melissa shared earlier for cultural and linguistically appropriate materials, especially during COVID. COVID has taught us so very much, but it has also allowed us to see the need for materials and websites to be translated in a variety of languages. For instance, we did work with the Somali population and we intentionally strategized how to better connect and share guidance moving forward because we had those contacts already.

It was so much easier for us to do that work.

WhatsApp, we've discovered that WhatsApp is very culturally diverse and often heavily utilized by individuals talking internationally. So you can link WhatsApp with your Facebook to share information on the platform. Again, we use trusted partners within the community to share our materials on COVID.

And that was shared through WhatsApp ultimately. We also now have a bureau equity committee, and we are striving to increase the diversity, the respect and inclusivity of our bureau staff and foster a friendly and welcoming environment.

This includes being more intentional with our hiring and holding health equity and implicit bias virtual trainings

We encourage differences in the sharing of lived experiences. In fact, many of our staff members have family that are directly impacted by our Title five work, and we may never would have known that. Had we had that open, welcoming environment to share those things about ourselves within those different meeting opportunities, So our next example of bringing in again that lived experience voice is through Ohio Equity Institute, another acronym, OEI.

And so OEI is working to achieve equity and birth outcomes. It is a grant funded collaborate between the Department of Health here in Ohio and local partners, which was created in 2012 to address racial inequities in birth outcomes.

So you can see the three bullet points there on the screen.

One of the main goals is to partner with other institutes and communities of color to adopt and share agenda goals, objectives, data analysis and use coordinated strategies and develop consistent metrics to measure progress Local navigators are certainly most important in this process, and we'd like in them to neighborhood navigators some of you may be familiar with that term, and those local neighborhood navigators are able to then be within the community

and have that one on one conversation that is so very important to improve access to resources needed for a new and growing family.

We also establish a partnership with Queens Village.

Queens Village provides a safe space for black mothers to be, to support and be supported by their peers, to connect, to relieve stress, to produce trauma, and to build a better world together. When consulting the Queens Village community, our team gained some pretty invaluable and insightful information and was able to order our work, alter our work to better support black mothers

Next slide

So another myth is regarding teens what people think teens in use can sometimes be harder to reach their busy school and extra curricular schedules make it planning very difficult. We all know that teens also have busy schedules, and so often we think that teens, maybe they can't get to the table because they're struggling. Or teens that we speak to don't have the issues we are trying to address within the community. That's a total myth.

What reality is on the right side of the screen is you'll see that adolescents and young adults.

Yes, they do have busy lives, their schoolwork, sports, family, friends do do keep them busy.

But they do still want to have their voices heard.

So be flexible.

Don't expect an individual to be able to attend every meeting or every call hosted a weekend or an evening meeting. Adjust the numbers on your team to account for absences during those times when when some of them can't be available.

Create a diverse team.

But remember, things aren't always as they appear.

Individuals may be bringing trauma or insight to the table.

That you wouldn't expect.

For example, that A-plus student could still be homeless, could still be experiencing abuse or something else.

Find a way to make each volunteer feel valued and connected to the team.

Make sessions productive. Make them fun.

Use communication apps and encouraging engagement with their peers.

Find ways to creatively compensate volunteers for their time.

Next slide

So for youth homelessness, we know that through the Department of Health here in Ohio, we fund 13 agencies under two grant programs to address homelessness youth with ages 14 to 24.

We're very excited about this opportunity to serve the youth who are homeless here in Ohio.

And so we have grant deliverables that include coordinating a provision of housing services, behavioral and physical health services educational employment opportunities, fostering community and social connections, and outreach to youth experiencing homelessness.

Youth homelessness has its deliverable. That requires agencies to invite youths with lived experience to the project director's meetings.

This is very powerful.

Use our present at those meetings and help facilitate icebreakers. Many sub grantees have youth advisory boards, and the Department of Health is beginning efforts to create their own advisory board that will include that Youth Voice Stand up committees and teams for teens and young adults that can grow and bring that lived experience.

Voice.

You can see, too, on the screen as an example, is a youth advocacy fellowship with the Patch program. And so we're very excited to explore how we can replicate this at the Department of Health. And again, we are bringing that lived experience voice through youth into this work.

We're also working on creating a youth advisory committee for the CMH program.

And so we're very excited to have youth who are participants within the CMH program be able to be involved on that team. And we do look at that as a team effort because we want to make sure that lived experience voice is at the forefront, leading the work of what we do and how we do it. Next slide so I will turn it back over to Melissa.

And she's going to share some further information as we finish up our presentation.

Thank you.

One, two, three.

Thank you, can.

So some of our key takeaways that we wanted to share with you today are here on the screen.

And really, these are just messages that we felt very passionate about.

And it's how we tried to do a lot of the work we do as parent consultants. And so I think many of you know this, but now more than ever, families and individuals want to share, advocate and make change.

So do not fear that you are overwhelming them by reaching out.

These are opportunities that they crave and some of them actually need. And then also, remote meetings and presentations are giving more people

the chance to attend and join the conversation. So utilize this time of this crazy remote time and world to grow.

Embrace those online meetings.

And as Kim mentioned, am really giving them that online component. It means that they don't have to take 3 hours out of their day to drive or find child care or plan meals or do this and that they can just log in and be with a community.

Our next one is intertwined health equity into every step of your work.

Make sure your teams and community know that that is a priority. And that is what is so wonderful about our department and our bureau creating that health equity team that we have that really works with us as a department and as employees to constantly be thinking of that and making ourselves better and provide growth and resources for us to learn.

So we we definitely advocate for that.

And lastly, if no one on your team has lived experience regarding the work you're doing, you need to find someone who has. Don't move that work forward until you can speak to someone who is directly impacted by the work.

Every project needs.

Lived experience driving and guiding it.

And if the biggest thing we could take away from today

is lived experiences, passion.

And so we know passion can accomplish huge things and great things. And so Kim and I just want to definitely advocate for using that passion and using those things that drive the work forward and drive change.

And so we are so grateful to have you all with us today.

And we're definitely happy to answer any questions that you may have on the screen. You can also see our contact information as well as our parent consultant handout that we can also make available. And please feel free to connect with us and ask questions, but also reach out if you ever want to engage.

We're happy to meet and learn from all of you as well.

Thank you.

And we'll also be helpful to you.

We will include a link into the chat up this one pager and you'll have access to it as well as our contact information.

If you would like to reach out. Thank you.