

Transcript

Hello, everyone.

My name is Kendra Mitchell, and I am the director of

Integrated Systems of Services for Children and Youth with special health care needs at the Tennessee Department of Health's Central Office. I would like to take time to say welcome and thank you for joining our session today. As we discussed pertinent information around state Title five, agency and family led organizations shaping the future with intentional family engagement

Our presenters today will be myself, Ms. Jacqueline Johnson, who is the section chief of Children and Youth with special health care needs at the Tennessee Department of Health Central Office in care of the Director of Family Voices of Tennessee with our learning objectives today. We will demonstrate how title five family led organizations partner to empower youth and families to address critical issues, communicate the importance of family involvement in decision making around outcomes that impact their daily lives during a crisis or times of social unrest. Lastly, we will exhibit the benefits of including family and new entitlement programs, namely to improve diversity,

inclusion, health equity, and disparity elimination. At the end, we will provide a blueprint on how to model successful youth and family engagement in state What is family engagement?

Family News Engagement is the process in which families have a primary and meaningful role in all decision making efforts that impact youth and their families and focuses on improving positive outcomes across various domains

How is successful engagement measured?

When does it become evident?

Successful engagement is evident when families and you are routinely equal partners with state and local leaders in planning, designing any evaluation services, programs and policies that impact their lives How do you get there?

Let's discuss the three "C s".

Communicate, create and collaborate.

Communicate the importance of family and youth involvement in decision making around outcomes that impact their daily lives, especially during the time of crisis or times of social unrest.

Listen to the information and stories they share. Create opportunities for youth and families to connect with each other and build networks.

Create opportunities for them to build their own set of skills and knowledge.

Around topics that pertain to them. Lastly, create an open environment where all questions and concerns are welcome. The last thing is to collaborate, collaborate with youth and families regarding agency decisions, policy updates, community events and learning opportunities.

Often times, youth and families are the best teachers. We will get feedback from our family led organization regarding a few of these topics. Later in the presentation, We want to exhibit the benefits of including family and youth in Title five program planning to improve diversity, inclusion, health equity and disparity elimination. The Tennessee Department of Health, in partnership with Family Voices of Tennessee, collaborate to maintain a youth advisory council that is comprised of transition age to youth ranging from 14 to 24.

The youth are strong advocates and experts in mentoring.

As many have been diagnosed with physical, mental, developmental, behavioral or intellectual disabilities, the Council meets quarterly to discuss questions concerning policies and situations that are pertinent to their lives during the COVID 19 pandemic.

The youth met to discuss virtual versus in-person learning in mask mandates.

Prior to COVID, they had serious concerns about individualized education plans and understanding app meetings

We were able to work with the Tennessee Department of Education to have an IEP specialist attend their meeting and address all questions. Lastly, several of the members of the Youth

Advisory Council participate in Disability Day on the Hill and have opportunities to speak with their legislators.

These are only a few features of the Council. A few ways that we empower youth and families as a Title five state agency and family led organization are creating partnerships with the youth and families. It's vital to build rapport so youth and families will feel secure in walking beside you and not behind you during a critical situation.

Reassure them that solutions will be found together. Then, as we look about look or think about equality and inclusion, we do not tell youth and families that they are equal. We show them regardless of age,

race, religion, social status or disability. We provide the same rights and opportunities to all youth and families when barriers arise.

We work together to ensure equal and positive outcomes. Lastly, we promote and support self-advocacy.

It is vital that families in youth speak up, make their own decisions, and learn how to gather information so they can all successfully navigate systems of care, intimacy,

Another benefit to having a family and youth engagement involvement is participation in the title for maternal and child health programs. This is an area where intentional engagement is modeled on a state level through partnership, effective communication, respect, and shared goal setting.

Tennessee invites our youth to participate in key maternal and child health activities such as training, mentoring, and network opportunities with other young people and with MCH professionals. Ways that we have been successful with intentional engagement include providing opportunities for training, and that training is bi-directional.

We offer training, but we also receive training from our youth recipients. Tennessee is also intentional with providing space for mentoring, as this not only provides leadership development but it also somewhat creates a succession model in that as older youth aged out of our youth advisory committees, we have youth there waiting in the wings that have had an opportunity for leadership development and can move up into those leadership roles.

Youth are invited to participate in program and policy development, and we don't just send them information and ask for feedback. We actually invite them to have a seat at the table and to be full participants as the state formulates policies and procedures.

Next slide, please. Opportunities are provided for youth to facilitate meetings, conferences, planning presentations, as well as focus groups during our needs assessment and block grant planning processes.

The youth are included as valued stakeholders.

Meetings are often held at night or virtually prior to the virtual space. To ensure that we include their voice in all decision making along the maternal and child health spectrum.

Tennessee has also included family members and youth as coauthors on our family participation section of our Block Grant application. Intentional Youth Engagement was and is especially important during the recent pandemic, and any time that there is a crisis when the state moved into a virtual space, as Kendra has mentioned, youth were invited to provide input on returning to in-person learning or whether to remain virtual.

Youth also provided input on concerns related to care and especially access to care during the height of the pandemic.

Tennessee expects that the return on investment of intentionally engaging youth will come in the form of increased engagement, mentoring and leadership, as well as opportunities for youth to lead others and to participate in shared decision making and provide positive impacts to improve the health and well-being of children and families in the future.

Next slide, please.

In 2020, not only was Tennessee hit with devastating tornadoes and floods across the state, but COVID 19 pandemic transpired shortly after.

During this time, youth and families aided our department in creating two statewide emergency preparedness initiatives. The emergency alert vehicle on the left were designed to alert first responders that there is a youth with a special health care need in the vehicle or home during emergency situations. The emergency toolkits on the right consist of masks, hand sanitizers, first aid kit, travel document folders, flashlights, the label checklists and resource cards to assist families during emergency situations as well. Once these items were distributed across the state, we received even more feedback from youth and families on ways to improve materials for the next round. As Jackie mentioned before, benefits of family engagement, its participation in planning annual youth conferences.

These events are designed to teach you how to successfully transition into adulthood in 2019. We hosted the first multi-agency youth led conference where you can families learned how to navigate systems of peer intimacy in 2021. The conference was virtual youth were not ready to return to in-person events due to the pandemic. In a recent meeting we hosted towards the end of last year, the youth shared with us that they did not necessarily want to learn how to adapt to the community this time.

They wanted to teach the community how to adapt to them. So the 2022 youth conference will be youth and family led at this time.

We will bring in our family led organization represented by Kiera Adams.

Carol Boo, as she recently got married to address a few of the questions we have. The first question is what opportunities do family voices of Tennessee provide where families can connect and build networks with each other? Family Voices actually provides many opportunities for families to connect with each other and build networks.

We comprised of six different programs obviously one included in our youth program.

But then we also have our parent to parent program.

We have our family, the Family Health Information Center program, our Peers Program, which focuses on parents that have kiddos that are deaf and hard of hearing. And then lastly, we have our Voices for Choices program which is our leadership program.

We provide trainings to those that really want to get more in the community on a stay, either on a hospital level or on a state level Our next question.

Does your agency offer any trainings geared specifically towards families We have a variety of different trainings that we offer to families and youth towards anything from leadership skills or how to be more proactive in your health care.

We have trainings on how to navigate our crazy health care system. We also have trainings and empowering workshops on leadership development.

Whether or not that you want to sit on a state council or whether you want to promote change by talking to your legislator I'm sharing your story in an effective way that can promote change. And in addition, we also have many training opportunities for our youth, whether we call them third space boot camps or our boot camps, are everything from how to be more proactive in your own health care.

How do you talk to your doctor and then how do you talk to your legislator about changes that you want to see in your state? So there's many opportunities for our families and our youth to get some type of empowerment or training to help them further along their journey. next question, Kara, explain your agency's role in the title MCH Block Grant Process

We as Jacquie mentioned before, we actually are very much involved in the Title five block grant process.

Not only are youth involved, but also our family members. So we provide a perspective when it pertains to the needs assessment going into the block grant process.

We participate in the stakeholder meetings that are held quarterly.

We also are actually written into the block grant.

This is where our youth advisory council comes into play.

And then also our parent to parent program. This program is where we're able to match families together that have been through similar situations. So we have a mentor that is trained through our training that they are able to provide that support for families that have maybe a new diagnosis or maybe they're experiencing something new within their child's care. Along the way, we also sit in myself, along with another family member, sit in on the block and the block grant review every single year. So I feel that the Title five and Family Voices, we're right there in the in it together, but we make sure that each of us has that relationship, that relationship that is that mutual beneficial partnership.

They really want to hear from the family voice, from the youth voice. And you feel that it's not just a token family member, so to speak, but it is really a hear an ear to listen to so they can make the best policies for the state of Tennessee.

Thank you for sharing that.

That's so important to hear from.

Kara, our last question, we're going to bring out the parents aspect of your life.

Can you share just a little bit about your role as a parent and especially as a parent who you've gone through that process of having a child with special care needs? What are the benefits of youth and family inclusion in the Title five program planning?

So can you share a little bit about your your process with CYSHCN and then to go into the benefits a little bit of what you see this question might make me cry

as my child just turned 18 is about to graduate high school. So as a parent this is obviously where we get to talk a whole lot about. But there are so many benefits that the list goes on and on and I could probably do a whole presentation just with that this one question. But as a parent being involved in a title, my process and being involved and just hearing our perspective, it offers us a voice. It offers not only for my family but for all the families in the state of Tennessee. And it is sitting beside me having a seat at the table, listening to our issues.

Our problems are sometimes celebrations, right?

So those are important too.

But it's ultimately we can't do anything. There's no policies, there's no procedures, there's nothing that can be done without actually listening and hearing from the people that are going through it.

And that is exactly what is being happened.

And that's a huge benefit because then we know that these things are working really well or maybe they're not working really well. And as a parent of a kid, with a special health care needs is still going to be a kiddo even when he's 40 years old.

Right.

You want to make sure that your child grows up to be a successful chief, grows up to be just aa n individual that contributes to society, but not only that, lives a long and healthy life.

So as we have a seat at the table and that they're listening to us and that they're hearing from what we have to say, that makes all the difference at the world, building these relationships not only with other family members but with people that make those decisions. That helps us and empowers us to really go out and sit on councils, really to go out and make a difference for the state of Tennessee.

There's still a lot of work to be done.

We have just made huge strides, and that's with the partnership and then having a seat at the table, being able to sit side by side, having that mutually beneficial partnership with with Title five programs and ultimately, because we want our children to live a long and healthy life and not

only want to live a long and healthy life, I want to empower my son to be able to speak up and be part of his own health care.

But not only that, to go above and beyond. Right.

So he hears me speak,

but it's one thing to hear a parent speak, and that's my perspective. It's a totally different perspective to hear my son speak because he is the one that is a person with special health care needs.

Right.

So he is the one that has a totally different perspective. He has a seat at the table and that has empowered him to go out and do so many more things that I never thought that he would do. It's empowered him to share his story and be proud of what he has gone through.

It's also gave him courage to talk to other kiddos just like them, to empower them.

This is all the benefits of just being having that relationship with outside of my program. And I'm just one family And family voices often say we serve thousands and thousands of families a year. So this is not only helping my family, but it's helping all of those families across the state of Tennessee.

And that makes a big, huge difference.

And sometimes it's hard to see that because you take one step and you kind of go backwards just a little bit.

But knowing that you just help make one family and one life to life, actually, not only the parents, but the child's life a little bit different and helping them along the way.

Makes all the difference in the world. I am grinning from ear to ear that that was the most remarkable.

You are a remarkable person and you do so much.

And we just want to say thank you for what you all do.

And being a partner with us Next, we're going to discuss building your blueprint.

Let's revisit a couple of our learning objectives here. We demonstrated how state Title five and family led organizations partner to empower youth and families.

We communicate at the importance of family and youth involvement in decision making process, and we exhibited benefits of including family and youth entitlement program planning to improve diversity, inclusion, health equity and disparity elimination.

Now it's your turn.

Let's create a blueprint for you to use in your state.

These next couple of slides. Mascara is going to guide you through some of the questions that we would like you to consider.

As she goes through the questions.

Feel free to post them in the chat box. We will have a live Q&A shortly after this presentation, where you can still voice your opinion there as well.

But we would love you to really, really think about these questions, how they can affect your agency, how they can affect your state.

And let us see those responses in the chat So make it a blueprint.

And Megan, it cuts to customizing it to your state. Some of the questions that you might want to ask are what is my role in family and youth engagement?

Why is my role important?

And let me just say that every person, their role is important and they have a tremendous place in in creating that family. And engagement doesn't matter if you're an employee, doesn't matter if you're a director, if you're a family, led organization, every single person matters.

And it's an important role to take.

Number two, what are my current partners and connects as you look across the state of your state? Obviously, there's many partners that you don't even think about even within your own department.

Right.

Those can really make a big difference in learning about what they're doing with their family engagement.

And who can I bring to the table?

So who will Maybe it is a useful person.

Maybe it is a grandparent who can give back a perspective that is so neat. It looks like other questions to consider.

How can I empower youth and family?

What can I give them?

What tools can I give them to empower?

How can they share effective communication?

And just let me say that as a family member and as a youth, our most powerful tool that we have is sharing our story. So how can you empower them to share a story that can create change, that can promote change? What decisions are being discussed at my agency we're using families can be involved.

How are you involving youth and families?

Do they have a seat at the table?

There's a big difference between checking out that list and then actually hearing and having that mutual beneficial partnership.

Understand that that shared decision making process. And lastly, how will family and youth engagement benefit my agency?

I think it's a no brainer, right?

I don't think you can go wrong by including family members and youth and in any type of this or even having a discussion about what things and what topics can be helped because you're getting a different perspective that you might not have had otherwise. So I don't think that there is a negative side of this only think about how can it benefit us and what ways can we use them effectively to help make our agency better

Thank you so much for sharing those questions with us again.

We would love to see your responses in the chat box. Cara and Kendra, you have done an awesome job this afternoon presenting how Tennessee intentionally engages our youth and not just our youth, but our families as we make changes in policy and procedures and just continue to keep that as a robust part of what we do in the maternal and child health space.

And in conclusion, I would just like to leave a couple of thoughts with you guys. And one is that, you know, it is vital for our agency partners and families to collaborate excuse me, in making decisions and especially those decisions that address their youth's unique strengths and their needs.

Intentional family engagement requires state and local leaders to model family participation anchored by a mutual respect. And as I mentioned before, a bi directional communication and shared goals.

Our adolescents and young adult

are in a critical stage of human development.

Their knowledge, attitudes and behaviors that are molded during this period will continue to endure well into adulthood.

And can be influential in their health and their well-being.

Often, however, youth are not involved. They're not integrated or prioritized when it comes to the various policies and programs that impact them. Tennessee is committed to providing a space and audience so that the youth perspective is recognized and integrated into the maternal and child health priorities.

Thank you so much for joining us this afternoon.

Next slide Jackie.

Thank you so much for participating in this presentation.

It's been a phenomenal experience

The questions that were the slide that you saw here we will use during the last session to take as many questions as we have time for regarding our presentation or any thoughts or feedback that you have.

And here is our contact information.

If you think of something that you don't necessarily feel comfortable sharing in large session or you think of anything after the conference, please feel free to reach out to us.