

Insights

Inviting and Engaging Family Partners in Your Work

by **Domonique Davis**, Communications & Digital Strategy Manager

July 20, 2023

Patient and family partnerships are an essential element of health equity. By supporting patient and family voices and encouraging space for collaboration, public health professionals can help ensure shared vision and values are at the forefront of determining solutions to improve a community's health outcomes.

The National Institute for Children's Health Quality (NICHQ) and the Florida Department of Health Office of Children's Medical Services Managed Care Plan and Specialty Programs developed a [Roadmap to Inviting, Engaging, and Including Patient/Family Partners in Quality Improvement and Other Related Initiatives](#).

Domonique Davis: Hello and welcome back to another episode of Before Birth and Beyond. This month we're going to be talking about family partner engagement, and I'm joined today by Kelly Edwards, a senior project manager here at NICHQ, who works on our supporting Healthy Start Performance Project and the Florida Children's Medical Services Learning and Action Network.

NICHQ Partners with the Florida Department of Health. Office of Children's Medical Services Managed Care Plan and Specialty Programs to develop and facilitate the Learning and Action Network. The Learning and Action Network have worked to improve family engagement and increase family professional partnerships.

I'm super excited to chat today with Kelly so you can share a little bit more about the project and your family partner initiatives. Thank you for joining us today, Kelly.

Kelly: Thank you so much for having me.

Domonique Davis: How did the Florida Children's Medical Services Learning and Action Network or Florida CMS LAN project begin including family partners in your work?

Kelly: Yeah, great question. Family partnership involvement was always a key component from the beginning, and one of the crucial pieces to that work was our team's partnership with our wonderful colleague at the Florida Department of Health, Linda Starnes, who herself, she's a statewide family leader with the Title V Children and Youth with Special Healthcare Needs Program. Her voice and presence at the table at this project was designed from the beginning and has been instrumental as we've really grown from the ground up and been influential in many ways, but especially as she's really had an impact on the continued inclusion of family partners that we're seeing now many years later since the start of this project. What we did in the beginning was focus on gathering information. So, we really wanted to understand who was in the network, what barriers teams were experiencing, a family partner, successes teams were having, what resources teams were aware of to help engage family partners. And so really all of that learning led us down a path of a handful of resources for our Learning and Action Network, specifically around family partnership and quality improvement projects.

Domonique Davis: Why do you think it's important and why have y'all felt it's so important in this project to engage with family partners?

Kelly: Yeah, it's truly so, so important. It has been one of our main goals of this project is to support the incorporation of family partners at the healthcare level as these teams are working on these quality improvement projects, and our team, with the Florida Department of Health team has. I would say we really, truly believe that family partners are the heart of the initiative.

They're why we're here, they're what we're doing this work for. And they should be really involved at all levels of the program and especially in quality improvement projects, which I think can be a little bit scary, like a little bit separate from other commonly projects that include family partners.

So that's why our real focus was how can we support teams bring, bring family partners in to this concept of quality improvement and the projects that are currently being done in our Learning and Action Network all have the goal of improving the care for children and youth with special healthcare needs in some way or another. So having individuals with the highest level of expertise, which is their continued lived experience, that healthcare system to help brainstorm, design, implement, and adjust these quality improvement projects, we believe that will undoubtedly improve their chance at making a real change in the clinics, in the hospitals and so forth. But really what we know because of what we heard and our experiences working with family partners and having them on our team as well in this design, is that it really takes authentic engagement and it has to be compensated appropriately, and it has to take into account the specific needs of the family partners that are working with you. And so that's why we've really done our best so far and continue to create resources in order to enhance that. We're excited to keep working with these family partners and see what other amazing things they come up with.

Domonique Davis: Linda, just wanted to ask you how you got started in family partner work and where your motivation comes from?

Linda Starnes: Well, my main motivation, it goes back a long way. My daughter is 30 and my son is 27, and they each have very different rare, genetic conditions and my son's actually is

ultra-rare, and they both had significant medical complexities at birth as well.

So that was the ultimate of motivation for knowing that I had to be in partnership with the healthcare system because we covered 15 different subspecialties or therapy activities with our children at the time that they were kind of the height of all of their needs. We had to be a partner or they were not going to thrive. It started in partnership. Direct care and shared decision making with the care teams that we were working with. I had also been a special educator as my very first career. And I knew the needs of families already from the educational side, having been a special educator and encountering those needs. It's all kind of wrapped up together. The whole child, they needed to be as healthy as they could be in order to be a part of the rest of the community and educational system. So, I started offering services to be on different boards and committees that were related to healthcare or to disability in general, and that has grown ever since.

So, I've sat on a variety of different boards and councils and work groups from the national level to the local level. And with that came the opportunity after my children were grown and I could consider possibly stepping back into the workforce. And that's when I met Johnny Hollis. It was just one of those coincidence moments. And we realized there was an opportunity, so I started working with the [Florida] Department of Health about three and a half years ago. And I am their statewide family leader for the children and youth with special healthcare needs.

Domonique Davis: That's fantastic, Linda. Why do you think it's so important that we get these connections and collaborations made and built engaging with our family partners?

Linda Starnes: Well, family partners are living it 24/7 and as much as a physician, or a social worker, or anybody else within the healthcare system thinks that they might know. Unless you truly have that 24/7 experience day after day, week after week, keeping up with all of the ever-changing situations that come with children with disabilities and complex care, you really don't know.

You do not have that in the trenches, boots on the ground perspective, you haven't pulled the all-nighters that I've pulled, I guarantee. When nurse didn't show up for nursing duty, cause our son is a ventilator graduate and he has a G-tube and a trach even as an adult, I became the nurse on duty. Every time. And it happened way too often.

So, we have extraordinary experiences, and we have those experiences from office to office to office to have comparisons of, "they really do intake so much better than this office, I wish this office did it better." I had the experience of comparison that some of our providers might not ever get to have. So, I come with a lot of information when I'm in a meeting, whether it's for direct care for my child back in the day. They're now grown and they're handling their care for the most part, all on their own. But also, in partnership with, at a clinic or a systems level. I also come with other skill sets. I mean, I was trained as a special educator as my first career. I worked for the federal government. Some of the highest levels that one can work. So, I've got a lot of other experiences that can also support a lot of collaboration and mutual learning in that give and take.

Domonique Davis: Somebody who's starting out an organization, who's trying to really engage family partners, how do they start? Where do they start?

Linda Starnes: Well, it starts with relationship. It always does. And trust building. What we recommend with the clinical groups that are working with us on a statewide quality improvement initiative with NICHQ as our partner, we say start small. Having those kinds of conversations with families that seem receptive and engaged in the direct care of their child and that maybe would like to consider taking the knowledge they have a little bit forward to help the clinic be a better clinic for all the families that they're serving. Sometimes that's a one-on-one conversation. Other clinics take it in a different way and have a little application process of, would you like to be a part of a work group? Here's what we're doing. If you're interested, just fill out a simple application. There's a lot of different ways to let families know we need your help, we want your help, your viewpoint is important to us, and it will help us be better. There's a lot of families that would resonate with that if they were made aware that that's a possibility. If clinics were truly authentic and welcoming them and hearing their voice and including them from the start. One thing not to do is to create a tool for families or a new policy or any other type of process or resource that you have in your clinic and get it all put together and show a family and say, we'd like to collaborate with you. What do you think about something we just put together that we think is really great?

That's not going to elicit the best response. What if I don't like it? But I don't want to hurt your feelings. I don't want to harm our relationship and tell you I don't think it's any good. If you had had me in the beginning when you started the process of figuring out what it is we think could help families, that's when I really need to be working with you, and all the way through. That's when I can be of the most benefit as well, and you end up with a much better product that's going to be helpful for families.

Domonique Davis: How has it been communicating the importance of family partner engagement and what's the reception like with the healthcare community, and how do we get them on board?

Linda Starnes: Well, it's as varied response as there are people in the healthcare community. Because there's just different aspects of experience of if they've ever been exposed to this idea of working in tandem with a patient advocate or a family advocate. If that's never been a part of their experience in their work life, I think there's some hesitancy. I think there's some bias in all honesty, because, no, I don't have a medical degree. I don't speak medical language and acronyms, but that's why you need me there. Because I come from a completely different lens. If I spoke and thought just like you, it's not going to help you. That's where I can be of benefit.

You need to think about, okay, how do we make that family partner feel like they truly are included in our team as we work on a project or an initiative together? Yes. You have to be thoughtful. You have to be welcoming. It's not like a colleague coming in who can sit down and start on a conversation with all the jargon that's flowing. You need to do some preparatory kinds of things so that they feel like that they will be able to understand and engage with your team. But, it can be done. There's a lot of resources out there now more than ever for being able to learn. What are some steps to include diverse voices. We don't just want the one older white mom who's already been through it. We need the younger Hispanic mom. The dad who's maybe interested in and wants to engage, and dads are far and few between in this world that we work in, but very necessary and needed. In different geographies, different conditions, depending on your clinic. You have to think about the diversity of it too, cause I can't represent everybody. I

have a heart for everybody, and I want all families to have the best care for their kids. But I am clearly not representative of all of those voices. So you want several.

Domonique Davis: I know there's a network that's being built. And that's a big piece of making this a model that's scalable. What are the next steps for this network and what do you see for the future of it?

Linda Starnes: Well, we've developed a roadmap that NICHQ has helped to promote. And for anyone listening to this, I would say do look at it. It gives information specific to quality improvement initiatives, but it really could be spread to other kinds of initiatives, not just quality improvement activity.

But also we have been having kind of networking meetings with the family partners that are already on board, and then we also try to bring all those voices in at different times during our monthly sessions with learning sessions with the whole group of the 31 clinics that we are working with across the state of Florida, so that we'll have different family voices besides mine who are heard, those who are at that local clinical level to other people who work at a little bit more of a regional or state level as well.

Then also, I'm proud that Florida and my program, I started something called the Florida Family Leader Network, and we are about 250 strong now. It's been an organization that got established about five years ago and we fund the coordination of this so we can collaborate and network, and we also have the champions in the world of healthcare and academia and public health who are people that maybe work professionally, but they so appreciate this aspect of family leadership that's unfolded into the world of public health and healthcare. And we also have champion members who are working alongside with us on this network. So, Florida's a little ahead.

Domonique Davis: Antoshia Reed is a member of this family partner network. She's an advocate for her 14-year old daughter Rani, and used the lessons she's learned in carrying for Rani to help improve the Florida healthcare system for other children living with special healthcare needs. Getting started, I'd love for you to introduce yourselves.

Antoshia Reed: All right. I'm Antoshia Reed.

Rani Reed: And I'm Rani Reed.

Domonique Davis: As a family partner you bring an interesting perspective, just talking with Linda, we talked about the importance of having voices from diverse backgrounds. What kind of challenges do you have to navigate through this system and how are you lending that perspective as a family partner?

Antoshia Reed: When they say about, well, with a Black woman, you know, you may have had to do extra and do this or whatever. I guess because of my mentality and then my makeup, meaning I'm a go getter, meaning I'm not going to sit back. You don't have to motivate me. So, I'm actually going to go and reach out and do, and that's what I learned that I had to do for my daughter cause when she was born, The nurse in the NICU that I met that took care of my daughter, she told me, she said, "you going to have to be your daughter's advocate." I didn't

know what that meant. You know? I'm just like, oh, okay. Oh, whatever. But not realizing that means like the lawyer, you're going to have to be her lawyer. You're going to have to be everything to make sure that the care that she gets is top. So, for me it was that made me be more not scared to ask, not scared to reach out, not scared to say hey, and to get a lot of resources. If anything, that was probably the learning curve for me and being able to be like, okay, y'all are going to do this cause this is what my child needs. So, however y'all need to work that out.

Domonique Davis: In terms of, Rani getting older, how do you see the passing of the guard as she starts to handle her own care, and how do you prepare her for being her own advocate?

Antoshia Reed: She started; I think third grade. She was starting to catheterize herself. So, I started a little bit early when I saw that she was going to be responsible enough.

So, when we did that, it was starting to free me up. Cause you get burned out, you know? So now she does everything herself. Now, what Dr. Panzorino is including, even more, she used to bring it up in our meetings is, "So Rani, your next appointment, I want you to be able to tell me all your medicines." I actually take a sheet that I printed out with all of her medicines and all of her procedures that I take to each doctor's appointment, cause I can't remember all that. So, I made her a copy, and now she carries it in her wallet. When we're there together, she'll ask her, "okay, Rani, let's go over your medicine." So, I'm learning how to step back when we're in appointments and just hush. Let her answer first. If she doesn't know, she'll look at me and say, mom, you know, and I will. So now we're transitioning into the medicine where she wanted her to learn how to do her own prescriptions through the website. So, I told her I'm going to be working on that cause it makes sense with the transition I'm going to write that down. Because I'm one of them ones. We are going to go and have a conversation with these doctors. That's been my support system. No lie. Not even, I'm not going to lie to you. Not even family. It's very minimum when I say family. But it's okay cause it's something that I had to adapt to. What am I going to do, I'm going to cry over it and then I'm taken away from doing the care that I need with my daughter.

Domonique Davis: I think folks are starting to be more receptive to family partners and even though, may not be trained in the medical profession, really respecting your opinions and your voices. What has the experience been? How has it changed throughout the years?

Antoshia Reed: I would say, being able to have the relationship that I have with her, I keep saying nephrologist because she's my go-to. Because if something goes wrong with that kidney. That's the main thing right now that we deal and keep trying to make sure it's good and stay good. I would say by having that rapport with her and then being on that team, the CCKFC at first, I'm gonna be honest with you, I was attending all the meetings. But I felt like for a while, I was just there. I ain't know where I would fit in. I ain't know what I should be doing. Even though they was telling me it still wasn't clicking. And I'm like, okay, I don't wanna not come on here, maybe it's coming. You know, just stick it out. Stick it out. And I'm so glad I did because when NICHQ asked me to present my daughter's story, that was the open up for me. It was like, Oh, okay. You want me to do who and what? I was so nervous, but I knew it was of preparation for what we do also in our own community. So, I was able to do that. And then, because they already had the project they were doing in our group, I really didn't have much of an input from the start. If I'm not there from the start, I get a little confused on, how do I fit in? I can give you

my opinion. Also, where they say, well share some of your daughter's history and your take as a parent. And I'm like, that gets old after so long. So now I'm like, what else do I do with this group? When they just started a new project, that's when I was able to be like, now it's my turn. We're doing a parent guide for kidney transplant. And I did the voiceover. I was able to do that and be able to understand that if I had this tool before I went through with my daughter, this would've helped me in so many ways.

Domonique Davis: In terms of, Rani getting older, how do you see the passing of the guard as she starts to handle her own care, and how do you prepare her for being her own advocate?

Antoshia Reed: She started; I think third grade. She was starting to catheterize herself. So, I started a little bit early when I saw that she was going to be responsible enough.

So, when we did that, it was starting to free me up. Cause you get burned out, you know? So now she does everything herself. Now, what Dr. Panzarino is including, even more, she used to bring it up in our meetings is, "So Rani, your next appointment, I want you to be able to tell me all your medicines." I actually take a sheet that I printed out with all of her medicines and all of her procedures that I take to each doctor's appointment, cause I can't remember all that. So, I made her a copy, and now she carries it in her wallet. When we're there together, she'll ask her, "okay, Rani, let's go over your medicine." So, I'm learning how to step back when we're in appointments and just hush. Let her answer first. If she doesn't know, she'll look at me and say, mom, you know, and I will. So now we're transitioning into the medicine where she wanted her to learn how to do her own prescriptions through the website. So, I told her I'm going to be working on that cause it makes sense with the transition I'm going to write that down. Because I'm one of them ones. We are going to go and have a conversation with these doctors. That's been my support system. No lie. Not even, I'm not going to lie to you. Not even family. It's very minimum when I say family. But it's okay cause it's something that I had to adapt to. What am I going to do, I'm going to cry over it and then I'm taken away from doing the care that I need with my daughter.