

Contents

Proem 00:54 1

Introducing Nikki Montgomery 01:33..... 1

Patient-caregiver member on Board 04:43..... 2

Story collector 08:29 3

Keeping fingers on the pulse of an organization 11:21 4

Building coalitions on a board 14:54 4

Begin the board relationship 16:42 5

Recognizing success 20:07 6

Continual safety and equity 24:18..... 7

Sustaining the gains and then some 25:32 7

Leveraging privilege 26:57 8

Reflection 30:28..... 8

Proem 00:54

As you know, I’m on the Board of Governors for PCORI (Patient-Centered Outcomes Research Institute). The view, the possibilities, and the levers of power are different in a Board seat than in an advisory, leader, or staff seat. I’m gaining my sea legs, building trust, relationships, and learning about strategy, dashboards, and figuring out how to best support staff and leadership from my perch.

Introducing Nikki Montgomery 01:33

I met Nikki Montgomery a couple of months ago when Dr. Knitasha Washington and Desiree Collins Bradley, and Hala Durrah interviewed us together about the practice of equitable, patient-centered measurement. A collaborative partnership had been formed between the [American Institutes for Research](#) and [ATW Health Solutions](#) to examine equity, diversity, and inclusion within patient-centered measurement. Meeting Nikki, I realized I was in the presence of something special. Nikki Montgomery is the executive director of [Madvocator Educational & Healthcare Advocacy Training](#) and the author of the [Super Safe Kids](#) patient safety book series. Nikki is a patient advocate, hospital board member, and the past president of the [Patient and Family Partnership Council at University Hospitals’ Rainbow Babies & Children’s Hospital in Cleveland, Ohio](#). She is also the project coordinator for The [Beryl Institute’s Patient Experience Policy Forum](#) (PXPf) and serves on the [Global Patient and Family Advisory Board](#). As the parent of a child with complex medical needs, she has spent lots of time in healthcare settings and is interested in improving equity, engagement, and communication with patients.



<https://www.health-hats.com/pod110>

Health Hats: Nikki. Thank you so much for joining me. I appreciate this. I'm excited to have this conversation because I don't know many patient-caregiver stakeholders on boards of larger health organizations instead of being on an advisory panel. Why don't you start by introducing yourself to our listeners?

Nikki Montgomery: Thank you for having me. I'm Nikki Montgomery, a patient advocate. I came to patient advocacy because of my role as the parent of a child with complex health needs for the last nine years. Also, because I was raised as the sibling of a person with complex health needs and a disability, I came into that role doing advisory groups first and was later invited to join a board. I've been happy to contribute in that way because I also don't know that many people who can do that. But it's a lot to navigate sometimes, too. Especially for me because my child is receiving care at the place where I'm on the board. There's some complexity there. I enjoy the journey of learning how to do this better. I don't think it's a given. There was no blueprint. I was the first parent invited to a board at our hospital. I'm still trying to figure out what that path should look like.

Patient-caregiver member on Board 04:43

Health Hats: That's interesting. Being invited versus inviting yourself are different paths to being on a board. How did it happen that you got invited?

Nikki Montgomery: I was president of our Patient and Family Partnership Council. I served as vice-president for two years, then president. During that time I spoken at management forums. I did a lot of things in the hospital in a teaching way. I think that probably got some attention from people who were leaders in the hospital. I also have an academic background. I think that instills some trust in a way that not everyone has the privilege to be able to do. I have a bachelor's and master's in English. I have a master's in educational psychology with research focused on engaging medically complex children's families. I also have a graduate certificate in patient advocacy. On paper, I look like the kind of person you might want to invite to your board. I would love it if every person were the kind of person you could invite to your board. I would love to see doors open in that way. But honestly, I feel like that played a big role in my invitation. The hospital turned a corner in how they viewed patient safety and patient experience. They saw the value of having a patient or family member on these boards. That all converged as I was playing a leadership role in that institution.

Health Hats: Were you invited by the CEO or the Board Chair?

Nikki Montgomery: The hospital president invited me.

Health Hats: Wow. Okay. When leadership thinks of patient-caregiver engagement at a leadership level, that shows self-confidence.

Nikki Montgomery: I think so. They wanted to be open about their processes. It shows transparency; it shows engagement and all of those different things and solutions for patient safety as an organization that many Children's Hospitals are involved in. They give you a little extra bump in your status, in their network when you have those involvements on your board and safety and quality committees. I know



<https://www.health-hats.com/pod110>

that plays a role when hospitals see it as something important for their status for safety. I think that's part of the reason my hospital invited me as well. They wanted to engage a patient in a meaningful way, according to those standards.

Health Hats: Being a first, as you were saying, there's no blueprint. There isn't an orientation or a mentorship program, or job description.

Nikki Montgomery: You get the board orientation. If you've been on boards before, it's familiar. There's no template: this is how family members should be interacting in this space. Often, boards are made up of donors and other community partners and community leaders, but I didn't come in with that kind of role. For me, it was hard to figure out where my voice should be applied and how I could use the template of how we worked with our Patient and Family Advisory Council when we would have leaders come, and we'd ask questions and understand what their roles were. I used that as a template, but I was pulling from my own experience, not from any training I received on how to do this well.

Story collector 08:29

Health Hats: As a family member engaged in leadership, you can come from the point of view of your experience with a child in this system. You can come from the point of view that you are a passionate advocate for health equity, and you're thinking about system issues with the personal experience perspectives.

Nikki Montgomery: I see my role as a story collector. Not just me sharing my own experience, but me having experience with other families and sharing their experiences too. That's part of it, not just my story. It's a collection of stories I bring to the table. Looking at it system-wide, I see how any gaps would affect those families whose stories I know. In a systemic view, I want to know how the families I know will navigate any changes that we see in policy and what the obstacles are going to be for them.

Health Hats: Wow. I love that 'collector of stories.' You meant that pretty literally. It's not just that you're filing them away; you're bringing them up. You either share them or you invite somebody to share.

Nikki Montgomery: Yes. I have a background in literature that comes naturally. I want to know the story. I want to know where the pitfalls were in that story because focusing on those pitfalls shows where the work needs to be done. Anything that causes that family additional stress or harm, those are the areas where the work is needed. When I talked to multiple families in a system and visit hospital floors before COVID and talk to families, those are stories I'm gathering. I understand more largely what happens with experiences like in the institution and what safety is like. Those are the stories I want to bring to the table when it's time to discuss even a new facility. Will your new facility have bathrooms that are accessible to people who have adults with disabilities? That's something that has come up in our meetings and come up in my interactions to bring that to the table. Those small experiences that I can gather from other people are ways to integrate into the policy discussions.



Keeping fingers on the pulse of an organization 11:21

Health Hats: Sometimes, boards review a dashboard. Whether the dashboard is about perception, finance, access, or publicity, there's the linking of metrics and how we keep taking our pulse. We take a pulse on how the organization, the system is doing and bringing in stories to put meat on the bones. They inform the statistics. How does that work where you're sitting there listening to stuff or reading stuff?

Nikki Montgomery: I'm fortunate to work in a system where I feel like there's some excellence in getting to the details. I love that when we're talking about a medical error, for example, there is a discussion of that individual error, of what individually caused that, what systemic changes need to happen. That gives me hope. I got into this work because I want to see how the sausage is made. I want to know that my voice is represented at these tables. That is why I wanted to get involved. Sometimes without my voice in that room, my experience would not be represented, which is the reason I continue to enter all these different rooms as I have opportunities. That kind of role means that I have to think about the dashboard and think about the people who make up the dashboard numbers. I love seeing when they take such a granular approach to handle errors. When they take a granular approach to handle any conflicts or difficulties that says to me, you're looking at these as individual people too, and not just a roundup of numbers. That's reassuring when I see that. I've been fortunate to serve on patient and family advisory councils now at two different hospitals, a quality committee at one hospital, where we talked about those errors that happen in medicine and being able to be transparent about that and really dig down into why this happened to this one child. That has renewed my faith in the process that when a child enters the system, he's not just a number.

Now a word about our sponsor, ABRIDGE.

Use Abridge to record your doctor visit. Push the big pink button and record the conversation. Read the transcript or listen to clips when you get home. Check out the app at abridge.com or download it on the Apple App Store or Google Play Store. Record your health care conversations. Let me know how it went!"

Building coalitions on a board 14:54

Health Hats: This issue of having influence is partially about your individual action at the board meeting, the homework you do to prepare it for it, and there's the factor of building coalitions within the board. How does that happen? What are your relationships with other board members?

Nikki Montgomery: This is the part that has been most difficult because of COVID and just difficult in general. In my board group, I'm the only woman of color. I don't have a kind of group of people that have the same life experiences I have. There are people from different classes. A lot of them are donors and business owners and things like that. That's been a challenge for me to figure out how to build those coalitions. I think everyone understands my role. I think they appreciate that role, but in terms of really



<https://www.health-hats.com/pod110>

working on things and maybe meeting outside of the board meetings, I have not been able to figure out how to do that and manage the rest of my life.

Health Hats: Yes. It's a commitment.

Nikki Montgomery: It is. That's more difficult for me in general. I want to get more of those relationships. I want to understand how we can work together. I don't feel like I'm running into problems in voicing my thoughts and the patient population's needs. I don't think I've done that well enough to give advice on it. Honestly, I that's where I'd love to grow.

Begin the board relationship 16:42

Health Hats: What advice would you give organizations that are wanting to put their toe in the water?

Nikki Montgomery: Mentorship and training. Anytime you walk into a new job that no one's ever had before, I think you're creating a template, and you depend on the strength of that person to create the template. Ideally, this is something that systemically we prepare for, and we don't leave them to navigate it on their own. When I first started, I met with the president of the hospital individually. She invited me, told me what my role would be on the board. That was a good move. There should be periodic check-ins at least once a year to say, what are your goals for this year? Here's how you can grow your contribution. I think that has to be treated almost like an employee relationship in some ways because this is a person you're giving trust to I would love to see the structure behind inviting family members to a board so that they know what their exact role should be, so that they know where their contributions are going to be most valued and so that they can focus their own efforts. Then how some of the simple stuff that I wouldn't know without my business background. How do you prepare for a board meeting? You get this giant packet of stuff. If I had not had background experience, I would not have known what to do. We have to broaden who we invite. It can't always be your gold star patients, your patient who seems to stand out for education or communication. Sometimes we should be inviting a broad swath of our patient population. It is a privilege to do this role, but it shouldn't require privilege to do this role. Those are the things I'd like people to think about as they embark on that journey.

Health Hats: Turn it the other way. Say that you're advising somebody who has an investment in an organization because they make use of it, and there's something that they admire about it. They want to get involved at the leadership level, which is different than being on an advisory council. What advice would you give to that?

Nikki Montgomery: I talked to parents about this all the time. Parents often navigate multiple systems. Sometimes they feel lost in those systems. They feel lost, or their voices are not at the table where decisions are being made. I encourage families to invite themselves to those tables. If there's an organization that's serving you well, or you feel like it needs to be serving you better, ask how you can get involved, ask what leadership roles are available and then ask about that board. There are some barriers to being on a board that are financial. Suppose there's an organization that you want to join and have a financial commitment that's required to be on boards. In that case, that happens more with



<https://www.health-hats.com/pod110>

community organizations and hospitals - but asked for a waiver of that to join this body help to guide it. Family voices are tremendously valuable. We know that and inviting family voices into those spaces should be practiced, but I think families need to pull up a chair when it's not.

Recognizing success 20:07

Health Hats: I'm going to circle back a little bit. How do you recognize that you've been successful in influencing health equity in your organization?

Nikki Montgomery: Right now, the way that I'm trying to go about that is by bringing it up at every opportunity possible. I'm successful when I don't have to be the voice bringing it up.

Health Hats: Oh. I like that. One of the challenges about measurement is often the measuring is more work than the value of the response, what you get out of it. Y you're not assigning anybody work. Collect this data for me. I like that a lot.

Nikki Montgomery: My goal is that multiple voices speak for the things that I find important. I said before about wanting to see how the sausage is made. Part of the trouble with building trust with healthcare is knowing that you're not represented in some way spaces. When I feel like that representation is not necessary, it will be because the values I have are infused throughout the system that they don't need to be brought up by someone with my face and my experiences, but that they will exist independently. So that's my dream for healthcare.

Health Hats: Wow. What should we have talked about that we haven't?

Nikki Montgomery: Maybe the politics of getting care in a space and being in that space as leadership as well. I've had great experiences, but many of my experiences are colored by the fact that people where we're getting care know who I am. That's a weird feeling. I remember being able to be a secret shopper before. I'm not a secret shopper anymore. I love that my experience is great, but the thing that brought me into this work actually was my son was in the NICU for two months or in the PICU for two months., trached, ventilated, all that stuff. I slept in a chair in the PICU for two months, and I would see these nurses come in and have a great experience and conversation with us and all of that. They would then go two doors down to a super frustrated family, and that family would not get the same kind of attention and care. That was the inequity that I could see right in that space that brought me into this work.

I thought it's great that I have a great experience. I'm concerned that families who don't know how to navigate don't get the same experience. So ultimately, my goal is that everybody gets that kind of care. I'm not able to see that from our ground. Even at my own hospital, we had a safety incident that happened. It happened when I was on the board, and it shook me like I know the place is safe. I felt like it was safe. I was on the Safety Committee, I was on the board, and it made me realize that no matter how much involvement I have, that doesn't guarantee safety for my family. So it was an interesting experience. In some ways, the hospital was probably concerned about my thoughts and potential actions surrounding that safety experience. I think they handled it well. Let me talk to who I needed to



<https://www.health-hats.com/pod110>

talk to. I asked for meetings with the people I felt like I needed to meet with, but it also showed me again that I knew the pathway. I knew the people to talk to, to resolve my issue. That's another level of privilege created that is not accessible to everyone. I feel like that navigation is so hard because I'm navigating the system as a patient and family member and trying to protect and uphold that institution on the other side. That creates a different balance in what I'm going to do in response to something like that.

Continual safety and equity 24:18

Health Hats: Wow. Wow. That's so interesting. One of the things I pull out of what you just said is that with safety or equity, you're never there and done. It is a constant. It's what we're dealing with now with democracy. Democracy takes work; it takes work all the time. I feel the same with safety and equity. You can have a moment of celebration. But then it's like back to work.

Nikki Montgomery: That work is never done. It requires constant maintenance.

Health Hats: Oh, it's exhausting.

Nikki Montgomery: It can be. I have a goal in mind. I want my voice to not be required in this space. I'd like to work myself out of a job here. If I do that, then I hope I won't feel exhausted. Sometimes that can feel like a heavy lift, but I also see it as a privilege to be in a space to influence these things. I can have discussions that patients have never been able to have before. So, it does feel historic in that way, too.

Sustaining the gains and then some 25:32

Health Hats: One last thing then, will you just so how is the organization preparing itself to add another member or have a member when you've had enough?

Nikki Montgomery: I don't know that's happened yet. I'd love to see a plan of succession. And what I'd like to do is see it happen the same way it did for me, where the Patient and Family Partnership Councils leaders are able to step into that role. That would be an ideal way to continue this for now, but I'd also like to see that broader. I'd like to see family members who don't have multiple degrees on this board. I'd like to see a lot of, a lot more diversity in that space too.

Health Hats: It's a lot of work to figure out the right fit. There are many levels of engagement. There's engagement filling out a survey. There's the engagement of being on a board. Those are really different and then whatever in between. So figuring out that the right sizing of that and the capability of the organization to work with people that aren't credentialed up the wazoo,

Nikki Montgomery: There's a balance. Some people are super capable, super insightful who don't have a ton of degrees. Those people exist. There's a middle ground here. That's what I'd like to see. I know plenty of brilliant people who have a mind for this kind of work but who don't have a ton of degrees. And I would like to see at least that opening happening,



Leveraging privilege 26:57

Health Hats: I'm a man in nursing. My first nursing experience was at Wayne County Community College School of Nursing in Detroit as a quadruple minority. I went to school with middle-aged women of color. I was a white boy from the suburbs. I really learned a lot. It was a great setting for me. I knew how to study, and they knew about life. Putting those together in terms of education changed my outlook on health and they passed because we had study groups that they hosted and cooked. I ate well. Now, my brand is Health Hats. I'm a person with multiple sclerosis; I've been care partner to several family members. I'm a registered nurse. I've been in the C suite. I've led EHR implementation. People like to use me because they can check off a lot of boxes. There was a time when I felt bad about that privilege. Now I think it's a different kind of privilege, and what am I going to do with it? I got it. So that's the way it is. I don't get any mileage out of feeling bad about myself. What am I going to do with it? It's fascinating.

Nikki Montgomery: I identify with that feeling. My job then is to hold the door open for the next person. I fill that space in a way that makes it easy for the next person to come in. I don't feel like this is necessarily the work that I'll do for the rest of my life. I'm enjoying it. I'm learning. From it, but I want to usher in more voices. Our Patient and Family Partnership Council had two people of color on it when I joined. Now it's about half and half. We still have other kinds of diversity we need to get. I think it's interesting that all of our moms of color almost all have master's degrees and are married. There is a lot of diversity that we still need to seek. I'd love to see more of that. I feel like adding those voices makes such a richer conversation, and there are things you're going to miss when you don't have representation from these different groups. I'm starting at those council level and advisory councils and moving on through. We need to have more voices of the people that are being served. That's what I have a passion for: making sure that those people get connected.

Health Hats: Nikki. This is great. Thank you so much.

Nikki Montgomery: Thank you. I appreciate your invitation.

Reflection 30:28

"Leadership is the art of giving people a platform for spreading ideas that work." --Seth Godin

As a student of organizations and leadership, I appreciate the opportunities and challenges of the scarce and evolving roles patients and caregivers fill on healthcare boards. Nikki describes her function as a story collector. Stories and a buck and a quarter will buy you a Pepsi. It's not sufficient. Nikki's also a translator, a spreader, and an integrator. The stories she collects motivate action, action by the board and the organization. It's no mean feat. My hat's off to Nikki Montgomery. We have much to still learn. Do you sit on a healthcare organization's board of governors or directors? Reach out to me at info@safeliving.tech. Have you gotten your vaccination yet? How did that go? Let me know. Same email address.



<https://www.health-hats.com/pod110>

I recommend a YouTube series by my dear friend, Fateemah, [Thriving with Sickle Cell](#), dating, marriage, babies, and more. Fateemah and I worked together for several years, bonding over management of chronic illness, family life, bowties and hijabs. Check out Fateemah [here](#)



<https://www.health-hats.com/pod110>