E05-pbb Stop Talking! Equity begins by listening

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SPEAKERS

Madge Kaplan, Paul Batalden, Sonja Batalden, Diane Banigo

Madge Kaplan 00:00
Welcome to the Power of Coproduction, a podcast series that explores the lived experiences of patients and professionals who are redesigning healthcare service to achieve better health through mutual respect, collaboration and science-informed practices. Your host and guide is Paul Batalden, professor emeritus of the Dartmouth Institute for Health Policy and Clinical Practice, and a guest Professor at Jönköping Academy. The Power of Coproduction is produced in partnership with the International Coproduction of Health Network (ICoHN), the Dartmouth Institute, Jönköping Academy and the Health Assessment Lab. On Episode Five, “Stop Talking! Equity begins by listening,” Paul is joined by Diane Banigo and Sonja Batalden. They've designed a pregnancy center for African American women in Minnesota called the Diva Moms Program. In this instance, awareness of historic racial inequities with access and care, magnified by the women's stories, inform and deepen new processes and the coproduction necessary to create equity and respect. Here's Paul,

Paul Batalden 01:13
Welcome. Our guests today are Diane Banigo and Sonja Batalden from St. Paul, Minnesota. As creative nurse midwives, they have developed an innovative program that supports pregnant women of color. We're interested in hearing what you have created and how you did this. Thanks so much for being with us. And welcome.

Diane Banigo
Thank you.

Sonja Batalden 01:36
Thanks for having us.

Paul Batalden 01:37
So why did you develop this program?

Diane Banigo 01:42
I always say Sonja, you were there at the beginning, before you brought me on. So I always like to have you start.

Sonja Batalden 01:47
I think that the disparities and the inequities and outcomes for African American women during childbirth and for their children are one of the biggest crises in health care right now in our country. And they've been long standing, and they're not getting better. So it's time to think outside the box and jump in to try and address these issues.

Paul Batalden
How did you start?

Sonja Batalden
So this started when there was a call for proposals to work on this issue, as a lot of people were starting to think about it. And our organization came to me because I was the director of the midwife service and said, “Sonja, would you help us design this?” And I said, “You know, I don't think I'm the right person to do this.” We, if we're going to be serious about this, we do not need a white woman leading this effort up. We need to have somebody from the community, and who truly understands these issues in a different way. So this is close to my heart, I want to work on this. But if you want to do this, and we're going to design something, then I want us to reach out to my friend, Diane, so that we can work together on this. That's sort of where this actual project began. And then I'll sort of pass the ball to Diane to talk a little bit about how we went about building the program that we did.

Diane Banigo 02:59
So when Sonja reached out to me, it happened to parallel well with some work that I was doing for my doctorate. And so Sonja had also gathered some information about the patients within our systems. We wanted to make sure that we connected with the women to hear how can we create a program that really worked for them. And so we created a small team, and we started listening.

Paul Batalden 03:22
So you began by listening!

Diane Banigo 03:25
Yeah, I met Sonja when she came in to cover my maternity leave with my first son. And so I had been with Minnesota Community Care, then West Side for several years, and so had established good relationships with some of the women. So it was nice to reach out to some of the women that I had birthed years ago, and ask them would they come in. And so we created a listening session or focus group, and we had people from the community just come and tell us their story and how they had experienced health. And then we used that information that we gathered to identify some things and then address them in new ways to deliver care.

Sonja Batalden 03:58
I think one of the things that's so key and what Diane was just talking about is that longevity and trust and relationship, because it's more than just calling together a focus group. One of my favorite theologians talks about “hearing people into speech.” And if you cannot create a space where you can make it safe for people to talk to tell their stories to say what's going on, then it doesn't really matter if you get everybody into the same room, you've really got to have a safe space and a trusting place to do that.

Diane Banigo 04:28
You know, that's something that's been missing in, and disguised in healthcare. And so there's definitely something about history and depth in relationships, and trust. And so we were able to leverage some of that, that we had with the community. And even you know, the people that we had on our team, our patient navigator was someone that had worked with, you know, the community and so we have had to be intentional about who we invited to be a part of this team to break this ground.

Paul Batalden 04:56
So what did they tell you?

Diane Banigo 04:57
We heard a lot of different things. We approached it from a clinical perspective, we approached it from barriers to actually getting care, we just asked a lot of different questions. But essentially, what they affirmed is that racism is real, that they feel invisible, invisible in the system that they find themselves in. And a lot of times they prefer to do without care than to be mistreated when they show up. Most of them love their actual midwives, but they didn't like the system that they had to access to get them. And they just didn't feel “seen”. So they felt invisible within this health system that's supposed to be there to serve them. Sonja, what else?

Sonja Batalden 05:30
When I think about it, it's just like this multi-layered impact of racism from our culture. And you hear that in their stories from how they feel when they walk in the door, who's the person that has the job behind the desk, who's the person that has the job rooming them, who's the person that's the provider, and all of those things matter and shape their care. And some of those things are so deep and long standing that are barriers, really shaped the way people experience their care, make them decide either they feel comfortable or welcome to come into that clinic or to access care or not. Do they feel heard? Do they feel seen? And then that impacts all the way down the road.You know, do they have transportation to get there? Do they have a stable job that would allow them to have the transportation? Do they have a safe place to sleep? Do they have a safe relationship, all of these things that really, if you start to really listen to people, what’s shaping their well being and their health, it's all of those things mixed together and so many different layers.

Diane Banigo 06:30
And to add to that, like even who the system allows to be with them on their journey. I remember one of the comments about who was able to be in the room with them during their birth. And the comments that were being made when you thought they couldn't hear you about, you know, them or their people,

their support people. And so a lot of times, the women also expressed a feeling; it wasn't something tangible that they can touch or see. But they just they didn't feel welcome. Or the body language and nonverbals. And so like Sonja said, it's definitely multifactorial in their experience. And so what we learned is that care extends beyond the clinical room. Care is something that is an experience and not an event. And so we tried to make sure that we tailored the experience in a way that celebrated them, and gave them permission to utilize their own voice after we talked about some of the things that they maybe needed to know to make better decisions, or more informed decisions.

Sonja Batalden 07:28
Diane, I think about that, just even that thing of what it looks like who they want to be there in their care. And I think of so many ways in which we, in unspoken ways, set up parameters for how people should show up in labor, for example, because the way you should do it is you should have a partner who preferably you're married to, who is really polite and supportive and rubbing your back, and they're with you all the time and should be pleasant and not getting in the way. That's sort of the rule.You shouldn't have to have any of your children there. And you certainly shouldn't have a lot of family coming and going because that is a problem. But then it's also a problem if you don't have that and you're all alone, because then you are that single black mom alone, isolated, things like that. So you're kind of damned if you do and damned if you don't. But what if we turned that upside down and began to celebrate that people had this lively and wonderful circle of people around them celebrating this new life in their way and celebrating the joyous noise or celebrating that the children might be coming and going.

Diane Banigo 08:36
And then even when they didn't have someone, what I appreciated about what we were able to create is that Diva was able to step into that role, right? You know, and be there for those people that didn't have anyone, even if not physically, right, because sometimes we were doing other things, but they appreciated just a call or we would go down before an induction and answer any questions that they had, and check in on them in the middle of the day and see how things are going. And so they really felt supported, even when they couldn't have the traditional people in the room, for whatever reason. So they did not have to feel alone on this journey, which is what our intentions were when we created it to be with them on the journey of care.

Sonja Batalden 09:12
A really memorable image that I'll never forget from during the pandemic was one particular birth where the woman had really wanted to have this circle of women of aunties and sisters at her birth. And that wasn't possible because of the pandemic. But we were able to bring in an iPad on the stand. And so we had nine women on this screen. And in the middle was the birthing woman and the way it just fell on the screen. Somebody actually took a screenshot at the moment that the baby was born. And it was all of these just elated faces. And I thought wow, I mean, we can't be together in the traditional way right now. But what does this mean to have this circle of women surrounding this birth? It was just beautiful.

Paul Batalden 09:57

You had this information that these people gave you as you listened to them. And as you were sort of now trying to make this program real, you had to connect with what was going on around you. Were there things that were going on around you that were helpful to the development of this program?

Diane Banigo 10:19
Yes, my first thought would be, you know, having Sonja as a leader, someone that was willing to trust the process, right, and allow us to innovate. And we were able to morph the program into what it needed to be. It didn't remain rigid. Diva is different things to different people, right. For some folks, it's just a phone call assist or check in. Sometimes we're resources, sometimes we're coaches and doulas and providers. So that's what I appreciated about the program is that to have someone that really understood the value in doing this work and allowing it to morph into what it needed to be to co-create, right? That's what this is about, how do we do something together that serves the greater good, and even if we don't understand it, to not be discouraged in the process of the creation of it.

Paul Batalden 11:07
One time, you mentioned that there was a birthing center that was being created, as well. Can you talk a little bit about the connection between Diva and this birthing center?

Sonja Batalden 11:21
Well, one of the things that's happened in the course of this program is the hospital that we're connected with has built a new building, the family birth center. And we were invited to be the one community member who was in on that planning. During that process, we held up equity as one of the three pillars of the whole process as we went along. So we began to ask, you know, what does it look like if you say equity is what this building is about? And how do we start to shape a building that might look differently? And some of those things would be like, how do we design a patient board that people from different cultural groups and different languages can interact with and understand? How do we create a welcome for all different cultures? But I also think it's been work with staff around our own implicit biases, and how those play out in care. It's also been around staffing. The hospital has worked with our patient navigator from Diva to do rounds once a week, talking and listening. And like I said," hearing people into speech" about their experiences, and then giving direct feedback to both individuals and processes and committees about how we can continue to be an anti-racist organization.

Diane Banigo 12:32
And I think it's just been instrumental to have people in positions and with platforms that are willing to challenge systems and to think outside the box. And so in the work that happened internally, you had people that wanted to see something different, because even though the stats have not changed, they've been around forever, people are paying attention to them. And so were ready for something else. And so we were the something else. They were ready for something new and innovation was welcomed, which hasn't always been the case in the past.

Sonja Batalden 13:03
I also want to call out how important power is in this whole process. And who is at the leadership table and who has the power. Because some of the other things that have happened during this time, is that our organization has been really intentional about who are our executive leaders…what do they look

like? What is their experience? And do they reflect the people that we care for? So we now have a senior leader, the president of our organization, who's an African American man, the Director of Nursing at the hospital and labor and delivery is an African American woman, our lead nurse is a trans man. So we've just diversified at that highest level of leadership. And that is so important that we start to turn those tables of power and leadership.

Paul Batalden 13:50
How do you work on trust?

Diane Banigo 13:54
Continuously. I think that's my first thought. But I think one of the things that you have to do is acknowledge if it's not there, right? And to go back to as far as you can remember, and to recount the events that may have made things go awry, and to affirm and celebrate the things that have worked well, and to recommit to moving forth in a way that feels trusting and safe to all parties that are involved. So I think trust is a process, and both parties have to be willing to work at it continuously.

Sonja Batalden 14:30
One story that has been so impactful for me as a provider who identifies as white, working with people who primarily do not identify as white, is a story that happened to me many years ago. I had a patient come in, in early labor, and I went in to introduce myself and basically just let them know what was happening…bring them a glass of water, tell them what was going to happen…and so I just walked in for a few minutes. It to me seemed like a very pleasant interaction. Everyone seemed to be in a good mood. I left the water and said, "I will be back in about five minutes." As I turned to go, I heard the father of the baby say under his breath, "white bitch". And I stopped. And I thought, wow, okay, this is, there's a lot more going on here than I understand. And I think so often we take these things on such an individual level that we start to think it must have been something that I did. And it actually wasn't probably anything that I personally did walking into that room. It was about 400 years of slavery, and discrimination and racism in our country and power dynamics. And I turned around and I said, "Wait, okay, let's stop, because that is not why I came to work tonight. And that is not how I want to interact together. So let's figure out what's going on and how we can, you know, everyone feel respected in this room." And as I listened, it turned out, they'd just come from the emergency room where their family member was a victim of a gunshot wound, and had been dealing with all sorts of things before they came up. So one of the things I think in building trust is realizing that what is going on when we have a one on one interaction is so much bigger than the words or the attitude, or the moment… it's the whole history and the societal reality and the systems that we live within. And especially as a white person of power, I need to be able to step back from that and not be so fragile or so personally offended by that. But instead step back and say, OK, why might someone feel that way right now, and so that we can get back to a trusting conversation.

Diane Banigo 16:40
I think we need to create space for the realization that people are holding things… they're just holding and consuming. You know, it's eaten away at our bodies and our wounds in our minds. And I have a whole other theory about why black folks are just sick more often than our counterparts. But when you're trying to establish a trusting relationship, you have to give communities permission to unpack

and to put the bags down that they carry. And you really need to care. Like don't ask how your day is going, if you really don't care how your day is going. When I'm with someone and I'll say, “How you doing?” I'm like, good. I'm like, well, you don't look good. Your body, you're saying you're good. But your body language is telling me something different. I heard you arguing on the phone when I walked in. What's really going on? Like, I really care about you. This, whatever we're dealing with at the time, that can wait. If I can't see you, and you can't see me as your true, authentic self, then what I'm talking about, you won't retain it, it won't even matter. So how are you really, because I want to care for your whole person: mind, body and spirit. And so to just be aware of what's going on in the verbals and nonverbals and to give people permission to unpack and put the bags down, because the weight that we're carrying, I mean, it's breaking our backs as a community. And that requires you as the person clinician, whoever, to be vulnerable and to maybe share some of your own story so that they understand that you too have been journeying and that they're not alone. Right? And so that it takes a certain level of vulnerability to have people trust you

Paul Batalden 18:12
So powerful. How do you know Diva is working?

Diane Banigo 18:18
The story that comes to my mind is when I was fired. Because I did exactly what I said I was going to do and be truthful. There was a client that wanted her FOB, father of baby, to be involved that was in another relationship. Because we know research shows that when partners are involved kids do better, particularly black men. And so we invited him to show up in the way that he could and he said no. And he gave the reasons why. And I was honest with her about why that was. And so she fired us and didn't come to Diva for a long time. And then somehow she reconnected because she needed a service. And she was amazed that we welcomed her back with open arms. And so she thought that by knowing her true story, we would pass judgment on her and we say Diva is a judgment free zone. We all got stuff, but we got to get through it together. And so we do fun things. And so we had our Diva Dance for Valentine's Day. And I remember her telling me shortly afterwards, when she saw me hold her daughter, she realized that I loved her, you know, she could tell how much I cared for her by the way that I looked at her daughter. And that when she circled back, we were still standing where she left us just ready to move forward with her because we understood that her situation was something that she was going through but it didn't define who she was or who she could become as a mother and we wanted to support her in that. And so people don't say thank you often enough, you know and people don't acknowledge, but when you give individuals an opportunity to come back and reflect and to just be honest about what they were experiencing, you can see the gratitude. And so it's amazing, even when they don't say something, when you can just feel that there's a connection and that now you guys can go hand in hand and continue to take the next step.

Sonja Batalden 20:06
I think of a story when I think about how we know something's working. One night, we had our, what we call our “Drop in Diva Evening”, where we have different topics and different ways of engaging that. And we were talking about trauma and how trauma impacts our lives. And we were going to do an art project that I was leading called “painting on a common canvas about trauma.” And I'm going to be honest, I was a little bit anxious about how this might go and what sort of things might come up during

this. And the women who gathered in the room were a wide variety of ages, a wide variety of socio economic and educational levels that were there. And I thought this will be interesting to see what we do. And we started going around and painting on this canvas together, reflecting on trauma and healing. And it was such an amazing evening, not only what came out of it in the art, but in the conversations, and people were able to be really vulnerable. And I was amazed what happens when you can create a space like that, where people are able to share their stories and come together.

Diane Banigo 21:09
And from that same incident, I just remember the transfer of power. I remember the other women in the circle just coming around and championing and lifting and building this mom up when she was telling her story about child protection and sexual trauma that she had experienced with her children and partners. And you just felt them just wrap their arms around her and she just cried…and I'm getting chills just thinking about it now, she just cried. And to know that this trust can be transferred.

And so I happen to know this mom in another space. And because of the relationship that we built within this program, she was able to get support services through ECFE, Early Childhood Family Education, and to learn how to be a better parent…and she had another opportunity to rear her kids when her other kids had been removed for various reasons, right? And so trust can be transferred. And so even though we're starting to create pathways within the healthcare system, they can be communal because it, care, happens outside of the clinic walls. Care happens in the community. Care happens wherever people are. And so we have to be willing to rethink what it means to provide care for someone. And that is a great example of how you know something is working, when you can see the benefits of it in another setting.

Paul Batalden 22:21
What an amazing story. Are there things that I haven't asked but that you wanted to share?

Diane Banigo 22:29
I remember being asked before, “What is our greatest challenge in coproducing and in co-creating a healthcare experience?” And the thing that always comes to my mind are the moms, right? The Divas themselves. I always say often and I'm going to continue to say that being a diva is “hard” work, with a D and “heart” work with a T.

But black women, particularly US born black women, descendants of slaves, have been so conditioned to think that they are undeserving, unworthy of what could be. I used to work somewhere else at a birth center. And I remember this mother told this daughter that this place was too nice for you to come here. Even though she had insurance, she didn't deserve to be in something so beautiful and so glamorous. And this is what a mom told her, her daughter that was carrying a baby. And so there's something about intergenerational curses and how people, things just transfer. And people do not think that they're worthy of great things or great care or safe care. And so I often say that it's so hard to convince the women that they deserve it. You know, we're very prideful people, even when we don't have anything, we don't want handouts. We don't want your pity. We don't, you know, we don't want those things. We're very prideful people. But to some regard it is to our own disadvantage. And so sometimes we have to convince women that this journey is not meant to be done alone, that I want to be with you on

this journey. And life was not meant to be lived alone. So why not partner with us so that we can all get to the next level. And we can thrive as a community.

And so I think our hardest challenge is sometimes the families themselves. And so we continue to create opportunities to talk about what is and what could be, encouraging them to tap into their own power and to just imagine and be the narrators and authors of their own stories. Like, it may start this way. But you get to write the end. And so we really, really try to encourage women to offer their own stories. And we, we model that by truth telling.

Paul Batalden 24:27
Thank you very much. This has been a wonderful gift that you've given in sharing this story.

Diane Banigo 24:34
Thank you for having us.

Sonja Batalden
Yes, thank you.

Paul Batalden 24:40
Inequities, disrespect and racism in health care are common experiences for African American women during pregnancy and childbirth. Addressing these issues in the United States has taken on new urgency as the country confronts the glaring and disproportionate impact that the COVID 19 pandemic has had on communities of color, reflecting many of the same underlying drivers of inadequate access to high quality care.

Understanding the lived reality of the pregnant woman's life and situation was the beginning point for the Diva moms program at Minnesota Community Care in St. Paul, Minnesota. The midwives, Sonja Batalden and Diane Banigo, tell us about that. In many ways midwives, by the very role they play, are natural, coproducing professional persons. They don't have the baby, they support the person whose baby is coming. Midwives know that their job is to help the mother to-be get what she needs for a good outcome. This is by definition coproduction, a truly collaborative effort. Still, despite all the positives that are intrinsic to Midwifery, there's a lot more to overcoming inequities.

As a first step to building the Diva program, the nurse midwives and their colleagues conducted an intense listening effort, they created a safe space, they established their trustworthiness as listeners. They listened so that pregnant women's words became their voices. They incorporated the experiences, hopes and needs they heard about into new ways of knowing their own roles as midwives.

The nurse midwives turned next to their own assumptions, their practices and those of the settings in which they worked to identify how they might create a new alternative for women of color. The new program had to be able to connect to the resources and capabilities of the pregnant women in their lived realities. The language had to invite and not inadvertently judge or diminish. The Diva program, they all agreed, had to bridge the power gaps between the pregnant person and the professional person's knowledge, skill and capability, as together they worked to coproduce the services needed.

Diane said that Diva work was both “hard” with a D and “heart” with a T work– hard and heart. They had to continually examine and reexamine their assumptions, their practices, their habits, and as professional persons they had to show up as whole persons trying to create authentic relationships of trust. Showing up as a person as well as a role holder sometimes makes professional persons feel vulnerable. Yet that willingness to be vulnerable helps create truly honest relationships between and among persons who hold different roles such as patient or family member or life partner.

Health inequity has many faces that have formed over centuries, a legacy of disrespectful interactions, the ways in which differences in education, economics, opportunities have played out eroding trust in others. Role conflicts as patients and professionals have struggled to understand each other, and so much more. Sensitivity to all these things is fundamental to creating equity and begins with serious listening and serious attention to all the negative consequences of power dynamics. These same principles and methods apply to the design of coproducing service with many different populations, but especially marginalized communities of color who come by their mistrust quite honestly.

The Diva program also discovered the importance of making sure their program resonated beyond a midwifery project. As the hospital was creating a new birthing center Diva leadership became part of the policy and practice team that was planning the center. In this way, the insights that were underlining the Diva program helped shape the new birthing center that would serve African American women as well as women and families of multiple ethnic groups. Thanks again to Diane and Sonja for showing us how coproduction can help inform a program like Diva dedicated to addressing inequities in health care and helping all to truly belong to the birth of their new babies.

Thank you. I'm Paul Batalden.

Madge Kaplan 29:48
Thank you for listening to Episode Five of the podcast series, The Power of Coproduction, with Paul Batalden. On the next podcast, Paul takes a pause in order to provide some context for Episodes 6,7,8 and 9, which focus on the varying roles of science in coproduction.

Every working day in Sweden, a pause such as this might occur in a tradition called “fika”: a time for coffee, some bread and discussion amongst your colleagues. It's also reflective time to share what's been happening and what's ahead. So in that spirit, the next podcast in this series is called Coproduction Fika:time set aside for Paul to discuss how science informs the practice of healthcare service coproduction. After the fika, on Episode Six, “The biology of it all,” Paul will be joined by Bruce Marshall. His work with cystic fibrosis illustrates how science informs our understanding of a disease and how that understanding effectively informs the practice of coproduction. All podcasts in the series, including an overview of coproduction are available at ICoHN.org/podcasts. The website is where you'll find supplementary materials, guest bios and brief profiles of the production team. You can subscribe to the podcast series wherever you get your podcasts. Thanks for listening.