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Episode 3: Redistributing power to marginalized individuals and communities and creating systems that meet people's needs inside and outside the formal health care system.

Dr. Reagan McDonald Mosley:

Hello, and welcome to a new podcast series, focused on advancing equity and family planning. This podcast is a partnership between Power to Decide and the Reproductive Health National Training Center, with funding from the Office of Population Affairs and the Office on Women's health. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of OPA or HHS.

Throughout this series, we will explore tactics, programs, frameworks, and ideals to increase reproductive and sexual health equity in health centers across the country. Through this podcast, we hope to give Title X clinics providers and staffers practical, easy to access action-oriented training resources in order to advance health equity at family planning service sites. My name is Dr. Reagan McDonald Mosley, and I'm the CEO of Power to Decide, the campaign to prevent unplanned pregnancy. I have over 20 years experience in this field, including as a practicing OB GYN with a dedication and commitment to reproductive health and justice.

Today we have with us, Dr. Karen Scott. Dr. Scott is a reproductive justice, informed sexual reproductive and perinatal epidemiologist, educator and obstetric hospitalist. With more than 20 years of experience in supporting persons across the sexual and reproductive life course in high need, low resource communities across different practice types and locations. Dr. Scott's research focuses on the analysis of structural, institutional and interpersonal factors that inform healthcare access, quality and utilization. Focusing on equitable patient provider and community hospital partnerships and shared decision-making.

Additionally, we have Mandy Fleming with us today. Mandy Fleming is the manager at Flathead Family Planning in Kalispell, Montana. She has over a decade of experience conducting youth outreach and providing sexual health education to her community. Mandy's goal is to normalize talking about sexual health. In this episode, we're going to discuss centering the needs of, and redistributing power to individuals and communities that have historically been inadequately served by the healthcare system, in order to create systems that meet patient's needs inside and outside of the formal healthcare system. So, let's dive in.

Mandy:

Flathead Family Planning has been providing outreach and STI testing services to inmates at our local detention facility for over a decade. While providing these services, we decided that we needed to go a step further and figure out how we could help these folks succeed, once they were released. While conducting services, our staff had open and candid conversations regarding what the inmates felt like they needed to be successful when they were released and what barriers they were facing around their health. We also had folks fill out an anonymous surveys regarding their needs. The topic that trended the most was a need for a local syringe exchange program. After hearing this, Shauna, our HIV prevention specialist, said she would go to the end of the earth to create a syringe exchange program, so she could help the population. In less than a year, she did just that. She created and deployed a syringe exchange program that's housed in our family planning clinic.

The goal of the program was not only to provide safe injection supplies, but to build relationships and to learn the needs of this population, as well as provide wraparound services. At first, participants were hesitant to discuss their health care needs with Shauna, as they've had negative experiences with healthcare providers in the past and were concerned about being judged. As time went on, she put in the work and she developed relationships and trust with the participants. She was able to successfully provide thousands of referrals and were handoffs to our family planning clinic to primary care, to social service agencies and to substance use service providers. Her passion and drive to build trust with these folks was key. We saw people accessing care who had not seen a provider in years. So this partnership has helped family planning clinics make connections and build trust with folks who have continued to seek out reproductive health services at our clinic. We were lucky to have passionate and driven staff who truly care about our community and are excited to continue the work in the future.

Dr. Reagan McDonald Mosley:

Wow. Strong work, Mandy to you and your team. And thanks so much for joining us and telling us about your efforts. So now I want to pivot to you Dr. Scott. How can healthcare providers, clinic administrators work to redistribute power to communities most affected by historical instructional forces that limit their ability to achieve reproductive and sexual health equity and reproductive well-being?

Dr. Karen Scott:

Yes, Dr. McDonald Mosley. What I think like the beginning needs to be is just shared language. Using concepts such as sexual and reproductive health equity, means different things to different people. And so I would imagine just first, so we could start off with history and then with shared language around what sexual and reproductive health equity means to individuals, to systems and to disciplines across different power relations, differences in dynamics. I also think about the most, the consequences for

like misalignment with the healthcare provider and the payer matrix. The consequences disproportionately fall on the population seeking the care and not usually on the individuals or systems providing or paying for care. When we look at healthcare supply and demand, what actual consequences do systems, including health plans and healthcare systems experience for failing to meet the sexual and reproductive health needs and priorities of the general population, let alone, historically, systematically, instructionally excluded and erased or minoritized marginalized populations.

So in thinking about redistributing power, I'm always thinking about, what if, instead of exclusively focusing on clinical outcomes, we focus on the patient experience of navigating elitist, racist, sexist, trans, and queer phobic, body shaming and ageist institutions. And what does it feel to be in the hands of our care versus being handled in our care? And what if we expanded our knowledge and beliefs about safety -- right -- beyond the absence of adverse events and efficacy beyond the ability to do what is defined as desired, which is usually based on the perspectives of scientists, providers, and payers. So I imagine this redistribution of power would require us asking patients to redesign or re-imagine safety, quality, value, and efficacy from a place of belonging, like liberation, autonomy, love, great question.

Dr. Reagan McDonald Mosley:

Wow, I love the framework that you have provided for us to think about these concepts and to really focus on the patient experience rather than just clinical outcomes. Right? And I think that's sort of what, Mandy and her colleagues at Flathead Family Planning attempted to do by asking the community what they needed. And if they had just focused on their clinical outcomes, it might have led them in a different direction to use their resources, to focus on STI rates or unintended pregnancy. But instead the community said, you know what, what we really need here is a needle exchange program. And so that led their efforts. So in that vein, of what Mandy discussed with us and in your experience, what are some person centered models of health care that you have encountered? And when people talk about providing culturally humble or appropriate care, what does that look like in practice?

Dr. Karen Scott:

Person focused models of care, see the person as a human being, sees their humanity in context with their, in context within their life course, within their relationships, within their community. And you also see person focused models of care that actually have patient or public representation as like a decision maker, right? Either on the board of directors or a part of like the policies, maybe development and review process, or actually builds the capacity and activates the power, not empowers, but activates the innate power, potential promise of the person or the persons and community to be a part of health services, design, provision, evaluation, and training. It's almost like the peer models, right? Where you see people, like if someone has completed or graduated from a program or been a

patient at a healthcare system over time, you see that pathway and strategy to build up their skills, to be a part of the health care system is not just a recipient or a beneficiary, but as a change maker, as a thought partner, an action partner.

And I see most person focused models of care, they're like midwifery models of care, or with models of care that utilizes like multi-disciplinary teams, but not just when thinking about medicine nursing. But, the community health workers might model, right? Like having someone with lived experience also be a part of the health provision, the health service provision team. Again, it, I'm always thinking about ways to like dismantle that hierarchy, close that gap between those with power about, we know people's health and their bodies versus those living in their bodies who have their own power. And how do we facilitate the ways in which they can, show up in their bodies, show up in their health that most aligns with how they view themselves, how the community views things, right? And so I just always see doulas, I think of midwives, doulas support models, midwifery led models.

I think of even the Dr. Shalon, right? Maternal action project that's being led with you and miss Wanda, it's sparked by someone's experience that usually is, is having lived experience right through this phenomenon that we're trying to observe and modify and transform. And when it can't be that person directly, but someone in relationship with them, I think those are the models that those are types of models of person focused care that we need to think about in the ways of re-imagining and re-design the health services provision. This kind of one-to-one, you need directional physician or nurse practitioner to patient model is not going to save us. It's not going to save our communities. And the more we continue to hold fast to that, unidirectional model, really exchange and have information and knowledge around advancing our health and our wellness.

We're going to continue to fail miserably. So I just always felt like, whose power I should say has been constrained. I don't think we have the least power, but whose power has been constrained and controlled the most by structures and systems, we should always start there and think of those in relationship with those who sit at the margins cause, we're not dealing with single issue human beings, right? We are always thinking we are living as human beings in relationship, even if we don't admit it. So I think again, person focused models, really are like multi-issue models that really bring the community together. And there's this consensus building right? In decision-making, whether it's through screening tool that you use, right? The way the diagnosis is given, how it's shared, how it's documented the different types of treatment models don't always have to be pharmacological, they can be non-pharmacological, they really adjust the body, mind, soul. That's what I think about. And I again see those usually in spaces that are not focused only on the eradication of disease or are physician led.

Dr. Reagan McDonald Mosley:

I love that. And I think, words are important in sort of changing the model from a patient centered approach to a person centered approach is important. Because that person is only a patient for a moment and they may walk out of our door and they are a person in the middle of their community with all of their intersectional identities. Then I also love the idea of really thinking of the people we serve as thought partners, rather than just, identities or entities that we need to treat or manage, right? But actually thought partners and really centering the folks with the most barriers to access and the most barriers to success in our society, and really using them to help inform our strategies. I love that.

And how do we also push the systems to be better? How do we push the systems to this reorientation to humanity and to focusing on the person, right? Rather than, sort of the bottom line, how can we, communicate and with transparency and center the person in front of us while we're also disrupting to make the system better?

Dr. Karen Scott:

When the system is able to acknowledge and then reconcile that traditional individual level disease, centered, oriented interventions are not working for community. When you keep doing things over and over again, and it's not producing the outcomes that are intended. And again, outcomes are not exclusive to, the goal is not exclusive to the outcome, but also the experience. And I think when actually asking patients what they, when asking the public and the community, what is it that they need to again, be able to pay, to reach, to seek help in healthcare within a system. Again, what are their barriers? Where are their burdens? What are their benefits to engaging your health system? And if we actually listened to the community and then mapped those right areas that are different across, again, that concept of risk facilitator burden barrier benefit.

I think we would begin, I think it would then identify opportunities for the system to reimagine the provision of care and support and services from the perspective of the community, that's actually engaging the system and has been doing that for decades. But also just being in the community, right? And so, health systems don't exist as an island, although we think we do. But what if we actually again apply this kind of social ecological, model this relational power, power differential perspective on to the health system. Then I think the health system will realize that it sits in relationship to the local pharmacy, to the local grocery tour, to the local faith-based institutions, the local gangs, honestly, right? The local, the people who are living or trying to survive on the streets, the health system may think that it is a place of safety that people enter into and think that they are separate from the system in which they were built themselves, but they're not.

And so I think community driven, patient driven, systems or interventions are ones that connect history with contemporary times and brings that, that

grounding of truth to a health system to say, Hey, you may be, X number C or a leader in this hospital, but our families have been here for, centuries or for decades or since the 1930s or 40s and 60s, and we've seen the pattern over and over and over again, which may be new to you, but it is not new to us. And I think that is the humility, that grounding of truth, right? That there are many different truths. And the one that hospitals and health systems hold usually it's incomplete. And what if we were to, again, build the capacity of the community to identify the problem, characterize the problem, characterize the solutions, and then provide the solutions that always involve them, right? At every decision point from design to dissemination. That is actually when we see success, right? Because we did something very simple. You made space for the community to solve their own or manage or address their own needs based upon how they defined them. But also based on the ways that they believe are the most authentic to fulfilling their needs with the health system as a partner and not as the sole leader or owners of power.

Dr. Reagan McDonald Mosley:

I love that. I love that. I've been following your work for some time, which is super powerful and centers around advancing cultural rigor and quality improvement, science practice, and interprofessional education and training. How do you see this framework playing out in the setting of family planning health centers, right? And what would your family planning utopia look like?

Dr. Karen Scott:

Wow, that is an amazing question. And thank you for the positive feedback. So for cultural, like rigor, I see four modalities, right? One is a vision as a praxis, as an analytic framework. And I believe family planning has already adopted the concept of seeing itself. Seeing itself, meaning it's special to you or to a group of discipline as a movement, right? As a movement in the provision of sexual reproductive health in a way that I don't see other parts of our specialty as we can about OB GYN in general.

What I, this utopia by what, really think about it is going back to, it would recognize that for centuries, historically instructionally, minority and marginalized communities have been erased or excluded in just like the existence of their own bodies. And right, it goes to this concept of like, production versus reproduction in this utopia of family planning, I would need to bring in cultural humility, but expanding upon that, that it's not just in the training, but it's also in how one shows up in the interaction, and the communication, and the counseling, and the decision-making, and the documentation, and the dissemination of information, right? In a patient handoff or an electronic health record.

We need to really build the consciousness and the skillset to ask, to inquire from a place of, again, cultivating belonging. Like that's what's on my heart. And I'm like, if we were led by the motivation to curate spaces and health systems where people feel belonged, where people can feel liberated, they

can be the autonomous agent of their body of their life, and also feel loved, I think we would behave and think and do differently in our questioning, right?

In our history taking and the options that we would describe to someone that there are, again, options because no one really, truly has choice when they come into a system and the providers are already hired and working that day. I tell that to systems, when I do train that, people really don't have a choice when they show up and you're on the schedule. We think that they do, but they didn't get to choose, they didn't build the health care system, they didn't recruit, select and hire the providers. They didn't even choose who gets to work on the day they show up. So again, that's that cultural humility showing up saying that, there are always, there's always a presence of constraint, period.

Dr. Reagan McDonald Mosley:

I love that. I love that. So, I mean, it seems like the sort of thread I'm hearing throughout our conversation, right? And like designing your family planning utopia is again, really seeing the person in their totality and complexity and having a healthcare system and institutions that help people to meet their goals, understanding that they're the experts of their lives, right? Rather than, the other way around, designing the healthcare system, such that we meet our goals through, through the patient. And really centering cultural, cultural, humility, and love and care for people that we are interacting with. I love all of that. So for our last moment, any action items or things that you want to implore our listeners to take away from this conversation and to implement in their own settings?

Dr. Karen Scott:

Yes. I would like,. I always ask health systems, what community based organizations are you in relationship with? They named some of them, no, but what does that relationship look like? Who does the community trust? Not who does the hospital trust? So I would ask health systems to really begin to, again, reimagine or reflect upon their existing partnerships with the community and are those relationships with the community reflective of who the community would deem, right? As being trustworthy, and safe for them to also navigate. And I think I would love for health systems to bring on the community as a part of, again, their internal review board, or their like QI Committee, like what are ways that community can show up. And some of the ways in which policies are, and practices are developed, but also evaluated.

So I would recommend what I'm thinking about, right? The practice of cultural humility and person focused care is where does the person, the community show up in the evaluation of your systems. And if there is a lack of community participation in quality improvement evaluation, then that is a message to the community that the impact of care is of no value or consequence to the provision of care. And I would love to see more representation, participation and actually power decision-making

participation from, again, those who have been historically and structurally excluded and erased in society again, like where do they show up in places of power decision-making and the provision care? So I just think, more community led models, more peer-- like really supporting people who are living through something and have been able to navigate the system in the context of their lives, really building their capacity to be heard and to partner with other community people.

So we support peer support, which would go back to supporting, which would go back to devesting as opposed to divesting from, right? Capital social networks, what's, as I speak for as a black woman, that there are many opportunities to, for systems to learn the power of black sisterhood or kinship. I speak a lot about that. I would love to see that, what would it be like to have our chosen and given fam or tribe, show up in the care and be a part of the care and be able to critique the care and redesign the care. I think communities would be so much more responsive if the health system acted as a community. Which I don't know if it can, but I think that we need to, as health care providers working in this matrix, really just take a pause and look at what communities are already doing, right. In terms of their acts of resilience and resistance and replicate those models because the community has been taking care of itself for a long time.

Dr. Reagan McDonald Mosley:

That's such a powerful framework, to think of the healthcare system as a community, within a larger community. And those two entities interacting positively rather than sort of a top down approach. That's really positive. Well, thank you so much, Dr. Scott, for this informative discussion., You have given us so much to think about and to our listeners, we hope that you will walk away with not only a better understanding of how to advance equity and family planning and reproductive well-being, but also actionable steps you can enact today.

To follow the work of Dr. Scott, and to hear more about the work that she's doing, please follow her @rjepiobwarrior, again, that's @rjepiobwarrior on Twitter. Follow me at @drreagan on Twitter, and please stay connected with Power to Decide by following us at @powertodecide on all platforms.

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