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Advocacy can be a lonely and frustrating calling. Ironically, it’s a long game requiring patience, planting seeds, persistence, and gratitude – think thousand-year-old eggs. Ironic, as many people called to advocacy, have barely reigned in passion. Rather, they push, push, push; never quite satisfied; never quite feeling home and done. A thriving community of advocates, activists recognize the loneliness and offer inspiration to recharge and pull forward. Advocate communities cross-pollinate.

Introducing Neely Williams 01:41

My guest, Neely Williams, inspires me as a minister, a community advocate, and a community organizer. We worked together on PCORI’s (the Patient-Centered Outcomes Research Institute) Patient Engagement Advisory Panel (PEAP). Neely isn’t an extrovert like me. Her strength is quiet, intense. She talks to people about things that matter to them, like their health struggles and how to improve their lives.

Health Hats: Neely Williams. I am so delighted to have you as a guest. I don't see you enough.

Neely Williams: Lots going on.

Health Hats: Isn't there. How do you introduce yourself in a social situation?

Neely Williams: Usually, in a social situation, it's pretty much just Neely. It depends on what we're there to do or the setting - a community leader or a pastor. Generally, it's just Neely. I like to come from the Neely perspective; then, you determine whether I'm worthy of any of those other things.

Health Hats: Tell me more about being a community leader.

Neely Williams: The community leader role emerged from my commitment to be a change agent in my community toward making a difference. A journey that began at a vacation Bible school class some 35,

40 years ago. I believe it was for young men dealing with HIV and AIDS ravages at that time, 1985, to stand before our class and give a first-person presentation. I felt like if they were brave enough to do that, I would be brave enough to go to whatever means necessary to be an advocate for them and their families on their journey. The next week, I began my first American Red Cross training class to educate the community about HIV and AIDS and its impact on the lives of the people who were dealing with it. That began my role officially. I launched myself without any intention of becoming a community leader, but just the intent of being a person who had to make a difference.

Health Hats: Was that before you were a pastor or after?

Neely Williams: That was before. I was still bargaining with God at that time. I was trying to cook enough macaroni and cheese and bake enough pies and sew enough curtains not to have to be a pastor. But God and I kept working until I stepped into that role five, six years later. The gold rolled on. I went back to school and under my pastor's guidance, who suggested that to be a route for me. And that's how I found him, the re-emerging of educating myself all over again. I worked for the bank for twenty plus years, and I had lots of college courses and had not completed a degree - courses in accounting and bookkeeping and all the things that went along with working at the bank. But at that point, my focus shifted to sociology and theology.

Health Hats: Were you a pioneer in your community? Was being a woman as a pastor new or not so much?

Neely Williams: Oh, yes. That was very new for my Southern Baptist roots as a black Baptist congregant. That was not something I had seen. It had been something that was very much not encouraged in my tradition. My pastor had been one of the persons who was a spokesperson for that strand of thought. He reports that he went to the Bible to prove that he was right, and the Bible proved him wrong. And from there, he became an affirmative actor for women in ministry. So, I was very comfortable sitting on that third-row seat, and I was justified because everything I was taught says women aren't supposed to preach. Women aren't supposed to be leading the church. The irony of all of that is I don't really interpret my call as a call to preach. My call is to minister and to serve. Preaching is part of what I do, but it's not the focus or the total sum of what I do.

Community health, spiritual health 07:07

Health Hats: We met at a PCORI (Patient-Centered Outcomes Research Institute) annual meeting five, six years ago. Then we participated together in the Patient Engagement Advisory Panel (PEAP) as well. The thing that attracted you to me was your community health focus. Sometimes I'm underwhelmed with the amount of focus research has on community and community health. I was interested that you had a ministry and that you considered the spiritual health of your community. Can you talk more about the spiritual health of communities, however communities are defined?

Neely Williams: Yes, I think they are so intertwined that we can't separate the spiritual from the physical. We do ourselves an injustice when we try to pocket it or say this over here is about health, and this is about research, and this is about this part and over here is about spiritual. These all work together. For me, there is no separation line. If a community is going to be physically healthy, it has to be spiritually healthy. And for it to be spiritually healthy, it has to have some concept of physical health.

Now, we diverge a little bit on how we identify that problem; that diversion probably comes from more in the sense of the church and its theology. That probably happens more as we relate to how we think about whether or not a community or how we relate to the physical health versus the spiritual health of a community. In some traditions of faith, physical health, and healing, it's the absence of disease or the absence of suffering, but that's not the total sum of what it means to be physically healthy or healed. In the work that we do, we're coming at it from both perspectives. So, physical health, relieved of pain, released from suffering, often that release comes whether or not the body is healed. Whether or not there's a restoration or restoring of total physical health. Persons can make peace with their health and care. What was particularly powerful for me is that as I began to step into this work around HIV and AIDS, that earlier point in time, it wasn't about an absence of death or the presence of long term survivability, but about how such persons live out every day of the rest of their lives? That was a powerful place for me to be able to be a steward and a minister. The minister in presence and minister with those dealing with the day-to-day repercussions of the gravity of that disease. Finding that I've had so many folks that I've worked with say that they didn't begin to live until they had HIV. Their life had become such an entanglement of sufferings of the addictions and all the things that went with those addictions that they began to live again when they found some grounding in the end; living day-by-day with their affliction. Those dynamics are the things that helped shape the way I think about health and the way I think about ministry. It's not always shared; there may be people you would meet today who say she's really not in ministry. She's doing some public health thing. That's okay if that's what they think. But I see myself totally as a ministry still doing health and health-related issues.

Health Hats: I'm with you a hundred percent. I look at health as first spiritual, then mental, then physical. I know if my spiritual health is strong. Because spiritual, mental, and physical health varies from day to day, moment to moment. But clearly, spiritual strength trumps everything.



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Neely Williams: Absolutely. It's my awakening. It's my conscious; my consciousness of being present in the day began with my assessment of my spiritual. Where I am in my spirit at that moment? Before I can deal with the physical pains in my body, I have to deal with where I am spiritually. When I can be sanctioned in that moment with my spirit, the rest of it can fall into place. If there's a day that I have to go slower because of my physical health, then I can do that. And if there's a day where I can explore, and I am exuberant, and I want to plant flowers and harvest beans, then that's wonderful, too. They don't all come that way. They come with various degrees, And so I think if we can help individuals to be able to make peace with those things, in that making peace, it's not to sell for or to succumb to, but it's to be able to garner the richness of every day, to be able to explore the genuine good that's in that day for you and those around you in creating and making the world a better place.

Health Hats: I had a son who passed away at 26 of melanoma metastasis. He was spiritually strong in his last year of life. Not so much before that. It was such a transformation for everybody, that experience. The way he put it, he would say, I wasn't born with a tattoo on my ass telling me how long I had to live. My words were accepting what is, and then move on. Then what are we going to do with symptoms and pain and whatever? But first, it was that acceptance.

Community-based research 14:41

Health Hats: I want to shift a little bit; the work that you do - that you and I have done together has been in the research world. My mission in research is shifting the power dynamics from academia and the research industry toward communities. I remember being in the lobby of some hotel, probably in DC

with you. I don't remember who was with us, maybe Beverly, but we talked about helping communities direct research that answered questions they wanted to have answered. If I recall that conversation and I'm not known for the quality of my recollections, I remember having a conversation about helping communities feel that strength of 'this is what we need to know. Now we need to get some help from people who can study it for us.' Can you talk a little bit about your experience, about working with your communities to own the research, to direct the research to find the research that will help them answer questions or move along in their health?

Neely Williams: Oh, I would love to be able to say we have made that shift. I'm sure in that moment of after having had some explosive experiences that we had in that conference, some eye-opening, some eye shattering revelations that I had on some rose-colored glasses at that time. Patients can do this. One of my perches that I used to perch on is we keep asking the powerful to teach the powerless that they are powerful. That's a lot. And it is so. But even to that degree now, even more so than then the promise that our communities are suffering have in many ways put us another place, Danny. I'm not so sure my community right now and please pardon my French here, give a damn about research. I think they are trying to live, surviving, trying to make it through the next newscast, to see what traumatic thing has befallen our nation and that's going to impact their unemployment coming forth or their employment of being able to get a job next week. These things are so germane to the livelihood of human beings today, too. It seems like it has even put us in a furthering of distancing farther from where we wanted to go. The notion of community empowered to ask those questions to bring it down to where, so what am I common sense analysis that community people are speaking in problems. Researchers think research questions, hypothesis, methodologies, research design. Community people don't have the luxury of dealing with that. We can tell you what our problem is. Now, suppose you want to take that problem and put it in an equation that can render itself into a hypothesis or can render itself into a proper research question that can be posed to researchers to answer. In that case, that's wonderful, but not only do we not have the skills for that, that's not our interest. That's not our priority list. So, we've got to do some shifting, I think, in how we think about who we're making responsible for asking the right questions or forming the right research. I keep hearing in the work that I'm doing right now about community-led research or patient-driven, and I keep saying to some of the powers that be, that's an ideal situation. I'd love to see that happen. Right now, I want you to have the community at the table. I want you to hear the community's voices and the concerns that they have about the work that's going on. I want you to listen to the voices of the people who say, I cannot trust you to take your vaccine, and you dare to listen as they tell why they can't trust. Those are the things that I am most concerned about right now. Those are the ways that we're going to move the dialogue further as we can really reassess where people think about in this present day and time; what is the most important to the people that's most impacted?

[Profound listening 20:55](#)

Health Hats: Yah. It's funny because what you're talking about is profound listening. This is probably blasphemy for me, but my experience is - this sounds so weird - I don't think researchers by and large are that good at listening.

Neely Williams: No. I can agree with that.

Health Hats: Oh, that's such a problem, huh? Goodness.

Neely Williams: That's not been one of the skill sets that they would talk, they needed to develop, that you needed to listen well, to assess a problem. Not so much. That's not necessarily the pathway to becoming a great researcher. Purchasing, maybe, fundraising. Yes, absolutely. Getting through tenure, making full professor, and having a set of skills and set of things you learn. These are things you have to do to get this done, but nobody ever said, 'to do good research, you have to learn how to listen to people that you're researching or to the ones most impacted by the problem with research.' Nope. Maybe that's something some of our behavioral sciences can lend to the field of research in that they say for a counselor to be good at what they do, they have to be able to listen more. So how do we take this now and shift this and say, okay, for researchers for you to be good at what you do, but you have to be able to produce research that matters, you'll have to learn how to listen to the people it's most impacted by that?

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Listening while on the PCORI Board of Governors 23:31

Health Hats: I was just appointed to the PCORI Board of Governors, a humbling and awesome position. This business that we're just now talking about - listening to what communities, what problems communities are dealing with has to be at the core of my mission in the seat. I met with Nakela Cook, PCORI Executive Director, the other day to introduce my board seat. I said that my priority was health equity. But actually, I think listening is at the core of equity. Before you can deal with the power dynamics that we were talking about, you've got to know about listening. Do you have any advice for me? I want to make something of this position.

Neely Williams: I want to say to you, I certainly appreciate your approach, Danny. This is not our first conversation since you had this appointment, and I am excited about this appointment for you. I was excited even in the earlier part of the year when you sent out the solicitation of letting us know you were interested in that position and foster advocacy to that end. And I'm grateful for what is the culmination of. I believe that you are a man of wisdom and the way you are approaching it. It speaks so well to me of who you are because if you had a different agenda with this position, taken a different approach, but because you truly are who you have been representing yourself to be on the PEAP. Now I'm looking at the other roles that we've seen you play in the community. I do not doubt that you will marshal this opportunity or this responsibility to benefit the community, people who were impacted by the inequities and the injustice in our streets, then replicated in our research. I'm grateful that you have that position that you are the one.

Health Hats: Thank you. I'm challenged to do this listening business. It's a challenge as you rise in an organization. I found that when I went from being a director of something to a VP (Vice President) of something and in the C suite, it gets increasingly difficult to stay in touch with what's happening in the street; what's happening on the ground; what's happening in the office, what's happening in the clinic.

The forces are different, the responsibilities are different, and the people you talk to most of the time are different. You sit at a table talking to the same people every day, every week or every month, or whatever the cycle. That challenge of staying in touch gets harder. I don't know if it gets harder, because it's always hard, but it's different. The PEAP, the Patient Engagement Advisory Panel, is meeting next week, and instead of being an active participant, I'm going to be a lurker. I'm going to listen. I want to try to do the same at other advisory panels. That's one way to listen. Another way to listen is podcasting like this, you and me. That's another way to listen. I'm nervous about my ability to keep listening. It's not a given.

Neely Williams: I think the ability to listen is often driven by our tendency to be distracted. The more grounded we are in where we're going, where we're coming from, what my experiences have been, what we perceive to be a success, or what we are. All those things we'll have a significant impact on how our ability not to be distracted.

Health Hats: I think you're saying that's a sort of meditation. Listening is meditation.

Appreciating a different role, different responsibilities 29:02

Neely Williams: Yes, it is. And it's a presence also. We do listen by intentional, active listening. We have all of that engaging, listening, these different terminologies for listening and behavioral science. But we also have to listen by being present with folks and just sitting back where they are. So, you're able to listen as both a former member of the PEAP and now being a new member of the governance board, being able to shift that hat. Because the people who you will most likely interact with are the people who knew you as a PEAP member, but the people who are looking on might be the people who are saying, let's see who this person is coming into this governor's role. Is he serious enough? Is he whatever? You're the one who has to balance your ability to listen as you have new responsibilities. When you were there as a PEAP member, such as me, you didn't know about those responsibilities. Those weren't things that were on your plate so that you could blast it. I get that. I have the freedom to say something that you may not have the freedom to say because you're in a different place. You have a different level of responsibility. I take that to the same degree when it comes to my community. And I have a level of responsibility for my community. It's not just about being able to sit in the seat and say, I'm here to represent my community. Still, I also have a responsibility to represent my community and the voices of my people who are in pain and who are suffering, who don't know what to make of all of these things that's going on. And they're not able to get a grasp on how the pieces are shifting and where the power is going. Who's going to make the decisions? What's going to be researched and when? What would a vaccine look like, and who will get it? Why will it benefit this group and not benefit this other group? And how are you going to use this information? Right now, as we hear it played out over airways, we must get black and brown people involved in the tribe. Is it a call to get us involved, or is this a set up to say, since you're not involved and can't hold me responsible? These are all undercurrents. These are all things that are there. These are all people's survival instincts, and we've learned how to carve our weight, make our way, navigate our way through the thickness and the brushes, and the other thickets of life. And now we are facing something unprecedented. We've never seen this before. Don't know how it's going to play out. We don't know what's going to happen next. And we have to be diligent in our efforts just to be present with the people. So, what if they wear me out for working with Vanderbilt and these new circles. So what? Is my self-esteem or my feelings so soft

on my shoulders that I want you to think I'm doing good? And then you don't think I'm doing good. Listen, people are suffering. That's my advice to you. Be the authentic you. The most authentic you that you can be responsible for the risk with the responsibility. So, you can be present. Because it won't do us any good for you to have been selected, and you cannot hold your own in that setting. You can see we need you there because there are many you there, but not many of you have the sensitivities you have.

Health Hats: This is a very sober conversation, Neely. I didn't think I was going to get into this in this conversation but thank you. Thank you. Wow.

Mutual refreshment 33:36

Health Hats: What should I be asking you, or what should we be talking about that we haven't?

Neely Williams: Danny, we press our way through this work every week. I can only imagine for you and many others like yourself and myself that we get to Friday, and we exhale. We try to incorporate normal life into the next couple of days - just doing the ordinary thing, washing dishes for myself, or cooking a meal or whatever. And then Monday morning, I'm ready to go again with whatever meeting, whatever I have to do to be a voice for the voiceless in this process. So those are the things that keep us afloat every day. Some of the things that we've had conversations about today have already begun to refresh me and for the journey next week. Oh, you reminded me that even as I speak it out, that we have to listen. I also have to continue to cultivate my listening skills and listen to my external and internal. The voices of those that are clamoring from the outside that does not understand, cannot understand, will not understand them. The processes and the ways that we have to go at this, as well as my own internal turmoil. No, there's something, there's a part of me that sometimes just want to shuck it. Just say, this is not changing. I've been at this a long time. Let somebody else take the whim of this. I've had to go back and forth on something here in the last day or so that's just redundant. It's not necessary for me, but for the people I'm seeking to equip to go with me on this journey, it is necessary because they haven't heard the conversations I've heard. They haven't had the conversations I've had. They haven't been in some of the decision-making places I've been. So, they can't be held responsible for the things that they don't know.



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Transparency, an antidote to mistrust. 35:47

Health Hats: So that's the other side of it. One side is the listening part, and the other part of it is trust. You spoke earlier in the conversation about this epidemic of mistrust, those might not have been your words, but you did say mistrust. Part of it is listening, but the other part is being transparent about how the sausage is made. Which I don't know is is totally like absolute, like you got to know every gory detail, but still, that when you're saying this redundancy, I'll bet part of that is saying over and over. This is how this is; it's how it works right now. It doesn't have to stay this way, but this is what it's like now because my faith in people is mostly - because nothing is always, but mostly when people understand circumstances, they're more able to meet challenges. The other side of this being on the Board of Governors is to share this is how this works. Maybe the constituency for that isn't necessarily the public at large, but people like you. People who represent communities, people who communities trust. So, a whole other side of being out there with this is what's going on. This is how your tax dollars are spent. These are the priorities right now. What do you think?

Neely Williams: I think you're on to something in that you have a unique opportunity; others may not have the constituency or the company or community that you had, right? You may have the same skills. You'll know what to do. There's no lacking in capability, but you didn't come the same way. No one else on the Board of Governors will have sat on the PEAP.

Health Hats: Not at this time. And I've been a merit reviewer.

Leadership, perception, intoxication 38:51

Neely Williams: All right. Those are some things that you bring in a different manner to the Governors. You asked, do I have advice for you - hold on to that? Don't dismiss that as not important in the grand scheme of things because those are the things that those glasses you're wearing; those are the things that tint the lenses. When you can take those things and with your ability to articulate, with your skills, to understand where they're coming from, you'll be able to give them a richness for making decisions that they would not have had without having you. I have wrestled with having been chosen, this whole notion of being the chosen one or being the one who can verbalize well, or the one who can pull through. When we only think about the privilege, we miss the rock. We miss the boat. It's about responsibility. In our faith tradition, the dynamics of their approach to being a minister is grounded in perception. If it's being upfront, the one with the mic, the one where everybody sees, the one who everybody knows, the one who everybody can call you Reverend by name. If that's your focus, then you got to approach that different from someone who like myself or others who are laborers in the vineyard, who came to this thing, not to be seen, not to be hoisted up. And the most glorious ways and all of us not to be cavalier about fame and influence. It's intoxicating to anyone - recognition. It's nice to walk into a restaurant, and people start pulling out chairs for you. They know who you are, and you have never seen them before. It's easy to get caught up in that. But when you have to go back to why you're in it. See, I go back to those four young men who many of them have all long since left this earth, but they had a life. And when I can see their faces, then it takes all the shine off of any little glorification that my little mind could conceptualize about where they called me Reverend. When they ask, I tell people why don't you tell people you are Reverend Williams or that you are a pastor? I said, I would hope that my behavior will tell you that rather than me telling you that verbally, not because I'm trying to be modest or incognito or some false sense of something. But I can drive up to a drive-up window, and that attendant will say 'have a blessed day.' I drive away from that window saying, 'What made her or him feel that they needed to use the word blessing with me rather than have a nice day or get out of my face.' You don't want it. And though that's the piece. I never said to that person, good morning. I'm Reverend Williams and I like my sausage and biscuits on the left or the right and the coffee piping hot, and you don't have to do all of that. We don't have to do all that. You don't have to change to be on the Board of the Governors.

Health Hats: You're a wise woman. I think we will have more conversations because I'm going to need some of that. I'm going to need some of that inspiration to keep going sometimes.

Neely Williams: If the role I can play is to support you in any way. I can say that during your podcast, or you can edit it out, or you can whatever. But this, with the sincerity of heart, we seek to do the best we can for the people we serve. And it doesn't matter who is the one to do whatever it is. We all are needed. I'm trying to say so any conversations, Danny and I truly mean that from the depths of my heart, and I knew you from a distance and the last year I've come to know you from a little bit closer up

in the PEAP. And I certainly more than ever understand how the PEAP is the greatest of community that we come, and we encapsulate each other. We don't judge each other about what your phraseology is. You got your Freddie's, and you got your Als, and you got your Dannys, and you got your Neelys. You got everybody that's part of your Beverlys and all of us, that's part of it. And we are all a part of one. Call anytime, email anytime, reach out anytime, and you will often be in my thoughts as you go forward. I know that you're going to do a wonderful job. I know it's profound, but you'd be at this time.

Health Hats: Thank you so much. And thanks for joining me for this. I appreciate it. This has been fun. Great.

Neely Williams: I'm going to continue to keep you in my thoughts. I'm going to hop off and hop on another meeting now. Good. Okay. Okay. Bye-bye.

Reflection 44:56

Should I be surprised at the artful ministering I received from Neely Williams? My spiritual health can always use a tune-up. I gravitate toward spiritually healthy teams, groups, and settings and away from the opposite. I leave clinicians who aren't themselves spiritually healthy, have left jobs, and dropped out of groups. Personal spiritual health deserves, craves community spiritual health. Inclusion, healthy critique, acceptance, calculated risk-taking, listening, humility demonstrate spiritual health. How do you create and nurture spiritual health for yourself or your communities?