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## Introducing Keith Scott 00:53

A few weeks after I started as Vice President of Quality Management at Advocates, Inc., I attended my first Board committee meeting. Advocates champions people who face developmental, mental health, or other life challenges. They partner with over 23,000 individuals and families to shape creative solutions to even the greatest obstacles. Advocates says, “First, we listen. Then, together, we do what it takes to help people thrive.” Midway into the meeting, a gentleman spoke for five full minutes in what seemed to my naïve ears as stream of consciousness passion. I thought, “What is this man saying? Wait, everyone’s listening intently.” When he stopped, the Medical Director said, “Let’s take a minute and digest what we just heard.” Again, I’m thinking, “Everyone’s silent! What’s going on here?” Then I stopped and thought, “Wait, he had an important point to make.” After the silence, attendees started with, “I think I heard you say this…” After another five minutes of discussion, a decision was made sparked by the gentleman’s comments. A good decision, a different and unexpected decision. After the meeting, I spoke with my guest, Keith Scott, who told me that the gentleman was a person that made use of Advocates services and that many, if not most, of Advocates governance committees included people supported by Advocates. My mind was blown. Let’s listen in to my recent conversation with Keith.

**Health Hats:** Keith Scott, I'm excited to be talking to you. I haven't seen you in a few years. You’ve been important to my education about peer support and self-advocacy. I think about you often in the work I do now. How do you usually introduce yourself to people?

**Keith Scott:** Professionally, I introduce myself as Keith Scott. Depending on the situation and if it's appropriate or desired that I use my job title, I'll introduce myself as Keith Scott, Vice President of Peer Support and Self-Advocacy. Generally, I introduced myself as Keith and, and then see where the conversation goes from there. As people are more curious about me and what I do, then I'm happy to answer any questions they have.

**Health Hats:** Where were you when you first realized that health was fragile?

**Keith Scott:** I was in my late teens when I had my first hospitalization, a psychiatric hospitalization. That wasn't something that I wanted, but it was something that my family felt was necessary at the time. It was through the process of that hospitalization and coming out on the other side of it that things

changed for me significantly. The most important of those changes and something that I struggle with from that moment to this moment is needing to take medication in order to be well, stay out of the hospital, and have a shot at a good life. Being confronted with that situation was the first time I realized that maybe I wasn't whole as a person without medication or maybe there was something wrong with my brain. That was probably the first time that I started to question that life was going to be different, if that makes sense?

### Peer Support: equilibrium, reciprocity, mutuality 05:15

**Health Hats:** Totally. Keith, before I met you at Advocates, Inc., I was familiar with peer support. I had worked in behavioral health and addiction recovery, not as a clinician, but as a quality management professional. But I didn't appreciate the nuances and the opportunity of peer support until I met you. I'm going to take a stab at what I think peer support is, and then you set me straight. I think peer support is offered by people who've had lived experience similar to mine - whoever I happen to be - and have reached some equilibrium in their lives. They offer informed listening, mentoring, guidance to people who are newer to the circumstances or are desiring to learn and grow towards more equilibrium. And that peer support system has also refined the peer's communication skills and maybe their systems thinking to better serve their supportee. I know that I've just given a general definition of peer support as opposed to specific for behavioral health. Can you explain it better for people?

**Keith Scott:** Maybe not, Danny. First, I really liked the term *equilibrium*. I never really thought about where people want to be in their life as *equilibrium*, but that resonates with me. So, thank you for that. I'm going to steal it. Peer support, most simply, is one person helping another person with some reciprocity. The platform for the *reciprocity* is a shared lived experience. Plus, this idea of *mutuality* - that I have something to give you, but you also have something to offer me. Non-professional peer support can look and feel a lot like friendship. I've had that experience in places like 12-step self-help groups where the playing field is relatively level. Professional peer support differs in that one person is often paid. Sometimes it's a volunteer, but the way that we do it at Advocates, one person is paid, and the other person is not. We try to be transparent about that because effectively, we can't really be friends. But the relationship often feels very much like friendship, often as genuine affinity between the two people. Often that's because of the shared lived experience - I've been through things and you've been through things. They may not be identical, but they're close enough where I feel like you're somebody who can truly understand what I'm going through, what I'm thinking, and how I'm feeling. I hope that you would feel similarly about the things that I'm sharing with you. It's not any more complicated than that. Part of the challenge is keeping it as simple as that. When you professionalize these relationships, there's a tendency to want to define and manualize and regulate and provide oversight. Some of that is necessary, of course, but we must be vigilant not to allow those mechanisms to start to pull what we do out of this realm of mutuality. That's the chief struggle we constantly find ourselves in: how do we stay in this place of mutuality when forces are trying to pull us in other directions?

**Health Hats:** Say a little bit more about mutuality. You said earlier that we both have something to contribute.

## Everybody possesses wisdom about themselves 10:18

**Keith Scott:** We come at this work with this idea that everybody possesses some innate wisdom about themselves, about what they've been through. We tend to minimize that in ways that are not necessarily helpful either to ourselves or to other people around us. This mutual relationship is built on the idea that I have something to offer you, and you have something to offer me. The connection point is around our shared lived experience. We want to be careful, particularly as professional peer supporters to not put barriers between the other person and us if we can avoid it. The first barrier is that one person was paid, and the other person is not. Above and beyond that, there were all sorts of things that the field would like to insert between the two people. A potential barrier to the mutuality could be if I were to read your clinical chart before meeting you. I now have information that's been provided by multiple third parties that may not be accurate from your perspective. You might see it as a violation of the unspoken contract that we have between one another. The same is true if I did assessments or evaluations or if I write clinical notes or if I have an opinion or an agenda with regards to whether you should or shouldn't take medication. Or I have an agenda with regard to what you should or shouldn't do with your own money. Or I take restraint training, which is often euphemistically referred to as crisis intervention training. Any of those things, I would argue all of those things, pose potential barriers to the mutuality that can exist between the two people above and beyond the fact that one person is paid, and one is not. That's the foundation of everything we do. We try to be vigilant not to let these other things get between the person and us. Some people refer to it as peer counseling. We don't see it or operationalize it that way. We don't give advice. We don't tell people that they should or need to do anything. We try to help the person understand that they possess this innate wisdom about themselves. They can tap into that. Often that is Information about what other people have done, information about what's available in terms of resources and education in the community. Sometimes it's about more than that. It's about having someone who says over and over again, “I don't know the answer to your question, but I believe that you know the answer to your question. I'm here to provide you with any information you need, support to access resources in the community.” or just to be patient and listen. And through that process, when the other person starts to understand that I'm not going to force them to do anything. I'm not going to coerce them to do anything. I'm not going to convince them that they need to do anything. The magic of peer support if you will, starts to happen. And what's key to this process is patience and kindness in all of the interactions. It boils down to be patient and to be kind to get people to trust you in a way that they've not been able to trust other professionals. If at the end of the day, I think what's valuable about this is that the person understands that they always have someone that they can go to and that they can tell sort of the most concerning things, the most worrisome things, the most traumatizing things about themselves to get whatever help and support that they need. The worst possible thing for any human being, I think, is to be wrestling with something like wanting to end your life, and not have someone that you feel. You can absolutely trust to tell that too, and that they won't do something to you. They won't act on your behalf. They won't take away your personal agency to continue to make decisions for yourself. And I think that's kind of really what's special about this is, these peer support relationships engender a level of trust that is difficult to replicate in any other type of professional relationship is all of those other professional relationships have attached to them this responsibility, to communicate about, not just with, but communicate about. And often the way that that's done, particularly in the mental health system, can be extremely depersonalizing. The way we talk about people as the sum of their symptoms, or we used diagnostic and

pathologizing language to describe them. To convince someone that the relationship is different often can take an enormous amount of time and we're prepared for that. We understand that it's a marathon and not a sprint. Many of the people that we attempt to connect with through peer support have had the experience for decades of not being listened to, of not being allowed to make choices about themselves. It's like nothing they've ever experienced before in the system.

### Impact learning 16:14

**Health Hats:** So, this is a different angle on professionalism. You're not born a good peer support person. it's a journey and it's trial and error. It's learning. Before I met you and the work you've done, I don't know that I've ever seen such a learning environment. I wasn't a peer support person but working with you, I appreciated how much I had to learn. I felt safe learning about peer support. Everything you just said sounds ideal. You seemed to me to be a mindful person thinking about the words you use, the setting. How have you fostered that learning environment for people providing peer support or working with a peer support ecosystem?

**Keith Scott:** That's an excellent question. I spend a lot of time focusing on that. It's a continuous process. When we hire someone to do peer support work at Advocates, we want to make sure that people are as trained and as educated about the role as they possibly can be, even before they come to us. An organization in Massachusetts, The Transformation Center, has been providing statewide training and certification for peer specialists for 14 or 15 years. Eighty hours of training covering the basics - everything from "how do you share your own personal recovery story" to "how do you deal with complex situations in which you have to confront a situation that is not supporting and nurturing a person's recovery process" to "how do you help a person envision the kind of life that they want when they've been in a system which is not supported or encouraged"? In some cases, it's decades. That's where people start. Then we add 40 hours of intentional peer support training. We train for understanding how housing works, how the eviction process works, on SSDI and SSI, and other benefits like food stamps and section eight housing. We want people working in peer support roles to have as much information and as many tools and skills as possible because it's a complex system that we're trying to help people navigate. The more skills, the more training, the more confidence we have in our ability to help a person navigate that world. We collaborate all the time with people who aren't peer support professionals like psychiatrists, therapists, senior clinical staff, people working in direct support roles. We offer periodic training. We do a presentation for our new hire orientations, which is a brief introduction to peer support and this idea of recovery. To me, recovery means a person moving their life forward in a positive direction. Again, I really liked the term equilibrium, to try to find that equilibrium in their own life. We introduce peer support in new hire orientation. On an ongoing day to day basis, everybody working in a peer support role is constantly educating and coming at questions from a place of genuine curiosity. An example might be, walking into a group living environment as a peer specialist and finding out quickly that their house locks up the knives. People who live there have significant mental health challenges and the house locks up the knives. The people in peer support roles feel like staff may be unaware of the message that that conveys to the people that they're trying to help. From my own lived experience and from that of other people on the team, that message is "you're dangerous." Once somebody thinks you're dangerous, that's not a recipe for trust. I don't trust anybody who assumes that I'm dangerous and takes actions based on that assumption. So, when we're in that program, it's not as though we jump up on our soapbox and say, "you can't lock up knives. You

understand how damaging this is." We approach it from this place of curiosity, trying to understand ourselves better, why people make these decisions. But also try to use it as an opportunity to help other people understand, implications for those kinds of decisions that they may or may not have been aware of or thought through. So, we'll say things like, "help me understand why you decided to lock up the knives." Invariably people are reticent to say these things out loud because they understand on some level. that it's hurtful. But what they say is in low tones, almost a whisper, "these people are mentally ill." That starts to open the conversation, "tell me why you think people who are diagnosed with these psychiatric conditions are inherently dangerous?" That leads us to a larger conversation about what it is we're trying to do and why and how. We try to have those conversations over and over and over. For many people, it's the first time they've heard this idea. Also, there's enormous turnover. So, the people that I'm having these conversations with today and tomorrow and next week will be gone in three months, six months, a year, and we have to continue to have that conversation with a whole new group of people. This is a constantly happening, constantly evolving process of educating everybody about what peer support is and what it isn't and help them understand why it is we've made the decisions and how we want to provide it. Every day we help people better understand what it is that we do and why we feel like it's so important and why we're asking them to join with us around things like not using pathologizing language. Pathologizing language depersonalizes and starts to treat the other person as being distinctly separate from us. A lot of us interpret that as being less human than the rest of the world. I don't think anybody intends to communicate that message. So, we try to use that as a basis for a conversation that people want to buy into. Because people who come to work in this field do so because they have a strong desire to help people. And often they come to the field, whether they're even cognizant of it or not because they've been in a situation in which this kind of help has been provided or it's not been provided. Yes, education and training and ongoing learning are essential components to what we do and take up a sizable chunk of our daily activity.



### Peer support at the leadership table 25:32

**Health Hats:** Before I worked at Advocates and I met you, I had never seen an organization that had peer support sitting at the table of governance. In my work now, in the introduction to this podcast, I often introduce myself as a two-legged cis-gender, old white man of privilege. I'm often invited or invite myself to sit at a lot of tables. It's part of my responsibility of being a two-legged cis-gender, old white man of privilege to open more seats at the table of governance, operations, learning for people with different experiences than mine. I've been inspired by working at Advocates and seeing that peer support has seats at so many tables. That the people we support have seats at so many of these tables. How did that evolve for you and how has that been for you to have a seat at the table of governance as a VP?

**Keith Scott:** As somebody who's been involved in the mental health system for the last 43, 44 years as a service user and for the last 33 years as someone trying to provide services from this particular perspective, it's always seemed clear to me that for the system to change in a direction that's going to be beneficial to the people that it serves, the folks that it serves have to be involved in the decision-making process. They must be involved in planning. They must be involved in every conversation about their treatment. If the fundamental idea is recovery as a personal responsibility, for anyone to hold someone accountable, you also must allow them all the liberties and privileges and rights of everybody else. It was clear it wasn't happening. I've always had this belief that I wanted to be at the table. I know what it feels like to be in the hospital and have very powerful people in a room behind closed-door making decisions about you that you're not involved in. That's incredibly disempowering. It doesn't create a situation in which you trust the people providing your care. For me to trust you, I have to understand why you would meet behind the closed door to decide my fate without involving me. I've been incredibly, incredibly lucky, beyond words, to work for the agency that I worked for. Beth Lacey, Senior Vice President of Community Services, hired me at Advocates. She had the vision of providing the person leading peer support and being responsible for integrating peer-supported a seat at the table at the highest levels of the organization. When she decided to do that, not a lot of other provider organizations were doing it. For several years, I was the only person in a role like mine that sat on the senior leadership team and had a voice that was supported and encouraged. It's one thing to get a seat at the table. It's another thing to feel empowered to use that seat as a platform to bring to light some of the issues that affect the people that we support. I've always been encouraged to do that. I can't recall any time inside Advocates where there was an attempt to shut that down or to silence me or any of the members of the team. It's enabled us to integrate services fully. We still have a lot of work to do. I've appreciated the continued support over 13 years. I appreciate the continued support to allow this to evolve, to have difficult conversations about why we're doing the things that we're doing. Like holding the line on not having peer specialists do clinical documentation, administer medication, control people's money, or read charts, et cetera, et cetera. That's been a difficult line to hold. Other providers have done different things. We've decided that this is what we want to do. I had incredible support to be empowered to grow the team from one part-time person and me 13 years ago, to the point now that we have 35 peer specialists and eight recovery coaches and a family partner. It couldn't happen without the support from leadership, Beth Lacey and Diane Gould, the CEO. I feel incredibly valued. Over time that's translated into the entire team feeling incredibly valued. Our former medical director, Chris Gordon, routinely sent psychiatry interns to the peer specialist team to spend a day shadowing us, to attend our team meeting, to learn what it is we're all about. At Advocates, Diane Gould, our CEO, when confronted with a difficult decision with an impact on the people that we support, will come to the peer specialist team meeting, lay out the dilemma, and get feedback from people. She genuinely takes that in and uses it as part of her decision-making process. We spend a good portion of our time now collecting data and trying to justify on the value of what we're doing through outcomes, so we can say that we're making a difference. Sometimes I feel a little bit like the language police or the politically correct, social justice warrior. It's coming from this place of understanding the power of language. Language generally shapes attitudes. The people we serve understand that. They pick up on it very, very quickly. They see the difference between somebody who refuses to use pathologizing diagnostic language and someone who doesn't. We don't use words like clients or caseload or super utilizer, or patient or consumer, or decompensation. Jargon that exists only inside the mental health system. The point of not using that

language is doing everything that we can do every day not to reinforce that which is most dangerous in the psychiatric system - depersonalization, not seeing people as fully human, not connecting with them around shared, lived experience, marginalizing them as a result. We're trying to help people understand that when you've gone through years or decades of this kind of experience and you felt disempowered and you've given up on making choices about your life, every little thing that we can focus on that helps change the way that you see the people trying to help you is important for us to focus on. We also consider the environment. When we operate programs and the building has peeling paint and broken clapboards. You go inside and it's dirty and there's no art on the wall, and no personal items to suggest that this is a person's home. When staff is in the office with the door closed and the people who live in the house are isolated and by themselves for long periods of every day. Those things are incredibly damaging to people above and beyond the damage that they've already suffered. We raise that as an issue for everyone working at the organization. We try to live by the principle, first, do no harm.

### Integrating with medical care 35:34

**Health Hats:** Wow. Let me shift a bit. As behavioral health becomes more integrated with medical care out of pocket costs are getting higher and higher. What kind of pressures are you feeling as a leader, as a result of those external forces?

**Keith Scott:** We're spending a lot of time trying to plan for the medicalization of peer support. Insurance companies are now getting on board and seeing the value - not always the full value or not always the value and the context in which we would like them to see it. But they're looking to buy these services, for their members. It's a great opportunity. We would love to be in more of the medical world providing this kind of support to people, but we're always worried about the cost with respect to how we believe peer support services need to be provided and potential barriers to mutuality. One of those being a lot of the insurance companies want documentation to bill. All the insurance companies require medical necessity justification that naturally leads to diagnosis and the use of language that we find hurtful. So, we wrestle with how much compromise can we make before we start to mitigate the impact that peer support can have. We're dipping our toes into the water here and there and working with a couple of private insurance companies which so far has been wonderful partners and has encouraged us to do this work the way we feel like it needs to be done. We've been concerned about these opportunities to grow beyond the mental health system. I think that would be incredibly valuable for lots of people who've never experienced these kinds of relationships. We want to be cautious and thoughtful about the price that we would pay through those compromises. We could learn from the medical world. My experience of being a patient in the medical world includes my medical doctor never makes a decision about me without involving me. I'm always engaged in the conversation about what do I want. What do I hope for? How are my experiences impacting my overall health and wellness? Often all we're asking for in the psychiatric system is for people to do the same. Not doing the same thing, not making decisions about a person without involving them extensively in their own care. There's a lot the mental health system can learn from the medical world.

**Health Hats** Keith, you're one of my heroes. I have learned so much from you. We didn't work together that long, just a couple of years, but you moved my work and my advocacy in a different direction. I appreciate it.

**Keith Scott:** Thank you very much. Danny, you give me far too much credit. In your time at Advocates, I appreciated your openness to these ideas, your willingness to seek me out. I remember when you first got to Advocates, you reached out to me to set up a meeting to sit down and talk about what it is I do and how you could be helpful to that. I deeply appreciated that someone in your position at the organization wanting to understand this better and wanting to understand how you can support it. You left an indelible impression on me as well.

**Health Hats:** Thanks, Keith, for taking the time.

**Keith Scott:** Thanks for giving me the time, Danny.

## Reflections 40:51

*Everybody possesses innate wisdom about themselves*. *I don't know the answer to your question, but I believe that you know the answer to your question. I'm here to provide you with any information you need, support to access resources in the community or just to be patient and listen."* Powerful words. *For me to trust you, I have to understand why you would meet behind the closed door to decide my fate without involving me.* More powerful words. *Peer support is patience and kindness*. Even more. Let's take a couple of minutes and digest. No wonder Keith and Advocates, Inc. have had such an impact on me and my activism.