



FOUNDATION FOR Health Care Quality

WASHINGTON PATIENT SAFETY COALITION

Washington Patient Safety Coalition
New Wave of Healthcare Podcast
Episode 7: Patient Safety and Disability
Episode Transcript
Episode Released: Friday, December 2, 2021

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0:00:00

Steve Levy (SL): *(Intro Music in Background)* Thank you for joining the Washington patient safety Coalition's podcast series. Today we're going to be talking about individuals with disabilities in the healthcare system. *(Intro Music Fades)*.

People with disabilities face many barriers to good health. About one in four people in the United States have a disability. According to the World Health Organization, the number of people with disability are dramatically increasing. This is due to demographic trends and increases in chronic health conditions, among other causes. Almost everyone is likely to experience some form of disability, temporary or permanent, at some point in life.

The Center for Disease Control states that people with disabilities face many barriers to good health. Studies show that individuals with disabilities are more likely than people without disabilities to report having poor overall health, having less access to adequate health care and engaging in risky health behaviors including smoking and physical inactivity.

The World Health Organization noted that people with disability are disproportionately affected during the COVID-19 pandemic, and notice they use the present tense because we're not out of it yet. This was made apparent here in the US and certainly in Washington state where COVID-19 got its foothold in a long-term care facility. It's unfortunate that it took a pandemic to raise our awareness of the healthcare issues people with disabilities face.

Today we're going to discuss the barriers that people with disabilities face in healthcare, with Kim Connor, Executive Director of the Washington State Independent Living Council, and Mark

Leeper, executive director of Disability Action Network Northwest. What I'd like to do first is have them introduce themselves and talk a little bit about their background, so Mark let me turn it over to you. Tell us a little bit about yourself and your organization.

0:01:55

Mark Leeper (ML): Well, thank you, Steve. I'm Mark Leeper and I was actually born in Idaho, I now live in Washington State. But I also lived part of my life up in Canada, so I've had that experience of living on two sides of an international border.

I have a personal history of mental health issues that led to a significant involvement in the medical system over the course of a number of years. I'm always happy to have contributed lots of money to various expenses in the medical field, I'm sure. I am a suicide survivor, I never saw myself as working in the field of disability, and I really never saw myself as a person with a disability. And some days I still struggle with that, partly for reasons that we'll talk about later I'm sure, just that whole sense of what is a disability.

I work with Disability Action Center Northwest. It's one of about 400 Centers for Independent Living across the country that are characterized by being run by people with various kinds of disabilities. I always talk about us as having kind of a two-prong approach. We work with individuals with a disability, any kind of disability, to realize their goals for living as independently as they choose and having the control over their lives that they choose. And then we work with communities, to try to help them understand about the broad nature of humanity as it pertains to disability. And each of those kind of dovetails with the other.

It's, I think, an interesting, interesting, interesting process because so many people with a disability have not ever really thought about it in that same way. So we end up training both communities and individuals. We've been around since the late 70s, the Centers for Independent Living and Disability Action Center, which is actually housed as its primary location in Moscow Idaho was formed in 1980.

Washington currently has five centers with four of them based in Washington. And again, all characterized by being run by folks with a disability and based on that peer model that we as people with a disability know an awful lot about our own lives and can kind of support each other in gaining control over them.

0:04:35

SL: Thanks, Mark. How about you, Kim?

Kim Connor (KC): Thanks Steve, I am Kim Connor and I work for the Washington State Independent Living Council. I've worked for them for coming up on five years now. I have always worked in the social justice arena in my career. And now I'm working in the disability community which has been very interesting as I learned more about disability and self-

determination and what that looks like for individuals, reflecting on my own family, and the history of mental health disabilities in my family is quite introspective for me.

I work for a council, that is, by law made up of at least 51% of people with disabilities that identified having a disability. We are a governor appointed counsel and we are a statewide cross-disability network that advocates, educates, and collaborates with the broader community, and around disability issues and systemic issues in our systems that create barriers for people with disabilities. We work very closely with the centers for Independent Living we are actually through the rehabilitation tied together as equal working partners.

So we work together as a family and just like a family we, for the most part work well together and sometimes we disagree, and that's okay. But ultimately our goal is to serve the people with disabilities in the state of Washington.

0:06:54

SL: Kim, do you find that the state is very supportive of the work you're doing?

KC: I do. We sit kind of funny we are, like I said, a governor appointed organization, but through federal law we sit independently. Although physically we sit within state offices with the Department of Vocational Rehab in Lacey Washington. Because we sit inside of that department we have those relationships that we build with within DSHS, Department of Social and Health Services, and other agencies – like the Department of Health, actually through the COVID-19 pandemic and I'll talk more about that a little bit later - we've really developed our relationships with them and the emergency management departments at the state level as well as local levels. Some really good partnerships have come out of the pandemic.

0:07:58

SL: That's great.

So you know I guess I'd like to start with something really basic for those folks who are listening who may not, you know, really be familiar with it. When we talk about people disabilities, who are we actually referring to? And I know Mark, you already mentioned, mental health experience. Tell me more about, what is it disability and who's impacted?

0:08:25

ML: Well, that's an interesting question because it kind of goes back a little bit to Kim's response about the state supporting the state Independent Living counsel and independent living. There are numerous traditional systems. And then there's kind of what really is out on the street, and so on.

So, in a real sense and official sense you have workers compensation will have one definition of disability, Social Security has a different definition, the Americans with Disabilities Act talks

about somebody with a physical or mental impairment that substantially limits a major life activity or somebody with a history of an impairment like that or who might be seen as having that sort of impairment. All of these things are kind of the official view. What we're basically talking about is somebody that has an impact on their life, that is occurring because of something that we would say is a physical or mental impairment. I guess the ABA is really the broadest definition. We estimate about 54 million people in the country are covered by that definition.

I think it's it's really hard because the image or the view that people have of disability often is focused on one particular group, and it's whoever they identify with initially is the first thought that comes into mind is somebody who uses a wheelchair. So it's a physical disability, and then oh yeah somebody who's blind so then they you know they think about that and then somebody who's deaf or somebody with an intellectual disability so it really depends people tend to compartmentalize. That definition of disability, while it's really really broad, tends to be interpreted very differently by different folks.

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KC: And to add that you have the unseen disabilities, right. So you have people that have cerebral palsy in the early stages, or MS, where you visually cannot see that but that doesn't mean that their life is not altered or they don't do things differently because they have a disability. Or people that have chronic pain, severe chronic pain, you can't tell by looking at them, that they have a disability but they are you know managing their lives, making sure whatever their regimen is so that they can function the way that they want to function in their life is different than the way an able body person functions in a day.

ML: Traumatic brain injury is another great example because we're seeing so much in terms of the accumulated effects of impacts like playing football, playing soccer. And so those things that really aren't seen sometimes are discounted for a long period of time. But that's part of that disability community and it really, really affects the medical community a lot because they can have such an impact on person's health care.

SL: You know it's interesting, as I listened to the two of you, you come to realize that a disability is not necessarily specific to a group of people. We all at some point in our lives, might, you know, might have a disability or different degrees of disability. I think, as someone who maybe temporarily does not have a disability, that it's really not realistic to look at it from afar. You know, you have to think that this could happen to me, or in some respect it is happening to me already and I may not even recognize it. I think it seems like my naivety of growing up in the healthcare system United States, it was always something that was kind of looked at as a separate defined group of people and I think that it's not. I mean that's kind of the realization that I'm coming to.

ML: Well there's so much that's involved in terms of stigma related to disability. A lot of times people try to talk you out of affiliating with a disability - 'no, you don't really have a disability,

you just have this going on, you just have this'- And so there's that tendency to draw away from that affiliation. And yet, at some point, we all need something related to some sensory impact as we age, physical impact as we age. I mean it's just like you say, it's going to happen and it's just a matter of when.

SL: Exactly

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KC: When you talk about that it makes me think about our aging population. Our population is aging, and people are slowing down and they need assistive technology like a walker, a cane, or a wheelchair because their mobility is limited. And we've always talked about it for decades. 'Oh, it's just people getting old.' What if we would have, 50 years ago, talked about our aging population in terms of How can we make it better for them? How can we make things more accessible? We might have had curb cuts 50 years ago, instead of just recently if we would have thought about it in those terms instead of attaching that stigma and shame not wanting, as Mark said, to belong to that population.

SL: Exactly, you know I think about our technology too. It seems that our technology has been keeping pace with the baby boomers who are the largest users of the technology. And, you know, they're the driving force as opposed to like you were saying, Kim, if we had taken a realization because we would have been way ahead of the curve, you know, before this.

Speaking about things that that have really brought this to the forefront, let's talk a little bit about COVID-19 and the pandemic. How has this incredible event that we are still in, how has our healthcare system addressed people living with a disability over the past year. What's been the impact of COVID-19 and that experience for people with disabilities.

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KC: Yeah, that's a big question, and it can go in a lot of different directions, so I'll just start the conversation and see where we go with that. So in general, it's impacted the disability community hugely. If you are a person with a disability and your disability compromises your immune system in any way, whatever that may be - could be in an autoimmune condition or it could be another kind of disabilities where you're just more susceptible - you started isolating and isolating probably more so than other folks. And we've talked about in general public how people's mental health has declined with isolation.

People with disabilities were in their homes, they weren't getting out because they weren't being able to access suitable transportation. If you use transportation, if you don't drive and use para-transportation, then all of a sudden you can't be safe because para-transportation is multiple people in a small vehicle, like a small bus.

So it's had a very dramatic impact on the disability community and not to mention the access to healthcare, access to getting a test, access to a vaccine site. Having the policymakers and planners actually thinking about the disability community when they're not used to thinking about the disability community. And thinking about not only the disability community but you have the intersectionality of other undervalued communities that the disability community is in. They're in the black indigenous people of color communities, they're in the LGBTQ communities, disability is everywhere. So when you identify with several different populations that are undervalued, it increases your risk and increases your vulnerability.

SL: Mark, you'd mentioned that, you work with homes for people, if I'm correct, where people just live together. Any examples at all from your experience of what happened over the past year?

ML: Well, we actually don't do any, any kind of residential stuff, but we do work closely with them. One of our core services actually is helping people get out of institutional settings, and that's been a huge endeavor nationwide, because of the death rate, quite frankly, of COVID in institutional settings. So what we heard were a lot of things with respect to disability. Number one is that people couldn't get personal assistance into their living situation, they couldn't get people in that would help them do things. Communication access wasn't happening because people wouldn't either have the electronics that they needed and folks they were communicating with might not have the technology to have interpreters. So we ran into a lot of those issues related to COVID in various places. A lot of the federal funding, actually, that centers like ours got to help with mitigate some of those issues that people with disabilities were facing across the board because of COVID went to try and help people get out of those institutional settings.

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SL: This was a horrible situation, especially in the beginning because they didn't even know how it spread. What can you tell me about how are people were getting out of those institutions?

ML: Well, you know, a lot of strong advocates kind of came and there were some legal challenges saying that people had to have access to the supports they needed. At the early parts of it, it was really a moving target and there wasn't a whole lot that people were able to do. It was six months after the fact that really, people started to be helped to move out. Early on, nobody knew what they were dealing with. Things like the Americans with Disabilities Act require that people have reasonable modifications to policies, practices, and procedures unless there's a legitimate safety concern. Like you said, nobody knew exactly the transmission methodology was early on in the process. So places went on lockdown and places are still on lockdown in many respects.

My mother lives in a place up in Calgary, Alberta and they just recently had an outbreak and they were entirely shut down and she said if she ever saw another meal in a styrofoam box she'd probably just quit eating. It was just an incredibly hard time.

As it started to open up a little bit and people got in contact with folks, then a lot of advocacy organizations started to talk to people and helped pay for hotel rooms, whatever to get folks out of those congregate settings so that they could be a little bit safer. But it was very much a moving target. It was certainly helped by the infusion of a whole lot of money, nationwide to try to support people.

SL: This is the thing that I still can't really comprehend is that someone with a disability might require you know support, like people around them for physical assistance. We were trying to avoid each other, so how did that all work out? That's what's so crazy.

ML: It is indeed, and that was tough.

KC: It's tough to do that. The whole country was on a learning curve as well, we're all on a learning curve and we understand that. It was tough not to do that and I think we hear stories that people really cared about personal assistance. There are folks that require a certain amount of hours of personal assistance a day to live their lives and there were personal assistants that that's their paid job that that went in and did that work even though they didn't know. Because it, there's because we're talking about human beings, and they cared about the human beings that they were taking care of, or that they were providing services to. So I mean that that that just happened and there was a lot of fear.

And it was there's a lot of fear for the person with a disability too, knowing that they needed the support services to be able to live their independent life, but not having a lot of control over who's coming in their house and and are they getting PPE and personal care attendants were not one of the top priorities to get PPE. And navigating how to get testing so that you're, you know not spreading covered and it was tough. It was, it was really tough and people had to make some very hard decisions.

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SL: You just remind me of something with the testing and related to that is access to the vaccination. I mean, I remember when I was first tested it was very difficult to find a testing center, much less one that was not going to charge you. And on the disability side of things I can imagine that must have just been incrementally more difficult. Were there any services that were actually going out and making house calls, so to speak? What was happening?

KC: Not for testing. They are now for vaccinations. We worked really closely with the Department of Health had conversations so they now have a system in place to provide mobile vaccines. They can go into someone's home that's not able to leave their house to get vaccines and vaccinate, folks.

We've been working closely with the Department of Health since the outbreak. We have a program at WASCIL, that's our acronym, called the coalition for inclusive emergency preparedness, or planning, and it is a statewide network that's going on it's sixth year, and it's

specifically designed for people with disabilities to make partnerships with other organizations and local jurisdictions to help their sections and emergency managers really talk about when, how to include the disability community when a disaster happens. And how the coalition can then support these other systems around disability, people with disabilities. And we are one of two states, two or maybe three states, in the country that have this kind of network in our state. When we went into stand up mode just like emergency management department did, and Department of Health did with COVID, we went into stand up mode and we're meeting weekly to talk about what was going on throughout the state and then working with our partners at Department of Health and Emergency Management Department, Red Cross, FEMA, local jurisdictions, and really having that conversation about 'hey we're not having effective communication, we need to make sure that at your COVID testing sites and vaccine sites that you have cards with simple language and pictures on it for people that either English is not their first language or they have an intellectual disability, so that they can understand what's going on. Making sure that sites have interpreters for the deaf and hard of hearing community. You know, all the, all the things that came up. They individuals to go to these testing sites while some people with disabilities needed a support person to go with them.

So we've been working very closely with these entities to make these sites, accessible, and to get the information out to the disability community. A lot of times undervalued communities will get this information, after the fact or later, rather than making sure that we're getting in at the same time.

ML: It could be a whole additional topic, couldn't it. There's been such a grassroots movement of people with disabilities across country really since Katrina. They saw the poor response in the emergency management system to people with a disability, there's been a quite a movement nationwide and of course the pandemic just really reinforced this and made it mainstream. And one of the players in that of course is the medical system, but it's one of the players there's all those others that are involved. That's a whole topic unto itself, for sure.

SL: That's a really good point Mark. With this disease emergency that we've had I've kind of forgot about all the other aspects of it. I grew up in Florida, and I should think about, we mentioned Katrina, I mean what we know about hurricane timeliness, you kind of wonder were we prepared for this? And as we move out of it now, now that we're lifting all the restrictions, with only 40% of population vaccinated, I mean, are we ready to let these restrictions? When I go into a business now should I wear a mask, not wear a mask? How about folks that are compromised somehow?

ML: I just had a conversation with a person I know this morning who is compromised. She can't get the vaccination because she has an allergic reaction them. So we were talking about what do you do? I work in Idaho, so it's reinforced there with a whole lot of folks that won't be getting the vaccination so how do you keep people safe? What is appropriate? And so that that's kind of the moving target isn't it.

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SL: Yeah. And are we moving forward with a plan that has considered the population with disabilities or are we just reverting back to where we were beforehand. I mean, have we made any progress, are we ready to move forward with this or are we leaving people behind?

ML: Well I think it's, it's a good question because I mean one thing I always say to folks is remember people with disabilities are always people first. They have varying opinions within the disability community, the same as everybody else has varying opinions.

I personally will go out on a limb and say that anybody that doesn't get vaccinated if they can or doesn't take care of other people around them by wearing a mask, when it's appropriate, is really being rather selfish, to say the least. I'm a real proponent of taking the steps necessary to keep people safe but I talked to some people in the disability community who are concerned and maybe they're not going to get vaccinated. I mean unfortunately we have a polarized nation, and and people have politicized all sorts of medical issues. And it makes the science probably one of the least attended to issues in a sense, and so I don't know. I mean, from a medical standpoint I suspect there's still a lot of caution out there in most folks. In a public policy context, I suspect we're moving forward. And so my advice, and I know this person's intent, will be to wear a mask when out in public still, and I tend to do that, partly just to make a statement because I want to make sure other folks around me are safe.

SL: And that's not to belabor you know the COVID-19 piece, but, but I do want to ask if either of you had any observations about how folks with disabilities were treated in the healthcare system when things got really bad? I know they were prioritizing ventilators and things like that. Any observations, any stories, anything you heard about perhaps the healthcare system being so stressed that there may not have - I don't want to say there wasn't equal care - but how did the health care system deal with all of this?

KC: Well, I'll start off with a positive story, because I mean, this is, this is a rough time so I'm sure we have a lot more stories where we could have done better. And also recognizing that everybody was doing the best that they could, because nobody really knew how to deal with this. None of us have gotten through this before so I tend to believe that people were doing their best and putting their best foot forward.

But I also believe that when, when disability isn't always on the table and you're not talking about it all the time in your discussions, whatever realm you're in: medical realm, policymakers, government, if they're not at the table, if you're not at the table, then you're not part of the solution.

But with that said, I know of a person who is deaf, and apparently his physician provides services to a lot of deaf people, and his physician reached out to him and scheduled an appointment for him to get his vaccine. And when he went in for his vaccine what the doctor's office had done was reach out to all of their deaf and hard of hearing folks and scheduled them vaccines within the same time period, and had multiple interpreters there for the folks coming

in for vaccines. They could get the information in the appropriate way through sign language, ASL interpreters. So his experience was really good.

And that, you know, that was that doctor who had his practice and understood the needs and the accessibility needs of his clientele.

SL: Wow, that's fantastic, that that that is a good story. That's really good.

You know, and I don't want to rain on the parade at all. So, reluctantly I guess I'll ask, you talked about hidden disabilities or invisible ones, and I would imagine that this was a very difficult time with anyone who actually caught COVID-19 if they weren't able to somehow express themselves to the care community or the medical records were not there or just due to the, you know, volume and stress in the healthcare system itself, being able to accommodate people, you know, both in diagnosis and also in treatment. I mean, it must have been pretty hectic, at some point.

ML: Well there's barriers I think on all sides for providers that wanted to provide those accessible services and so on. Being able to find folk, people to do that, being able to find interpreters, being able to find and handle the technology. If they're doing telehealth are offering telehealth, knowing that their patient has the ability to access that.

So luckily, that was one of the pushes nationally was to get some money out to try to help people with a disability who were facing barriers because of COVID, not just due to access to medical services but access to food, shelter, etc. So we had a number of centers, such as ours who were actually helping people get devices, tablets and so on, access to internet mobile hotspots, so that they could continue their telehealth. Otherwise they were going without services and sadly sometimes some of their other services were contingent on attending class, whether it's substance abuse or some other service. And their entire life was in jeopardy because of that access.

COVID had a huge impact and there's no question and it continues to do so. But luckily, we're able to do some of those things. We had one individual who had COVID and it was so severe that they had to be air lifted up to Spokane, but in the rapidity of moving them they had animals that were locked into their place. A couple weeks later, folks realized that, so these rather not doing real well animals were taken care of, but the place was in shambles.

The person came back and we were able to actually pay them to get new carpet get all of those things taken care of for this person. But this is on the top of all of the things of dealing with health that landed them in an intensive care unit and an airlift. And then in the process of coming back having a hotel throw them out after learning of their diagnosis because medical people showed up wearing full hazmat gear. Even though the Health Department said no, they weren't a risk. But because the particles still show up in the bloodstream, then another health provider panicked.

I mean the long story is that it ended up really great, and she got back, got her place and got her pets back and another donor covered the cost for that and so on and so forth. People kind of coming together was the good story, the bad story was the disjointed nature of things to begin with.

SL: So, kind of looking at that, do you think our health care system has learned anything from this experience? Thinking about non-COVID stuff, just the average day in the life of someone, what barriers and issues do folks with disabilities have interacted with the healthcare system? What's your thought on that and what are some examples of the barriers that we need to recognize and probably work on?

0:39:05

KC: That's a good question and just to kind of step away from COVID, because I we are still in it, and people are feeling the effects of it, but just in general, people with disabilities accessing healthcare. So some of the things that I've heard is around having a person with a disability, come there with with a person, along with them, and then having healthcare professionals not talk to the person. Talk to the caregiver or the personal attendant that's with them. Somehow making these assumptions that because of their physical disability or cognitive disability or brain disability that they shouldn't be talked to. It's pretty common for a lot of, lot of different folks. So that's, that's generally one that we hear about frequently.

Another one is when you walk in you started being treated based on your disability, not on your symptoms. And I think Mark has a great story about that. I'll let him tell that if you want to jump in.

ML: Sure yeah i can i can address that and some others. But actually there's one other thing I was going to add on, right away, was that the term I heard today in talking with a friend was visual bias. That bias that a practitioner immediately has when they see the disability and not the person. She's a wheelchair user, and often she's gone in to see a provider and their first move is to say, well, we probably don't have the ability to serve you, because we're not a specialist in spinal cord injury. 'Well, yeah I'm in because I have a respiratory issue going on.' It has nothing to do with using the wheelchair, but that visual bias is present. And that happens in terms seeing somebody, but certainly in terms of diagnostics. Another friend who's a high-level quad was finally was admitted to hospital with high fever and a whole bunch of things going on. They went through this then this and this related to somebody with a high spinal cord injury, and before she nearly died finally somebody discovered she had appendicitis.

So there's that tendency to assume the disability is everything, or assume that you can't treat somebody with a disability. The other part is barriers like the lack of respect for the knowledge of the individual. Some of this stems from an historic grouping of disability as a medical issue. As if disability is kind of been treated as something that should be a part of the medical system, even though it has nothing to do with medical services. Medical people sign off on long term care services, medical people sign off on durable medical supplies that really don't require

medical assignment or whatever. So medical folks think that they're supposed to be able to deal with this stuff.

And I think that's, that often is a mindset that they go in with. And often a person with a disability, particularly somebody who's you know 30 years post injury using the wheelchair, they have more knowledge about their own body and the disability than that medical practitioner will. If you can form that partnership between person with disability and medical practitioner, saying I know my body and how it reacts it's not reacting the way it normally does, what about, is there an intestinal issue I can't diagnose? you have the ability, from your training to help with that so kind of getting off of that perception of the disabling condition and saying, 'what's the medical condition' is a big part. I think that being able to develop that partnership, that's where a lot of people run into the barrier there isn't that.

And then sometimes it really is something related to a common occurrence, with respect to and again I'll use the example of using a wheelchair. And a lot of times people won't know about how to number one recognize when an ulcer is beginning or understand how to treat that and there really aren't good referral mechanisms for that so people run into that issue. So a lot of times some of those specialty things still are barriers as well. But that partnership can really help alleviate that.

SL: Do you think that's an issue with the educational system for doctors coming up, or any clinician, that the training and the education hasn't really addressed what you're saying? They look at someone who comes in wheelchairs as another thing to fix. What's your thought about that?

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ML: Why yeah I think there's, there's a lot of validity in that. We tend to try to compartmentalize things. So diagnoses have to do with specific body functions. We tend to view disability as a part of that. But in fact if I use a wheelchair, and I get around fine, and I've got an issue with my throat. There's really nothing having do with the wheelchair. That wheelchair is not a medical issue, it's a device that allows me to move around.

If I've got an issue with pressure on my prosthesis, then, that has to do with a disability, but everything else is a medical issue, we tend to lump them together. The medical world's a reflection of the society it's in, we tend to do that as a society we try to compartmentalize folks and I love what Kim said earlier about the intersectionality of disability with every other group. It doesn't matter whether you're male, female, LGBTQ. Whether you're a person of color, whatever nationality, you can have a disability, and all of these things are going to cross over.

But we tend to want to compartmentalize and disability has been compartmentalized as a medical issue for a long time. And I think that gets in the way sometimes, the expectation that that's the way we should respond when in fact, you know the life issue is much bigger issue.

SL: Right and you know and it brings up something that that I think I've observed in the world of patient safety and quality. Over the years, we've gotten better in the medical community about this, but we're trying to fix and cure a particular moment in time, rather than look at the person's overall life goals. When somebody comes in, let's say in a wheelchair, the first thought might be, how do we get them out of that wheelchair, rather than asking the person 'Oh, I see that you're, you have a disability or mobility issue. How you feeling about that?' 'Oh, I've been this way since I was a child.' 'Oh really. Well, you know, you've come in with this particular symptom, having nothing to do with you know your mobility issue. What are your goals?' 'Well, I'd like to be able to make it to my son's wedding next year. And if my diagnosis is going to prevent me from doing that let's work on that.' But what are your overall goals for this person as opposed to immediately needing to fix you.

ML: One of the biggest fears that people with a long-term significant disability have is that they will have a medical person or people devalue their life based on the perception of their disability. You know, 'your quality of life can't be good your quadriplegic so you have no quality of life.; So that fear that fear of having treatment that's based on that perception, that the treatment is not as aggressive, it's not as positive, it's not as thorough, because the life has already been devalued. That's, that's a huge fear that people with a significant disability have. And I've heard that for years.

KC: I think it's not only a fear I think it's, I think it happens.

ML: Well, yeah. So, it's a founded fear.

KC: Yeah, I think it does, it does happen. We know about that we know about the gentleman in Texas, who got COVID, and wasn't valued. And basically the system took his rights away and then send him to a nursing home where he could die. It was very well publicized in the beginning when COVID hit, that's not unusual experience in the disability community.

0:49:15

SL: You know, and what's interesting about this is that it seems that the interaction with the health care system isn't necessarily one of primarily the medical issue, the underlying foundation to all this is how you perceive and interact with someone who you've compartmentalized or who you feel you know doesn't fit into the your standard of what the healthy person should look like. It seems like these barriers and issues really aren't necessarily one of how do we develop better treatments for people with disabilities, but more of how do we treat people with disabilities. Does that makes sense or not? How do we interact better.

Where do you think that most of these issues in healthcare take place? We've talked a lot about the interaction at the bedside, so to speak. The one on one with the care provider or the clinician. But do you think the issues are focused on that or do you think it might be something more, other than care delivery maybe it's something with policies or, as I mentioned in the schooling or how we handle post treatment. What are your thoughts about what are we doing

well in and what areas of the healthcare system do we really need improvements on? Is it at the bedside, is it when the patient walks through the emergency room doors, or is it when they're walking out of the hospital, or is it during their stay in the hospital that these issues arise with the disability community? What are your thoughts on that?

KC: I mean I think that's, I think that's huge. I think the short answer is, it's in the whole system. So, what you just kind of called out are all the different smaller systems within the bigger healthcare system. I don't have a healthcare background or medical background so I don't feel like I could analyze that and make a statement about that. What I can say is it's probably a systemic thing. I think this is very similar to the conversation that you're having with the black community and the BIPOC community at large, about how their level of care is different than the white community in general. There's lots of studies and statistics and stuff that that you have that you know this to be true and then how do you address it? And how you address it is, is that you have more people of color in policymaking positions or training positions, sitting at the table having those discussions to make change. So this is systemic change that's how you do that. You can't change unless you invite new people to the table and really sit down and have these those conversations to figure that out. And I think that's the same with the disability community.

It's systemic, it's in all of what you talked about. I always believed that there's hope that's just kind of who I am. That's why I'm here talking with you and Mark today because it's an opportunity to talk about disability. There's some harsh realities to it and some good stories and some harsh stories around it but bottom line, if this can be an introduction for somebody who's listening to this podcast today to say, 'Oh yeah, maybe we need to have more people with disabilities that are, you know, in those discussions that are doctors that are care providers that are in management at hospitals or clinics and that are sitting at the table and bring that perspective,' or 'how are we reaching out to the disability community and engaging and eliciting their thoughts and conversations to help us better manage these systems and include disability voices.'

I would hope that you know these are seeds for that, so that there can be change. Because I believe the medical community wants to change and wants to be better at how they're providing services.

ML: That's exactly what I was going to say Kim. I think a lot of folks within the systems that I talked to get frustrated with the system in terms of the way the framework is set up now. There's not enough time to deal with wellness, there's not enough time to carve out the things that seemed like they have more value. Disability is, as I mentioned before, it's kind of a subset, it's got a whole societal view. Somehow disability has long been a charitable kind of thing, we see people with disabilities as objects of charity, and we see long term services as medical services when in fact there may not be medical issues going on. And I think a lot of providers would love to have a system where they could actually focus on what they had been trained to do and not be drawn so much into these other areas.

And people with disabilities, they've been brought up in the same system. And they really haven't had the supports to say well you can be your own best self-advocate, you can be in charge of your own life, you don't have to sit back and wait for somebody to prescribe to you what your life would look like. And so that's where we kind of come in with those peer connections of supporting each other to become better patients when we need medical services and be more in control of the rest of our lives so it's not kind of commingled

But it's a challenge. I think that access to health care is so broad. You talk about a community, where are the health care providers in a community. What's transportation like to get there. Is there public transportation in rural areas. Is there internet if somebody has to do telehealth. And of course we know with all of the different providers some areas don't have internet, they don't have cellular service unless it's profitable.. And until we as a society address some of those things it puts all of us that do human services in a kind of a tough position.

It's how connected are the folks that do the transportation, with the people that do the scheduling. How long does somebody who has to access a medical appointment have to sit and wait for the bus to show up afterwards. All of those things are intertwined and yet we don't really spend very much time, addressing those connections and seeing how we can make it more efficient. I think that makes it tough on everybody: patient, provider, and the community at large.

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SL: I think that historically, we haven't fostered that concept of independence. We've tried to keep folks who have a disability captive within the healthcare system. You look at policing today, not to change the subject at all, but there are discussions now that we're starting to believe that it's not a valuable use of time for police officer to be doing like traffic patrol or parking. And it seems like there's probably a better use of the health care system than interacting with people with disabilities, where there's really no need to. They should be fostering that the independence and encouraging it. But that concept really wasn't part I guess it the thinking has historically.

So it is interesting to think about the care delivery system. When I was growing up and I know I'm kind of aging myself here but the doctor made house calls. And now, you go to a major city, and all the hospitals are grouped on the big hill within the city and I always look at that think 'well that just doesn't make sense to me.' The first issue is how do I even get there, you know, and when I'm there or how do I even park. And it runs contrary to that concept of independence really. It's almost like our lifestyles are there to help the healthcare community as opposed to the healthcare community helping our lifestyles. It is kind of interesting.

I know you want to kind of wrap things up now and I really appreciate your time. We've really scratched the surface on a lot of this. And I know one of the things that we want to do is follow up with this. Provide some resources for people and some articles and things like that that people can come to our website and look at.

I guess one of the things that I'd like to end this with is kind of getting back to where we were before. I want to focus not so much on COVID-19 but I think I'd like to focus more on other events you mentioned, like Katrina or other things. When certain events have happened in our society to destabilize or change the way that we've approached things. Do you think that as we move ahead that we've learned anything? And maybe that's not the right way to say this, but are we going to incorporate any of the good things that we've done over the last couple years and build upon our experiences even before COVID-19 with the pandemic just being another layer of that to make things better as we move forward? And you mentioned about the curbs, are there new curves that we're going to see, you know, being redesigned moving forward based on our cumulative experience over the last several years, culminating with this pandemic? What are your thoughts on that?

1:00:26

KC: Well, I would hope so. And historically speaking, it's usually the groups in power that make the changes and the groups that aren't in power continue to provide advocacy and knock on doors and get invited to the tables. So yeah I mean I like I said earlier, my hope is always that there will be some seeds, because these systems are made up of human beings as well, right. So, the more that the people learn and understand something that maybe they didn't understand before then, there's more opportunity for change, and thinking universally about all people.

ML: I'm with Kim. I like to think that that some of these changes are lasting. I think for some time we've been seeing kind of an interesting difference between the national view of things and what folks are doing in the local level. In the medical world I've just been so pleased at some of the new facilities at new clinics - a person I was just speaking to recently has a new doctor who spends time with her has adjustable height exam tables, she can get on every piece of equipment. Except the mammogram, mammograms tend not to be accessible. And so she hadn't had a mammogram for a long time but this doctor finally said they could do an ultrasound. A lot of people don't know that, they don't talk about doing ultrasounds, they talk about doing mammograms. But mammogram machines, they aren't accessible. And so my friend had one in her entire life.

But folks are kind of getting it. They're doing things, the Americans with Disabilities Act information is out there. That grassroots effort is really starting to make some changes. We're seeing medical providers that are becoming more interested in establishing those relationships with their patients, and not being part of a more industrial complex that that some of these systems have been geared toward recently. So it's similar things kind of on that local level, we're seeing people do things even while there's gridlock in Washington, DC.

So I think with some of the response in emergency management, responses in this pandemic where people with disabilities have been at the table with emergency managers, with health experts, we're still working and rolling out vaccination sites trying to talk people into getting

vaccinations and finding out what the barriers are to getting the vaccinations to them. Looking at incentives, as a lot of states are, to help people be safe. There's some new partnerships that hopefully will continue and my personal hope is that they're going to allow medical folks to concentrate more on what they do best and draw some of the attention to these other life issues, access issues, out into the kind of the mainstream, where they should be attended to.

1:04:09

SL: That's good to know. I know we've talked a little bit in our educational programs about the concept of implicit bias, and the stigmas that that are out there. I think there's a self-recognition among healthcare providers that these exist. I was on an improving diagnostic process conference earlier today and one of the presenters was talking all about the idea of the bias that you bring in. That awareness is now transitioning into actual education, which is something good. It's no longer just acknowledging it, but I think there's activity you know to move forward from there.

Well, I want to thank you both for your time you know, thank you, thank you very much and. Would it be okay for me to put your contact information on our website at all.

KC: Absolutely.

SL: Great. Well thanks and thanks for offering you know to give us more information and this I know will just be the start of our initial conversation. I really want to say thank you for giving me the time and being involved today.

KC: Thank you Steve for inviting us in to the table.

SL: Yeah, thanks.

ML: Yeah, thank you.

End of Podcast