

*[Music by Molly Joyce 00:00 - 00:15]*

**Bonnie:** Welcome to *Included: The Disability Equity Podcast*, brought to you by the Johns Hopkins University Disability Health Research Center. This podcast challenges stereotypes of disability by sharing stories, data, and news. Each season digs deep into topics, offering multiple perspectives, and will expand your view of disability. We are your hosts. I am Bonnielin Swenor, director of the Johns Hopkins Disability Health Research Center.

**Nick:** I'm Nick Reed, assistant professor at Johns Hopkins University Bloomberg School of Public Health. Our guest today is Sarah Szanton. Dr. Szanton holds the Patricia M. Davidson professorship for health equity and social justice and is the director of the Center for Innovative Care in Aging at the Johns Hopkins University School of Nursing. Dr. Szanton's research focuses on healthcare disparities, aging, chronic care, nursing, and public health. Her work is informed by her own experiences as a nurse practitioner to homebound, low-income elderly patients in West Baltimore.

After witnessing firsthand that environmental challenges were as pressing as her patients' health challenges, she developed a program of research on the role of the environment and stressors in health disparities in older adults called Capable. The Capable model has been highlighted in major news outlets, including *Time* magazine, *Forbes*, and *The New York Times*. It has even made it into a speech by then candidate and now President Joe Biden on health and wellness.

*[Music by Molly Joyce 01:47 - 01:56]*

**Nick:** Sarah, thank you so much for joining us.

**Sarah Szanton:** My pleasure. I'm so happy to be here.

**Bonnie:** Thank you, Sarah. Let's get right to it. Your innovative work has combined multifactorial interventions really focused on helping people age in place. Can you start by describing to our audience the Capable model that you've developed?

**Sarah Szanton:** Sure. I co-developed it with Dr. Laura Gitlin and adapted it from the Able program. The Capable program is four months. It's time limited. It works with an older adult to identify what matters to them and what they would like to be able to do to age with dignity and independence at home. It provides 10 home visits, 6 of which are with an occupational therapist and 4 of which are with a nurse.

Then up to \$1,300 of resources for home repair, home modification, items, and assisted devices to work with the goals that the older adult defines to be able to age at home. They may wanna be able to take a bath by themselves and currently a grandchild gives them a bed bath instead. They wanna be able to get outside and get down their front steps into their daughter's car, for example. We can talk more about it later. That's the basic gist of it.

*Nick:* I love how person-centered you pull it back to when you describe the program. It's about the individual's goals and what they want to achieve. I know I mentioned it in the intro, but can you tell us more about how you really became interested in this? This is something you decided to dedicate such a large portion of your career to.

*Sarah Szanton:* Right. I'm a nurse practitioner with a PhD. All of the nursing and nurse practitioner roles I've had were really at the intersection of housing and health. My first nursing job was with migrant farm workers, some of whom lived in chicken coops that had been changed over for people. Then my next job was with homeless adults, some in shelter, some on the street, and some doubled up. Then, as you mentioned in the intro, provided years of house calls to people who were homebound. A lot of times, they were homebound almost as much by their house as by their own abilities. Several of them would have holes in their floors or linoleum that was torn up where it was safer to sit in one place than to walk around.

If you put together some environmental risks with some dizziness or weakness or someone's on 26 medications when they could be on 10, you get a whole lot of risk and a lot less ability to engage in what matters to them. Thank you for bringing it back to the person focus. I think that we often think of older adults who have disability as people who need to be taken care of or their costs managed. Really, as people like to say, older adults are a growing natural resource.

Look in the pandemic. Providing Zoom school for grandchildren and *[unintelligible 05:06]* safety nets for small businesses. We need to get to the point where we look at what's modifiable about disability and what is modifiable about the environment and to be the most inclusive we can. As a society, we really need all hands on deck. Older adults just get wiser and wiser and have more pattern recognition and thoughtful exploration of what matters in

life. We need to shift from a deficit model to a strengths model and see how we can enable those strengths to express themselves.

*Bonnie:*

Thank you. I wholeheartedly agree, and I very much value and appreciate that perspective, focusing on the environment and focusing on the individual. We've talked a lot about those themes, I think, across this podcast. Could you share a little bit about the impact of Capable from some of the work you've done? I think our audience may be interested to know that. There's been several studies conducted on the efficacy and effectiveness of the Capable model. What have the results been?

*Sarah Szanton:*

Thank you. I tend to focus on the individuals, but being as a researcher, we've published, I think, about 25 papers at this point. The major results are that Capable pretty much cuts in half the burden of disability that people are having over time. For example, if they come into Capable with four areas that are difficult for them—it's difficult to bathe, to dress, to manage their food, and to walk across a small room—they end up with two. That's actually an undercount because they might've gone from it being very difficult to a little difficult to, let's say, get into the bath. That change isn't counted in those numbers that I'm saying. On average, about 75 percent of a cohort, of a group, have that average reduction in the half.

The evaluators for CMS, the Center for Medicare and Medicaid Services have found that it saves Medicare about \$22,000 a person on average, and it only costs about \$3,000 a person. That's a more than seven to one return on investment. Importantly, that's a return on things that nobody wants—no one wants to be hospitalized or in a nursing home. If the Medicare spend was on something that was useful and important for people, like a hip replacement or a knee surgery, maybe the numbers wouldn't be so powerful. The spending that it's averting on hospitalization and nursing home that nobody wants.

Then, just on a personal level, we hear all the time people say things like, "I used to have to go up my steps on my hands and knees. Now I can walk upright like a human," or, "I used to have my grandson to have to bathe me in the bed. Now I can get in and out of the bath myself." Those kinds of things are immeasurable in terms of the amount of dignity and the decrease in stressors and even physiologic stressors and the ability to, then, give back and do more in their own family because they can be active.

*Nick:*

Wow. I have read a lot of your work. The cost effectiveness had never hit me that you guys have focused specifically on things that you view as cost effective and also, to a certain extent, wasteful, something that somebody doesn't necessarily want. That's super, super interesting. Again, just to reemphasize for our *[laughter]* audience, I love that you brought it back, though. That the biggest impact is on the person aligning their life goals, what they actually want. It's so clear that the environment is so important. We probably need to start thinking more about ensuring accessible and equitable living environments within the context of healthcare.

I hear people throwing around phrases like "wellness is more important than healthcare" sometimes. It still seems like this is a foreign concept to our healthcare system. When you're in the clinic with your primary care physician, for example, or a specialist or an allied healthcare professional, we're not always talking about that. How do you think we can better tie healthcare and the environment together?

*Sarah Szanton:*

Well, thank you. There's a lot to unpack with what you've just said. I guess I would start with I think primary care of the future is gonna be a team model. The National Academy of Sciences just released a report about the future of primary care and said that and that reimbursement needs to go along to that team. That team could be pretty broad. I'm a nurse practitioner. If you have a 15-minute visit with someone who comes in and they are in pain and depressed and come in in a wheelchair and they're on dialysis with a completely blank expression and on 10 medications, you get 15 minutes, you're pretty much just thinking about renewing the prescriptions, getting lab values, and out they go.

If you see the same person in their home and they have primary care that's not you and you are asking, "What would you like to be able to do? What matters to you?" it's a totally different conversation. You have long enough to do it, and then you uncover what they wanna be able to do is get out the back stoop and listen to the birds. They wanna be able to shave standing up instead of in an wheelchair. We've shown that those things can be modifiable, and they can be changed by this combination of the nurse and the occupational therapist and the attention to the home.

Now the person's able to do those. Now they don't have a flat—their depression lifts, and you've helped take care of their pain. Then not only are they having a better life, they're also more engaged in primary care. Then the nurse practitioner, when they

see them, they can do more, more preventively because the person is more engaged in the primary care.

To your question about healthcare versus health and wellness, I think we all know now that healthcare itself in terms of hospitalizations and primary care is just a drop in the bucket to someone's health. Where you live, what the home is like, the food you have access to, do you have enough money, all of those things are what create health. Older adults are able to improve physiologically up until the last few months of life. To potentiate that is just as important as for a child.

From a savings perspective, it's actually more important. If you're looking at—we've got only a certain amount of money in this country. Spending money to save money on the people who are gonna be costly soon to the healthcare system is a really good investment. Obviously, spending money on children is really important and pre-natal care. I wouldn't say it's not. If you can spend \$3,000 on someone who's likely to cost the health system \$10,000 of avoidable healthcare in the next year and pull that back, then that other \$7,000 can go to something else that our society needs.

*Nick:*

Take note, everyone. It's like we're getting a lesson on how to make a policy change right here. I love the way you frame it. The big picture all the way down to the little picture. Your work, it's garnered heavy interest from CMS, the Centers for Medicare and Medicaid Services. Can you comment a little on policy approaches, really, that we could tackle focusing on the environment in the context of equitable health for people with disabilities?

*Sarah Szanton:*

There's a lot of exciting movement. First, you have to believe that a value-based model is good for people with disabilities, which I know a lot of people are nervous about. We need to keep studying that and understanding that and seeing if that's going to be true. We know that the fee-for-service model [*laughter*] doesn't work very well for inclusion and equity. Just for your listeners who might not be aware. In the fee-for-service model, when there's a clinic visit or a hospital visit or a procedure, the doctor's office or the hospital creates a bill for that and gets paid for it. That creates the incentive of more, more, more, more, more procedures, more hospitalizations, more—we need there to be low-birth-weight babies 'cause we've got this fancy NICU.

Asking a hospital to put money into prevention is like asking Target to tell customers to stay away. It doesn't make sense from a bean-counting perspective. Of course, it makes sense from a human perspective. If fee-for-service doesn't work, the opposite is trying to cover whole populations, trying to change the health of whole populations. Because hospitals and big health systems are the 800-pound gorilla in health, what that means is trying to get them to focus on that prevention. I think a lot of people would say, "Isn't that what our public health system is for? What about our health department?" Health departments are really, really important players. We saw that so much this year in COVID.

Ideally, the big players are partnering with health systems and with area agencies on aging and with the agencies for people with disabilities. Bringing it back to the policy change, we're in the middle of a big change of going away from fee-for-service and towards value-based payment. In a well-designed value-based structure, you would want all the people who are covered to be able to bathe themselves and dress themselves and do what's meaningful to them. Then they will have fewer hospitalizations and nursing home admissions.

Something like Capable becomes important then, so does decreasing financial strain and food security and housing security and many other things that lead to a healthier population. We're just in this transition now where some health systems—they talk about it as they've got one foot on the dock and one foot in the canoe. The canoe is taking off, and that's the value-based system. They just don't know when to pick up their other foot and put it in the boat. I think we haven't come close to the potential we have for the value-based structure to be able to build equity and inclusion for people with all kinds of abilities.

*Bonnie:*

That was a very clear and, I think, helpful description of the landscape. I think that really is critical and such interesting paradigm at this moment when we're thinking about this podcast is all about inclusion and equity. Thank you so much for laying that out. Sarah, I know you, and I know your work has been so important in this space in changing the game, really. I also know you're doing a whole lot more than Capable. It's really important work. Would you mind sharing with our audience where you're moving your research and your efforts to now? I think that would be really important.

*Sarah Szanton:*

Thank you. I have three streams of research. One involves Capable and other interventions that are strength-based, resilience-based

notions for having people be able to live the life that they most want at home with independence. The other two, one of them is on financial strain and ability to age independently. Some of that I'm doing with you, luckily. My PhD dissertation was about financial strain and mortality. Women with the same income and the same comorbidity or the same sicknesses were 57 percent more likely to die in the next five years as people who didn't have financial strain.

Financial strain, to those who aren't geeks like me, means not having enough money to pay the bills. Some people have more than enough. Some people have just enough. Some people have not enough. If you just cut it by those three categories, you see incredibly powerful differences in health outcomes between people who are financially strained and people who are not. From a policy perspective, financial strain is really important to focus on because it's a lever you can change from two different directions. It's about resources meeting need. You can either help people get those resources, or you can have there be less need for the resources. For example, with medications, someone may be on a \$100 medication a month. If they can get on a \$3 generic one, they've got 97 more dollars there. That's decreasing their financial strain, even though you didn't give them more money. If they can have a more efficient house, then they save money on heating.

There's a lot of work to be done on understanding financial strain and then changing it. What policies? Just as one example, older adults who are low income enough to be able to be on SNAP, what used to be called food stamps, fewer than 50 percent of them are on it. A lot of them, it's 'cause they didn't know they were eligible. That's an entitlement. We should be able to get people onto SNAP and get them more healthier. An older adult who's food insecure, meaning that they either have had to skip meals or have smaller meals than they needed, have the disability of someone 14 years older than them. A 70-year-old who's food insecure has the [unintelligible 18:32] of daily living disability of an 84-year-old who is food secure. We can change that.

The other bigger stream of my research is about structural racial discrimination and how that effects health. I think, especially in this last year or two, are learning more about structural discrimination. I majored in African-American studies in college 40 years ago, and I've been working on these issues for a long time. I think that the best analogy that I've heard for lay audiences about structural racial discrimination is by the Racial Equity Institute. If you came upon a lake with some fish belly up, who

were dead, and others that were swimming fine, you would wonder what was wrong with those fish. How did they get sick? What's wrong with them? Maybe there wasn't enough—they couldn't get access to the food in some kind of way.

Then if you come to another lake and see the same thing, you might have the same reaction, but you might start thinking, "I wonder what's going on with these lakes." Then you come to another lake, and you start to think about the groundwater. What's poisoning these lakes that some of the fish aren't doing well? If you think about one—in that example, one lake might be food policy. One might be redlining and residential segregation. Another might be the education system. African-Americans have worse health outcomes and a harder time getting employed and so many things across those lakes that we have a big job between us to decrease structural racial discrimination. We have a big new NHI grant working on that in terms of measurement and understanding how that effects cognition and other diseases and life trajectories.

*Nick:* Wow. *[Laughter]* Your three lines of research could each be *[laughter]* multiple lines within. It's a whole career. That's amazing. Wow. I loved the fish and lake analogy. I have to admit—

*Sarah Szanton:* Isn't that great? Not original to me. It's the Racial Equity Institute.

*Nick:* It's just beautiful. As three researchers based out of Hopkins and in Baltimore, it just—obviously, Baltimore has a lot of issues with structural racism. It's such a clear analogy there, too, thinking of the city as the lake. That's for another time, though. Sarah, I'm a native Baltimorean. I grew up in Fells Point. My family owned a fish market. Whenever people start to think about these things, I just can't get off the topic. I wanna ask a broader question here, at the end. Especially for you, Sarah, your work is so broad. You've impacted so many different areas of thinking about our healthcare system and wellness. What are one or two changes that you think are vital to erasing healthcare inequities among people with disabilities? We can make this United States-centric, perhaps, just because I know it is different when we think globally.

*Sarah Szanton:* Well, I think the first thing is visibility and representation and empathy. Walk a mile in one's shoes. I think that if you look back at when curb cuts were first happening and people thought, "That's not worth it." Then people were like, "Oh, yeah, but strollers." *[Laughter]* The real reason to do this is for kids. I think we have

such an ableist society, and there are so many—really, we’re all on the spectrum of every kind of ability and disability. There’s so many spectrums that intersect. I think part of it is a mindset and that we all have a lot of internalized bias, I think. It’s heavy, deep work similar to structural racial discrimination, I think.

That’s not really a great answer in terms of from a policy perspective. How does one do that? There’s not a pill to take. There’s not a “Read this book and you’re set.” That deep work is—think of all the discoveries that haven’t been made or the new tools and stuff that haven’t been made because some people haven’t been included as much. I think that the pandemic and having to teach on Zoom, we’re all just—there are so many cards that are thrown up in the air right now. How some people say that disability is the mother of innovation, so our pandemics.

*[Laughter]* We’re in a time now of really rethinking a lot. I’m hopeful, but it’s gonna, I think, take a lot of push for the fresh look that everything’s getting to keep on going.

For example, I think there have been way more articles than there would’ve been about as we move back to in person, what about people with disabilities? What about people who need this or that? What about people who thrive in a different environment? I’m not giving you a great answer, but I think, at the very first, it’s mindset. I don’t have a great policy answer, I guess.

*Nick:*

I think there’s probably a lot of policy answers. Bonnie chime in, but I feel like, from the big picture, you’re absolutely right. It is changing the mindset and removing these implicit biases and this ableist attitude that—on another episode, we recently just about it. People don’t even realize. They don’t even realize they’re being ableist, first off. Second off, they don’t even realize it’s a bad thing. The way that they view ableism, they just think, “Yeah, well, I can’t. This is the way it is. That’s what we’re gonna do.” We were very struck at a recent conversation with Dr. Iezzoni on how many physicians just seem to just admit they’re ableist. They don’t view it as a problem, necessarily. I think that gets at a very deep, deep conversation that harkens back to what you’re talking about now with changing the mindset.

*Bonnie:*

Thank you for that answer, Sarah. I think, from my perspective, this is a question I think about a lot is part of changing policy to change society and change the inclusion of people with disabilities, there’s still some part of changing ableism to get that policy changed. It doesn’t happen in a vacuum or in a void. It’s a huge challenge. I think, one, that is, as you indicated, gotten some

traction, finally. *[Laughter]* We have not been part of the conversation or the equation. I am hopeful that will continue throughout the pandemic. Thank you so much. I think that was a wonderful answer.

*Nick:* Sarah, this has been an amazing conversation. I think you have not only succinctly described this entire area of research and all the new area research you're doing, you've also laid the groundwork for people listening to just have a better understanding of how we can take public health from a big picture, epidemiologic inference, to the clinical trial level, back to how we make it an effective policy approach by analyzing it in a very specific way and making it into a cost-effective benefit that stills benefits people at a person-centered level. We just went across public health to clinical health *[laughter]* to the environment to the clinical healthcare. It's amazing. Thank you so much for walking us through everything today.

*Sarah Szanton:* It's been my great pleasure to be with both of you.

*Bonnie:* Thank you so much, Sarah. Where could people go if they wanna learn more about you and your work?

*Sarah Szanton:* Thank you. My name, Sarah Szanton, and Johns Hopkins, if you google those, you'll come up with the Capable program that we discussed at the beginning. Also, we have a new Nadler center called the Resilience Center that we're very grateful for and which has some research projects that are adaptations of Capable and also the Chicago Parent Program for people with disabilities and their caregivers. Then the structural racial discrimination work is in its infancy. We are publishing work soon, but we don't have anything online yet.

*Bonnie:* Thank you so much for taking time and being our guest today.

*Sarah Szanton:* It was my pleasure. Thank you.

*Bonnie:* You have been listening to *Included: The Disability Equity Podcast* brought to you by the Johns Hopkins Disability Health Research Center.

*Nick:* Thank you to our *Included Podcast* team and everyone that made this podcast possible, especially Sabrina Epstein, Prateek Gajwani, Curtis Nishimoto, and our guests. Music is by Molly Joyce. This podcast is supported by a Johns Hopkins Ten by Twenty Challenge Grant.

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