

Philip D.: Hello inclusion believers and welcome to the Access Champions podcast. I'm your host, Phil Dallmann for this week's journey into the galaxies of accessibility, diversity and inclusion. We got another great episode for you guys this week coming in from the city of brotherly love. We have Susan Shifrin, who's the executive director and founder of ArtZ Philadelphia, and that's artz with a Z. And they're doing really incredible work for individuals living with dementia and their caregivers and their families. Really taking this holistic approach to not only creating access to the arts, but to de-stigmatizing the illness and the community as a whole. So really excited to share that with you guys. Shout out to Alanna Raffel who tagged them in my sort of reach out to the universe of who's doing dope work. Please send them my way, so I appreciate that. And speaking of that again, if you know somebody who's doing dope work, please feel free to send that suggestion our way.

Philip D.: Either you can message us across all of our social media platforms we're @AccessChampion on Instagram and Twitter and The Access Champions Podcast on Facebook. We accept messages all through them or email us at accesschampion@gmail.com if there's and that also goes for any topics. Maybe not just a guest, maybe you're yearning for a specific topic to be covered or a current event I'm so open to the suggestions. Our entire team is we'll welcome them with open arms. So again that's accesschampion@gmail.com. We are still building our advisory group for our ASL videos, so if you are interested in that, again, hit up accesschampion@gmail.com and we're going to start building an advisory group for our new website. So again, accesschampion@gmail.com. And now a quick word about Patreon.

Sofiya Cheyenne: Hello, inclusion believers, this is Sofiya Cheyenne from episodes three and 77 and I wanted to take a moment to chat with you about Patreon. Patreon is a great way for you, the listener to be a part of the podcast by supporting it for as little as \$1 a month. Guys, \$1 a month. Not only do you get access to exclusive content and swag, you also help facilitate the podcast being accessible and inclusive with transcripts, accessible recording spaces for interviews and the upcoming ASL videos. So not only are you rewarded for your commitment, you are actively making accessibility and inclusion information more and more accessible. And that is the heart of the show. Obviously if you listen to Phil every week, you believe in inclusion and you believe in access and that's what being a Patreon supporter does. So please consider committing just \$1 a month and you can go to patreon.com/accesschampions today and together we can run through this brick wall.

Philip D.: Thanks Sofiya. And if you're not able to support us via Patreon, which again is \$1 a month or starting at \$1 a month, awesome swag, et cetera, et cetera, you can also support us by rating and reviewing us. So wherever you consume your podcasts, again, hit us with that five star review. If you're thinking about giving us a four star review stop, email us at the previously mentioned accesschampion@gmail.com and tell me how can we get a five star review from you. And I will do my best to make it happen. So please rate and review us. We sincerely appreciate it. We hope you appreciate us because we appreciate you,

all of our listeners and those ratings and reviews help us find more and more listeners to help spread the good word of accessibility, diversity, and inclusion across the universe. So that's that. So without further ado, access champion, Susan Shifrin.

Philip D.: All right. And we are here with Susan Shifrin, the executive director and founder of ArtZ Philadelphia. Thanks so much for taking the time to chat.

Susan S.: It's my pleasure.

Philip D.: So just like few of our previous guests, I love that you came out of my now semiannual, putting it out into the universe. Hey, who knows somebody doing something great.

Susan S.: Well lucky for me that you did that for me annually.

Philip D.: So shout out to Alanna Raffel, who tagged you guys in this? So we were just chatting briefly and before I hit record and obviously as a South Jersey boy, I'm always excited about great work happening in Philly. But as I admitted I was unfamiliar with your organization and the work that you guys are doing. But so I'd love to hear from you how ArtZ Philadelphia came to be.

Susan S.: Well, so that is a decade old story I think. In around 2010 I was working as the associate director for education at a small college museum outside of Philadelphia. And the majority of my work was to do all of the outreach, all of the educational programming and lots of things in between. And one of the things-

Philip D.: I love that phrase, lots of things in between. That's the most nonprofit phrase I think I've ever heard-

Susan S.: Exactly. Other duties as required.

Philip D.: Yep.

Susan S.: And I had been thinking for a long time and the students who had worked with me had been thinking for a long time that there were a number of communities to whom we were not reaching out effectively. And among those communities were historically underserved communities, people with low vision, people on the spectrum. People, oh well for instance, people with dementia. And with some of my students, we decided that we wanted to do an exhibition that would use our permanent collections to exemplify how even the smallest museum could reach out to communities that they were not properly serving through their permanent collections and make those collections not only interesting to folks who had not visited the museum before because they frankly didn't feel welcome, but also to specifically speak to them. It was an exhibition that we called Accessibility. And in the course of preparing for that

exhibition, I was looking around for some counsel about how should a museum go about serving people with dementia.

Susan S.: This had all started by the way, as origin stories always come from somebody else. So this all started with a very persistent social worker named Debbie Davis, who was the social worker at a local care community. And knocked on my door one day and said, "We love bringing our independent living folks to your museum. They have such a good time But can't you do anything for our residents in our memory care unit because they have nothing?" My mother had been diagnosed with dementia about five years before that and I knew exactly what Debbie was talking about and I promised her that if she came back every few months and knocked on my door and reminded me that I had said this, I was going to find a way to get some funding together and to get the training we needed to create a program for her residence.

Susan S.: Accessibility grew out of that. The training came from an organization called Artists for Alzheimer's that had been born in the Boston area in the early two thousands. They were the only such organization in the country helping museums to understand how best to serve people with dementia and after some workshops with them, we started inviting people into our museum. People living with dementia and what I saw in the galleries absolutely stunned me. There were people who were far enough along in their illnesses that they had pretty much stopped talking. People who were kind of withdrawn, isolated. And what happened when they came into the galleries was that all evaporated. They started talking. They started, in fact, one of the most fun times I remember was the session that I facilitated in which two of the participants actually started kind of jokingly arguing with each other about what a piece of art we were looking at actually meant. This is people with dementia. The folks who are supposedly not there anymore.

Susan S.: So to make a long story short, when my position was eliminated I had a choice to make. My choice was either to find a directorial position at another college museum or it was to take what I had seen in the galleries. And thinking that we had people visiting us from Baltimore, we had people coming from New York actually. Obviously there was a need for an arts based interactive program of some sort for people living with dementia and their care partners. So in my mid 50s I took the leap and ArtZ Philadelphia was the result of that leap.

Philip D.: That's amazing. And I can semi-relate to stepping out off that ledge and deciding that you're going to go do the thing. I want to scoot back just a bit because you talked about the training that was done. Can you just briefly describe some of the elements of that training? What your staff was being trained for essentially?

Susan S.: So the thing that I think we all of us who come into contact with people living with dementia or frankly other cognitive issues, the thing we all seem to have the most difficulty with is how do I communicate? How do I communicate in a respectful, appropriate, engaged way that is not patronizing, that is not off putting. That seems to be the fundamental question. Not just if you're

developing a program for people with dementia. But if you are living with a family member with dementia, that is the fundamental question.

Susan S.: And so the training revolved around some of the possible answers to that question. And it was ways to ask questions that are just open ended enough to welcome creativity and kind of a looseness in the answer. But not so open ended as to be confusing. Not so specific I mean, you see what I'm saying? I now train, I would say in some sense I train medical students and health profession students how to engage with people with dementia and a lot of it is what do you do when you meet anyone for the first time? Right? We are so caught up in the idea that oh, this person is not what they used to be. This person is damaged in some way that we forget that at their core they're human beings just like we are.

Philip D.: If I could tell you how many times I've said on this show, humans are humans.

Susan S.: Yes, exactly. That's it. So it's both being aware of some of the approaches that are most inviting and create the safest spaces for people who unfortunately have experienced stigma upon stigma. But also as you just said, humans are humans and that's the fundamental truth that underlies everything we do.

Philip D.: Fantastic. We're going to take a brief break, but when we come back, I want to hear more about the launch of ArtZ Philadelphia and what that journey was like of starting your own company.

Speaker 4: Hey Phil, what's the last thing you binge watched?

Philip D.: It definitely wasn't three seasons of Chrisley Knows Best.

Speaker 4: Well, I just finished bingeing Able on Amazon Prime.

Philip D.: All right. Is that super dope show with all those artists with disabilities?

Speaker 4: [inaudible 00:15:34].

Philip D.: I should have my own show. Phil Knows Best.

Speaker 4: Well, until you do and it's fun through the podcast, can we get back to talking about the actual show?

Philip D.: I guess.

Speaker 4: Able consists of interviews featuring actors, writers, comedians and creatives with disabilities. Their candid conversations host Alie B. Gorrie and Kallen Blair meet with featured guests to discuss the importance and non-negotiable nature of inclusion in the art. For more visit ableseries.com or head on over to Amazon Prime and start bingeing now.

Philip D.: All right, and we are here with Susan Shifrin and I have again, limited experience in this realm. I'd love to hear from you a little bit about the early days of ArtZ Philadelphia.

Susan S.: Scary.

Philip D.: I appreciate the candidness.

Susan S.: So again not to emphasize this overly much, but my plan had actually been to start arts while I was still working. And to take my time building the organization and have an income in the meantime. It didn't quite work out that way.

Philip D.: Never does.

Susan S.: It never does. And from where I sit now, it actually was an incredible gift that I was thrown into this. But I didn't quite understand that at the time. So for the first year, I mean I like to tell people the first year our budget was zero. The second year our budget was 30,000. I'm happy to say that incrementally, we did pretty well year on year. But those first few years I started the organization as a sole proprietorship. I was the organization, I did all of the programs. I actually, it was my job to find partners who would give us a place to do the programs.

Susan S.: So our way of doing business is almost as strange as public radio. We don't have a premises where we do programs. Our programs happen in museum spaces. They happen in care community, breakfast rooms, they happen in day centers. And so in order to deliver programs to our constituents, we have to have partners. So the first couple of years were me both literally and figuratively, knocking on doors and making cold calls and hoping that people would either be foolish or adventurous enough to give us a shot. And my policy was that we would do programs for free for two to three months. So that by the time I actually ask a museum or a care community to invest financially in the program, they would have seen it in action and they would know what they were getting into. That I have to say, proved to be a pretty savvy way of doing things although it caused the budget to be zero.

Susan S.: So, but what slowly happened was that the first six adventuresome people with dementia and their care partners started spreading news of what we were doing by word of mouth. And word of mouth has really been the most reliable source of new participants for us. Because the primary issue I have found in starting an organization like this and really gathering some sort of following is trust. Particularly for people living with dementia and their families. The stigmas around dementia like many other disabilities are more damaging than the condition itself. And once you've been out of your house and felt people staring at you, once you've been a care partner and seen the person you love acting a little strangely and engendering whispers, you're not going to go out again and you're not going to take the chance to go to some program you know nothing about where this is going to happen to you again.

Susan S.: So that's why I say it is fundamentally all about trust. And we needed to earn the trust of our partners who gave us the space in which to do the programs. We needed to earn the trust of the early participants so that they could tell other participants. It's okay, they actually get it. We actually enjoyed ourselves there and that's what the first few years were about. I think I might've mentioned that we started as an affiliate of a preexisting 501(c) (3) Artists for Alzheimer's.

Susan S.: Two years into that we decided to go our own way and become a 501(c) (3). So I convened a board and we applied for 501(c) (3) status. We have been an independent 501(c) (3) for I guess five years now. So a lot of that early stuff was logistical and strategic and oh my God, I'm making it up as I go along. But happily I think because in part I had been the daughter of a mother with dementia and had done what I now understand to be all not the wrong things because we're all human beings and we make mistakes. But things that were without my knowing, it guaranteed to backfire. So I had my head in the sand, I was angry with my mom for being sick. So I get what family members are going through and they, I guess, can feel that I get it.

Philip D.: Yeah, I mean that you can't create that kind of personal connection to the work and to the community. You're a member of the community that you're trying to serve.

Susan S.: Exactly. Exactly. Right. And that's a very wonderful way of putting it. And that's how it felt to me from the beginning. And I think that's how those initial years were seen by the folks who took part in our programs. So we started with one museum program at I want to give a shout out to Woodmere Art Museum which has been our museum partner from the beginning and is an incredible partner. And we had one program at a care community, the same care community that we had partnered with when I was still at the museum. And then gradually over time we've gotten to the place where we now work with anywhere from eight to 12 care communities at a time and five or six museums at a time.

Susan S.: And so for the first few years it was about building our so called flagship programs, arts to the museum where we have conversations in museum galleries about one or two works of art, arts on the road where we kind of take the museum conversation on the road to care communities or day centers. Arts in the making, which is exactly what it sounds like. It's hands on art making programs usually in care communities but sometimes in day centers. And then a program I think that came right from my own experience, Cafes for Care Partners, which is a program, it's not a support group for care partners, but it is an opportunity for them to have time to themselves, intellectual creative stimulation. The same kinds of things we want for people with dementia. We need to make sure we provide for their care partners. And so-

Philip D.: Are you thinking about the community holistically rather than just the individual with the disability or yeah.

Susan S.: Exactly. And the fact is that dementia is not the disease of a single person. It is the disease of that person. It's the illness of that person and everyone around them and everyone around them so that it is truly a community. It is a public health issue. And part of maintaining the public health is recognizing that we have conclusive research that the impact on water euphemistically called informal care partners, i. e. the family members who essentially do the care 24 seven that the impact on their health is devastating and that too many times actually care partners die before the illness takes the person they've been caring for. So Cafe for Care Partners became our fourth flagship program. We spent a few years building up those programs and then we started focusing a little more parallel to that on the educational part of our mission, which is really to do all we can to disrupt the stigmas that, as I said earlier, I mean we have research that shows that people living with dementia feel much worse about how they're treated by other people than about what they're experiencing neurologically, behaviorally, or psychologically.

Susan S.: So we in 2016 started a program that we started calling Arts at Jefferson, which is essentially a mentoring program in which people with dementia and their care partners serve as mentors for medical students, nursing students, students across the health professions. And the idea is they get to know people with dementia and their care partners as human beings. Here we go again, humans are humans, right? And they spend almost a semester getting to know each other and talking about the things that these people with rich lives and incredible experiences have done in their lives. And also eventually, again once trust has been built, talking about the experience of living with dementia. And we've actually had some medical students who have changed to geriatric or geriatric neurology tracks because of the impact of their mentors. So that program has been going on since 2016 and we just recently started a project in North Philadelphia because as we say, we have Philadelphia in our name, it's done a lot of work in the suburbs, not so much in the city and we're trying to rectify that.

Susan S.: So we have a project going on in two neighborhoods of North Philadelphia in which we are working with community members, some of whom are living with dementia, some of whom are care partners to see what we can do to create programs for them that are co-created with them. So rather than coming in and saying, "We have this standard program that we do fit yourself into it." So for instance, we're working with a community advisory group in Hunting Park in a neighborhood that is largely bilingual. And we are working with them to figure out in terms of their own life experiences, what are the things that will make them happy? What are the things that will give meaning to their days? And those are the things that become the basis for a new program.

Philip D.: I love that so much. To go along with the humans are humans, are humans. Probably the other thing that we talk about so much on this show is not doing something for the sake of doing it but doing it, creating programming that actually works for the community that you're trying to serve.

Susan S.: Exactly.

Philip D.: And that's just so wonderful to hear.

Susan S.: Oh, thank you. And it's, we are learning absolutely every day that we spend with our community advisors. And I will say they are teaching us things that cause us to go back to our existing programs and say, "Hmm maybe we should get some more input from the participants." You know? So they are really in some ways our community partners in North Philly are becoming our conscience and integral parts of our team. I mean our team, our official team is two full time staff people and a board.

Philip D.: All right.

Susan S.: And a couple of wonderful part-time program facilitators. But our relationship with folks in North Philly is becoming deeper and deeper and they are really becoming part of our team.

Philip D.: That's fantastic.

Susan S.: So it has been an incredible experience.

Philip D.: Yeah, that sounds absolutely fantastic. And also what a wonderful organic journey and growth and I mean you're hitting all of my favorite notes along the way when it comes to building trust in a community and using their feedback and building on that and being so intentional in your programming. I'll get you out of here on this. It's my favorite part of the show because as you are a team of two plus a board, I don't know how often you get asked this, but to sort of dream your dreams without a budget, no budget attached, what is your hope for the future of ArtZ Philadelphia as it moves forward?

Susan S.: Interestingly enough, we talk about this all the time.

Philip D.: Can I come work for you guys? Because this would be great.

Susan S.: So I think the first and most important thing is that right now we don't have the capacity to serve everyone that we want to serve. We have had a waiting list for a while of care communities who want to work with us and we just don't have enough of us to do that. So my greatest dream would be to be able to say yes to absolutely everyone. Now that's not altogether practical, but you said there's no budget-

Philip D.: There's no budget on the Access Champions podcast except for our own internal budget.

Susan S.: Okay. So that is really a big part of it. The other thing is, and we are starting to work on this, the work that we've done with Jefferson students and I want again

to shout out to Jefferson for being forward looking enough to gamble on us and on this one of a kind program. My hope is that in as little as 10 years we're going to see programs like Arts at Jefferson in the majority of medical and other health professions training schools. Harvard Medical School is currently considering adding to their curriculum an elective that is modeled on Arts at Jefferson. We're in conversation with some other Philadelphia based hospitals and institutions. That is truly one of my greatest desires because I think if our goal is to really dismantle stigma, it needs to start number one with people under 30, and number two it needs to start with the medical profession. So I would say being able to say yes to whoever feels they would get something out of working with us and to see our program replicated. Those are the two things that I dream about.

Philip D.: I think those are fantastic and based on our conversation today, it's very achievable dreams. I have faith in you.

Susan S.: Thanks so much. Thank you.

Philip D.: Well, thank you so much for taking the time to chat today Susan. Thank you for all of the work that you're doing and have done and continue to do and thank you for being an access champion.

Susan S.: Thank you very much.

Philip D.: Thanks again to Susan for taking the time to chat and thank you to Alanna Raffel, previous podcast guest for tagging ArtZ Philadelphia in my reach out into the universe for people doing incredible work. It's my favorite type of organic guest when they come with that sort of stamp of approval. And even at the end of the conversation with Susan, she gave me a suggestion for a future guest as well. So I love that. If you guys have any suggestions of again for guests or topics, please hit us up accesschampion@gmail.com. That's the same address you can hit up if you're interested in being part of any of our advisory groups, either our ASL videos or our upcoming relaunch of the website or a frankly launch of its own independent website. And please remember that Patreon exists, we have exclusive content on there. It's \$1 a month is all you have to commit to get access to that exclusive content.

Philip D.: We also provide swag from stickers to tee shirts, to mugs, etc. For obviously different levels of giving, but the baseline of \$1 a month, you get a sticker and access to all the content and we are incredibly appreciative of their support. And again, if you can't support us in that way, please consider rating and reviewing us. Hit us with that five star review and that's that.

Philip D.: So thank you as always to our executive producer Matt Kerstetter for making our sound great each and every single week. Thank you to our associate producer, Miss Kelsey Rose Brown as we hold onto her for last couple of weeks with her as she pulls double time with all of her grad school work and helping

out with the podcast. And thank you to our champion intern Savannah Cooper for all the work that she does as well. We'll be back again next week and remember, inclusion believers never stop running through that brick wall.