

Ep. 16 Megan Best, Sarah Demissie, and Amanda Johnston

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SPEAKERS

Matt Wappett, Sarah Demissie, Amanda Johnston, Megan Best,

Matt Wappett 00:14

Hi everybody. Welcome to the Developmental Disabilities Network journals, author, insights, Podcast. I'm Dr Matthew Wappett, the editor in chief of the Developmental Disabilities Network journal and the executive director of the Utah State University Institute for Disability research, policy and practice, where Utah's UCEDD program, and it's my privilege to host this podcast. Today, we are going to be talking with some researchers from the University of Illinois and Vanderbilt, but it's a broad team that worked on this project. There's folks from Maryland, Boston, yeah, Northern Illinois. Anyway, a broad team looking who conducted a pilot evaluation of a civic engagement program for youth with disabilities. Now we're super excited about this one, because not only is it about civic engagement, which is becoming increasingly important, but it's also by some doctoral students, and it had a broad self-advocate research team involved. So, this was not only research about people with disabilities. This article is research with people with disabilities, and that is something that we really, really like to highlight, and we're excited to have one of the self-advocates on the podcast today to talk with us about her experience working with the researchers on this project. So anyway, before we get to that conversation, just a quick reminder, please subscribe to this podcast on wherever it is you listen to podcasts, we're on every platform. So, Apple, Spotify, Stitcher, overcast, Podbean, anywhere you can get a podcast, we're there and so please subscribe, leave us a rating, leave us a review, and please share this podcast with your friends and colleagues. That helps get the word out. It helps raise the visibility of the podcast, the journal and the folks who we have on here, so they may your ratings, reviews and shares. They really make a difference. So anyway, please do that. And then, in terms of other business, just a quick reminder that this podcast is just another way that you can access the information in the Developmental Disabilities Network journal. We decided to do this because we recognize that not everyone wants to read, and sometimes it's nice to listen to what's happening and to get the information in a different format, and so this podcast, again, is another way for you to kind of keep up with what's happening in the journal with the research that we're publishing, and to get to know the researchers who are working in the field today. So going to today's episode, we are excited to have

with us today, Megan Best, Amanda Johnston and Sarah Demissie now, Megan and Amanda are doctoral candidates, and Sarah is a self advocate researcher, and we are, like I said, just super thrilled about this opportunity to highlight their inclusive research project and the outcomes of their civic engagement pilot program. So with that said, let me do a quick intro to our guest today. So first up, and the first author on this article was Megan Best. Megan is a fourth year doctoral candidate at the University of Illinois, Urbana Champaign. Her research focuses on empowering self advocacy for young adults with intellectual and developmental disabilities. And prior to pursuing her PhD in special ed, she worked for 10 years as a high school special ed teacher and administrator in the Chicago area. Amanda Johnston, who is also with us today, is also a doctoral candidate at Vanderbilt University. Her research interests include parental advocacy, knowledge of systems and supports and family professional partnerships, specifically those involving families from low resource backgrounds. And finally, but certainly not least, we have Sarah Demissie. Sarah is a self-advocate researcher working remotely with Vanderbilt University. Sarah lives in the Chicago area, but has been involved with different research projects like the Spencer project and collaborating with a lot of other researchers with and without disabilities over the last few years, she identifies as a person with a disability and has worked within individuals with disabilities, including youth, as is reflected in this project, and she's done lots of presentations about her experience with self-advocacy, and as you'll hear, she loves to continue to learn things and to grow. So we're excited to have Megan, Amanda and Sarah on the podcast today to talk about their article conducting a pilot evaluation of a civic engagement program for youth with disabilities. So welcome Megan, Amanda and Sarah to the podcast today. We're excited to visit with you. We're talking today about your article, conducting a pilot evaluation of a civic engagement program for youth with disabilities. And we're lucky to have three of you here, although you have a whole bunch of authors on this, which is really cool. But why don't we start with you, Megan, and if you could tell us a little bit about your background and the path that brought you to this, this project.

Megan Best 06:02

Yeah, absolutely. Thank you so much for having us again. My name is Megan Best. I'm currently a doctoral candidate at the University of Illinois at Urbana Champaign, and I was brought onto this project as part of learning and RA research assistant opportunity through my advisor at the time, Dr Megan Burke, I came into my program with a lot of experience teaching young adults with disabilities in the high school setting, and I'm really interested and passionate about empowering young adults with disabilities in their educational journey and their advocacy and learning more about that journey along the way. So, for this project, while we're all authors, Dr. Megan Burke at Vanderbilt University and Dr. Zach Rosetti at Boston University are actually the PIs or principal investigators. And so this was a multiple University study, kind of looking really at how to how to take a program that was working related to parent advocacy and civic engagement and kind of explore if we could adapt it for young adults with disabilities. And so, when the opportunity came up to work on this project, I was very excited. It was right in my wheelhouse of interest. And yeah, it's been a great learning opportunity.

Matt Wappett 07:20

Awesome. What about What about you, Sarah? Give us a little bit about your background and how you got involved with this project.

Sarah Demissie 07:29

Okay, so my name is Sarah, and I am currently a self-advocacy researcher through the Vanderbilt University, remotely, where I work with the Megan Burke on like different projects, but in but for the Spencer Project, how I got introduced to it was through Megan Burke, where she got me, like, hired to work for the project with her and Zach and I, and I, and I really enjoy, like, working with, like, people with CO well, with I've, I happen to be a co researcher, and I happen to have some and I'm also, I also have a disability too. So for so having the opportunity to work on this project with other researchers, both with and without disabilities, that I was able to give my insights to how the project was, how the project should be when it comes to like, modifying the youth curriculum training from the parent curriculum training and so and I also have a lot of background experience when it comes to, like, my own experiences, like with involving self-advocacy, because, because I've done a lot of presentations about it before, and I have also, not only have worked with alongside researchers and researchers with and without disabilities, but I have also more had the opportunity to work with youth and young adults with disabilities, like, generally speaking, individuals with disabilities, and I'm very passionate about leadership and research, and most importantly, since I'm a curious person and have. A curious mind about a lot of stuff that I enjoy learning things about my job when it comes to leadership and advocacy, as well as other things outside of my job.

Matt Wappett 10:15

Yeah, and we're super excited to have you, because this is an this is a project that actually involved co researchers with disabilities. So, we're going to actually jump into that a little bit later on and kind of get your insights on that Sarah. Amanda, what about you? Give us a little bit about your background and how you got involved with this project.

Amanda Johnston 10:36

Yeah, again, thanks for having us. So, a little bit about me. My name is Amanda, and I'm a doctoral candidate at Vanderbilt University. Similar to Megan, I was brought on as a research assistant per advisor, Dr. Megan Burke, my background is as a school teacher, and I just have a general interest in supporting families, in accessing needed supports and services, special education process, things like that. And so I was excited about this opportunity to translate and transform this curriculum to be from appearance focused to youth who are directly affected or benefit from idea.

Matt Wappett 11:18

awesome, and yeah, and we'll jump into that parent piece in a bit here too. We're excited to kind of see how you've addressed that involvement. But before we get too far along in the conversation, just because not everybody may have read the article, can you give us a quick summary of the article in a couple of minutes?

Amanda Johnston 11:42

Yeah, I can go ahead and take that one. So, the article itself is about a civic engagement training for youth with disabilities, focusing on the Individuals with Disabilities, Education Act or IDEA, as well as self-advocacy. The article discusses the development of a program developed alongside co researchers with disabilities as well as parent and training information center staff across multiple different states. The article shares information about the program's implementation from a pilot so its inception to hosting that program across multiple states. So, throughout the course of the program, the

youth had the opportunity to learn more about IDEA, share about their own experiences in schools, as well as suggest changes to current legislation based on their own lived experiences. So the final products, I think, of this, were based on different methods of advocacy presented during that training or program, including contacting legislators via legislative testimonies, writing letters or emails to your legislators, or posting on social media platforms for the youth to share their own testimony. So the overall findings were specific to the youth themselves as they related to the future reauthorization of IDEA and included specific suggestions based on their own experiences in schools, such as having increased time during tests and having increased independence in the school environment, and this push for increased access to self-advocacy programming, as well as issues that are broader to education, things like community accessibility or just this push for inclusion of people with disabilities in specific settings, such as higher education settings, thinking about the transition age youth we were working with kind of thinking, what are those next steps? And then the PTI also provided feedback on the training and program itself and shared that you know what would work well and what could benefit a program moving forward. So, talking about how the youth might have preferences, especially post pandemic, thinking about remote meetings and how that could be a more inclusive option, as well as how we are presenting information so that youth could be fully engaged and included in this work. Moving forward.

Matt Wappett 14:08

Yeah, so were the were the youth and the parents and others who were involved in this project? Were they all in one state or location, or were they spread out? Kind of where were the participants. Yeah,

Amanda Johnston 14:20

they were across six different states. It was Illinois, New Mexico, Louisiana, Maine, Massachusetts, and there is one more that is escaping me in this moment.

Megan Best 14:37

We didn't end up having any youth at the New Mexico site, but actually while we ran the parent one at six sites, Amanda, I'm thinking we only did it at those four locations, Massachusetts, Illinois, Louisiana and Maine and I apologize, we ran the parent one at each site, but the youth one, we visited each site twice. So sorry about that.

Matt Wappett 14:56

No, that's totally fine. I yeah, I was as you were. Kind of talking about it. I realized, oh, it might be good to know that this was more of a broad, multi state initiative, as opposed to a single location. Yeah,

Amanda Johnston 15:10

and I think the hope was to get youth across those six locations. But I think it does speak to like your some of your later points about you know, is it accessible? Are youth interested? Do they know of its importance, things like that. So, we did try. I just think that we were up against some other barriers that didn't make it come to fruition.

Matt Wappett 15:31

Yeah, yeah, no. It can be really hard to coordinate these things. So did you do this? And again, this is like another question I didn't put in there. But did you start on this during the pandemic, or was this something that was kind of post pandemic?

Sarah Demissie 15:48

Yes. So, we started this during the pandemic. So, at the time that I started working on this project was back in 2021 and I and where they were at, we ended up where I had started my work with giving insight was we were modifying the youth, the parent curriculum training to be able to adapt the accommodations for the youth. So, we created the youth curriculum training with like just modifying the just basically, like modifying the curriculum training itself so that it will be accessible and for youths with disabilities to understand when we had conducted the training. So, for example, we included like visual aids, like pictures and plain language words, like, like other and other things we included in there were like, clip arts and we role play scenarios. Was another one we included in there. And then we also included, like, Babe, I think, oh, yeah, so and so I think, and I think that's one of those things there. So we Oh yeah. And also, we talked, there were like a jam board where they where we write down ideas of like, like facilitators. We would say it would be regarding like, IDEA, like experiences like who we are, like what our background was, and also how, how our experiences, like in high school, like for high school youths, and also what, what Like, what would have been better like for to have the change done in IDEA like, what thing, what specific things should be changed to better access, to be able to basically have access to youth, being able to understand and advocate for themselves. So basically, so it's pretty much like so, for example, like with myself, because this came self-advocacy came later on, like in my adulthood, as opposed to my youth when I was back in, back in high school, that I talked about some of the things that helped me to that would have been helpful for me at the time, of how I could be able to learn self-advocacy when I was in high school, and what kind of like project I would like present in high School, like, and one of them was like, stop bullying and also and promote inclusion. So that was my example, when I had given like, when I was co facilitating the youth curriculum training. But each one of them the youth had their own ideas so that, and so it was written like on a like they called the jam board, where the where their ideas were taken down. And even though we didn't actually go through like in length, like every single one of them, or like the role play scenarios. We didn't actually do the role play. It was just there so that, that way they can understand better, have a better understanding, and also, because of time constraints, to time crunch with ours. With the timing of the training, which was out like between three and six hours long. Correct me, if I'm wrong, Megan or Amanda, but yeah, it was quite because we had so much time, it was so much information, that it was hard. We couldn't try to frame everything together, and it didn't quite work out with the learning of the youth, as well as like when the PTIs were listening in to our curriculum training that we were conducting. Yeah.

Megan Best 20:35

Thank you, Sarah, for adding all that. I think it really speaks to that this process and adaptations was a very iterative process. So well, the development and adaptation started during the pandemic, because of the pandemic piloting of this happened online. But then when we moved into conducting these, I should say that was a pre pilot, because these were a pilot program. Those were all in person, at different sites. And so, I think, to Sarah's point, I think a strength kind of that came out of this at being at different sites at PTI was this co-facilitation piece with COVID, with disability self-advocates at each state location. So Sarah was sharing a bit about when she and I co facilitated at our Illinois location,

and it was so much content, and it was the first one we did, and we didn't get quite to like the role play scenario, but then at a different site, you know, we had a bit more time and were able to kind of dive into some parts of that program. And so, I know that for myself, I currently do not identify as having a disability, and I recognize that as a limitation, especially when facilitating or doing this kind of work. And so, it was a really rich and positive experience to lean into Sarah and her experiences and her willingness to be transparent and vulnerable about some of the things she went through that really, I think, deepen the experiences of our participants. And so, yeah, I think kind of wrapping all the different things we've been chatting about, I think it was really positive when we were able to do it in person, too.

Matt Wappett 22:05

Yeah, yeah. Well, and it sounds like you were able to kind of present multiple things using multiple tools to write, make the content and the ideas and as accessible as possible, which is great. I mean, it's, yeah, that's one of the things I think, that we often overlook with training programs, we're just going to deliver it as a lecture, right, or a presentation, but using, you know, more interactive technologies, especially things that came out during the pandemic, I think, is a great way to get people more engaged, right in the process.

Megan Best 22:41

Absolutely, and I think too, and thinking about shifting and adapting this from for parents to young adults, there's a lot more culturally and technology relevant ways to kind of get out that testimony or those advocacy experiences. And so, we'll kind of share about these templates that the team created, but it really allowed for a lot of participant voice and autonomy, and how they wanted to choose to advocate for what might be changed or made better in special education, as well as across for idea in the future of reauthorization.

Matt Wappett 23:12

Yeah, so let's cut, let's kind of go back and kind of maybe set some groundwork here. The article is about civic engagement for youth with disabilities. Tell us a little bit about why it's important for youth with disabilities to get involved in civic engagement initiatives.

Sarah Demissie 23:32

Yes, so because I think it's important for youth to understand how advocacy works, and not only how it works, but also being able to learn how to advocate for themselves as well as what to advocate for and advocating for others as well and not. And also because I think that that's important to have, for them to have, like firsthand, hands on, experience with how what self-advocacy is, and having the experience and knowledge of being able to practice on advocating for themselves and for others, so that that way, when they become adult, it will become second nature for them, and they will at least have the skills to advocate for the things they want need and believe in, at least for the times when they need them, whether they're passionate about advocates, self-advocacy or not,

Megan Best 24:35

absolutely. And also, you know, so many of the policies that we have in place, especially for individuals with disabilities, have been put into place in been put into place and written by people without disabilities. And so, it's really lacking that lived experience and input, and it's so necessary when

considering revisions or development of policies, when we specifically think about when IDEA was reauthorized in 2004 Are only 1% of for public comment. Everyone has an there's a public comment opportunity where people can come in and get feedback. And out of that, that full public comment, only 1% was given by people with disabilities. And so there really is an opportunity to empower young adults in advocacy and to encourage them to be engaged in civic engagement, so that we can move forward and really develop and empower more inclusive, to Sarah's point, more inclusive policies that really are going to benefit everyone and not one set of the population.

Matt Wappett 25:35

Yeah, I'm shocked that only 1% I'd never heard that number, but that's incredible, that only 1% of the public comment way back in 2004 with people with disabilities. That's kind of depressing, actually. Okay, well, so we one of the things that makes this project a little bit different than maybe a traditional research project is that you involved co researchers with disabilities in the approach, and we're lucky to have Sarah here, who was one of the co researchers on the project. What were some of the benefits and challenges that you found in working with co researchers on this project?

Sarah Demissie 26:19

I would say the strength, like with co-researcher working with other co researchers, that they had a lot of ideas and insights to that they came up with, that I probably wouldn't have thought about, but also like being able to learn from their perspective and my perspective, and through collaboration that we would, that we were able to come up with, like some, like, different ideas on how to make the project work. And I think, and I would say, like, the challenge might be, like, being able to, like, you find some kind of, like common ground, like, you know, like the technical issues come up, like, like, when facilitating a training, and then something goes wrong, and then you have to, like, backtrack or like a focus group, or others, like presentation stuff that just being able to, like, figure out, like, where you stopped at, like Where the stopping point was, because, depending upon like, the issue that might come up, but otherwise, like, we work pretty well together as a team, and we're able to problem solve or find an alternative to challenges that might like, get us down for a moment, like the technical issues, but that's the only thing I can think of in terms of, like, strengths and challenges.

Matt Wappett 28:11

How many co researchers were involved in this project? I don't know if you know that. Off the top of your head,

Sarah Demissie 28:18

I would say that it was at least, like the two of us, one with the with, like, who was with a disability, but like, what was, but it was combined with both people, researchers with and without disabilities. Yeah. And then there was like one other, like the person with a disability who came like afterwards, like when once the post pan, like post pandemic. So, there was that it was like the three of us, like from our different state, like from Boston, one from Boston, and the other us from Illinois. You want to add something else? Megan,

Megan Best 29:03

yeah, no, I think that. I really appreciate you sharing that. Sarah, um, to Sarah's point, we had kind of like an internal and external team, if you will. So, we had our internal team that was, you know, affiliated with university and having two co researchers with disabilities. And then we also have this external kind of collaboration with the PTIs as well, and so each PTI also had at least one disability self advocate who was contributing and giving feedback and then also co facilitating at those PTI sites, if that makes sense.

Matt Wappett 29:32

Yeah. Yeah, absolutely.

Megan Best 29:35

I also wanted to add, if I may, I think that I would highly encourage everyone to engage in inclusive research and co-conducting, creating collaborative teams that have both co researchers with and without disabilities. And I also want to like highlight that sometimes it's not the easiest work. I think historically, individuals with disabilities have been excluded from opportunities to engage as co researchers, and perhaps in the past, it's been not, not a career path that's been highlighted or encouraged, and so I think I can, I can share it's been a learning journey for me, and there's always ways to improve as a team. But I think a strength of this collaboration has been that everyone's been open and responsive and willing to kind of work through both the good and sometimes the challenging aspects that could come up. And if I can highlight that Sarah's work, she was involved in all aspects of this project, from conception to data collection to analysis, to writing it up, as was our colleague, Tim. And so, I just think that it was really a really enjoyable, collaborative process that we all were able to participate in. And I also want to highlight Dr. Burke and Dr. Rossetti, who are the PIs on this project, and ensured that there was funding and kind of the pathways there to infrastructure there to make sure that our colleagues, that everyone had the opportunity to participate in this work.

Matt Wappett 31:05

Yeah, no, and I appreciate you bringing that up, because it doesn't happen organically. Sometimes it has to be intentional right to make to put the supports and the processes and the funding in place to ensure that right individuals with disabilities are included as equals, right on those teams. So, I'm, yeah, I appreciate you bringing that up. So going, going back you brought up PTIs, and that is kind of the next question here. But before we talk about that, can and maybe, and maybe, Amanda, you can do this, can you tell us a little bit about what a PTI is? I am assuming a lot of folks who listen to this probably know, but just in case they don't what is a PTI?

Amanda Johnston 31:51

Yeah, a PTI is a Parent Training Information centers. They are federally funded organizations that do receive funding to support students with disabilities and their families, and just help those families acquire knowledge and resources and support as they navigate through life. I think right there are different types of programming, different kinds of resources, very dependent on a family's needs, but also kind of like geographical locations and what that might differ state to state. And that was another interesting piece of this project. We got to see how, you know, the Illinois PTI might differ from the Louisiana PTI, even though all of them are covered under IDEA it might look a little different state to state. So, it's an opportunity for families to reach out and find support, through support groups, through

trainings. They have webinars most often, if you look. But then there's also the opportunity, I think, for collaborations as I don't know who the viewers of your podcast are, but the opportunity for researchers to collaborate with those organizations as well, I would imagine,

Matt Wappett 33:10

yeah, well, and it's, it's often PTI is do a lot of training, and they're right, but it's oftentimes rare for us to see a PTI actually engaged as part of the research. So, as you worked with the PTI is, what were some of the benefits you found of collaborating with them on this project?

Amanda Johnston 33:29

Yeah, I think the first thing is they kind of knew the lay of the land, in a way, right? I mentioned that each state is covered under IDEA. But again, state to state, that could look a little different in terms of what this school district offers versus what this school district offers or does not offer to their students with disabilities. And so PTI is kind of have like this on the ground, insider knowledge on what that looks like and for families, and could provide insight to us, kind of coming in, well, it's done this way, or, Oh, we should highlight this practice of a little bit more, or we should provide more clarity on this to make it more, I think, meaningful for the families and therefore the youth in this case, as we're presenting this information, they also had connections to youth and families to participate in this project. They also had different, again, connections with school districts, those sorts of things to help with recruitment. So then it's kind of like everyone is working together to, you know, hopefully empower youth to become better advocates in terms of civic engagement.

Matt Wappett 34:48

Yeah. And I think you bring up a really good point a lot of times. I think people assume, especially if they don't work in special education, that special education is the same right from state to state, and it is not. It varies widely terms of how it looks, who qualifies, what services and supports are available. And so yeah, it totally makes sense that those PTIs would be really, really integral to understanding kind of the lay of the land in the different states that you were working, working in so what are some tips you might have for other researchers who could potentially benefit from working with PTIs, were there things you learned in working with PTIs? that you know, you'd say, oh, this might help others.

Amanda Johnston 35:34

I think the first thing that comes to my mind and Megan and Sarah, you could jump in, is to just talk, right? Communicate. See what their needs are, see what their families and students needs are, and see if you can help. Right? It's not always about I have this really cool idea as a researcher, right? I think that PTI is have this knowledge, and they are supporting family's kind of on the ground. And how can we work together to make this something that's not just beneficial for me, but beneficial for everybody? And I think that that's not just a one-off thing either, right? We had week, I want to say, monthly meetings with at least monthly meetings with PTIs across the different locations for feedback, for questions, for kind of all sorts of things, to really make sure that it was a group effort.

Matt Wappett 36:28

Yeah, go ahead, Sarah,

Sarah Demissie 36:30

so, I was good. So I think it's just like Amanda said that like to be able to, like, give, ask, like, what provide accommodations and see, like, how we can help other people and like, be able and be able to work with them to like, just basically knowing what they want or what they need, and then just being able to like, address and go according to what works best for them. Everybody has like different learning styles, so being able to find out what learning style works for you and what might work for someone else would be would definitely be helpful to ask and to be able to go from there so that way, that you'll be on the same page, and then to avoid as much confusion as possible, like when communicating with others. So basically, communicate more communication in the right on the right path, then the better the outcome will be.

Matt Wappett 37:46

So, it's I wanted to highlight that because, again, having co researchers with disabilities is incredibly important, and I think it's becoming more and more common, but certainly it's not. It's nowhere near as common as it should be, right? But also involving parents, right? And those parents who have this lived experience of helping their kids navigate these school systems and these challenges, is really important as well. And having that parent perspective, I think it's a natural, it's a natural partnership with the PTIs and they bring, I think, so much value to the process. So, I was excited to see that you'd worked with them. I've been on the board of our PTI here in Utah for six years. And, yeah, we find them to be just an incredible partner. So next question, so we kind of get back to the theme of civic engagement, as you engaged in this process, and you went through the project, did the training. What were some of the barriers that you've discovered to civic engagement for youth with disabilities?

Amanda Johnston 39:00

One of the first barriers, I think, that we kind of encountered was this piece that there was, like, limited knowledge about civic engagement, right, about your rights, and what idea was and how it impacts you, and like knowing that, like you play a role in that as a youth with a disability. So something that was mentioned when discussing the findings, either, you know, at the training, or after the training, or even afterwards, when they were, like looking at the data and things were that many youth hadn't heard this information before, and that's interesting, if we think about, you know, history is taught right in high school, in elementary school, middle school, right? We have history classes, and we learn about the Civil Rights Movement, and we learn about all these different things across history, but we don't often teach disability history and disability rights or even self-advocacy. In school, even though that this is very much a part of who people are, and it is, you know, directly influencing who they are and the things that we now have, or things like that. And then another barrier kind of related is this piece of self-advocacy, right? Not only is like disability rights in history not taught, self-advocacy isn't always taught and mentioned and expected for youth. We think about IEP meetings, and if I feel like, if you're in this world, you know that youth could be involved. But is it the expectation that youth are involved in their IEP meetings, right? Is that is something that parents know that, like your youth, from as young as they can be, can be involved and have a right to be there, or is that just skipped over and those sorts of things, and then in thinking about IEP meetings themselves, right? Are they accessible, or IEP the documents accessible. So, in thinking about this, I just think that there's a limited knowledge of what you're entitled to, your rights, those sorts of things. And I feel like we kind of were presented with a lot of that in this program and this project, or youth were just kind of unaware about it all.

Matt Wappett 41:24

Yeah, well, and you bring up a really, really good point right into students with disabilities are the only group that have a legal right to a free and appropriate public education for everybody else. It's, you know, kind of, you know, we give it to you because we're nice, right? But there's, it's actually enshrined in policy that it's a right for students with disabilities. And I think when we look at people with disabilities, right, there's so many federal laws and policies and rights and state laws and policies, and a lot of times the lives right, of these students, these families, these adults with disabilities, are controlled and bounded by these laws. And as you pointed out, a lot of times, people with disabilities are not engaged in the making or the feedback or the advocacy right for those laws and changes that need to be made. So, so what are some of the ideas that came out of this project to address some of these barriers to civic engagement?

Megan Best 42:30

Yeah, definitely, I think, to Amanda's point, this was new learning, or newer learning, for many of the participants. And so, it was exciting to see advocacy suggestions and seeing the advocacy effort kind of that scoped even beyond the educational setting. So, in our article, you'll kind of see from all of our youth, there's quite a variety of ideas and suggestions. So, I can highlight a few of that that works?

Matt Wappett 42:58

Yeah, absolutely.

Megan Best 42:58

So, one of our participants shared that they'd like increased time during test taking, so IDEA should allow more time while other people with disabilities take their tests. I thought this was an interesting suggestion because it highlights that while this is something that would be considered an accommodation under IDEA and their experience, this wasn't something they were receiving that they would find to be a benefit, you know? And so, I think I found that to be really interesting. And IDEA could change schools by making sure this idea around bullying, like, if you keep getting bullied, that there would be consequences for bullies. And so just this idea, whatever that might look like. But in this young adult experience, they had experienced bullying specifically related to their disability, and they felt really frustrated and not heard, and that this ongoing problem was just kind of perpetuating so this idea of including some sort of aspect related to that within IDEA, and then, you know another student, a young adult, I should say sorry. Had shared that she really wanted to be a nurse in the future, and so, of course that she wanted to take was related to, like, health occupations class within her district, but she wasn't allowed to take it because she didn't have the quote, unquote pre reqs. But wasn't given access to those pre reqs. And so really thinking about kind of course of study advocacy and like, what courses games with disabilities have access to, and just sometimes there's some red tape around, like getting access to the courses that they're interested kind of based on district policy. And so thinking even around like IDEA and transition planning and how maybe there could be some updates and adaptations to make sure that you know, the courses these young adults can participate in, you know, reflect their goals too, even if that might, like, look a little bit different than their peers in accessing those in the school setting. Yeah.

Matt Wappett 44:55

Sarah, well, I'm going to ask you, because, again, you're in. Involved in this, as you went through this, what were some of the ideas that kind of you came up with around how to get youth more and more engaged?

Sarah Demissie 45:12

So, it's pretty much from my past experiences and how I function and my learning style, like, since I'm a visual learner that primarily that I just I use, like pictures, like visual aids and video and stuff like that. Mean those things, along with, like plain language, as opposed to just words, especially complex words that are hard to understand, such as medical terminology, for instance. So, I just so pretty much going back through and thinking what would have helped me when I was going through high school, that I thought maybe it would work. Those things could work for youth who are currently in school, like high school, and see like how well they could benefit from it at their age, while they're still in school as so try to give them something that I wish I had growing up, because I used to get bullied a lot in school, and so I know how it's, like, understand, like, how frustrating the experience was and it there was little to no, like, protection for me or support from teachers To prevent students from, like, constantly bullying me so. So pretty much growing up and then going back to the things of what could have helped me, that I wanted to be able to help other individuals, like young adults and youth with disabilities, be able to live a better life and also empower them and encourage like in a way, like just to introduce them to self-advocacy, because I know, because this, I demonstrate a lot in action like this one, as opposed to like giving advice. So the message I send across, most importantly, is if I can do it, so can anyone so like, if that, if I can be a leader in my own life and advocate for myself, then I know that it could work for any, ever, anyone, everyone, can be a leader in their own lives and a self-advocate. Is this basically that the one thing that I really in a way, like surprised me, but also like made me proud, was also when the youth and the young adults during the trainings had, like, demonstrated interest, and not only learning what self-advocacy was like and how it worked and what to advocate for, but to also practice those opportunities and apply their skills in their everyday lives, especially when they become adults

Matt Wappett 48:18

well and you bring up such an important such an important thing in your answer there, Sarah, is the importance of role models, right? And other students with disabilities being able to see you and hear your experience and see you, right? Advocating makes a huge difference, because a lot of times we don't believe we can do something until we see somebody like us, right? Yeah, lead and do that. And so, yeah, I appreciate you bringing that up.

Sarah Demissie 48:50

Oh, okay, I was also going to say, I mean, I've also had like, leaders I've looked up to in my life, and I've like and I've also been able to experience some of what they might have experienced and to also, and then used it, what helped me and then be able to pass it on to other people.

Matt Wappett 49:09

Yeah, that's so, so important, and

Sarah Demissie 49:13

that's why, and that's in part, why I like, why I enjoy doing the work that I do. Like seeing the rewards in people. Like it like it's like a reward within itself, like you, if something that you wish you had, or what worked for you, and also be able to pass it on to someone else. And they do the same thing.

Matt Wappett 49:34

yeah, yep. No. Super important. Thank you. So, one of the things that we like to do is a lot of times when you read an article right, it appears so clean and everything went right, and there was, you know, you don't see some of the drama and the memorable experiences that happened behind the scenes. And so, one of the questions that I like to ask is to give us kind of a picture of what happened behind the scenes. Share with us a memorable story or event that occurred as you worked on this project.

Megan Best 50:13

I would say, I'll give two examples. I think one is around recruitment, like it was just difficult to recruit young adults who wanted to participate on a Saturday afternoon for five to six hours of their time. And so, some of our groups were quite small, but I think it was really still an enjoyable experience. But I think just like the recruitment efforts and support from PTIs to really, you know, try and make this work, and Amanda and I spent a lot of time traveling that year, flying to and from different PTIs sites in different states. And so, we have a lot of memories ourselves in that way, but a kind of different memorable story I wanted to share is to kind of Sarah's point about just the power of these group facilitations happening by disability self-advocates. And there's one specific focus group that stands out to me where there were two young adults who were in their early 20s and one young adult who was kind of earlier in their career path, you know, 14-16, and that young adult was really going through some really hard times in schooling and really struggling with issues of bullying and feeling very frustrated and almost was pretty just kind of felt a bit down in that focus group and kind of a little bit more quiet to get started. And I'll always remember, and I'll always be grateful that I was there to witness this, but the other two focus group participants really stepped into this, this mentorship space of support, like listening, echoing the feelings and experiences, saying it's going to be better, it can be better. And just like the relationships that developed between the participants, I think was not something that we could have planned for. But I think when beyond the scope of this study, like that was an important moment for that youth, and it was really a privilege to be witness, to see just the power of pouring into somebody else and supporting them wherever they're on their wherever they are at on their journey.

Matt Wappett 52:13

Yeah, no, and that's again, those are those little social interactions that occur right when you're working on a project like this that oftentimes aren't reflected and yet are so, so important, I think, to the overall impact of this work. So, thanks for sharing that well, so kind of coming to the end here, if, if there was a message that you wanted folks to take away from your article, what? What is that take home message? What do you want readers to remember?

Amanda Johnston 52:45

Yeah, we were talking about this, and I think one of the major takeaways is that just to do it, right? take the leap to include individuals with disabilities as researchers in your projects, really highlight their voice, right? I think we've talked a little bit about some of the barriers, right? It might feel weird at first.

It's not typically what has been done, even though we all kind of come to this conclusion that it should, what it should, what it is, what should be done, right? And I think in reflecting now, even as we have Sarah and we have other members with disabilities on our research team, I think they're just so full. They're so rich. I think there's this perspective that I'm always thankful for. Every time I'm done meeting with Sarah, I am just so thankful that she is there because of her experiences, but also because I value Sarah, right, like, there's and like, I think that our projects are better because of it. I think that the outcomes are better for me as a researcher to like, really be mindful of things that I don't have an awareness of. And I would say that that is on the research side, but it's also very applicable to the practice side. And so, I just think, if anything, you know, take the leap, you're going to have bumps, it's going to maybe feel weird or different, but that's okay. I think that's just part of the process.

Matt Wappett 54:17

Yeah, well, and I so I should note, as you were saying, that, Amanda, we don't use the video from this, but I don't know if you saw the smile on Sarah's face, as you said that. I wish we could capture that, because that was, that was so cool. I don't I'm really sorry nobody could see that, but I do agree that was, that's such an important part of this well,

Amanda Johnston 54:41

and like, Sarah and I actually, like, live not too far from each other, but, like, without this project, I would have never known Sarah, right? And so, I think like that, that is an interesting piece of this whole thing too, where, like, we probably lived by each other for a long time. But, you know, without this, I. Know, I'm just very grateful for this project, for the opportunities to be a part of them.

Matt Wappett 54:42

Yeah, absolutely. Well, and like and like has come up over and over. Right? The relationships that are created through things like this become so important and lifelong, right, relationships that make a difference in the world. So yeah, so the last two questions, and I'm going to have you all answer these, and they're questions that we ask everybody at the end here, because I think it's interesting for our listeners and the readers to kind of get a little more insight into who the authors are. So, the first question is, what motivates you to do this work? Why do you do what you do? And why don't we start with you, Megan, and then we can go Sarah, you unmuted. Let's go with you, Sarah, we'll go with Sarah, then Megan, then Amanda. So why do you do what you do? Sarah?

Sarah Demissie 55:58

Oh, okay, so I so the reason why I do the work, that I do is because I believe that it's important for like individuals with disabilities, especially youths, to be able to have the opportunity and the knowledge and the experience of what self-advocacy is, and how they can become a self-advocate. I in their own lives, whether they're passionate about it or not, and because they'll have it when they need it. And also, I really I enjoy, like working alongside researchers with and without disabilities to get input. So, I'm grateful for that, and also to be able to work with like young adults and youth with disabilities too, in the process. So and because we work so well together, it makes me want to continue doing what I'm doing as a self not only as a self-advocate, but also just a person myself in my life, and not just because I have a disability, but just basically for who I am, because I'm very passionate about learning things like self-advocacy, leadership and also communicating and doing things at that I may not imagine doing like

it, just going beyond my wildest dreams and also being able to see my dreams come to life when it comes to helping other people making a difference, one person at a time.

Matt Wappett 57:46

Thank you, Sarah. That was, anyway, that may be one of the best responses I've had to that question on the podcast. Megan, what about you? Why do you do what you do?

Megan Best 57:59

Thank you for asking, although I do think Sarah's answer was just so incredible and just fantastic. So, thank you for sharing that Sarah. I am motivated to do this work because I feel very strongly and passionately that everyone should have a voice and opportunity to give input and insight, and just historically, there have been many voices across many people that have been not been included, not only for civic engagement, but across the lifespan, and across every you know, area of life. And as a special education teacher, I really valued having my students at the time, you know, take the lead and take the leadership role in their plans and in their futures. And it was, it's been disheartening, I think, to see and experience tangentially, you know, through other students or colleagues or friends that continue to face and experience access barriers in adulthood, and so I think really zooming in and focusing on youth advocacy and empowering youth for this next generation is so important. And so, I think it's exciting, and I'm really hopeful for what's to come. And I think that I've just grown so much, and I'm grateful for the collaborations that I've experienced, and I'm eager to continue growing and learning, because I just think things will just be better when we work collectively and we have all those shared experiences. And I think if we're in the field of disability work or special education, specifically like we really need to make sure that we are amplifying the voices of individuals with disabilities to ensure we're moving in the right it's in the right direction.

Matt Wappett 59:45

Yeah, absolutely, I could not agree more. So, Amanda, what about you? Why do you do what you do?

Amanda Johnston 59:53

Those are both such good responses, I think, for. Me, it kind of stems from my experience as a teacher. I think I saw similar to Megan, a lot of like injustice and a lot of like lack of or limited knowledge about what school is and how you can make school work, or feel like there's like this hidden curriculum of sorts on like school and like how to make it work, and like how advocacy plays a role in all of this. And so, I do what I do because I think it's important, and I think this lack of knowledge can have, like detrimental outcomes on certain things and certain individuals who are already, I think marginalized in other ways, right? And so, I do this because I want better outcomes for my past students, for potential future students, and I think the world as a whole. But again, I think that all of this begins with kind of, this common, shared knowledge of this is what this is. This is how it plays out. And you have a role in this too.

Matt Wappett 1:01:08

Yeah, yeah. Well, and I have to give a shout out to you. I'm a teacher as well. I'm taught in middle school, way back in the day, in a former iteration of my life, but I'm so excited you brought up the idea of the hidden curriculum. I haven't heard that in a very long time, and yet it is still very much a reality

within our schools, whether it's students with disabilities, whether it's students from other diverse backgrounds, there are these hidden normative forces that kind of are pushed through our system, that if you're not educated about them, and you don't understand how to navigate them, can be a huge liability, I think, for a lot of these students. So, thank you for bringing up the hidden curriculum.

Amanda Johnston 1:01:55

you're welcome. I think it comes up a lot in my world. So yeah, absolutely. Yes, there is still hope for it. Hopefully.

Matt Wappett 1:02:03

yep, yep. Absolutely, you just have to make it you have to make it unhidden. You have to make it visible. So last question, because one of the things we're trying to do is make content and ideas more inclusive and accessible. I think this whole conversation has been a great example of how to make research more inclusive. But what's one thing that each of you have been doing to make your day-to-day work more inclusive and accessible? And I don't know Megan, why don't we start with you this time?

Megan Best 1:02:38

Yeah, I just think in practice, every I would say all research teams that I'm on now are inclusive research teams that have co researchers with and without disabilities. And I believe that will be a cornerstone of my work, and something I really value, and kind of a non-negotiable. And so, I do think kind of keeping that in mind as I think about future projects, and building networks and relationships is important. I do want to share. I had the opportunity to sit on a panel last year at a conference around doing inclusive research, and a colleague who's a disability self-advocate, was sharing about sharing about how often for individuals with disabilities, we talk about jobs, but not necessarily career path. And I really believe that being a co researcher and working in this way is a career path. And so, through some collaborations with University of Illinois, Urbana Champaign, I've had the opportunity to hire a young adult from our local community transition program to work in as an exploratory research assistant role. And she's supporting, you know, my dissertation and other projects within our department. But really, you know, thinking about, I do a lot of work, kind of in this young adult transition space, and really wanting to make sure that we're seeking these opportunities and building infrastructure that allows for continued opportunities for others. And so that's something I'm very excited about my colleague, and you know, just it's been a really exciting opportunity to work together to develop a role that makes the most sense for her, that she's interested in, but also like really investing in self-advocacy and thinking about all these, all the different opportunities that come with it.

Matt Wappett 1:04:32

And I that you bring up a lot of really good points there. You know that notion of jobs versus careers, but it's yeah, anyway, that's incredible that you've been able to carve out that role, right, and give somebody an opportunity to be involved that way. It makes me think we need to have just a podcast with about inclusive research and inclusive research practices. That's exciting.

Megan Best 1:04:57

That would be great. Yeah.

Matt Wappett 1:04:59

Well. Yeah, it's an idea I'm going to write down here. Amanda, what about you? What's one thing you've been doing to make your work more inclusive and accessible?

Amanda Johnston 1:05:11

Yeah, so I wanted to share about kind of where this project has led itself to. Yeah. So, some of us who had still kind of worked, it's not the full research teams listed on the paper, but Sarah, myself and a colleague from Boston University have taken this curriculum because we didn't want it to just sit there, right? We wanted it to still have life and be beneficial beyond now, we had worked to transition the materials to an online platform. So, we used it. We met and we recorded it. Sarah herself recorded it and presented the information so now teachers and youth can still access this. It's on EdPuzzle, and it's free for presenters, so if it was a PTI, they could use it, if it was some sort of disability organization, if it was teachers, right? We kind of had this conversation about, well, this isn't taught in school, so how could we kind of provide this as a resource. So, we have taken this curriculum, we've put it on EdPuzzle. Instead of it being presented with like the verbal questions that it usually is, we embedded some questions, so hopefully it's still moderately interactive, but also that the presenters themselves can add in their own questions, or cut it up and kind of splice it themselves and kind of make it their own to be more accessible to the students or to the youth or to whoever would be, kind of on that receiving end.

Matt Wappett 1:06:51

And we'll make sure to put those in the show notes so that folks listening can find, find this resource and potentially use it and adapt it for what they need in their individual state. So yeah, I appreciate you bringing that up. Amanda, thank you. Okay, Sarah, last, but certainly not least, what is one thing you've been doing to make your work more inclusive and accessible,

Sarah Demissie 1:07:18

so being able to stay as involved with the process as possible, like in research, and being able to learn what I can so that that way, like, if I see someone else, like who has a disability, like myself, or who's just interested in research, even if they don't have a disability, and I would that we try to help recruit like them, like see if they're interested in being to join the team of researchers like with and without disabilities, and be able to find as many people that I know might be interested as possible, so that we can have more people, like with or without disabilities, to be involved in like research like this, if they're if I know they're interested, or if they show interest. So that's pretty much all I do. Like, like, whatever I think that I learned from, I try to pass on, like, any knowledge or experience or opportunities that I have had that someone else might benefit from, and then just go from and just go from there, like, see if they're interested or not, yeah. And go from there.

Matt Wappett 1:08:43

Yeah, yeah, no. And that's again, kind of going to that leadership thing. A lot of people don't know what's possible until they see right somebody else showing them and giving them an opportunity to get involved. And so again, that leadership from you, Sarah, is incredibly important, I think, to making inclusive research more acceptable and possible right across various programs so well. So, I want to

thank you all for your time today. It's been an incredibly engaging conversation. I have loved this. Any last thoughts you want to include before we say goodbye?

Megan Best 1:09:21

I think I just like to thank you again for this opportunity and thinking innovatively about how to make research more accessible and inclusive, and having a podcast like this is a great step in that direction. So, thank you for the conversation.

Matt Wappett 1:09:34

Yeah, absolutely well, and thank you for taking the lead on making this happen. You know, I see a lot of people talking about inclusive research, but a lot of times we don't see it actually happening, and I think this is such a great example of seeing that happen. So yeah, thank you for your work and what you've done here. Okay, that's it. For our conversation today, I would like to thank our guests. Was a privilege to have this conversation and to learn more about your work and inclusive research in general. This podcast did not necessarily go in a direction I anticipated, but I'm thrilled that it did go where it went, and it was really exciting to hear about some of the work that they're doing and just excited to see more from them. One of the great things that we do we like to do here at the Developmental Disabilities Network journal is support and publish up and coming right scholars and researchers, and particularly those who are committed to inclusive research practices. It's hard to break into the publishing world. Sometimes it's hard to get your work noticed. And we really enjoy highlighting the work of folks who are coming into the field and who are bringing passion new ideas. And today's episode, I think, is a great example of some folks who are doing that. So here, at the end, as always, I'd like to thank our DDNJ Managing Editor and author insights Podcast Producer Alex Schiwal, for her hard work to get the podcast out. She keeps the journal afloat, and Alex is sort of the backbone and the support for a lot of this work. So, thanks, Alex. We'd also like to thank the Utah State University Institute for Disability Research, Policy & Practice for their financial and in-kind support for this podcast and the journal. And the journal also received support from the Utah State University Library and Digital Commons, and we're grateful for their ongoing efforts to promote this work in the Developmental Disabilities Network Journal. So, as I mentioned earlier, please subscribe, leave reviews and share this podcast. It makes a difference. It helps us raise the visibility of this work and these issues. Your ratings and reviews help us. So please make sure that you are, yeah, linking, sharing, doing all those things because they help us. Yeah, get in front I guess you don't get in front of ears, but get into more ears, as it were. So you can learn more about the Developmental Disabilities Network Journal at the DDNJ website, which is digitalcommons.usu.edu/ddnj and you can download the podcast transcript in English and Spanish and learn more about our podcast guests at the IDRPP website, which is idrpp.usu.edu, when You go there, go to the About menu, and under that, you'll see Developmental Disabilities Network Journal. Go there, and you will find all the information on this episode's guests and the links to the resources that they brought up. So, thanks so much for listening. Keep up the good work. You're making a difference, and we want you to know that what you do matters. Stay tuned for our next episode and have a great rest of your day.