Inclusion

My Experiences as a Researcher

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Abstract

My name is Brad Linnenkamp and in this article, I will share about my lived experience as a researcher, including my experience transitioning from an advocate to a researcher. I currently work as a paid Researcher at the Kansas University Center on Developmental Disabilities (KUCDD) and have a long history of engagement in disability advocacy. I think it’s been really important as a person with a disability to be involved in the research and being a researcher gives me an opportunity to shape what is happening and educate individuals with and without disabilities and also teach them how to communicate in a way that is easier for others to understand. I also share about barriers I have faced, especially when getting started and various projects I have worked on. All the research in its own way really means something to me, and it means something to me to be a part of all parts of research.

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My Experiences as a Researcher

My name is Brad Linnenkamp. I am a paid Researcher at the Kansas University Center on Developmental Disabilities (KUCDD). I have a long history of engagement in disability advocacy and identify as a white man with a disability. My experience transitioning from an advocate to a researcher has had many areas where I've had to learn different things about research. I value using my lived experience to guide the research.

Why I wanted to be a Researcher

My main background, before coming to KUCDD, was as an advocate for people with intellectual and developmental disabilities (IDD) in Kansas. The first things that I did when I was getting my feet wet into the advocacy side was getting involved with the local self-advocacy group in my town. I initially started going to the regular monthly meetings and learning what an advocacy group is, because like everybody else, we all had to start from the beginning, to learn whether or not we had the skills needed to advocate. I was a part of that group for a couple years. And then, I moved to another town for an employment opportunity. My new job was to support people with IDD to develop self-determination - so I had to step away from the advocacy group.

I worked in this job for a few years and then moved back. I got involved again with the local group. Then I was hired to work for the Self-Advocate Coalition of Kansas (SACK) in January 1999. And from there, I continued to work on developing my advocacy skills. I found out that I was really good at doing presentations, being in front of groups, and going out and helping start self-advocacy groups around the State of Kansas. I also got involved, over the years, with the legislative side of advocacy. I would go and testify at the Capitol about disability issues. I seem to have the ability to connect with people, find out different things in regards to disability, and then use this to advocate.

I spent 20 years with SACK. Then, one day I was on my way home from a meeting of the Self-Advocacy Resource and Technical Assistance Center (SARTAC), a national self-advocacy group that I am on the Board of and found out through a friend that a position was opening at KUCDD. They wanted to hire a researcher with lived experience of disability to be a part of grant projects.

The opportunity to work at KUCDD came along at the right time because I was looking for a change and a new challenge. I knew I still had a lot to give, so when the opportunity came up for me to move to KUCDD, it was a no-brainer. I really enjoy working with other colleagues, and people, it's inclusive. And it's just a totally different environment.

I’ve been here for over three years and I am still learning about the research side of things. I'm trying to improve my communication skills when it comes to presenting research materials. I also want to find the best ways to present that information in an understandable way. Because when we share our research, we are still probably talking to people that don't do research on an everyday basis. So presenting research in a way that's understandable means that people can use the research to advocate for their needs or for changes in their community. And I just hope that in the end this is a way for me to grow and become stronger and get more information and advocacy happening.

Transitioning from an Advocacy Role to a Researcher Role

I think it’s been really important as a person with a disability to be involved in the research. A lot of times in my life, I have had people put words in my mouth. People can sometimes assume who I am rather than getting to know me. I didn’t want the research to do the same thing.

When I joined KUCDD, at times I felt out of place when I was trying to figure out how to contribute to the research. I had to ask myself “What's the best way for me to be a part of this group? And what can I contribute to the group?" Sometimes research can be very complex, and I had to stop and ask questions and have the other researchers explain things in a more understandable way. Sometimes when people talk about their research, they will go really fast, and I need to have them stop in order to provide me the time to process. I think over time everyone that I’ve worked with has grown and we have all figured out our strengths and how we can best work together.

For me, being a researcher is an opportunity to shape what is happening and educate individuals with and without disabilities and also teach them how to communicate in a way that is easier for others to understand. I’m good at critical thinking and understanding what it's like to not only live with a disability, but also how to take what advocates know and use it in research. I can use my experiences to make the research process more relevant to people with lived experience.

Barriers to Getting Started with Research

I think my biggest barrier at the very beginning was just figuring out the supports that I needed to be able to do the work. I needed to find the best way for giving my input and using my experience. During this time, it took a little while to figure out what supports I needed. I think the one thing that I really relied on was being able to ask questions as we went along. I can understand things when someone explains them, but they have to be willing to do that. Having others use plain language is important for me. Things just need to be explained in a way so that people that aren't around research on a daily basis can still be a part of it. That’s one of the strengths I bring – helping researchers talk in plain language so everybody can understand.

Another way people support me is with organizing materials. I know what I want to say, but someone supports me by typing out my thoughts. This person also helps me stay on top of my email and calendar.

The more I've gotten involved with the research, I'm getting better and better every day. Now that I've been doing it a little longer it makes me think a little differently about our projects. I'm always asking myself and the team: "What else do we need?"; "What and who else do we need to include?"   Now that I've been doing it for a while, I'm starting to think of things in a different way and expand. A lot of that is due to the leadership strategies that I learned and how I can use that to my advantage.

I also really like being a part of a team. I've taken on roles and lead different projects, and I'm glad to do that; but I feel like when I'm part of a team we're all working on things together. It's not all on me.

Examples of Projects I have Worked on

One research project that I have been working on focuses on Supported Decision-Making. I use supported decision-making in my daily life. So I feel like when I started doing the research that I already had a lot of ideas and examples of things that people could use for Supported Decision-Making and I could share these ideas and who we needed to get more ideas from. And, I love disseminating. I wanted to talk about why it is important for people to use Supported Decision-Making and not go into guardianship. I was able to bring together my experiences and our research projects. This gave me an advantage.

Another project was a project I developed was a project where we interviewed self-advocates about their experiences during COVID-19 and their thoughts about COVID-19 vaccines. For this project, I helped write the interview questions to ask other self-advocates about their experience with COVID-19 and how they coped. We asked the questions at a community event. An example of their concerns was loss of social interaction with other people. After the event, I wanted to create a social media campaign to educate people about getting vaccinated and the impact of COVID-19 on people's lives. I went back and looked at the interviews we recorded, and I picked out the most important points people made about COVID-19 and other issues they wanted to talk about. Employment and getting out and doing what they wanted to do were two big ways the pandemic impacted people. Once put together, I prepared and read a script to introduce the videos and our video expert incorporated the recording into the videos.

Let me tell you, when we were setting up in the park where we did the interviews with people with IDD I appreciated having a team figuring out all the technology about how to do the recordings. I could focus on the questions and interviews. Working together as a team made the research that much more effective. I think one of the things that was great was how we came up with the themes after the interviews. What I really liked is how my supporter and I went in and worked together and went through each video. I listened to each one, and then I picked out the best quotes that I thought were relevant. We worked together and got into a routine and learned how to do the analysis together. It went really smooth. We'd listen to each interview. Then, whenever I heard something that I thought really needed to be emphasized, we'd stop the video and then she would document it in a way so that whenever we went back and edited the videos that the information was there.

I am so thankful for all the supports that I have, to help me do my work. And to be able to bounce questions off people, when I get stuck. I don't think I could be as productive as I could have been, if I didn't have the supports that I have from other researchers, the staff, and all the students. Plus I get to interact within all the different communities and groups that we're all a part of outside of KUCDD. And, its not just a job. When I go out to do social activities with people at work we'll talk a little bit about work and then just about how things are going.

Supporting Self-Advocates to be Researchers

The one thing I tell researchers is that if you support advocates to be co-researchers, your research will be that much more believable. If you get input from people with disabilities, the research can end up being more true and maybe not just made up by people that do not have that perspective.

I think the most important thing to figure out with people with disabilities is what works best for them. For example, we've figured out that for me to give information on research in meetings or presentations, it works better if we do an interview process, where I can answer open questions. That may not work for everyone, though. I also prepare better for meetings when I can look through information that will be presented and talk through my ideas with someone before the meeting. I have all these ideas in my head but getting them down on paper is an obstacle at times. So, I need somebody to help me get it down on paper. I also think researchers need to ask the person with the disability who are being included in research how they want to be supported. It does take time to figure out how to include different people. But in the long run, the research will be that much better.

I know some of the projects we've started include more self-advocates and more advocates as co-researchers. So, it's just trying to figure out what's the best way to include advocates in the research – and how everyone wants to be involved. Some people may want to be involved all the way through and become a researcher like me, but other people may really like communicating the results or developing infographics, or just participating. Someone else may be good at connecting with people in interviews or mentoring people as part of an intervention.

So just being sure people have opportunities to be involved in ways they want to be involved and that they get paid for that work.

I think the one thing I've learned about doing our research is that everybody must work together. It's better that we can work as a team.

Conclusion

All the research in its own way really means something to me, and it means something to me to be a part of all parts of research. I think we all need to get better at presenting research and the research process in such a way that I understand it and that other people with disabilities understand it as well. And I think I noticed that I'm starting to get a little better about asking questions, even as we're talking about all the different parts of a research project. I think that's what you have to do. I go back to it again and again and everybody learns differently. So, I guess the big thing since I started until now is it's been one big learning experience. And it will continue to be that way. But, all I needed to become a researcher was the opportunity to learn. I think in the long run, it's not only good for the research, but it's also good for the researchers to help each other out. We need to make sure that no one is denied the opportunity to be a researcher, just because of their disability.