

Inclusion

Advocacy and Research Coming Together

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ADVOCACY AND RESEARCH

1

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Abstract

My name is Ski Adams and, in this article, I share my perspective and experience with research and advocacy. I have recently started a job as a researcher, and I am learning a lot about how research and advocacy complement each other. It's exciting to be able to learn new research skills. It has been challenging to start as a researcher. I've been working on learning the tools I need to be a researcher. There is a lot to learn and a lot of skills to develop. My team supports me in many ways, which I describe in the article. It is crucial to have self-advocate involvement in research because the research affects our lives and we have unique insights from our lived experience. For years, we have been left out of the design of research. When self-advocates are involved, the research is going to be more meaningful to people with disabilities.

Keywords. Inclusive Research, Lived Experience, intellectual and developmental disability, advocacy

My name is Askia Adams. I am a research assistant with the Kansas University Center on Developmental Disabilities, (KUCDD; the UCEDD in Kansas). My educational background includes a bachelor's degree in Elementary Education with an emphasis on Assistive Technology. Most of my field work during college focused around working with students to determine the appropriate equipment that would assist them in the classroom. My other degree is in accounting.

Before coming to KUCDD I worked in the advocacy arena for over twenty years. This work has ranged from meeting with federal legislators to assisting in the passage of the Employment First law in Kansas. I have been at KUCDD for 3 months, and this is my first time being on a research team. The biggest difference in the two roles so far seems to be that as a research assistant I have greater access to data to bolster my case as an advocate. For years when meeting with policymakers I spoke from personal experience. Speaking from personal experience is powerful, however using research strengthens those experiences and increases the impact of what is being said.

The two activities (research and advocacy) are more complementary than different. One is a tool to enhance the other one. Researchers gather and analyze information, so advocates can use it when they meet with decision makers. In this way, researchers play a supportive role for advocates. Advocates also support the research process by identifying issues that need more research. In the past when attending the policy seminar in Washington DC and meeting with federal officials, I used data from research to assist with making the case for the issue I was advocating for. One year I advocated for increased funding for services for individuals with disabilities by including figures from a one-page brief provided at the seminar. The brief allowed me to share numbers about how many people in Kansas had developmental disabilities. Using

these numbers showed lawmakers how increased funding would improve the lives of Kansans with disabilities.

It is exciting to be able to learn new research skills. Before coming to KUCDD my only experience with research was participating in research projects as a subject. I can now assist with the development of the research tools. Being someone with a disability gives me a unique perspective on research. For example, since I use a communication device, I would have a unique perspective that would be beneficial to a team working on projects around these issues. The State of the States has asked me to review The Communication Technology and Accessibility Act. The legislation is important because it opens new horizons for individuals with disabilities. The field of academic research is totally new for me. It will be interesting to see how real-life experience intersects with Academic Research.

There is one project that I have been working on prior to joining the KUCDD staff that I continue working on which is a great example of how real life and Academic Research combine. Over the last year I have worked with the center to investigate how we can support college students who use AAC, (Augmentative and Alternative Communication). This was the first investigational project I helped design. This project is important to me, because I used AAC in college and my teachers didn't know how to best support me. Participating in class discussion was difficult, due to my delay in response. Many times, by the time I had my comment or question ready on my device the class had moved on. Based on this research, we created a training for faculty and staffed to teach them how to support college students who use AAC. Hopefully, students who use AAC will have an easier time because of this project. I look forward to continuing to be involved in research.

My challenge starting out has been gathering the tools I need to be a researcher. Building a research toolbox is difficult because the field is unfamiliar to me. I have a lot to learn about research and get to develop new skills. There are so many different elements involved in conducting research, ranging from conducting community engagement to working with different research tools. As someone who has never done academic research knowing which tools to acquire first is challenging. It is hard to know where to start.

The team at KUCDD supports my involvement in research in several ways. One of the challenges for me is being unable to physically write and take notes during meetings. When we meet on Zoom our meeting is recorded and saved, so I can review the meeting later and take notes. This accommodation is helpful when discussing projects, I am working on, because I can focus on the meeting rather than trying to take notes. Another support the team offers is sending questions before meetings, so I can preprogram my communication device. The ability to have messages preprogrammed allows me to participate in meetings more efficiently. Sometimes I review surveys we are working on, and a teammate will write my answers and suggestions down.

Having someone be my scribe helps me complete projects in a timely manner. Recently, I was asked to serve on a search committee. To facilitate my involvement in the process the applicant review form was in electronic format, so I could type my impression of the candidates. Self-advocate involvement with research is crucial for three reasons: (1) the research affects our lives, (2) we have unique insights from our lived experience, and (3) for years we have been left out of the design of research. Sometimes researchers may believe they are designing a project to address an issue, however when they talk with the people who are affected researchers find the issue is different. Self-advocates can ensure that the research is going to be meaningful for individuals with disabilities.

Part of the way to get more self-advocates involved in research is reaching out. There are probably many self-advocates who would be interested in helping with research, however they have never been asked. For example, I had never thought about being a part of a research team until last winter when KUCDD approached me. There are people who could provide valuable input if someone would reach out to them. Inclusive research is new, so most self-advocates have never been asked to be a part of a research team. Collaborating with groups such as SACK and Kansas Leadership Center would be a way to recruit self-advocates for inclusive research. By working with these groups KUCDD could develop trainings around inclusive research.