

Inclusion

Pauline Bosma's Tips on How to Be a Good Research Ally

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Abstract:	<p>My name is Pauline Bosma and in this article I share my lived experience as a researcher. I have worked on projects that support people with disabilities to recognize, respond to, and report abuse. I am now leading a research study with other self-advocates to interview LGBT adults with intellectual and developmental disabilities about their lives. I have also worked on projects with the Social Security Administration. I like doing research because it helps people. In this article, I also offer recommendations for other research teams who want to practice inclusive research.</p>

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Abstract

My name is Pauline Bosma and in this article I share my lived experience as a researcher. I have worked on projects that support people with disabilities to recognize, respond to, and report abuse. I am now leading a research study with other self-advocates to interview LGBT adults with intellectual and developmental disabilities about their lives. I have also worked on projects with the Social Security Administration. I like doing research because it helps people. In this article, I also offer recommendations for other research teams who want to practice inclusive research.

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Becoming a Researcher

What made me want to be a researcher is to learn new things and teach people new things to better lives of self-advocates overall. I was curious and wanted to learn where I was going in my life. It was important to discover new things for the future. It was easy to go from being an advocate to being a researcher. I love being a researcher and being able to learn things and coming up with new ideas, regardless of if there is a grant or a research project.

Being a Researcher

The first research project I did was to help create curriculum for Awareness & Action, which is a training that was developed for people with disability on how to recognize, respond to, and report abuse. Massachusetts was the first to do this peer-to-peer training. Since the Awareness & Action project, I also helped create other research projects that branched off, like the R³ project, which is a project to take the Awareness & Action training and put it on an app to be used on a phone or tablet. That was created with two other self-advocates. We also created Mass Rights for Change with Massachusetts Advocates Standing Strong (MASS), the Victim Rights Law Center, and Pathways for Change, which is a rape crisis center.

My role on these research projects is as a self-advocate project consultant. I give input on each of these projects, like what we think has to be improved, how the pictures look, how everything looks. It can take us, people with disabilities, a little bit longer to understand. Sometimes we go over one part of the project three or four times just so we understand it. It's not easy for us to understand so we go over it a couple times and have people read it to us so we can understand. The biggest change that I made for the Mass Rights for Change project was to

include LGBT issues onto the project because that is important for people to understand. It is important to know that people with disabilities can LGBT people too.

Research can be a little bit difficult. There are times when it gets mundane because we have to look at the same papers over and over and over again until we have made all the alterations. It's hard, but we did it. Then we move on to the next part. The thing that I never do is I never really give up. I try to do the best I can do. I may have my moments when I want to walk away. Sometimes someone says something that isn't right, and I have to say something and tell them, "That wasn't the right word. That wasn't the right thing to say."

I want to learn more about supporting LGBT people with intellectual and developmental disabilities so I can grow my Rainbow Groups even more [<https://www.wearemass.org/rainbow-group>]. My assistant suggested we do a research study. Now I am on the research team for that study, with two other self-advocates. We wrote interview questions. My assistant interviewed LGBT adults with intellectual and developmental disabilities about their lives and opinions. We talked about the different struggles people are going through and the support and opportunities that they want, and used the information we learned to choose a project. We decided as a team to write a guidebook about LGBT people with intellectual and developmental disabilities. We had many meetings to choose topics for the guidebook chapters and to decide on what messages we wanted to send. We used the interviews to share quotes and stories so that people can learn about our experiences. We give advice for supporting people to express themselves and tips for teaching sexuality education. Please check it out at RainbowGuidebook.com.

I was recently invited to be on a technical working group for a research study by the Social Security Administration (SSA). They are studying the experiences of people with disabilities in the United States. The technical working group is all people with disabilities. This

may be the first time the SSA is doing a study where they are paying people based on their personal experiences only, instead of based on what degree or professional expertise they have. We gave suggestions for their interview questions. For example, I told them that some of their questions were too long and confusing. They changed the questions to be more clear and understandable. Next, we are going to help the SSA find people to interview and then summarize what people talked about.

Helping People

The research projects I have been on have helped to make resources that people with disabilities can actually use. For example, part of the Mass Rights for Change project was that MASS created a survivor support package for self-advocates to use [<https://www.wearemass.org/survivor-support-packet>]. It has been very well received. It helps a lot of people understand where they can get input or help guiding themselves through the process of being a victim. I also worked with a group of self-advocates to help the Department of Developmental Services create a plain language guide on how to take action and be responsible for your own Individual Support Plan (ISP). The guide is so that when you go to your ISP meeting you are not intimidated by all the people who are there. I also used to work on the Explore, Prepare, Act employment training research project. We made a guide for people with disabilities about resume writing and job interviews. For the Rainbow Group research project, our guidebook is about what LGBT people with intellectual and developmental disabilities go through and how they want to be supported. We hope that people will better understand LGBT people with disabilities, from their own voices and opinions and then they will be more accepted and supported. Hopefully the project will open up a lot of people's minds to LGBT people with intellectual and developmental disabilities for the future.

Recommendations for Inclusive Research

The MASS motto says, “Nothing about us without us.” If you get a grant or do a research project, have self-advocates on that grant because it helps a lot to better what the research project is. Self-advocates are bringing their expertise on what they know about their disability. Self-advocates also respect each other, and they help the research team to get along. Some people on a research team might have negative opinions about people with disabilities. Self-advocates will have respect for people with disabilities and make sure the research is positive. When we were creating the Mass Rights for Change project in the beginning we had a few people involved who were not self-advocates. Some people have a tendency of using words that are complicated. We had to tell them to come down to our level, where we understand. Gradually they changed their wording and how they present their papers. They literally changed their mindset on how to speak to us and how to present a paper with easy to understand wording, explanations, and pictures. Now we say, “Oh, we like this!” It made it really fun and interesting.

I think the most important thing is to have a good person in charge of the research grant. A good project manager understands where both parties are coming from. You might have a person without a disability and a person with a disability and the manager should help bridge that gap.

When you are doing your research, it is always good to have some kind of pictures or icons throughout the project so people can look at it and say, “I understand what you’re saying.”

You might have a person that needs a communication board to give their opinion. You might have someone who talks slow. We have a person on one of our grants that was talking too slow so we bought him a button that he can press when he wants to talk to us. When he presses

that button, we know he wants to talk in the meeting. It's really important to bring people with all different disabilities to the mix because it makes it interesting.

I was on one project where self-advocates took pictures. I never saw what happened to the pictures or what the pictures were for. I think the grant ended and I don't know what happened next. One important lesson I learned is that you should try to follow through on the project and keep it going.

Conclusion

I hope this article gets a lot of interest. I want to say thank you.