

Inclusion

My Experiences Making Decisions and Working Together in Research

--Manuscript Draft--

Manuscript Number:	INCLUSION-SPECIAL-ISSUE-S-23-00052
Article Type:	Perspectives
Keywords:	Inclusive Research, Lived Experience, intellectual and developmental disability, advocacy
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Manuscript Region of Origin:	UNITED STATES
Abstract:	<p>My name is Jacob Myers and, in this article, I describe my research experiences over the last 10 years. I like doing research because I get into the details and figure out answers to questions in research studies. I have worked on two main projects: making the Pediatric Evaluation of Disability Inventory-Patient Reported Outcome (PEDI-PRO) and Research Ethics for All. I also do projects with other researchers at other universities. In the article, I also offer suggestions on how to work together as a team and be sure that people with disabilities are meaningfully included on research teams. It's important for people with disabilities to do research because they can relate to the studies and the participants. I hope people with and without disabilities can keep being a part of research to help their communities to make positive changes.</p>

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My name is Jacob Myers and, in this article, I describe my research experiences over the last 10 years. I like doing research because I get into the details and figure out answers to questions in research studies. I have worked on two main projects: making the Pediatric Evaluation of Disability Inventory-Patient Reported Outcome (PEDI-PRO) and Research Ethics for All. I also do projects with other researchers at other universities. In the article, I also offer suggestions on how to work together as a team and be sure that people with disabilities are meaningfully included on research teams. It's important for people with disabilities to do research because they can relate to the studies and the participants. I hope people with and without disabilities can keep being a part of research to help their communities to make positive changes.

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My Research Experiences

My name is Jacob and I have been a researcher for 10 years. I like doing research because I get into the details and figure out answers to questions in the research studies. I've done research at Boston University from 2013-2021. Now I still work with the same researchers, Ariel and Jessica, but they are now at different places-Massachusetts General Hospital Institute of Health Professions and the University of Florida. This article is about my research experiences and how researchers with and without disabilities can work as a team.

I have worked on two main projects: making the Pediatric Evaluation of Disability Inventory-Patient Reported Outcome (PEDI-PRO) and Research Ethics for All. I have been working on the PEDI-PRO since 2013 (Schwartz, Kramer, & PEDI-PRO Youth Team, 2021). The PEDI-PRO is a self-report that helps people with disabilities figure out what everyday things are easy and what things are hard for them, like moving their bodies while playing sports and communicating with other people when they go to the doctor. I like working on the PEDI-PRO, because I get to help people with disabilities share their ideas and understand their challenges. The PEDI-PRO helps people say what is hard and easy for them in their everyday lives. It's amazing. I love it!

Now I am also helping make a research ethics training as a member of the Research Ethics for All Steering Committee. The training will help people know how to make research safer and help people with disabilities feel safe and connected during research.

I like Research Ethics for All, because we get to help other people understand about research ethics. I can make sure people understand all of the big words that are part of research ethics and

the research ethics laws, like the Belmont Principles. It is important so we can really understand what to do in research.

I also do projects with other researchers at other universities. I like participating in research. I recently was a participant for a project on peer support. I enjoy learning about research and helping with the different projects. I think the research is important, and that's why I give my time to it. It makes a difference. By doing research, I can help other people understand how to contribute and be a researcher one day. I wish there were more projects I could help with, so I could do this as a part time job instead of just a few hours a month.

The job I have right now is working at Whole Foods. I have been working at Whole Foods for 5 years.

How to Work As a Team

My Opinions Matter

To work together, we ask everyone their opinion about what different topics mean to them and what they have learned. I feel good sharing my opinions because I know people might agree. Not everyone will, but at least I share my ideas. I really like when people give me positive feedback about my ideas and say things like, "Nice job Jacob," or "good idea." It makes me feel good to be paid for all the work that I do—it acknowledges that I'm helping.

Feeling Comfortable on a Team

Teamwork is really important in research. It helps to know who is in the group. Knowing people over time helps me trust them. It also is helpful to know who is leading the group. If you trust the leader, then you know that they will make sure it goes well. And, then at least you will know one person, so you will be comfortable and have at least one person to connect with. For example, when I started working on Research Ethics for All, I only knew Ariel. She introduced

me to the other leader, Katie. Knowing the two leaders helped me feel comfortable meeting everyone else. We have a schedule about what will happen during the meeting and we take time to get to know each other, and not just talk about research so we can relate to each other. Being part of the projects helps me feel part of something.

I really like to think about other people, because they may be similar to me. I think we can make people feel comfortable by making sure there is a table and chair and a whiteboard. It is important to be welcoming-don't be rude or mad. Using positive body language and tone of voice and having a happy personality shows you are connected to the group. I think that wearing work clothes can also show respect.

Rules for Working Together

I think rules for working together are important in research, because if we don't come up with rules, then our work together will not feel organized. Rules can be a strategy to help you stay organized. For Research Ethics for All, we connect with each other Zoom. Before we have a big group meeting, I meet with Ariel to make sure I'm ready. We go through the slides to make sure I understand what we're talking about so if there are any questions, I am ready to answer them and give my opinion.

The group came up with rules together. We each suggested rules for the group. We wrote them all down on a list and voted on which rules to keep and which rules to not keep or to change. For example, raising our hands to talk and being on mute when we do not talk. These rules are important so everyone can have a turn and that other people stay muted while they talk. We also want to make sure everyone feels welcome. We really want to hear everyone's opinion. It was important to make the rules together so we know what we are going to focus on and how we will do it.

Making Decisions

The PEDI-PRO asks people about the activities that are easy and hard for them. For each activity, there is a picture. We looked at different pictures and topics to include in the PEDI-PRO. We wanted everything to be easy for people with disabilities to understand. We voted to make a lot of our decisions. We voted in different ways for different decisions. Sometimes we raised our hands and sometimes we used stickers to show our favorite topics. When we were picking topics for the PEDI-PRO first we started with a lot. We voted so we would have fewer. Then we voted again to pick the final topics. We also asked other people what they thought about the pictures and words in the PEDI-PRO—that's why it took a long time to make.

We were working on figuring out what to teach in Research Ethics for All. To decide, we looked at PowerPoints with different topics we could teach. We asked other people what they thought we should teach. We shared our opinions and talked as a group to decide what was important to teach.

For both projects we voted and had discussions to make decisions. I like voting in research because it is easier to get the answer. You just have to count the votes. Discussion is also a good way to make decisions, because you get to talk as a group and get to hear from other people and what they have to say. My advice for making decisions is: make sure you make researchers with disabilities feel welcome and know what topic they are talking about. If someone shares an idea, try to use it.

Summary

I like doing research, because I get to really go deep into a topic and help people with disabilities. My tips for working together are:

1. Welcome people by helping them understand what the group is talking about.

2. Share your opinions and be open to other people's opinions.
3. Get to know each other and make sure everyone has fun as a group.

It's important for people with disabilities to do research because they can relate to the studies and the participants. I hope people with and without disabilities can keep being a part of research to help their communities to make positive changes.

References

Schwartz, A. E., Kramer, J. M., & PEDI- PRO Youth Team. (2021). Inclusive approaches to developing content valid patient- reported outcome measure response scales for youth with intellectual/developmental disabilities. *British journal of learning disabilities*, 49(1), 100-110. <https://doi.org/10.1111/bld.12346>