

Lived-experience leadership in Inclusive Research

Plain English Summary



This is a summary of a research article about community researchers with intellectual disability taking the lead in research projects. This article shows that when community researchers lead in inclusive research projects, there are many benefits.

Introduction

We chose to do inclusive research to learn about everyday harm and how to prevent it. Inclusive research means that people with disability are active members of the research team. In inclusive teams everyone works together to share power and make decisions about the research.

How did we do the research?

We are a large research team from different parts of Australia. We have worked together for three years. Our team includes four community researchers with intellectual disability. Two of the researchers, Ruby and Rachel, work at a university. Another two community researchers, Hannah and Tyra, work at a disability organisation. They guided the research design, did interviews, helped the team understand the interview data and made new ways to share the research findings. During the project our team listened and learned from each other.

What did we find?

The community researchers chose two stories to show how they led our inclusive research team and improved our work. The team read their stories and spoke about how the community researchers changed the way the team worked through their leadership.

Story 1: Rules and vibes.

Ruby and Rachel created the rules and vibes with input from the research team. Rules are the agreements about how the team works. For example, meetings are organised so everyone gets a chance to share ideas, and everyone listens. Vibes are about how the team feels, or our team culture. The rules made a vibe where people in the team felt safe and respected because the processes we used were fair.

Story 2: The big café

Hannah and Tyra made the big café presentations as a way to share what we learned about everyday harm. First, they presented the big café at a conference with researchers. Later, they did the presentation at their organisation to help people with disability and staff learn about how to prevent and address everyday harm.

People in the team learned from the community researchers' leadership. They said:

- Making clear rules and vibes improved teamwork and made sure we worked in accessible ways.
- The big café was a creative way to make research easier to understand and more interesting.
- Leadership needs planning, time, accessibility, and trust.

Because of the leadership of the community researchers, we all learned new ways to make research fairer and more inclusive. Working together made the research stronger.

What is important to learn from this research?

This article shows how community researchers take the lead in inclusive research projects. The two stories from our project show how their leadership made research fairer, safer and easier to understand. We all learned a lot from the leadership of the community researcher team. It helped make our research better. We took the lessons into other parts of our lives as well.

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