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Our Recipe for Good Inclusive Research

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Abstract: Co-researchers with intellectual disabilities and a Ph.D. student formed an inclusive research team. The co-researchers joined the inclusive research team so they could learn more about research and have control over the research. Our team have held regular research skills meetings. The focus of these meetings was getting to know each other and learning what each person brought to the team, as well as learning what inclusive research is and how to conduct research together. Learning these things has helped to design and undertake an inclusive research project about pets for people with intellectual disabilities. In this article, our team shares our experience of conducting inclusive research. We have learnt that each team member brings their own strengths to the team and we have connected and formed friendships. We completed an inclusive research project and found there were some challenges our team had to overcome. We conclude that people with intellectual disabilities are capable of leading research. Being part of an inclusive research team enables co-researchers to show others what they can do. Sharing what our team has found out can help others to conduct inclusive research.

Keywords: inclusive research; co-research; research with people with intellectual disability

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1. Introduction

1.1. What This Article Is about

Our inclusive research team worked together to write this article. There were four people in our inclusive research team: a Ph.D. student and three co-researchers with intellectual disabilities. We also had support from the Ph.D. student's supervisor, who has a Ph.D. and works as an academic at the university.

This article reflects on our experience as an inclusive research team learning about inclusive research and conducting inclusive research together. The focus of the inclusive research study our team chose was people with intellectual disabilities' experience of having pets or wanting pets.

Inclusive research is when people with and without intellectual disabilities conduct research together (Johnson and Walmsley 2003). Our inclusive research team was involved in all parts of the research process. Co-researchers with intellectual disabilities had control over the research instead of others controlling it. The co-researchers performed all parts of the research with some support. The co-researchers choose the direction our research went in and the topics we wanted to research. They set the pace of the work, took their time, and moved on when they were ready. All of these ways of working inclusively align with the definition of inclusive research that our team followed (Johnson and Walmsley 2003; Walmsley et al. 2018).

1.2. Why We Completed This Project

Our team completed this project because one of the researchers (first author) was conducting a Ph.D. focussing on the experiences of inclusive researchers when they are part of a research project from start to finish. Our team would not exist otherwise. This

is what each of our team members had say about why they wanted to be involved in the research team:

Fourth Author: "The research group was something different to do so I'm not stuck at home. I also wanted to meet new people and make new friends".

Second Author: "I wanted to learn about research from the other side after being a guinea pig in lots of other research".

Third Author: "I wanted to be part of the inclusive research team because it's something I always believed in".

First Author: "I wanted to give people with intellectual disability another way to have a voice about things that are important to them. So, I started an inclusive research group. I wanted to know what the experience is like for the inclusive research team".

Last Author: "It is very important to have people with lived experience contributing to every part of the research project if possible, to make sure the project is relevant and accessible".

Other people with intellectual disabilities were involved as co-researchers in our team along the way as well. The team started with seven co-researchers with intellectual disability, but four of them stopped attending because of personal reasons such as moving where they lived or changing their choice to participate in other activities. They told our team that they had initially become involved because they wanted to show that people with intellectual disabilities are capable of being researchers.

1.3. How We Wrote This Article

"Normally I use Easy Read so putting it into academic speak was hard for me, that's where (first author) came in."—Second Author

The Ph.D. student (first author) initiated a discussion about our research outputs, one of which was a journal article, and the team agreed to write the article. It was important to all members of our inclusive research team that they were all involved in writing this journal article together. Our team started the process by having a discussion and brainstorming our responses to each section of the article. The section headings are based on some Easy Read author guidelines from a journal. The Ph.D. student (first author) and one of the co-researchers (second author) who had an interest in being more involved in the article performed some more brainstorming together to expand on the responses. They had several meetings to discuss the findings and the sections of the article. The second author dictated commentary while the first author typed it up. The first author then translated some of the information into a more academic format, with support from the university supervisor (last author).

Once the article had been written, the Ph.D. student (first author) met with each of the co-researchers individually to read the article to ensure it still reflected their experience correctly. They performed this again when revisions were made to the article during the publication process.

This article will now explain what our team achieved, how it was performed, and what was found.

2. Our Background and How We Grew While Working as a Research Team

"Research training was fun."—Fourth Author

Our team was started by the Ph.D. student (first author). Her Ph.D. looks into the experience of our inclusive research team. She invited each of the co-researchers to join the inclusive research team to learn all about research and undertake an inclusive research project. While conducting this work together, the first author looked at our experience of being part of an inclusive research team and what the research process was like for all members of our inclusive research team. The research question this study aimed to answer was as follows: what are the experiences of an inclusive research team when co-researchers with intellectual disabilities are involved in an inclusive research project from start to finish?

Our team worked together over five years. We had some long breaks in between because the Ph.D. student had a baby and then COVID-19 interrupted our research. The Ph.D. student (first author) recruited co-researchers through sharing recruitment information with disability service providers. Some of these disability service providers invited her to run information sessions so people could decide if they were interested in joining the research team, others passed the recruitment information on to individual people with intellectual disabilities they thought might be interested. Some of the co-researchers knew each other because they received support from the same disability service providers or went to some of the same activities, although some of the co-researchers did not know each other prior to joining the team.

"Visuals are the best way for me to learn because it helps me understand"—Third Author

Our team had research meetings to get to know each other and to learn about research and what inclusive research is. Some of the ways our team learnt were through watching videos, talking about the topics, and brainstorming ideas. The first author (Ph.D. student) changed the information into an Easy Read format to help co-researchers to understand it better. The co-researchers gave the Ph.D. student advice at the end of each research meeting about things she could improve on for the next meeting. For example, some of the co-researchers said they were visual learners, so the Ph.D. student looked for opportunities to include videos and practical activities in the research meetings.

"It was fun playing games to get to know each other. I liked the game where we threw the ball and it had questions about ourselves we had to answer"—Second Author

During the first few research meetings, the team spent time getting to know each other. The team wanted to make sure they were comfortable with each other. Games and one-page profiles were used to get to know each other. A one-page profile is a person-centred tool that uses three headings to capture important information about a person (Sanderson 2024). The three headings helped the team to learn what was important to each group member, what other people liked and admired about them, and how our team could support each other in the group.

"We worked to our strengths–like mine is speaking but don't quite have the words, that's where First Author comes in again. Whereas others like to have more background roles, while I love to do everything."—Second Author

The team also spent time talking about each person's strengths. This helped us to think about who could perform each research task in the group. For example, one co-researcher was not comfortable interviewing participants, so they played a support role helping other co-researchers to role-play practising an interview. Some of the co-researchers have experience being in front of a camera, so they took the lead starring in videos developed to share our research findings in an accessible way. However, the team all worked together to write the scripts, so everyone still had a role and was part of deciding what to include in the videos.

The team learnt about qualitative and quantitative data by looking at journal articles with examples (Scorzato et al. 2017; Baum and Burns 2007). The co-researchers decided that quantitative data had too much mathematics and that they preferred working with words, because it gave more information about people's experiences.

The co-researchers agreed that learning what information could be trusted was very difficult. They had not heard of "peer-reviewed" before, nor had they searched for journal articles. The Ph.D. student showed the co-researchers how to search a database; it was important to the co-researchers to attempt this and learn how it was conducted. The co-researchers decided it was hard to understand many of the articles, so they asked the Ph.D. student to conduct further searches of the literature and create Easy Read summaries about the research topics they were interested in. The Ph.D. student was already experienced at Easy Read translations, having undertaken training in this area and developed these skills working in another role.

The team spent a lot of time learning about research. They completed some training in research and the co-researchers led the planning of their own research study. The purpose of the training was to ensure all researchers (with and without intellectual disabilities) understood research methods.

> *"Research training was interesting, I liked the PowerPoints First Author made because they were easy to understand. The journal articles however were not."—Second Author*

Initially, the training began with team building and providing an overview of research. This allowed the inclusive research team to choose the topic of their inclusive research study and begin to design their study. The training continued throughout the course of the inclusive research study and the training provided was specific to the skills and knowledge needed to carry out each aspect of the study. For example, an overview of possible research methods the inclusive research team could choose to use was provided so they could then be supported to choose their research methods. Once the team had chosen their data collection method of semi-structured interviews, specific training was provided about how to conduct interviews. Further details about the research skills training will be published separately.

2.1. Deciding on a Research Topic

> *"I have friends with pets so that topic was of interest to me, seeing their connection with the animal."—Third Author*

To decide the direction of the research, the team came up with a few broad research topics that were of interest:

- Parents with intellectual disabilities;
- National Disability Insurance Scheme (NDIS);
- Therapy animals.

These topics were of interest to the co-researchers because they were relevant to their own lives and those of their peers with intellectual disabilities. The team looked at what research had already been conducted on these topics and found there was already a lot of research on all of these topics. Since there was already some research about therapy animals, the team had the idea to look at pets and people with intellectual disabilities. The team could not find much research on this. Pets were a topic of interest because some of the co-researchers had pets and really valued them, and others in the group really wanted pets but could not have them. They wanted to know what the experiences of other people with intellectual disabilities and pets were.

The team also talked about parents with intellectual disabilities being a sensitive topic because some team member had experiences of having their children being taken away from them. Some of the group found it upsetting to talk about this topic and others were worried that if this was the research topic it would be hard to find people to participate in the research because they might not want to talk about it. The team had to find a research topic the co-researchers were comfortable with. They narrowed it down to a choice between NDIS or pets for people with intellectual disabilities. They found another inclusive research team was already conducting a research project about the NDIS and did not want to risk repeating their work. The group settled on pets to ensure their research project was unique.

> *"It was difficult to find a topic because there were so many to choose from, we didn't want to double up on other research and we wanted to make sure it was a topic people would be interested in."—Second Author*

It was interesting that all of the topics the co-researchers came up with were things that impact their lives. They could have chosen to research anything, but they were all very interested in the topics, and felt strongly that the topic would be of interest to other people with intellectual disability and those that support them. They also thought that their research findings could help with recommendations for people with intellectual disabilities who have or want pets.

The overall purpose of this inclusive research project was to look at the experiences of people with intellectual disabilities who have a pet or would like a pet. This research explored the benefits of having a pet and the barriers to having a pet.

2.2. Who Participated?

The team talked about who would participate in the study. They wanted to keep the focus narrow so they did not become overwhelmed with data and have to conduct many interviews. The team talked about whether they would interview families, support workers, or people with intellectual disabilities. The co-researchers decided on people with intellectual disabilities because they all have an intellectual disability and they think it is important to hear from people with intellectual disabilities.

2.3. Learning about Ethics

The team had to learn about ethics, so they asked the Ph.D. supervisor (last author), who is an experienced researcher, to come and talk to them about it. The Ph.D. supervisor taught the team about the principles of ethics. The team then started on their own ethics application to the university's ethics committee. The application had to be carried out online. The Ph.D. student (first author) broke down the questions for the co-researchers and, as a team, they discussed the answers. The questions that were asked on the ethics application were not in plain English and were more suited to academics. The Ph.D. student then went away and wrote up the application based on what was discussed. An important ethical consideration for the project was ensuring people with intellectual disabilities had information presented to them in a way they could understand so they could make an informed decision about their participation and how the information they shared would be used.

Another challenge of obtaining ethics approval was having to complete a working-with-vulnerable-persons check. This meant all team members had to have identification documents and fill in a long and complicated government form. The ethics committee became slightly confused between our ethics application and another similar one at the time from another research group, so the team had to correct the committee on that. The team were relieved when they finally obtained ethics approval (project number HEG2441-1).

Once the team had ethics approval, they began to undertake their research study about pets for people with intellectual disabilities. The findings of their inclusive research study will be reported in another paper.

3. What We Found Out about Inclusive Research

There were many good things about being part of the inclusive research team. The good things and the challenges will now be explained and discussed.

3.1. Getting Paid

"I like the fact that we got paid, it made me feel like my time was valuable"—Second Author

"The pay helped me with bills, your supposed to be paid when you do something like this, to keep going in life"—Third Author

"It was good to be paid to learn new things"—Fourth Author

The co-researchers were all paid for being part of the inclusive research team. The Ph.D. student (first author) did not, since she was completing this as part of her Ph.D. studies and her supervisor was completing this as part of her usual academic research work. The co-researchers thought they were volunteering to complete the research project at first (without expecting any payment); however, the Ph.D. student was successful with an Endeavour Foundation grant, which meant the co-researchers received a monthly voucher for the time they put into the group. The co-researchers all agree that being paid for doing the research project was a positive. For some co-researchers, if they had not been paid, they may not have continued to be involved in the team, because everyone needs money to get

by in life. Being paid also made the co-researchers feel they had accomplished something and that what they were doing was worthwhile. This is consistent with other inclusive research teams who found payments for co-researchers were an important way of making them feel their contribution was valued (Butler et al. 2012).

3.2. Learning

The co-researchers all learnt new things:

- What research is about and why research is conducted.
- Different ways research can be carried out, like interviews, focus groups, and surveys.
- There are lots of steps in the research process, like deciding what research to conduct and how to conduct it, collecting information, looking at the information, and sharing the research finding.
- It is important to know what information can be trusted when conducting research. It can be hard to know what information can be trusted. For example, the co-researchers learnt that websites like Wikipedia are not trustworthy because anyone can write what they want on there.
- How to use Zoom so the team could continue their research during COVID-19.

3.3. Further Opportunities

"Because of this research I got a job at a university which I love and get paid award wages."—Second Author

Two of the co-researchers were able to secure a job because of the research skills they learnt. They both now work at a university as research assistants, contributing lived experience perspectives to inclusive research teams.

3.4. Social Aspects

"Coming to the research meetings helped me in a social aspect because if I wasn't coming to the meetings I would be doing absolutely nothing or watching Netflix."—Second Author

"I enjoyed learning about different things and meeting Second Author"—Fourth Author

The co-researchers were able to get to know each other and meet new people. Some even see each other outside of the research group meetings. Participating in inclusive research gave the co-researchers the opportunity to come together as a group. They all agreed that the social aspect of the group and making new friends was a positive of the research. Having a friendly group and taking the opportunity to get to know each other helped the group work together as a team.

3.5. Personal Development

"This research project gave me the opportunity to do public speaking. I have improved a lot. I used to get massive stage fright but now that's improved"—Second Author

Participating in inclusive research developed the co-researcher's self-confidence. They had the opportunity to try new things like public speaking. For some, it was the first time they had achieved something like this and having the opportunity to take part showed them they could achieve it.

3.6. Challenges

There were challenges for the inclusive research team. One of the most difficult parts of the research process was deciding on a research topic. The team had many ideas, but all members had to agree on just one. They also wanted to make sure the research project did not repeat research that had already been conducted.

Many parts of the research process were difficult or confusing; for example, understanding journal articles and applying for ethics approval. The co-researchers all agreed about the importance of having someone to break things down and putting things into Easy Read to make the research process accessible.

"The biggest challenge was that pesky virus that turned up in 2020. It meant we couldn't meet in person, we had to meet online"—Second Author

COVID-19 was challenging and meant that sometimes the team had to find different ways of working together. When the team could not meet in person they would meet on Zoom. This was something completely new for the co-researchers. When the team was able to meet again in person, they had to learn new rules like social distancing. COVID-19 was also challenging as it slowed the research down significantly because people with intellectual disabilities, disability service providers, and families were busy focussing on keeping safe from COVID-19. There were also times when the team had planned to meet as a research group or with participants that had to be cancelled because of COVID-19 diagnosis or symptoms.

4. What It Meant to Us to Conducted Inclusive Research

"People with intellectual disability should be given the same opportunities to do research as everyone else. We might need help with things, but we're just as capable as everyone else"—Second Author

From the team's experience of learning about and conducting inclusive research, they learnt about good inclusive research. Taking their time, getting to know each other, and believing they are capable were all important ingredients in their recipe for good inclusive research.

The team know that good inclusive research takes time, especially when co-researchers with intellectual disabilities are part of every step of the research process, from determining the research topic right through to dissemination of the findings. There is a lot to learn about conducting research and a lot to plan to carry out the chosen research. It is important that there is time and support to break things down.

Our inclusive research team's experience is similar to what other studies have reported. Hewitt et al. (2023) conducted a systematic review looking at the experiences of inclusive research teams. All studies in the review identified the importance of making the research methodology and presentation of research findings accessible. Many of the strategies to achieve this align with those our team used, as described earlier in this paper, such as verbal discussions (brainstorming), presenting data in multiple formats (Easy Read summaries), and controlling the pace of meetings (we worked at our pace, we took our time, and we moved on when we were ready). This is an important consideration for university researchers when deciding to use inclusive research methods, as funding and academic deadlines are often barriers to allowing sufficient time (Bigby and Frawley 2010; Bjornsdottir and Svensdottir 2008).

Getting to know each other was important. It helped the team to work well as a group and feel comfortable with each other. Other inclusive research teams have also reported getting to know each other and being able to work as a team as important (Grayson et al. 2013; Haigh et al. 2013; Hewitt et al. 2023).

The team's experience learning and conducting inclusive research has shown people with intellectual disabilities are capable of being part of a research team for the whole project and contributing to every part of the research process. Being involved in the inclusive research team gave them the opportunity to show other people what they can achieve. This project adds to other studies, because it is one of the only ones that describes co-researchers being involved from the beginning, participating in all parts of the research process, and making decisions about what was researched and how it was carried out. The co-researcher's involvement in the inclusive research team was not just about conducting research; it was also about what can be achieved with that research. The co-researchers believe their inclusive research study about pets for people with intellectual disability will provide the following:

- Give a better understanding of why pets are important to people with intellectual disabilities.

- Help to learn about barriers to having a pet, so this can be addressed.
- Educate NDIS, the government, service providers, and families about pets for people with intellectual disabilities.
- Check people with intellectual disabilities' understanding of the responsibilities of having a pet. This will help to teach them what they need to know to become a pet owner.

Other inclusive research teams have also reported their research having a larger impact, such as giving a voice to people with intellectual disabilities (e.g., Williams and Simons 2005; Money and Tilly 2012; Grayson et al. 2013; Rogers and Tuckwell 2016; Riches and O'Brien 2020) and creating change in programmes, society, and policy (e.g., Hreinsdottir and Stefansdottir 2010; Stanley et al. 2019).

5. Final Words

The team's experiences as an inclusive research team reflect the experiences of other inclusive researchers. The team's experiences learning about and conducting inclusive research led them to all agree that including people with intellectual disabilities in conducting the research is important and should always happen. Conducting research enabled the team to learn new skills, show others what people with intellectual disabilities are capable of, and have a greater voice about a topic of importance to them and others with intellectual disabilities. In the words of one of the co-researchers (third author):

"It is our society and our world, so we should be involved".

The inclusive research team hope that other people can learn from them and that they will become involved in inclusive research too.

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