



Case Report

Being an Inclusive Researcher in a National Consultation Exercise—A Case Study

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Abstract: This paper presents a case study of the Inclusive Research Network (IRN), an inclusive research group founded by the Centre for Disability Studies, contributing to a National Disability Research Agenda (NDRA) setting project. IRN members with ID carried out their own consultations with disability stakeholders. This paper sets out the experiences of the IRN members in facilitating focus groups as part of phase 2 of the NDRA project. As this project took place during the COVID-19 pandemic and state lockdowns, this paper also provides a reflection on new ways of carrying out research and provides an insight into the process for other groups seeking to engage in inclusive research of this nature in a challenging and changing environment. IRN members showed great interest in being involved in the project, and their motivations aligned with the project's objectives. Facilitating the focus groups on Zoom took some preparation and posed accessibility challenges but enabled a more diverse group of people to attend. IRN members with ID improved their online facilitation skills and confidence but concluded that they preferred working face to face. IRN members overcame the challenges presented by online focus groups, and their involvement added value to the NDRA project. Researchers are encouraged to continue practicing inclusive research in times of remote working and virtual interaction and to share their experiences for mutual learning.

Keywords: inclusive research; intellectual disability; disability studies; qualitative research; COVID-19; lived experience



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Accessible abstract: Doing research about people with intellectual disability together with people with intellectual disability is called inclusive research. It is important to do inclusive research, but sometimes, it is difficult to do. It is important that researchers who do inclusive research write about how they did it and explain how they solved problems so other people can learn from them. In this paper, we describe how a group of researchers with intellectual disability reflected on interviews that they did with a group of people as part of a research project. They did this reflection by thinking and talking about the interviews to find out what went well and what did not during the research process. The researchers found that COVID-19 made it harder to do research. The focus groups had to be done online, and this made it harder. Even though there were difficulties, the researchers were good at learning new ways of doing research. Reflecting on this process gave us some new information about how to do inclusive research.

1. Introduction

Inclusive research has become increasingly recognised as a fundamental part of best practice in conducting research with people with intellectual disability and is a core part of intellectual disability research. Inclusive research was developed out of the emancipatory and participatory paradigms of disability research. These emphasise the rights that people with disability have to be involved in and drive the research about the issues that affect them. They also seek to empower and protect people from marginalised communities

(St John et al. 2018; Stone and Priestley 1996; Walmsley and Johnson 2003). While there is an increasing body of literature around the conceptual underpinnings of inclusive research (Bigby et al. 2014a), there is often little practical information on how to conduct this kind of research in collaboration with co-researchers.

Inclusive research with people with disability has been a part of the disability studies discourse for almost three decades. Walmsley (2001) coined the term ‘inclusive research’ to denote research involving people with intellectual disability as ‘more than just subjects or respondents’, and it is recognised as best practice to ensure that people with disability are included in research (Bigby et al. 2014a; García Iriarte et al. 2014, 2021; O’Brien et al. 2014; Walmsley 2001; Walmsley et al. 2018). Inclusive research focusing on the lived experience of people with disability can be used to empower and recognise the contributions of people with intellectual disability (Bigby et al. 2014b; Walmsley et al. 2018). It can also be used as a powerful tool for advocacy and to enact social change (Johnson et al. 2014).

The Inclusive Research Network (IRN) is a research group run by the Centre for Disability Studies (CDS), an affiliate research centre of the University of Sydney, Australia. It includes people with and without intellectual disability who develop and work on their own research and participate in other research projects. The group has been active since 2009 and has been involved in a number of research projects over the last 12 years. The members of the group have extensive experience as researchers, and the group has presented the results of their research at national and international conferences and published multiple peer-reviewed articles (Adrian et al. 2013; Riches et al. 2017, 2020). The IRN takes the form of a collaborative working group as described by Bigby et al. (2014b). The group has shared purpose between the academics and co-researchers, and control of the group is dispersed among group members (Bigby et al. 2014b). The group aims to develop new knowledge to improve advocacy and generate social change.

The National Disability Research Agenda (NDRA) was a project funded by the Commonwealth Government of Australia through the National Disability Research Partnership and co-led by the University of Sydney Centre for Disability, Research and Policy and CDS. The aim of the project was to create an agenda that would provide a clear vision to disability research and is based on the knowledge of lived experience. There were three phases to the project: Phase one involved a research mapping exercise to identify existing disability research, research gaps and priorities. Phase two comprised a national survey and consultations with stakeholders carried out by disabled people’s organisations, advocacy organisations and project consortium members. Phase two aimed to determine these stakeholders’ priorities for disability research. Phase three constituted the synthesis of the findings from previous phases, the refinement of prioritisation and the proposal of areas of research to inform a research agenda (Smith-Merry et al. 2022). Inclusive research is an embedded principle in the Australian disability research agenda, and as such, consultations led by and involving people with disabilities, including people with intellectual disability, were supported.

This paper sets out the experiences of the IRN members in participating in and facilitating focus groups as part of phase 2 of the National Disability Research Agenda project. As this project took place during the COVID-19 pandemic and state lockdowns, this paper also provides a reflection on new ways of carrying out research and provides an insight into the process for other groups seeking to engage in inclusive research of this nature in a challenging and changing environment.

2. Materials and Methods

The IRN group supported the NDRA in two different ways. Firstly, in April 2021, five IRN members participated in a consultation, facilitated by a CDS research team staff member, to share their own views on disability research priorities. Secondly, in July and August 2021, the IRN carried out their own consultations with disability stakeholders in the form of three focus groups. Prior to that, the IRN met to discuss who IRN members with intellectual disability thought should be invited to the focus groups. Responses included

other people with disability, family members, professionals and politicians. Another meeting was arranged to revise the focus group questions that had been prepared by the NDRA project team in consultation with disability organisations (Smith-Merry et al. 2022). Questions were revised to ensure that they were worded in an accessible way based on the perspective and expertise of the IRN members. Before each focus group session, a short meeting took place to agree who would ask each question.

Focus group participants were recruited via the CDS mailing list and received the National Disability Research Agenda participant information sheet and consent form. Ethical approval for the consultations was received by the University of Sydney.

2.1. NDRA Consultations

In total, 18 people, including people with disability, family members, carers and service providers participated in the focus groups which were held via Zoom. Each session was facilitated by 4–5 IRN members with intellectual disability and the IRN facilitators (the first and second author of this paper) without intellectual disability. Facilitators without intellectual disability welcomed participants and facilitated introduction rounds of the sessions. Then, IRN members with intellectual disability and IRN facilitators without intellectual disability took turns in asking participants questions from the focus group guide. The ‘share screen’ function on Zoom was used during the sessions to share the focus group guide. This way, each IRN member could read aloud the questions they had chosen to ask participants.

2.2. Reflection Process

The findings that are presented in this paper are the result of a reflection process about the NDRA consultations undergone by IRN members with intellectual disability and IRN facilitators without intellectual disability. The reflection process took place during the group’s monthly meetings between September and November 2021. The reflection was integrated into the usual meeting agenda and took approximately 30 min in each meeting. At each meeting, approximately 3–5 members were present. The first reflection step was to ensure that the IRN members would be interested in discussing and writing about their experiences. Once that was confirmed, the group agreed questions that each person would reflect on and answer as a way to share the learning from the project experience. This was done by explaining the concept of reflection to the group and then asking members to come up with questions the group could ask themselves to structurally think about and tell other people about the consultation process. The group decided to reflect on their motivations for joining the project as participants and as facilitators, how the focus groups were held and strengths and areas of improvement of the process. Next, the IRN came together again to go through these questions, reflect on the focus group sessions and answer the questions while the IRN facilitators took notes. Afterwards, the IRN facilitators without intellectual disability met to reflect on these questions and on the topics IRN members with intellectual disability had highlighted.

2.3. Process of Writing This Paper

It was the aim of this paper to include IRN members with intellectual disability in the writing process to ensure involvement in the research process across all stages. However, the aforementioned lockdowns in New South Wales prevented the group from meeting face to face and changed the way we work. Previously, IRN members worked on papers using practical and visual approaches, for example, bus stops (participants rotate between several stations and reflect on questions or provide content to a certain topic while using comments from the previous groups as prompts), working with flip charts and coloured markers to highlight and interlink concepts. Many of these methods did not translate to Zoom or required the use of several additional platforms that would have made participation more challenging and potentially excluded some members. Furthermore, keeping the group focused and engaged was hampered by the online environment. As a response, we decided

to decrease the meeting duration and hold some short, additional meetings as needed. Therefore, fully co-authoring this paper was not possible under the given circumstances. Nevertheless, IRN members with intellectual disability provided reflection which was written up together as a group and represents one part of the paper. IRN members also reviewed and provided feedback on the final draft. The following gives a brief overview of our inclusive writing process: Once the reflections were recorded as notes, the group turned these notes into reflective paragraphs from the perspective of the IRN members with intellectual disability, which are highlighted throughout the text. This was again done on Zoom through a simple shared screen that showed the reflection notes. With an IRN facilitator without intellectual disability as the scribe, these notes were turned into full sentences. The IRN facilitators without intellectual disability further added their own reflections to the paper and discussed the findings. This process resulted in the present paper, with sections of the results written by the IRN members with intellectual disability and all other sections written by the authors without intellectual disability. The finished text was taken back to the IRN members and was revised in summary together. This means that the IRN facilitators without intellectual disability summarised the key points of each section and presented them to the group to ensure that everyone agreed with the final product. This was done as it could not be expected that every member read the paper individually, and reading out the full paper during a meeting while ensuring engagement was deemed as unrealistic.

3. Results

The following section presents IRN members' and facilitators' reflections about the focus group experience including some learnings made. Reflections cover IRN members' participation in the focus groups, their motivations for being involved in the project as a researcher, the process of facilitating their own focus groups, things that went well and areas of improvement.

3.1. Why Were We Interested in Joining the Focus Group as Participants?

Perspective of co-researchers with Intellectual Disability

We wanted to join the focus group because we wanted to find out more information about disability research. We were interested to hear about other people's views, and we wanted to make sure that people hear what we think is important. We also joined to feel included in making decisions.

Perspective of researchers without Intellectual Disability

When we asked the IRN members whether they wanted to be involved in the project, they were very motivated. Most of them had been involved in the IRN for years and were familiar with focus group participation, inclusive research and advocacy work. Hearing the IRN members' responses to this question was very encouraging, as their narrative about inclusion in decision making and having a voice reflected the purpose of the NDRA project we were working on. As researchers who feel strongly about the inclusion of people with intellectual disability, it was motivating to hear that the IRN members saw the focus group as an opportunity for exactly that.

3.2. Why Were We Interested in Being the Researchers?

Perspective of co-researchers with Intellectual Disability

We were interested in being the researchers because we wanted to get useful information from other people, especially with lived experience of disability. We were hoping to find out about their stories. We noticed that it was difficult for some people to answer the questions because they did not have a lived experience of disability.

Perspective of researchers without Intellectual Disability

When preparing for the project and asking the IRN members whether they were interested in co-facilitating, they were never hesitant to commit to being the researchers; in fact, they were very excited about it and suggested who should be invited to the focus groups. They were comfortable asking questions with appropriate support, and it was clear that they have had previous experience in interview and focus group co-facilitation.

Apart from the overall project objectives of inclusion in decision making, IRN members placed emphasis on hearing about other people's experiences. This was also highlighted whenever we reflected on the focus groups experiences in a group meeting, as IRN members recalled participants' stories and said how interesting they had found hearing them. At the same time, as researchers, they placed substantially more weight on stories of lived experience of disability. Taking place during a long COVID-19 lockdown in New South Wales, the organised focus groups also created opportunities for social interaction and storytelling, which was otherwise limited. The social aspect of the groups also became apparent when some focus group participants and IRN members mutually agreed that they would like to stay connected after the project.

*3.3. How Did We Do the Focus Groups?**Perspective of co-researchers with Intellectual Disability*

We did the focus groups on Zoom. We split up into smaller groups of about 4–5 participants. This made it easier to speak up, and we felt positive about asking questions. We felt that it got easier to ask the questions the more often we had done it. We liked it better to ask questions than being the one answering them. One thing that happened was that participants without intellectual disability sometimes turned the questions on to us. We didn't feel like that was very respectful of our role as researchers.

Perspective of researchers without Intellectual Disability

We started our preparation a few weeks before the first focus group. At a meeting, we revised the NDRA focus group questions. Prior to that, one of us had already put the questions into an Easy Read format that included photo symbols. At the meeting, the IRN members decided to reduce the amount of questions we should ask. Questions that asked about two concepts, for example, "What are the most important things people can research about disability and the lives of people with disability?" were broken down into two separate questions, as the IRN members said this would be easier to understand. We also included a short definition of research, in Easy English, as an IRN member pointed out that some focus group participants might not know what research is. It was great to see how the IRN members took charge of the questions and were confident enough to point out questions they found—or thought that others could find—hard to understand.

Facilitating focus groups during a phase of lockdown in New South Wales meant that we had to conduct them virtually via Zoom. One IRN facilitator without intellectual disability recruited participants via email, coordinated and scheduled the groups. Co-facilitating focus groups with researchers with intellectual disability on Zoom was a completely new experience for the facilitators without intellectual disability. Through previous IRN meetings on Zoom, members were familiar with the medium, but even though they are experienced in focus group facilitation, they had not done this on Zoom before. This meant that the entire group learned together from experience. The IRN members reflected this shared learning when they described how asking questions got easier over time.

The IRN members indicated that they preferred being the researcher to the researched. However, in some cases, they were called on by group participants to answer questions in the focus groups. Most participants indicated that the lived experience of people with disability should be privileged over that of service providers and carers. This meant that sometimes, the IRN members were called on to give their perspectives rather than simply facilitate the group as was intended. It was clear that people were intending to be inclusive, but in some cases, it did not feel as though the IRN members' roles as researchers was being respected. This was a very unexpected observation, as both IRN facilitators have previously held focus groups and never had a similar experience.

3.4. What Went Well?

Perspective of co-researchers with Intellectual Disability

We had a mix of people with and without disabilities and people coming from different organisations. It was good to hear different views about what the National Disability Insurance Scheme can do better for people with disabilities.

Perspective of researchers without Intellectual Disability

Conducting the focus groups via Zoom meant that a wider range of participants were able to attend. It was a useful opportunity to obtain a variety of perspectives on key areas of disability research.

We found that using Zoom made it easier for people to attend from different regions. This way, we were not restricted by distance. People also did not need to make travel or accessibility arrangements as they were attending from their own homes.

3.5. What Did Not Go Well and What Can We Do Better Next Time?

Perspective of co-researchers with Intellectual Disability

It would have been good to meet the participants face to face. This would have made participation easier for some of them. Some things were difficult on Zoom. Next time we do a focus group, we want it to be face to face. We have done other focus groups in the past where we visited people in person. We liked that much better.

Perspective of researchers without Intellectual Disability

There were a number of issues that arose conducting these focus groups. Some of these were logistical. We encountered a number of difficulties using Zoom. We found that conversation was sometimes stilted via Zoom and it was difficult for conversation to flow, particularly when the researchers needed to read the shared screen.

We also found that there were some accessibility issues with Zoom. We had an ASL interpreter attending one of the groups, but it was difficult to have the screens reflecting focus group participants while still ensuring that the interpreter was appropriately visible. It was also an issue for the facilitators who needed to read the questions from our shared screens. We finally solved this issue by posting the questions in the chat box.

We found that in some cases, the heterogeneous mix of service providers and people with disability meant that the discussions were inaccessible to the IRN members. Some of the service providers used jargon and did not adjust their language appropriately. This may have made it more difficult for the IRN members to facilitate the groups, and may have contributed to a feeling of "speaking over" the IRN members.

As mentioned previously, the IRN members have conducted face to face focus groups. When we reflected on the process of conducting these focus groups, they were clear that they much preferred face to face interactions, and that they were looking forward to going back to that mode of interaction. While they adapted to the online environment and were happy to have learnt new skills, we all agreed that it was overall a more difficult process via Zoom.

4. Discussion

The purpose of this paper was to describe and critically reflect on our experience, as an Inclusive Research Network of people with and without intellectual disability, of conducting inclusive research for a national research project during the COVID-19 pandemic. We believe that it is crucial to regularly reflect on our practice to ensure that we can improve and grow. Even more so, we find it is key to share our own experiences, critical reflections and resulting learnings with others who want to practice inclusive research. During our own journey of working with the IRN, we have been actively seeking other inclusive researchers' accounts to learn from their successes and mistakes. We found that often, the importance of conducting research inclusively and the resulting benefits are highlighted, and this is crucial to motivate others to work inclusively. However, we found that even though many academics report difficulties, the research process and the challenges connected

with it were only described by a few researchers in detail (Miller and van Heumen 2021; Tuffrey-Wijne et al. 2020). Our hopes are that by being transparent about the challenges that can arise when conducting research inclusively, but describing how we overcame them, showing that our project was still successful, we can take away some of the unknown some researchers might feel who are at the beginning of an inclusive research project.

Reflecting on our work on the NDRA, we found that the IRN members showed a great interest in being involved in the project, and their motivations for doing so aligned with the project's objective of hearing the voices of people with lived experience. The IRN members reported that they enjoyed being the researchers and asking questions and that they preferred this over being the researched. Facilitating the focus groups on Zoom took some preparation and offered some accessibility challenges. On the other hand, it enabled a more diverse group of people to attend, as they were not restricted by distance. Overall, IRN members with intellectual disability enjoyed working on the project and developed their Zoom facilitation skills but concluded that they preferred working face to face.

Throughout the project and during reflection, the IRN members demonstrated how they had internalised the project objectives and recognised it as an opportunity to have their voices heard and influence decision making. It is part of the IRN's vision that people with disability can and should be involved at every stage of research, and it appears that members recognised this project as an opportunity to do so. Even though the project was not initiated by the IRN, they showed interest in the project, took ownership of the research and its objectives and exercised some control over the process. They worked as collaborators with us researchers without intellectual disability. Riches et al. (2017) previously reported how these characteristics of the IRN's work showed consistency with the principles of inclusive research that Walmsley and Johnson (2003) published almost 20 years ago. This paper is an opportunity for the IRN members with intellectual disability to demonstrate the importance of lived experience in inclusive research as well as the research skills they have developed over time.

An observation that made a lasting impression on IRN members and facilitators alike was how participants called on the IRN members with intellectual disability to answer some of the questions. This was only done by focus group participants without intellectual disability and was very unexpected to us, since as researchers without intellectual disability, we had never experienced this before. Given the groups were mixed and there was a tendency for providers to ask questions of the researchers with intellectual disability, in future, it may be better to ensure all participants in a particular group are service providers, or carers, or people with disability rather than mixing the groups. It may also be necessary in the future to reiterate that the IRN members are facilitating in their capacity as researchers. This may highlight an education need among non-researchers/service providers as to the role and potential of people with intellectual disability as researchers. To date, academic accounts focus on inclusive research training for people with disability (Morgan et al. 2015; Nind et al. 2016; Tuffrey-Wijne et al. 2020). Training that teaches researchers and service providers how to work with inclusive researchers is not widely available. One example of such training developed in the Netherlands was reported by Sergeant et al. (2020). Implementing such training more widely could also potentially shift the roles for people with intellectual disability from being the one who is trained to being the expert and trainer.

IRN members advised who should be invited to focus groups and were involved in question revision, focus group facilitation and reporting. Their feedback during question revision facilitated important insights on the level of difficulty and allowed for the modification of the questions to ensure all participants were supported to participate in focus groups. Recognising that the questions needed adjustment and ensuring that they were easy to understand was a 'distinctive contribution which only co-researchers with intellectual disability [could] make' (Walmsley et al. 2018). Walmsley and colleagues identified this 'distinctive contribution' as an important characteristic of inclusive research that adds value to a project. Other characteristics include that the co-researchers' contributions are highlighted and that the work positively impacts on the lives of people with intellectual

disability (Walmsley et al. 2018). In the project described, IRN members with intellectual disabilities' contributions were highlighted throughout the process and in the present paper. Improving the lives of people with disability through creating disability research priorities is the ultimate aim of the NDRA. Thus, it can be inferred that the involvement of the IRN in the NDRA added value to the project.

Drawing on previous focus group experience, IRN members with intellectual disability successfully co-facilitated the focus groups. It must be noted here that IRN members' previous experience with focus groups was in face-to-face environments using tools such as flipcharts and coloured markers to record discussed themes. Working remotely for an extended period of time made it impossible to use these methods and presented a challenge for IRN members with intellectual disability to transfer their experiences. Nevertheless, the group adapted well to the online environment and developed more confidence in Zoom facilitation.

A possible limitation to this project is the potential influence of acquiescence and repetition on responses in individuals with and without intellectual disabilities (Perry and Felce 2004). In the weeks leading up to the focus group, we held several short information sessions about the project and purpose. The repetition of the project agenda could have potentially influenced members' responses and led them to give desirable answers, for example, that they are interested in the project even though they may not be. We made efforts to minimise this risk by regularly asking the IRN members whether they were still interested in the project, explaining to them that there were no right or wrong answers to this question and that answering no would be totally acceptable. We believe it is important to be aware of this potential bias when researching inclusively. Regularly checking in with project team members to ensure that they support the project and its aims is crucial.

5. Conclusions

In the future, we think it is essential that more researchers report in detail about their inclusive research processes to ensure critical reflection and learning and to encourage other researchers to make their own projects more inclusive. Working inclusively under COVID-19 restrictions can seem daunting and impossible, but we would like to encourage researchers to do it. Despite the challenges, inclusive research can successfully be completed online. Nevertheless, we do not believe that virtual meetings should replace face-to-face interaction past the point of COVID-19 restrictions, as our reflections have shown that the IRN members with intellectual disability value face-to-face meetings. When working with people with intellectual disability as co-facilitators of interviews or focus groups, particularly when the interviewees do not have a lived experience of disability, it might be necessary to clearly define and reiterate the roles of the persons participating in the interview to prevent questions being turned back on co-researchers. Another way of addressing the issue could be that inclusive research groups develop training for researchers and service providers, to teach them about how to work with inclusive researchers.

Together, we learned that even though conducting inclusive focus groups online presented multiple challenges, we still managed to facilitate fruitful discussions that generated valuable insights for the NDRA project. Likewise, even though facilitating focus groups on Zoom was not necessarily something most IRN members liked, they persisted, gained experience, and improved their confidence in the Zoom environment. When working with co-facilitators with intellectual disability, the roles of everyone involved in the focus group need to be clearly defined and might have to be reiterated for focus group participants.

We encourage researchers who practice inclusive research to share details of their research processes, challenges faced and strategies used to overcome them to promote critical reflection and learning and to encourage other researchers to work inclusively.

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Institutional Review Board Statement: The study was conducted in accordance with the Declaration of Helsinki, and approved by the Human Research Ethics Committee of The University of Sydney (2021/443 2 July 2021).

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