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Article

Celebrating Thirty Years of Inclusive Research

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Abstract: Inclusive research has been an important way of increasing the understanding of the lives and issues of people with intellectual (learning) disabilities for 30 years. Three authors of this paper, Amanda, J and Kelley, are Australian and have been conducting inclusive research for much of this time. The other three, D, Shaun and Jan, are English. Jan has been doing it for a long time, while the others are relatively new to it. In this paper, we explore together what inclusive research has achieved in its original aims of supporting people with intellectual (learning) disabilities to have a heard voice and in working towards changing attitudes, policies and practices in relation to supporting them to lead good lives. Fundamental to achieving these aims was the need for active participation by people with intellectual (learning) disabilities in conducting research relevant to them. We record what we have done, how we did it and why it was important to do this work together. We focus on what inclusive research has meant to us and how it has been used to get positive change for people with intellectual disabilities. We end with a summary of what we think inclusive research can achieve and where we think it needs to go next.

Keywords: inclusive; research; learning/intellectual disability; impact; life history; rights; community

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1. Introduction

This paper is by six people. Kelley Johnson, Amanda Millear and Janice Slattery live and work in Australia. Danielle Garratt, Shaun Picken and Jan Walmsley live and work in England. All of us work as inclusive researchers, and four of us have been doing inclusive research since the 1990s—or even earlier.

In this paper, we tell the story of inclusive research as we have experienced it, and end with some ideas about where it might go next. The paper consists of six brief life histories which provide an account of the meanings inclusive research have had for us and what has been achieved. The life histories include references to published inclusive research by each of the authors. We aimed for this paper to provide an example of how inclusive research can be done in ways that make it as accessible as possible.

1.1. What Is Inclusive Research?

Two of the paper authors, Jan and Kelley, came up with a definition of inclusive research which has been cited many times since it was published in 2003.

Here it is:

- The research problem must be owned (not necessarily initiated) by disabled people.
- It should further the interests of disabled people; nondisabled researchers should be on the side of people with learning disabilities.
- It should be collaborative—people with learning disabilities should be involved in the process of doing the research.

- People with learning disabilities should be able to exert some control over its process and outcomes.
- The research question, process and reports must be accessible to people with learning disabilities.

(Walmsley and Johnson 2003, Box 3.1, p. 64)

Almost 20 years on, Learning Disability England, a charity representing self-advocates, families and service providers encouraged its members and others to adopt these principles, which are listed below.

We will work alongside self-advocates and/or families to decide what to research.
We will prioritise research which matters to self-advocates and families.
We will involve self-advocates and/or families in doing the research, as advisors and/or as co-researchers at all stages.
Nobody should be excluded from research. We will work hard to make sure that people with different needs and from different backgrounds are included in our research.
We will pay self-advocates and family members (and/or their organisations) for their work. We will make sure our systems make payment possible in fair and flexible ways.
We will learn together how to do research. We will support each other. We will invest in developing people's skills as we learn to work together.
We will share what we find out in accessible ways. We will consult with our partners before we publish and we will recognise the work of self-advocates and families in our publications and other outputs, as well as co-authoring (writing) together. We will budget for co-researchers to present at conferences, too. We will make sure we have a plan for how the work will make a difference. We will use our research findings to help people with learning disabilities and their families get better lives.

Other than the requirement to pay co-researchers and others, these principles are very similar to those written 20 years previously. However, while the principles may not have changed very much, in the intervening time, inclusive research has become more widely practised and in many more parts of the world.

1.2. The Words We Use

When writing about inclusive research the words we use matter, but they are often difficult too. We use 'inclusive research' to refer to research where people with learning/intellectual disabilities play an active part. But there are other ways to describe this, such as 'participatory research' or 'co-production'.

The words we use to label people as having a learning or intellectual disability are also difficult. In Australia, and in this Journal, intellectual disability is used. But in England and Wales where three authors live and work the term is 'learning disability', and we know some self-advocates really dislike 'intellectual disability' (Armstrong et al. 2022). In this paper, we use the terms with which the authors in each country are most comfortable.

Finally, what to call the different partners in inclusive research? Co-researcher is quite commonly used to refer to the researcher with a learning or intellectual disability. Some people say everyone is a co-researcher, so that will not do. Are there alternatives

that do not use lots of words? Jan worked a lot with Alan Armstrong, and he called her an ‘academic researcher’ and himself an ‘activist researcher’. (Armstrong et al. 2022). In this paper, we use different terms according to how people choose to describe themselves.

2. How We Wrote This Paper

We wrote this paper with difficulty. Jan and Kelley each invited two people with whom they had conducted research to write it with them. Everyone was enthusiastic to take part. But it was not easy. Not only were we working across the world, we were also working during a pandemic which, for long periods, forbade us to meet face to face. When the work started, Jan had not even met Danielle in person, despite having done a lot of work together over the previous year. In spite of these challenges, commitment, phone calls, Zoom and Skype all made it possible to collaborate.

We prepared for the paper by agreeing on some questions to address, with some support when necessary, about our experiences of inclusive research. Jan talked through the questions with Shaun, recorded the conversation, then wrote his answers. Kelley met with Amanda and Janice to build their stories. Danielle preferred to write her piece and then to respond to written comments and questions.

Once we had done this preliminary work, the highlight was a meeting of the six people on Zoom in December 2021. The time difference made this a challenge. At the time, Melbourne was 11 h ahead of the UK. It meant that a meeting had to be early in the UK morning while the Aussies had to stay up late. But we did it, after careful preparation, and everyone had a great time, lots of laughter and camaraderie.

Then, we all went away and worked on our personal accounts. Jan and Kelley had to make lots of changes because their language was not accessible. It was interesting that the Australian researchers were not familiar with the term ‘co-production’ which is used very widely in UK. And sadly, other than Kelley and Jan, no one knew the meaning of normalisation, social role valorisation, or the social model of disability, even though these are big ideas that have shaped the way we think about disability over the past 50 years. Jan and Kelley then wrote the beginning and end of the paper and shared it with everyone. And this paper is the result.

The next section of this paper consists of two sets of reflections, one from the UK and one from Australia. There are three reflections in each section. Essentially, these are life stories which seek to capture the importance of inclusive research in each of our lives.

3. Reflections from the UK

This section consists of three reflections or life stories about the involvement of Jan, Danielle and Shaun in inclusive research.

3.1. Personal Reflections on Inclusive Research

Jan Walmsley

In writing this, I want to say how much I owe to people who have worked with me. Kelley, one of the co-authors of this paper, has been alongside for much of the journey. Alan Armstrong, who tragically died of COVID-19 in February 2021, really pushed me to work out my position as a researcher. He was not going to be fobbed off with slogans such as ‘Nothing About Us Without Us’ when it did not mean anything in practice, while working with Danielle has given me confidence because she can make videos and I cannot.

It is a matter of awe and wonder to me that by inventing the words inclusive research I made my name, and it gave me a passport to many exciting places and people.

Now, over 20 years later, inclusive research is not only in the English speaking world but way beyond it. Tessa Frankena et al.’s (2018) paper is an example of a truly international collaboration on inclusive health research. I wrote a paper with some friends from Norway who are trying to start inclusive research there (Chalachanová et al 2020). Japanese colleagues are really keen to get started (see Tilley et al. 2020). Furthermore, inclusive

research has gained strength from people with learning disabilities. For example, some self-advocates in England and Wales now say all journal papers about research should be written with a researcher with a learning disability—or for there to be a good excuse if they are not.

I came up with the term ‘inclusive research’ at a dark period in my life. Divorce, my father had died, my daughter had had a serious head injury and my mother had breast cancer—and our beloved dog too had died. This provided me with the space to do some deep thinking about the contrasts and contradictions inherent in normalisation/srv¹ and the social model of disability². I remember wrestling for days to get my ideas straight, and they were published in the journal *Disability and Society* in 2001—the best thing I have ever written (Walmsley 2001).

Research as a ‘valued social role’ was one of the things I wrote about. It remains true that sometimes people are included because it looks good rather than adds to the project. The Social Model of disability, in particular Mike Oliver’s powerful argument for disabled people to control the research agenda (Oliver 1990), was also a strong influence. It left me and other equally sensitive souls floundering, wondering how to justify our continued professional existence.

It became important to work through these ideas, something I did with Kelley, which emerged as our 2003 book (Walmsley and Johnson 2003). I am proud that that book has stood the test of time. It continues to be read and used by lots of people. Since then, I have become more certain that it is not enough to justify inclusive research just to make research look good and inclusive. A few years ago, I wrote about the ‘added value’ of inclusive research, meaning that working alongside self-advocates in a research project has to bring something extra to the table (Walmsley et al. 2017). It has taken many years to work out what that added value might be, and I still think there is a way to go in identifying it. But here is an attempt.

Most certainly access is one area where working together pays off. When approaching self-advocacy organisations or individuals, it helps if self-advocates are part of the team.

Activist researchers (Alan Armstrong’s term) can draw attention to what matters to people with learning disabilities. For example, helping self-advocacy groups evaluate their own projects, something we wrote about together (Armstrong et al. 2019). Activist researchers can advise on what is accessible and can also explain answers which might seem surprising. The best example of this that I know of was the high number of people saying they had a direct payment in the 2003 England National Survey (Emerson et al. 2005). The People First team members who were activist researchers in the project explained that people did not understand ‘direct payment’ as being a type of benefit, such as NDIS in Australia, but rather saw it as simply getting money out of a bank or post office!

A recent example of working with self-advocates in planning research was to ask for feedback from three different groups on the value of a widely used set of questions to measure self-esteem for a project on self-advocacy and well-being. We paid each group a small sum to evaluate the questions. We received very strong advice not to use it from all three groups.

‘The risk of emotional harm is too high’ said one. ‘I feel a lot of the questions have a negative aspect to them.’

Another:

‘The questions confused me. They’re asking about how I felt generally about myself, what I can do, what I’m worth. Since my feelings about all this can vary so much day to day I had to answer neutrally to all of them.’

A third person pointed out that his situation is fluid.

‘As of right now the survey is not allowing me to give straight answers that will stay accurate.’

You might argue that these answers are so obvious as to merely be good research. True, but our ability to obtain these honest responses was built on long-term partnerships with the groups concerned. Anne Collis, my friend, and Alan's too, argues that inclusive research is the only tool we have to address the exclusion of people with learning disabilities from universities and other places that conduct research. If people like Alan want to carry out research, it is the only avenue open to them. Furthermore, it also addresses what Ann calls hermeneutic injustice, which means that people are unable to comment upon or interpret their own lives. Inclusive research opens the door to change this (Armstrong et al. 2022).

I am still learning how inclusive research can challenge things we take for granted. For me, the most exciting development is *In Response*, an initiative by journal editor Melanie Nind to give self-advocates a platform to respond to an article in every issue of *The British Journal of Learning Disabilities*. It started as a well-boundaried initiative, and one that has been widely welcomed, even by the academics whose work has been looked at, often critically, by a self-advocacy group (See for example Blackley et al. 2021). It is developing into something more. An online public meeting in autumn 2021 between the groups who did the first three In Responses and the Journal editor produced these ideas:

- Change the questions referees (who make decisions about whether research will be published) are asked to answer.
- A request that self-advocates have their own special issue of the journal.
- A suggestion that journal paper *titles* should be in plain English.
- An insistence that accessible summaries really are accessible.

The doors are opening in all sorts of directions, and though I am not naïve enough to think the world will change overnight, it is indeed exciting to watch inclusive research challenging established norms—as it has from the start.

3.2. *Respect Us as We Respect You*

Danielle Garratt

Hello, my name is Danielle, and I am a learning disability voices project worker at Brighton and Hove Speak Out in England. Speak Out is a self-advocacy organisation that lets people with a learning disability speak up and take action about things that matter to them. My first ever research project was at the beginning of the pandemic, I did not know what my job would include. I started doing social media and posting things on there until one day in July 2020 my colleague was talking about how it would be a good idea to create a video series on how people with learning disabilities are coping with the pandemic and to give advice to other people about how people have coped. The project's name was called *Speak Out with Danielle*. I started thinking about who I would like to interview and started thinking about how to create a video. I started to get into recording people and interviewing people over Zoom, and it sparked an interest of wanting to conduct more research. In this research, I think that being able to talk to people in this particular time was hard, as everyone's emotions were up in the air, and they did not know what was going to happen and how long we were going to be stuck indoors. Another thing that was hard was relying on Zoom and if the internet went down or buffered, it was even harder. Being able to talk to people and being there for them to chat went really well. This is where I fell in love with creating videos and also conducting research. I want to do more to try and help people with learning disabilities and get across to others how hard it was for people who do not have internet and do not know how to read and write.

For my next research project, I stepped in and helped Jan with *50 years of Speaking Up in England towards an important history* (Walmsley et al. 2022). This was a project to interview people who remembered the early days of self-advocacy in England. This project had started already, and I was asked to help out as Ian Davies, who had started it, could not help anymore, so I stepped in as everything was set up ready. This project was really interesting as I was a part of hearing other people's stories about the institutions where they had lived and seeing how they coped with it. This research project made me really

think about the history of people with learning disabilities, and being able to tell their history to someone was a real pleasure to listen to and ask questions about. Having someone else with me to help ask more in-depth questions to obtain more answers out of them was really helpful as this was my first proper research with it being written down as well. I think doing the interviews online got in the way, even though it was during the pandemic, because it was more difficult to engage with people than it would have been in person. Diving in the deep end with this research was a bit scary as I had not spoken to any of the people before, so I had to get to know them a bit while doing the research.

Doing these two different research projects has made me realise that I want to conduct more research and find out more about people with a learning disability and the history of people as, if we do not do it now, the older people will not be about for the younger generation to learn from them about how the institutions were for people and how they were treated compared with now.

The current research project I am helping out with is called *COVID Stories*. This is a project speaking to people that have not been able to get online during the pandemic. In this project, I was asked some questions by my boss that she thought would be good for this project, and I responded with how I coped with the pandemic, and then a few weeks later I interviewed someone, and while I was hearing her answers to the same questions, I found she had completely different responses of how she coped during the pandemic. This really opened my eyes up to see how other people coped and how much they struggled. I am hoping this project will make people think about what people with a learning disability felt during the pandemic: not being able to know what is going on and not being able to go to groups that they used to go to.

Becoming a researcher has really opened my mind up to all things that need to be researched about people who have a learning disability, and being able to spread awareness is one thing I am going to focus on by conducting research.

I have not had training to conduct research. I have trained myself to create videos, and also I have some training of video editing to help me edit the videos for the Speak Out with Danielle series on YouTube. I would like some training on being able to get people to elaborate on their answers and to be able to get them to dive deeper.

3.3. Do Not Sweep Us under the Carpet

Shaun Picken

I am Shaun. I work for My Life My Choice. My Life My Choice is a self-advocacy organisation based in Oxford, England (<https://www.mylifemychoice.org.uk/>). I am a consultant, which means I am paid for the work I do. I have a zero-hours contract, I only get paid for the jobs I do; I do not have a regular wage.

Research is important to me. We—My Life My Choice—do a lot of campaigning, evaluations and consultancy work. A total of 25% of my time is spent on research.

The best thing about research is what I am doing right now. Doing the epilepsy project. It is about helping people with epilepsy and their carers to know what are the triggers, how you can manage and the medication and its impact and side effects. We know all this, it is about putting it in an easy framework that people can use. It is basically me and a couple of others from My Life My Choice. Only 7% have photo-sensitive epilepsy. It used to be called grand mal. It is no longer politically correct to use that term.

I feel I am really making a difference. Epilepsy Action (<https://www.epilepsy.org.uk/>) is running the research. They are a charity who offer support and advice to people with epilepsy.

I did not have any training to conduct research. I do not think you really need it. You are used to it from the other things you do. If you have not carried it out before you might need it. But you get the knack quite quickly. I have been on computers since I was 5 years old. If I want to know something, I use Wikipedia. But I have never conducted research interviews. With the epilepsy research, we were given the questions to answer. If I was

conducting research interviews, I would welcome some training. But I have never performed that. For the epilepsy research, it is me answering the questions.

I do get paid sometimes if I am working for My Life My Choice. But it has never been about money for me. I have done work with the Open University. I have been on advisory groups for projects about self-advocacy. One was about how they worked during the COVID-19 pandemic, all the things they did to keep people going. And the other one was about how self-advocacy is funded. One is called '*Filling the Gap*' (Tilley et al. 2021) and the other one '*Funding the Gap*' (Tilley et al. 2022). I helped by suggesting ways to get the messages out there using social media.

I also told my story for a video in a course. The course is called Exploring Learning Disabilities—Supporting Belonging, and you can see my story on this link below. Thousands of people have studied it. It makes me very proud³.

Research is both my hobby and my job. I have been able to conduct my own research such as looking at how many countries are pro LGBTQ. It is growing by the year. Western Europe is high.

At the moment, half my time is on the epilepsy research and half is on the *Don't Lock Us Away* campaign. It is a campaign to stop people being locked away in hospitals when all they need is support to live a good life in their own communities. I tell you more about it on this link: <https://www.mylifemychoice.org.uk/pages/20-don-t-lock-us-away>. That one has been lingering a bit too long, maybe it needs more research.

Why do we need inclusive research? That is a really hard question. It is about better lives. Valuing People⁴ did it, but that was 20 years ago.

My friend says, 'Don't sweep us under the carpet'. I think that is the big message.

4. Reflections from Australia

Kelley, Amanda and Janice were able to meet twice together to discuss our experiences of researching together, and then we Zoomed twice to develop our reflections further.

4.1. *Living and Working for Change*

Kelley Johnson

I used this title as a starting point for this brief history of my involvement in inclusive research because it is what made me start doing it so long ago and what motivates and excites me still after more than 25 years of researching inclusively with people with intellectual disabilities. Change means many different things to me when I think about inclusive research. It has changed me in many ways, helping to create who I am and what inspires me. I think too it has through its processes led some people with intellectual disabilities to view their lives and those of others, differently. And finally, it has, not as often as we would like, led to changes, or at least supported them, in disability policies and in the power and participation which people with intellectual disabilities have in their communities and their lives.

So, starting with me. I came to inclusive research through working with a man who had a commitment to participatory action research, which involves community members and is strongly about getting change to happen. As a young researcher, I worked with him as he evaluated services and undertook community development in Melbourne. I changed from seeing research as something which only trained researchers conducted to one where it was self-evident that people about whom research was conducted, should be involved in carrying it out if it were to lead to wider social change. From this work, I went to London and spent 12 months at the Tavistock Institute, then the home of action research. I loved the experience and came back to Australia excited by what I had learned. From then on, I began, as a research consultant, to conduct research that always included people about whom the research was undertaken. Gradually, through changes in my life and concern about what I saw as injustices, my research focused more on undertaking research with people with intellectual disabilities. However, I did not then use the term

inclusive research. It is thanks to Jan that my views of this kind of research developed further, and our discussions, writing and friendship have been extremely important in my research since our first meeting. Watching and participating in the growth of inclusive research since our book on it was published (Walmsley and Johnson 2003) has been in a way like being a parent. I have been part of its growth and learned enormously from my involvement, and I have seen inclusive research go in directions that I would not have thought of in the beginning of the work. The use of computers and social media, photographs and film and the growing links between self-advocacy and research by people with intellectual disabilities have transformed the processes and impact of inclusive research. I learn new things each time I work with people on research that is important to all of us.

Sometimes I do think inclusive research is written about as if its primary importance is change that may happen in the lives of individuals with intellectual disabilities who are researchers. One does not read very much about how conducting inclusive research may have changed those who do not identify as having an intellectual disability. I think my argument would be that all of us involved in such research experience change. For example, I found it interesting that the stories written for this paper by my colleagues all tended to pick out common themes: new learning, confidence, changing attitudes and new skills and sometimes a recognition of skills yet to be learned. When I think of this mutual learning I remember back to the beginning of a project in Ireland where I was co-ordinating the development of inclusive research (Johnson 2009). I went to talk with a group of people with intellectual disabilities who used a service in the country Ireland. I was excited at the possibility of developing an inclusive research project with them, but our first meeting was a disaster, as I talked about what research was and suggested possible topics which were met with silence. I almost fled back to Australia. At our second meeting, I asked them to talk in pairs about things which were important to them or which they found to be problems. The discussion was lively and went on for a long time. At the end, we all talked about what had been discussed. Topics included: I want to know how to make my coffee shop better; I want to stop being bullied because I am afraid to leave my house; I want to stop the service from closing the garden where I have worked for 20 years; and I want to talk about poetry. All of these topics were taken up by the group (except for the poetry, unfortunately) and became research projects (Hogan et al. 2007; Minogue et al. 2007; Johnson 2009). All of them led to some changes in the issues raised. For example, in relation to bullying, a small research project led to a commitment by a manager of Dublin buses to reduce bullying; researchers in this area went on radio to talk about the issues, and a national anti-bullying project gradually developed from smaller ones. People in the original group began to speak out about what they wanted, and they developed ideas for how the research would happen. Some of these people have now taken up strong roles in self-advocacy, have travelled overseas to talk about their work or to teach other people about conducting research (Johnson et al. 2014). I learned to listen and to find ways of supporting people to conduct research that they saw was important.

So, inclusive research can lead to change for individuals. And it gains value in the contributions which all those involved make to it from life experiences, formal and informal learning and commitment. However, inclusive research does also have at least three goals: one is to better understand the issues and concerns of people with intellectual disabilities and the part that people not identifying as disabled play in them and, secondly, to support and advocate for changes in the community, which becomes clear from the research findings. The third goal is one which is achieved when we work together as a team. There are now numerous instances where the impact of research findings has supported or led to change. For example, a national inclusive research network in Ireland has developed, with a strong focus on rights (Johnson et al. 2020). People with intellectual disabilities for the first time have been consulted about changes to a law which made it very difficult for them to have sexual relationships. In Australia, people with intellectual disabilities involved in inclusive research have used peer education to teach others in different local government areas to run their own workshops on sexuality and relationship

rights for people living in their areas (Frawley and O'Shea 2018). I could go on for a long time and I could also record those disappointing times when good inclusive research has not been taken up or led to the recommended change.

But the research goes on and it remains an exciting adventure for those people committed to it. Furthermore, it now can lead to positive changes in the lives of all those researching inclusively and in the ways people with learning disabilities live their lives in their communities.

4.2. *A Link in a Chain*

Amanda Milliar

This story is just a few drops of water from the enormous glass full of my life.

For me, research is a link in a chain. I have been a self-advocate since the 1980s and have conducted research since the late 1990s. Research for me is finding out information I want to know, working with other people to find out about things that are important to people with disabilities, talking with people about what we have found out and trying to get them to see us. So, research and self-advocacy are mingled, for me, they are knotted together. Research, self-advocacy, sharing information and telling our stories are all links.

From conducting research, I have got knowledge and skills. It has helped me with other things in my life. I became more observant. Research allowed me to explore things a lot more deeply, seeing things I have never seen before. For example, when we carried out a research project looking at the history of self-advocacy (Frawley and Bigby 2014) there were things I had not thought of before, such as how to work in a group. I had not been able to work in a group before, but I learned to do it in a research way.

I look up information now on Google. Getting an iPad has been great. Sometimes I just put in a word and dig deeper from 1–6 and it just depends on what turns up on the screen. Since 2012, I have had my iPad, and now I am on my second. By conducting research, I think about different things and now, with the iPad, I know how to find out more about them.

I have kept a record of what we do. I learned to do this in our research. I take photographs of things that are important to me and the research we have conducted. I keep them in files at home.

From doing research, I learned about public speaking or 'barking'. I have been doing that since 1981. I would do preparation for talks and sometimes I would read up on the thing I was going to talk about, but ad lib is my best style. You have to know what you are supposed to be talking about and you have to conduct research so that you know this.

For 11 years, I went and taught medical students at Monash University about what it is like for people with disabilities to go to the doctor. In doing this, I shared my experience. I had to be flexible and know the topic. I have learned to use photos and flash cards to talk with people. I learned you have to start at the bottom and work your way up to the top when you are talking. Sometimes, I have flown by my pants or my imagination, but I do try to have a plan B if there are problems. You have to be flexible, alert, observant, willing to change if the situation changes, adapting to the situation. It is important to find ways of telling a story from a clear beginning through to the end so that people can understand it. Hopefully, they can see the picture from what I am describing to them.

I was the founder member of a programme named *Raising Our Voices* on community radio. I got the idea sitting in a café and did most of the work, with some support, to get it going. The first show was on 17 August 1987. We now have a team which meets to plan each show that is coming up. Over the years, this programme has raised important issues that people with disabilities want to know about. Some have been touchy subjects where we have shared life experiences or sexuality and our research. Other topics have included housing, transport, pensions and closing large institutions. There are many other issues we have talked about. I have been on *Raising our Voices* talking about topics that I am involved in for 35 years.

I learned that my work was valuable, and I could be paid for it. Some research you do not even get paid for, and that is not right in my book.

I learned to speak up. I do not let things go. I bark loudly. I do not like jargon. I hope that people will see past the disability and give us a go, and not just look at the things we cannot do but the things we can do. I might walk around with a white cane, but I am still a person and need to be recognised as one. I want to lay down a path that the people who come after me can use, such as our research on sexuality that changed the laws about people with disabilities being able to have sexual lives (Johnson et al. 2000).

When you do research, you start small and grow bigger like a tree.

4.3. Why Research Is Important

Janice Slattery

Research has been important in my life. It has made me feel proud of conducting research and proud of passing it on to other people. A highlight of my life was in 2018 when I received the Lesley Hall Life Time Achievement Award, which celebrated my work in research and advocacy.

It is important to know what happens to research that we conduct.

In conducting research, I learned lots of different things. When I was involved in the research, *Living Safer Sexual Lives* (Johnson et al. 2000) and the later project *Sexual Lives and Respectful Relationships*, (Frawley and O'Shea 2018), I learned from the life stories we collected about sexuality and abuse of women. I learned that abuse happens to others (not just me), both single and married women. It took courage but I shared my story with other people and helped women in workshops and in talking with them.

As part of the *Living Safer Sexual Lives* research, I was involved in reading the life stories that were collected from people with intellectual disabilities about their sexual relationships. I acted in one of the films that we made where we read the life stories so that people with intellectual disabilities and other people could see and hear what we had found out in the person's own words.

After *Living Safer Sexual Lives* was finished, people on the reference group were asked to meet with people in the government for about 12 months, and they used what we had found out to get a change to the Victorian law which gave people with disabilities more rights about sexual relationships.

As part of the *Sexual Lives and Respectful Relationships* research in which I was a researcher from 2009–2019 (Frawley and O'Shea 2018), I interviewed peer workers at six different sites in Australia and trained them how to run their own groups with people with intellectual disabilities about sexuality. They were able to go on doing this in their own areas.

I have taught medical students about what it is like going to the doctor if you have a disability and particularly what women may experience about things such as breast screening. The students were interested in what we had to say. They asked a lot of questions, and we taught them that when people with intellectual disabilities go to the doctor, the doctor needs to listen to them, understand them and be a little bit patient with them.

Because of being a researcher, I have travelled lots: Seattle, England, Iceland and Sweden. I gave papers at conferences about our research. Travel gave me confidence in giving papers overseas. People at the conferences were excited that people with disabilities could stand up and give research papers. They were most interested. They did not know much about Australia or Australian research, so it was good we could go over it. And we did not know much about their cultures either, so I learned a lot.

I think it is important for people to know about research. I am the editor of the *Reinforce* (self-advocacy organisation) newsletter, which goes out every three months to members and workers. It tells them about research that is happening. For example, when we were doing the history of *Reinforce* (Frawley and Bigby 2014), we talked about the history research project and told people what we had found out in the newsletter. I know that

self-advocacy groups get a little more funding now, and I hope it had something to do with our research. But it is still not enough!! I also have been involved with a community radio programme for people with disabilities called Raising Our Voices. I used this to talk about the history of the self-advocacy project, giving people information and telling them where they could get the book. The newsletter and community radio tell people about things they may not know about.

Because of my work, I was asked to sit on the National Disability Advisory Committee for people with disabilities. It was a national government committee and was about housing, employment and pensions for people with disabilities. It was tough sitting on the committee. Half of the information went over my head, and I stood up and told them so, but they did not listen. That is the thing with government people, they do not listen to people with disabilities!! I was disappointed that it did not really change things and was not accessible. (I did stay at a fancy hotel though!)

Some of us have been involved in a lot of research. I think because of us some of the research has been conducted differently because we taught other researchers how to conduct it better. We can do that because we are part of the research, and we are the history of people with intellectual disabilities. We have been here since the 1980s, and we know more about our history than other people.

Conducting research, we have all learned things we never knew.

5. Inclusive Research: Where to from Here

Our reflections are a starting point for thinking about where inclusive research might go from here. We consider some themes which came out of our work together, and what the future might hold.

5.1. Learning

All six reflections in this paper show how inclusive research has helped to develop our learning. Amanda and Janice talk of the confidence gained from conducting research and the skills of working with others either as a member of a team or in sharing difficult experiences. Shaun is aware of his own skills in undertaking research but also expressed the need to learn how to conduct interviews with others, something he has not done before. Danielle has learned about issues which are important to people with learning/intellectual disabilities and recognises a need for training to conduct interviews. Jan and Kelley celebrate the long and continuing learning curve they have experienced in conducting inclusive research.

Everyone agrees that learning while doing is important because it supports us to gain confidence, to identify the important issues, apply skills in new contexts and gain new knowledge. But we also recognise that people need opportunities to develop their skills and knowledge further. There have been some opportunities for some activist researchers to learn skills to help them conduct inclusive research, including at Iceland's University of Reykjavik, University of Sydney Australia, the Open University in the UK and Trinity College Ireland (High and Robinson 2021; Rillotta et al. 2020; Stefánsdóttir and Björnsdóttir 2015). But our reflections suggest there needs to be more. New opportunities should include courses which allow activist and academic researchers to learn about inclusive research together and opportunities to learn about the big ideas—such as normalisation and the social model of disability—which have shaped the way disability is viewed.

5.2. *Breaking Down the Barriers*

All the authors of this paper have been involved in advocacy in relation to people with intellectual/learning disabilities. Some have been long-term members of self-advocacy organisations, others had been more recently involved as employees or as members of management committees. All had undertaken research about histories of self-advocacy organisations or issues relating to their work. Everyone saw it as important to use research to work for social change or to support people with disabilities to live good lives. Unfortunately, it is still the case that much research relating to issues which are important to people with disabilities remains inaccessible to them, in academic journals behind a pay-wall. We applaud the initiative of *The British Journal of Learning Disabilities* for In Response, a forum for people with learning disabilities to critique articles submitted for publication. This journal is considering more active roles for self-advocates, in co-producing papers, refereeing articles and becoming involved in journal management. These are ideas that could be taken up by other academic publications.

More could be done. Self-advocacy organisations know many of the issues affecting people with disabilities. University research centres could include their members as paid representatives on advisory groups. This would enable more funded research to be undertaken which reflects their needs and aspirations. We also believe it is important to have academic researchers available to self-advocacy organisations if they see a need for research to be conducted and to offer advice on funding, methods and practical support.

5.3. *Communicating and Social Change*

The importance of finding ways to communicate about research was emphasised by all six authors. Our joint meeting on Zoom revealed anger from all the activist researchers about the use of 'jargon' in research. Amanda and Janice wrote about this in their contributions. There is increasing diversity in ways to share research. Academic books and articles about inclusive research were cited by Kelley and Jan, but these were not accessible easily to people with learning/intellectual disabilities. More accessible ways to communicate were mentioned by the authors of this paper. The founding and development of a community radio programme for people with disabilities, which included references to research and its findings, had involved Janice and Amanda. Danielle, amongst others, has pioneered the use of photographs, videos and social media to both undertake research and share its findings, which was seen as important for people with intellectual/learning disabilities. In our view, these different forms of communication should be considered as a matter of course by academic researchers undertaking inclusive research. BJLD's encouragement to authors to add a video abstract to published papers is a small step in this direction. Thinking about the forms of communication that best suit the people who will be involved in the research and those who will be interested in it needs to be considered at the beginning of the research and planned for to make sure as many people as possible can benefit.

6. Conclusions

Like other inclusive research projects, the writing of this paper has been an interesting, if at times, difficult journey. Our meetings in either the UK or Australia led to a sharing of experiences at a personal level but also in terms of how important inclusive research is in changing attitudes and policies. Frustration at not being heard was there for all of us whether this was in national consultations or in workplaces. For all of us, there were shared experiences of excitement and a sense of being involved in work that was important and that could lead to change in all our lives.

If readers of this paper would like to pursue the themes we have aired, we leave you with two important questions:

What would it mean to be working as an inclusive researcher from your perspective?

How can inclusive research be used to have an impact on the lives of people with intellectual/learning disabilities?

There is plenty to be done.

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Notes

1. Normalisation and social role valorisation are ideas that were around in the late twentieth century. People who believe in it say that we can change things by giving people with learning disabilities ‘valued social roles’ such as being a researcher and having friends who are not disabled.
2. The social model of disability is the idea that people are not disabled by their impairment but by the way society is organised. If everyone was deaf, deaf people would not have a hard time. So the answer is ‘change society’.
3. <https://www.open.edu/openlearn/health-sports-psychology/exploring-learning-disabilities-supporting-belonging/> (accessed on 20 May 2022).
4. Valuing People was a policy launched in England and Wales in 2001, promising better lives.

References

- Armstrong, A., A. Collis, and J. Walmsley. 2022. The Messy Realities of inclusive Research. In *Handbook of Social Inclusion*. Edited by Pranee Liamputtong. Cham: Springer.
- Armstrong, A., A. Mal Cansdale, A. Collis, B. Collis, S. Simon Rice, and J. Jan Walmsley. 2019. What Makes a Good Self Advocacy Project: The Added Value of Co-Production. *Disability and Society* 34: 1289–311. <https://doi.org/10.1080/09687599.2019.1613960>.
- Blackley, Joe, Dawn Gullis, Becky Haines, Phil James, Joanna Jones, Zarah Kaleem, Katie Lee, Anthony Mitchell, Jeff Morgan, Janice Partridge, and et al. 2021. Response to Birdsey (2020) “I don’t wanna be mad and sad”: Using individual systemic therapy to help manage anger and low mood in an adult with a learning disability. *British Journal of Learning Disabilities* 49: 191–94. <https://doi.org/10.1111/bld.12384>. (Example of In Response)
- Chalachanová, Anna, Melanie Nind, Andy Power, Elizabeth Tilley, Jan Walmsley, Britt-Evy Westergård, May Ostby, Torill Heia, Alf Magne Gerhardsen, Ole Magnus Oterhals, and et al. 2020. Building Relationships in Inclusive Research in Diverse Contexts. *Scandinavian Journal of Disability Research* 22: 147–57.
- Emerson, Eric, S. Malam, I. Davies, and K. Spencer. 2005. *Adults with Learning Difficulties in England 2003/4*. Leeds Health and Social Care Information Centre.
- Frankena, Tessa K., Jenneken Naaldenberg, M. Cardol, Edurne Garcia Iriarte, Tobias Buchner, Katie Brooker, P. Embregts, E. Joosa, Felicity Crowther, A. Fudge Schormans, and et al. 2018. A consensus statement on how to conduct inclusive health research. *Journal of Intellectual Disability Research* 63: 1–11. <https://doi.org/10.1111/jir.12486>.
- Frawley, Patsie, and Amie O’Shea. 2018. Sexual lives and respectful relationships: A rights based approach. *Intellectual Disability Australasia* 39: 22–24.
- Frawley, Patsie, and Christine Bigby. 2014. I’m in their shoes: Experiences of peer educators in sexuality and relationship education. *Journal of Intellectual and Developmental Disability* 39: 167–76.
- High, Rachel, and Sally Robinson. 2021. Graduating University as a Woman with Down Syndrome: Reflecting on My Education. *Social Sciences* 10: 444. <https://doi.org/10.3390/socsci10110444>.
- Hogan, B., G. Minogue, J. Hartney, J. McGrath, K. Johnson, P. Luque, and R. Collins. 2007. *Brian and Joe’s Coffee Shop*. Ennis County Clare: Brothers of Charity.
- Johnson, Kelley. 2009. No longer researching about us without us: A researcher’s reflection on rights and inclusive research in Ireland. *British Journal of Learning Disabilities* 37: 50–56.
- Johnson, Kelley, Gerard Minogue, and Rob Hopklins. 2014. Inclusive research: Making a difference to policy and legislation. *Journal of Applied Research in Intellectual Disability* 27: 76–84.
- Johnson, Kelley, Patsie Frawley, Lynne Hillier, and Lyn Harrison. 2000. Living safer sexual lives. From research to practice. *Intellectual Disability* 21: 25–28.

- Johnson, Kelley, Rob Hopkins, and Gerard Minogue. 2020. Research, advocacy and activism. A necessary interaction? In *Global Perspectives on Disability Activism and Advocacy. Our Way*. Edited by Karen Soldatic and Kelley Johnson. Abingdon: Routledge, pp. 114–25.
- Minogue, G., J. Rynne, K. Johnson, L. Cooney, P. Luque, and P. Kearney. 2007. *The Garden Story*. Ennis County Clare: The Brothers of Charity.
- Oliver, Michael. 1990. *The Politics of Disablement*. London: MacMillan.
- Rillotta, Fiona, Jillian Arthur, Claire Hutchinson, and Parimala Raghavendra. 2020. Inclusive university experience in Australia: Perspectives of students with intellectual disability and their mentors. *Journal of Intellectual Disabilities* 24: 102–17.
- Stefánsdóttir, Gudrun, and Kristin Björnsdóttir. 2015. 'I am a college student' postsecondary education for students with intellectual disabilities. *Scandinavian Journal of Disability Research* 18: 328–42.
- Tilley, Liz, Hiromi Moriguchi, Ian Davies, Liz Ellis, Sara Ryan, Jan Sunman, Jan Walmsley, Marin Fujino, Chie Kasahara, Azusa Omori, and et al. 2020. UK Japan Report on Learning Disability and Belonging. Available online: <https://www.open.ac.uk/health-and-social-care/research/shld/sites/www.open.ac.uk/health-and-social-care-research/shld/files/files/UK%20Japan%20report%20on%20learning%20disability%20and%20belonging.pdf> (accessed on 18 July 2022).
- Tilley, Liz, Lorna Rouse, Jan Walmsley, and Shaun Picken. 2021. Filling the Gap. Available online: <https://www.open.ac.uk/health-and-social-care/research/shld/node/371> (accessed on 17 July 2022).
- Tilley, Liz, Lorna Rouse, Jan Walmsley, and Shaun Picken. 2022. Funding the Gap. Available online: <https://www.open.ac.uk/health-and-social-care/research/shld/node/371> (accessed on 17 July 2022).
- Walmsley, Jan. 2001. Normalisation, Emancipatory Research and Intellectual Disability. *Disability and Society* 16: 187–205.
- Walmsley, Jan, and K. Johnson. 2003. *Inclusive Research with People with Intellectual Disabilities: Past, Present and Futures*. London: Jessica Kingsley Publishers.
- Walmsley, Jan, Ian Davies, and Danielle Garratt. 2022. 50 Years of Speaking Up in England: Towards an important history. *British Journal of Learning Disabilities* 50: 208–19.
- Walmsley, Jan, Iva Strnadová, and Kelley Johnson. 2017. The added value of inclusive research. *JARID* 31: 751759.