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## Diverse faces of inclusive research: reflecting on three research studies

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Inclusive research has become an increasing focus of research with people with disabilities, particularly people with intellectual disabilities. In this paper the authors argue that this generalized term covers a range of different approaches to including people with intellectual disabilities in research. Based on three case studies in which the authors were academic researchers the paper explores different approaches to inclusive research, raises questions about the place of inclusive research in relation to advocacy and academic research and explores some of the benefits and challenges of inclusive research with people with learning disabilities.

**Keywords:** intellectual disabilities; inclusive research; advocacy

### Introduction

The motto of the self-advocacy movement, ‘Nothing about us without us’, has been reflected not only in the areas of social inclusion and self-advocacy, but also in the field of disability research. This is demonstrated in the literature by the extensive use of inclusive research approaches, where issues of concern to people with intellectual disabilities<sup>1</sup> are the topic of research and where they are members of teams conducting the research. ‘Inclusive research’, a term coined by Walmsley (2001), encapsulates both participatory research, where people with disabilities work in partnership with academic researchers, and emancipatory research, where the aspiration is for people with disabilities to lead and control the research, changing the relationships of research production (Oliver 1992). While emancipatory research is seen to be the ideal by many people with disabilities, participatory research has been more extensively used with people with intellectual disabilities.

An increasing number of papers reflecting the experience of participatory research teams have been published during the last two decades (Bigby and Frawley 2010; Gilbert 2004; Johnson 2009; Walmsley 2004; Williams, Simons, and Swindon People First Research Team 2005).

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The research reported in this paper has been written with people with intellectual disabilities in separate publications. In this paper we seek to understand better inclusive research from an academic researcher’s position.

Whether or not the research is emancipatory or participatory the tenets of inclusive research demand a shift in power from academic researchers without disability to people with intellectual disabilities. The degree to which this happens varies with the particular study. Indeed Bigby, Frawley, and Ramcharan (2014) propose that inclusive research sits on a spectrum, from an advisory function to working alongside academic researchers (participatory research in Oliver's terms) to initiation and control of a project (emancipatory).

There are a number of questions that arise for academic researchers involved in or committed to inclusive research. These include a tension between research that is academically rigorous and that which is relevant to the people who are subject to it, which is relevant to their needs and can inform and promote needed social change (Walmsley and Johnson 2003, 9). There are also tensions between the degree of emphasis in the research given to its process (the degree to which it focuses on people learning skills and taking power) and the outcomes of the research. Conducting research with people who are not trained researchers and who have intellectual disabilities also raises challenges about methodology in the research.

This article analyses three research projects conducted by teams consisting of academic researchers and researchers with intellectual disabilities in the UK, Ireland and Australia. The authors have chosen to focus on three studies because while much has been written about inclusive research there is little which demonstrates both the diversity of models used in this kind of research and the challenges and benefits experienced in each. Thus the authors aim to raise questions and to explore some of the issues, which have either inspired or challenged them as academic researchers, working with people in inclusive research.

The authors use the definition of inclusive research by Walmsley and Johnson (2003, 9): 'research in which people with learning disabilities<sup>2</sup> are active participants, not only as subjects but also as initiators, doers, writers and disseminators of research', as a basis for their reflection on the three studies conducted. They will also reflect on the principles of inclusive research outlined by Walmsley and Johnson (2003, 16), which are that research:

- (1) 'must address issues which really matter to people with learning disabilities, and which ultimately leads to improved lives for them,
- (2) must access and represent their views and experiences,
- (3) along with the research community, must treat people with learning disabilities with respect'.

The three research studies discussed in this article were designed and conducted independently, and they aimed to answer different research questions. Based on their experiences, the authors went back to data gathered within these three research teams, to reflect on the definition and principles of inclusive research in the light of their experiences. It needs to be noted that the reflections about the research studies presented in this article represent the perspectives of the authors and not all of the members of the three research teams.

### **Study 1: well-being of ageing women with intellectual disabilities**

Strnadová et al. ('Building an Inclusive Research Team,' 2014; 'And Older Women with Disabilities,' 2014) conducted an inclusive study that examined the well-being of ageing women with intellectual disabilities in Australia. For the purpose of the study, the term 'well-being' was used consistently with Walsh & LeRoy's definition, according to which well-being 'connotes the distinctive and irrefutable sense of how well a person feels about

how she fares and whether she believes that her interests are served' (2004, 102). The research team consisted of eight researchers – four academic researchers and four older women with intellectual disabilities. Over the course of two years, the research team undertook research training over a period of 15 weeks, followed by conducting the research study itself, in which 15 women with intellectual disabilities aged 53–71 years were interviewed. The academic researchers initiated this research study. It could be argued that the need to conduct a research study on this topic came, to some extent, from these women themselves. The first author conducted an earlier study focusing on subjective well-being of older women with intellectual disabilities in two countries (Strnadová 2009; Strnadová and Evans 2012), and based the study presented in this article on the results of the previous study. Although Study 1 is grounded in the experiences and concerns of 55 older women with intellectual disabilities, it was not a direct initiative of women with intellectual disabilities.

One of the recruitment criteria for both the researchers with intellectual disabilities and the participants was that they had a mild to moderate level of intellectual disabilities and possessed the ability to communicate well verbally. The research team obtained informed consent from all of the participating women, who received pictorial consent forms in plain English. The consent forms were also verbally explained to each of them.

The researchers with intellectual disabilities were 'doers' in this research in the sense of being instrumental in the development of the interview protocol. Several of the interview questions they suggested (such as questions about case managers, volunteering, frequency of change in carers) would not have occurred to the academic researchers, as they did not have the lived experience of people with this disability. The researchers with intellectual disabilities also had an important role in participant recruitment, as their networks were utilized to access some of the respondents. Lastly, the interviews were conducted in dyads of one academic researcher and one researcher with intellectual disabilities.

There were, however, a number of instances where the researchers with intellectual disabilities were less involved, especially during the data analysis stage. The whole team met several times during the open coding of the interviews, and while the researchers with intellectual disabilities made several enriching comments; they tended to compare the data to their own life experiences without proceeding to generalizations. Thus the academic researchers conducted the formal data analysis and the results were discussed within the whole team, with the assistance of diagrams. While the authors acknowledge that different methods could have been used to make these phases more attractive for the researchers, the decision of the three researchers with intellectual disabilities not to be involved in data analysis was viewed as self-determined behaviour, as they decided which parts of the research study they wished to be involved in and in what way.

The researchers with intellectual disabilities in this study were not 'writers' of research in the academic sense of the word. This was not due to the research team's lack of effort, but rather to the level of support the researchers needed. Although three of them possessed the ability to read and write, the physical changes associated with ageing, such as arthritis and hand tremors, prevented them from taking notes. While three of the researchers did not demonstrate an interest in the writing part of the project, and chose not to engage with the team during this phase, one researcher chose to be involved by reading a draft of the article and providing feedback.

The researchers with intellectual disabilities in this study were 'disseminators' of the results, but on individual levels. Three discussed their participation in the research meetings with their friends, assistants and family members, but omitted the research

results. Although three of the researchers with intellectual disabilities lacked the funding for support and travel to conferences, one had the opportunity to attend a conference, as she was funded through another project. She chose her topic and wrote her part of the presentation for this project.

## **Study 2: inclusive research within self-advocacy organisations**

*Central England People First* (CEPF) is a self-advocacy organization based in Northamptonshire, England. In 2010 it won Heritage Lottery Fund money to record its history since its foundation in 1990. A team was set up consisting of five members of CEPF, with a dedicated project worker selected after an open recruitment exercise. Three CEPF members, with one person without disability, conducted the job interview. The research team was augmented by an Advisory Group, which met every three months, and comprised three academics who had supported CEPF in different ways for the previous 10 years. This study was written by one of those academics who was able to observe the project from inception to launch.

People with intellectual disabilities initiated this project, with practical assistance and advice from support workers and academic friends of the organization to obtain the funding. At its outset, the project met all of the criteria of inclusive research as enunciated by Walmsley and Johnson (2003). Unusually for a research project, the resource was held by the self-advocacy organization – which gave CEPF members considerably more leverage than if a university had held it.

The project involved setting up an accessible website; sorting and scanning documents, photos and video footage, interviewing people who had been involved with CEPF over the years, in one to one or group ‘memory lane’ sessions. CEPF members learnt about archiving, interviewing, scanning and website design. The work was disseminated via the website, a video, a booklet and an exhibition.

This was the first fully documented history of a self-advocacy organization in England providing a resource for historians. Although people with intellectual disabilities initiated this research study, they were not always the ‘doers’ in the sense of data collection. One example is the role of interviewing former members. The research team had anticipated that CEPF members would undertake all interviews, but it eventually became clear that some people had left because of interpersonal issues, and were unwilling to be interviewed by former colleagues. An independent researcher without disabilities had to be paid to do these interviews. Few organizational histories are easy to write, as they can stir up old wounds and enmities, and calling a project ‘inclusive’ is unlikely to change that (Davies and Beach 2000).

As in other organizational histories (Atkinson and Walmsley 2010) the process of research brought up an important question: ‘Whose voice counts?’ A former support worker challenged the historical account constructed by CEPF members, arguing that some key events had been omitted or downplayed. The CEPF history team reflected on this and recorded their views: ‘For us it was more important to record in the booklet the things members remember. It was hard to think of anything we didn’t remember as being important’ (Walmsley and CEPF 2014, 40).

The process of data analysis and writing up the research results brought to light other issues: some parts of the history were difficult as they involved disagreements and sometimes, bullying behaviour. The team decided they could not record this, as if people were still around, it would be hurtful. It was left out. ‘If we dug into this we really would be history because we would not be able to carry on’ (Walmsley and CEPF 2014, 41).

Thus from this perspective this is a partial history, as the history is reported through the accounts of past and present members, and therefore events were included subject to the memories of individuals and the importance each ascribed to them. The views of other stakeholders, such as former staff, were accorded less weight. And sensitive issues were omitted if they were likely to rock the boat.

Compromises were also made around the fifth principle of inclusive research, that all outputs should be accessible. The CEPF team wanted to extend the audience for their work to commissioners of services and academics. In order to achieve this, they recruited an academic to write the history of self-advocacy. The resulting booklet was not fully accessible, but it is important to note that this was a decision made by people with intellectual disabilities, as project leaders, after extensive discussion.

The research had practical benefits for the organization in prompting members to consider their future by highlighting how weak and ineffective it had become since its heyday. Once the history project was complete, CEPF commissioned some research of its own, to find out how its *modus operandi* compared to other UK self-advocacy groups. Ian Davies, former chair, and Walmsley, independent researcher, visited and interviewed eight other self-advocacy groups to find out how they were managing issues which CEPF struggle with, such as how much of the day-to-day work should be delegated to paid support. CEPF agreed on the questions and which groups should be included. Based on their research, the researchers wrote a report, with choices for CEPF's management team to make. This enabled CEPF to determine how it wanted to move forward into the future (CEPF and Walmsley 2012).

### **Study 3: 'it will break me old heart if the garden goes'**

This comment, from one of the people using the Brothers of Charity Services in County Clare, Ireland, was the beginning of an oral history project documenting the work of people with intellectual disabilities in creating a garden at a workshop in Ennis. Patrick Kearney's comment was made to a group of people with intellectual disabilities who were deciding what they wanted to research as part of a national project called, 'No longer researching about us without us'. The comment, which was prompted by a decision to close the workshop, caused an immediate reaction among other members of the group who had worked in the garden. The group was concerned that with the workshop closure the garden they had created would be lost and forgotten. A decision was made by the group to tell the garden's story through the voices of those who worked there. It therefore met the first criterion for inclusive research in that it arose directly from the concerns of people with intellectual disabilities (Walmsley and Johnson 2003). The research was carried out by those who were interested in telling the story of the garden, particularly two men who had worked there consistently and one who was interested in doing research but had less interest in the garden itself.

Given that none of the researchers with intellectual disabilities had very much experience in undertaking research, and because the study involved exploring the garden (past and present) the group decided to use photographs to document the discussions both within the group and outside it (Emmison, Smith, and Mayall 2012). One person in the group was keenly interested in photography, the others in the group learned how to use a digital camera as preparation. Johnson prepared some training materials, which included working with the group to find out what they wanted to know from workers in the garden, ethics of using a camera in research and how to talk with others in the garden

about their experiences. Support staff at the service worked with the researchers with intellectual disabilities to develop their skills in these areas.

As noted by previous authors using photographs to generate discussion proved a useful method (Clark-Ibanez 2007). They enabled the researchers to select those parts of the garden about which they felt strongly and acted as a stimulus during fieldwork and during discussion by the group. The images chosen by the researchers were often quite different to those that might have been taken by someone unfamiliar with the garden and the workers.

The interviews were undertaken on a day visit to the garden. The researchers walked together and took photographs of places that were important to them in the garden and shared stories about them. They interviewed managers and people who were working in the garden about why people liked it and what it meant to them. This part of the research met the criteria for inclusive research in that people with intellectual disabilities were involved in undertaking the research (Walmsley and Johnson 2003).

The recordings from the interviews were transcribed by one of the support workers. Two of the people involved in doing the interviews were not interested in developing a written account of the garden story, so Johnson, one researcher with intellectual disabilities and a support worker wrote the account using only the words of participants. The photographs with subtitles were used with recorded accounts from participants in a book, making it more accessible to those who found reading difficult. One researcher with intellectual disabilities was responsible for the photographs, captioning, and approved a verbal reading of the different sections. The support worker searched for historical records then discussed these with the rest of the team. The service management published the book. Senior managers in the service were given copies of the book. While no promise was made to keep the garden, one of the managers commented 'The garden at Gort Rd will be maintained while people still choose to come and work there' (Minogue et al. 2007, 32). Six years later the garden is still maintained.

The story of the garden gave a voice to people who felt passionate about something beautiful which they had created and provided a means of advocating for its survival. The project also met most of the criteria of inclusive research. However being that it was a developmental project, none of the researchers with intellectual disabilities had undertaken research before and this was a learning experience.

## **Discussion**

There are a number of questions about inclusive research with people with intellectual disabilities that have been raised by these three research studies.

### ***Should the definition of inclusive research posed by Walmsley and Johnson be more 'flexible' and reflect different levels of involvement of people with intellectual disabilities research?***

To answer this, one must first determine if the current studies were inclusive as defined by Walmsley and Johnson (2003, 9). If people with intellectual disabilities initiate and control the project – as was the case of Study 2 – are they entitled to depart from the principles as set out by Walmsley and Johnson, and does this compromise its status as inclusive research? The authors would suggest that it does not, and that the key issue here is power over resources and decisions, rather than the minutiae of how the research is conducted. In Study 1, although the researchers with intellectual disabilities did not

initiate the study, nor did they fully participate in the activities of every phase of research, they fully participated in the phases that they were interested in participating in. They had a crucial consultation role, particularly in the areas of creating an interview protocol and recruiting participants. They also co-interviewed the participants. However the academic researchers conducted the data analysis and most of the dissemination. The authors believe that the decision of the three researchers with intellectual disabilities to not be involved in data analysis was an example of their self-determined behaviour, in which they decided which parts of the research study they wished to be involved and in what way.

As obvious from the three studies, there are ‘different faces’ of inclusive research, with diverse methodologies and levels of involvement of people with intellectual disabilities in the capacity of researchers. The level of involvement of researchers with disabilities reported in the literature spans from consultative roles to active research roles. In their conceptualization of inclusive research with people with intellectual disabilities, Bigby, Frawley, and Ramcharan (2014) distinguish three approaches, where people with intellectual disabilities are: ‘(i) advisors to researchers, governments and organizations about research agendas, conduct or dissemination of research (...); (ii) leaders or controllers of research (...) and (iii) collaborators in specific studies with researchers without intellectual disability’ (4). From this perspective, it would be indeed difficult to categorize the three presented inclusive research studies. If we perceive Bigby et al.’s suggested three approaches to the role of people with intellectual disabilities in inclusive research on a spectrum, then in Study 1 they had ‘advisors’ roles’ and ‘collaborators’ roles’; in Study 2, the role of leaders or controllers of the research; and in Study 3 ‘collaborators’ role’.

It would also seem that the level of involvement of researchers with intellectual disabilities is influenced by the level of their support needs. This seems to be a non-addressed ‘elephant in the room’ in inclusive research. While some research has involved academic researchers and funded support workers (Williams et al. 2010), it is not always possible to get funding for this. Study 2 was unusual in being well enough resourced for CEPF to employ a dedicated project worker, whose role encompassed both practical support to the researchers and expertise in oral history projects.

***Are some types of research (such as oral histories) more appropriate for inclusive research than others (such as quantitative research or grounded theory)?***

A number of inclusive research studies (Atkinson and Walmsley 2010; Bentley et al. 2011; Bjornsdottir and Svendsdottir 2008; Dias et al. 2012; Hreinsdottir and Stefansdottir 2010; Manning 2010) used an oral history research approach, which was also the case in Studies 2 and 3. Other research approaches used successfully in inclusive and participatory research are conversation analysis (Williams et al. 2010) or photovoice (Jurkowski and Ferguson 2008). Unlike Studies 2 and 3, Study 1 used the grounded theory approach. Both the oral history and grounded theory approaches use similar techniques, such as interviews, group interviews, etc., however methods of analysis such as those used in the grounded theory approach seem to be less accessible for researchers with intellectual disabilities, as it can involve years of academic training and experience before a researcher is proficient in understanding and using them. Perhaps it is a matter of self-determination, personal preference or lack of knowledge?

A related question posed by Study 2 is how appropriate is inclusive research as a way of recording an organization’s history? The conclusion of Walmsley, as an academic who

was closely involved through the Project Advisory Group, is that in this project inclusive research was able to answer the question ‘what happened’, but was less useful when seeking to answer ‘why’ questions – why CEPF flourished in the 1990s, only to struggle in the 2000s, for example. To achieve this, it would have been necessary to involve an academic historian who could bring an understanding of the wider context, and some objectivity and distance to the project.

***Do certain topics lend themselves more to inclusive research and others to advocacy?***

According to the first principle of inclusive research (Walmsley and Johnson 2003, 16), this type of research ‘must address issues which really matter to people with learning disabilities, and which ultimately leads to improved lives for them’. In Study 1 it was the well-being of ageing women with intellectual disabilities, in Study 2 it was a self-advocacy history important to people with intellectual disabilities and in Study 3 it was a garden loved by people with intellectual disabilities, along with providing opportunities for their employment. In Studies 2 and 3, the inclusive research resulted in very concrete changes (i.e., in Study 2 an impetus to review the organization’s governance, in Study 3 a positive response from the service).

This brings up the topic of motivation for research. None of the participants in the studies mentioned above were motivated to disseminate the results of the data they had gathered in a traditional academic manner, their purpose for the research was mostly to have their voices heard about issues that were important to them. This may fit Van Reusen’s (1996, 50) definition of advocacy ‘an individual’s ability to effectively communicate, convey, negotiate or assert his or her own interests, desires, needs, and rights. It involves making informed decisions and taking responsibility for those decisions’ even more than it fits the definition of inclusive research. Perhaps it is both? Based on the studies presented in this article, the authors believe that some inclusive research gives a positive grounding for advocacy.

How inclusive research is used to bring about change is a problematic issue, advocacy is not always the underlying motivation for people wanting to do research, and it is important that all team members agree upon the purpose of the research. If advocacy is the aim of the research from the beginning then it may influence the way the research is done or its results. If we are serious about people with intellectual disabilities being involved in research that is relevant to them then we need to embrace the principle that research should be oriented to practical positive outcomes.

***Do researchers with intellectual disabilities need training in research and research methodology?***

While some researchers believe that having the lived experience of being a person with intellectual disabilities is enough to be a researcher, others (Johnson 2009) do acknowledge that lived experience in itself is not enough to qualify a person to be a researcher. Furthermore Bigby, Frawley, and Ramcharan (2014) highlight a danger of recruiting participants just on the basis of having intellectual disabilities and ‘assuming there is an intellectual disability perspective’ (6). The authors believe that having a lived experience is an important, but not sufficient qualification to become a researcher on its own. People with intellectual disabilities share their lived experience both by joining self-advocacy groups and by having a voice when participating in research studies. To become a researcher, knowledge of research methodology and research processes is

essential. Research training was an important part of Studies 1 and 3, but featured less prominently in Study 2, where overt project aim was to enable CEPF members to acquire new skills.

An additional point that can be made here is whether generic research training should be used or whether it should be project specific. Are we teaching researchers with intellectual disabilities to be researchers or to research a specific topic/area that is important to them? This is a crucial question if people with intellectual disabilities are to work as equal partners in a range of research projects. We would argue that Studies 2 and 3 provided researchers with some general research skills that can be used in future projects, should they choose to pursue further research.

It is important to recognize that not everyone wants to be a researcher. Of the people involved in Studies 1 and 3, only one researcher with intellectual disabilities from each project went on to do further research. The other researchers with intellectual disabilities may have enjoyed the experience, but did not want to continue to do other research at the conclusion of their respective projects. It is important for academic researchers to avoid making a paternalistic judgement that all people with intellectual disabilities are interested in doing research, and suggests that more rigorous selection criteria than have hitherto been deployed would be valuable if an aim is to develop a cadre of research ready people with intellectual disabilities.

### ***Are some of the challenges faced by researchers with intellectual disabilities embedded in academia itself?***

Some of the challenges of inclusive research are systemic – that is they involve a lack of understanding by traditional academic funding sources, ethics committees and journals. Organizations that provide research funding may have difficulty understanding the concept of inclusive research and viewing the researchers with intellectual disabilities as researchers that deserve payment for the work they perform, rather than simply participants, who merit only a token of appreciation for participating. In two of the studies presented here, the issue of payment to researchers with intellectual disabilities was an important one. While in Study 3 the researchers with intellectual disabilities did not receive any payment, in Study 1 they received a few gift vouchers throughout the study as a thank you for their participation, which is not sufficient payment for the amount of time and energy that they spent on the project. In Study 2, payment was less of an issue, the funding bid was premised upon enabling volunteers, the members of CEPF, to participate and gain new skills. Indeed, offering payment would have compromised members' welfare benefits, and given it was time limited, the decision was made at an early stage not to seek funding for their participation. Although compromises were made over some principles of inclusive research, power (and control of the money) remained in the hands of the CEPF research team, who made all key decisions.

While funding organizations are now much more committed to the importance of participation by those 'subject to research' there remains a view that 'doing research' is a way of providing an activity for people with intellectual disabilities rather than it being seen as real work.

University and organization ethics committees sometimes have difficulty understanding that individuals belonging to what they class as a 'vulnerable population' can also take the role of researcher. They may require university researchers to list their co-researchers as participants. They also may not approve appropriate remuneration for the researchers with intellectual disabilities, as was the experience of the research team in

the Study 1. There are real dilemmas when researchers with intellectual disabilities are asked to sign consent forms to participate in the research. Academic researchers need to educate ethics committees about this in order to ensure that researchers with intellectual disabilities are treated equally with other researchers, including being paid for their part in conducting the research. Studies 2 and 3 escaped these strictures, as they originated outside academia – but this perhaps compromises their status as research.

There are occasions where academic journals do not understand the need to publish a plain English summary of the findings of inclusive research projects. The timelines and deadlines involved in academic writing can also prove to be a challenge for inclusive research teams, due to the amount of time spent on training and support. There is also then the issue of authorship – if the researchers with intellectual disabilities do not actually write any of the submitted manuscript, do they merit a byline as authors for their efforts on the project that is being reported? Is it tokenism or well-deserved credit? There are examples in the inclusive research literature of both byline's (Deguara et al. 2012; White and Morgan 2012) and credit given as more of an acknowledgement or showing of gratitude (Bell and Mortimer 2013).

It can be argued that while having an intellectual disability can be somewhat limiting for a researcher, the more disabling issue is the way research is traditionally presented. As Walmsley and Johnson (2003) rightly point out 'If, as is the case, most people with learning disabilities cannot read, then imagination is needed to ensure that research findings are open to them' (172). This would account for the popularity of methodologies such as participatory photography and oral history in inclusive research projects (Aldridge 2007). Study 3 provided an example of how inclusive research could be used by a service to explore how people with intellectual disabilities saw their work and the service itself. This was not without its challenges, given the difficulties the group had in relating to the written results, it may have been far more accessible to use film to provide an accessible report. It is doubtful that many of the people involved in either the service or the research were either motivated or able to read the resulting book, although the photographs were discussed in the group and individuals were very proud of the book.

### ***How does inclusive research fit in with academic rigour?***

While Study 1 took a more traditional approach to the research design, data analysis and dissemination, this tact may have contributed to less participation by the researchers with intellectual disabilities. Study 3, on the other hand, was a small research project, and in terms of academic rigour it could be criticized on a number of counts. There was no sampling of the interviewees. People varied in their interviewing skills and involvement in the later stages of the project. A stronger historical account of the garden could have been developed had archival documents been used. Although small in scale, the research raised a much larger issue about the value of the work of people with intellectual disabilities (which is often unpaid), especially in times of change.

### **Conclusions**

The authors reflected on three inclusive research studies, in which people with intellectual disabilities in the capacity of researchers were involved in different ways. This reflection raised a number of questions about inclusive research that need to be considered. Answering these will require honesty and the courage to recognize the issues for what they are and address them. While inclusive research is one way to acknowledge the rights

of people with intellectual disabilities and promote social inclusion, the temptation for tokenism in the name of ‘inclusivity’ and ‘political correctness’ cannot be ignored.

Despite the unanswered questions and challenges, most that have been involved in conducting inclusive research would agree that in addition to being ‘the right thing to do,’ it is beneficial to all members of the team. There is ample evidence that people who have become involved in inclusive research as active participants experience considerable benefits. This is consonant with the principles of action research (Freire 1996), and has been widely reported in INVOLVE’s overviews of public involvement in research such as those by Slaley (2009) and Faulkner (2010). Such benefits are consistently featured in inclusive research publications. The benefits include increased skills and confidence, a sense of making a difference, social benefits and important learning. Williams, Simons, and Swindon People First Research Team (2005), however, argue that perceived benefits need to go beyond this, to awareness of the significance of having a role as a self-advocate researcher; this appears to have proved more elusive.

The research studies presented here show that there are positives in people with intellectual disabilities being involved in research, both for them and for the research studies. Researchers with intellectual disabilities in the three research studies presented played several roles from initiators of research to doers and disseminators. Academic researchers need to consider some of the issues addressed in this article, such as striking a balance between meeting all of the criteria of inclusive research and complying with academic rigour. The research methodology should be accessible, and researchers with intellectual disabilities should be provided with all necessary supports to allow full participation. It is also crucial to see inclusive research as developmental in nature, so that people are not expected to be researchers all at once.

Challenges to inclusive research also remain – academia is rife with inherent barriers to inclusive research, such as difficult timelines, funding requirements, ethics committee misunderstandings in regard to inclusive research and publication policies. Study 2 shows how different things are when the co-researchers hold the budget. There is still a way to go in regard to effecting the systemic changes that will make inclusive research fully inclusive. There is good evidence that people with intellectual disabilities can and do make a valuable contribution to research, so it is crucial that the necessary supports are in place, academic requirements are acknowledged and all involved work as a team, in order to develop each researcher’s particular interests and skills.

## Notes

1. Different terms and definitions relate to people with cognitive impairments, including intellectual disabilities, learning disabilities and learning difficulties. The three inclusive research studies presented in this article were conducted in different countries – Australia, Ireland and UK – in which different terminology is used. People with this disability themselves use the term intellectual disability in Ireland and in Australia, while in the UK the preferred terms used by people with intellectual disabilities are people with learning difficulties or learning disabilities. Given the cross-cultural nature of this manuscript, the authors decided to use the term people with intellectual disabilities. However we remain troubled by the differences in terminology.
2. The terms ‘learning disabilities’ and ‘intellectual disabilities’ are interchangeable.

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