Reflections on doing inclusive research in the "Making Life Good in the Community" study

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Abstract

Background   The involvement of people with intellectual disability in research is framed as inclusive, denoting their active participation in its processes. However, questions are raised about ownership and control, genuineness of involvement, and the need for honest accounts to develop practice. Such issues are particularly pressing in Australia, where there is the absence of a strong self-advocacy movement to partner with academics or hold them to account.
Method   Action research was used to reflect on and progressively refine the support provided by a research mentor to a co-researcher with intellectual disability employed on a large multimethod study.
Results and Conclusions   Accepting the co-researcher's strengths and designing support on the job rather than teaching them to "pass" before venturing out in the field are important in ceding control. Support required for a co-researcher is more than practical and involves developing a relationship that can actively challenge views and foster reflection. Ownership of questions and disseminating of outcomes are hampered by contextual factors such as tender processes, short-term positions, and a failure to acknowledge the support required to present findings.

Keywords: *inclusive research, participatory research, self-advocacy*

Introduction

The dictum of the British social model of disability "Nothing about us, without us" reflects an emancipatory model that all research about people with disability should be based on their own interests and conducted by them with the aim of social change (Barnes, 2003). Those who have worked as research partners with people with intellectual disability have questioned the applicability of this approach (Chapman, 2005; Dowse, 2001; Minkes, Townsley, Weston, & Williams, 1995; Ramcharan, Grant, & Flynn, 2004; Stalker, 1998; Townson et al., 2004; Walmsley, 2001, 2004; Walmsley & Johnson, 2003). Chapman (2005), for example, suggested that although emancipatory research had been a powerful tool for the disability movement, it "... does not quite reach into the current experience of people with learning difficulties as researchers. Apart from the issue of accessibility, people with learning difficulties ... are not in the position to 'own and control' their own research" (p. 384).

Research with people with intellectual disability is increasingly framed as "inclusive," which Walmsley and Johnson (2003, p. 9) suggested includes people with intellectual disability as "active participants, not only as subjects but as initiators, doers, writers and

disseminators." They provided a useful framework of its key components, which they set out as people with intellectual disability (a) having ownership of research questions; (b) being collaborators; that is, involved in the doing of the work; (c) exercising some control over process and outcomes; (d) being able to access questions, reports and outcomes; and finally (e) that outcomes will further the interests of people with intellectual disability.

Accounts of the practice of inclusive research demonstrate the challenges of this approach (Chapman, 2005; McClimens, 2008; Williams et al., 2005). For example, Chapman (2005) suggested those who occupy support roles in both self-advocacy and inclusive research require a great deal of reflexivity to ensure that they do not "take over," and that they remain in facilitative rather than leadership roles. In a similar vein, Williams et al. (2005) identified the need to consider power relationships and the way tasks are shared to ensure people with intellectual disability, rather than supporters, are "doing" the research. She questioned too whether people with intellectual disability can be meaningfully involved in data analysis and points out the need for "... honest accounts of practice [to] help us all consider the issues and dilemmas, and

thereby contribute to theory'' (Williams et al., 2005, p. 33).

Collaboration is central to inclusive research as is the teaching, learning, and power issues faced in these relationships. The Life History research group at the Open University in the UK provides examples of how collaborations have been sustained and enabled people with an intellectual disability to research their own life stories (Atkinson et al., 2000; Open University, 2007, 2008). The Life History research group's work highlights the time and commitment required, as well as strategies such as recording meetings and conversations and using transcripts as a reflective tool (Atkinson & Walmsley, 1999; Atkinson, 2004; Björnsdóttir & Soffia Svensdóttir, 2008). Seldom, however, does research that claims to be inclusive give detailed descriptions of the involvement of people with an intellectual disability, their roles, contribution, the challenges encountered, or the support provided. For example, a large-scale survey of the life circumstances in the UK that employed a small group of people with intellectual disability as part of the research team (Emerson, Malam, Davies, & Spencer, 2005) did not report any of these elements. The absence of description and perhaps too a questioning of the genuineness of ''so-called'' inclusive research leads to the need to ''reveal what is happening with the research process, certainly to ascertain the extent of people's inclusion'' (Chapman, 2005, p. 384).

Walmsley and Johnson's (2003) framework pre-supposes the existence of contextual factors supportive of inclusive research. These include (a) groups of people with an intellectual disability who understand the nature of research, are in a position to express their views about needed research, and can be considered representative of the group more broadly; (b) mechanisms to facilitate research partnerships, enabling governments or researchers to find, consult, and recruit individuals or groups of people with intellectual disability to be involved; and (c) resources to support participation that take into account the time and expertise required to do so. While in the UK some of these conditions have been generated through sustained funding for the self-advocacy movement and the Learning Disability Research Initiative (Grant & Ramcharan, 2007), they are largely absent in Australia. It has been surmised that the development of inclusive research in Australia has been hampered by a self-advocacy movement that is less well established and less influential in government policy making and advisory structures than in the UK (Bigby & Ramcharan, 2008). There have, for example, been no specific forums for people with intellectual disability to represent their research interests to government, and self-advocates are poorly represented and supported on more generic disability advisory bodies (Frawley, 2008). Almost no formal knowledge exists in Australia about either self-advocacy or supporting inclusive research that might inform practice, government policies, or lobbying for change (Fyffe, McCubbery, Frawley, Laurie, & Bigby, 2004). These differences suggest the need to explore the ways people with an intellectual disability in Australia can be involved in research without the presence of many of the supportive contextual factors assumed by Walmsley and Johnson's framework. If inclusive research is to be furthered in Australia by the academic and nongovernment sectors, and granting bodies are to be successfully lobbied for the necessary funding, greater exploration is required about both the practice and conditions necessary for its conduct. This paper uses Walmsley and Johnson's components of inclusive research to reflect on supporting a co-researcher with an intellectual disability in the ''Homeliness'' project, which was part of ''Making Life Good in the Community,''[1] a large government-funded research project (Bigby, Clement, Mansell, & Beadle-Brown, 2009; Clement & Bigby, 2009a, 2009b).

Background

Making Life Good in the Community was a 3.5 year study about community living following the closure of an institution, funded through a competitive tender process won by two academics from two universities in Melbourne, one of whom left the project to take up a position overseas after the first year. It was a complex and multifaceted study involving a large quantitative outcome survey, ethnographic, and action research in five group homes and several other spin-off projects. The project was led by the first author and included a full-time research fellow and several casual research assistants. For one year, a co-researcher[2] with intellectual disability was employed one day a week and a research mentor[3] for one and a half days a week. The tendered proposal included the co-researcher's salary but no specific funds for support, nor any description of the expected roles. During the first year of the project the team realised it had no capacity to support a co-researcher and if the position was to be more than tokenistic, funding for specific support would be required. A philanthropic trust gave a small grant to employ a research mentor one and half days a week to both support the co-researcher and reflect on the processes needed for the ''development and support of a co researcher''

(Bigby, 2006). The second author Patsie Frawley, then a PhD student with a background in education and extensive experience in working with self-advocates, was employed in this role.

A job description for the co-researcher was developed, which broadly set out the role and expected tasks. It stated:

> The co-researcher will spend time with people with an intellectual disability, staff and family members to find out what living in the community is like for the people with an intellectual disability. They will record what they find and talk about this with the other researchers.

It was intended that the co-researcher would work as part of the team and have some control over his work, but at this stage we left unplanned how this might occur or be supported. Following an advertisement circulated to disability employment services and self-advocacy groups, Alan Robertson was interviewed and appointed. He had not applied initially as others had led him to doubt he could do the job as he had not attended university. He had worked in self-advocacy groups as a project worker, facilitator, and trainer, and had membership of a disability advisory body and various other reference groups. However, he reflected that in these roles he "hadn't had much input."

During the recruitment process key stakeholders of Making Life Good in the Community participated in a workshop to discuss initial findings and prioritise the focus of the next stage. The concept of "homeliness" was identified as warranting further investigation, and the team decided it was both a relatively bounded topic and relevant to the expertise the co-researcher brought to his position. The broad questions for the Homeliness project were formulated by the team as (a) How "homely" were the group homes in which ex-institutional residents lived? (b) How could they be made more homely? A research plan was sketched out which included briefing the co-researcher about Making Life Good in the Community; orientating him to research principles; finding out about homes and homeliness through visits to various homes; a brief literature review by the research mentor; investigating homeliness through observations in the five study site houses concentrating on physical and social characteristics; and conducting informal interviews with house supervisors. The report of the Homeliness project (Robertson, Frawley & Bigby, 2008) is available online, but it is the process of supporting the co-researcher[4] to undertake this research rather than its findings that is the focus of this paper.

Method

The study used action research to reflect on supporting a person with intellectual disability to be a co-researcher. This type of methodology allows the "immediacy of the researcher's involvement in the action process" (Rapoport, 1970, cited in Walmsley & Johnson, 2003, p. 27). This meant that learnings and new ideas about support for Alan derived from the reflective process could immediately be trialled in practice. The intention was that the whole research team would be the subjects of the research and contribute their individual and group-based reflections on the processes and practices of including Alan in Making Life Good in the Community.

Over the 12 months of the Homeliness project, four meetings of the team including Alan occurred; a further three with the team and research mentor. Regular face-to-face or phone discussion occurred between the research mentor and first author, which took the form of action research cycles, involving reflection, analysis, and a plan for the reformulation of support. Either detailed notes or recordings were made of the team meetings and other discussions, and these formed the majority of the data. Additional data comprised field notes compiled by the research mentor, the text of emails between team members, and reflective notes of both authors. A thematic analysis of the data was undertaken focusing on the research mentoring relationship and process using Walmsley and Johnson's (2003) components of inclusive research as the starting codes. The research mentor developed a table that recorded cycles of reflection, observation, planning, and action (Seymour-Rolls & Hughes, 1999), which chronologically detailed reflections on each part of each cycle. Length restrictions preclude the recounting of each cycle in this paper, but rather the substance of the main themes identified is discussed.

Involving Alan in any type of formal self-reflection was a significant challenge, which is discussed in later sections in regard to his work on the Homeliness project. In respect to the support he received and his role in the study, an open offer was made for him to phone and debrief with other members of the team. Alan did not take up this offer, but did talk with the research mentor about their working relationship. His comments were incorporated into the data used for this paper, either through being recorded and transcribed as part of the conversations with the mentor or incorporated into the mentor's field notes.

Independent self-reflection by Alan, particularly about the research collaboration, remained an issue, and although he was comfortable talking at conferences about his experience of doing the research, he had no interest in being involved in analysing or writing about it. As he was not involved in the conception, design, analysis, or interpretation of the data for this paper, nor in the drafting or revising of it, he only met one of the three criteria for authorship set out by the university's guidelines for research (La Trobe University, 2003). Alan's omission as an author reflects our attempt to give an honest portrayal of inclusive research processes and not to objectify him. Alan was aware of the paper's content and gave consent for the use of his name. Ethics approval for this study was granted by the La Trobe University Human Ethics Committee.

Findings and discussion

Ownership

When considered against the first component of inclusive research—ownership of research questions—the study failed. The questions could not be conceived in any way as being owned or even influenced by either the co-researcher or a collective of people with intellectual disability. The Department of Human Services, in a competitive tender, framed the research questions, whilst the methodology and design were created by two academics. The short tender timelines and complexity of the brief alone curtailed the chances of any consultation with people with intellectual disability. The impact of these two factors was compounded by the absence of any requirements by the funding body to consult with people with an intellectual disability, a lack of support available to self-advocacy groups to participate in formulating research ideas, and the limited research experience among known self-advocacy groups or individuals. Meaningful involvement in the tender process by self-advocates would have taken longer than feasible within the timelines or workloads of the academics.

Despite a strong commitment to the principles of inclusion, neither academic had experience of employing and supporting a co-researcher on a large project such as this. No simple blueprints existed and most examples in the literature related to including people with intellectual disability on research reference groups, working individually on life story work, and contracted or self-funded research work undertaken by self-advocacy groups. When the tender was written, surprisingly little thought was given to how the co-researcher might be supported other than to

say it would be the responsibility of one of the chief investigators. The financial parameters of the tender prevented a more substantial position for a co-researcher or the support this would have necessitated. Also, changes to the research team meant that the chief investigator who intended to take responsibility for this aspect of the study and was most experienced in working with co researchers was not available after the first year.

Even when the tender had been won, additional funding found, and it was decided the co-researcher would undertake the discrete Homeliness project, concerns about rigor, keeping it manageable, and adherence to "traditional" ways of formulating a study, mixed with a degree of anxiety, meant the team designed this project, effectively denying Alan any ownership of the questions. This became evident in the early stages of data collection when it was clear that Alan's frame of reference was to compare the homeliness of group homes to that of institutions, and the research questions had framed comparison to be against abstract "disability standards" or community norms.

Control: Practicing and passing

Alan arrived a year into Making Life Good in the Community to the designated position of "co-researcher." Such a late entry, which would have posed difficulties for any researcher, resulted from our failure to seriously engage in early planning for this aspect of the project and a desire to carefully think it through to avoid tokenism. He had no formal research training or experience but was very happy to have a well-paid job one day a week in a university. Enabling Alan to have a degree of control over his contribution and how his job would be done was difficult. It meant accepting and valuing Alan for who he was and acknowledging the way he preferred to do things rather than trying to mould him into our view of how he should proceed. Initially the focus was on treating Alan "equally," in much the same way as any other new, relatively inexperienced research assistant, but paying particular attention to issues of comprehension and literacy. One team member used plain English techniques to develop materials to orientate Alan to the project and to "educate" him about the research methodology. After this lengthy session, Alan admitted to the research mentor that he had not understood what was discussed and was not interested in it. We included Alan in team and reference group meetings in an attempt to connect him to the ideas from previous research and develop strategies for undertaking his study. However, Alan noted very

early that he did not want to go to any more ''boring'' meetings and would rather just get on with the research.

Central to this period was our fixation on the prerequisites of being a researcher, that work in the field required preparation and planning, protocols being developed, interviews and observations to be piloted, and so on. This was a disaster: if we had wanted a researcher with the skills commensurate to the rest of the team we should have hired one; by ''pretending'' that in the space of a few months we could teach Alan all about the project and research processes, we completely disempowered him. We had treated Alan differently but not differently enough to accommodate his needs or support him satisfactorily. Alan refused to go along with our views of how he should ''become a researcher'' and prepare for the job. He seemed totally disinterested in discussing the research, what he might do, and how it might be done. Instead, he wanted to get on with it. We began to ask whether he was engaged at all or was it just a job to him? The first author wrote, ''Is it worth it? Have we got time? How will it work?'' Slowly we began to realise what had gone wrong. By failing to work from a strengths perspective, we had ignored Alan's own knowledge about himself and how he normally did things, and his views and preferences for doing this job. By expecting him to ''pass'' as a researcher before actually being allowed to do it, we effectively denied him any control over how he did this work. The first author wrote:

> I am now fairly sure that a lot of what we are talking about is not understood by Alan, this is a large complex piece of research, and it is not simple interviews which is what most of the examples seem to be . . . Alan is almost on the verge of getting angry with us for making him come to meetings and forcing him to talk and explain to us or the steering committee what he is doing or has been doing. [In making him verbally report to the steering committee] we are simply mimicking what others do, but why do we do this, it is written and we already know and others at the steering committee would know if they had read the documents . . . We are falling in to a trap of expecting Alan to do what we do. All the talking and planning is making little sense and he sees the research as being in the houses, and talking to people. . . . My sense is that we should split off this part of the project, it is Alan's part, he leads and we support, it is separate from the rest.

About the same time that this was written, Alan confided his feelings to the research mentor, saying he did not feel the need to keep ''talking and talking'' about what he was doing. Around this time too, the research mentor wrote:

> I have spent 3 months working with [Alan] trying to find out what he thinks he would be looking for, how he would record these, how he could find out more, how he can reflect on these. We have done a lot of preparation and planning work and I feel like I have been through a process of assessing him so I know where he is at so I can assist him. He has done a very good job of avoiding what he does not know, his argument never shifts – just let me go and do it.

After this cycle of reflection and planning, it became clear that it was not a lack of interest on Alan's part, but a mixture of his low confidence in talking with ''academics'' and his difficulties in remembering from week to week information about the project. We were confronted by the whole notion of assessing his skills. Practising doing research had revealed what Alan struggled with in his everyday life: remembering, reading, and in this new job, moving from describing what he saw to forming ideas or ''interpreting'' what he observed.

Our experience suggested that some form of ''assessment'' was necessary to inform the type of support we provided. We should have known from the assessment literature that it would be much more empowering to focus on strengths and address the difficulties in the natural context of Alan's work tasks, rather than in the form of the more formal training we had attempted (O'Brien & O'Brien, 2002; Saleebey, 2008). Furthermore, the supported employment literature strongly suggests that assessment and training should occur in the natural context rather than in the more formal type of classroom-based setting we had used (Wilson, 2003). We had not applied this knowledge, which stemmed from our professional training, in a context that fell outside the professional client relationship. Doing this inclusive research represented a curious juxtaposition of a rights perspective (equal status and anyone can do anything with the support and environmental adaptation) and the professional perspective that proceeds on the basis that individualised assessment, planning, and implementation is important in deciding the type of support provided (Bigby & Frawley, 2009). Rather than discarding professional skills of assessment in research partnerships, these need to be applied within a rights framework, to ensure differences are not ignored and the ''right'' type of support is provided in a respectful manner.

Three key issues came to the fore once we altered our expectations, listened to how Alan wanted to do the work, and realised that for him doing the job and figuring out strategies to provide support had to occur concurrently, not sequentially. The issues

became: (a) how to provide support that enabled Alan and not the research mentor to lead the research, (b) how to support Alan to be reflective, and (c) to reach some clarity about the "expertise" that Alan brought to the project. This reflection from the research mentor encapsulated all three:

> I know, from being in the houses with him that I am following him around prompting him. How much of this is me telling him what he needs to do – me influencing what he sees, how he sees it and what he thinks about it? What is the difference between Alan as the researcher and someone we might get off the street and say can you check out if these houses are homely? Why have we got Alan doing this research and how can we maximise what he has to bring to it?

Collaboration rather than leading

A key component of qualitative research is a naturalistic approach where phenomena are studied in their natural settings and an attempt is made to interpret them (Denzin & Lincoln, 1998). Although one member of the team remained sceptical, the research mentor expected Alan to interpret what he saw and develop more than his initial personal view about this and what it meant. This meant supporting him not only with the practicalities of recording and producing data, but also with analysing it.

At the practical level the research mentor drew on ideas from "Photovoice" (Jurkowski, 2008) to record Alan's observations in the group homes and discussions with house supervisors. Alan hung a digital recorder around his neck to record his comments as he moved around the houses and spoke to staff. The research mentor took photos with a digital camera. On the way home from each visit, they recorded their "conversation" about what Alan had observed. The transcripts and the photos were then used in a "reflection" meeting held before the next visit. The mentor recorded the notes from this meeting on a flip chart, later putting them into a document with the photos. These were, however, more than normal "conversations." Alan's responses were often general rather than specific ("it was all right"), or at times value-laden ("it's better than where I live"). Supporting Alan to be reflective required a dialogue which the research mentor provoked by directly challenging what he said, and continually asking questions about his statements of what he had seen or been told by house supervisors. The research mentor constantly tried to get Alan to think further or differently, although at times he would not be drawn on what he said and did not see the reason for going over the same point more than once. During this process, the research mentor was acutely aware

of her potential to influence his ideas and the research outcomes, which is a major issue raised in the literature (Williams, 1999; Williams et al., 2005). The research mentor wrote:

> Alan is still not showing interest in the work we do together and is quite off hand about his need to have input, think about what we are doing and keep it in his head so we can build on it. I am concerned that I am influencing Alan's thinking because I am challenging him, his ideas and views. I am concerned he might end up saying things he thinks I want to hear just to get me off his back.

Reflection and analysis was a cumulative process; going over the same visit many times, looking at the one photo and talking about it at different times, each time noting Alan's ideas, reflections, and thoughts. The process occurred within the context of the relationship between Alan and the researcher mentor, which strengthened and became more reciprocal as time went on. The research mentor wrote:

> Alan is beginning to understand the need to ask questions and think about what he is seeing in a more critical way. He still does not like reflecting and describes things as he sees them – I do a lot of challenging of his responses in particular in relation to the role of staff. I need to consider how to get Alan to take more responsibility for his work. I want Alan to be able to talk about what he is doing in an informed way and to communicate his opinions based on his research.

Gradually, Alan began to share more responsibility for the work by deciding when and where meetings should be held and beginning conversations about his thinking since the last visit to a house or the last reflection session. He started to make decisions about recording thoughts, which photos to use to show certain aspects of what was homely or not. He even felt sufficiently in control to ask the research mentor to stop pushing him so hard in the sessions. Towards the end of the project the research mentor wrote:

> Alan told me today that he is really enjoying the work now and it was good I had relaxed a bit. I told him I had relaxed because he was taking more control of the work and was doing a really good job. . . . Alan is starting to analyse what he is seeing in the houses and drawing together themes. It's been really hard work to get him to say what he thinks are the main issues but he is getting there.

Over time, Alan developed very clear ideas about the homeliness of these houses and how it could be

improved but they had not come without significant input by the research mentor. By the end of the project the research mentor was satisfied that the ideas captured in the report were not hers, but the outcome of a collaborative partnership between them, during which Alan's ideas had been shaped by her questioning, challenging, knowledge of the subject, passion for deinstitutionalisation, and awareness that his views would take some time to form. One clear indicator of this was Alan's concerns about the potential implications of anything he wrote or said about the government department that funded the community houses. Alan was clear he did not want the report to say anything too controversial that might get him ''in trouble'' with the Department, whereas this would not have concerned the research mentor had she been leading.

Accessible outputs and meaningful outcomes

Early in the project it was clear that although Alan could read plain English text, written material held little meaning for him. The checklists designed as prompts for observations and interviews were discarded by Alan before he got into the field, he did not read the transcripts summarised in plain English, or find it useful for these to be read to him. As the study progressed these things were replaced with conversations summarised on flip charts and documents that juxtaposed digital photos and short comments.

The research report used a similar mode drawing on the photos taken during the study and accompanying these with plain English reflections. More importantly perhaps, Alan, with the support of the research mentor, presented the findings at various national and local conferences where audiences were self-advocates, service providers, and policy makers. His preferred way of presenting remained a collaborative question and answer style developed with the research mentor. Like any other piece of research, its impact will eventually be determined by how well it is disseminated and the serendipitous way in which it is taken up by those with power and influence. The lengthy process of dissemination created similar tensions to those found in other situations where some members of a team are employed on time-limited contracts. Should the chief investigator take over dissemination once Alan's contract expired, aware that by doing so the impact and authenticity of conference presentations would be reduced and Alan would be robbed of the chance to be acknowledged? The wider disability sector seemed oblivious to this issue, and we were astonished with the frequency that conference organisers or service providers invited Alan to present the findings, but failed to take any account that he was a man with intellectual disability who was unemployed and would most likely require funding and support to do this. Our solution to making the output accessible and ensuring it had the strongest impact was to invite Alan and the research mentor to do countless hours of unpaid work in the form of presentations, negotiation, and support. Finding ways to maintain both co-researcher and research mentor roles for the critical but often lengthy dissemination phase is a key challenge for inclusive projects funded on a short-term basis.

Experts by experience

The Making Life Good in the Community project did not conform to an ideal type of inclusive research initiated directly by people with intellectual disability, owned by them, and reflective of their interests and experience. Rather like many researchers, Alan was contracted to work on someone else's project. Perhaps for these reasons throughout the project, as hinted in one of the research mentor's earlier reflections, we wrestled with what ''expertise'' legitimated Alan's involvement in this project. Grant and Ramcharan (2007) refer to the ''expertise by experience'' that people with intellectual disability bring to research. But using one's own experience still requires the capacity for personal reflexivity, reflecting on the ways one's own values, experiences, and political commitments shape what is seen, as well as trying to *stand with* those on whom the research is focused to break down barriers between self and others (Walmsley & Johnson, 2003, p. 19).

The struggles Alan had with being reflexive fuelled our debates. He found ''standing with'' particularly difficult and was confronted by his ''difference'' from the residents with severe and profound intellectual disability living in the group homes studied. He was much more comfortable talking to staff than interacting with the residents, and voiced at one time the view that ''they would not know any difference between the institution and the house.'' We debated whether Alan was better placed than any of us to do this research and to stand in the shoes of residents with severe intellectual disability and construct what ''homely'' meant for them. The hierarchy of impairment Alan had encountered in his institutional experiences, which meant those with the most severe impairments were the least valued, may have reinforced his distance from people with more severe disability rather than developed his empathy for this group. These issues have only just begun to be debated in the context of inclusive research but are similar to those raised more broadly in service user

research, where standpoint theory is challenged by some (McLaughlin, 2009). For example, McLaughlin cites the argument put forward by Hammersley that:

> . . . while we must recognise that people in different social locations may have divergent perspectives giving them distinctive insights, it is not clear why we should believe the implausible claim that some category of people have privileged access to knowledge while others are blinded by ideology (Hammersley, cited in McLaughlin, 2009, p. 13).

Similarly, Barnes and Mercer (2006) suggest it is absurd to believe that just because someone is disabled it necessarily gives them an affinity with other disabled people. Our experience reinforces the need for inclusive researchers and funding bodies to grapple with the notion of ''experts by experience'' and to take care not to disregard the differences between people with intellectual disability, or assume those with milder disability have more empathy and can better represent the views of those with more severe disability than can people without disability but well-honed reflexivity.

Conclusions mentoring: An ally or collaborator

Walmsley & Johnson (2003, p. 62) suggested that ''a sympathetic ally'' is necessary to work alongside people with intellectual disability if they are to participate actively in research. Our experience has helped to tease out the multifaceted nature of this role, and suggests that collaborating in the research endeavour and providing support are integrally related. The research mentor created the scaffolding for the work of the co-researcher, which comprised the very practical tasks of negotiating and organising field work, taking care of the hardware, recording, transcribing and so on, as well as collaborating to reflect on and analyse the data. The mentor's role was not passive or explicitly directed by the co-researcher as an attendant carer might be. Naming this role as a research mentor reinforces its active nature, its multiple tasks, and the necessity to have skills both in working with people with an intellectual disability and as a researcher, and the capacity to build an open and honest relationship. The other ingredient in this case was an unwavering commitment that the co-researcher and not the mentor should take primary responsibility for the research outcomes.

Eighteen months after the conclusion of this project and near to the final draft of this paper, Alan discussed with the mentor his advice about the job to potential co-researchers. His tips, summarised

The people who you work with:
• You need to be able to trust them
• You need to be comfortable with each other, respect each other, be honest with each other
• They need to be organised, skilled, reliable
• Be able to get you involved—not do the work for you
The project:
• Something you are interested in and have some experience of
• Something you care about
• Something you can do
The job—what you need:
• A clear job description
• Someone to do the paperwork
• Work out the pay and get paid the right amount at the right time

Figure 1.   Alan Robertson's tips for being a co-researcher.

in Figure 1, highlight the importance of the research relationship and a collaborative way of working, having a sense of ownership and control over the nature of the research as well as the very practical aspect of dealing with organisational systems.

We have not documented many of the more mundane practical challenges of supporting a co-researcher, such as dealing with a university system that assumes literacy skills, or reporting earnings to the social security system. We have, however, unpacked and illustrated some the processes that both support and obstruct the implementation of inclusive research in the Australian context. One measure of our success was Alan's assessment of his work: ''it is the best job I have ever done. I was a researcher and I want to do more research.''

Acknowledgements

Notes

1   The seven reports associated with this project can be downloaded from http://www.dhs.vic.gov.au/disability/improving_supports/kew_redevelopment/evaluation_of_community_living and http://www.latrobe.edu.au/socialwork/schoolstaff/chris.htm
2   We have used the term ''co-researcher'' to refer to the researcher with intellectual disability, as we used this in the original proposal and throughout the project and use it now for clarity.
3   We used the term ''research mentor'' to refer to the researcher employed to support the co-researcher.
4   From this point in the paper, to avoid objectifying Alan we use his name rather than referring to him as the co-researcher.

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