

A collaborative group method of inclusive research

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Background: Funding bodies in Australia and the UK require research on issues that affect the lives of people with intellectual disability to be inclusive. Debate continues about the nature and benefits of inclusive research, which has become an umbrella term encompassing a broad spectrum of approaches. *Method:* This paper proposes one method of inclusive research, the 'collaborative group' approach. It examines the processes used to conduct a study involving academics and self-advocates, presenting findings derived from an inductive analysis of field note data, interview and meeting transcripts. *Results:* Five components are identified: shared and distinct purposes of participants equally valued, shared involvement and distinct contributions equally valued, flexible, adapted research methods, working as a group with trusting relationships and dispersed power, and scaffolding for inclusion. *Conclusions:* This collaborative group method potentially results in better research than either academics or self-advocates could achieve alone and has multiple knowledge outcomes with differing accessibility and complexity.

Accessible Abstract

Background. When people with an intellectual disability and researchers from universities or other organisations do research together it is called inclusive research. People have worked together on research for a long time but there are still some questions about why we should do it and the best way to do it. Method. This paper talks about one way of doing inclusive research that the people who wrote the paper call ‘collaborative group approach’. They did a big project with a group of people with an intellectual disability and talked and thought a lot about what they were doing. What they found out. There are five parts to working this way; 1. Having some of the same and some different reasons for doing the research 2. Doing some things together and doing some things apart 3. Being able to change things as you go so people can do what they want to do and are good at. 4 Knowing each other well and being able to work together equally. 5 Thinking about the way you work all the time to make sure people are doing what they are good at and what they want to do. Conclusion. If people work this way it might lead to better research and understanding about the lives of people with an intellectual disability.

A collaborative group method of inclusive research

It is no longer accepted that researchers will ‘decide what topics should be researched and be in control of the whole process of research production’ (Oliver, 1992, p.102). A shift toward inclusive research dates back to 1994 when the Rowntree Trust decided that involvement in the conception, planning and execution of research of those it was intended to benefit would be a criteria for funding (Ward, 1998). The Australian federal government now requires that genuine effort be made to include people with disability, their families, and representative organisations in research (Disability Policy and Research Working Group, 2011). This begs the question however about the meaning of inclusive research.

The UK disability movement created the impetus for inclusive research through development of an emancipatory disability research paradigm (Zarb, 1992). However it gave little attention to people with intellectual disability, who as Chapman (2005) suggested were not in the position to ‘own and control’ their own research (p. 384). Walmsley (2001), who first coined the term inclusive research, referred to it as the involvement of people with intellectual disability as ‘more than just subjects or respondents’. She and Johnson later suggested key components: (a) that people with intellectual disability had ownership of research questions; (b) they were collaborators involved in the doing of the work; (c) they exercised some control over process and outcomes; (d) they could access questions, reports and outcomes; (e) that the outcomes furthered their interests; and (f) it was most commonly associated with participatory, action or emancipatory paradigms (Walmsley & Johnson, 2003, p. 9-10).

The argument for inclusive research has been based on values rather than evidence about its contribution to knowledge (Nind, 2008). Using traditional academic benchmarks it has been critiqued as lacking rigor (Clement, 2004; Fynn, 2003) or in danger of remaining ‘trapped in a cycle of sentimental biography and individual anecdotes’ (Walmsley, 2004, p. 65). Earlier allegations of ventriloquism and a lack of transparency about the nature of support (Clement, 2004; McClimens, 2008) have become less frequent as more explicit accounts of research practices and the respective roles of researchers with and without disabilities appear in the literature (see for example Bigby & Frawley, 2010; Conder, Milner, & Mirfin-Veitch; Stevenson, 2010).

Inclusive research has been regarded as a singular 'target' by its critics, and yet a comprehensive review demonstrated that it falls along a continuum that spans from involvement in an advisory capacity to control and leadership of research projects (Bigby, Frawley, & Ramcharan, in press). Theoretical prescriptions (Walmsely & Johnson, 2003; Zarb, 1992), while useful for guiding inclusive research endeavours, have led to researchers shoe-horning their work into poorly fitting frameworks derived from values or writing apologetic accounts of their failure to do so (Ramcharan, Grant, & Flynn, 2004). A deeper consideration of its methods and the knowledges produced can be gained from first order constructs derived from analysis of what actually happens in research that aims to be inclusive. This paper proposes a method of inclusive research, the 'collaborative group' approach, derived from an analysis of qualitative data about the processes used to conduct a study involving academics and self-advocates in Victoria, Australia - 'Speaking up over the years' (the History project). The overarching research question addressed is 'what were the key components of the method of inclusive research used in this study'?

Background

The History group comprised five self-advocates, who were members of Reinforce, the first self-advocacy group established in Victoria, and three academics who worked together from 2006 to 2012¹. The study was funded by the Australian Research Council between 2010 to 2012, and prior to that the work was largely unfunded. The funding submission stated:

This collaborative research project undertaken *with* self-advocates aims to examine the significance of self-advocacy in building the individual, social and political inclusion of people with an intellectual disability (Bigby & Ramcharan, 2008).

Funds were sufficient to employ a historian for 12 months, who worked individually with group members on their life stories; a research fellow one day a week for 3 years; a Ph.D. student who undertook a study about self-advocacy and individual identity. The funding agreement contracted RMIT and LaTrobe Universities to allocate a day a week of each of the two chief investigators for 3 years. Funds were available to pay self-advocates for their time. Many more than the funded hours were put into the project by all group members.

This paper examines the processes used by the History Group to research the history of self-advocacy, rather than those of the Ph.D. student or the historian. The intensity of the work varied over the life of the project. At the time of writing the group had met

¹ One of the self-advocates passed away in April 2012.

approximately 44 times, an average of 8 meetings a year (excluding coming together to conduct interviews), and in addition the academic members met 42 times. Twenty-seven interviews had been undertaken, with 8 self-advocates, 16 allies and 3 government staff. Seven conference presentations had been given by various combinations of presenters and a publication had been submitted for review. The remaining work is dissemination of findings through journal articles, conferences and an accessible 'coffee table' book.

Method

An approach that drew on action research cycles of plan, act, observe, and reflect was adopted to document and review the research processes and practices (Heron, 1996). The regular meetings of the three academics (CI meetings) were a 'non accessible space', and one of many practices used to scaffold inclusion. They served multiple purposes, including planning, analysis, making practical arrangements, and reflection on how inclusive the method was for self-advocate group members. Aspects considered included: the engagement and types of contributions of self-advocates, exercise of power, and with whom control and decision-making lay. These brief excerpts provide examples of the type of reflection that occurred.

Concern we may have lost momentum with Reinforce as we have not met for some time and it now seems that various other things are happening on the day of the planned meeting in Dec. Part of the problem may be that there has not been any identifiable action for a while ... We have been doing ground work on which to build action and have left Reinforce out of this (²CI101209).

If the group has been central then our CI meetings have been separate but connected but why do they exist separately- to pursue the interests that are particular to us i.e. academic analysis? (CI090610)

Reflection by self-advocate group members about the research processes occurred in History group meetings and informally in email correspondence, or between the second author and a self-advocate who had known each other for a long time. Both CI and History Group meetings were recorded and transcribed or detailed notes were written. All of the

² All data excerpts are labeled using a similar format; source, for example, CI meetings (CI), Interviews (I), History group meeting minutes (Mins) and the date.

aforementioned documents constituted the data which were analysed and reported in this paper.

An inductive thematic analysis was used to interpret the data about research processes that evolved during the study (Miles & Huberman, 1994). The analysis, undertaken by the academic group members was iterative, involving progressive cycles of reading documents, discussing, refining initial interpretations and returning to the data to test emergent concepts. The inductive approach meant we did not begin with any preconceived categories or concepts. However, as part of the analysis, emerging themes were compared and contrasted to existing accounts of inclusive research and the nature of research groups (Mauthner & Doucet, 2008; Nind, 2011). Given the limitations of space, this paper describes the themes induced through these discussions rather than tracing the unfolding processes that gave rise to them.

Findings

As Figure 1 shows five overarching components of the collaborative group approach were identified. Four are set out in detail in the following sections and the fifth component, scaffolding for inclusion, is summarized only briefly as it is fully reported in a separate paper (Bigby, Frawley, & Ramcharan, in preparation).

Insert Figure 1 about here

Shared and distinct purposes – equally valued

Academic and self-advocate History Group members shared a common purpose of wanting to strengthen self-advocacy in Victoria, but each sub-group also had distinct purposes. Self-advocates saw writing their history as one way of strengthening Reinforce and gaining more members. After attending the annual general meeting of Reinforce, one of the academics wrote that members were interested in bringing together and using their history to find ways of expanding self-advocacy. They had begun work on the history several times; a short self-published book had been produced (Reinforce u.d) and a partial chronology. Importantly, this previous work had not been framed as research.

Throughout the study, self-advocate group members spoke further about their purpose and expected outcomes of the research. For example, one member said he hoped it would ‘lead to Reinforce holding a world conference’ and another that ‘it’s important to know that

self-advocacy has been going for a long time for the new people coming in.... when the ‘old people retire’ (Mins310510). For the self- advocates, although the target audience was primarily other self-advocates, they were also interested in promoting wide recognition of self-advocacy. For the academics, primary audiences were other researchers, policy-makers and others with influence to recognise, promote and fund self-advocacy. As the minutes noted:

The idea itself came from the group of self-advocates, recovering their history, we saw this in its broader context and that this may be a vehicle for bringing about some change in the way self-advocacy is regarded and making it stronger in Victoria’. (CI 250510)

The research grew out of a broad shared purpose and was crafted by the academics into a set of research questions. Framing, the self-advocates’ idea of doing their history as research legitimated involvement of the academics, who could bring their expertise and at the same time pursue their purposes of writing and gaining competitive funding.

Self-advocates were aware of the distinct purposes the academics also had to pursue. For example, when the group discussed what academics would gain from the study, a self-advocate said “knowledge and learning about self-advocacy (Mins, 310510). They were however not interested in pursuing these things together. For example, as described later, when the academics attempted to engage self- advocates in a deeper interpretation of interview data their comments included ‘we have done this already’ and ‘it’s boring’.

Efforts were made to give equal value and similar attention, time and energy to the shared and distinct purposes. Some actions or events were designed to serve both research rigor and to raise the profile of Reinforce. For example, a self-advocacy reunion and the organisation of a self-advocacy strand at a disability conference promoted self-advocacy and supported recruitment of informants to the study by tracing past Reinforce members and allies.

Shared involvement and distinct contributions – equally valued

Distinct contributions

As in other research groups, each member had their own unique combination of knowledge, skills and experience. As a group, the self-advocates brought their networks and experiences as active members of Reinforce over many years. They brought knowledge of past members and allies, campaigns and projects, and interactions with politicians and bureaucrats. Their

skills included confidence in talking with different types of people, working in groups and public speaking.

There was no formal research training that is often found in other reports of inclusive research. As one member said, when asked what skills training she had been given, “What skills? We are the history, we don’t need skills, but we didn’t get skills, they’re already there” (Mins, 210311). She is referring not so much to her knowledge about the history that a research informant might bring, but to her capacity to use this knowledge and her social skills as part of the group that conducted interviews. This involved questioning interviewees about their version of events or pressing them for more information. Similarly the academics brought their networks and own lived experiences of disability policy in Victoria, as well as more formalised research and organisational skills.

Shared involvement

Regular meetings ensured everyone knew what was happening, although not everyone was involved in every task. Different combinations of group members and academics worked together depending on the task and availability. Some tasks were shared by all but relied particularly on the self-advocate group members. For example, identifying informants drew on their knowledge about past members, and construction of the key moments interview guide, described below, relied on their knowledge of events, ability to put names to people in photos, recall events and remember dates. Some tasks were done solely by academics, such as an examination of organisational documents, compilation of an archive, a policy analysis, and preparation of a keynote address about inclusive research. There was little to be gained from sharing such tasks which required high level reading and critical appraisal skills that self-advocate group members did not possess. However, information about work done separately was always discussed with the whole group. Inevitably this added another layer, the self-advocates’ perspectives, to that work. For example when the academics reported their mapping of the key policy events and players from 1970s -2000s, the self-advocates provided a commentary about Reinforce’s involvement with various politicians, such as a sit in at ‘Snappy Tom’s’ office (the Labour Health Minister 1982-1985).

All interviews were done collectively, involving various combinations of group members. As described later, the analysis was multi-layered, and although the bulk was done by academics, the self-advocates contributed in various ways

Equally valued

The equal value accorded to different research tasks regardless of their nature, and to all contributions avoided the hierarchical social relations typical of research groups (Mauthner & Doucet, 2008). The mutual respect that stemmed from the acknowledged interdependence of each sub-part of the group and recognition of the different skills each brought was illustrated by one self-advocate who spoke about respective contributions of self-advocate and academic group members:

We have got the experience and knowledge but we haven't got the skills what you all have; like taking that on tapes and all that....Yes, sharing skills. ..Yes, it's a joint venture, we work together. ...but it's also our history because without you, there won't be any history.... (Mins, 210310)

Equal value of all contributions was reflected in the decision to use the available funding to pay all self-advocate group members for their time at University research assistant rates. This did not mean however they undertook the more tedious aspects of the research process, expected in other scenarios of research assistants (see for example Mauthner & Doucet, 2008). Instead, the often undervalued practical organisational work, that might not ordinarily accrue to CI's was done by the academics representing an adaptation of presumed formal roles.

Working as a Group with Trusting Relationships and Dispersed Power

The History group did not operate as a formal committee which was normally the case for Reinforce projects. In fact much of the actual work of research, such as interviewing and reflecting on interviews, occurred in the group.

Trust, camaraderie and collegiality

The History Group cycled through the stages of forming, storming, norming and performing (Tuckman, 1965), requiring attention be given to group processes as well as research tasks. Norms were established as members got to know each other better and became familiar with the group's purpose. The easy consensual tone that characterised meetings developed into a strong sense of trust and camaraderie, as members accepted and worked with each other's quirks and foibles. The excerpt from a meeting transcript when one member DB came in late illustrates the light hearted banter between members.

DB Sorry I'm late, Chris, because I had a doctor's appointment. JS: That's Patsie!
PF: Mm! (laugh). JS: Are you talking to Chris or Patsie? DB: Anyone who'll listen!
PF: Oh! CB: I'm listening, even though you were looking at Patsie. (Mins, 120911)

A sense of trust among the group grew out the process of working together and meeting regularly, nurtured by reliability and delivering whatever had been promised. Discussing this, one self-advocate group member said:

Some academics do let people down, but not you, because we have met, constantly, ongoing, every fortnight, you said what you're going to do and all that, and we said what we're going to do (Mins, 210311) .

Relationships among group members were essentially collegial and when one member of the group died during the project everyone attended his memorial and provided emotional support to each other. The same was true for a long standing member of Reinforce whose contribution to the organisation had been central to its success. Not dissimilar to the types of extraneous 'helping' that occurs among any collegial group, on some occasions, relationships could be characterised as 'helping', particularly when self-advocates sought support with various things such as how to deal with a difficult colleague.

Dispersed power

Although the academics managed much of the regular work of the project, group discussion of all major decisions helped to ensure power was dispersed and ensure everyone had the opportunity to have a say. One self-advocate group member made this point very strongly:

Well, we had different ideas, different points of views about it, and no matter what, it all seemed to work, with everyone bringing their ideas to the table, and that, and [about] what works best, and what's not work[ing] best? (Mins, 210311)

During one of the regular discussions about research processes a self-advocate group member noted there were no problems and if academics tried to take too much control it would be dealt with by self-advocates, saying "we just tell you to be quiet, we're talking".

Decisions about who to interview and scheduling interviews were made together but were driven primarily by self-advocate group members. As one member said, 'we tell you who's good, who will be better, being a better interview and everything'. This is evident in the following excerpt where the difficulty of contacting the long-time worker from another self-advocacy group was being discussed;

JS: I was just thinking, we interviewed workers and that, but we haven't interviewed many of the self-advocates..... Yes, so we need many more. JH: We should

interview some of the people from down there [the other self advocacy group] JS:
What about GG and all of them? GG was around in those days? (Mins, 230911)

Later in the conversation one of the academic group members proposed another self-advocate, whose inclusion was weighed up and dismissed by group members.

PR: We don't want to do, [name of self-advocate from another group] as well? PF:
We could. JS: who? ..AH: .. he's had very little to do with Reinforce, but he's very involved in [other self-advocacy group] and that other stuff too.. JS: He wasn't really around back then. (Mins, 230911)

Language conveyed a sense of the group, as members consistently spoke about 'we' rather than 'I' or 'them and us'. Introducing the study to one of the interviewees, a self-advocate said;

The history's been going since 2006... And we had a big reunion in 2007... And, yes, and now we've been talking about gathering information, and now we're interviewing a lot of people, past and present, and self-advocates. (I, BL, 130910)

Power was not dispersed by dictat but through the collegial approach and regular conversations where people felt comfortable to challenge, claim roles and establish how the relationships and information flow would operate. In some senses the claiming of such roles marked the boundaries of each person's felt capabilities, making ascription of tasks unnecessary.

Flexible Adapted Research Methods

Research methods were adapted to build on the strengths and skills of group members, take account of their limitations, and provide the type of support needed to work effectively together. Adapted methods evolved through a continuous process of reflection and adjustment.

Preparation for interviews

Rather than devise an interview schedule, a pictorial interview guide of key moments in Reinforce's history was prepared to act as a prompt and enable members to be involved in interviews. A skeleton of dates and events was created from an interview with one member. It was fleshed out by the academics using the analysis of policy and organisational documents, and by the self-advocates' memories aided by reflection on photographs. As successive drafts

were discussed, new memories were prompted and included. The excerpt below is drawn from a discussion on a draft prepared by one of the academics:

PF: So 1977, Middle Park Social Club. AH: Yep. PF:... ..a group, called Force 10, didn't happen until after Lancefield, is that right? DB: No, it happened at Inverloch, in 1980. AH: Oh. Yes! DB: But that's where it started. (Mins, 120911)

The process of compiling the interview guide meant the material to be covered was firmly in the self-advocate interviewers' heads by the time interviewing began, and remarkably they rarely referred to the guide during interviews. There was no interview script as illustrated by the following excerpt from a self-advocate who was asked at a conference how they did the interviews:

No, no, no, no we haven't, off the cuff, off the cuff! JH: (laugh) Off the cuff! JS: We were relying on our memories to say it all. (Mins, 120911)

No, not a list of questions, but we know them, because we know all these questions because, we just know. (Mins, 2103110)

The real value of the interview guide was as a preparatory tool for interviewees that contributed to the rich data that were collected. The guide was sent out prior to the interview and interviewee comments suggested it provided an important prompt that helped to mine their memories. They said about the guide for example:

BW: Yes, it was good, it really did bring back some, jogged my memory on some things and I was going: "Oh yes, that's right, yes that's right, that happened", and it was good, it was a nice sort of timeline and it gives a nice overview, and it picks up on most of the things, and some of the things I'd forgotten about, and so I was reminded about. (I, BW, 120710)

Interviewing

Most interviews were held in the familiar meeting room at the Reinforce office, and conducted by various combinations of group members and academics, with one and sometimes two interviewees. At times they resembled reminiscences or conversations between old friends or acquaintances. For example, a group member was late, and as she walked into the room noticing the interviewee she said;

AH: Your face it looks familiar from somewhere? BR: Yes, you'd remember me from Middle Park days, when I worked at Middle Park centre at the social club. AH: .. well

that's turning back the time a little bit!.BR: About 1981, '82, '83? AH: Oh, not
[names interviewee] BR: Yes! (I, BR, 121110)

The interview transcripts show the attentiveness of all interviewers who regularly signalled their engagement by affirming 'mm's' and 'arr's' or other responses. All group members contributed to the flow of the interview and the richness of the data that were collected. The self-advocate interviewers often prompted interviewees for further details or queried the accuracy of what had been said. Reflecting on the interview process one member said:

'Yes, yes, because, when you've got to listen to what they're saying, or that person might have left something out: "Hey! Yes, I just remembered something you left something out", you fill in what that person's missed out (Mins, 040711)

By fleshing out what interviewees said, self-advocates added their own knowledge and reflections to the data. In these ways the group co-constructed the data with interviewees and began to make meaning of it during the process. The extracts below illustrate how the self-advocate group members (identified by initials) added to the information given by an interviewee prompting them to expand on it further;

Interviewee: Yes, that's right, so it was getting support by other groups, and maybe in those early years, it was a real kind of radical organisation too ...DB: Were we what! AH: Yes, what! Interviewee: Remember it was called, it was the Union. DB: Yes..Interviewee: You were the Union of people.... DB: That's how we originally started. Interviewee:... and it had that feel about it...DB: Yes, well when we had the conference down at Inverloch it was decided we'd call ourselves the Union... it was around '84, before we went to America...Norrie: Mm.DB:...we had a conference out at [name of training centre], and Mandy'd probably remember it. (I, IP, 180411)

The academics played important roles in clarifying other points made by interviewees and following lines of enquiry about policy that arose from other informants.

Analysis and Reporting

Interviews lasted one or two hours, amounting to 40 pages or more of transcribed text each. Reading this volume of words was beyond the literacy skills of self-advocate group members. As one member said, "Well I'm good on computer, but...reading, it has to be in plain English for me to read it". As already suggested some reflection occurred during the interviews, and in group discussion directly afterwards. Various other methods of involving self-advocates in the analysis were attempted such as; academics presenting short excerpts of the text and

leading a brain storm about its meaning, or presenting to the group an interpretative summary for discussion. Neither of these approaches made much sense to the self-advocates who, although they participated, were puzzled. They saw little point in going over the same material again and again, pointing out this work had already been done, and doing it again made little sense to them. While this formal approach at co-analysis did not work as intended, the discussion of interview summaries did provide another layer of data generation and meaning creation. The excerpt below from discussion about another interviewee's view that self-advocates had been manipulated to make a particular decision, illustrates different interpretations of the event from the perspective of self-advocate group members.

DH: I think it's interesting that he says he's got this very visual memory of standing out the door.... that everyone was conspiring, or being, manipulated by co-workers, he's got a very sort of strong image of what was going on there. JS: ...but the self-advocates didn't want to go for it.... PR: So nobody manipulated you, nobody told you that's what you should say or think? JS: No! No! No! ...JH, we've had our own ideas, and things....support workers weren't nudging us: "Come on, say that" (laughter)..... It was own, our own, our own ideas, about that. DB: But there were some support workers that tried to influence against [manager of advocacy group] NB: Yes. (Mins,150911)

Data can be analysed at varying depths and from different perspectives. This study provides not one, but several perspectives of the history of Reinforce as a self-advocacy group. The different authorship of papers illustrated these different perspectives and the varying audiences for this work. For example, self-advocates led a presentation at a self-advocacy conference about an 'insider perspective' and academics a conceptual paper characterising different periods in the history of Reinforce for an audience of academics (Frawley, Bigby, & Ramcharan, 2012).

Scaffolding for inclusion

The four components described above were underpinned by continued and explicit attention to enabling participation of the self-advocates. These practices were based on the value position that people with intellectual disability have the right to be accorded equal value and respect in all relationships. It was also underpinned by an interactional model of disability, recognising the disabling nature of social structures and processes as well as the effect of cognitive impairment. This means that in some instances, differences in individual capacity

need to be accommodated (Bigby & Frawley, 2010; Shakespeare, 2007) and tasks adapted to enable access or participation. Multiple and interconnected practices were used to scaffold inclusion, some of which were common in other settings (Frawley & Bigby, 2011), whilst others were more specific to research. The approach was nuanced and relational, paying attention to group processes by regular engagement, building trust, pacing work, attending to practicalities and devising differentiated outcomes. Access was mediated by preparation and context setting, creation of accessible work space and use of non-accessible space. These practices, though largely driven by the academics, were reinforced by self-advocate prompts about such things as adjusting language and avoiding jargon. They were tailored to the group and depended on the task at hand and the length of time the group had worked together. To avoid the critique that practice has not been sufficiently transparent in accounts of inclusive research and ensure adequate attention is given to enabling practices, they are fully explored in a companion paper (Bigby, Frawley, & Ramcharan, in preparation).

Discussion

The work of the History group was not explicitly based on existing models of inclusive research. Rather its evolution was guided by values about the right of people with intellectual disability to participate in rigorous research that produced meaningful outcomes for multiple audiences. That evolution was iterative and involved reflection on practice and change as necessary. The resultant collaborative group approach showed that shared and distinct purposes, shared involvement with distinct contributions and adapted methods could flourish amongst a group of individuals who were different but equal. It reflects some of the principles of co-operative inquiry (Heron, 1996) and inclusive research (Walmsley & Johnson, 2003) but provides a more finely grained relational perspective, where, shared rather than sole ownership of research questions and processes of doing research can take advantage of common interests of self-advocates and their allies.

Recognising that the interests of self-advocates may be shared with others opens space for academic research partnerships and access to University resources to explore issues important to people with intellectual disability. This holds the potential to combine different types of knowledge and skills. By giving equal value to different types of contributions, this model ensures maximum advantage is taken of the skills and experience self-advocates bring to research rather than wasting resources teaching skills that duplicate or mimic those of academics.

The adapted research methods used in this approach are similar to the description of the inclusive approach to analysis described by Nind as a “process of dialogue, seeking input and feedback rather than sitting down together to do a task or a mechanical application of a technique or method”(2011, p 358). While it is common for research findings to be presented in varying formats, this method of inclusive research enables different levels of analysis to be presented, that meet differing purposes and interests. The findings and outputs that were accessible and meaningful to self-advocates, perhaps represent one type of knowledge, while others which were not, represent another that is more theoretical or complex and make for a different type of contribution. Self-advocates are enabled to take on roles that are meaningful to them, which are well as mutually beneficial to the group, without the pressure to participate in tasks that have little meaning for them, such as academic writing. This is similar to Nind’s (2011) approach, where she describes, for example, academic partners alone developing a theoretical model from a corpus of work they had jointly developed with people with intellectual disability.

The emphasis on collaboration in this method brings realism to inclusive research that recognises the abstract conceptual thought and literacy required for some aspects of research. Sharing tasks between group members enables parts of the work to be done by academic partners, while the emphasis on working as a group ensures the outcomes of such work are shared and built on by group members with intellectual disability. This ensures the research is rigorous, for instance by situating it in the existing body of literature about the subject, or moving analysis to a conceptual or theoretical level. In this way, the concerns about inclusive research remaining at a descriptive level, and thus having limited value are avoided (Walmsley, 2004).

The added value of making research inclusive were illustrated by the wide range of contributions made by the self-advocate group members such as: the interview guide that neither academics or self-advocates could have constructed alone, but which proved a powerful data collection tool, enabling a richer data set than might otherwise have been the case; the reach into self-advocacy networks to recruit participants; the additional data gained as a result of self-advocate insiders questioning the accounts of others, and the differing interpretations of Reinforce’s history.

The History Group research used an interpretative paradigm, demonstrating that inclusive research can explore questions outside participatory or emancipatory paradigms. Use of this paradigm enabled different perspectives on the data which addresses the tensions

identified by Walmsley (in press) about whose voices should be included in research about self advocacy or which interpretation should take precedence. Rather than obscuring differences, this collaborative approach enabled voices to more easily stand alongside each other, and when necessary be explicitly owned by different members of the research group.

The centrality of the group in this approach and the dispersed power avoids the emancipatory disability research requirement of full control by people with intellectual disability and arguments about whether that is really possible (Chapman, 2005; Stevenson, 2011). The common research group workspace, as a place where all members understand, have a valued and rightful place, and where support is grounded in collegial relationships has many of the characteristics that Seale and Nind, (2010) identify as necessary to enable access for people with intellectual disability in other contexts. The approach is similar also to the milieu identified as necessary for their meaningful inclusion on advisory boards (Frawley & Bigby, 2011), reinforcing the view that a relational approach to access and inclusion has merit.

Building a group that has cohesion, trust and collegial relationships such as that described in this study, requires skills, conscious attention to processes and lengthy engagement (Brown, 1999; McDermott, 2002; Tuckman, 1965). This method of inclusive research is unlikely to be suited to projects with tight timelines, and the attention to multiple purposes will add to the necessary time and other resources required.

Various other researchers have highlighted the often deep and close relationships between partners in inclusive research, and some have suggested that, as people with intellectual disability invest more in these relationships than academics, they are open to exploitation (Atkinson, 2005; Booth & Booth, 1996; Redmond, 2005). This study suggested however that collegial relationships, “getting to know the insides and the outs’ (Mins,120911) are not an optional extra but fundamental to collaboration. The focus needs to more firmly be the dignity of risk rather than on protection. Not all collegial relationships have expectations of long term friendship but most hold the potential for ongoing acquaintanceships, for people with intellectual disability and academics alike.

The capacity for continuing reflection, flexibility and responding to the urgency of the moment are key skills required to work with complex organisations such as self-advocacy groups. In this paper, rather than ticking off elusive inclusive research criteria, based on principles derived from theory, an analysis of method derived from the experiences of

working with self-advocates to undertake a piece of rigorous research has been presented. The components allow for the different interests, activities and outcomes of academics and people with intellectual disability, and through the creation of a strong shared space, their common interests, activities and outcomes. This method tackles many of the critiques levelled against inclusive research and although it is not applicable to all the research questions of interest to people with intellectual disability, it is potentially applicable to research about questions asked by those with a strong insider knowledge of a topic who can find academic partners who share a common interest..

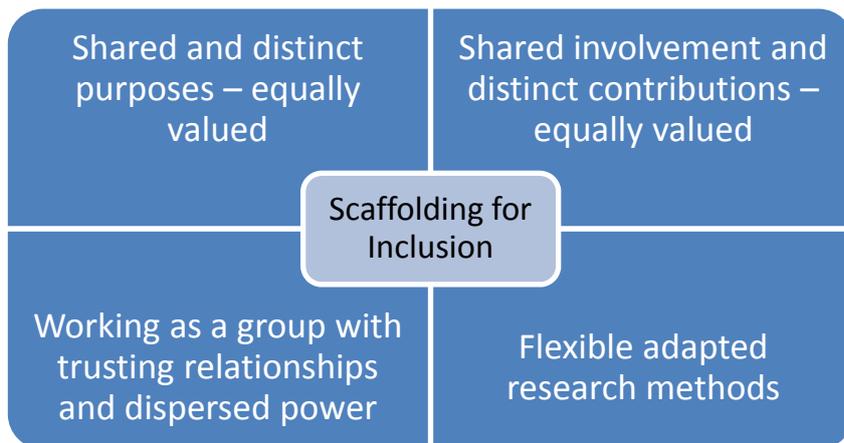


Figure 1. Components of a Collaborative Group Model

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