Conceptualising Inclusive Research with People with Intellectual Disability

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Abstract

Background. The inclusion of people with intellectual disability in research is a common requirement of research funding. Little conceptual clarity is available to guide the conduct of inclusive research or judge its fidelity, there is minimal evidence of its impact, and questions remain about its feasibility and rigor. Method. A comprehensive review of the peer reviewed literature and key texts was undertaken to more clearly conceptualise inclusive research and identify the issues associated with ways of approaching it. Finding. Three approaches to inclusive research were identified; advisory, leading and controlling, and collaborative group. Using the literature and the authors’ own experience each approach is illustrated and discussed. Conclusions. A clearer conceptual framework is developed to guide researchers and administrators as they consider inclusive research and its feasibility to particular research questions. A strong self advocacy movement is identified as one of the conditions necessary for inclusive research to flourish.
Accessible Abstract

Background. Organisations including government that fund research about people with an intellectual disability in the UK and Australia say it is important that people with an intellectual disability are involved in planning and doing research that is about them; this is called inclusive research. Some people have written about what they have done but not enough has been written and shared about the different ways of doing inclusive research. Method. The people who wrote this paper looked at all the literature about ways of doing inclusive research and reflected on the way they had worked with a group of self advocates in writing about their history. Results. There are three main ways of doing inclusive research; 1. Where people with an intellectual disability give advice about what to do; 2. Where people with an intellectual disability lead and control research 3. Where people with and without intellectual disability work together as a group with different jobs based on their different interests and skills. Conclusions. In the past there has been an idea that there is only one way to do inclusive research. This paper talks about the advantages and disadvantages of different ways of doing inclusive research, and when you might choose one way rather than another.
Conceptualising Inclusive Research with People with Intellectual Disability

Walmsley (2001) coined the term ‘inclusive research’ to denote research involving people with intellectual disability as ‘more than just subjects or respondents’. The inclusion in research of people with disability, their families and representative organisations is now embedded as a principle in Australia’s first national disability research agenda (Disability Policy and Research Working Group, 2011). This has been driven by the view that people with intellectual disability have the right to be involved in issues that affect their lives, and the assumed benefits that flow from their participation (Walmsley, 2001, 2004; Richardson, 1997; Stalker, 1998; Ward, 1998). There remains however, little conceptual clarity about the nature of inclusive research to guide researchers or judge its fidelity, minimal solid evidence of its impact (Nind, 2011), and questions about its feasibility and rigor (Keiran, 1999; Conder et al., 2011; Ramcharan, Grant & Flynn, 2004).

Walmsley & Johnson (2003, p. 10) defined inclusive research as ‘a range of research approaches that traditionally have been termed ‘participatory’, ‘action’ or ‘emancipatory’. This umbrella definition created space for diverse approaches and forms of involvement by people with intellectual disability (see, for example, the British Journal of Learning Disabilities special issue, 2012). Accounts demonstrate the breadth of ways inclusive research has been framed, representing quite different roles and outcomes for people with intellectual disability who are involved. For example, inclusive research has been framed as; participatory (Brooks & Davies, 2007; Chappell, 2000; Atkinson, 2005; Sample, 1996), collaborative (Knox, Mok, Parmenter, 2000; McClimens, 2008), co-researching (Redmond, 2004), cooperative (Schoeters et al., 2005), partnership (Ward, 1998; Williams, Simon & Swindon People First Research Team, 2005; Chapman & McNulty, 2004) and people led (Towson et al., 2004). A downside of the broad umbrella however, may be the use of similar terms to refer to quite different approaches. For example, Williams et al. (2005) refer to a 'participatory' approach emphasizing leadership and control by people with intellectual disability while in contrast Conder et al. (2011) use a similar term to describe a project that was clearly led by academic researchers. The literature suggests too that inclusive research has not been restricted to the type of qualitative method and collaborative enquiry where all participants share an equal voice and power in the research process, characteristic of the participatory or emancipatory paradigms. Turk et al., (2012) for example, reported on the participation of adults with intellectual disability in a large quantitative study that involved a randomized control trial.
As inclusive research becomes an imperative for Australian disability researchers, it is an opportune time to conceptualise it more clearly, consider its strengths and weaknesses, and the conditions needed for it to flourish. This paper draws on a comprehensive review of the peer reviewed literature on inclusive research, together with the key texts or grey literature from the UK and New Zealand and Australia. It is also grounded in the authors’ experiences of a six-year inclusive study with self advocates during which the need for a conceptual framework to guide inclusive researchers became apparent. The aim of this paper is to begin a process of more clearly conceptualising approaches to inclusion of people with intellectual disability in research. The paper draws on and develops further earlier work by Ward & Simons (1998), McLaughlin (2010) and Walmsley & Johnson (2003) which alludes to three approaches; people with intellectual disability as: 1) advisors to researchers, governments and organisations about research agendas, conduct or dissemination of research (called “advisory or reference groups” by Walmsley and Johnson, 2003, p. 146); 2) leaders or controllers of research (called “beyond co-researching - taking charge” by Walmsley and Johnson, 2003, p. 152), and; 3) collaborators in specific studies with researchers without intellectual disability (similar but not the same as what was called ‘co-researching’ by Walmsley and Johnson, 2003, p. 148). The common starting point of all three approaches is a respectful relationship and regard for the perspective of people with intellectual disability.

The paper grapples with issues which were not of interest to self-advocates with whom we worked. Positioning the academic research partners as sole authors reflects the potential for participants in inclusive research collaborations to have both shared and distinct purposes, which we have argued elsewhere was a key component of own approach (Bigby, Frawley, & Ramcharan, under review).

Table 1 briefly describes these three approaches and the discussion about each provides illustrations and draws out the issues associated with application in practice. Rather than a general discussion of the pros and cons of inclusive research broadly it is intended that organizing the paper this way will lead to a clearer conceptualization of approaches that will assist in guiding the increasing number of academics and higher degree students who are likely to adopt inclusive research in the future.

Table 1 about here

Advisory

An advisory approach may involve participation in setting research priorities or decisions about funding (Ward, 1998). For example, people with intellectual disability were
included on a steering group as part of the UK Learning Disability Research Initiative and were involved in reviewing and making recommendations about research proposals (Grant & Ramcharan, 2007). More commonly people with intellectual disability are included on research reference or advisory groups where, either as a separate group or with others, they provide advice to research teams about a project’s broad directions, or a specific issue brought to the group (Rodgers, 1999; Ward, 1998; Johnson, Frawley, Hillier, & Harrison, 2002). In this capacity people with intellectual disability may be actively involved advising about research design, recruitment strategies, data collection or dissemination methods. For example, as advisors to Emerson and his colleagues about the design of a national survey of people with intellectual disability, a group of self advocates suggested questions that should be included and the wording to be used (Emerson et al., 2005). Brookes and Davies (2007), as part of the development of a psychological therapy outcome measure brought together ‘experts’ with intellectual disability, who had experienced this type of therapy, to help researchers describe the dimensions of ‘how it feels to face cognitive limitations’. Their involvement was more than as informants in a focus group, extending to repeated discussion and trialing of the measure. Keonig (2011) provides a rare and detailed description of the involvement of reference group members with intellectual disability in data analysis and Whittaker (1997) of their employment to conduct a specific aspect of a study.

People with intellectual disability who are advisors to research in these ways have little control over how and indeed whether or not they are included. Those who issue the invitation to participate, either to individuals or a self-advocacy group, generally determine the parameters of involvement.

**Issues for Consideration**

Grant & Ramcharan (2007) suggest that participation in an advisory capacity is the most common way people with intellectual disability are included in research and that in this approach they are seen as ‘experts by experience’ who should be called on to prioritise, design, advise on and disseminate research. As participants have said, ‘we will make a difference if we are there’ (Grant & Ramcharan, 2007, p. 8).

Our experience in Victoria highlights some of the potential issues discussed in the literature that arise with this approach. Those who are invited are not always ‘experts by experience’ about the substantive content but simply the ‘most likely suspects’ by being among the few active or well known self advocates available (Bigby & Frawley, 2010; Nind, 2011). For example, in Victoria most of the small group of self advocates have little or no experience of specialist disability services but are often invited to be members of reference
groups about service-related research. The question of ‘expertise’ and ‘relevance’ is not an easy one to resolve. For some people their closeness to a topic might impede their ability to provide broad ‘advice’ about the direction a study should take or appropriate methods. For others, their lack of experience of the topic may not be an issue because they are able to see the world from a broad perspective and through their self advocacy skills in particular be able to link the personal and the political. Similar issues arise in some respect of other minority groups where a member is appointed to act in an advisory capacity based only the characteristic of belonging to that group, which used to be common for women. Limited development and support of self advocacy may restrict the pool of people with the experience or skills to undertake this work; or the lack of personal relationships between academics or government officials and people with an intellectual disability may limit the scope for recruitment of potential participants (Bigby & Frawley, 2010; Frawley & Bigby, 2011). In some cases, where people with an intellectual disability are appointed as advisors, there is a danger of simply inviting participants based on their characteristic of intellectual disability and assuming there is ‘an intellectual disability perspective’ (Frawley & Bigby, 2011). A related issue is the important point made by Walmsley (2004), who cites the research by McCarthy and Millard (2003) on menopause, which they found to be little understood by women with intellectual disability, and thus unlikely to be have been identified as relevant or a priority by them, yet turned out to be so.

This approach can ensure publicly funded research is relevant to the lives of people with intellectual disability, and improve the quality of research by for example; better recruitment processes, ensuring measures or methods of data collection are accessible and meaningful to informants, and enabling wider dissemination. Involvement may also provide paid employment for people with intellectual disability. An issue consistently raised about this type of inclusion is that of tokenism, form versus substance, whereby self advocates are ‘just being used to rubber stamp the process and not true partners’ (McLaughlin, 2010). The meaningfulness of participation depends on the milieu of the group, and the effectiveness of support strategies to ensure participants understand the decisions being made, the issues debated and the relevant materials (Frawley & Bigby, 2011). Our study of the history of self advocacy in Victoria (Bigby, Frawley, & Ramcharan, 2011) has uncovered numerous examples of the failure to adequately support self advocates who are invited to act in an advisory capacity and where people recalled contributing little and feeling disempowered. The failure to adapt meeting processes or devise other ways to enable participation may be compounded by issues of timing, such as long intervals between meetings, making it difficult
to stay well connected to a project. Finally, questions of representativeness arise, particularly in regard to advising on research relevance and funding priorities. As people with mild impairment make up the majority of active self advocacy group members they are more likely to be involved in advisory roles (Nind, 2011). This can mean they will represent their own experiences or perspective and will find it more difficult to represent those of others with more severe impairments (Bigby & Frawley, 2010). Recognition of the need for proxy representation of people with more severe intellectual impairment as well is therefore critical, particularly if advisory group membership includes more articulate people with other forms of impairment.

**Leading and Controlling**

This approach aims to give control to people with intellectual disability to initiate, lead and execute their own research about issues that are important to them. The proponents of this approach argue that ownership of research processes is paramount and if people with intellectual disability do not control research, then non-disabled researchers will continue to be responsible for producing knowledge (Nind, 2011), and ‘there would be little point in doing it’ (Williams et al., 2005, p 10). This approach most commonly uses action research, and participatory or emancipatory methodologies, that aim to raise awareness of structural factors and mean people with intellectual disability become subjects of their own enquiry. For example, the Carlisle Cooperative Research group asked questions about bullying (Towson, et al., 2005) and the Bristol Self Advocacy group about the experience of self advocacy groups (Williams, 1999). Valade (2008) provides an example of a participatory action research project where she supported a small group of people to discuss their problems with the local transport system, identify possible causes, points where pressure might be applied, and advocate for change to institutional and political representatives.

Involvement is usually as a member of a self-advocacy group, although examples are found of groups of service users or more individualised participation (Stevenson, 2010; Bjornsdottir & Svensdottir, 2008). Although the role of ‘research advisors’ and ‘supporters’ are acknowledged and explained in varying detail, accounts emphasise the steps to ensure that people with intellectual disability have as much control over as many elements of the research process as feasible in the particular context (Stevenson, 2010; Bjornsdottir & Svensdottir, 2008; Williams, 1999). For example, Williams and her colleagues describe the University-based research advisor and supporter as a facilitator whose aim was ‘for all stages of the research to be carried out by People First researchers, to the greatest extent possible, including analysis’ (Williams et al., 2005, p 8.). This aim was echoed by one of the self
advocates involved who said, “the supporter tells us what options we have, and of course tells us places that may be good to look at, but it’s our opinion that counts, nobody else’s” (p.10). Similarly the Carlisle Cooperative Research group (Towson et al., 2004; Chapman & McNulty, 2004) describe their approach as ‘people led’. Although advisors and supporters are regarded as equal members of the group, those who are labeled as having a learning disability drive the way the group works because they are the experts in this area’ (Chapman & McNulty, 2004, p.81).

Accounts of research where people with intellectual disability are in control often refer to training and preparation for data collection through the use of scripts or strategies such as turn taking. Descriptions are also found of undertaking line by line coding (Stevenson, 2011), or group-based thematic analysis that seeks to identify the ‘bits that are interesting’ or that works with selected portions of interview transcripts (Williams et al., 2005; Nind, 2011). Participants with intellectual disability are also commonly sole or joint authors of research publications. While papers about processes or methods are often found in the peer reviewed literature, papers that report findings are less common and are more likely to be found in unpublished research reports. This has meant much of the knowledge from this work, especially from the pre-digital age, is inaccessible to wider student and academic audiences.

**Issues for Consideration**

Doubt has been raised about the conceptual capabilities of people with intellectual disability to lead research (Kiernan, 1999) and it is suggested that “very little is known about the potential implications of intellectual impairment on the research process” (Stalker, 1998, p. 15). Concerns such as this arise if it is assumed that research led and controlled by people with intellectual disability is simply mimicking academic research using traditional methods rather than utilizing the real strengths, knowledge and skills that they bring to research from their life experiences (Ramcharan, Grant, & Flynn 2004; Bigby & Frawley, 2010).

The issue of support is crucial. As Chappell (2000, p.41) comments, “if people with intellectual disability need non disabled allies in the research process how can the integrity of their account be maintained… how can we prevent the non disabled researchers from assuming a dominant role in the research process?” Early commentaries raised concerns about the transparency and honesty of support, suggesting it had been obscured or undervalued (Nind, 2008; Gilbert, 2004). Allegations have been made of ghost writing (McClimens, 2008), stage management (Riddell et al., 1998) and of people with intellectual
disability being used as puppets (Aspis, 2000, cited Nind, 2011). These issues have been
recognized and tackled in recent papers through more detailed accounts of respective roles
played by researchers with and without disabilities (Conder et al., 2011; Bigby & Frawley,
2010, Chapman & McNulty, 2004; Williams et al., 2005; Stevenson, 2011). They reflect too
the long standing broader debate about supporters’ roles in the self advocacy movement, and
the contention that being in control, just as being independent, does not mean doing things on
your own (Goodley, 1998).

Few have expressed doubt about the individual benefits that flow from this approach
to inclusive research, which are assumed to include increased confidence, the chance to
understand more fully one’s own place in the world, enhanced knowledge about early life or
discriminatory experiences, greater respect from institutional office bearers and opportunities
for paid work. Beyond the individual, life story work in particular has been acknowledged as
adding missing accounts of people with intellectual disability to disability and institutional
histories (Atkinson, 2004). An important point is raised however, by Richardson (1997) who
warns of the potential damage to self esteem of participants as a result of delving into ‘cover
stories’, and forcing a reevaluation of status and circumstances necessitated if people with
intellectual disability investigate their own experiences of oppression.

Some commentaries have taken issue about the rigor of research led and controlled by
people with intellectual disability, and the value and quality of the knowledge created as
findings often remain at a descriptive level without interpretation or connection to other
literature, wider ideas or policy (Ramcharan, 2003; Flynn, 2003). Bjornsodtir and
Svensdottir (2008), for example, cite Walmsley’s comments about sensitivity to taking
control that can mean supporters fail to challenge or hone further work of researchers with
intellectual disability, and which as a result ‘says very little’.

There is a need for those involved to consider more deeply the nature of knowledge
developed from this type of inclusive research, to find different ways of interpreting and
judging its value or contribution to social change and to talk about these as part of the
dissemination process. Thinking about the nature of knowledge stemming from inclusive
research may also help to more clearly differentiate between inclusive research and more
straightforward advocacy or community development work (which normally employs less
costly, non-academic staff) and makes a different type of value claim.

Collaborative Groups

As suggested earlier, accounts of inclusive research have used similar terms like
collaboration, co-researching and partnership to mean different things, and sometimes to refer
to research that is led and controlled by people with intellectual disability where researchers without disability are allies or supporters. For example, Walmsley and Johnson (2003) suggest co-researching “implies an equal partnership, where researchers work with people with learning disabilities to pool expertise” (p. 148) but frame the non-disabled researcher as the ‘helper’. Our conceptualisation of collaborative groups is somewhat different from this type of co-researching and refers to partnerships or collaborations in which people with and without disabilities who work together have both shared and distinct purposes which are given similar attention and make contributions that are equally valued. The position of the people with intellectual disability is not privileged in terms of power or control and researchers are not simply there to assist. This approach was conceptualized through analysis of data from the authors’ 6 year ‘self advocacy history project’ (Bigby, Frawley, & Ramcharan, in press) but our review of the literature suggests it has wider applicability, and we illustrate it with examples from published studies.

A collaborative group approach combines the skills of academic researchers or others with those of people with intellectual disability to generate new knowledge that neither group could do alone. The group is characterised by reciprocal relationships based on trust, and a genuine belief there is much to learn from being involved in processes together (Nind, 2011; Bigby et al., 2010). For example, a New Zealand project that investigated the constituents of a great life comprised six people with intellectual disability (termed ‘co-researchers’, four people without intellectual disability termed ‘contracted researchers’, and several other people without intellectual disability termed ‘the co-researchers support team’) (Conder et al., 2011). The ‘group’ may also be a partnership of just two people, such as that described between Mabel Cooper and Dorothy Atkinson (Atkinson, 2004). All members have a sense of the whole project but may not be involved in every aspect of it (Ward, 1998; Nind, 2011) and each member brings distinct skills and experiences and makes their own distinct contribution.

Members share a common purpose for their involvement but also have their own distinctive purposes. For example, people with intellectual disability are unlikely to share academic purposes of publishing in refereed journals or conducting research that stands up to the applicable tests of rigor. Academics may not share a self-advocate’s purpose in recruiting new members or passing on group achievements to the younger generation (Bigby, Frawley, Ramcharan, 2010). Central to a collaborative approach is the equal value accorded to each member’s contributions, and a commitment to use resources to give equal attention to the diverse purposes of members. For example, the partnership between Mabel Cooper and
Dorothy Atkinson gave attention both to presenting their work to self-advocates in an accessible form and in less accessible academic arenas. Similarly, not all work publications or presentations will be co-authored.

While control is dispersed among group members, leadership of the research process often rests with a senior researcher. For example, although the ‘Great life’ (Conder, et al., 2011) project was unequivocally led by contracted researchers, who designed its methods and made decisions about needed changes, the influence of participants with intellectual disability on research processes was very clear when they refused to accept that a statement could not be representative of multiple quality of life domains forcing contracted researchers “to rethink the next step of the analysis” (p.44). Unlike the advisory approach, people with intellectual disability are more likely to initiate or negotiate their involvement in a collaborative group approach through replying to advertisements or being part of a network that enables mutual interests with academics to surface.

Research methods are usually but not necessarily drawn from qualitative traditions, and, as may occur in other approaches, are often adapted, taking a strengths perspective that uses existing skills and knowledge of group members. Individual methods of data collection or analysis may be transformed into group processes, as illustrated by Nind, who used seminars to present grounded stories that became the vehicle for concept development as the ensuing discussions moved between the concrete and abstract. In this way she explains “data generation and analysis occurred concurrently in conversation and in directed activities….., as new seminar inputs were assimilated into evolving concepts” (Nind, 2011, p.356). Adapting research methods in this way moves away from mimicking traditional methods through mechanical application of a technique or method to more of a “process of dialogue, seeking input and feedback rather than sitting down together to do a task” (Nind, 2011, p 358).

**Issues for Consideration**

This approach confronts some of the longstanding issues in inclusive research, whereby; ‘some jobs are for non disabled researchers….. yet academics do retain some roles without being explicit about it’ (Nind, 2011, p. 351). It tackles the issue that ‘control requires some reconfiguration in respect of people with learning difficulties (Stevenson, 2011, p.270). It has the potential to deal with the critiques leveled at inclusive research whilst maintaining the integrity and authenticity of the contributions made by people with intellectual disability. The knowledge/s generated are of a hybrid kind through indivisible intermingling of contributions and interpretations of all group members; both academics and people with
intellectual disability. By working at various levels of abstraction, with multiple layers of analysis and concepts, and producing different types of outputs, the frustrations expressed by Walmsley at the inability to share abstract skills with people with intellectual disability and to produce deeper analysis as part of inclusive research are to some extent resolved. It becomes legitimate, for example, to produce both a stand-alone life story as well as a more analytical and inaccessible interpretative account. This point is well illustrated by Nind’s comment that in addition to the other outcomes from her access study, “my colleagues and I developed a multi-dimensional model of access based on a synthesis of the data and analysis from the journey” (2011 p.357).

Implicit in this approach is the use of what we have called ‘non accessible space,’ which is similar to what Walmsley and Johnson (2003, p 15) refer to as ‘space’ to air arguments and debate, independent of the pressure of ‘nothing about us without us,’ and prior to translation into accessible formats for a wider audience. This is also an important space for academic writing and development of strategies needed to scaffold inclusion. Use of non-accessible space stands alongside creation of accessible work spaces for the whole group, which Nind (2011, p. 356) describes as ‘interactive space in which relationships, familiar ground and common assumptions can be built’.

The major issue with this approach is the sheer volume and scope of resources necessary if it is to be done properly - time, money, and commitment of funding bodies, academics and people with intellectual disabilities. Initiating research ideas, writing grant proposals or responding to tenders requires much longer than the time frames normally given, and devoting equal attention to the multiple purposes of group members, or producing multiple outputs, multiplies two or threefold the resources required for similar non inclusive research. As Atkinson (2005) and others (Redmond, 2005) have suggested too, the development of deep and trusting relationships between group members which underpins this way of working, places extraordinary demands and, at times, may also pose unique ethical challenges researchers find difficult, and some may not be willing or able to manage.

**Adopting Inclusive Research as a Core Principle for Disability Research**

This paper aimed to contribute some conceptual clarity to the overarching notion of inclusive research. It has highlighted the advantages, benefits and challenges of three broadly different approaches but in doing this does not intend them to be prescriptive, rigid or exclusionary categories, but rather used to help gain a better understanding of the diversity of approaches that fall under the umbrella of inclusive research.
Understanding the diverse approaches to inclusive research is critical for academics if it is to be meaningfully enacted and embraced by more than the handful of current disciples. Greater specificity about approach may lay the foundation for robust research design and support development of good practice and identification of the skills required. Implementing an inclusive disability research agenda should require researchers to provide demonstrable indicators of inclusion, applicable to their chosen topic, questions and design, and government administrators and academics to be realistic about time frames and expectations about the resources necessary to carry it out well. Greater clarity about approaches will enable administrators to draw up funding guidelines that clearly frame expectations, and avert the misuse of simplistic edicts about inclusion irrespective of the people, and severity or type of their impairment, on whom the research is to focus.

Importantly it must be recognised that inclusive research is not a panacea, and cannot be the universal remedy for including perspectives of people with intellectual disability, or for the generation of knowledge about their lives, policy or services they use. Too great an emphasis on inclusive research by funding bodies carries with it ‘the danger of omission in research of those with the greatest disabilities’ (Kellett & Nind, 2001, p. 51). Not all research lends itself to an inclusive approach, most participants are people with mild intellectual impairment as not “everyone with intellectual disability is able or willing to be involved” (Ward & Simons, 1998, p 131). Research about interventions or circumstances of people with severe or profound intellectual disability who are powerless to make even their basic needs known, for example meet both these conditions (Walmsley, 2004; Kellet & Nind, 2001). Strategies are needed to accord value and effectively canvass perspectives of others with knowledge about issues that impact on people with intellectual disability, such as families, friends, advocates or academics, and to recognise the value of methods such as participant observation to gain insights into perspective or quality of service delivery for people with severe and profound intellectual impairment. There will also be topics, relevant to people with intellectual disability that are identified as important by others, but which they would not identify as important. This does not necessarily make such topics any less worthy of research attention. In adopting the principle of inclusive research, care must be taken to avoid conformity at any cost, since this will inevitably foster tokenism and risk abandonment of important areas of research. Room must be left for researchers to make a case for non inclusive research without the application of penalties.

Particularly when research is controlled and led people with intellectual disability there is important intellectual work still to be done to theorise the type of knowledge.
developed, articulate its value and the means by which it should be judged. Evidence needs to be gathered about the value added to research endeavours by the participation of people with intellectual disability through the different inclusive approaches discussed in this paper. The value of inclusive research should not be assumed or overrated. As McLaughlin (2010, p 1600 & 1604) points out “we should pay such research the same respect we pay other research and examine its methods and claims critically and avoid giving it a ‘softer touch’ just because it is undertaken in collaboration with or by service user researchers”.

Greater conceptual clarity about expectations of inclusive research will lay the groundwork for understanding its application in practice and the components that should be embedded in research training at all academic levels. Without these steps there are clear dangers that policies about inclusive research will remain at a rhetorical level and not be well implemented. Finally, a major challenge in Australia, is the continuing development of a self-advocacy movement which is a prerequisite for generating the types of experiences and skills that equip individual self advocates to participate in any type of inclusive research. Self advocacy organisations are also central to building the networks necessary to bring together the shared and sometimes diverse research interests of people with intellectual disability, academics, policy-makers and service-providers needed as the catalyst for meaningful inclusive research endeavors.
References


Bigby, Frawley, Ramcharan (manuscript in preparation) A Collaborative Group Model as a Method of Inclusive Research


Mauthner, N., & Doucet, A, (2008) Knowledge once divided can be hard to put together again’: an epistemological critique of collaborative and team-based research practices. *Sociology 2008; 42; 971


Table 1. Broad approaches to inclusion of people with intellectual disability in research

<table>
<thead>
<tr>
<th>Paradigm to which most suited</th>
<th>Advisory</th>
<th>Leading and Controlling (People led)</th>
<th>Collaborative group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positivistic or social constructionist</td>
<td>Emancipatory disability, participatory/advocacy</td>
<td>Positivistic or social constructionist, participatory</td>
<td></td>
</tr>
<tr>
<td>People with intellectual disability experienced in either the particular issue or as self advocates</td>
<td>Individuals with intellectual disability or organisations of people with intellectual disability who identify the research issue as relevant to their life experiences or the collective group</td>
<td>People with intellectual disability who have lived experience of the particular research area</td>
<td></td>
</tr>
<tr>
<td>Overarching research priorities, or part of whole of a specific project</td>
<td>Whole project –research group supported by allies.</td>
<td>Whole project – part of a groups comprising people with and without intellectual disability</td>
<td></td>
</tr>
<tr>
<td>Reactive involvement, initiated by government, academics or organisations</td>
<td>Ideally but not always proactive and initiated by people with intellectual disability</td>
<td>Proactive involvement sole or joint initiation</td>
<td></td>
</tr>
<tr>
<td>Government, organisation or academic</td>
<td>People with intellectual disability</td>
<td>Academic</td>
<td></td>
</tr>
<tr>
<td>Government, organisation or academic</td>
<td>People with intellectual disability</td>
<td>Dispersed among group members</td>
<td></td>
</tr>
<tr>
<td>Government, organisation or academic</td>
<td>People with intellectual disability, individually or collectively</td>
<td>Shared and distinctive purposes between academics and people with intellectual disability</td>
<td></td>
</tr>
<tr>
<td>Priorities for funding or new knowledge for social change</td>
<td>Advocacy/immediate social change</td>
<td>New knowledge for social change</td>
<td></td>
</tr>
<tr>
<td>Group based consultation, trial of questions, review of materials</td>
<td>Participatory action research, surveys, interviews, workshops.</td>
<td>Adapted methods such as collective interviews, focus groups, iterative analysis</td>
<td></td>
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