

National Centre for Research Methods
Methodological Review paper

Practical considerations in doing research inclusively and doing it well: Lessons for inclusive researchers

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Practical considerations in doing research inclusively and doing it well: lessons for inclusive researchers

Introduction

This NCRM Methodological Review paper follows on from an earlier Review, *Conducting qualitative research with people with communication, learning and other disabilities: Methodological challenges* (Nind, 2008). That earlier review concluded that the practical, political and ethical challenges of inclusive research, together with the sensitivities of the process, were being embraced not just by the pioneers in the field but by researchers in different disciplines who would no longer be conducting research *on* people with learning and communication difficulties but *with* them. This paper builds from the conclusions of that earlier review, but is distinctive in that it is concerned only with doing research *with*, rather than *on*,

people with learning disabilities and others. The focus is on the practicalities of such research - often known as participatory research – that is research that ‘involves those being researched in the decision-making and conduct of the research, including project planning, research design, data collection and analysis, and/or the distribution and application of research findings’ (Bourke, 2009, p.458). We also look at research done *by* people with learning disabilities, often labelled emancipatory research. The focus is on researching in ways that are respectful and inclusive of the community being researched, on problems they feel ownership of, in ways that support them and that involve collaboration and openness (see Walmsley & Johnson, 2003; Nind, in press for a full discussion of inclusive research). The review is also usefully considered alongside the NCRM reviews of Kellett (2005), Holland and colleagues (2008), and Frankham (2009) where complementary syntheses of literature and discussion can be found.

Our focus in this paper is on learning about the practicalities associated with inclusive ways of doing research from the field of learning disability. These practicalities will be of relevance to researchers working in other fields and seeking participation of different groups in the research process; the intended audience is therefore broad. We are aware this

This review is about the ways research has been done together with people with learning disabilities.

Also about research done **by** people with learning disabilities



is not a fully accessible document, nonetheless we have included some visual cues and foregrounded messages from people who have been involved - voices of experience - as a way of engaging with and being respectful to researchers with learning disabilities who may be interested in this review. The focus of the review is timely because there is increased desire among government bodies, charitable organizations and research councils to commission research that embraces participatory or inclusive principles. This reflects concerns with participation of service-users and with social inclusion, citizenship, and the democratization of research (Nind, in press). It reflects a concern to hear the voices of ordinary people more directly in research. Here, Gary Butler, who has learning disabilities, explains how he sees it.

Irene managed to get funding to do more studies. It can be quite hard to get research funding, but funders probably realise how important it is to have people with learning disabilities involved in studies right from the start, because it means that the studies really matter to them. (Butler et al., 2012: 135)

Often, however, the desire to conduct research inclusively is not matched with the practical knowledge of how this can be achieved. Each new research project brings challenges in terms of breaking down barriers to participation and pursuing solutions to matters such as how to share control of decision-making, develop necessary skills, and negotiate uncomfortable territory in academia as well as in advocacy. In response to this situation this review provides an overview of a range of studies and a synthesis of emergent challenges and solutions as well as on-going practical issues. It incorporates the views of those experiencing these processes - the 'voices of experience'. The review enables a range of practical lessons to be gathered in one place; some of those included here were elicited from published sources, but many were shared in a series of focus groups we conducted in 2011-12. The focus groups were part of an ESRC-funded study designed to take stock of the state of the knowledge base and to produce criteria for quality in inclusive research with people with learning disabilities (Nind & Vinha, 2012). The review also reflects (i) our stance that there are various ways of doing research inclusively and not only one correct approach; and (ii) a bias towards qualitative research. This qualitative bias is inevitable as participatory research has some of its roots in the development of qualitative research and the concern within grounding research in the experiences and views of respondents. In reality, the vast majority of inclusive research is qualitative. Our examples and discussion reflect this. There will be added challenges when inclusive research has quantitative dimensions, and we look forward to seeing progress in addressing these.

We structure the review as a progression – divided into three sets of challenges – which echo the research process from getting started, through doing the research, to making impact. We combine images and different voices and avoid unnecessary academic jargon – without reducing the content to over-simplified messages – with the aim of enabling engagement and readability for broad audiences. We conclude the review with some pointers to resources that may be useful for anyone wishing to adopt a principled, effective inclusive approach.

Challenge 1: Getting started

Defining everyone's relationship to the research

We think it is very important to do 'ethical research'. This means treating everyone involved in the research with care and respect. It is also important that the research should empower people, not put people down. This is important because for many years research was done by people who had lots of power to say what people's lives were like, even if they did not have the life experiences they were researching about. These researchers were called 'experts' and they made their careers by researching people who were called 'subjects'. (Learning Disability Research Team, 2006, p47)

Doing research inclusively – or increasing participation – often begins with a concern with everyone's relationship to the research. The driving force might be a view of what makes research ethical, as the Learning Disability Research Team argues above. This might lead to changing the relationship between those who are the researchers and those who are the researched, so that it is more equal, or blurred, or there is more dialogue between the two. Townson et al. (2007) describe the main purpose of the Carlisle People First research team as being to do research that benefits people with learning difficulties and inherent to this, to develop an inclusive approach. The practical realities of what an inclusive approach might mean for the research process can be barely visible in research reporting, hidden in the language of partnership, user-involvement, people-led research and so on. However, there are increasingly calls for the process to be more transparent, so that the research can be properly judged and so that others might replicate, or learn from, the process (see e.g. Northway, 2000; Walmsley, 2004). This openness begins with the ideas for the research and how these are negotiated and shaped into a research proposal or research design.



As a funder, I love [it] when we get ideas that have been developed and where, from the outset, that's been developed with people with learning disabilities for example, or older people.

Starting with ideas

If one of the reasons for doing research inclusively is so that the research is in the interests of a particular group, that group will have something to say about how the idea for the research should be generated. Obviously, therefore, they will have something to say about what this means in practice. Carlisle People First Research Team (Townson et al., 2004, p.524) prefer it if 'projects undertaken by the team are based on the people's own interests or that of advocacy group members'. They make this a reality when they find and control their own funding and it is the people with learning disabilities who employ and supervise paid researchers. Ideas come out of their talk together and plans are made through their 'PATH process [which] is graphic and accessible and allows space for everyone to put forward their views and aspirations about how they feel a project could work' (Dias et al., 2012, p34).

As a support worker, I think that when research is completely initiated by people with learning disabilities it is much more meaningful.



Members of Carlisle People First were of the opinion that the regular self-advocacy group model, practised by People First and other groups around the UK, may not be the right way to provide advocacy for people living with autism. One of the members of the research team who was particularly concerned about autism suggested that we should look into the matter. (Townson et al., 2007, p.524)

As often happens, one piece of research may raise new ideas and generate new questions.

The research started because of other research Irene and Gary did before, about people with learning disabilities, cancer and dying. That study found that nobody knew how to tell people with learning disabilities bad news about cancer and dying (Tuffrey-Wijne et al. 2010a). We also found that nobody had thought much about the needs of the patients' friends and family members with learning disabilities (Tuffrey-Wijne 2010). (Butler et al., 2012, p. 135)

There are a minority of funders amongst the bodies that support research that are very interested in what users of services think. While some funders may have somewhat empty rhetoric about user-involvement, genuinely committed funders also value honesty and transparency regarding people's ideas about the kind of collaboration their research involves.

The practical challenges are likely to centre on how the ideas of the people who are usually researched by others get onto the agendas of research teams, or how those people become part of the research teams. One group of adults with learning disabilities and health researchers and practitioners recount how they tackled the challenge of developing ideas within and across meetings about researching keeping fit with so much else going on for those involved. They promote the use of video for this:

What worries me is if we receive proposals that are over-claiming or using words almost because they are designed to be words to appeal for a funder rather than actually describing the processes that are marked out in the proposal.



Members agreed to video record the meetings for future analysis and to create a permanent record of the group's work. Video recording did not appear to hinder members' contributions or the initial stages of getting to know each other. Indeed, as the project progressed, the members enjoyed looking back over the videos to aid recall. As five out of the eight participants did not read, it was also important to have visual representations of the meetings to aid recall, and to show the skills and development that had been achieved over a period of time. (Burke et al., 2003, p.67)

Ideas are not always generated in an organic way, however, and there can be false starts. Johnson (2009), seeking to undertake inclusive research with people with learning disabilities in Ireland, had to negotiate with service providers and make use of a senior manager's interest in research as a way of increasing participation of people with intellectual disabilities in the service. From this came discussion with staff and a service user, some easy to read advertising about the research and a 'disastrous first meeting' (Johnson, 2009, p.253). Johnson describes finding herself 'in the difficult position of trying to explain just what research was' (p.253). When they started again they got round their initial difficulties. 'At our next meeting we began by splitting into pairs and sharing stories about our lives. We then came back to talk about these, and together identified three issues which were seen to be important by people with intellectual disabilities in the group' (p.253).

Working inclusively at the ideas stage then, can be made to work by starting from people's lives and stories about lives. This can mean that the research becomes about painful or difficult experiences and a desire to make things better. In Johnson's (2009) case, the advisory group identified bullying as a shared problem, and a lack of anything useful to address it, led to action. Inclusive research of this kind can be emotionally charged and we include more discussion about this later in the review.

Promoting ethics – practical politics

Townson et al. (2004, p.73) make an ethical argument for research to be led by the people concerned:

If people do their own research it's about doing things for themselves and for their groups and not being led, or rejected by others. So that is why it is called 'people-led research' and not 'rejecting research'. It is started and led by us, we are not following someone else, or being partly included, which also means partly rejected, by someone else. There is a long history of 'Rejecting Research'. For research to be person-led it has to be done by people themselves right from the beginning by using the words people want to use, putting together reports and papers that are understandable for them and others, and using the methods that make the most out of each person's skills. Then we have real ownership of the research.



Their experiences, however, taught them that who was in charge of the research may not actually be what matters most. The group moved from a 'person-led' position to become a cooperative and worked on ways of working together so that academic researchers and support workers were not excluded from the decision-making either, but that took into account their differences in power:

We felt we wanted to do something different, where we were all included, where no one is rejected and we all work in partnership. The work is split in the research group according to people's skills and what they want to do, we decide as we go along. We all work together and the pace is just right. (Townson et al., 2004, p.75)

Griffin and Balandin (2004) use the concept of distributive justice when considering ethical research. They argue that it is injustice when groups are selected out of research, that is, when they are excluded from sampling frames such that findings are not relevant to them: 'Justice is a matter of distributing across groups for whom the research is intended both the benefits and the burdens' (Griffin and Balandin, 2004, p.66). Tuffrey-Wijne & Butler (2010, p.181) also reflect on this idea; they cite McClimens et al. (2007): 'Including those less able to communicate may well present insurmountable methodological difficulties and this exposes an ideological dilemma at the core of user involvement'. This is a challenge that is being taken on by inclusive research teams and by academics seeking to be inclusive in terms of decisions about who is researched and who the research is for.

There are ways of doing it, we are aware that the whole consent [issue] needs to be dealt with dynamically, and flexibility and respectfully. But what we will not allow to happen is that because of the fears of ethics committees these people's lives get, or continue to be, hidden.



Griffin & Balandin (2004) also discuss the danger of researching marginalised people in ways that reproduce their marginality. Furthermore, they see ‘sincere participatory approaches’ as ‘less likely to exploit the power imbalances between researchers and participants with intellectual disabilities in the planning, conduct, and dissemination of research’ (p.78). The debates about whether inclusive research approaches are more ethical in themselves are already well rehearsed (see Gallacher & Gallagher, 2008; Holland et al., 2008; Nind, in press). The practical realities involve ensuring that people who are moving to positions of partnership in research are neither over-burdened nor over-protected. They involve balancing costs and benefits beyond the usual matters of ethical regulation considered by ethics committees.

Ramcharan, Grant & Flynn (2004) discuss the ethics of accessibility and the concept that if ideas are not understandable by would-be partners in research then it is hard to imagine how they can be used to change their lives. They qualify this argument into ‘such ideas cannot be used meaningfully by people with intellectual disabilities *themselves* in seeking to change their lives’ (p.86). Working inclusively can mean working to make the ideas accessible or working only with more accessible ideas. More sophisticated ideas may be used in research *for* people with learning disabilities (or any marginalised group), and this may be a practical, less inclusive but equally ethical alternative. Ramcharan, Grant & Flynn (2004) point out that working with people’s own ideas does not automatically lead to gains for them. They cite the example of the research done by self-advocacy groups in which people with learning disabilities may collude with systems that oppress them.

Safeguarding ethics: information and consent

Tuffrey-Wijne & Butler (2010, p.177) argue that it is important to locate where the researchers with learning disabilities can contribute to projects to best effect – such as ‘advising on the suitability of research proposals, designing study information materials, wording ideas in an accessible way and disseminating research findings’. They also highlight their important role in helping to ‘safeguard ethical standards by asking important and relevant questions about the participants’. Gary Butler reflects on this, observing that it was easier for him as a researcher with learning disabilities to give his opinion when he was no longer the only person with learning disabilities on the advisory group. His involvement in the ethical process permeated across the study:

There’s also ethics, asking if we thought we were exploiting people, but I don’t think we were. There was one time when everybody got really upset, when we read one of the stories. That was heart-wrenching. The agenda went clean out the window! We broke for tea and had more of a personal discussion. (Tuffrey-Wijne & Butler, 2010, p.179-80).

Tuffrey-Wijne and Butler (an academic researcher and a person with learning disabilities employed in the same university department) have tackled various ethical challenges together and with their wider team. They have useful examples of participant information sheets that are easy to read with photographs and line drawings (see Butler et al., 2012).

Others can learn from these and from their process of developing informational DVDs and showing and discussing these as part of their information and consent processes. Similarly, the Learning Disability Research Team (2006) advocate asking people with learning disabilities for their advice on the design and working of consent forms before putting them to use.

So we thought how can we make the consent forms better? We should actually bother to go around and see what form of communication people use, what method. Do they talk? Do they sign? Do they use pictures? Just go the extra mile, and find out which form of communication they use. As a self-advocate, that's what I think you should do



Safeguarding ethics: anonymisation

An ethical or 'methodological given' (Tilley & Woodthorpe, 2011, p.199) is protecting the anonymity of those involved in research. Tilley & Woodthorpe (2011) argue that the requirement for this that is written into a range of guidelines is rarely critiqued as an ethical principle. Consequently, they highlight, qualitative researchers who are committed to participatory or emancipatory approaches 'can find themselves in something of an ethical and methodological tight spot' (p.199). Revealing identities is in contrast to normal expectations, but 'where participants are active agents in the research - as they can be

within participatory or emancipatory approaches – there is a strong case to be made for offering individuals and organizations the choice as to whether or not their identities are disclosed’ (p.199).

Tilley & Woodthorpe (2011) cite Grinyer’s (2002) writing on respondents losing their ‘ownership’ of anonymised data, and furthermore how potential for empowerment can be lost in the process, which poses a new ethical challenge. They refer to the researcher’s ‘two-fold task: first to produce knowledge and analysis that contributes to intellectual discussion reviewed by our peers, and second to disseminate this in appropriate forms and via a range of avenues into wider society’ (p.204). The

principle of anonymity is a good fit for the former task but not for the latter. Making the research meaningful for the wider world is enhanced when the real-world environment of the research is visible, when there are photographs and real people rather than abstract, nameless people and places. Inclusive researchers may feel the pull to authenticity more than they feel the pull to anonymity. Some of the Carlisle People First research team discuss their position on this, respecting that people with learning disabilities want credit for their own words, and they outline their practical approach:

Often people [have] got ideas and sit down in a group and at some point what can be conceived as an idea pops out [of] somebody's head. But can you actually say that belongs to that person? To what extent [is it] a by-product of a discussion, where you have got facilitators, advocates, support workers, people with learning disabilities, all making their contributions ... this idea arose out of a process of discussion and debate where people could speak freely.



... we used the real names of the interviewees. This is because the people interviewed wanted to be named and we therefore gathered consent for this. Where points were being made in the article that were not very positive, we used the terms 'one of the men' or 'one of the women' so we did not offend people. (Dias et al., 2012, p.46)

The push and pull at work between wanting to give/claim credit and usual requirements for anonymity have an impact when it comes to archiving data too. We faced this in our study of quality in inclusive research because it was funded by the ESRC (Economic and Social Research Council) who usually require that data from research they fund is archived so that it is available for other researchers to use for secondary analysis. We had to explain all of this to our participants and we used accessible exit consent forms to give people who had contributed data choices about whether (and how) they were named in the archives as well as in the final report and publications. We explained the ethics of our processes and decisions to the people at the archives and found them to be very helpful and receptive to our different approach to anonymity.

Trust and rapport

Trust and rapport are central to the relationships in most qualitative research. Butler et al (2012) found value in repeated meetings, ice-breakers and familiar routines - starting in the same way each time providing a sense of security which built up over time. Perhaps more a matter of degree than difference, inclusive research projects may require methods to be tailored to individual preferences and needs:

Flexible. Each group had different needs and wishes. One group wanted Irene to explain facts about cancer, so she prepared a slide show for this. One group wanted more pictures and stories to think about. One group wanted more time to talk about their experiences. (Butler et al., 2012, p.139)

What may be different, however, is the dynamic between participants and researchers. This features as important in many accounts of the research process. For example:

In order to facilitate effective sharing within the group, what was needed was not Gary and Amanda's impartiality. On the contrary: their facilitative power lay in their ability to share of themselves within the group, to give their opinion about participants' contributions and to resonate with them. Both had personal experience of a parent dying of cancer; Amanda had been a cancer patient herself. (Butler et al., 2012, p.141)

Many people have been rejected in their lives and rejected at school. We have been rejected from society and should not be rejected from research, especially when it is about us. People who are not in the same boat as us don't understand what it is like to be us, they have not had our experiences. People with learning difficulties know that we have been through difficult times in our lives; we all have problems and have been mistreated. Because of this people want to talk to us. We know what they are talking about and understand them. (Townson et al., 2004, p.73)

Researchers said that small groups and one-to-one meetings were often the best way to involve people well. Some projects found it was very important to develop a personal relationship with participants and their families, to build trust and continuity so that people felt safe enough to give their views. This seems to be especially important when people have higher support needs and need support to get involved and when research takes place within minority ethnic communities. In this case, knowledge of the community and its culture and language, plus time and effort to build relationships, seems particularly important. (Learning Disability Research Team, 2006, p.70)

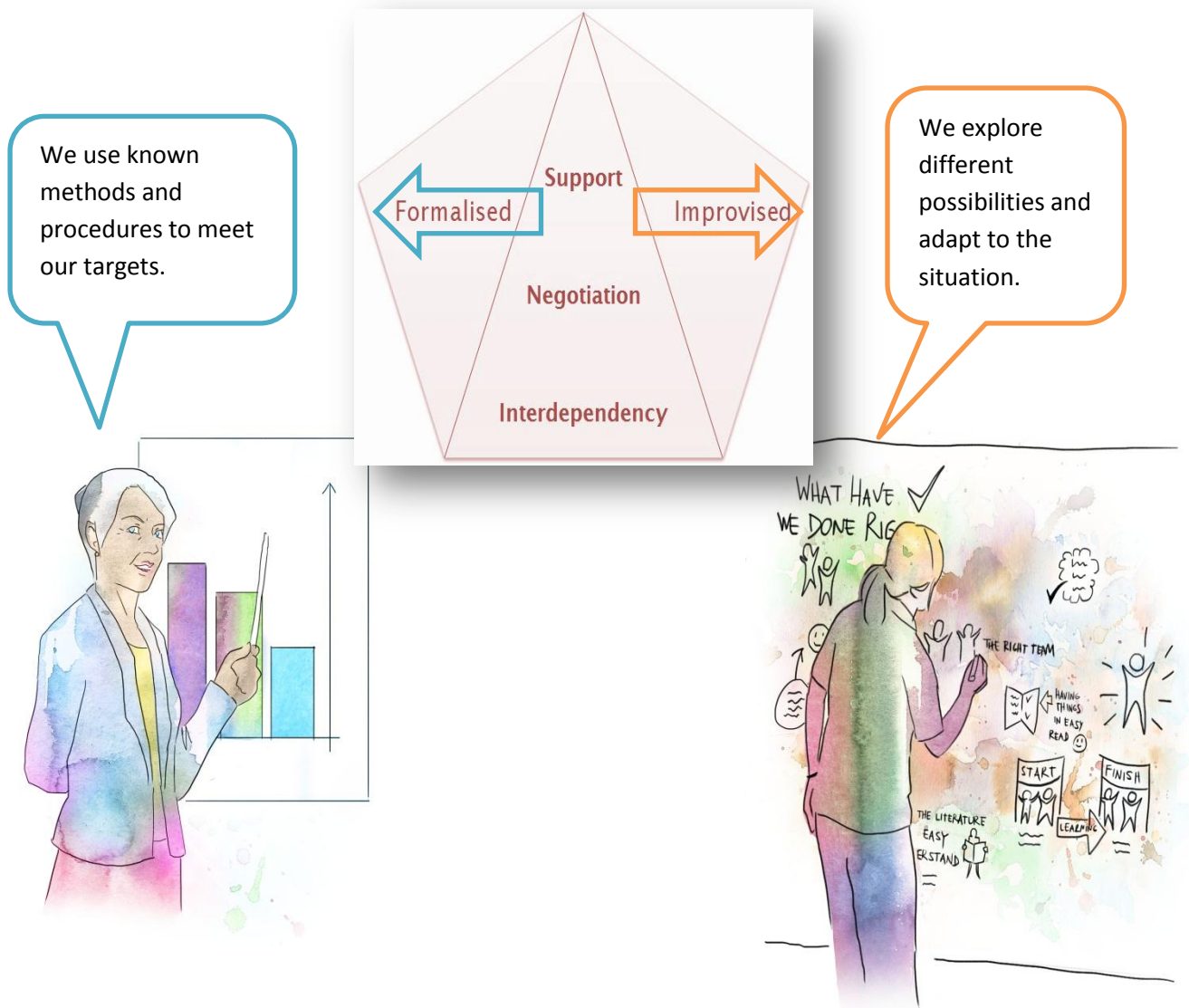
Again, not altogether uncommon with other qualitative research, inclusive researchers face working out how to bring the research relationships to some kind of close. Atkinson (2013) is candid about how hard this can be with people doing life history work together. One possible ending is that adopted in the study of experiences of cancer.

We ended the group with a celebration. We brought food and drink and just relaxed together. We took some time to talk about what it was like to be in the group. We had a laugh, which was important because we wanted it to be fun as well. We did not want people to leave feeling sad. It was also a way of saying goodbye to the group. (Butler et al., 2012, p.140)

Challenge 2: Generating and making sense of data

Team dynamics

Conducting inclusive research tests out the team dynamics as the group works together to generate and make sense of data. Usually the values of the research team set the tone for how things should proceed and then there are some compromises along the way. From analysis of the focus group data of experienced researchers we were able to identify the different ways they worked together in inclusive research and to describe these in terms of an overall model (Nind & Vinha, 2012, p.30).



There are practical choices to be made then, between ways of working together that are formalised - often pre-planned or regulated through advisory groups - or improvised - more responsive and less rule-bound (Nind & Vinha, 2013), though it is possible to combine the two in one project. More fundamentally, the emphasis in the team dynamic may be placed on support, negotiation or interdependence.

When support is emphasised some people are understood to work in support of others; there are experts who are decision-makers and leaders and there are people who support them. ... "It's not always easy, because I may have an opinion ... but I think that ultimately we make sure the co-researchers make the decisions. ...

When negotiation is emphasised the people working together put considerable time and energy into negotiating their processes and agreeing how to proceed. This can be as important as the research itself. ... "We, the support workers who are involved in the research team and don't have a label of learning disability are required to hold back what we want to say until everybody else in the group have had their say, to make sure we don't take over too much, which we can do by accident sometimes, it's a difficult thing to monitor. ...

When interdependency is emphasised, support and negotiation are secondary to enjoying cooperation in teamwork. Levels of trust and communication are high ... People work together on problems but also share out roles and tasks according to strengths. Considerable value is placed on listening to, and learning from, each other. No one is more expert than any other to the extent that they do not need the other and this leads to strong mutual respect. (Nind & Vinha, 2013, pp.5-6)

In practical terms working verbally and making video has proved helpful for groups working on reviewing the literature together as well as sharing ideas. Practical changes can affect the balance of participation.

Each presentation lasted \cong 5 min, followed by \cong 10 min for discussion. However, it is possible that insufficient breaks were built into the session (there was one break after about 40 min), and some people had a somewhat glazed expression by the end of the session. ... Because of the mixed feelings about the success of the second session, the third meeting reviewed the videotape and developed key points from the literature review. This promoted increased involvement by everyone and helped to set the context for participation. (Burke et al., 2003, p.67)

This group learnt by experience that it was not helpful to rush on, or to do lots of background work as in the usual sequence of research events. Nor could they bounce ideas around freely. They needed a structured approach to meetings with agendas and minutes to aid everyone's memory – and they found that getting into a predictable pattern for meeting helped people's involvement but without taking away the excitement of the research. Another practical solution to the challenge of moving forward with their ideas was found when they produced a visual metaphor of a road of their progress and decisions. They used this to present the next stage of the road at each meeting. In our study we used visual newsletters and poems generated from narrative statements for similar purposes.

Methods and roles

While some of the above translates into decisions having to be made about who gets paid and who does what, there is a natural follow through into decisions about collecting and analysing data. This may mean choosing methods that people can do rather than those beyond their immediate capacity, or getting round challenges 'with a bit of imagination and planning' finding creative ways to incorporate people's '(often hidden) talents, experiences and views' (Learning Disability Research Team, 2006, pp.21-22). Transcribing interviews is not easy or fruitful for people with literacy or keyboard difficulties, but using audio-recordings and visual reminders may work equally well (Dias et al., 2012).

The experiences from inclusive research involving people with learning disabilities is that support staff or academic researchers may be essential to helping projects run smoothly and with tackling everyday obstacles like finding somewhere to meet, organising transport, and getting past gatekeepers. But clarity is needed regarding what is required of people supporting researchers or supporting participants.

So it is a completely joint project in respect that a couple of people, I can't remember all their names, came over and they learned how to do interviews, focus groups, because there is a huge number of skills to be learned, huge skills, you may take for granted.



Support workers chipping in with their opinion were rarely helpful. This was demonstrated very clearly at the first meeting of one group, where I had failed to brief a support worker properly about his role. (Butler et al., 2012, p.141)

Johnson (2009, p.254) reflects on her learning about roles:

Part of my learning was the need to let go and to see myself as a resource and a consultant to the people who were doing the research locally. No Longer Researching About Us Without Us brought people together to talk about their lives in a space that was different to that of 'being a service user'.

Chapman & McNulty (2004, p.77) reflect on the issues of roles in depth, arguing from their position supporting people with learning disabilities doing research that 'we need to think about how people can keep control of their own research if other research support people are involved as well'. For them, 'unless the process of support is clearly out in the open ... it cannot be challenged by others or improved upon' (p.78). They discuss how support workers may not know more about research than the people they are supporting, and those they support may also know more about what they want from support workers. In an interdependent process, people learn about research and support relationships together.

Groups have learned through experience that some methods just don't work well, such as writing to people as a means of recruiting participants. Alternatives are necessary:

One project organised a day out as a way of meeting people and getting them involved. In another project, the people with learning difficulties involved had produced a video to recruit more people. (Learning Disability Research Team, 2006, p.71)

They have also learned that people with learning disabilities can add value to the implementation of frequently used methods like focus groups.

The participants really liked the fact that Amanda and Gary helped to run the groups. One participant said: 'It would be hard without them in the group. I wouldn't have been able to cope.' Another said: 'I wouldn't find it easy to explain things if they weren't there.' And another: 'It breaks the ice with the group when you two speak.' One support worker commented: 'It's empowering for people to see Gary and Amanda in that role.' ... It became clear that this kind of facilitation could only come from researchers with learning disabilities. (Butler et al., 2012, p.140)

More recently the Carlisle People First research team have found value in their particular informal approach adopted by people with learning disabilities interviewing other people with learning disabilities (Dias et al., 2012). Williams & Barbour (2013) have reflected on the benefits accrued by people with learning disabilities when they break with established traditions in interviewing by, for example, spontaneously chiming in and empathising freely.

The value added by working in an inclusive way needs to be tangible as there is considerable consensus that doing research inclusively takes more time and, by implication, is therefore more costly (Staley, 2009; Nind & Vinha, 2012).

A lot of the teams had not really thought about involving people with learning difficulties as paid researchers. This needs to be thought through when a grant proposal is being developed, as it requires the right budget to make it happen. ... Most of the teams thought that a lot more time would be needed if people with learning difficulties were involved in projects as researchers. (Learning Disability Research Team, 2006, p.58)

In their analysis of the work of a range of projects the Learning Disability Research Team highlight that funders need to be prepared to pay for meaningful involvement of people with learning disabilities as researchers, which is likely to mean imaginative methods, additional materials and longer timescales. There is also often a need for additional training. Many projects use advisory groups to include the views of lay people, but even the method of employing advisory groups, when combining different stakeholders, may require training on what is involved and how to work together across differences in power and experience (Johnson, 2009).

Methods of analysis

The challenges of gathering or generating data have been readily taken on by people with learning difficulties who have learned on the job, or through training provided by academics or each other, how to use qualitative methods in particular. The practical challenges, therefore, are surmountable. People with learning disabilities have learned, used and adapted the methods of interviews and focus groups, life story and oral history. These have been particularly relevant to concerns within inclusive research with bringing people's lived experiences to the attention of others. One group of self-advocates involved in the first survey of the lives of people with learning difficulties (Emerson et al., 2005) strongly influenced the questions that were asked and how, thus avoiding confusion among respondents.

Perhaps providing more challenge is the issue of participatory data analysis. This is a less well-developed and less transparent dimension of inclusive research (Nind, 2011). Nonetheless, coming to make sense of the data is in many ways a crucial time for perspectives of people affected by the research issues to shape the conclusions drawn from the study and the core messages that are shared. Gary Butler (2010) regards collaborating on analysis as worthwhile if time-consuming. He also explains how people without an academic background come to understand what data analysis is about and what it involves.

Here is the question Irene asked the research team: 'We've had 12 h of meetings with people with learning disabilities, and they told us lots and lots of things. If we have just 15 min to tell others what we found, what will we say? What is at the heart of the groups' experiences and opinions?' Well, there is a challenge. We had to do what is called 'data analysis' to get to the bottom of things. (Butler et al., 2012, p.140)

Carlisle People First Research Team (Townson et al., 2013) refer to this as 'finding out about what we found out about'.

The most accessible and meaningful form of data analysis for research teams including people with learning disabilities seems to have been identifying themes and their significance for the people the research is about. In Butler et al.'s (2012) team the academic team members identified the themes from immersion in the transcripts and the whole team allocated quotes to themes.

They put all the same ideas together and called them 'themes'. All four of us then looked at these themes and read out loud sections of what people had said to see whether they fitted into the themes. This took several months. We had to look at the themes and read different sections several times, because to begin with it did not all fit in. Niki thought up the names of the themes, but when we talked about it, we sometimes found that they were not quite right. Gary and Amanda really helped with this. For example, when Niki explained her ideas about people being 'excluded', Gary and Amanda felt that it was not totally true. They thought that it was really about being 'protected'. Niki went back to her desk to look at everything again, and the next time we met, we found that everything fitted better." (Butler et al., 2012, p.140)

This has echoes of analysis stories in all kinds of research teams, but here those with and without learning disabilities found a way to have dialogue and to value everyone's distinctive insights. They have worked through the practical challenges by allocating tasks according to strengths with the academic (Irene Tuffrey) condensing data into vignettes of participants for collaborative teams to work with. They have noted and used the responses of those with learning disabilities to the data while they get used to extracting themes for themselves. There were mutual benefits to this (and a kind of interdependence) as Irene Tuffrey reflects.

There were moments when, maybe for the first time in our working relationship, I felt supported by Gary in my role as a qualitative researcher with ill and dying people, not only practically but also emotionally. ... maybe patronizingly, I had not expected such genuine support from Gary; I had anticipated a need to help and support him in his tasks, as I had always done. Reading extracts from my field notes, which contained vivid descriptions of the deep suffering of people with learning disabilities and of my relationships with them, Gary's compassion for the challenges I faced in my efforts to understand the participants' lives turned us into equal colleagues, not just on paper but in practice. This was, I believe, empowering for both of us, because it constituted a true partnership where I was supported as well as supporting. I was amazed and humbled by Gary's ability to consider each story in great depth; to be outraged, uplifted and moved in quick succession; to give his own perspective and his considered opinion; to comment on my influence on the data" (Tuffrey-Wijne & Butler, 2009, p.179)

Gary Butler describes getting to grips with qualitative data analysis as being about 'stories and experiences' (Tuffrey-Wijne & Butler, 2009, p.179), which may be 'harrowing at times' (p.180). He reflects on the emotional labour of this, leaving work behind at the end of the day and the value of working within a team that supports its members.

Some teams argue against academic researchers leading the analysis process. For example, the Carlisle People First Team argue

Our team has always been clear that analysis, like any other part of the research cycle, has to be accessible and undertaken by the team. (Dias et al., 2012, p.43).

Importantly, we did not have a non-disabled researcher analysing the transcriptions first – it was a joint effort. ... A lot of collaborative research relies on research supporters sifting through data before team members hear or see it (Dias et al., 2012, p.44).

Their research group have used colour coding of transcripts aided by photos and plenty of time for the process. In other projects they avoided transcripts and worked with the audio data only.

Like many researchers before them, people who have traditionally been the mere subjects of research - when tackling analysis of quantities of data - have faced the challenge by mapping things out on 'big pieces of flipchart on the wall' (Learning Disability Research

Team, 2006, p.34). They have found that it takes practice before being able to see what the data is telling them, and training to learn how to check evidence for the claims they want to make. Doing research inclusively may constrain the options for how analysis is conducted, which will be 'limited by the researcher's and co-researcher's analytic capabilities' (Ramcharan, Grant & Flynn, 2004, p.96). This may make the choice of analytic approach a pragmatic one. For some the best option is to narrow down the scope of the task, ruling out the use of software packages with technical skill requirements. For others, such as Tuffrey-Wijne & Butler (2010) the need to use software for the vast quantity of data from their ethnographic study meant that first attempts at including Gary Butler, who had no formal training in data analysis, involved him more as a consultant, sharing his important perspective on the analysis, rather than as a full analyst.

Quality research

There is something about you wanting to invest and see it as process through people get involved as co-researchers shaping all aspects of themselves ... changing their own lives, the lives of the group, life beyond the research output, that is added value that comes of something that is co-produced



Ramcharan, Grant & Flynn (2004, p.97) argue that, 'as with all other research, participatory research should seek to make clear the grounds for rigour when making knowledge claims'. For some inclusive researchers, decisions are influenced more by the importance given to rigour and for some they are influenced more by the importance given to inclusion. Prioritising rigour may mean compromising on the analytical contribution of non-academics and therefore perhaps the authenticity of the knowledge claims. Prioritising inclusion may mean other compromises in relation to the extent of theorisation of data for example. Some inclusive researchers get round this with parallel processes and products from the research: an accessible outcome and a theoretical one. Funders willing to pay more for inclusive research look for quality of course. One funder has described looking for 'shared purpose' (Nind & Vinha, 2012, p.27), genuine partnership and 'life beyond the research output' (Nind & Vinha, 2012, p.36) but there is little said about the specifics of a quality report itself.

Some inclusive researchers have responded to the challenge of delivering quality research and social inclusion by being very transparent about where they have shared purposes and where they may have different interests. They have discussed the processes and benefits that have unfolded as well as the findings. Walmsley & Central England People First (in press)

for example, discuss how researching the history of their own People First group mattered most to the self-advocates but that they wanted Walmsley, their academic partner, to set this within a wider history of self-advocacy. Some groups have stressed that there are different, rather than better or worse ways of knowing. In turn they have reflected explicitly on the distinctive qualities that their ways of knowing offer, such as using and extending the insider cultural knowledge of learning disability (Nind & Vinha, 2012). Some groups have addressed the quality issue by stressing what they value in research, such as the involvement of people with learning disabilities throughout the research process and producing findings that are understandable and useful to them.

There is some common ground in terms of traditional markers of quality in qualitative research and markers of quality stressed by those involved in inclusive projects. Establishing this was one of the outcomes of our focus groups with over 60 researchers working in varied inclusive ways in the field of learning disabilities (Nind & Vinha, 2012). Quality inclusive research, we concluded, was that which:

- answers important research questions that could not be answered (so well) without an inclusive approach;
- reaches participants, communities and knowledge that otherwise would not be accessed;
- uses and reflects on insider cultural knowledge;
- is authentic, that is, recognisable to the people involved; and which
- makes positive impact on the lives of those involved.

What counts as knowledge? And what knowledge counts? ... We are still stuck in this thing about hierarchies of evidence, peer reviewed, non-peer reviewed, journal ranking, and all the rest of it ... the inclusive research project is to me very much about relational practice, it's about pluralities of knowledge and people valuing and recognizing that and not putting one set of voices above another.



These quality criteria allow for more nuanced judgements about how inclusive research should be done than those allowed within the mantra of *nothing about us without us*. They

support inclusive researchers to think about what those people who have more often been the subjects of research bring to the research to enrich it. They can also be used as a guide to principled but practical decision-making.

Challenge 3: Making research impact

Audience

For many traditional academic researchers the question of disseminating the research comes once a study is completed: this is the end point. For many people with learning disabilities the question of who will read the report and what difference it will make is more of a starting point. The whole point of doing the research is that it will lead to people sitting up and listening.

I think people don't listen to you [academics] because they think, oh well yeah yeah ok that's just another birdie talking off on a roof top, whereas [if it] is people with learning difficulties are doing the research ... shock horror, these people should be in an institution but they're doing research, we better listen to them because it's like shock horror



Practical decision-making about the means of dissemination needs to come early in an inclusive research project. The accessible products of researchers that our focus groups participants reported developing included:

- an accessible title!
- an accessible report
- easyread versions of academic reports
- versions in different formats, languages and font sizes
- a joint presentation
- multimedia outputs: video/DVD/websites/podcasts/exhibitions/dramas

The Learning Disability Research Team (2006) additionally report use of audio tapes, CDs, interviews on local radio, visits to schools and word of mouth. While some of these can be

developed retrospectively, multimedia outputs in particular require the gathering of images, video and so on throughout.

The mode of reporting is all about audience. While, Kerrie's experience told her that the shock value of a person with a learning disability reporting research had a desired impact on her intended audience, self-advocates from Central England People First came to a different conclusion about their study of the history of their organization:

For professionals and other important people we need to influence we needed to write something that helped explain self advocacy. We knew that they might want more detail than would normally be in an easy read document. This was a difficult decision but we decided that with help we could write something that we couldn't write by ourselves but that we could understand.

We were not keen to have things which were not in easy read, but we understand that sometimes it is important to make exceptions to our rules. (Walmsley & CEPF, in press).

For them, their concern with audience and purpose led to a somewhat uncomfortable decision to have the academic employed by them to help with the research write some academic material for an academic audience, while they wrote from their experience for other self-advocacy groups. This group was reflective about the major questions of voice and audience, and transparent about their reflections also. When choices are made in a less considered way, the assumptions behind them can leak through to say something about the whole dynamic, as Balandin (2003, p.78) argues 'access to findings is a litmus test of who the beneficiaries of research really are'.

Much less is written about the process of disseminating through conference papers than through written accounts. Niall in Chapman & McNulty (2004), however, usefully describes the process of providing supportive 'scaffolding' to people with learning disabilities in making presentations, using an interview format to prompt and direct the focus and gradually fading such support as skills and confidence grow. The Learning Disability Research Team (2006, p.36) reflects on their processes in a large conference.

For the conference we organised creative workshops and presentations using drama and imaginative visual examples. One presentation involved a giant snakes and ladders board, the height of the room, to show the ups and downs of doing research. Another presentation involved a real washing line, with various items pegged onto it, to describe the journey of the researcher. We mixed a real cake in one workshop to show the mix of ingredients needed for good inclusive research and did a 'crystal maze' game in another to show how you can overcome barriers to inclusion.

Transparency

It is frequently impossible to tell who has contributed what in an academic paper with more than one author. This is largely regarded as unimportant for the integrity of the paper (though it may matter for the careers and academic credentials of the people involved). For inclusive research though, where there is often a string of names associated with a paper, this has greater importance. Who did what in these instances makes a difference to the credibility of the paper as authentically representing the thoughts or words of all the partners. It is widely recognised that academics have greater power and resources when it comes to sitting down at the keyboard or submitting to journals and so doubts arise in people's minds about who is really authoring the paper. This leads to calls for greater transparency. Walmsley (2004), for example, argues that amongst all the talk of people's involvement 'it is important to reclaim the word researcher as it is conventionally used' and to clarify roles regarding the process and product to make them 'ethically sound' and 'methodologically rigorous' (p.68) as otherwise:

The hard work, the finely honed skills, the self restraint researchers need to exercise have been camouflaged, as are the particular contributions made by people with learning difficulties. (Walmsley, 2004, p.69)

She concludes with the impassioned and convincing argument:

People with learning disabilities have made and will continue to make valuable input to research. They do not need obscurantist language to prove that. Rather, they need the contributions they make to be named and described and recognized for what they are, not for what we wish they could be. (Walmsley, 2004, p.69)

We can see manifestations of this. Chapman & McNulty (2004) describe the process of supporting the writing of the paper, 'We are all in the same boat', including the many iterations and the compromises that had to be made given pressures on time and resources. Butler et al. (2012) begin their paper by spelling out the (payment) status, roles and experiences of the four members of the research team, and they each have an individual space with their own voice in the paper in addition to their joint story. Burke et al. (2003, p.65) explain how they discussed the sequence in which their names should appear as authors, jointly agreeing on alphabetical order 'as the best indicator of equality'. Williams & Simons (2005) used a change of type face to identify speakers in joint writing and Walmsley and Central England People First have experimented with using facing pages to position different voices alongside each other

McClimens (2007, p.272), though, tells an honest but less consensual story of the writing process. He had wanted to co-write with his co-researchers with learning disabilities:

I tried to impress on our collaborators that here was evidence of a public desire for accounts of shared working. In this way, we argued, we could simultaneously bring our work to the attention of a wider and scholarly audience while demonstrating our commitment to the cause of collaboration in all things related to learning disability research. Our partners were enthusiastic. After all, this just echoed the words of one of the group, Peter, who said 'We want to put it in a magazine so people can read it'.

Ultimately McClimens, the academic, opted to write a 'minority report' (p.273) or individual account of his own after protracted, messy attempts at shared writing failed. He reminds us that language, the core ingredient of writing, is 'the site of a struggle for control, for knowledge and for truth' (p.273). His 'partial, incomplete, subjective and wholly biased account', he reminds us, 'is therefore my truth' (p.273). Just as the meaning-making involved in co-analysis is only just coming to be developed, so too is the largely language-dependent meaning-making of co-writing across major differences in power and resource. McClimens therefore makes distinctions between 'authorship and editorial control, between copy typing and creative writing, between writing up and writing down' (p.273). There are lots of practical lessons to be learned from his account. Our own boxing up of particular voices echoes strategies used that show exactly who is co-ordinating the exercise. Speeding ahead, and privileging the theoretical may not be acceptable moves to non-academic researchers in a team as McClimens found (or even between academics with different background experiences as we have discussed). While matters of vocabulary and jargon may be more contentious in the learning disability field than any other, pace and style are focal points for any collaborators in writing. Attention also needs to be paid to questions of who the writing is for – including the benefits to the authors and readers – and how can it be achieved. Matters of voice, length (LDRT, 2006) and presentation matter to people and can take time to resolve.

One team, who have been through extensive discussions together, have ventured into the new territory of editing a journal special issue together, on the theme of inclusive research.

We wanted to see a partnership approach to the whole process of peer review and publishing research

... we met with the editor of the journal, Professor Duncan Mitchell to ask whether our group could, for the first time in the UK, complete the whole process for a special edition of the journal: that is, to peer review articles and write the editorial in partnership. We were very pleased that he was open to our request and allowed us the space to put the idea into practice. This 'special edition' is the result. (Blunt et al., 2012, p.83)

The whole process took two years (Holman, 2012, p.86) with much learning involved about what makes papers good enough and inclusive to earn their place in the issue and how terms like 'inclusive' and 'partnership' are used to mean different things. From this the partnership team concluded that it is 'good to point out exactly what the 'sharing' or 'inclusive' process is so that nothing is hidden from the readers view' (Blunt et al., 2012, p.83). They model this in their own reflections on their discussions during the editorial process about what to do with papers with difficult language or that 'talked about people with learning disabilities as if they were all the same, that is, just one big group of similar people' (Blunt et al., 2012, p.84).

Conclusion: Adding to the body of knowledge

One of the key findings from our focus group study with inclusive researchers in the learning disability field was that people ask a lot from inclusive research.

It became clear that everyone wants inclusive research to do a lot of things:

- create knowledge (the research goal)
- give voice and build self-advocacy (the political goal)
- bring funding to organizations (the practical, sustainability goal)
- provide training, skills, jobs, networks, and friendships (the wider agenda)

(Nind & Vinha, 2012, pp.36-37)

In this review we have focused on the methodological challenges, showing the political nature of practical actions in this context. This extends beyond data methods to a wider range of methods from conceiving ideas in teams to co-presenting. It is also clear that researchers grappling with, and writing reflectively about, such methodological challenges are adding to the body of knowledge, not just in substantive areas but in the field of methodology itself. We have illustrated some of the lessons that can be learned for a much wider audience from the inclusive research work with people with learning disabilities. If more of the methodological learning can be brought together in resource documents like this review paper, it may be that inclusive researchers are freed up to put more of their energies into creating substantial, substantive knowledge, from which we can learn more about the products of changing mechanisms of knowledge production and about the pluralities of valid ways of knowing. Similarly, it may allow for greater focus on making a difference, which is at the heart of all of this.

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Further resources for inclusive researchers

Further reading & practical examples from the field of learning disability

British Journal of Learning Disabilities, 40(2), 2012

(Special issue on the Research and Work of Learning Disabled People with their Allies and Supporters)

Journal of Applied Research in Intellectual Disabilities

(Forthcoming special issue on New Directions in Inclusive Research)

The Learning Difficulties Research Team '*Let Me In – I'm a Researcher!*'

(Discusses and illustrates the ways in which research commissioned following the Department of Health Valuing People White Paper succeeded, or otherwise, in being inclusive)

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4132916

Nind, M. & Vinha, H. '*Doing Research Inclusively, Doing Research Well?*'

(Reports on research about quality in inclusive research with people with learning disabilities involving focus group dialogue with inclusive researchers. Report includes case study materials; website includes video material)

<http://www.doingresearchinclusively.org/>

The inclusive research network (in development)

<http://www.inclusiveresearch.net/doing-inclusive-research/>

Emerson *et al.* 'National Survey of Adults with Learning Disabilities in England'.

(Website includes materials used)

http://www.dh.gov.uk/en/Publicationsandstatistics/PublishedSurvey/ListOfSurveySince1990/Generalsurveys/DH_4081207

'Plain Facts', accessible research summaries produced by the Norah Fry Research Centre

<http://www.bristol.ac.uk/Depts/NorahFry/PlainFacts/index.html>

A. Aide-memoires for practice

This series of questions is not intended to specify one correct way of working: there are many ways of doing research inclusively and different perspectives on what makes it good. It is instead intended to provoke reflection and stimulated considered action.

QUALITY: Questions to ask yourself when judging the quality of inclusive research with people with learning disabilities (Nind & Vinha, 2012, p.60)

1. Is the topic relevant to the lives of people with learning disabilities and interesting to them? Could it become relevant?
2. Does the research involve people with learning disabilities in a meaningful and active way?
3. Are the participants in the research treated with respect?
4. Is the research communicated in a way people with learning disabilities can understand and respond to?
5. Is there honesty and transparency about everyone's role and contribution?
6. Were the ways of working carefully thought through and adapted in response to needs?
7. Does the research create worthwhile knowledge?
8. Are there likely long-term wider benefits for the people involved e.g. new networks, skills, funds, roles, social inclusion?
9. Are the research questions the kind that inclusive research can best answer?
10. Does the research reach participants, communities and knowledge that other research could not reach?
11. Does the research use, and reflect on, the insider cultural knowledge of people with learning disabilities?
12. Is the research genuine and meaningful?
13. Will the research make impact that people with learning disabilities value?

TEAMWORK: Questions to ask yourself when working out how to work together in inclusive research (Nind & Vinha, 2012, p.61)

1. Why are you working together on the research? Do you have a shared purpose, or do you want different things from it?
2. What do you each understand inclusive research to be?
3. What values guide the way you want to work together? How will you put those values into action?
4. What terms will you use to describe yourselves? (co-researchers, partners, team members etc) What does your choice of the terms say about you?
5. How will you talk about the research? (How often, where etc)
6. Who is setting the agenda?
7. Does everyone have equal right to speak? How will you make sure everyone is heard?
8. What skills, knowledge and qualities do each of you offer?
9. What will you do together and what tasks will you need to divide out?
10. What can you plan in advance and where might you need to adapt as you go along?
11. What kinds of support are needed?
12. How will you work through differences of opinion and challenges?
13. How will you learn from each other?
14. Are you placing most importance on support, on negotiation or on interdependence?
15. What will work best for this particular project at this time?

ETHICS: Questions to ask yourself when developing ethics protocols for inclusive research

1. Who feels ownership of the research and why?
2. Who is included, who is excluded and who is marginal? Can you justify this to yourself and others?
3. Who will benefit most from the research and why?
4. What do participants and fellow researchers stand to lose and gain and is this understood by them?
5. Are different parties in danger of being over-burdened or over-protected?
6. How will support be provided for the emotional demands of the research?
7. Are people clear about their roles? Are those roles visible to others where this matters to the credibility of the research?
8. Have you thought about what boundaries you might want to push and why? Have you been honest about your limitation?
9. Is information for participants provided in the mode most preferred by them? Who is advising on this and how?
10. Who will be anonymised in the research and who will be named? What choice have fellow researchers, supporters and participants had over this?
11. How is the value you place on fellow researchers, supporters and participants communicated to them and others?
12. Who decides on what the key messages from the research are, how they will be communicated and to whom?