

Exploring ethical issues arising from ten years of inclusive research with people with a learning disability

Liz Tilly, Director of Building Bridges Training and Senior Lecturer in Social Care, University of Wolverhampton, UK, liz@building-bridges-training.org

Abstract

Inclusive research enables people with a learning disability, with support, to take a lead role at all stages of the research, including the design, process and dissemination, rather than just contributing to the data collection (Walmsley and Johnson, 2003). In 2010 a short-term research project enabled a group of people with a learning disability to 'research their own lives'. An unexpected outcome was that the members greatly valued the opportunity to tell their stories and wanted to continue. Ten years later the group continues to research issues affecting them and their peers from a disability rights (United Nations General Assembly, 2006) and social model of disability perspective.

This article is based on the personal observations and reflections of their non-disabled group facilitator and fellow researcher, regarding a range of ethical issues and dilemmas raised by this inclusive research approach. They include anonymity and confidentiality, the need for flexible roles of the group facilitator, including advocate and supporter, and the extent that this conflicts with the role of co-researcher. Power, ownership and control of the research agenda are also discussed.

Introduction

This article explores and reflects on some of the ethical issues, challenges and dilemmas raised in the journey of doing research with co-researchers with a learning disability, an approach termed 'inclusive research' (Walmsley and Johnson, 2003). It will first outline the main features of inclusive research methodology, then describe and discuss ethical issues encountered in practice and finally suggest recommendations for future similar research collaborations.

Inclusive research

Research about people with disabilities has traditionally been done by non-disabled people, by relatively powerful experts on relatively powerless subjects and therefore on an unequal basis (Ward and Flynn, 1994). Decades ago, people with a learning disability were not asked their opinions and choices, instead their parents or staff were asked to speak for them. However, from the late 1960s changes in attitude meant that people with a learning disability started to be consulted for their personal views, and gradually genuine participation commenced (Walmsley, 2001).

Although research about people with a learning disability has been slow to involve them in the process at any level (Kiernan, 1999), they are increasingly taking a more active role (Walmsley and Johnson, 2003; Zarb, 1992; Minkes et al., 1995). There has been a development from accepting that people with learning disabilities have opinions and the right to express them (Stalker, 1998) and they are the best informants concerning their experiences (Chappell, 2000), towards a more general understanding that speaking up about one's experiences is a fundamental human right (United Nations, 2007). As a result, research involving the collaboration of people with learning disabilities is taking an increasingly prominent place in current literature on learning disability related issues (Walmsley, 2001; Nind, 2014).

The emergence of the social model of disability from the late 1970s identified the social barriers experienced as the disabling factor, as opposed to a person's impairments (Barnes and Mercer, 2004). This social movement has enabled the development of an approach to research where people with disabilities are equal partners. Typically disability research either considers the experience of disability or the structural barriers, which by some are considered to be oppositional. Emancipatory research, where people with disabilities are central to both the process and analysis, can be challenging for those with a learning disability to do without support. There are, however, calls for all research concerning people with learning disabilities to be emancipatory and to lead to real social change (Watson, 2004; Oliver, 1992). Inclusive research is grounded in these values and is an approach where support is integral without undermining the ownership of the research project (Walmsley, Strnadová and Johnson, 2018).

Inclusive research is also known by other names: co-research, collaborative, user-led, partnership and participatory research (Nind, 2014). There is not scope here to explain the history and nuances between these terms and approaches. For the purpose of this article, inclusive research is understood to be where people with a learning disability identify the research topic, take a lead role, with support, in all aspects of the research process, including deciding the research topic, methodology, analysis and dissemination, and are far more than just data informants (Walmsley and Johnson, 2003; Walmsley, Strnadová and Johnson, 2018; Nind, 2017). It acknowledges that people with a learning disability are best placed to identify the social barriers they experience and the societal changes that should be made. It gives voice to not only their experience but also their own way of communicating this (Herron, Priest and Read, 2015).

The Building Bridges Research Group

Building Bridges is a social enterprise which co-delivers training about learning disability and instigated the research group. In 2010 a short-term project was established to enable a group of people with a learning disability to 'research their own lives' using focus groups and creative activities. They completed the project by producing a report of their findings (Money Friends and Making Ends Meet Research Group, 2011).

The members greatly valued the opportunity to meet regularly and tell their stories, with the status of being researchers. Ten years later, the group is still meeting regularly to research issues affecting them in their social networks (Building Bridges Research Group, 2014, 2016). They have also written or contributed to a number of peer reviewed journal articles (Mooney, Rafique and Tilly, 2019; Tilly, 2019, 2013a, 2014, 2013b, 2016; Tilly and Building Bridges Research Group, 2015). Subjects include housing, welfare benefits, coping with independent living, health and managing money, and enabling professionals and academics to better comprehend their challenges in daily living. The group has seen changes in membership over the years, but averages eight members. The members mainly live independently and none have any support from learning disability services.

Positive benefits for co-researchers

The members' participation in the research group has brought immense personal benefits. Membership of the research group provides a range of functions such as friendship, fun, peer support and an opportunity to identify and resolve issues and social barriers. Where they may lack tenacity with other commitments, such as volunteering in charity shops or participating in schemes and courses they are required to attend as part of benefit claims, attending this group is a high priority usually achieving 100% attendance, signalling its importance to them as an anchor in their lives.

Other outcomes include increased confidence and assertiveness among the members, and heightened awareness of their rights. They see the group as a place to record and discuss social injustices they experience. When they experience frustrations, for example relating to public transport or housing issues, invariably they will say 'we'll have to talk about this in the group!'

The group relish participating in the dissemination of their research, at events, conferences and university training, and they particularly welcome the opportunity it affords to travel to new places as well as the occasional free meals! Furthermore it gives them the status of experts, with respect and acknowledgement. They are also immensely and rightfully proud of their reports and articles. It has a huge impact on the professionals and students who hear their first-hand accounts. This is evidenced in their references to our original report which revealed the lived experiences of this group who are usually hidden from mainstream and learning disability support services.

While having huge respect and admiration for the group's tenacity, commitment, personal growth and group achievements, it has also led me to reflect on a number of dilemmas, challenges and ethical issues encountered over the previous decade. The article henceforth is written in the first person as it is based on my observations and reflections as the non-disabled researcher who has worked with the group over the last decade, and in the context of the wider literature. These issues are now outlined and discussed.

Identification of the research topic and question and seeking ethical approval

A crucial element of inclusive research is that the research topic should be identified by people with a learning disability themselves as being an issue or social barrier for them and their peers (Nind, 2017; Walmsley, Strnadová and Johnson, 2018). However, in practice, this may not happen for various reasons. For example, the initial idea may be triggered by the availability of funding applied for by the non-disabled researcher who then recruits the co-researchers.

A strong ethical grounding is a core feature of social and participatory research. However, the process of requesting ethical approval can itself present a conundrum. Should the co-researcher wait for approval from a university ethics committee before approaching the co-researchers, thereby excluding them from the first hurdle? Their involvement in developing the research proposal, however, risks contravening the ethical guidelines about not approaching 'vulnerable' people until ethical approval for the research project is awarded. Ethical approval is usually gained on their behalf by a non-disabled collaborator from an academic institution (Northway et al., 2014; Ham et al., 2004). What typically happens with our research group is that ideas for projects emerge from group discussions and develop into a more structured proposal which I then take forward as an ethics proposal application without their involvement.

Consent and motivation to participate

It could be argued that true consent is difficult for people with a learning disability, regardless of providing accessible information sheets and consent forms. They may not fully understand what they are consenting to or appreciate the reach of the dissemination, especially if it is outside their experience. Many people with a learning disability also tend to acquiesce and be compliant (Clare and Gudjonsson, 1993). An important ethical issue is that people with a learning disability often have unfulfilled lives and therefore may agree to participate to fill otherwise unoccupied time. They typically have limited income from welfare benefits and therefore even a £5 or £10 voucher, or free lunch, may be strong motivation for some to participate (Money Friends and Making Ends Meet Research Group, 2011). This creates a dilemma when recruiting research participants but is particularly problematic when recruiting co-researchers, where the role is even more complex.

Validity and equality

Inclusive research requires a strong rapport between all group members. A non-disabled researcher cannot suddenly decide to work inclusively and launch into it. It needs an environment of trust and relationships to be nurtured and built up over time. There also needs to be consideration of roles and equality of power in the decision-making. While the non-disabled researcher may have different roles in the research project, such as managing budgets, leading on accountability and reporting to funders, there must be equality in the research process. The academic researcher may be more articulate but the co-researchers are the ones with the lived experience and unique insight into both the challenges and solutions. It is this shared partnership that adds value to inclusive research (Nind, 2017).

It is important that co-researchers are not involved just for lip service, and that participatory research is not wrongly labelled as inclusive. Genuine participation is extremely time-consuming, for example preparing easy read information or taking time to explain, remind and assure. But making reasonable adjustments can enable greater inclusion and therefore more pertinent research findings (Northway, Howarth and Evans, 2015).

Another issue is the cost of attending conferences and events which may be prohibitive for co-researchers, denying them opportunity and status. Funding applications should take into account the need for all the team to be able to share in this opportunity. On occasions we have been able to disseminate findings as a research group at UK conferences, especially where reduced fees apply for contributors with a learning disability. But for international conferences I sometimes have to attend on my own. I am sometimes able to access funds from my academic institution to do this, but I am struck by the injustice in this.

Mission creep, self-advocacy and tenacity

One of the dilemmas in our research group was the tendency to become a self-help group, or a place to moan and gripe, with interest waning from an initially 'hot topic'. One such example was a survey with peers to establish which social landlords provided carbon monoxide detectors, to form the basis for a campaign to get detectors provided for all tenants. There was initially a high level of enthusiasm for the project. We produced easy read questionnaires for members to approach their peers and started to collect responses, but the project fizzled out. It requires considerable time management and support to sustain the group from concept to

completion. Goodley (2000) notes a mutually beneficial link between self-advocacy groups and co-researchers, which can be a focus of activity for when research projects come to a close. However, this blurring of roles between advocacy and inclusive research can have negative consequences; one funding application failed when the funder insisted we were a self-help group rather than a research group. To overcome this, there is a need to regularly remind the group's members of the role of the group, and to help them understand and reflect on the nuanced roles of letting off steam, advocacy, research, dissemination and campaigning. There is a time and a place for all of these functions, but they can require subtle and supportive management.

A further ethical issue is that this research approach also identifies current issues that co-researchers and people they interview have in living independently and the lack of support from both informal support networks and formal services. These can be serious concerns which I feel need addressing as a priority with policy makers, above disseminating as a research output. As a co-researcher it leaves me with knowledge that needs to be urgently addressed, for example disparity in welfare benefit assessments, lack of support for health and wellbeing, limited supported housing options that needs social change above research dissemination.

Personal issues creating tension in roles

Over the ten years of working with the group, members have sometimes shared very personal and painful stories, such as having children removed, bereavement and poverty. When such issues arise, the inclusive researcher needs to know how to support them. In practice, however, there are limited services and resources for referral to, for example, grief counselling. This has put pressure on me, and added tension to my role as the non-disabled person in the group, feeling obliged to help meet the need or pursue support elsewhere. A range of issues and situations have come to light which, while not safeguarding concerns, were cause for concern, including oppressive relationships, debt, poor personal hygiene, unintentional neglect of pets' needs and home health and safety. Sometimes, with no one else to turn to, members have approached me for help and support. To counteract the power imbalance this could cause, I share issues in my own life which adds to the richness of our relationship and the bond of trust. I am always touched by the members following up with me how I am and about these issues, and it contributes to the equality in the group.

Similarly, issues can arise where co-researchers share discriminatory views or demonstrate 'othering' (Traustadottir and Johnson, 2000). Examples included social workers, and other community groups such as Travellers and newcomers from Eastern Europe. These incidents have resulted from negative personal experiences, a lack of awareness, sharing views of other people in their social network or the need to elevate their personal social status. This requires sensitivity if these views are to be challenged in a timely and appropriate way (Simons, 1999), but the act of challenging itself can bring another dynamic to the co-researching concept.

Implications of increased self-confidence and awareness of rights

Williams (2011) notes there can be huge contrasts between the private lives of people with a learning disability and their public strong collective voices in the role of self-advocates and researchers. Some of our research group members have grown in confidence and gained new-found freedom of expression. Some have grown in confidence from barely speaking in our group to now being able to present in front of hundreds of people with confidence and also ask questions in seminars. However, this new assertiveness can see a backlash when it threatens the status quo at home. When two emboldened female group members challenged their male relations by being more assertive, wanting more autonomy in the home, including control of their own money, this has led to tensions. In one case a member was temporarily prevented from attending meetings by her family.

Ownership and anonymity

One of the biggest ethical concerns with inclusive research is the issue of anonymity (Tilley and Woodthorpe, 2011). How do we balance protecting people's identities while enabling them to be proud of who they are and their story, which often include aspiring elements of survival and resilience? In the original research project in 2010, university ethical approval was gained which assured anonymity of the participants. Later these participants wrote their report, with no names being mentioned, but this led to an article for a practitioner journal, where the group members not only wanted their full names included but also their photographs, indicating personal and collective pride and the desire for acknowledgement. After discussion, a compromise was reached where first names only were used.

A similar issue arose with the Kew Gardens oral history project where a participant wanted to be identified. The author was concerned about de-identifying people against their wishes, suggesting that this point should be included in the assent process in future work (Manning, 2010). However, even with consent, there is the issue of a lack of awareness of how research is now digitally disseminated and the implications of this, which needs to be taken into consideration.

Confidentiality

‘What’s said in the room, stays in the room’ is our group’s mantra to reinforce the importance of confidentiality and is one of the ground rules for the meetings. However, there have occasionally been minor breaches. One individual was motivated to use information gained in the group to give him status with others outside the group, with huge implications for the group dynamics when this came to light. It should be recognised that friendships within and outside the group can be fluid, fragile and tenuous at times. The social circles of the group are small and their allegiances can fluctuate. The information shared in the group needs to be managed carefully, and regular reiteration of the ground rules is vital.

Realistic expectations for change

In social research there is much talk of ‘impact’ and expectations that research should be transformational (Danchev and Ross, 2014). However, academic researchers understand that policy and public attitudes can take a long time to change. This can be hard to understand for researchers with a learning disability and often leads to frustration. For example, on a research project about the transfer from Disability Living Allowance to Personal Independence Payment – the new disability welfare benefit and its associated assessment procedure – the co-researchers’ conclusion was that the system was unfair and there was an expectation that there should be immediate change. It is therefore the role of the non-disabled researcher to provide support to aid the group’s understanding of the wider policy context and to manage these expectations for change without dampening a belief that social change should and can happen. They should also facilitate this change happening through using the inclusive research findings to generate wider awareness and support campaigns as appropriate.

Creating new knowledge

Another issue is that academia tends to fund research to enable academic discourse and publishes peer-reviewed findings which hold academic rigour. This leaves little space for the work of researchers with a learning disability whose analyses will typically make a more simple and pertinent contribution, often focusing on required social change (Smillie, 2015). In order to get work published in peer-reviewed journals it may need an academic to add a further layer of ‘theory’ and discussion, challenging the ownership of the research. The researchers with a learning disability must be made fully aware of this and the reasons for it, and given reassurance that it is there to strengthen and not lessen their contribution.

Endings

It is important that the ending of the research project is planned from the start. Typically an inclusive research project will be short-term, perhaps under a year, due to the nature of the funding. However the termination of the group meetings and activities and relationships can mean a significant loss for the members with learning disability, who may have nothing to replace it and miss the relationships. In the case of this group the original plan was to exist for one year, but the members had other ideas (Tilly and Building Bridges Research Group, 2015). The group has continued to meet, but it has been an ongoing challenge to find further funding. If the research project is time-limited, it is essential that this is made clear at the outset and the ending is planned carefully and sensitively (Danchev and Ross, 2014).

Conclusion

The benefits of inclusive research for both people with a learning disability and for increasing knowledge and understanding by far outweigh the ethical issues raised. There needs to be consideration of how to enable genuine disability activism, how to use research to inform campaign work, and even be political, while also helping people to understand that change at a policy level can be complex and take time. Awareness of the ethical issues outlined above, and how to manage them is of paramount importance. The highlighted issues should be acknowledged in applications for ethical approval, and continually monitored throughout the research journey.

More people with a learning disability should have the opportunity to do inclusive research, but this will require their co-researchers to assess the potential challenges and issues and implement appropriate plans. University ethics committees should be willing to accept applications where non-academic co-researchers have contributed to the ethics application, enabling them to be part of every stage of the research process. Finally, as Richardson (2012) suggests, we could see people with a learning disability, with support, having a place at the table on ethics committees in the future.

Acknowledgements

With thanks to this research group whose work has enabled others to understand the lived experience of people with a learning disability, and the support needed to live a full, safe and included life.

References

Barnes, C. and Mercer, G. (eds.) (2004) *Implementing the Social Model of Disability: Theory and Research*. Leeds: The Disability Press.

Building Bridges Research Group (2014) *Small Things That Make a Big Difference*. Sandwell: Building Bridges Training.

Building Bridges Research Group (2016) *Living Our Lives*. Sandwell: Building Bridges Training.

Chappell, A. (2000) Emergence of Participatory Methodology in Learning Difficulty Research: Understanding the Context, *British Journal of Learning Disabilities*, 28(1), 38-43.

Clare, I. and Gudjonsson, G. (1993) Interrogative suggestibility, confabulation and acquiescence in people with mild learning disabilities (mental handicap); implications for reliability for police interrogations, *British Journal of Clinical Psychology*, 32, 295-310.

Danchev, D. and Ross, A. (2014) *Research Ethics for Counsellors, Nurses and Social Workers*. London: Sage Publications.

Goodley, D. (2000) *Self-advocacy in the Lives of People with Learning Difficulties: the Politics of Resilience. Disability, Human Rights, and Society*. Buckingham: Open University.

Ham, M., Jones, N., Mansell, I., Northway, R., Price, L. and Walker, G. (2004) 'I'm a Researcher!' Working together to gain Ethical Approval for a Participatory Research Study, *Journal of Learning Disabilities*, 8(4), 397-407.

Herron, D., Priest, H M. and Read, S. (2015) Working alongside older people with a learning disability: informing and shaping research design, *British Journal of Learning Disabilities*, 43(4), 261-269.

Kiernan, C. (1999) Participation in Research by People with Learning Disability: Origins and Issues, *British Journal of Learning Disabilities*, 27(2), 43-47.

Manning, C. (2010) "My Memory's Back!" Inclusive Learning Disability Research Using Ethics, Oral History and Digital Storytelling, *British Journal of Learning Disabilities*, 38(3), 160-167.

Minkes, J., Townsley, R., Weston, C., Williams, C. and Jan, T. (1995) Having a Voice: Involving People with Learning Disabilities in Research, *British Journal of Learning Disabilities*, 23, 93-97.

Money Friends and Making Ends Meet Research Group (2011) *Money, Friends and Making Ends Meet Final Report*. Sandwell: Building Bridges Training.

Mooney, F., Rafique, N. and Tilly, L. (2019) Getting involved in the community—What stops us? Findings from an inclusive research project, *British Journal of Learning Disabilities*, 47(4), 241-246.

Nind, M. (2014) *What is inclusive research?* London: Bloomsbury.

-
- Nind, M. (2017) The practical wisdom of inclusive research, *Qualitative Research*, 17(3), 278-288.
- Northway, R., Howarth, J. and Evans, L. (2015) Participatory research, people with intellectual disabilities and ethical approval: making reasonable adjustments to enable participation, *Journal of Clinical Nursing*, 24(3-4), 573-581.
- Northway, R., Hurley, K., O'Connor, C., Thomas, H., Howarth, J., Langley, E. and Bale, S. (2014) Deciding what to research: an overview of a participatory workshop, *British Journal of Learning Disabilities*, 42(4), 323-327.
- Oliver, M. (1992) Changing the Social Relations of Research Production?, *Disability, Handicap & Society*, 7(2), 101-114.
- Richardson, M. (2012) Reach for the stars, *Learning Disability Practice*, 15(9), 9-9.
- Simons, K. (1999) *A Place at the Table*. Kidderminster: BILD Publications.
- Smillie, V. (2015) Qualitative research about intellectual disability: who publishes it and how can it be better?, *The Learning Disabilities Elf*.
- Stalker, K. (1998) Some Ethical and Methodological Issues in Research with People with Learning Difficulties, *Disability and Society*, 13(1), 5-19.
- Tilley, L. and Woodthorpe, K. (2011) Is it the end for anonymity as we know it? A critical examination of the ethical principle of anonymity in the context of 21st century demands on the qualitative researcher, *Qualitative Research*, 11(April 2011), 197-212.
- Tilly, L. (2013a) An Enduring Sense of Loss, *Community Living*, 26(3), 18-19.
- Tilly, L. (2013b) 'I ain't been bothered to go': managing health problems in people with a learning disability who live without support, *Diversity and Equality in Health and Care*, 10(4), 223-230.
- Tilly, L. (2014) 'Making End Meet', *Learning Disability Today*, Jan/Feb, 14-15.
- Tilly, L. (2016) Issues relating to using a co-productive approach in an accessible technology project, *Improving Social Inclusion using NLP: Tools and resources; LREC Workshop*, Portorož, Slovenia 23.5.16.
- Tilly, L. (2019) Afraid to leave the house: issues leading to social exclusion and loneliness for people with a learning disability, *Tizard Learning Disability Review*, 24(4), 168-175.
- Tilly, L. and Building Bridges Research Group (2015) Being Researchers for the First Time: Reflections on the development of an inclusive research group, *British Journal of Learning Disabilities*, 43(2), 121-127.
- Traustadottir, R. and Johnson, K. (eds.) (2000) *Women with Intellectual Disabilities: Finding a place in the world*. London: Jessica Kingsley.
- United Nations (2007) *United Nations Conventions on the Rights of Persons with Disabilities*. Geneva: United Nations.
- United Nations General Assembly (2006) *Convention on the Rights of Persons with Disabilities. Operation protocol to the Convention*. New York: United Nations.
- Walmsley, J. (2001) Normalisation, Emancipatory Research and Inclusive Research in Learning Disability, *Disability & Society*, 16(2), 187-205.
- Walmsley, J. and Johnson, K. (2003) *Inclusive Research with People with Learning Disabilities: Past, Present and Futures*. London: Jessica Kingsley.
- Walmsley, J., Strnadová, I. and Johnson, K. (2018) The added value of inclusive research, *Journal of Applied Research in Intellectual Disabilities*, 31(5), 751-759.
-

Ward, L. and Flynn, M. (1994) What Matters Most: Disability, Research and Empowerment, in Rioux, M. and Bach, M. (eds.) *Disability is not Measles: New Research Paradigms in Disability*. Ontario: Roeher Institute.

Watson, N. (2004) The Dialectics of Disability: a social model for the 21st Century?, in Barnes, C. and Mercer, G. (eds.) *Implementing the Social Model of Disability: Theory and Research*. Leeds: The Disability Press.

Williams, V. (2011) *Disability and Discourse: Analysing inclusive conversation with people with intellectual disabilities*. Oxford: Wiley-Blackwell.

Zarb, G. (1992) On the Road to Damascus: First Steps Toward Changing the Relations of Research Production, *Disability, Handicap and Society*, 7(2), 125-38.