Being researchers for the first time: reflections on the development of an inclusive research group

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Accessible summary
- A group of people with a learning disability joined a group to talk about their lives
- Being part of it was important, and they have continued as a research group
- The group gives the members a voice and it helps them to know other people have similar issues to deal with.
- It has also shaped their identity – how they feel about their lives and themselves.

Summary

Money, Friends and Making Ends Meet was an inclusive research project; it enabled a group of people with a learning disability who do not receive specialist support services to explore their own lives. This group are often labelled as having a mild learning disability. The research project focused on the strategies they used to cope with day to day living, their experiences of poverty and the support received from their social networks and social capital. The group members found participation in the research project enabled them to have a voice, identify the social barriers in their lives and gave them support and confidence to take action about them and so resolve some of their difficulties. They also embraced the label of learning disability and wanted staff in front-line services to be aware of this, so they had greater understanding and support. This article is written by the instigator of the research group, but with a central part written by the group members in their own words. It focusses on how participation in the research project had a major impact on the group members as they moved from individuals involved in a short term research project to an established research group with its own motivation and direction. The group has since received further grant funding to research the effects of the welfare reform on their lives, and some have completed a bespoke accredited course on doing inclusive research.

Keywords *Identity, inclusive and participatory research, learning disability*

Introduction

Over the past 20 years, there has been growing interest in emancipatory, participatory and inclusive research designs (Chappell 2000; Northway 2000; Oliver 1992). In fact, this journal launched a special issue on the topic in 2012 and in that edition, the Building Bridges research group discussed the findings of their research, which took place as part of

PhD study at Norah Fry Research Centre. They discussed the emerging findings that they wished to highlight about their lives as people who identified as having a 'mild learning disability', including poverty, difficulties in copying day-to-day, emotional difficulties due to children being taken into care, and lack of supportive social networks. However, group members also mentioned in their own article the effect that inclusive research had had on them personally:

> We all feel it has made us more confident and able to stand up for ourselves more. Now, we know we do not have to put up with things as they are, but we can challenge them. For example, one person said 'I speak up more now and they listen to me. (Money Friends and Making Ends Meet Research Group 2012: 131)

This article follows up the comments made by group members about their experience in an inclusive research group, taking a longer view of the group, its growing sense of purpose and the effect on group members' views and experiences of identity and labelling.

Walmsley & Johnson (2003) give a definition of inclusive research outlining certain criteria, which the current project aimed for. For instance, it included people with a learning disability as more than just 'research subjects, and it furthered their interests with the researcher 'on their side'. The aim was for this group of people to have a voice and take a leading role in how the research developed, rather than just contribute to the data collection (Townson *et al.* 2004; Walmsley & Johnson 2003).

The research project

The research group members were recruited through previously known contacts of the researcher with an organisation providing support for those on the border-line of services, and they were all initially asked whether they would like to participate through a third party. Seven people, four women and three men, agreed to take part. They all lived independently without support from any services. This was mainly due to not meeting eligibility criteria for funded learning disability services. They had all attended special schools followed by vocational services after which they became permanently unemployed.

Following ethical approval from the University of Bristol, the fieldwork took place between 2010 and 2011. A grounded theory approach was selected because it was considered to be organic, flexible and compatible with inclusive research and a person-centred approach. Grounded theory is described as a voyage of discovery, commencing without fixed ideas (Denscombe 2007). It is an iterative process in which the researcher and group members create a shared understanding of the issues they are considering (Fyson & Ward 2004).

Grounded theory has been used in previous studies about people with learning disabilities. For example, Llewellyn & Northway (2008) used this approach to explore experiences of advocacy. Grounded theory has been used to analyse life stories as:

> It offers a well-established approach to ensuring that the ideas and recommendations which the researcher develops and makes, emerge *from* the data, are *grounded in* what key group members have contributed though their words and experiences (Goodley *et al.* 2004: 119) (Italics in the original).

The group collected data from their own experiences, using multiple methods that included 10 focus group meetings, unstructured interviews, and the researcher's notes from observations and reflections. This produced almost 64 hours of transcribed interviews (Tilly 2013). The actual topics discussed in the research group were their choice. As the analysis proceeded, themes emerged which then prompted re-examination with the group members. For instance, one of the issues that emerged was the importance of church in their lives.

This research enabled the group to explore their own lives, with a particular focus on the strategies they used to cope with day-to-day living, experiences of poverty, and the extent of their social capital and support received from their social networks (Tilly 2012; Money Friends and Making Ends Meet Research Group 2012). We found that the group members' level of income and experience of poverty resulted in social exclusion which limited their access to social capital and so exacerbated the challenges of living with a learning disability. This is how members put the point:

> Although some of us know many people, most of us have very few close friends and do very few activities with other people. Most people's friends and family contacts are with other people who also have a learning disability (Money Friends and Making Ends Meet Research Group 2012: 132).

The research project also explored issues of identity and labelling and enabled this excluded group to have a voice and raise awareness about what life is like for people with a learning disability who live without support services. Despite the differences in personality and their individual circumstances, there were many shared significant issues, namely poverty, limited social capital and repeated crises due to lack of support.

Issues of ownership

Inclusive research raises particular ethical considerations concerning ownership; the current project for instance constitutes for group members the story of their lives, and not just research data (Atkinson 1998; Gray & Ridden 1999;

Hewitt 2006). The success of the group led to a further ethical dilemma; as they developed their identity as a research group, they not only wanted to be the recognised authors of their published work (White & Morgan 2012), but also to have their photographs printed with their articles. In other words, they wished to be named as authors. However, because their circumstances and data were so deeply personal, the group finally agreed to be referred to as the Building Bridges research group, and we used unnamed photographs in our publications as a compromise. Although the group members are now authors, they have published under the title of the group, rather than their individual names (Money Friends and Making Ends Meet Research Group 2012).

The research group members had a central role in the research design, allowing them to determine the direction and shape of the project, and to develop their own views about how the findings should be framed (Chapman & McNulty 2004). The central part of this paper is thus written directly by group members, in their own words. They aim here to explore what the research group means to them.

What research means to us

Being in our research group is important to us as it is about sharing the things about our own lives that other group members can understand as it is also part of their experience. It helps us to understand our own situations and issues better as we think about them and what causes the situations we have and how it makes us feel.

It is also helpful to share frustrating experiences with each other, like going to Jobcentre Plus. For example, we all feel they keep pressuring us to look for jobs when there aren't any jobs for people like us. We all felt angry when they mess about with our (benefit) money or say 'you haven't done enough job searching'. We all contribute to the things we want to talk about in the group. When any of us has a problem, we now say 'we'll talk about that at our next group'.

Running our group

It is important to get on with other people when you were in a research group. It is hard when everyone talks at once and does not listen to others when they speak. Having ground rules was a big help and an important part of the meeting. Some of us said waiting for buses to get to the meetings was a pain. We would like to have more social activities together outside the meetings. We all like having lunch together after our meeting.

Thinking more about our own lives

[Through research] you found more things about everything – what you need to know...about your life. Knowing about own life, like...asking people questions about their life. We know about what's going on, in their lives and ask them 'what you doing'. We tell each other, to make sure we go to meetings and that with the [job centre]. Group meetings have been good because of talking about things with other people. We just talk about it.

Over time, we've got more aware of what's going on in the world. The MPs can't see there's no work going for people who are on the dole. We can't get jobs, if you see what I mean. We'd all like more money to live on. They say.... 'oh, I'm doing this for you', but they ain't doing anything. They say one thing and then they change the words and do something else. For instance, 'I ain't gonna stop your benefit' – but they end up doing it. There's nothing going . . . no jobs going.

We think that some of the reasons why we don't get the good support we need, and that we should be entitled to, are because we are not recognised as having a learning disability. Liz describes us as being 'on the edge' because we are not supported by learning disability services and have no other support. So we have difficulty with things like the benefits system and Jobcentre Plus. We don't have much spare money for leisure and social activities, so that limits what we can do and who we can mix with. Many people have other personal problems such as having our children removed by social services, or being a victim of mate crime, that affect how we feel in ourselves.

The research project we've done has had some effect on our own lives. One person said that he felt he was able to be more assertive at Jobcentre Plus.

> One thing that gets my back up is the job centre. But now, right, they listen to me.

What is inclusive research to us?

Our group is about money management. Well, we've been doing lots of stuff. Sometimes we do pictures, and we've been talking about our life stories. We also do things about housing and talking about social services. But it's not just about the money and the bills is it? No, it's our complete life.

It's our lives, so it's best that we do it ourselves. We can tell them what we have to do to make ends meet – we're telling other people what it is. The problem is that the group was going to stop. We said: 'I wanna...we wanna carry on'. We did not want to go. After our first conference presentation, this was our conversation to Liz:

> I want to do it next year man. I love it – love to talk to people I do...you get new faces. New....where they've come from. I'm good at talking.

Being in the group has given us all more confidence to try new things and to be able to speak up. We all feel that we have a stronger voice together and really like speaking to

other people such as at conferences. What we do is a bit like self-advocacy, but we put together our stories into reports, films and PowerPoint presentations and tell them to other people as we want things to change for us and other people like us. We've started to be researchers, not just people with learning disabilities.

The importance of group membership and roles in the group

As discussed by members in their contribution above, membership of the group gave a sense of belonging to something and a purpose, and for many in the group, this was a unique experience compared with other aspects of their lives. For most of the group members, the salient parts of the meetings were the social aspects, such as lunchtime, and the routine of coming together and seeing each other. Clearly, the dissemination and public events were important for group identity, which was strengthened by having a presence as a group at external events and their publications. Everyone was involved with at least one external/additional activity, and four took part in conference presentations to professionals, something that no one could have envisaged at the beginning of the research.

As with other researchers with a learning disability (Abell *et al.* 2007) the group members took on roles in the group. For example one welcomed and thanked visitors and asked whether they consented to having their voices recorded on the digital recorder, and she became increasingly annoyed and vocal whenever she saw written text with no pictures. They are now the ones who take the lead in recruiting new members to the group, making suggestions to the others of people they would like to invite.

Participation also gave meaning to their lived experiences. For many, this was the only regular activity they had in their lives, and for all of them, it was the only real chance they had to talk and have their voice heard. Although it was hard for them to understand what 'research' was, it can be seen how group participation enabled them to formulate their political views, for example about the lack of suitable work opportunities. By the end of the project however, they had a noticeably broader understanding of inclusive research as being about their agenda and all the issues that were pertinent to them, arguing how important it was for them to be doing their own research.

The stages in the life cycle of a research group

Tuckman's (1965) model of Group Dynamics was explored, with reference to our experiences, and we could see that most of the phases described by Tuckman did in fact take place in our group – 'forming, storming, norming and performing'. For instance, an important point in our process was when we had an hour-long meeting with our local MP. This represented a major step-change for the group, when group members clearly articulated many issues that were of concern to them. They spoke assertively about their experiences and the barriers they faced, such as difficulties in providing job searches for their benefit claims, frustration with local public transport and housing repair delays. This opportunity seemed to have crystallised that what they had to say was of value and enabled them to reposition themselves as researchers rather than as participants in a research project.

Tuckman & Jensen (1977) refer to 'adjourning' a group as the mourning stage, as there is often reluctance for group members to end their group, and there can be an associated sense of loss (Kindred 1987). This was very true for our group, as when they were informed that the grant funding was coming to an end and therefore the group meetings would be finishing, the group members clearly articulated that they did not want the group to terminate and expressed a strong desire to continue. This was not surprising since they were all unemployed, many had experienced loss in their lives and had nothing to occupy the space the research group had filled, in terms of status, time and the opportunity for personal development and interaction with others. The group thus became something more than simply 'research'; it was an important part of their life, as Northway (2000) also found:

> The research may thus afford participants a valued status and provide the opportunity for the development of relationships. Given, therefore, that participatory research focuses primarily on the situation of oppressed groups, ending such research may have a negative impact on participants. (Northway 2000: 30)

The members saw the group as somewhere they could bring their own problems, discuss them and could reflect on their lives. That in itself started to change the way they saw themselves, from 'isolated victims of circumstances' as they had at the beginning of the project to having an increased collective identity where they could challenge the barriers they experienced. They started to share solutions with each other and became stronger in their identity as research group members. As the project progressed, and members had opportunities to travel and share their research, and saw their contributions were valued, they began to see themselves as researchers, rather than just as people 'with learning disabilities'. Nevertheless, the issues they continue to address are personal, individual ones – rather than wider political ones which might entail joint action with other people with disabilities.

The group were asked whether they thought that being in the research group had made any difference to them personally. One researcher responded: 'Found out more things about your life' 'You found more things about

everything – what you need to know' referring to being clearer about the issues that were important, the barriers in society and feeling he now had a voice and opportunity to speak out and be heard.

The group has continued to meet since the Money, Friends and Making Ends Meet research project was completed and has chosen to stay together as a group, obtaining additional funding for a project about the effects of the welfare reforms and other issues on their agenda. Ongoing funding in the form of small grants has enabled their continuation as researchers and they continue to enjoy the social benefits of meeting together and also the status and sense of empowerment as researchers.

The impact of doing research on identity

Identity was a key theme throughout the research. The group members all identified themselves as people with a learning disability although this could be both a negative and positive label. It gave understanding to those parts of everyday living that were difficult and where they needed support. They were clear that they wanted to be known as having a learning disability by front-line services and to be treated equally and with respect.

Much of the literature about labelling and identity has shown by contrast that 'learning disability' or 'learning difficulty' is a negative or even 'toxic' label for people with a learning disability (Todd & Shearn 1997). Bogdan and Taylor observed that people with a learning disability can be labelled with a 'cloak of incompetence' (1982: 222), that is they are assumed to be incompetent due to their label of learning disability. This can limit opportunities and will also affect how they are seen by others.

Davies & Jenkins (1997) found that people with a learning disability were willing to talk about the concept of disability, and some related the concept to those with physical disabilities or literacy difficulties. They showed, too, how labels can have power, which has major implications for people's lives. The current group referred to disability as a label given to them by others, usually professionals; 'They said I'm classed disabled anyway. The doctor reckons I'm classed disabled'. One group member referred to herself as having 'full learning disabilities' as she could not read or write at all, and compared herself to a friend who she was aware could read and write a little. When asked how they felt about other people knowing that they had a learning disability, they responded that it could be positive because 'They can help you', and so they preferred front-line services such as doctors' receptionists to know. Sometimes, however, group members described their disability in a way that could be considered as derogatory with one member in particular doing this:

Probably because I'm a bit backward and went to a backward school probably... a special school.

The research group membership in some senses enabled the group to change their self-perceptions from being different to others to a positive one of being a researcher, a group member, and having a shared purpose. Like other advocacy and inclusive research groups (Brookes *et al.* 2012; Simons 1992; Williams 2011), this group wanted to keep the label 'people with a learning disability'; to have a label gave them an identity which enabled them to feel located in society and was needed in the absence of other labels in their situations. For example, they could not claim the labels relating to employment, of being parents, or owning material possessions such as house or car owner. Therefore, having a learning disability gave them a name to describe the difficulties in coping with daily life and was also a way of identifying with other similar people. One group member put it: 'anybody like us who has learning difficulties, they need people there to help 'em.'

The label also gave them a group identity, which located them in society and enabled opportunities such as the status of being in this research group. For most of their adult lives, these group members had lived without many labels, and it is interesting to note that they heard the term 'people with a learning disability' more through association with the research group than they had from other contacts, both immediate social networks and from services such as Jobcentre Plus. The group members' shared experience of poverty meant there was also a strong survival need to be associated with the label of learning disability. The label also gave financial advantages through the receipt of disability benefits and other disability-related concessions such as bus passes.

This research project suggests the need for a larger scale research study to establish the identity trends amongst people on the fringes of the 'learning disability' continuum, as it has demonstrated some new thinking about identity. Instead of denying the identity of learning disability, in this research project people who did not receive services reacted positively to the label seeing it as something that helps explain the difference in coping day to day, characterises their family and friends, as well as themselves, and is also as a way to claim their entitlement to much needed additional income.

Conclusion

Inclusive research is now sometimes referred to as co-produced research, as it is developed and delivered in partnership. It has many similarities to community development work which involves working to capitalise

on existing strengths and enhancing the capacity of a neighbourhood or community to solve its problems. Community development encourages both individuals and collective action, allowing people to identify their own potential, understand the processes of disadvantage and exclusion and participate in the mainstream of their community and on the margins (Canaan & Warren 1997).

The research described here aimed to be political, as Oliver (1992) suggests research should be for people with disabilities, and attempted to be emancipatory by giving them a voice. Thus, the outcomes and impact of this type of research are not simply about understanding more about this group of people, but about seeking recognition for the issues they face and campaigning for changes that will enable them to live fulfilled lives through both positive opportunities but also through providing appropriate support. For this group, they became passionate about telling their stories to others via their two reports, conference presentations, and in a more recent project through making a short film. One member explained 'I love to talk to people I do…you get new faces. New….-where they've come from. I'm good at talking'

The group continue to seize any opportunity to share their research and issues they face, and this has also included one couple going back to see their MP at his surgery, and going to speak to student social workers at local universities. In discussions about funding applications for future work, opportunities for dissemination is their high priority.

Important though that impact is, this study demonstrates how important the impact of inclusive research is on people's own lives. We need to be mindful of that impact, and to ensure that people with learning disabilities who do inclusive research have ways of continuing to benefit from the support they are offered in the research process. There may be many ways to develop that continuity, and our own group history is an ongoing one, with stories still to tell.

Acknowledgements

For further information or a Pdf copy of the research reports published in September 2011 and March 2014, please contact:

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