

**People with Learning Disabilities Participating in Research as
Members of a Steering Group**

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People with Learning Disabilities Participating in Research as Members of a Steering Group: A Research Report

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Abstract

As a result of the complexity of needs that people with learning disabilities have, this group of people often come into contact with a range of different health professionals and different types of teams. Despite this, people with learning disabilities are not always given the opportunity to share their knowledge and experience of being at the 'receiving end' of care and treatment from different types of teams.

This paper reports on a 14 month funded project in which people with learning disabilities participated in the research as steering group members and interview informants. More and more methods are being adopted that involve people with learning disabilities in research in general. However, limited work has been reported regarding people with learning disabilities' involvement as members of research steering groups. The main aim of the research was to explore what people with learning disabilities thought about team working and how this may benefit different health and social care students. The research adopts a participatory approach and reports on how the steering group functioned. The study provides some useful insights from people with learning disabilities themselves, into how team-working can be taught and includes wider team-working considerations for health and social care professionals.

Key words: Learning Disabilities, Team Working, Participatory Research, Steering Group.

Introduction

The promotion of user involvement is now part of the mainstream policy agenda in health and social care sectors (Hodge 2006). National bodies involved in the funding, quality assurance, regulation, or support of higher education teaching such as the Higher Education Funding Council for England, (HEFCE, 2007), the Quality Assurance Agency for Higher Education (QAA 2007), and Social Care Institute for Excellence (SCIE) are keen to ensure that partnership working and service user involvement are developed and clearly evidenced in academic activities. However, establishing inclusive models of involvement and participation in research with disabled people, that moves away from claims of 'tokenism' and 'populism', can be challenging (Beresford 2001). This research report describes how the 'steering group' can be an effective method for collaborating with people with learning disabilities on an important topic to all health and social care students and professionals.

Background Literature

Research with people with learning disabilities

Nowadays more research methods are being sought that seek to explore the 'lived experience' of people with learning disabilities on different topics (Northway 2000). Different research methods are being adopted that enable people with learning disabilities to be collaborators and co-researchers in the research process (Walmsley and Johnson, 2003). These have included life histories and narrative work (Atkinson, 2005), participatory approaches (Kiernan 1999 and Mclimens 1999), ethnographic approaches (Goodley 2000) and collaborative approaches (Williams 1999). All these methods have become viewed recently, within disability research, as ways that people with learning disabilities can become

more meaningfully involved in research. This is in direct opposition to a previous situation where this group of people were more subjects of research, rather than being partners in the research process (Northway 2000, Walmsley and Johnson 2003). More recent attempts have been made to recognise people with learning disabilities as key informants accepting that individuals are the best authority on their own lives, experiences and feelings (Dowse 2009).

Steering Group and Research

The steering group has been utilised within research in a number of different ways. Within public health research, a project steering group was adopted to oversee the viewpoints of local communities in Pembrokeshire who were in receipt of 'healthy living' interventions (Rapport et al 2008). The steering group members in this research had a strong representation from different local agencies and sectors and worked on a regular basis to oversee the work of different community researchers (Rapport et al 2008). Medical research has highlighted the benefit of undertaking preliminary work with a steering group of consumers to refine both intended interventions and outcomes before undertaking a trial, therefore bolstering the proposed research (Thornton et al 2003). A study exploring the views of staff involved in providing key worker services for disabled children employed multi-agency steering groups. These steering groups took on more of a management role in defining service criteria and finding funding for the services. A couple of issues were reported as problematic in this study, namely how representative the steering groups were, and poor attendance at the steering groups meetings (Greco et al 2006). Other research has convened a steering group to operate as an expert panel on a certain topic. In developing a National Mental Health Continuous Quality Improvement tool (Brooker and Curran 2005), a group of authoritative individuals were drawn from key organisations within the mental health field to oversee the development of data collection tools relevant to this particular piece of work. There has been no definitive way in which a steering group can function within research and limited work has highlighted in more detail how people with learning disabilities can be involved as steering group members.

Team Working

It is now generally acknowledged that meeting the needs of a diverse range of patients/users within health and social settings requires expertise from more than one professional (Barr and Ross 2006). The potential benefits of team-working and effective collaboration for carers, professionals, and different patient and user groups, has been widely promoted (Leathard 2003). At the same time, the pitfalls leading to poor team-working amongst professionals, such as conflicting organisational and professional boundaries, lack of clarity over roles, have also been well documented (Pietroni 1992 and Meads and Ashcroft 2005). People with learning disabilities, apart from being one of the most socially disadvantaged groups within society (Disability Rights Commission 2006), often come into contact with a range of different health and social care professionals. As such, this group of people can be at the receiving end of different types of team working. Listening and learning from their experience can be the vector through which other professionals and students can come to an understanding and appreciation of team working.

Aims of the Study

1. To explore the viewpoints of people with learning disabilities regarding team-working.
2. To utilise the 'steering group' as a method of involving people with learning disabilities in the research process.
3. To examine to what extent the user experience can inform students' understanding of team-working.

Design

Participatory research, or collaborative research with service users in general, is viewed as the way in which the researcher involves the participants in as many of the research processes as possible (Walmsley and Johnson 2003). This approach has developed as researchers have come to appreciate the value of collaborating with individuals with learning disabilities, who in the past have been mere subjects of inquiry (Walmsley and Johnson 2003). This study aligned itself with a participatory approach focusing in particular on how people with learning disabilities contributed to being steering group members and how, as individuals, they were involved as principal informants.

Ethical Considerations

All people with learning disabilities in the study were paid an hourly rate commensurate with that of a Visiting Lecturer to value their involvement. The study received ethical approval from the University Ethics Committee. In doing so accessible information for all participants was provided to assist with written consent, ensuring confidentiality and clarity over the opportunity for participants to withdraw from the study at any stage they were involved. The main data collection method involved preliminary meetings, the steering group meetings and face to face interviews.

Content Analysis was adopted as the most suitable method to make sense of the data generated within this study. This is a method that analyses the documents and texts in order to quantify content in pre-determined categories and in a systematic and replicable manner (Bryman 2004). Any field notes, details from the steering group meetings, notes from the preliminary meetings prior to the interviews, were compiled and read before a coding scheme was established (Creswell 1998). The project was funded by the Centre for Online Interprofessional Learning (CiEPL) based at Coventry and Sheffield Hallam University.

Recruitment, Selection and Access

In order to recruit people with learning disabilities, a local advocacy organisation that regularly supports educational activities at Coventry University was approached. This was seen as advantageous and can assist the participatory approach (Atkinson 2005), as a relationship had been established with a number of members from this organisation. Once project workers at the advocacy organisation had identified potential volunteers for the study, a 'pool' of people with learning disabilities were approached to see if they would like to either form the steering group, or be involved through a face to face interview. The researcher (MB) and a project facilitator met initially with a number of individuals who declared an interest in being part of a steering group and to discuss what being part of a steering group could mean. This meeting was facilitated by members of the advocacy organisation who knew all the individuals well and introduced the volunteers to the researcher and project facilitator. This resulted in a group of four people with learning disabilities, two women and two men forming the steering group. Two different individuals, who will be referred to as Simon and Brian to maintain confidentiality, declared no interest in being part of a steering group, but volunteered to be interviewed. These interviews would form clips that would only be available for students undertaking inter-professional learning in their first year of training on different health and social programmes across the Faculty and Coventry University. Simon and Brian were shown the interview clips before they were made available.

All the participants had experience of health and social care teams, either as a 'user' or in the capacity of a paid advisor/auditor of local health care teams. All the volunteers making up the steering group had a Mild Learning Disability and were able to recall their own experiences and relate them to the purpose of the study (Diagnostic Statistical Manual 1V 2004). This is

not to preclude the relevance of the topic to other people with disabilities, but to foreground viewpoints on the topic that may in the future be applied to other people with disabilities. People with Mild Learning Disabilities are generally able to communicate and express their thoughts and feelings and can have basic literacy skills (Foundation for People with Learning Disabilities, 2006). All individuals in this instance had the capacity to give their consent to be involved.

Data Collection

As the participants wanted to know about the aims of the research, this initial meeting naturally led into a discussion of the purpose of the research and their role within the group. Through discussions, the group also provided useful insights themselves to the topic of the study. In this way they wanted this to become a source of data to share with others. At this juncture the role of the steering group became 'fuzzy', as the author's original idea was for this group to oversee the process of the study, not necessarily to be a source of data. However, given one of the key aims of the research was to explore to what extent the user experience could inform student understanding of team-working, and in keeping with a participatory approach (Walmsley and Johnson 2003), the group felt it was necessary for their collective views on team-working to be heard. In keeping with a participatory approach, this also shifted any power the researcher had to the participants themselves, as they decided how they wished to be involved. The dialogue that then emerged was therefore recorded and notes taken by the project facilitator.

The steering group met for a second time, to review the overall progress of the project, three months after the first meeting and a week after the interviews with Brian and Simon had taken place. Drawing on the group's ideas about team-working, the steering group were also able to comment on the potential structure and content of the questionnaire to be given to students, contributing to the kinds of questions students could be asked on team working. The third meeting of this group took place during the last month of the project. Given the time that had past since the last meeting, the group wanted a summary of the purpose of the study and the outcomes from the previous two meetings. This was provided through flip chart, pictorial information and general discussion. Some of the main themes emerging from the analysis were presented to the steering group as broad headings. The steering group did not contribute to the analysis any further but were interested in the process of the research, the uptake of questionnaires by students, and offering general comments about taking part.

Results

A number of main themes were elicited from the participants' responses. The following comments are drawn from notes taken during the initial meeting of the steering group and comments from interviews which explored ideas around team working.

Our Ideas About Team-Working

When asked about what make teams work badly the response was:

Some teams don't communicate, no eye contact, hear their own arguments, miscommunication, sure about opinions, can ignore people, not respectful. I feel rejected, it's all about prioritisation (Steering Group).

When asked about what makes teams work well there were clear comments from the steering group and Brian and Simon:

Working together, sticking together, liking each other, talking to each other, respecting each other, time keeping, looking smart, good appearance, being professional, kind, polite and respectful, doing things for other people (Steering group).

Yeah, I do Salsa dancing and that helps me work in a team, working together with my partner...it is important ...partnership, working together and pulling together. Leadership - that is important as well (Simon).

When asked what other things they thought made teams work well together the response was:

Regular meeting and discussions, communication with people with learning disabilities needs to be clear, precise, use appropriate sign language, showing people how to do things, team leadership, thinking before speak. (Steering Group)

The steering group did need to be guided to focus on different particular experiences. The following comment was related to what teams specifically in Acute Hospitals needed to know and what they thought students likely to be working in that sector needed to know:

What it is like for people with learning disabilities when admitted to hospital; what people with learning disabilities actually need when in hospital; what services already exist for people with learning disabilities; what personal experiences people with learning disabilities had already had of being in hospital; more about people with learning disabilities themselves. (Steering Group).

Key Knowledge on Team-working and Learning Disability

A number of comments were highlighted during the second meeting of the Steering Group which were helpful in putting together the questionnaire for students and presented wide issues of considerations for different teams coming into contact with this group of people.

Questions and comments put forward by different members of the steering group included:

When do professionals find out about the user's values and how do students get the training necessary to understand and support learning disability? (Steering Group)

Simon also added to the point about values in his interview:

It is important that all professionals have a strong value base. It means a lot so they can understand people with learning disabilities and adopt the RICl principles (Rights, Inclusion, Choice, independence). (Simon).

The issue of professionals needing a good value base was also identified by Brian in his interview:

I have just been diagnosed with diabetes and I can take my own medication...I had a bad experience with the diabetic nurse at my GPs, she was supposed to be a specialist diabetic nurse and she never took my blood pressure and she said I will tell you what is wrong with you, you are overweight...that happened before I left the practice. It was not very nice I expect the nurse to check me over and make sure I was alright and she never, she never...I was dismissed... she should have given me more time. (Brian).

How it would feel if you had disability?

We (as a steering group) need to take account of the stage of training the students were at when we think about what they are saying. First second and third year students know different things. (Steering Group)

The Importance of Involving Us

The third steering group meeting provided an opportunity for individuals to evaluate their involvement and comment generally on the project. Some comments from the interviews also had an evaluative purpose:

I think it is very important that adults with learning disabilities do things like this so that students can get good ideas when they become professionals... they will have a good idea of what it is like to have a learning disability. (Simon).

The steering group did recognise that they cannot represent the wider learning disability population. However they were able to suggest how people with more severe disabilities might be able to present their viewpoints on team-working:

Through using developing videos and art work, different pictures and perhaps some types of role play. (Steering Group)

Although the responses from the students is not reported in this paper, the uptake of the questionnaire was poor and this led to some disappointment for individual participants with learning disabilities:

They do not understand they need to learn about these things...They are not interested...they perhaps don't know what they need to know about team-working. (Individual steering group member).

Students can be too busy... they have other commitments. They might think that they have too many other topics. (Individual steering group member).

The participants with learning disabilities also commented positively about being involved as steering group members, collectively they commented:

It has been an interesting experience, hearing what students think and talking about team-working...I have enjoyed being part of this.. it felt good about sharing and showing my experience of teams. (Steering Group)

Discussion

Steering groups have been reported as being a useful aspect of the research process (Thornton et al, 2003; Rapport et al, 2008). Little work has been highlighted in which people with learning disabilities contribute as steering groups members. In this study participants with learning disabilities helped oversee the research and contributed as informants on the topic of team- working. The participant's own ideas on team-working also helped develop the questionnaire tool used at a later stage of the research with the students. Admittedly, the researcher originally thought the steering group's main function would be to oversee the study. This was challenged when the steering group wanted their viewpoints on team-working to be shared, therefore becoming informants and not just having an overseeing role. This process helped clarify the roles of the steering group in the study and assisted in building a collaborative relationship with the steering group, an important aspect of the

participatory approach (Walmsley and Johnson 2003). This highlights the ever open, fluid, sometimes messy process of sharing people's viewpoints based on their 'lived experience' (Dowse, 2009). Furthermore, Glasby and Beresford (2006) explain that recognising the 'lived experience' of service users and the practice wisdom of practitioners is just as valid a way of knowing the world as research. The steering group provides a useful way in which vulnerable groups of people can become involved in research.

A couple of members of the steering group were already known to the researcher and project facilitator. This prior relationship did help build rapport with the group and on this occasion assisted other members of the group to contribute, particularly in the first meeting. In line with a participatory approach, building a rapport is important when involving people with learning disabilities in research, in order to help facilitate a dialogue (Booth and Booth 1994, Walmsley 2001).

In this study, participants felt strongly that students needed to know about team-working and have ideas about what it is like having a learning disability. The participants were also able to recognise that students at different stages of their training needed to learn different things.

The perspectives on team working from participants within this study, such as working together, listening and being respectful, echo other general work highlighting the benefits of effective team-working (Leathard 2003). Moreover, specific commentaries from Brian and the steering group within this study relate to the experience of Acute and Primary care. Most health and social care professionals at some point within their career will come into contact with people with learning disabilities (Department of Health 2001). Within the Acute Care sector, recent evidence highlights incidents where people with learning disabilities have been denied basic forms of treatment and care that have resulted in unnecessary fatalities (Mencap 2007, Michael 2008). The same disadvantage has also been reported in the Primary Care sector where the general health needs of this group of people are frequently undetected (Disability Rights Commission 2006). These factors point to potentially wider lessons on team-working that can be learned from this group of people and developed in future research.

All the participants had a Mild Learning Disability and therefore claims cannot be made to represent the diverse range of needs and perspectives that this population has. This was acknowledged by the participants themselves. The study does however foreground future work with those with more profound and severe disabilities. It demonstrates the importance and benefits of seeking out different research strategies that can provide a voice, and promote involvement in research, for more vulnerable members of society, on important topics such as team-working.

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