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### **Making decisions together? Exploring the decision-making process in an inclusive research project**

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**Making decisions together? exploring the decision-making process in an inclusive research project**

Journal:	<i>Disability &amp; Society</i>
Manuscript ID	Draft
Manuscript Type:	Original Article
Keywords:	Decision-making., Learning disabilities, Inclusive research;, Qualitative research
Abstract:	<p>This paper explores the decision-making process with a group of people with learning difficulties in an inclusive research project. I explore the literature around people with learning difficulties and decision-making drawing in particular on studies using conversation analysis. Three examples drawn from the research process and illustrated by transcripts of video data, are then critically examined to unpick the author's claims of collaborative decision-making.</p> <p>Key words: Inclusive research; Learning disabilities; Decision-making.</p>

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## Making decisions together? exploring the decision-making process in an inclusive research project

### Points of interest

- This article is about an inclusive research project where I worked with four co-researchers.
- It looks at how we made some decisions about setting up the project.
- To do this I looked at video recordings of our discussions to see who actually made important decisions.
- The article shows that sharing decision-making is difficult, but can improve with practice.
- The article will help other researchers who try to do inclusive research.

## Making decisions together? exploring the decision-making process in an inclusive research project

*This paper explores the decision-making process with a group of people with learning difficulties in an inclusive research project. I explore the literature around people with learning difficulties and decision-making drawing in particular on studies using conversation analysis. Three examples drawn from the research process and illustrated by transcripts of video data, are then critically examined to unpick the author's claims of collaborative decision-making.*

**Key words:** Inclusive research; Learning disabilities; Decision-making.

### Points of interest

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- The article will help other researchers who try to do inclusive research.

*If controlling who may speak and what they may speak about is not social power then it is hard to say what is. (Dingwall, 1980:21)*

### Introduction

This paper explores the complexities of the decision-making process in inclusive research. It does this by firstly looking at the literature around decision-making by people with learning difficulties and in particular the way conversation analysis seeks to show

The research involved four co-researchers, all of whom identified as having learning difficulties. Whilst setting up the research process, I became increasingly troubled by my own 'we' claims. Conference presentations on the inclusive methodology I was

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3 using were littered with comments such as 'we decided...' and 'we discussed...' This  
4 paper is the response to the inevitable challenge to evidence these claims.  
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### 8 **People with Learning Difficulties Making Decisions**

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10 The rights and capacities of people with learning difficulties to make decisions, express  
11 choice and have autonomy have been explored and debated since the normalisation  
12 agenda contributed to the closure of large institutions (Parmenter 2001) in most  
13 developed countries. Over time, this culminated in autonomy and choice being  
14 considered a right for all disabled people, enshrined both in policy and legislation  
15 (Department of Health 2005; United Nations General Assembly 2006). This section  
16 begins by considering ways in which the decision making process has been analysed  
17 previously. It specifically explores the use of conversation analysis (CA) in some of the  
18 published analyses of decision-making relating to people with learning difficulties.  
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24 Much of the early literature that has looked into decision making by people with  
25 learning difficulties, starts from the assumption that restrictions on decision making are  
26 the *consequence* of incompetence (see Jenkinson, 1993 for an overview). Other  
27 perspectives suggest that such restrictions are the *cause* of incompetence (Bogdan &  
28 Taylor 1982; Goodley 1996) and that incompetence, along with learning disability is  
29 socially constructed. These two perspectives focusing on cause and effect continue to  
30 dominate discourse and research around the perceived capacity of people with learning  
31 difficulties to make choices (Arscott et al. 1999; Smyth & Bell 2006; Sims & Cabrita  
32 Gulyurtlu 2013).  
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40 The discourse around people with learning difficulties as empowered and  
41 competent citizens (Dowse 2009) within neoliberal agendas has created tensions.  
42 Thus people with learning difficulties attempt to negotiate systems which, whilst  
43 promoting self-advocacy, autonomy and individualism, also tie individuals to states of  
44 dependency (Dowse 2009). This results in supporters<sup>1</sup> experiencing tensions between  
45 needing to maintain professional competency whilst simultaneously respecting the  
46 autonomy and choice of people with learning difficulties (Pilnick et al. 2010). This  
47 sometimes results in supporters working in ways which are less about promoting  
48 advocacy and more about 'getting the job done' (Redley & Weinberg 2007).  
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56 <sup>1</sup> 'Supporter' is used here to signify those who work formally or informally with people with  
57 learning difficulties in ways which could be construed either superficially or in actuality as being  
58 allies.  
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3 Inclusive research with people with learning difficulties frequently makes  
4 reference to decision making in the first person plural (Brookes et al., 2012; Buettgen,  
5 Richardson, Beckham, Ward, & Riemer, 2012; Chapman & McNulty, 2004; Michell,  
6 2012) indicating that the decision making process is one in which the 'professional'  
7 researcher and the co-researchers have equal weight and authority within that process.  
8 It is common to see statements like the following in articles discussing inclusive  
9 research projects:  
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14 *As Ian, Sylvia and Beth discussed this early experience, we decided that...*

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16 (Brookes et al., 2012: 147)  
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20 *Between face-to-face meetings we would speak over the telephone to make*  
21 *collaborative decisions.* (Buettgen et al., 2012: 607)  
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25 *We had a big meeting to decide who did what; the Professor listened to us*  
26 *and together we decided who would do what.* (Michell, 2012: 154)  
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28 However, details of *how* that decision making process is accomplished and the reality  
29 of the power-sharing during that process is rarely (if ever) analysed in any depth in  
30 journal papers. This is not to say that professionals researching inclusively with people  
31 with learning difficulties misrepresent how decisions are made when they use the first  
32 person plural, but that it is not always transparent.  
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36 By being transparent about the decision making process, a more nuanced  
37 understanding of the role of the professional can be achieved. Chapman (2005), whilst  
38 noting the low numbers of people with learning difficulties involved within the decision  
39 making process of commissioning research, is explicit about her influence:  
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43 *It needs to be acknowledged that my role as a decision-maker within the*  
44 *team is likely to have been highly influential. I came to the group with*  
45 *knowledge and information, and had been teaching the group about research*  
46 *skills for a number of years before the project began (: 124)*  
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49 Chapman earlier in her thesis problematizes participation and partnership, including  
50 decision-making, and suggests that, for example, questioning the decision not to  
51 participate could result in empowerment by learning new skills or disempowerment by  
52 questioning that choice. This connects with the way professionals, parents, carers and  
53 supporters sometimes view the capacity of people with learning difficulties to make  
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3 decisions about how they want to live on a day-to-day basis or respond 'accurately' to a  
4 question.  
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6 In a reflexive ethnography of supporting a man (SW) with learning difficulties,  
7 Schelly (2008) reflected on these tensions between providing support and choice. As  
8 part of his ethnography, Schelly produced a short excerpt from a meeting between him  
9 (in his role of support worker), service providers and SW in order to set goals. Schelly  
10 saw SW's responses as either non-responses ('I don't know'), or as the result of  
11 acquiescence bias. Acquiescence bias is Sigelman *et al.*'s thesis that people with  
12 learning difficulties inevitably say 'yes' to closed questions even when the answer is  
13 obviously 'wrong' or contradictory (Sigelman, Budd, Spanhel, & Schoenrock, 1981).  
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16 The impact of Sigelman's work (Heal & Sigelman, 1995; Sigelman et al., 1981)  
17 around acquiescence bias in interviewing people with learning difficulties has been  
18 profound. Despite other researchers' findings failing to replicate the acquiescence bias  
19 thesis (see Finlay & Lyons, 2002; Matikka & Vesala, 1997; Ramirez, 2005),  
20 acquiescence bias has now become an accepted 'fact' and a component of the  
21 supposed incompetency of people with learning difficulties (Goodley & Rapley 2002).  
22 This has resulted in some research uncritically accepting that positive responses by  
23 people with learning difficulties are the result of acquiescence bias (see for example  
24 Rodgers, 1999; Schelly, 2008; Wistow & Schneider, 2003; Yacoub & Hall, 2009). This  
25 feeds into the assumption that *any* answers given by people with learning difficulties to  
26 *any* question in *any* context will most likely lack validity. As Rapley & Antaki (1996:  
27 223) argue this 'has encouraged a climate of opinion in which what people with learning  
28 disabilities have to say is (at least) open to the suspicion that they are merely offering  
29 what the questioner wants to hear'.  
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32 Sigelman et al's. (1981) thesis has been critiqued at length, specifically by  
33 Rapley with others (Rapley 2004; Rapley & Antaki 1996; Houtkoop-Steenstra & Antaki  
34 1997; Goodley & Rapley 2002). Taking a discursive psychological approach, Rapley  
35 (2004) argues that the questions upon which Sigelman's work is based are inherently  
36 flawed. Agreeing with Matikka & Vesala (1997), Rapley suggests the apparently  
37 contradictory 'yes' response to the question 'are you allowed to/is it against the rules...  
38 to hit someone', as cited by Heal & Sigelman (1995), *is* logical, because, whilst *inmates*  
39 in institutions are prohibited from hitting people, *staff* often do so. Flawed questions are  
40 also responsible for the supposed acquiescence of Schelly's (2008) client, SW who,  
41 when confronted with the convoluted question: 'SW, if you had to say one thing that is a  
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3 goal of yours for this next year, can you think of anything?', said 'I don't know'. As  
4 Finlay & Lyons, (2002) suggest, 'Acquiescence should be seen, then, as a problem of  
5 difficult or semantically complicated questions rather than as a problem of yes/no  
6 questions per se' (: 22). The difficulty of questions not being fit for purpose was also  
7 evident in Houtkoop-Steenstra & Antaki's (1997) research that found 'yes/no' questions  
8 tended to be couched in what they termed 'unmarked' forms which are the 'default  
9 formulations' and as such, are formulated in positive terms. Thus, an 'unmarked'  
10 question such as 'are you satisfied?' although supposedly neutral, tends to suggest a  
11 'no-problem' answer with a preference for agreement built into them. Compare this  
12 with a 'marked' form such as 'are you dissatisfied?' which, Houtkoop-Steenstra &  
13 Antaki, (1997) suggest, invites the question 'what makes you think so?'

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16 Rapley's analysis, whilst being drawn from discursive psychology, draws heavily  
17 upon CA in order to illuminate the challenges within Sigelman's thesis and to show how  
18 the category of learning difficulty is socially constructed. The use of CA is 'designed to  
19 deal with fundamental features of human action and interaction' (Heritage 2010).  
20 Hammersley (2002) suggests that CA as originally propounded by Sacks and Schegloff  
21 generally adopts a value-neutral stance and that inferences are made only on what is  
22 actually observable in the interaction under analysis. This, Hammersley argues, means  
23 that context, which remains unspoken, does not exist independently, but can only be  
24 constituted in and through talk. Heritage (1995) explains further that conversational  
25 practices are 'independent of the motivational, psychological or sociological  
26 characteristics of the participants' (: 396). This perspective suggests support for  
27 Rapley's (2004) argument that the category of 'intellectually disabled' is a product of  
28 social interaction between individuals and institutions which are, as Heritage (1995)  
29 suggests, normatively orientated. The difficulty with excluding context from interactions  
30 however, is that context in itself will create or influence certain kinds of interaction.  
31 Thus what Rapley (2004) suggests is a 'testing' context, such as where a person with  
32 learning difficulties is questioned by a service professional, *might* provide context from  
33 the talk alone (see Rapley, 2004: 90 extract 7 as an example), Goodley (1996) finds  
34 that the written form of extracts sometimes 'fails to convey the reality of the interview' (:  
35 339).

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38 Not all proponents of CA adhere to this perspective as it is applied to interaction  
39 with people with learning difficulties. Redley & Weinberg (2007) for example, argue  
40 that failing to acknowledge the 'obdurate social reality' (: 768) of learning difficulty will  
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3 eventually raise the question of why people with learning difficulties should be entitled  
4 to additional support. Redley & Weinberg (2007) introduce context into their analysis  
5 by using video and by knowledge of the 'institutional mandates', arguing that the  
6 interactions made by the Parliament for People with Learning Difficulties (PPLD) are  
7 shaped not just by talk and interactional cues, but by 'the distal institutional mandates  
8 that occasion its occurrence in the first place' (Redley & Weinberg, 2007: 770). The  
9 specific institutional mandates they refer to in this instance are those that support the  
10 PPLD's preference for empowering people with learning difficulties and imparting  
11 advice.  
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18 Redley & Weinberg's (2007) study, exploring the interactions between service  
19 professionals/decision-makers and 'MPs'<sup>2</sup> is sharply critical of self-advocacy talk as  
20 being normative in the PPLD and that what is termed self-advocacy is, in fact a form of  
21 'education' of people with learning difficulties. By this they mean that MPs 'taking the  
22 floor' is enforced by both decision-makers and MPs and that when an MP fails to do so,  
23 it causes what Redley and Weinberg term 'interactional trouble', identified as inaudible  
24 speech, failure to speak, refusal to speak and inappropriate speech. When there is  
25 interactional trouble, decision-makers and MPs create a discursive path to allow the  
26 decision-makers to take the floor whilst at the same time honouring the MP's  
27 possession of the narrative. They give an example, 'other forms of abuse and bullying'  
28 (: 771) as a parliament discussion theme, whereby 'advice' is given to MPs (to tell staff  
29 about bullying) rather than to decision-makers (thus removing the necessity for  
30 decision-makers to take appropriate action). Redley and Weinberg suggest that  
31 'instances of failure to speak' are based on an MP not making the desired discussion  
32 but reverting to a Q&A format (excerpt 6: 776). This format is familiar to many  
33 audiences of inclusive presentations in that it can help to act as a prompt for people  
34 with learning difficulties in what are stressful and pressured situations. In this particular  
35 sequence, although the Q&A format allows MPs voices to be heard, it also allows  
36 decision-makers to shift responsibility for bullying onto the MP and not adequately  
37 respond to what the MP is saying. For Redley and Weinberg, this is due to a deficit in  
38 the MP, rather than the decision-maker, because, they argue, the PPLD is fully  
39 accessible, negating arguments made by others that the decision-makers were  
40 unwilling to share power. This assertion is problematic because, irrespective of the  
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57 <sup>2</sup> MPs are individuals with learning difficulties elected by other people with learning difficulties  
58 to represent their views to decision-makers and service providers.  
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3 stated commitment of accessibility the PPLD might have, the *actual* accessibility and  
4 advocacy orientation or the organisation, might be experienced differently by people  
5 with learning difficulties.  
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8 One of the difficulties with Redley and Weinberg's paper is that the talk they  
9 analyse is also, to an extent, institutional 'testing' talk. Despite attempts made by  
10 PPLD to promote equality and power-sharing between MPs and decision-makers, the  
11 context is both artificial and, I would argue, deeply 'testing' for all but the most confident  
12 self-advocate. Further, it follows Houtkoop-Steenstra & Antaki's (1997) discussion of  
13 how interviewers re-orientate questions (in this case yes/no questionnaire questions  
14 requiring pre-coded response options) to minimise difficulties and help interviewees  
15 'save face'.  
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21 Although Redley & Weinberg's (2007) analysis within disability studies is  
22 somewhat contentious both in its critique of self-advocacy and in locating the deficit of  
23 intellectual impairment within the individual, they make a valid point about the  
24 importance of context, both proximal and distal when analysing talk, particularly  
25 institutional talk. This notion of 'institutional talk' is further interrogated by Williams,  
26 Ponting, Ford, & Rudge (2010) in an inclusive research project exploring interactions  
27 between personal assistants (PAs) and their clients, people with learning difficulties, to  
28 identify what 'good support' looks like. Williams et al. (2009) found that whilst there  
29 were examples of institutional talk used by PAs, both PAs and clients delicately side-  
30 stepped the institutional frame by using terms like 'mate' to mark out their relationship  
31 as a friendly one. Humour was also used to soften some of the institutional talk by PAs  
32 as they gave advice and helped clients make choices. Interestingly, there were also  
33 instances of institutional talk by clients in evaluating the performance of PAs which was  
34 again softened by the use of 'mate' but was still reinforcing the client's role as  
35 'employer' and thus more powerful. Such interactions rather than being instances of  
36 institutionally mandated talk, could be contextualised as negotiated forms of  
37 empowerment designed to give the client the maximal control they could manage at the  
38 time.  
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51 Whilst the PAs in Williams et al. (2009, 2010) were sensitive in how they  
52 supported adults to make choices, Pilnick et al. (2010) found that young people,  
53 especially school children, are seldom given the same sensitivity. Pilnick et al. (2010)  
54 highlighted that whilst 'special school' leavers were positioned as having choice and  
55 control as part of the neoliberal agenda around active citizenship, in reality, they were  
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3 not recognised as such by educational staff. Pilnick et al. (2010) illustrated how despite  
4 students making *interactionally* adequate and appropriate responses to questions  
5 during transition review meetings, interviewers failed to recognise the responses as  
6 such. This was sometimes because the interviewer failed to make clear and specific  
7 questions, recalling Schelly's (2008) interactional troubles. Sometimes it was because  
8 despite giving clear, unequivocal preferences, the answers were discounted as  
9 inappropriate by staff and/or parents, such as Alec's hopes of joining the police force.  
10 Finlay, Walton, & Antaki, (2008) note that such preferences 'are disempowering since  
11 they put additional obstacles in the way of people with learning disabilities in their  
12 attempts to exert control over their environments' (: 12). This highlights the preference  
13 professionals have for responses that are both appropriate/adequate and, significantly,  
14 verbal, which, as will be seen in the extracts in the following section, is a preference  
15 that I also made.  
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### 26 **Making decisions in setting up the project**

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28 The decision-making process in this research project was complex and, at times,  
29 fraught. Many decisions were made, such as topics to research, methods to be used,  
30 dates and places to meet<sup>3</sup>. Initially I saw my role, following Williams (1999), as a  
31 facilitator, with the research team taking responsibility for deciding what to research  
32 and how. Mindful of how people with learning difficulties can be disempowered in  
33 meetings because of non-disabled, more powerful others being directive (Finlay et al.,  
34 2008), I aimed to keep direction to a minimum. Unlike Williams however, who, whilst  
35 admitting that she influenced the research to some extent, my influence on the  
36 research, specifically in terms of final research topic, research questions and  
37 methods, was eventually far greater than I initially intended. As such, I radically (but  
38 temporarily) re-orientated my perspective from being a facilitator to being a manager  
39 early on. This consequently shifted my perspective of the team from full co-  
40 researchers to 'helping' me, thus mirroring (but in reverse) Buettgen et al.'s (2012)  
41 experience of co-researchers feeling like helpers to start with. Eventually this  
42 orientation again shifted towards something that, superficially anyway, felt more  
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57 <sup>3</sup> It is important to note that difficulties with transport and timetabling meant the research team  
58 divided into two geographical groups and later I worked with the co-researchers individually.  
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3 equal. This desire to 'feel' greater equality meant whilst that I aimed to make  
4 decisions jointly, this could sometimes be interpreted as tokenistic.

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6 That notwithstanding, the analysis of my talk is, at best, disconcerting and  
7 uncomfortable. For example, I made claims in the team's name based on  
8 contemporaneous field notes. However, on closer analysis of the actual video  
9 transcripts, it is *my* voice and not theirs upon which the claims are based. So, whilst I  
10 initially claimed that the substantive research questions were developed in  
11 *collaboration* with the co-researchers, and that is how I *experienced* this event, a  
12 more objective account would be to say they were developed in the *presence* of the  
13 co-researchers. This was not an intended deception on my part, but it demonstrates  
14 how a professional researcher working inclusively can, in effect, co-opt the normative  
15 language of self-advocacy (Redley & Weinberg 2007) and inclusive research  
16 collaboration, whilst failing to work in a fully collaborative way. It is however worth  
17 recognising that the 'clear, self-contained voice'<sup>4</sup> to which I was aspiring, in both the  
18 research process and in this analysis, is in itself an individualised and normative  
19 assumption, the pursuit of which might constitute a form of 'cruel optimism' (Berlant  
20 2006)

21  
22 I now interrogate in more detail how the co-researchers and I developed ways  
23 of decision-making illustrating these pendulum shifts in my role, from co-researching,  
24 to managing and back again. Three specific decisions, each of which presented  
25 specific dilemmas, have been selected to illustrate this process:

- 26 • How we arrived at the decision to eliminate health as a potential research  
27 topic.
- 28 • Stuart's choice of research method.
- 29 • Deciding where to go on Natasha's research trip.

30 They are organised thus:

- 31 • *Context* gives the background, chronology and actors involved.
- 32 • *Extract* is a verbatim extract from the transcript. My analysis of the interaction  
33 is woven around these extracts.
- 34 • *Reflections* is my personal reflection of the interaction.

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<sup>4</sup> I would like to thank the anonymous reviewer for their insightful and considered comments around the nature of 'voice' in research, highlighting that ownership of voice is complex and subject to normative assumptions.

## Eliminating Health

### *Context*

During the first meeting at SpeakUp<sup>5</sup> where I introduced myself to potential co-researchers, the members suggested many areas of research. These ranged from limitations on when bus passes can be used, to buildings being physically inaccessible to wheelchair users and people with pushchairs (FN: 28/2/12).

Throughout these initial meetings with SpeakUp, I noted topics frequently arising with a view to suggesting them as potential research areas. Members of SpeakUp who were interested in taking part in the research then formed a discrete group. Research team meetings followed a similar and thus familiar format to the SpeakUp monthly meetings in that we had a simple agenda:

- Catching up
- Recap of the last meeting
- What we will do in this meeting
- Planning the next meeting

When we first met in May 2012, the aim was to produce a shortlist of potential topics to explore before deciding on the final area of research. To avoid being too directive and thus, as I saw it, potentially disempowering, I avoided saying things such as 'why don't we research x?' during this process. This actually had the opposite effect of empowering, creating uncertainty and confusion amongst the co-researchers, with one eventually exclaiming, 'just tell us what you want us to do and we'll do it!' (FN: 9/5/12). The support worker reinforced this message by suggesting that I give more direction about what we discuss (FN: 9/5/12). They indicated that structure and guidance are crucial in supporting choice. This was one of many 'interactional troubles' in the decision-making process and came about because I clearly had what Redley & Weinberg (2007: 772) term an 'interactional preference for self-advocacy', a normative expectation that self-advocates 'take the floor'. The following extract is from the early part of the project when it was still one team. All the members present dropped out shortly afterwards for personal reasons but gave their permission for me to retain data from this period. The first meeting (M9/5/12) produced seven potential areas of research:

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<sup>5</sup> SpeakUp is the (anonymised) self-advocacy group from which the co-researchers were recruited.

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- 3 1. Benefit changes
- 4 2. Getting and keeping work
- 5 3. Health
- 6 4. Transport
- 7 5. Bullying
- 8 6. Getting on with people around us
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The second meeting (M15/5/12) reduced these down to *health*, *getting on with people around us* and *labelling*. Subsequent meetings aimed to focus on accessible reviews of the inclusive research literature, our experiences of the topic and changes we wanted to see in that area. The decision about the eventual research area, was to be decided after discussing all three topics. In the extract, I unpick the decision to reject health as a possible research topic. This took place during our third meeting. As Pilnick et al. (2010) suggest, the responses of the co-researchers were interactionally adequate and indeed appropriate to the matter in hand, that is, a discussion around health.

The meeting was between seven participants including me. Two participants, Sarah and Jenny were support workers and the remaining four, Michael, Dan, Helen and Lenny were people with learning difficulties. The conversation had been largely dominated by Dan, Sarah and Jenny and me, discussing various aspects of health, including mental health. As Sarah was explaining that her recent ill health was the accumulation of stress, lifestyle factors and childhood abuse, Dan spoke less and less. He physically shifted back in his seat at one point and looked towards the door as Lenny, Michael and Sarah bantered about football (following Sarah's joke that football supporting had also impacted on her health). At this point I pulled the discussion back to health and Dan started to raise his objections to the discussion of health but was unable to fully articulate it:

#### EXTRACT 1

Liz: It might be something worth thinking about if we decide to look at health,  
we might want to think about something around mental health

Dan: Yeah...

Liz: Mental health issues perhaps, it's something which seems to crop up but  
there's not much work done on it.

Michael: Look at different avenues of health...



1  
2  
3 Dan: I'm not being funny but I find this a bit heavy really

4 Liz & Sarah: Heavy?

5  
6 Dan: Yeah I-I-I can't...

7  
8 Jenny: Well I know you don't like about health, but it's no good closing your  
9 eyes always to it

10  
11 Dan: Yeah, I can't sort of... and I'm not closing my eyes

12  
13 Jenny: no...

14  
15 Dan: but I can't get my head round it at all, I can't.

16  
17 Liz: Am I not explaining it clearly enough?

18  
19 Dan: yeah... it's just me, I can't sort of I can't stomach it at all really, I'm sorry

20  
21 Sarah: OK, the point... the thing is

22  
23 Dan: I'm gonna go back down to my flat, leave you to carry on, I can't

24  
25 Sarah: OK

26  
27 Liz: OK

28  
29 Sarah: No problem

30  
31 Dan: I always find health a bit difficult to talk about

32  
33 Sarah: OK, that's understandable, what we'll do Dan is sit down and talk about  
34 certain areas that you're happy to talk about

35  
36 Jenny: what areas would you like to talk about with health?

37  
38 Sarah: or we could probably do that at a later date.... That let you get your  
39 head around...

40  
41 Dan: I just find it a bit... you carry on, I don't want to stop you, it's just me, I  
42 can't carry on

43  
44 Over the 20 minutes that the exchange as a whole took place, Dan, despite being  
45 clearly agitated and saying he didn't want to talk and wanted to leave, remained  
46 seated. He eventually articulated his objections to health as a research area:

#### 47 EXTRACT 2

48  
49 Dan: yeah, it was just the heaviness, I just found it a bit heavy and I just I  
50 always find health a bit awkward, I always feel a bit awkward talking about  
51 health... I always, ... my view is that health is a private issue between the  
52 person whose health it is and the doctor, it's not really something, maybe  
53 that's the way I was brought up, I don't know.

54  
55  
56 Dan remained seated and continued to remain so as I attempted to reassure Dan that  
57 it is all right to not take part in the discussion if he is uncomfortable and Jenny and  
58  
59  
60



1  
2  
3 Sarah reassure him that the research is not about him personally. Dan then clearly  
4 articulates his preference for researching around the other two topics of getting on  
5 with people and labelling. Dan is careful to emphasise that he is not directing the  
6 others to share his views by saying 'I wouldn't stop you from doing it':  
7  
8

9  
10 EXTRACT 3

11 Sarah: that's ok because what you've got to realise Dan is that you've only got  
12 to share what you want to share, yeah? And you only take part in what  
13 you want to take part in  
14

15  
16 Dan: mmm  
17

18 Sarah: you make the decision and if you want more information broken down to  
19 you maybe on a 1:1 basis then that's fine  
20

21 Dan: I mean I like the idea of talking about getting on with people and labelling,  
22 they're the two things... but health, I've always been  
23

24 Liz: yeah  
25

26 Dan: a bit  
27

28 Liz: you, you, so you'd be uncomfortable if we did the research around health  
29

30 Dan: yeah  
31

32 Liz: full stop, yeah?  
33

34 Dan: I'm not being... if you want to do it, I wouldn't stop you from doing it, I  
35 wouldn't stop you from doing it it's just  
36

37 Liz: no, but it's good for us to all want to do it and I think it's... if we take a  
38 democratic approach to it  
39

40 Dan: I'm sorry... I am sorry (starts to rise from chair)  
41

42 Sarah: you don't have to apologise, it that was the same for me  
43

44 Liz: you don't have to apologise  
45

46 Sarah: if it was a topic I wasn't comfortable with, I would say it as well  
47

48 Dan: that's why I'm saying, why I'm coming out with saying the wrong things  
49 because I'm feeling uncomfortable.  
50

51 A few moments later, Dan leaves, accompanied by Jenny. After Jenny returned she  
52 explained that Dan was feeling better. I asked what the others present felt about  
53 dropping health as a research area. Both Michael and Helen agreed that this was a  
54 good idea. Lenny\*\*\* remained silent but nodded agreement:  
55

56 EXTRACT 4  
57

58 Liz: although Natasha's not here, I mean, you know, if looking at health care is  
59  
60

1  
2  
3 something which is perhaps going to be something we're NOT going to do,  
4 now we have a choice, we can either still talk about our experiences  
5 around accessing health care, emm, ways to make health better, emm, or  
6 we can talk about something else or wrap it up early. I haven't prepared  
7 anything around community yet because I was just going to take it one  
8 topic at a time. So what do you feel?  
9

10  
11  
12  
13 Michael: I think health can be a bit of a stumbling block for Dan. It certainly  
14 unbalanced him a bit and

15  
16 I just don't think he's quite keen on doing it, like Kathy<sup>6</sup>. There's certain  
17 things and boundaries that you have to be careful around Dan because  
18 there's certain things he's not going to be happy about.  
19

20  
21 Liz: yeah

22  
23 Jenny: it took him a long time to go to the doctors a couple or three years ago

24  
25 Liz: yeah

26  
27 Jenny: you know him best dear, what do you think?

28  
29 Helen: What Michael says too, stop you know

30  
31 Jenny: health?

32  
33 Helen: health

34  
35 Liz: OK so we, so we, despite Natasha not being here, we agree we're not  
36 going to research health as our main topic

37  
38 Michael: yeah because it certainly unbalanced him

39  
40 Liz: yeah

41  
42 Michael: and he was a bit upset about it... he wasn't that keen to do it, so we  
43 might have to look at a different subject instead of health.

### 44 *Reflections*

45  
46 Whilst I feel comfortable that the decision was not specifically driven by agenda  
47 setting on my behalf, the interaction was problematic. Firstly, I did not pick up on  
48 Dan's growing discomfort early enough. Having been quite vocal throughout the first  
49 part of the meeting, I should have been alerted his decreasing participation.

50  
51 Secondly, allowing health to be eliminated without full consultation of all members  
52 discomfited me because, although it was the majority view of those present, the  
53 decision was not made by all the members. Rather than suggesting we reflect on the  
54  
55

56  
57  
58 <sup>6</sup> Kathy\* was another person who was then part of the team and later left.  
59  
60

1  
2  
3 situation over time, I immediately agreed that health be eliminated. With hindsight,  
4 this was probably the best course of action given that issues around attendance were  
5 already emerging and it was another month before we met again. This extract  
6 highlights how decision-making in groups is always dependent on negotiation, but  
7 when attempts are made to address real or perceived power imbalances, the process  
8 becomes more complex and messy.  
9  
10  
11  
12

### 13 **Deciding Which Research Method to Use**

#### 14 *Background and context*

15  
16 This meeting with Stuart took place in late October 2012. At this point, the research  
17 team had divided on geographical lines with Dan and Helen based in Redruth and  
18 Stuart, Natasha and Mark based in Truro. Despite this, the Truro team still had  
19 problems with timetabling so everyone could attend together. By this stage I had  
20 made the decision as described earlier, to focus the research area on how  
21 communities interact with people with learning difficulties. This decision was made  
22 unilaterally and without consultation with co-researchers and at the time, caused me  
23 a deal of discomfort. The justification for eliminating labelling, the remaining option,  
24 was based on the prior existence of inclusive research in this area (see for example  
25 Williams, 2002) alongside time pressures.  
26  
27  
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36 With the research area now defined, and the overarching research questions relating  
37 to the impact of rural environments developed, the next stages were to identify  
38 specific research questions with the co-researchers and decide on the research  
39 methods. I *felt* like the decision about the research questions had been made in  
40 collaboration, but on analysing the transcript more carefully, it emerged that I had in  
41 fact given Stuart (as the only other participant at that meeting) a list of questions that  
42 he then agreed with. That was one instance where I had previously made 'we' claims  
43 when in fact it was 'I'. The decision that immediately followed was one where Stuart  
44 made a clear decision about how he wanted to work. This choice was however later  
45 over-ruled.  
46  
47  
48  
49  
50  
51  
52  
53

54 Because of the co-researchers' lack of experience and previous guidance from the  
55 support workers and co-researchers themselves about needing more direction, I then  
56 suggested two potential avenues of research based on methods used previously by  
57  
58  
59  
60

1  
2  
3 inclusive researchers. I proposed that co-researchers either used forms of self-  
4 research, such as narrative or life history (Booth & Booth, 1996; Keyes & Brandon,  
5 2011; 2003; Rolph, 1999) or what could be considered more 'traditional'<sup>7</sup> forms of  
6 qualitative research such as interviewing and/or observation (Townson et al. 2007;  
7 Dias et al. 2011; Chapman 2005). By giving co-researchers limited but diverse  
8 choices, I aimed to refine it down to more specific ways of researching.  
9  
10  
11  
12

13  
14 The meeting from which this interaction is taken, should have included Natasha and  
15 Mark but both were unable to attend. Stuart and I had watched some video diaries  
16 that he, Natasha and I had made and talked about what we might like to see in other  
17 people's videos. I suggested some research questions that would relate specifically  
18 to our research and Stuart agreed they were good questions. This agreement by  
19 Stuart could, in isolation, be taken as typical acquiescence bias (Sigelman et al.  
20 1981b; Heal & Sigelman 1995). Alternatively, in my desire to get on with the research  
21 (my journal from this period shows extreme anxiety about my progress), I did not  
22 have so much the 'dominant voice' (Aldridge 2012) but what at times felt like the *only*  
23 voice. As Finlay et al. (2008) recognise, having knowledge and verbal fluency make  
24 it difficult for professionals to not dominate. Reviewing videos of our meetings,  
25 particularly where it is just me and a single co-researcher, shows that despite  
26 attempts to open up dialogue, I was dominating the conversation for large amounts of  
27 time.  
28  
29  
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36  
37

38 This is not to say that my co-conversationalist was silent, but made liberal use of  
39 'response tokens' such as 'hmm' and 'yeah'. Levinson (2005 :76) observes that the  
40 use of response tokens can be ambiguous in that they 'enable the ongoing display of  
41 competent attention without having to demonstrate comprehension.' This can mean  
42 that such response tokens could in fact act as 'fillers' and as Sacks (1995) suggests,  
43 when someone is only answering questions or using fillers of 'uh huh' or 'yeah' it isn't  
44 actually a conversation. Sacks' observations were not in relation to people who, for  
45 whatever reason, experience degrees of inarticulate speech, but he did observe how  
46 'silence is a terrible thing' (Sacks, 1995b :225). I thus felt a pressure as the  
47 'professional' to 'keep off silence by going on' (*ibid.*) when co-researchers did not  
48  
49  
50  
51  
52  
53  
54

55  
56 <sup>7</sup> Traditional is here used as shorthand for methods that are well established  
57 within the social sciences and, critically, were understood by the co-researchers  
58 as 'proper' research methods.  
59  
60

1  
2  
3 'take turns' in the conversation. This interactional trouble was more pronounced in  
4 early meetings and meetings with only one co-researcher.  
5  
6  
7

8 In the following extract Stuart's utterances are minimal to say the least:  
9

10 EXTRACT 5

11 Liz: it's a bit difficult to decide without Natasha or Mark here, but whether we're going  
12 to do the kind of self-research or the autoethnography... that's the big word for  
13 it... which is kind of like you are researching your own life...  
14  
15

16 Stuart: yeah  
17

18 Liz: So we could do that, or we could do... emm... the more traditional kind of  
19 research where there's the camera,  
20

21 Stuart: hum  
22

23 Liz: there's the recording device and then we ask questions and analyse what people  
24 say to us or  
25

26 Stuart: hmm  
27

28 Liz: or what we see umm... .. I mean do you have a preference for how you would  
29 like to do this... I mean do you want to explore your own life... or, do you want  
30 to be I don't know, say working with Kathy, seeing what Kathy's day is like  
31  
32

33 Stuart: yeah  
34

35 Liz: you prefer  
36

37 Stuart: working with people  
38

39 Liz: yeah, OK so... I think, I think that's the kind of thing Mark and emm Natasha  
40 would probably quite enjoy as well  
41

42 Stuart: yeah  
43

44 Liz: so I'll double check with them  
45

46 Stuart: yeah  
47

48 Liz: and see what they'd like  
49

50 *Analysis*

51 It seems that on the face of it, Stuart is saying 'yeah' to both propositions of self-  
52 research and 'traditional' research. The first instance of 'yay-saying' as Heal &  
53 Sigelman (1995) would typify it, is, after placing the interaction in context, more  
54 convincingly interpreted either as Stuart using 'yeah' as a response token to  
55 acknowledge and give understanding of what I meant by self-research. Finlay &  
56  
57  
58  
59  
60

1  
2  
3 Lyons (2002) in a review of the literature on acquiescence, suggest that yea-saying  
4 might occur in cases where someone is uncertain of the meaning of a question or  
5 where there is an unequal power relationship. In terms of 'talk time' as discussed  
6 earlier, mine was the dominant voice in the interaction, which could have set up this  
7 power inequality. This power inequality in turn produced something which is similar  
8 to a 'testing' situation as suggested by Rapley's (2004) analysis of Sigelman et al.'s  
9 (1981a) theory of acquiescence bias. It is therefore possible that Stuart's first,  
10 flat-sounding and non-committal 'yeah' was due to lack of understanding and the  
11 second, emphatic 'yeah' was because he had a traditional understanding of research  
12 as "working with people". As Finlay & Lyons (2002) suggest when someone is asked  
13 to make a decision about something they have not previously considered, it also  
14 creates uncertainty which in turn may lead to acquiescence. Whilst it could be  
15 argued that Stuart has not in fact fully understood what I said, my contextual  
16 interpretation was that he fully understood what I meant and was using 'yeah' as a  
17 response token. The flatness of this filler was, I believe, the result of Stuart being  
18 less than excited about the prospect of doing a form of research he had little interest  
19 in. As all the co-researchers had expressed a preference for interviewing others,  
20 perhaps because of the social interaction, researching one's own life might seem less  
21 enticing.  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35

### 36 *Reflections*

37  
38 This interaction, was not, on the surface of it, as emotional and disruptive as the  
39 earlier interaction with the group where Dan had become upset and left.  
40  
41 Nonetheless, the video makes uncomfortable viewing in that I can see and hear  
42 myself as the person who is driving the interaction. However, Stuart is emphatic  
43 about his wish to do a form of research which involves interacting with others but this  
44 was ultimately not possible, so although Stuart had made a clear decision about how  
45 he wanted to do the research, the decision about how we would do the research was  
46 made by me.  
47  
48  
49  
50  
51  
52

### 53 **Planning a trip**

#### 54 *Background and context*

55  
56 This meeting with Natasha was seven months after the above meeting. I was now  
57 working individually with Stuart, Natasha, John and Mark. The design had changed  
58  
59  
60

so we were now engaged in mobile interviewing (Clark & Emmel, 2010). There was a three-stage process for each trip with the co-researcher:

- Planning
- The journey
- Analysis

This discussion with Natasha aimed to plan the research trips. Initially there would be one planning meeting per trip. However, in planning the very first trip the week before with John, talking about and planning *all* the trips occurred in the natural flow of the conversation. This formed the basis for subsequent planning interactions including Natasha's.

The extract occurs after an hour discussing the places Natasha goes, the purpose of the trips and when they take place. The extract is about the second theme<sup>8</sup> *Places I go to regularly*, where Natasha has identified trips to Church, Art Club, Craft Club, Work and the supermarket on a regular basis:

#### EXTRACT 6

Liz: and whether there are any of these... I mean for example you might not want me to come to the church with you?

Natasha: yeah

Liz: or Art class or craft club in which case, you know, we're looking at doing work or Iceland<sup>9</sup>, you know whichever one

Natasha: I see

Liz: are there any of these which you wouldn't, wouldn't want me coming to... with you...

Natasha: ... uh, craft club and the church probably...

Liz: right... but you think art class might be ok...

Natasha: ... um... I'm not sure about that one either... that's an evening one

Liz: well it doesn't really matter when it is. I mean I can do... time doesn't really matter to me... um. It's whether you would feel comfortable with me being there... with you.

<sup>8</sup> The research themes are: 1) Places I feel good going to; 2) Places I go to regularly; 3) Outside my front door and 4) Places in my past.

<sup>9</sup> Iceland is a chain of budget supermarkets. In Cornwall they are usually small and located in town centres making them more accessible to people who lack access to private transport.



1  
2  
3 Because many of Natasha's regular trips are of an institutional or semi-institutional  
4 nature such as Church attendance or work (where she had access to confidential  
5 information), we needed to think carefully about how appropriate it was and how  
6 comfortable Natasha would be taking me along. I was highlighting negative aspects  
7 whilst keeping it as a viable option if Natasha wanted to make that choice.  
8  
9

## EXTRACT 7

10  
11  
12  
13 Liz: You see I could come with you on the trip to work but the, I mean we could  
14 make the trip to work... um... .. but I, I mean it would be quite problem.. I  
15 mean it would be quite difficult... for me to actually be with you while  
16 you're at work because of all kinds of confidentiality things  
17  
18

19  
20 Natasha: mmmm...

21 Liz: you know but I could make the journey from here to work with you umm or I  
22 could make the journey I could make the journey from here to church with  
23 you... and um wait until you came out of church if you didn't feel  
24 comfortable with me being in there and then we come back from art class  
25 or craft club  
26  
27  
28

29  
30 Natasha: Ummm... ..

31 Liz: or we could just do the supermarket... ..

32  
33 Natasha: uhhh, gosh, er.... .. come out of craft club and then (indistinct do the  
34 craft club one?)... come out of it and then came back?  
35

36 Liz: ... I mean maybe it would be better to do a supermarket?  
37

38 Natasha: might be, yeah...

39 Liz: cause I think it's... I think what I mean is, although it would be really  
40 interesting... to accompany you at work  
41

42  
43 Natasha: yeah

44 Liz: I think it would be too difficult because of all the confidentiality stuff  
45

46 Natasha: yeah I think (mumble)  
47

48 Liz: so I'm going to cross work off  
49

50 Natasha: do um... we could do Asda or something...

51 Liz: ... ok so a day when you're doing a slightly bigger shop... than you  
52 normally do?  
53

54  
55 Natasha: yeah... ..

56 Liz: ... I could help carry your bags then!  
57

58 Liz & Natasha: laughing  
59  
60

1  
2  
3 Liz: I'll be the donkey

4 Natasha: hahaha...

5  
6 Liz: OK so we'll do cross out arts and crafts clubs... and we'll do an Asda  
7 shop... ...  
8

9  
10 In the extract above, accompanying Natasha to work is an option, but my anxiety  
11 about managing issues of confidentiality even *if* we had permission from the office  
12 where she worked, were foremost. As Natasha demonstrated little enthusiasm for  
13 me accompanying her to work, I 'short-circuited' the decision-making cycle (Antaki, et  
14 al. 2006) and only needed Natasha's agreement that this was not an option. Once  
15 this was established, and I could eliminate what I felt to be an inappropriate trip,  
16 Natasha came up with the earlier suggestion of going to the supermarket.  
17  
18  
19  
20

### 21 *Reflections*

22  
23 This interaction was interesting because it took place as I was initially researching  
24 and writing this paper. Consequently during our meeting I was acutely sensitive to  
25 our interactions and analysed my own talk as the interaction occurred:  
26  
27

28 *FN: 7/513: As we were having problems spelling Penchwoone, I made a joke*  
29 *about how bad my spelling is and how many problems I have with it as well. I*  
30 *know my spelling isn't that bad really, and as I was saying it, I realised that I*  
31 *was actually hiding the 'face-threatening' nature of the talk and playing down my*  
32 *'expertise' to try and equalise the power differential.*  
33  
34  
35

36 This specifically related to Rapley & Antaki (1998) and demonstrated the way that I, a  
37 person with power, 'propose[d] a set of identities for [me] and [my] respondents very  
38 different from the institutional one' (Rapley & Antaki 1998: 590). Disclosing my poor  
39 spelling, moves me away from my 'institutional role', distracting attention from my  
40 knowledge and expertise. Creating this 'cover identity', Rapley and Antaki continue,  
41 helps me to elicit Natasha's views on where we should go on our trips by re-  
42 orientating from 'professional' to 'friend/equal'.  
43  
44  
45  
46  
47

48 This analysis of Rapley & Antaki's (1998) is however based upon assessment  
49 interviews which are different from the interactions between me and the co-  
50 researchers. I aimed to orientate myself, both consciously and subconsciously as  
51 equal because we were researching together in an interdependent relationship. As  
52 well as having a friendly and professional relationship, because that is a natural  
53 development of working with someone over time, in order to do the research, I  
54  
55  
56  
57  
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59  
60

1  
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3 needed the co-researchers to be invested in it and one way I hoped to achieve this  
4 was by making it a rewarding and worthwhile experience.  
5  
6  
7

## 8 **Conclusions**

9  
10 This paper has explored the complex process of my/our decision-making, thus  
11 providing a degree of transparency. I hope it gives encouragement to other  
12 researchers aiming to work inclusively, who, like me, find the lines between  
13 controlling, guiding and supporting the decision-making process sometimes blurred  
14 and indistinct. At heart, the examples serve to interrogate the assumption that people  
15 with learning difficulties are inherently incompetent in making decisions for  
16 themselves. Following Goodley (1996), Rapley (2004) and Bogdan & Taylor (1982), I  
17 conclude that incompetence is socially constructed and intimately connected to  
18 neoliberal ideals of independence. Like parenting (Tilly 2008; Shewan et al. 2014)  
19 and friendships (Ellis 2017), when it comes to decision-making, it appears that people  
20 with learning difficulties are held to higher standards than those without. The extracts  
21 also evidence the claim that although imperfect, the process strived for and  
22 sometimes achieved genuinely collaborative decision-making. The talk produced  
23 around the decisions was grounded within the context of the process, the  
24 chronological time frame and my own talk 'preferences' for advocacy and  
25 empowerment talk.  
26  
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36 This process of intently examining my own talk was intensely uncomfortable, but  
37 it has been invaluable. I make no claims of empowerment, but as far as possible, I  
38 tried not to disempower. Recalling Dingwall's, (1980) observation at the beginning, I  
39 worked towards giving the co-researchers as much voice as possible to make  
40 decisions, but recognise that paradoxically, my actions could sometimes be seen as  
41 denying them a voice. This was not done to exert my social power over the co-  
42 researchers thus *deliberately* disempowering them, but in order to maintain the  
43 opportunity as *whole* and to ensure the project remained viable. This I believe  
44 highlights the importance of understanding the wider context when analysing textual  
45 data.  
46  
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53 So, from the chaos of the first extract, where I abdicated all control for fear of  
54 disempowering the co-researchers, to the second example where I effectively ignored  
55 Stuart's preferences and finally the third example, where I negotiated an appropriate  
56  
57  
58  
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3 research trip with Natasha, the messy process of decision-making has been picked  
4 apart in order to expose the power relationships and cast light on the claims of co-  
5 produced decisions. The examples given thus illuminate some of the complexities of  
6 working collaboratively and provide learning points and insights for future inclusive  
7 researchers.  
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