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

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ABSTRACT

This article explores the decision-making process with a group of people with learning difficulties in an inclusive research project. The article explores 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 examined critically to unpick the author's claims of collaborative decision-making.

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KEYWORDS

Inclusive research; learning disabilities; decision-making

Points of interest

- This article is about an inclusive research project where the author worked with four co-researchers.
- The article looks at how we made some decisions about setting up the project.
- To do this, the author 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 perform 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, 171)

Introduction

This article explores the complexities of the decision-making process in inclusive research. The article firstly looks at the literature around decision-making by people with learning difficulties, particularly that using conversation analysis (CA), and then examines three examples from the research process.

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The research involved four co-researchers, all of whom identified as having learning difficulties. Whilst setting up the research process, the author became increasingly troubled by her own 'we' claims. Conference presentations on the inclusive methodology used were littered with comments such as 'we decided ...' and 'we discussed ...'. This article is the response to the inevitable challenge to evidence these claims.

People with learning difficulties making decisions

The rights and capacities of people with learning difficulties to make decisions, express choice and have autonomy have been explored and debated since the normalisation agenda contributed to the closure of large institutions (Parmenter 2001) in most developed countries. Over time, this culminated in autonomy and choice being considered a right for all disabled people, enshrined both in policy and legislation (Department of Health 2005; United Nations General Assembly 2006). This section begins by considering ways in which the decision-making process has been analysed previously. The section specifically explores the use of CA in some of the published analyses of decision-making relating to people with learning difficulties.

Much of the early literature that has looked into decision-making by people with learning difficulties starts from the assumption that restrictions on decision-making are the consequence of incompetence (see Jenkinson [1993] for an overview). Other perspectives suggest that such restrictions are the cause of incompetence (Bogdan and Taylor 1982; Goodley 1996) and that incompetence, along with learning disability, is socially constructed. These two perspectives focusing on cause and effect continue to dominate discourse and research around the perceived capacity of people with learning difficulties to make choices (Arscott, Dagnan, and Kroese 1999; Sims and Cabrita Gulyurtlu 2013; Smyth and Bell 2006).

The discourse around people with learning difficulties as empowered and competent citizens (Dowse 2009) within neoliberal agendas has created tensions. Thus, people with learning difficulties attempt to negotiate systems which, whilst promoting self-advocacy, autonomy and individualism, also tie individuals to states of dependency (Dowse 2009). This results in supporters¹ experiencing tensions between needing to maintain professional competency whilst simultaneously respecting the autonomy and choice of people with learning difficulties (Pilnick et al. 2010). This sometimes results in supporters working in ways which are less about promoting advocacy and more about 'getting the job done' (Redley and Weinberg 2007).

Inclusive research with people with learning difficulties frequently makes reference to decision-making in the first-person plural (Brookes et al. 2012; Buettgen et al. 2012; Chapman and McNulty 2004; Michell 2012), indicating that the decision-making process is one in which the 'professional' researcher and the

co-researchers have equal weight and authority within that process. It is common to see statements such as the following in articles discussing inclusive research projects:

As Ian, Sylvia and Beth discussed this early experience, *we* decided that ... (Brookes et al. 2012, 147; emphases added)

Between face-to-face meetings *we* would speak over the telephone to make collaborative decisions. (Buettgen et al. 2012, 603–616; emphases added)

We had a big meeting to decide who did what; the Professor listened to us and together *we* decided who would do what. (Michell 2012, 154; emphases added)

However, details of how that decision-making process is accomplished and the reality of the power-sharing during that process is rarely (if ever) analysed in any depth in journal papers. This is not to say that professionals researching inclusively with people with learning difficulties misrepresent how decisions are made when they use the first-person plural, but that it is not always transparent.

By being transparent about the decision-making process, a more nuanced understanding of the role of the professional can be achieved. Chapman, whilst noting the low numbers of people with learning difficulties involved within the decision-making process of commissioning research, is explicit about her influence:

It needs to be acknowledged that my role as a decision-maker within the team is likely to have been highly influential. I came to the group with knowledge and information, and had been teaching the group about research skills for a number of years before the project began. (2005, 124)

Chapman earlier in her thesis problematises participation and partnership, including decision-making, and suggests that, for example, questioning the decision not to participate could result in empowerment by learning new skills or disempowerment by questioning that choice. This connects with the way professionals, parents, carers and supporters sometimes view the capacity of people with learning difficulties to make decisions about how they want to live on a day-to-day basis or respond 'accurately' to a question.

In a reflexive ethnography of supporting a man (SW) with learning difficulties, Schelly (2008) reflected on these tensions between providing support and choice. As part of his ethnography, Schelly produced a short excerpt from a meeting between him (in his role of support worker), service providers and SW in order to set goals. Schelly saw SW's responses as either non-responses ('I don't know') or as the result of acquiescence bias. Acquiescence bias is Sigelman et al.'s thesis that people with learning difficulties inevitably say 'yes' to closed questions even when the answer is obviously 'wrong' or contradictory (Sigelman et al. 1981a).

The impact of Sigelman's work (Heal and Sigelman 1995; Sigelman et al., 1981a, b) around acquiescence bias in interviewing people with learning difficulties has been profound. Despite other researchers' findings failing to replicate the acquiescence bias thesis (see Finlay and Lyons 2002; Matikka and Vesala 1997; Ramirez 2005), acquiescence bias has now become an accepted 'fact' and a component

of the supposed incompetency of people with learning difficulties (Goodley and Rapley 2002). This has resulted in some research uncritically accepting that positive responses by people with learning difficulties are the result of acquiescence bias (see, for example, Rodgers 1999; Schelly 2008; Wistow and Schneider 2003; Yacoub and Hall 2009). This feeds into the assumption that any answers given by people with learning difficulties to any question in any context will most likely lack validity. As Rapley and Antaki (1996, 223) argue, this 'has encouraged a climate of opinion in which what people with learning disabilities have to say is (at least) open to the suspicion that they are merely offering what the questioner wants to hear'.

Sigelman et al.'s (1981a) thesis has been critiqued at length, specifically by Rapley with others (Goodley and Rapley 2002; Houtkoop-Steenstra and Antaki 1997; Rapley 2004; Rapley and Antaki 1996). Taking a discursive psychological approach, Rapley (2004) argues that the questions upon which Sigelman's work is based are inherently flawed. Agreeing with Matikka and Vesala (1997), Rapley suggests that the apparently contradictory 'yes' response to the question 'are you allowed to/is it against the rules ... to hit someone', as cited by Heal and Sigelman (1995), is logical because, whilst inmates in institutions are prohibited from hitting people, staff often do so. Flawed questions are also responsible for the supposed acquiescence of Schelly's (2008) client SW, who when confronted with the convoluted question 'SW, if you had to say one thing that is a goal of yours for this next year, can you think of anything?' said 'I don't know'. As Finlay and Lyons (2002, 22) suggest, 'Acquiescence should be seen, then, as a problem of difficult or semantically complicated questions rather than as a problem of yes/no questions per se'. The difficulty of questions not being fit for purpose was also evident in Houtkoop-Steenstra and Antaki's (1997) research that found 'yes/no' questions tended to be couched in what they termed 'unmarked' forms which are the 'default formulations' and, as such, are formulated in positive terms. Thus, an 'unmarked' question such as 'are you satisfied?'; although supposedly neutral, tends to suggest a 'no-problem' answer with a preference for agreement built into them. Compare this with a 'marked' form such as 'are you dissatisfied?' which, Houtkoop-Steenstra and Antaki (1997) suggest, invites the question 'what makes you think so?'

Rapley's analysis, whilst being drawn from discursive psychology, draws heavily upon CA in order to illuminate the challenges within Sigelman's thesis and to show how the category of learning difficulty is socially constructed. The use of CA is 'designed to deal with fundamental features of human action and interaction' (Heritage 2010, 207). Hammersley (2002) suggests that CA as originally propounded by Sacks and Schegloff generally adopts a value-neutral stance and that inferences are made only on what is actually observable in the interaction under analysis. This, Hammersley argues, means that context, which remains unspoken, does not exist independently, but can only be constituted in and through talk. Heritage (1995, 396) explains further that conversational practices are 'independent of the motivational, psychological or sociological characteristics of the participants'. This perspective suggests support for Rapley's (2004) argument that

the category of 'intellectually disabled' is a product of social interaction between individuals and institutions which are, as Heritage (1995) suggests, normatively orientated. The difficulty with excluding context from interactions, however, is that context in itself will create or influence certain kinds of interaction. Thus, what Rapley (2004) suggests is that a 'testing' context, such as where a person with learning difficulties is questioned by a service professional, might provide context from the talk alone (see, as an example, Rapley 2004, 90 extract 7), Goodley (1996, 339) finds that the written form of extracts sometimes 'fails to convey the reality of the interview'.

Not all proponents of CA adhere to this perspective as it is applied to interaction with people with learning difficulties. Redley and Weinberg (2007, 768), for example, argue that failing to acknowledge the 'obdurate social reality' of learning difficulty will eventually raise the question of why people with learning difficulties should be entitled to additional support. Redley and Weinberg (2007) introduce context into their analysis by using video and by knowledge of the 'institutional mandates', arguing that the interactions made by the Parliament for People with Learning Difficulties (PPLD) are shaped not just by talk and interactional cues, but by 'the distal institutional mandates that occasion its occurrence in the first place' (2007, 770). The specific institutional mandates they refer to in this instance are those that support the PPLD's preference for empowering people with learning difficulties and imparting advice.

Redley and Weinberg's (2007) study, exploring the interactions between service professionals/decision-makers and 'MPs',² is sharply critical of self-advocacy talk as being normative in the PPLD and that what is termed self-advocacy is, in fact a form of 'education' of people with learning difficulties. By this they mean that MPs 'taking the floor' is enforced by both decision-makers and MPs, and that when an MP fails to do so, it causes what Redley and Weinberg term 'interactional trouble', identified as inaudible speech, failure to speak, refusal to speak and inappropriate speech. When there is interactional trouble, decision-makers and MPs create a discursive path to allow the decision-makers to take the floor whilst at the same time honouring the MP's possession of the narrative. They give an example, 'other forms of abuse and bullying' (2007, 771) as a parliament discussion theme, whereby 'advice' is given to MPs (to tell staff about bullying) rather than to decision-makers (thus removing the necessity for decision-makers to take appropriate action). Redley and Weinberg suggest that 'instances of failure to speak' are based on an MP not making the desired discussion but reverting to a Q&A format (2007, 776 excerpt 6). This format is familiar to many audiences of inclusive presentations in that it can help to act as a prompt for people with learning difficulties in what are stressful and pressured situations. In this particular sequence, although the Q&A format allows MPs' voices to be heard, it also allows decision-makers to shift responsibility for bullying onto the MP and not adequately respond to what the MP is saying. For Redley and Weinberg, this is due to a deficit in the MP, rather than the decision-maker, because, they argue, the PPLD is fully accessible, negating arguments made by others that

the decision-makers were unwilling to share power. This assertion is problematic because, irrespective of the stated commitment of accessibility the PPLD might have, the actual accessibility and advocacy orientation or the organisation might be experienced differently by people with learning difficulties.

One of the difficulties with Redley and Weinberg's paper is that the talk they analyse is also, to an extent, institutional 'testing' talk. Despite attempts made by the PPLD to promote equality and power-sharing between MPs and decision-makers, the context is both artificial and, I would argue, deeply 'testing' for all but the most confident self-advocate. Further, it follows Houtkoop-Steenstra and Antaki's (1997) discussion of how interviewers re-orientate questions (in this case, yes/no questionnaire questions requiring pre-coded response options) to minimise difficulties and help interviewees 'save face'.

Although Redley and Weinberg's (2007) analysis within disability studies is somewhat contentious both in its critique of self-advocacy and in locating the deficit of intellectual impairment within the individual, they make a valid point about the importance of context, both proximal and distal when analysing talk, particularly institutional talk. This notion of 'institutional talk' is further interrogated by Williams et al. (2010) in an inclusive research project exploring interactions between personal assistants (PAs) and their clients, people with learning difficulties, to identify what 'good support' looks like. Williams, Ponting, and Ford (2009) found that whilst there were examples of institutional talk used by PAs, both PAs and clients delicately side-stepped the institutional frame by using terms like 'mate' to mark out their relationship as a friendly one. Humour was also used to soften some of the institutional talk by PAs as they gave advice and helped clients make choices. Interestingly, there were also instances of institutional talk by clients in evaluating the performance of PAs which was again softened by the use of 'mate' but was still reinforcing the client's role as 'employer' and thus more powerful. Such interactions, rather than being instances of institutionally mandated talk, could be contextualised as negotiated forms of empowerment designed to give the client the maximal control they could manage at the time.

Whilst the PAs in Williams, Ponting, and Ford (2009) and Williams et al. (2010) were sensitive in how they supported adults to make choices, Pilnick et al. (2010) found that young people, especially school children, are seldom given the same sensitivity. Pilnick et al. highlighted that whilst 'special school' leavers were positioned as having choice and control as part of the neoliberal agenda around active citizenship, in reality they were not recognised as such by educational staff. Pilnick et al. (2010) illustrated how despite students making interactionally adequate and appropriate responses to questions during transition review meetings, interviewers failed to recognise the responses as such. This was sometimes because the interviewer failed to make clear and specific questions, recalling Schelly's (2008) interactional troubles. Sometimes it was because, despite giving clear, unequivocal preferences, the answers were discounted as inappropriate by staff and/or parents, such as Alec's hopes of joining the police force. Finlay, Walton, and Antaki

(2008, 353) note that such preferences 'are disempowering since they put additional obstacles in the way of people with learning disabilities in their attempts to exert control over their environments'. This highlights the preference professionals have for responses that are both appropriate/adequate and, significantly, verbal, which, as will be seen in the extracts in the following section, is a preference that this author also made.

Making decisions in setting up the project

The decision-making process in this research project was complex and, at times, fraught. Many decisions were made, such as topics to research, methods to be used, dates and places to meet.³ Initially I saw my role, following Williams (1999), as a facilitator, with the research team taking responsibility for deciding what to research and how. Mindful of how people with learning difficulties can be disempowered in meetings because of non-disabled, more powerful others being directive (Finlay, Walton, and Antaki 2008), I aimed to keep direction to a minimum. Unlike Williams, however, who, whilst admitting that she influenced the research to some extent, my influence on the research, specifically in terms of final research topic, research questions and methods, was eventually far greater than I initially intended. As such, I radically (but temporarily) re-orientated my perspective from being a facilitator to being a manager early on. This consequently shifted my perspective of the team from full co-researchers to 'helping' me, thus mirroring (but in reverse) Buettgen et al.'s (2012) experience of co-researchers feeling like helpers to start with. Eventually this orientation again shifted towards something that, superficially anyway, felt more equal. This desire to 'feel' greater equality meant that whilst I aimed to make decisions jointly, this could sometimes be interpreted as tokenistic.

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

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

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

These are organised thus:

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

Eliminating health

Context

During the first meeting at SpeakUp⁵ 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 (Field Notes (FN), 28 February 2012). 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 May 2012). The support worker reinforced this message by suggesting that I give more direction about what we discuss (FN, 9 May 2012). 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 and 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 of 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 (M, 9 May 2012) produced seven potential areas of research:

1. Benefit changes.
2. Getting and keeping work.
3. Health.
4. Transport.
5. Bullying.
6. Getting on with people around us.
7. Labelling.

The second meeting (M, 15 May 2012) 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, 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 ...

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

Liz and Sarah: Heavy?

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

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

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

Jenny: no ...

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

Liz: Am I not explaining it clearly enough?

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

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

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

Sarah: OK

Liz: OK

Sarah: No problem

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

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

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

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

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

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

Extract 2

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

Dan remained seated and continued to remain so as I attempted to reassure him that it is all right to not take part in the discussion if he is uncomfortable and Jenny and Sarah reassured him that the research is not about him personally. Dan then clearly articulated his preference for researching around the other two topics of

getting on with people and labelling. Dan is careful to emphasise that he is not directing the others to share his views by saying 'I wouldn't stop you from doing it':

Extract 3

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

Dan: mmm

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

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

Liz: yeah

Dan: a bit

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

Dan: yeah

Liz: full stop, yeah?

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

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

Dan: I'm sorry ... I am sorry [starts to rise from chair]

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

Liz: you don't have to apologise

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

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

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

Extract 4

Liz: although Natasha's not here, I mean, you know, if looking at health care is something which is perhaps going to be something we're NOT going to do, now we have a choice, we can either still talk about our experiences around accessing health care, emm, ways to make health better, emm, or we can talk about something else or wrap it up early. I haven't prepared anything around community yet because I was just going to take it one topic at a time. So what do you feel?

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

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

Liz: yeah

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

Liz: yeah

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

Helen: What Michael says too, stop you know

Jenny: health?

Helen: health

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

Michael: yeah because it certainly unbalanced him

Liz: yeah

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

Reflections

Whilst I feel comfortable that the decision was not specifically driven by agenda setting on my behalf, the interaction was problematic. Firstly, I did not pick up on Dan's growing discomfort early enough. Having been quite vocal throughout the first part of the meeting, I should have been alerted to his decreasing participation. Secondly, allowing health to be eliminated without full consultation of all members discomfited me because, although it was the majority view of those present, the decision was not made by all of the members. Rather than suggesting we reflect on the situation over time, I immediately agreed that health should be eliminated. With hindsight, this was probably the best course of action given that issues around attendance were already emerging and it was another month before we met again. This extract highlights how decision-making in groups is always dependent on negotiation, but when attempts are made to address real or perceived power imbalances, the process becomes more complex and messy.

Deciding which research method to use

Background and context

This meeting with Stuart took place in late October 2012. At this point, the research team had divided on geographical lines with Dan and Helen based in Redruth

and Stuart, Natasha and Mark based in Truro. Despite this, the Truro team still had problems with timetabling so that everyone could attend together. By this stage I had made the decision as described earlier, to focus the research area on how communities interact with people with learning difficulties. This decision was made unilaterally and without consultation with co-researchers, and at the time caused me a deal of discomfort. The justification for eliminating labelling, the remaining option, was based on the prior existence of inclusive research in this area (see, for example, Williams 2002) alongside time pressures.

With the research area now defined, and the overarching research questions relating to the impact of rural environments developed, the next stages were to identify specific research questions with the co-researchers and decide on the research methods. I felt like the decision about the research questions had been made in collaboration, but on analysing the transcript more carefully it emerged that I had in fact given Stuart (as the only other participant at that meeting) a list of questions that he then agreed with. That was one instance where I had previously made 'we' claims when in fact it was 'I'. The decision that immediately followed was one where Stuart made a clear decision about how he wanted to work. This choice was, however, later over-ruled.

Because of the co-researchers' lack of experience and previous guidance from the support workers and co-researchers themselves about needing more direction, I then suggested two potential avenues of research based on methods used previously by inclusive researchers. I proposed that co-researchers either used forms of self-research, such as narrative or life history (Booth and Booth 1996; Keyes and Brandon 2012; Rolph 1999), or what could be considered more 'traditional'⁷ forms of qualitative research such as interviewing and/or observation (Chapman 2005; Dias et al. 2011; Townson et al. 2007). By giving co-researchers limited but diverse choices, I aimed to refine it down to more specific ways of researching.

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

This is not to say that my co-conversationalist was silent, but made liberal use of 'response tokens' such as 'hmm' and 'yeah'. Levinson (2005, 76) observes that the

use of response tokens can be ambiguous in that they 'enable the ongoing display of competent attention without having to demonstrate comprehension'. This can mean that such response tokens could in fact act as 'fillers' and, as Sacks (1995a) suggests, when someone is only answering questions or using fillers of 'uh huh' or 'yeah' it is not actually a conversation. Sacks' observations were not in relation to people who, for whatever reason, experience degrees of inarticulate speech, but he did observe how 'silence is a terrible thing' (Sacks 1995b, 225). I thus felt a pressure as the 'professional' to 'keep off silence by going on' (Sacks 1995b, 225) when co-researchers did not 'take turns' in the conversation. This interactional trouble was more pronounced in early meetings and meetings with only one co-researcher.

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

Extract 5

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

Stuart: yeah

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

Stuart: hum

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

Stuart: hmm

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

Stuart: yeah

Liz: you prefer

Stuart: working with people

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

Stuart: yeah

Liz: so I'll double check with them

Stuart: yeah

Liz: and see what they'd like

Analysis

It seems that, on the face of it, Stuart is saying 'yeah' to both propositions of self-research and 'traditional' research. The first instance of 'yay-saying', as Heal and

Sigelman (1995) would typify it, is, after placing the interaction in context, more convincingly interpreted as Stuart using 'yeah' as a response token to acknowledge and give understanding of what I meant by self-research. Finlay and Lyons (2002), in a review of the literature on acquiescence, suggest that yea-saying might occur in cases where someone is uncertain of the meaning of a question or where there is an unequal power relationship. In terms of 'talk time' as discussed earlier, mine was the dominant voice in the interaction, which could have set up this power inequality. This power inequality in turn produced something which is similar to a 'testing' situation as suggested by Rapley's (2004) analysis of Sigelman et al.'s (1981a) theory of acquiescence bias. It is therefore possible that Stuart's first, flat-sounding and non-committal 'yeah' was due to lack of understanding and the second, emphatic 'yeah' was because he had a traditional understanding of research as 'working with people'. As Finlay and Lyons (2002) suggest, when someone is asked to make a decision about something they have not previously considered, it also creates uncertainty which in turn may lead to acquiescence. Whilst it could be argued that Stuart has not in fact fully understood what I said, my contextual interpretation was that he fully understood what I meant and was using 'yeah' as a response token. The flatness of this filler was, I believe, the result of Stuart being less than excited about the prospect of doing a form of research he had little interest in. As all of the co-researchers had expressed a preference for interviewing others, perhaps because of the social interaction, researching one's own life might seem less enticing.

Reflections

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

Planning a trip

Background and context

This meeting with Natasha was seven months after the aforementioned meeting. I was now working individually with Stuart, Natasha, John and Mark. The design had changed so we were now engaged in mobile interviewing (Clark and 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 of 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 theme⁸ '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,⁹ 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.

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

Extract 7

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

Natasha: mmmm ...

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

Natasha: Ummm ...

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

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

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

Natasha: might be, yeah ...

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

Natasha: yeah

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

Natasha: yeah I think [mumble]

Liz: so I'm going to cross work off

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

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

Natasha: yeah ...

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

Liz and Natasha: [laughing]

Liz: I'll be the donkey

Natasha: hahaha ...

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

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

Reflections

This interaction was interesting because it took place as I was initially researching and writing this article. Consequently, during our meeting I was acutely sensitive to our interactions and analysed my own talk as the interaction occurred:

FN: 7 May 2013: As we were having problems spelling Penchwoone, I made a joke about how bad my spelling is and how many problems I have with it as well. I know my spelling isn't that bad really, and as I was saying it, I realised that I was actually hiding the 'face-threatening' nature of the talk and playing down my 'expertise' to try and equalise the power differential.

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

This analysis of Rapley and Antaki's (1998), however, is based upon assessment interviews which are different from the interactions between me and the co-researchers. I aimed to orientate myself, both consciously and subconsciously, as equal because we were researching together in an interdependent relationship. As well as having a friendly and professional relationship, because that is a natural development of working with someone over time, in order to do the research I needed the co-researchers to be invested in it, and one way I hoped to achieve this was by making it a rewarding and worthwhile experience.

Conclusions

This article has explored the complex process of my/our decision-making, thus providing a degree of transparency. I hope it gives encouragement to other researchers aiming to work inclusively, who, like me, find the lines between controlling, guiding and supporting the decision-making process sometimes blurred and indistinct. At heart, the examples serve to interrogate the assumption that people with learning difficulties are inherently incompetent in making decisions for themselves. Following Goodley (1996), Rapley (2004) and Bogdan and Taylor (1982), I conclude that incompetence is socially constructed and intimately connected to neoliberal ideals of independence. Like parenting (Shewan et al. 2014; Tilly 2008) and friendships (Ellis 2017), when it comes to decision-making it appears that people with learning difficulties are held to higher standards than those without. The extracts also evidence the claim that, although imperfect, the process strived for and sometimes achieved genuinely collaborative decision-making. The talk produced around the decisions was grounded within the context of the process, the chronological time frame and my own talk 'preferences' for advocacy and empowerment talk.

This process of intently examining my own talk was intensely uncomfortable, but it has been invaluable. I make no claims of empowerment, but as far as possible I tried not to disempower. Recalling Dingwall's (1980) observation at the beginning, I worked towards giving the co-researchers as much voice as possible

to make decisions, but recognise that, paradoxically, my actions could sometimes be seen as denying them a voice. This was not done to exert my social power over the co-researchers, thus deliberately disempowering them, but in order to maintain the opportunity as whole and to ensure the project remained viable. This, I believe, highlights the importance of understanding the wider context when analysing textual data.

So, from the chaos of the first extract, where I abdicated all control for fear of disempowering the co-researchers, to the second example, where I effectively ignored Stuart's preferences, and finally the third example, where I negotiated an appropriate research trip with Natasha, the messy process of decision-making has been picked apart in order to expose the power relationships and cast light on the claims of co-produced decisions. The examples given thus illuminate some of the complexities of working collaboratively and provide learning points and insights for future inclusive researchers.

Notes

1. 'Supporter' is used here to signify those who work formally or informally with people with learning difficulties in ways which could be construed either superficially or in actuality as being allies.
2. MPs are individuals with learning difficulties elected by other people with learning difficulties to represent their views to decision-makers and service providers.
3. It is important to note that difficulties with transport and timetabling meant that the research team divided into two geographical groups and later the author worked with the co-researchers individually.
4. 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.
5. SpeakUp is the (anonymised) self-advocacy group from which the co-researchers were recruited.
6. Kathy was another person who was then part of the team and later left.
7. Traditional is here used as shorthand for methods that are well established within the social sciences and, critically, were understood by the co-researchers as 'proper' research methods.
8. The research themes are: 'Places I feel good going to'; 'Places I go to regularly'; 'Outside my front door' and 'Places in my past'.
9. 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.

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