



This is a peer-reviewed, post-print (final draft post-refereeing) version of the following published document, This is an Accepted Manuscript of an article published by Taylor & Francis in Disability & Society on 16th March 2018 available online: <http://www.tandfonline.com/10.1080/09687599.2017.1392932>. and is licensed under All Rights Reserved license:

Ellis, Elizabeth ORCID logoORCID: <https://orcid.org/0000-0001-9628-8413> (2018) Making decisions together? Exploring the decision- making process in an inclusive research project. Disability and Society, 33 (3). pp. 454-475. doi:10.1080/09687599.2017.1392932

Official URL: <http://www.tandfonline.com/doi/full/10.1080/09687599.2017.1392932>
DOI: <http://dx.doi.org/10.1080/09687599.2017.1392932>
EPrint URI: <https://eprints.glos.ac.uk/id/eprint/5212>

Disclaimer

The University of Gloucestershire has obtained warranties from all depositors as to their title in the material deposited and as to their right to deposit such material.

The University of Gloucestershire makes no representation or warranties of commercial utility, title, or fitness for a particular purpose or any other warranty, express or implied in respect of any material deposited.

The University of Gloucestershire makes no representation that the use of the materials will not infringe any patent, copyright, trademark or other property or proprietary rights.

The University of Gloucestershire accepts no liability for any infringement of intellectual property rights in any material deposited but will remove such material from public view pending investigation in the event of an allegation of any such infringement.

PLEASE SCROLL DOWN FOR TEXT.

Making decisions together? Using conversation analysis to explore the decision-making process in an inclusive research project

Points of interest

- The research project discussed here is an inclusive research project where I worked with a team of four co-researchers.
- Inclusive researchers do not always make the decision-making process transparent. This article looks in detail at how some of the decisions taken in setting up the project were made and who made them.
- To do this I used conversation analysis, which is a way of looking at how people talk to each other and the words they use.
- The article shows how making decisions together can be difficult, but practice makes it easier.
- The article will help other inclusive researchers in making decisions together with co-researchers.

Making decisions together? Using conversation analysis to explore 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. Using a modified form of conversation analysis (CA) it begins by outlining the reasons for using CA and for using an adapted short form of the method. The literature using CA in relation to people with learning difficulties making decisions is then explored, specifically drawing on the literature that informed the author's own approach to the process. Two 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; Conversation analysis; Decision making.

Points of interest

- The research project discussed here is an inclusive research project where I worked with a team of four co-researchers.
- Inclusive researchers do not always make the decision-making process transparent. This article looks in detail at how some of the decisions taken in setting up the project were made and who made them.
- To do this I used conversation analysis, which is a way of looking at how people talk to each other and the words they use.
- The article shows how making decisions together can be difficult, but practice makes it easier.
- The article will help other inclusive researchers in making decisions together with co-researchers.

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 focuses on the decision-making process in setting up a small inclusive research project in a rural area. 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 using were littered with comments such as 'we decided...' and 'we discussed...' This paper is the response to the inevitable challenge to evidence these claims.

Why use CA?

My use of CA is restricted to this paper and not used to develop findings and outcomes for the research data generally. This is because CA is inaccessible for many people. The complex Jeffersonian transcription forms interrupt the flow of reading and novice readers are constantly 'translating' to 'normal' speech. Complex CA transcripts are problematic in

D&S paper draft 1

another way. Detailing stutters, in/outbreaths and fillers made by verbally articulate people may be enlightening, but I remain unconvinced the same could be said for people with learning difficulties or who are otherwise disfluent. My fear was that CA would, at best, obscure my aim in clarifying who decided what and at worst, unjustly misrepresent people as incompetent and inarticulate. This anxiety was exacerbated by the largely normative understandings of CA. Sacks suggests that ‘the pacing requirements of talk are such that they insure a lot of things happening that exhibit routine *normative* features...’ (Sacks, 1995: 772 my emphasis). Therefore using Jeffersonian transcription forms could lead to analysing the speech of a person with learning difficulties in the same way as a politician. There are thus a strong ethical and accessibility arguments *not* to use the Jeffersonian system for transcribing the talk of people with learning difficulties. Goodley (1996) also suggests that written forms of extracts sometimes ‘fail to convey the reality of the interview’ (: 339). This ‘reality of the interview’ connects with my contention that the style of transcript annotation used in many forms of CA can serve to diminish disfluent respondents.

Therefore, my ‘verbatim’ transcript is in fact no such thing. I omitted most stutters, multiple verbal fillers and so forth. In other words, I ‘cleaned’ the talk up in order to create a clear narrative of the conversation. In this respect, I have followed Williams, et al. (2010) and used a simplified version of CA suited to the specific analytical needs of this exercise. However, it is important to note that the analyses I made of the following extracts, taken directly from the videos, *do* take note of long pauses, speaking over and intonation.

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. It specifically explores the use of conversation analysis (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 & 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 et al. 1999; Smyth & Bell 2006; Sims & Cabrita Gulyurtlu 2013).

The discourse around people with learning difficulties as empowered and competent citizens (Dowse 2009) within neo-liberal 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

D&S paper draft 1

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 & 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, Richardson, Beckham, Ward, & Riemer, 2012; Chapman & 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 like 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)

Between face-to-face meetings we would speak over the telephone to make collaborative decisions. (Buettgen et al., 2012: 607)

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)

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 (2005), 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 (: 124)

Chapman earlier in her thesis problematizes 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

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.

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, Budd, Spanhel, & Schoenrock, 1981).

The impact of Sigelman's work (Heal & Sigelman, 1995; Sigelman *et al.*, 1981) 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 & Lyons, 2002; Matikka & 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 & 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 & Schneider, 2003; Yacoub & 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 & 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 (1981) thesis has been critiqued at length, specifically by Rapley with others (Rapley 2004; Rapley & Antaki 1996; Houtkoop-Steenstra & Antaki 1997; Goodley & Rapley 2002). Taking a discursive psychological approach, Rapley (2004) argues that the questions upon which Sigelman's work is based are inherently flawed. Agreeing with Matikka & Vesala (1997), Rapley suggests the apparently contradictory 'yes' response to the question 'are you allowed to/is it against the rules... to hit someone', as cited by Heal & 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 & Lyons, (2002) 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*' (: 22). The difficulty of questions not being fit for purpose was also evident in Houtkoop-Steenstra & 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 & 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). 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) elaborates that conversational practices are ‘independent of the motivational, psychological or sociological characteristics of the participants’ (: 396). 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 is that context in itself will create or influence certain kinds of interaction. Thus what Rapley (2004) suggests is a ‘testing’ context, where a person with learning difficulties is questioned by a service professional, *might* provide context from the talk alone (see Rapley, 2004: 90 extract 7 as an example).

Not all proponents of CA adhere to this perspective as it is applied to interaction with people with learning difficulties. Redley & Weinberg (2007) for example, argue that failing to acknowledge the ‘obdurate social reality’ (: 768) of learning difficulty will eventually raise the question of why people with learning difficulties should be entitled to additional support. Redley & 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 cue, but by ‘the distal institutional mandates that occasion its occurrence in the first place’ (Redley & Weinberg, 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 & 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’ (: 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 (excerpt 6: 776). 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

² MPs are individuals with learning difficulties elected by other people with learning difficulties to represent their views to decision-makers and service providers.

D&S paper draft 1

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 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 & 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 & 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, Ponting, Ford, & Rudge (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 et al. (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 et al. (2009, 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. (2010) highlighted that whilst 'special school' leavers were positioned as having choice and control as part of the neo-liberal 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, & Antaki, (2008) 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' (: 12). 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 I also made.

Making decisions in setting up the project

The decision-making process in the 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 meet³. 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 et al., 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 whilst that 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 & Weinberg 2007) and inclusive research collaboration, whilst failing to work in a fully collaborative way.

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. The examples are generally 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* is my personal reflection of the interaction.

The two decisions explored are:

- Eliminating health as a research topic.
- Deciding where to go on Natasha’s⁴ research trip.

Eliminating Health

³ It is important to note that difficulties with transport and timetabling meant the research team divided into two geographical groups and later I worked with the co-researchers individually.

⁴ Natasha is one of the final four co-researchers on the project who, along with Stuart, John and Mark, decided to forego anonymity. None of the co-researchers were present in the first extract and although Natasha was involved at that point the other three were not.

D&S paper draft 1

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 (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:

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 (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-

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

D&S paper draft 1

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, C**** and T*** were support workers and the remaining four, B****, K**, S*** and K***** were people with learning difficulties. The conversation had been largely dominated by K**, C**** and T*** and me, discussing various aspects of health, including mental health. As C**** was explaining that her recent ill health was the accumulation of stress, lifestyle factors and childhood abuse, K** spoke less and less. He physically shifted back in his seat at one point and looked towards the door as K*****, B**** and C**** bantered about football (following C****'s joke that football supporting had also impacted on her health). At this point I pulled the discussion back to health and K** 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

K**: Yeah...

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

B****: Look at different avenues of health...

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

Liz & C****: Heavy?

K**: Yeah I-I-I can't...

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

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

T***: no...

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

Liz: Am I not explaining it clearly enough?

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

C****: OK, the point... the thing is

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

C****: OK

Liz: OK

C****: No problem

K**: I always find health a bit difficult to talk about

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

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

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

K**: 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

D&S paper draft 1

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

EXTRACT 2

K**: 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.

K** remained seated and continued to remain so as I attempted to reassure K** that it is all right to not take part in the discussion if he is uncomfortable and T*** and C**** reassure him that the research is not about him personally. K** then clearly articulates his preference for researching around the other two topics of getting on with people and labelling. K** 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

C****: that's ok because what you've got to realise K** 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

K**: mmm

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

K**: → 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

K**: a bit

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

K**: yeah

Liz: full stop, yeah?

K**: 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

K**: I'm sorry... I am sorry (starts to rise from chair)

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

Liz: you don't have to apologise

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

K**: 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, K** leaves, accompanied by T***. After T*** returned she explained that K** was feeling better. I asked what the others present felt about dropping health as a research area. Both B**** and S*** agreed that this was a good idea. K***** remained silent but nodded agreement:

EXTRACT 4

D&S paper draft 1

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?

B****: I think health can be a bit of a stumbling block for K**. It certainly unbalanced
him a bit and

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

Liz: yeah

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

Liz: yeah

T***: you know him best dear, what do you think?

S***: →What B**** says too, stop you know

T***: health?

S***: 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

B****: yeah because it certainly unbalanced him

Liz: yeah

B****: 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 K**'s growing discomfort early enough. Having been quite vocal throughout the first part of the meeting, I should have been alerted 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 the members. Rather than suggesting we reflect on the situation over time, I immediately agreed that health 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.

Planning a trip

Background and context

This meeting with Natasha was seven months after the above 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 & Emmel, 2010). There was a three-stage process for each trip with the co-researcher:

- Planning

⁶ A***** was another person who was then part of the team and later left.

D&S paper draft 1

- 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 theme⁷ *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 5

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 Iceland⁸, 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. The first question I made was

EXTRACT 6

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...

⁷ 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.

⁸ 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.

D&S paper draft 1

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 & 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 the extract above, 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, were 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 researching and writing this paper. Consequently during our meeting I was acutely sensitive to our interactions and analysed my own talk as the interaction occurred:

FN: 7/513: 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 & 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' (Rapley & Antaki 1998: 590). Disclosing my poor spelling, moves me away from my 'institutional role', distracting attention from my knowledge and expertise.

D&S paper draft 1

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 & Antaki's (1998) is however 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 to achieve this is by making it a rewarding and worthwhile experience.

Conclusions

This paper has (hopefully) illuminated the complex process of my/our decision-making, 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. The extracts also evidence the claim that although imperfect, the process strived for and sometimes achieved genuinely collaborative decision-making. The talk produced around three 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, (1980), I worked towards giving the co-researchers as much voice as possible to make decisions, but recognise that also, sometimes, my actions denied them a voice. This was not done to exert my social power over them thus *deliberately* disempowering them, but in order to maintain the opportunity as *whole* and to ensure the project remained viable.

However, the two examples demonstrate an increasing confidence and competency on my part in working collaboratively. From the chaos of the first extract, where I effectively abdicated all control for fear of disempowering the co-researchers, to the second example where I negotiated an appropriate research trip with Natasha, I have developed my own capabilities and hopefully provided insights for other inclusive researchers. These experiences gave a good grounding for the complex and lengthy data collection that followed when we went out into the field.

References

- Antaki, C. et al., 2006. Producing Decisions in Service-User Groups for People With an Intellectual Disability: Two Contrasting Facilitator Styles. *Mental Retardation*, 44(1), pp.1–58.
- Arscott, K., Dagnan, D. & Kroese, B.S., 1999. Assessing the ability of people with a learning disability to give informed consent to treatment. *Psychological medicine*, 29(6), pp.1367–75.
- Bogdan, R. & Taylor, S., 1982. *Inside Out: The Social Meaning of Mental Retardation*, Toronto: University of Toronto.

D&S paper draft 1

- Brookes, I. et al., 2012. Finding the words to work together: developing a research design to explore risk and adult protection in co-produced research. *British Journal of Learning Disabilities*, 40(2), pp.143–151.
- Buettgen, A. et al., 2012. We did it together: a participatory action research study on poverty and disability. *Disability & Society*, 27(5), pp.37–41.
- Chapman, R., 2005. *The role of the self-advocacy support-worker in UK People First groups: Developing Inclusive Research*. The Open University.
- Chapman, R. & McNulty, N., 2004. Building bridges? The role of research support in self-advocacy. *British Journal of Learning Disabilities*, 32(2), pp.77–85.
- Clark, A. & Emmel, N., 2010. *Realities Toolkit # 13: Using walking interviews*,
- Department of Health, 2005. *Independence, Well-being and Choice: Our Vision for the Future of Social Care for Adults in England.*, UK.
- Dingwall, R., 1980. Orchestrated Encounters: An Essay in the Comparative Analysis of Speech-Exchange Systems. *Sociology of Health and Illness*, 2(2), pp.151–173.
- Dowse, L., 2009. “Some people are never going to be able to do that”. Challenges for people with intellectual disability in the 21st century. *Disability & Society*, 24(5), pp.571–584.
- Finlay, W. & Lyons, E., 2002. Acquiescence in interviews with people who have mental retardation. *Mental retardation*, 40(1), pp.14–29.
- Finlay, W., Walton, C. & Antaki, C., 2008. Promoting Choice and Control in Residential Services for People with Learning Disabilities. *Disability & Society*, 23(4), pp.349–360.
- Goodley, D., 1996. Tales of Hidden Lives: a critical examination of life history research with people who have learning difficulties. *Disability & Society*, 11(3), pp.333–348.
- Goodley, D. & Rapley, M., 2002. Changing the subject: Postmodernity and people with “learning difficulties.” In T. Shakespeare & M. Corker, eds. *Changing the subject: Postmodernity and people with “learning difficulties.”* London: Continuum International Publishing Group Ltd.
- Hammersley, M., 2002. Discourse Analysis: A Bibliographical Guide. *English*, (April).
- Heal, L.W. & Sigelman, C.K., 1995. Response biases in interviews of individuals with limited mental ability. *Journal of intellectual disability research : JIDR*, 39 (Pt 4)(August), pp.331–40.
- Heritage, J., 1995. Conversation Analysis: Methodological Aspects. In U. M. Quasthoff, ed. *Aspects of Oral Communication*. New York: Walter de Gruyter.

D&S paper draft 1

- Heritage, J., 2010. Conversation Analysis: Practices and Methods. In D. Silverman, ed. *Qualitative Research: Theory, Method and Practice*. London: Sag.
- Houtkoop-Steenstra, H. & Antaki, C., 1997. Creating Happy People by Asking Yes-No Questions. *Research on Language & Social Interaction*, 30(4), pp.37–41.
- Jenkinson, J., 1993. Who Shall Decide? The Relevance of Theory and Research to Decision-making by People with an Intellectual Disability. *Disability & Society*, 8(4), p.361.
- Matikka, L.M. & Vesala, H.T., 1997. Acquiescence in quality of life interviews with adults who have mental retardation. *Mental Retardation*, 35(2), pp.75–82.
- Michell, B., 2012. Checking Up On Des: My Life My Choice’s research into annual health checks for people with learning disabilities in Oxfordshire. *British Journal of Learning Disabilities*, 40(2), pp.152–161.
- Parmenter, T.R., 2001. Intellectual Disabilities— Quo Vadis? In G. L. Albrecht, K. Seelman, & M. Bury, eds. *Handbook of Disability Studies*. Sage Publications, pp. 267–296.
- Pilnick, A. et al., 2010. Questioning the answer: questioning style, choice and self-determination in interactions with young people with intellectual disabilities. *Sociology of health & illness*, 32(3), pp.415–36.
- Ramirez, S.Z., 2005. Evaluating Acquiescence to Yes – No Questions in Fear Assessment of Children With and Without Mental Retardation. *Journal of Developmental and Physical Disabilities*, 17(4), pp.337–343.
- Rapley, M., 2004. *The Social Construction of Intellectual Disability*, Cambridge University Press.
- Rapley, M. & Antaki, C., 1996. A Conversation Analysis of the “Acquiescence” of People with Learning Disabilities. *Journal of Community and Applied Social Psychology*, 6.
- Rapley, M. & Antaki, C., 1998. “What do you think about...?”: Generating views in an interview. *Text - Interdisciplinary Journal for the Study of Discourse*, 18(4), pp.587–608.
- Redley, M., 2009. Understanding the social exclusion and stalled welfare of citizens. *Disability & Society*, 24(4), pp.489–501.
- Redley, M. & Weinberg, D., 2007. Learning disability and the limits of liberal citizenship: interactional impediments to political empowerment. *Sociology of Health & Illness*, 29(5), p.20.
- Rodgers, J., 1999. Trying to Get it Right: undertaking research involving people with learning difficulties. *Disability & Society*, 14(4), pp.421–433.

D&S paper draft 1

- Sacks, H., 1995. *Lectures on Conversation* G. Jefferson, ed., Malden: Blackwell Publishing.
- Schelly, D., 2008. Problems associated with choice and quality of life for an individual with intellectual disability: a personal assistant's reflexive ethnography. *Disability & Society*, 23(7), pp.719–732.
- Sigelman, C.K. et al., 1981a. Asking questions of retarded persons: A comparison of yes–no and either–or formats. *Applied Research in Mental Retardation*, 2(4).
- Sigelman, C.K. et al., 1981b. When in doubt, say yes: Acquiescence in interviews with mentally retarded persons. *Mental Retardation*, 19(2).
- Sims, D. & Cabrita Gulyurtlu, S.S., 2013. A scoping review of personalisation in the UK: approaches to social work and people with learning disabilities. *Health & social care in the community*, pp.1–9.
- Smyth, C.M. & Bell, D., 2006. From biscuits to boyfriends : the ramifications of choice for people with learning disabilities. *British Journal of Learning Disabilities*, 34, pp.227–236.
- Trell, E. & van Hoven, B., 2010. Making sense of place: exploring creative and (inter) active research methods with young people Making sense of place. *FENNIA*, 188(1).
- United Nations General Assembly, 2006. *Final report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities A /61/611*,
- Williams, V., 1999. Researching Together. *British Journal Of Learning Disabilities*, 27, pp.48–51.
- Williams, V. et al., 2010. Skills for support: personal assistants and people with learning disabilities. *British Journal of Learning Disabilities*, 38(1), pp.59–67.
- Williams, V., Ponting, L. & Ford, K., 2009. “I do like the subtle touch”: interactions between people with learning difficulties and their personal assistants. *Disability & Society*, 24(7), pp.815–828.
- Wistow, R. & Schneider, J., 2003. Users' views on supported employment and social inclusion: a qualitative study of 30 people in work. *British Journal of Learning Disabilities*, 31, pp.166–174.
- Yacoub, E. & Hall, I., 2009. The sexual lives of men with mild learning disability: a qualitative study. *British Journal of Learning Disabilities*, 37(1), pp.5–11.