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Inclusive Conversation Analysis with Disabled People

Val Williams, Marcus Jepson, Lisa Ponting, and Kerrie Ford

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Introduction

Disability Studies (DS) approaches lie at the heart of this chapter, which concerns itself with an analysis of interactions in which people with the label of intellectual disabilities (ID) engage with social care workers. An intellectual disability, by definition, is a lifelong impairment, which involves cognitive limitations as well as difficulties with social functioning, and coping with everyday life (Emerson & Heslop, 2010). However, the category is very broad, differentiated, and often blurred (Williams, Swift, & Mason, 2015), and there are strong reasons for avoiding a prior impairment-related definition. In Disability Studies, the very notion of disability is critiqued and questioned, with social model adherents following Oliver (1990) in viewing disability as the product of a disabling society which fails to include disabled people. While not denying the embodied reality and impact of impairments on the individual (see Thomas, 2004; Shakespeare, 2006; Shakespeare & Watson, 2001), this chapter is simply more interested in the way in which categories of disability emerge from particular social circumstances, contexts and interactions. In

conducting the research, we have worked closely to include people with the label of ID as active participants in the research process, and we aim to explore some different ways in which this can be achieved in research about interaction.

In common with other chapters in this volume, we use conversation analysis (CA) (see Lester & O'Reilly, Chapter 1, this volume) to examine naturally occurring data (Ten Have, 2009; Wooffitt, 2005). CA is rarely used in disability studies, and yet the two areas of study are well matched, since this type of analysis can reveal how disability itself is reinforced in the flow of talk. The essential tool for analysis is the turn-by-turn examination of talk, looking for evidence as to how each speaker has taken the previous turn and how mutual understanding is maintained. As with other forms of 'institutional CA' (Heritage & Clayman, 2010), the analytic interest turns towards inequalities in the distribution of turns, the types of turns taken, and what may be done with those turns by various parties in the talk. This is a particularly useful approach for examining the interactions of adults with disabilities (Antaki, Finlay, Walton, & Sempik, Chapter 31, this volume).

Unusually for CA, the current chapter is also framed by an inclusive approach to research; indeed, the chapter is written inclusively, with people with intellectual disabilities as co-authors (Ford & Ponting). A word or two are in order then about what we mean by 'inclusive research'. Disability Studies approach are strongly associated with an 'emancipatory' paradigm in research, where disabled people themselves define their own theoretical stance, and where research is controlled by people representing the disability movement (Oliver, 1992). People with ID however were not at first included in these notions of emancipatory research, and the strides they took towards joining the research community took place largely because of support from non-disabled allies (Chappell, 2000; Walmsley, 2001; Williams, 1999). Nevertheless a large movement of what is often termed 'inclusive research' involving people with ID now exists (Bigby, Frawley, & Ramcharan, 2014; Walmsley & Johnson, 2003), and encompasses a wide variety of different formats and models (Marriott & Williams, 2011; Nind & Vinha, 2014), including team approaches as in the current work, where people with ID are supported to initiate their own ideas and to take on active roles as researchers. In summary, inclusive versions of conversation analysis aim to involve people with ID, not just as objects of our gaze but also as co-producers of knowledge. Examining data from three different sources, our focus in this chapter will be on interactional contexts which are ostensibly about people with ID exercising 'choice and control'. This liberal principle of individual autonomy lies at the heart of the policy shift towards personalisation in English social care (Lymbery, 2012), but can be contentious in practice when applied to people with ID. We therefore bring in here the voices of Lisa Ponting and Kerrie Ford, our co-authors, who are people who have the label of 'intellectual disability'. What do they feel about making their own decisions? Lisa and Kerrie both feel that making choices is good, even if you make a bad choice, because you learn from it. Taking control of your own life is much better than relying on other people. You've got to make mistakes in order to learn from them. However, there have long been concerns that some groups of disabled people fall short of the ideal of an 'autonomous citizen' (Dowse, 2009; Redley & Weinberg, 2007) and that they will need greater levels of protection and support to become involved in decision-making (Goodwin, 2011; Kendall & Cameron, 2013).

What is of interest here is to see how these tensions about power, identity, and choice play themselves out in the ebb and flow of talk. In this chapter, we will explore different ways in which people with the label of ID have been actively involved in collecting data, advising research studies, and in creating research impact by applying findings to their own lives. In Lisa Ponting's own words, 'We can get the inside of what they're saying out'. This chapter will examine some of the ways in which this may happen, and the resulting effect on the analysis about the interactional accomplishment of 'choice and control'.

Overview of projects

We draw on three studies in this chapter, which are outlined in Table 4.1 below.

All three studies received ethical approval, the first and the third from national research ethics committees, since they included arrangements under the Mental Capacity Act to include participants who lacked capacity to consent to the research. All three also developed accessible and iterative forms of informed consent to ensure people were aware of the use of their data in video formats, especially when that data were taken forward into training materials as in 'Skills for Support'.

Who decides?

Consideration of whether or not a person has made a 'bad' choice is of particular significance for people with ID, as we have mentioned in our opening remarks, and this has been brought to prominence in England and Wales under the Mental Capacity Act (MCA). One of the key principles of the MCA is that a person's capacity to make a decision is not to be judged solely on the basis of the supposed wisdom of any decision that they make. In the language of the MCA:

A person is not to be treated as unable to make a decision merely because he makes an unwise decision.(Mental Capacity Act, 2005. Part 1,1 [4])

Our first extract features Miriam – a woman with an ID, and Wilf – her personal assistant (PA). They are in Miriam's flat, preparing a shopping list for the week ahead.

1	Wilf	err Saturday what would you like for your lunch
2	Mir	(3.0) ((Miriam shrugs after 3 seconds))
3	Wilf	do you like beans on toast \uparrow (0.8) or another sort
4		what about a sandwich o:r what kind of things do you like
5	Mir	po chop
6	Wilf	pork chops↑
7	Mir	yeah
8	Wilf	you could have that as your dinner one evening
9		what about Friday evening you could have pork chops for
10		dinner

The first part of this extract follows the typical sequential progression seen in much of the 'Who Decides' data, and these opening steps provide a context for what is to follow, with Wilf introducing the decision-making act in line 1, Miriam displaying a sign of interactional trouble (although not necessarily a lack of capacity to make the decision) in line 2, and Wilf attempting to resolve the interactional trouble in his next turn.

In response to a question about 'what kind of things' she likes, Miriam responds in line 05 with a response interpretable to Wilf as 'pork chops', which Miriam confirms in her next turn. It is interesting at this point to note the way Wilf subtly appears to both endorse the suitability of 'pork chops' as a meal choice for Miriam but also reject it as suitable for lunch on Saturday; the meal decision-making act which he had initiated in opening this sequence. Instead, he makes a counter suggestion to Miriam, 'you could have that as your dinner one evening'.

We will now look at how this exchange progresses.

1	Wilf	yeah? we can buy some pork chops ((writing)) pork chops
2		pork chops what would you like with the pork chops
3	Mir	mash
4	Wilf	and mash pork chops and mash er:m so-
5	Mir	and two mash ((holds 2 fingers up))
6	Wilf	two mash
7	Mir	yeah
8	Wilf	so buy some potatoes to make mash
9	Mir	mmm

```
10
   Wilf what about some vegetables
11
     Mir
              (exhales)
12
     Wilf
               don't forget those like little frozen packs of vegetables
13
               (.) peas or something
14
               I^{\prime}m not too not too keen
     Mir
15
     Wilf not too keen on vegetables?
16
    Mir
              no
17
    Wilf
              what about erm gravy or something with them
18
    Mir
              ((shakes her head))
19
     Wilf
              no? (.) sweetcorn?
20
     Mir
              ((shakes her head))
21
     Wilf
             peas?
22
              ((shakes her head))
23
     Wilf
              carrots
24
     Mir
              ((shakes her head))
```

nothing like that ((both shake their heads)) okey dokey

25

Between lines 4 and 8, Wilf and Miriam establish that she will have 'mash' with her pork chops, understood by both parties as mashed potato, with Wilf then reporting the need to 'buy some potatoes to make mash'. Hereafter, Wilf introduces a new suggestion for inclusion with the meal, asking: 'what about some vegetables' in line 10. Miriam's immediate reaction is to display an indication of trouble with a long exhalation of air in line 11. Wilf persists with the idea of vegetables, reminding Miriam about 'little packs of frozen vegetables' which he embellishes adding a suggestion of 'peas or something'. Miriam gives a dispreferred response (Pomerantz, 1984) in line 14, which could relate to either peas or vegetables in general. However, following Wilf's checking turn in line 15, Miriam's response is unequivocal: she is not too keen on vegetables. It is perhaps unusual therefore, that after Miriam rejects 'gravy or something ...' as an accompaniment to her pork chop and mash Wilf suggests an alternative type of vegetable in each of his three self-initiated turns that follow in lines 19, 21 (particularly notable as he suggests 'peas' again here), and 23.

In this interaction, Wilf has twice undertaken to influence Miriam's decision. In the first instance, he has successfully taken Miriam's selection of pork chops as a meal preference and subtly transferred it from a possible lunch on Saturday, to a dinner choice on Friday evening. Wilf may consider 'pork chops' to be an inappropriate meal for a (Saturday) lunchtime. This assertion may be supported by looking back towards the start of this exchange and Wilf's initial introduction of 'beans on toast', or 'a sandwich'. Perhaps he has considered these 'snack-like' meals choices more appropriate for lunchtime.

Secondly, and less successfully, he goes to great lengths to persuade Miriam to select a vegetable to accompany her meal. Once more there was no explicit statement as to why he might consider it a good idea for Miriam to have vegetables. Plausibly he might have suggested that 'it's considered healthy to have vegetables'. However, without any such qualification the sequential progression could be viewed as Wilf ignoring or disregarding Miriam's stated wish – effectively a decision on her part – to not have vegetables with this meal.

What did Miriam herself make of this video? When we replayed this clip to her and to Wilf, the session resulted chiefly in Wilf reflecting on his actions. Miriam herself enjoyed seeing her data, but her contribution to the 'meaning of choice' was made chiefly through what she did during the actual interaction. Not only did she verbalise the fact that she was

'not too keen' on vegetables, but she actively maintained her resistance to Wilf's several persuasive attempts between lines 17 and 25. Thus, an active strategy of resistance is one important way in which a person with ID can assert their own autonomy. As Lisa and Kerrie remarked earlier, the right to make mistakes, or to make a 'bad choice', is important. However, if we want to include the voices of people with ID in shaping these ideas, then we clearly have to go further than enabling them to revisit their own data. That may be the first step, but in the next section, we will explore a more fully 'inclusive' approach to the research process itself.

Skills for support

Extract 3 below is one of several chosen from our 20 hours of video data by Lisa and Kerrie, co-researchers on 'Skills for Support'. In this part of the video, Fred's personal assistant (PA, or support worker) is seen sitting close to him, on the sofa in his flat. He is composing a letter to send to his aunt, and his PA, Penny, is helping him by writing down what he wants to say. As they are doing that, they mention the lunch club where Fred goes regularly, and Penny makes a joke about everyone coming to the lunch club with Fred. Then, the following snippet of conversation ensues:

```
1
       Pen
                we'll all come LF what did you have today↑ (.)
2
       ((looks up towards N, who is looking at letter))
3
       Fre
                cottage pie
4
                mm (.) ooo_{\uparrow\downarrow} (.) shall we put that down_{\uparrow} .hh do you want
       Pen
5
                to write that ↑ (3) yeah ↑
6
       Fre
                mm er
7
                 (LF) you don't have to (1) ((looks at N again))
       → Pen
8
                 °good°
       Fre
9
       Pen
                yeah↑
```

Fre I think (he) not interest what you get

Kerrie Ford and Lisa Ponting originally picked out this extract because they felt that it was about a support worker helping someone to get more 'confident'. The extract features on the training DVD (Ponting, Ford, Williams, Rudge, Francis, 2010) which they produced, and on it, we can see Kerrie and Lisa watching the film. As they say on the DVD, 'we are doing this project to make the support better for everybody, so that they do have choices'. They point out that Fred had lived previously in a long-stay hospital, and like many others, he was used to being told what to do, rather than choosing for himself. It was therefore important that he had asked his PA to help him write the letter, and Lisa says: 'In that way, it's a good communication'. They also comment on the body language and particularly the close physical proximity of Penny and Fred, sitting within touching distance of each other. Kerrie comments on the DVD that she would find that closeness intrusive ('I would be, get back!') but admits that everybody's different.

What of the talk itself? Lisa points out that the support worker, Penny, asks questions of Fred, and she characterises these as 'prompts' which help him through it, 'because sometimes you get stuck on various words'. From a CA perspective, the extract is a clear example of a couple of linked adjacency pairs, with the first part in each pair offered by Penny (lines 1 and 4). Although both these turns are formulated as questions, they do very different things: line 1 is a question which succeeds at eliciting a preferred response, when Fred supplies the information that he had 'cottage pie' today. Penny then uses that information, in order to formulate her subsequent, very positively tilted question, 'Shall we put that down?'; with pen in hand, she is clearly suggesting that she could write about the cottage pie in Fred's letter to his aunt. That too seems to be how Fred takes the suggestion, as he is looking down towards the letter throughout this extract. However, there is a three-second pause, followed by some hesitation as Fred says 'mm' and 'err'; from the evidence of line 7, 'you don't have to', it seems that Penny has taken Fred's hesitation as meaning that perhaps he disagrees with her suggestion, and so she swiftly mitigates her proposal, foregrounding Fred's right to choose.

This extract was included in our DVD, partly on the basis that it was picked out by Kerrie and Lisa, but also because it was typical of a pattern in the data, where support workers specifically foregrounded 'choice making' as a right, something that the person with

the label of ID should engage in. This frequently happened after the person had hesitated (as here), had appeared to accept a suggestion too readily, or had sought advice or guidance about what to do. This strategy suggests that, without their reminder about choice, Fred would be likely to defer to others' decisions and to seek direction rather than exercise his own autonomy. There is ample evidence elsewhere that this assumption is well founded, with people routinely deferring to their support workers, seeking approval for their own actions, and showing that they expected their staff to take responsibility for decisions. In the 20 hours of data we collected, it was rare for a person with the label of ID to initiate and choose a course of action which they defended and insisted on. Although Lisa and Kerrie, like other participants in the project, assumed that choice was important, they were quite shocked when they engaged with the videos which showed how rare choice making really was.

One of these rare examples is given at length in Williams (2011, pp. 99–100), where Charles is trying to organise a party. He wants to hire a hall, which could be expensive, while the manager of his services is trying to offer a counter-suggestion of a more informal and cheaper option with a friend who would run a disco within the service setting. Like Miriam and Fred, Charles actually sticks to his own plan, and the extract finishes like this:

Extract 4

1 um you know you're probably talking about 50 or 60 [pounds all 2 in so-3 Cha [yes OK yeah 4 Sue that's a lot cheaper 5 Cha alright 6 Sue I'll leave it entirely up to you 7 OK I'll see what happens and I'll let you know, any changes Cha 8 I'll let you know 9 all right Charles Sue

- $\,$ Cha $\,$ nothing to it is it \uparrow
- 11 Sue absolutely right Charles ((shakes head, smiling))

Sue presents Charles with the information about costs in line 1 of extract 3, and underlines that the option she suggests is 'a lot cheaper'. However, instead of conceding to her, Charles simply says 'alright', and it is at that point that Sue issues the familiar focus on choice making: 'I'll leave it entirely up to you'. Framing the person with ID as an independent choice-maker is a common tactic for support workers, but the take-up by Charles in lines 7–8 is rare. Not only does he take on the responsibility for making the decision, but he offers to put his plan into action and let Sue know 'any changes'.

Doing choice-making turns out to be not simply a matter of one person offering options and another person choosing between them. Instead, it is very tightly interwoven with the construction of an ID identity. Even Charles acknowledges that his right to decide on his party is 'noteworthy', as he comments in line 10, 'nothing to it is it', implying that he is countering the assumption that choice-making may be difficult. One can speculate that his service manager might well have felt that what was at stake here was Charles' ability to make a sensible decision about budgeting his money and spending a large amount on a birthday party (Williams, 2011). Sue follows the routine tack of agreeing and encouraging Charles' decision-making in extract 3, but then immediately switches to a protective mode of talk, warning Charles of the likely consequences, and proposing a far more 'sensible' solution for him.

What then did we make of this sort of debate in the 'Skills for Support' project? One of the points Kerrie and Lisa make on the DVD is that support workers should be there to advise and guide people like themselves, but that this advice and guidance should be given to people only when they ask for it. In order to make their point, the DVD also contains 'stories from the past' to illustrate problematic encounters and bad practice amongst support workers, chosen by Lisa and Kerrie from their own experience. One of those stories shows two women with ID having a drink in the living room; when they ask a support worker to open another bottle for them, the worker refuses, and says that they have had plenty to drink already! She goes further in complaining that it is not her role to sort out the drinking habits of another person, who she is not paid to work with. While this is a fictional scene, nevertheless, the themes on which it is based would be familiar to anyone working in this sector. Do support workers have a duty of care, and thus should they prevent service users making bad, or unwise, choices? The Mental Capacity Act would say that the women's choice to get drunk

should be respected, unless they lack capacity. However, the notion of capacity is at best a blurred one (Williams et al., 2015). Further, does the support worker's responsibility extend to people beyond her 'charge'? There are frequent debates about professional boundaries in the support worker role. Yet, Ponting et al. (2010) challenge support workers to see the task of support from the point of view of service users themselves. In the introduction to the section on 'Advice', Andy Pullin (Ponting et al., 2010) comments on how he sees his own right to choice and advice

[m]ake choices, be independent, what stuff you want to do and you can talk to the PA, if I needed any help with anything. And if they're there, and I'm doing anything stupid, they'll advise me on that. [Ponting et al., 2010: Advice section of DVD]

In the 'Skills for Support' project, we pushed the limits of this team approach to research. Instead of making assumptions about what the PA role entailed, we developed ways of listening to the views and explanations of people with the label of ID. They did not carry out a detailed CA analysis, yet their comments helped to guide the questions we pursued. What, for instance, does it mean to 'make choices' and 'be independent'? More subtly, how is advice given, and what happens if someone makes a bad choice? Some of these questions were explored further in the very different context of the audio data from support planning meetings in our final project in this chapter.

Support planning in practice

The policy of personalisation in English social care is enacted chiefly via the mechanism of a personal budget, which is intended to give people choices about how to manage their social care funding and to plan what types of support they would like, in order to meet their agreed 'outcomes'. That is the activity known as 'support planning' (DoH, 2008). However, some citizens may be assessed as lacking capacity to consent (specifically to a direct payment), and thus are assigned a 'suitable person' (DoH, 2009), normally a family member or close friend who will act in their best interests. Both the people who took part in recordings of support planning sessions in our study were in that situation. Although they were both encouraged to discuss low-level choices, their parents would have had the final say over allocation of budget. Thus, the talk in support planning sessions was conducted between three parties: a

practitioner, the focal person with ID, and a family member. We have considered elsewhere the supportive strategies used by family members, and the resultant shape of these three-way conversations (Williams & Porter, in press). For the purposes of this chapter, we are interested in just the few rather problematic stretches of talk, where the parent's interventions ran counter to the expressed wishes of the person with ID. For us, they raised some questions about how we interpret data like this, and what implications the data may have for different parties in the talk – including for people with the label of ID.

First, a short extract from 'Kia's' support planning session, to illustrate some of the lengths these practitioners and family members went to, simply to foreground choice and to encourage participation. In extract 5, Natalie the support planner was trying to encourage Kia to choose photos to display in her support plan. Kia however is unresponsive:

```
1
          ookay, well ehmm have you seen this Kia, (2) you haven't seen
    Nat
2
         this one have you I've got a [picture quite a few pictures here
3
          that's an old one
4
    ?
                                        [LF
5
         like (.) this one I took like (.) when I first met you that
6
          photo in the car I can't remember where we were going,
7
         ((gets up during this, takes photos over to kneel by K's
8
          side, shows them to her))
9
          o:h yeah we went for a milkshake didn't you↑=
10
          = yeah (.) erm (.) so that that's a really old one; but that's
    Nat
11
          (.) em Liverpool isn't it=
```

From lines 1 to 8, Natalie does several things to bring Kia into the conversation; she uses her name in line 1, she asks her a tag question (which should produce a 'no'); she refers to photos which she is sorting through (and which feature Kia herself), and she does 'forgetting' (Goodwin, 1987), a device that privileges Kia's knowledge. Despite all this, Kia does not answer, and her mum aligns with Natalie's efforts at line 9, with a second part turn that both deals with Natalie's 'not knowing', and then turns it back to Kia with a 'didn't you'. In Heritage's (2012) terms, Kia's mum exercises an epistemic privilege over Kia's affairs, and she uses this close personal knowledge to do a prompt; as Bolden (2012) explored, language competence and incompetence can be exposed via this type of repair activity, undertaken by parties who know each other well. Given Kia's silence, it is all too easy for the other two parties to start addressing each other, and there is certainly a danger of that at the end of this extract. Despite all this, choice is clearly on the agenda here, and there are many other examples in these data of family members promoting choice and supporting their relative to say what they want, doing subtle repair work, anticipating support needs, and clarifying their relative's turns.

Once the third party in these interactions has a turn, they can use that slot to start challenging what their relative is saying. One particular conflict in support planning is given in extract 6, where a young man, 'Karl', is meeting with Simon (a social worker) with his mum Asma to review a plan for his placement at a day centre. Extract 6 occurs at the point where Karl intervenes and disrupts matters by stating that he wants to go to the same place as his girlfriend.

- 6 Kal it's my girlfriend =
- 7 Si = your girlfriend, and where does she go to \uparrow I
- 8 thought the last time we met you had a girlfriend
- 9 a new girlfriend at college did you not \uparrow
- 10 Kal °no°
- 11 Si = no↑

Following Karl's 'no', his mum's quiet instruction at line 3 comes over very much as a repetition and a reminder to Karl, building on a shared understanding between herself and her son about this matter. His talk about his girlfriend has clearly been rehearsed within the family, and so his mother is 'knowledge plus' about Karl's affairs. In a sense, this closeness can be seen as a type of epistemic trap, from which it is hard for Karl to escape. Simon the support planner is however knowledge deficient about this matter, and so his question in lines 4–5 about the identity of Shirley gives Karl an opportunity to upgrade his claim to be together with Shirley, using the term 'girlfriend'. However, Simon subsequently starts supporting the family position, by questioning the long-term status of this girl – maybe Karl was swapping from one girlfriend to another rather rapidly. That at least is how Karl takes it, with his denial at line 10.

There follows an extended sequence of persuasion where Karl is reminded of the many benefits of the day centre, which sounds very much like a top-class leisure and sports club. Finally, Karl concedes that he remembers visiting the day centre, and has seen a swimming pool there. This detail is taken as confirmation of his agreement to go there, and the girlfriend is not mentioned again.

Karl's dilemma stood out from the rest of the data about support planning. Although they were not frequent, conflicts were interesting, since they underlined the limits of 'choice' for both Kia and Karl. Rather than leave the analysis where it stood, the questions in our minds were 'why does this matter?' and 'to whom does this matter?' The first author therefore took these extracts to a small group, which included Kerrie Ford and Lisa Ponting. After reading through a slightly simplified version of the transcript, we allocated roles and played the different parts, pausing to ask the group members what could have happened differently. Extract 7 occurs at the point when the group are role-playing Karl's problem about his girlfriend, with Val taking part:

```
1 Ker (playing 'As') ok no shirley's not going to the same place 
2 Val (playing Karl) why::\uparrow(2)
```

- 3 Ker why \uparrow (0.5) I don't know Karl shall we ask Shirley
- 4 ourselves↑(1)
- 5 Val but Shirley's not here (1.5)
- 6 Ker we could perhaps phone Shirley's carers and ask them why \uparrow

The point made by group members in this exercise was that Karl bore some responsibility himself for challenging what was happening in his support planning meeting. They first suggested that he needed an advocate, and that he should stop the meeting until he had one there. They then thought about the possibility of challenging Karl's mum, in the way played out in Extract 7. Interestingly, instead of Karl's mum being in possession of the facts about her son's private life, the challenge posed by Karl at line 2 puts her in a position of relative ignorance: in this role-played version, she does not in fact know about Shirley's decisions, and admits this, following up by a suggestion to ask her. This effectively introduces another set of conversations with Shirley and her carers, which has not yet taken place, but which might have a bearing on Karl's own decision. We felt that this suggestion was particularly important because it played precisely on the analytical point about 'who knows what' and the power of finding out and being in possession of insider knowledge.

Following our role-play session on these extracts, the same data were presented at two different seminars, where other research colleagues, practitioners and family members were present. Although the data from those sessions were not recorded, it is fair to say that none of these people reacted in the same way as the group of people with the label of ID. It was pointed out, for instance, that a support planning meeting does need to follow an agenda, and the issue about Karl's day centre placement was important, and had already been pursued in previous meetings. Therefore, his objections were not useful at this point in time. Further, his mother was acting as a good advocate for him, effectively speaking up in Karl's 'best interests'; given that he would lack capacity to make this big decision in his life, he would clearly need some guidance here. In fact, elsewhere in the data, Karl's mother had explained to Simon that Karl often pursued random, spontaneous lines of conversation and had great difficulty in really 'answering the question' or understanding the import of what was going on.

It seems therefore that there is never an absolute answer to 'what matters' in the data, however much we can deploy the neutral gaze of the CA analyst in working out what is going on in the talk. In fact, the repeated discussions on this extract led us to the conclusion that we should question some of the premises behind Karl's dilemma. The conflict in this extract is based on the fact that it is assumed that a relationship with a girlfriend or boyfriend can only be pursued in the context of a common day centre placement. However, most of us would

question the wisdom or necessity to work in the same place as a partner on a daily basis! It was this idea that was taken forward into the final product from this research, which was a DVD entitled 'How to Speak up about your Support Plan', acted out by group members, together with social work students. Instead of being forced into a day centre placement, in the DVD the service user chooses to attend part-time, and to see their partner on a different day of the week.

Practical relevance summary

This chapter set out to explore the different ways in which our understanding of interactional data could be enhanced by the inclusion of people with the label of intellectual disabilities. Therefore, the first point of practical relevance relates to the way in which we can productively include people with this label in the research process itself. Three different modes of inclusion have been explored; firstly, in the 'Who Decides?' project, it was clear that simply taking back data to the participants does not always draw out a considered or revealing response. People may be interested and engaged in re-exploring the issues they pursued in the talk, but in our case, participants in 'Who Decides?' did not really offer further insights through this method. By contrast, the 'Skills for Support' project offered two people the opportunity to engage over a period of time as analysts of others' data. Although they could not be seen as technical CA analysts, nevertheless, they did engage in some detailed noticing, tracking back over DVDs and thinking in detail about the exchanges. As Lisa Ponting remarked earlier, 'We can get the inside of what they're saying out': because of their own positioning, it was possible for Kerrie and Lisa to offer some guidance and direction based on the perspective of people with the label of ID.

The second area of practical relevance in this chapter relates to the actual findings of the three projects. All three projects produced detailed knowledge about how support interactions could be more effective in enabling people with ID to engage with everyday tasks in a more 'autonomous' manner. However, all three emphasised the fact that this autonomy is not an individual matter, with people abandoned to their own resources to make an isolated, individual decision. By contrast, the whole point in 'Skills for Support' was about relational decision-making and the emergence of decisions from sensitive interaction (Williams, Ponting, Ford, & Rudge, 2009a, 2009b, 2010). This chimes very much with the

turn towards ideas of relational autonomy (Wehmeyer & Bolding, 2001); Kerrie Ford and Lisa Ponting defined five outcomes of good support in their lives, which they listed as 'respect, choices, friendliness, advice and support to speak up'. These headlines are used as section headers for the practice DVD which they produced (Ponting et al., 2010), and in respect to choices, for instance, practitioners are urged to consider practical ways to allow people with ID to access information which they will need in order to manage their lives. Guided by Lisa and Kerrie's comments, we can conclude that it is helpful for support workers to set out the nature of the choice to be made, intervene only when asked, and define the issues together with their conversational partner.

The third and final way in which this chapter contributes to practice is through its consideration of the varying perspectives on defining a successful outcome. The final project discussed here, 'Support Planning in Practice', challenged us to think afresh about the validity of different points of view. In the end, there is no objective way to decide how an interaction can be most effective, since that effectiveness can be challenged from the point of view of the different social actors involved in it. Interventionist CA (Antaki, 2011) must thus be cautious since it often positions itself on the side of the practitioner, assisting with the accomplishment of tasks such as the personalisation of jobseeker interviews (Toerien, Irvine, Drew, Sainsbury, 2011) or an appointment in an audiology clinic (Egbert, 2011). What one party wants from an encounter might be different from another. From the professional point of view, these encounters were matters of balancing the viewpoints of several parties, notably the family and the service user. However, the suggestions made on our practice DVD, based on the insights of Kerrie Ford and others, included the fictional person with ID using her tablet computer to plan her life and discuss it with others before her encounter with the social worker. The conclusion was that it was important to take time for preparation, obtaining advocacy and challenging the 'knowledge plus' status of the parent. For a simple summary of the practical implications, please see Table 4.2

Summary

Research that offers a focus on the detail of everyday interaction helps us to discover much about how categories such as intellectual disability are constructed in the live to-and-fro of talk. However, if we are to move beyond the academic understanding of discourse, into

debates about practice, this chapter has suggested that we need to engage more with those who are most affected by those practices. By that very engagement, we change the terms of the *research* interaction, as is explored in Williams (2011). Instead of being the respondent, Lisa and Kerrie took on the interactional rights to ask questions, determine the agenda, and decide what counted as relevant data. These are powerful things to do for people whose lives and identities may have been defined by being treated as interactionally incompetent (Antaki, Walton, & Finlay, 2007; Williams et al., 2009b). Therefore, through their inclusion in research, people with intellectual disabilities can and do challenge and change the very terms of reference which define their own status as people with intellectual disabilities.

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Recommended reading

- Marriott, A., & Williams, V. (2011). Inclusive research: People with learning disabilities can be the 'artists of their lives'. In H. Atherton & D. Crickmore (Eds.), *Learning disability: Towards inclusion* (pp. 161–177). China: Elsevier.
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Table 4.1 Three studies

	Who Decides?	Skills for Support	Support Planning in Practice
	2008–2011	2004–2007	2010–2012
Funder and scope of study	PhD study funded by	Partnership study in four	Five site study, across
	Economic and Social	UK sites, with disabled	England, funded by the
	Science Research Council	people's organisation,	School for Social Care
		funded by the Big Lottery	Research. ¹
Goal	To examine how the Mental	To analyse what made	To find out how support
	Capacity Act was being	'good support' at the	planning is conducted with
	applied in everyday	interactional level, from the	personal budget users with
	interactions with people	point of view of people	complex needs.
	with ID	with ID	
Data (only the naturally	Nine hours of video data of	Over 20 hours of video data	Just over four hours of
occurring data are	discussions focusing on	of people with ID	audio recordings from four
mentioned here, as that is	everyday choices	interacting with support	support planning sessions,

the focus of this chapter)		workers during everyday routines	involving person with ID, worker, and parent.
Involvement of people with ID	Participants offered opportunity to review data	Two people with ID employed as researchers. They collected data, selected extracts for analysis, and commented on the analysis.	Five people with ID reviewed parts of the data, to recommend own solutions to interactional problems.
Products with people with ID		Training pack with DVD, showing clips of original data with commentary from team members with ID (Ponting et al., 2010)	DVD based on scenes role- played by people with ID and social work students, to help people with ID understand support planning (details from lead author)

1 The School for Social Care Research (SSCR) is part of the National Institute of Health Research in England, and is the major national funder for research about social services. The views expressed in this chapter are those of the authors, and not necessarily those of the SSCR.

Table 4.2 Disability studies and social care practice highlights

- 1. Interactions with support staff are key to the everyday experience of people with intellectual disabilities. Relational autonomy for people with ID depends on having respect, choices, friendliness, good advice and support to speak up. People with ID who want to train their own support staff can use the training DVD produced by Ponting, et al. (2010), available on Youtube.
- 2. With forward planning and funding, researchers with ID can be selected and supported to take on meaningful roles in the study of interaction. This requires enough time, support roles in a study, and a flexible research design. Video data are generally accessible, and a team approach to the research enables the insights from conversation analysis to be discussed within a mixed team. More details about the process of inclusive research are given in Marriott & Williams (2010) and in Williams (2011).
- 3. People with ID who are developing their own support plan for social care often have a family member present at meetings. The success of the interaction depends on how the family member's self-selected turns are taken up by the practitioner, who can treat those turns as prompts, clarifications, or support. Allowing time for good preparation of the person with ID is as important as managing the meeting, and the 'knowledge deficient' or naïve stance of a practitioner can be effective in enabling the person with ID to reach a considered decision.
- 4. The success of a social care interaction may be seen differently from the point of view of service users, family members and practitioners. It is helpful to take back key extracts of data to representatives of these different groups, and using role-play techniques, to work out possible solutions to the interactional problems. The outcomes of one attempt to do this can be seen in the DVD 'Speaking up about your support plan'.