Successful interviews with people with intellectual disability

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Abstract

People with intellectual disability who possess expressive language are able to participate successfully in qualitative interviews, providing the facilitator pays close attention to their communication preferences. This paper considers the successes and flaws in techniques utilised in a study that invited twelve men and 17 women to talk about sex, risk, social and leisure life. Questions were posed in plain language and accompanied by concrete reference tools, namely picture cards and photo-story vignettes. Adjusting the depth of questioning in line with what a respondent wants to or can offer enhanced the quality of data obtained. The discussion highlights that interviewer's actions may contribute to errors, which have previously been described in individualising terms as acquiescence, recency and unresponsiveness. The overall message of this paper is that a responsive approach to each participant's particular communication style, combined with avoidance of inaccessible question formats, are key ingredients of a successful interview.

Introduction

Authors such as Goodley (1996) and Atkinson (1997) point out that people with intellectual disability were historically excluded from research. When researchers first started to engage with this population, difficulties in interviewing were attributed to impairment effects (e.g. Sigelman et al., 1981). Cummins and Laraine Masters (2002) assert that even today the practice of seeking proxy responses by someone who knows a person well, for instance a professional, staff or family member, continues to be used at times to circumvent the methodological challenges that arise from speaking to people with intellectual disability themselves. Proxies may be asked to comment on anything from the success of resettlement (Doody, 2012) to highly subjective issues, such as quality of life (Hartnett et al., 2008). However, Lloyd *et al.* (2006) point out that proxies may find it hard to detach themselves from their own views and that such research may provide more information about the experiences and subjectivity of the substitute persons than about the individuals concerned.

In contrast, a wealth of authors have developed adaptive approaches for involving people with intellectual disability in research. Discussions about interviewing this group started to gain momentum in the 1980s. For instance, Sigelman et al. (1981) outlined the challenges in eliciting responses from this less responsive population. The authors were wary about respondent's capabilities to provide useable data. While they attributed fault for the problems that arose in interviews with people with intellectual disability to the respondents, the novelty at the time was that the group had been approached by researchers in the first place. Their accounts began to matter. This reflects changes that took place at the time: Sigelman et al.'s (1981) paper appeared in an edited collection about deinstitutionalisation. Flynn (1986) built on this work and offered some guidelines on interviewing techniques, much of which is still relevant today. For instance, she recommends that questions about time and frequency should be avoided, as many people with intellectual disability find these difficult to answer.

In the UK alone the 1990s saw some exciting developments. As part of their in-depth research with parents with intellectual disability Booth and Booth (1994) published some detailed accounts of techniques they found useful. For instance, following on from Flynn's (1986) point about difficulties with questions about time, they recommend the use of alternative reference points, such as events, like Christmases, birthdays or holidays, to establish when an event has taken place. Authors such as Goodley (1996) and Atkinson, Walmsley, and Jackson (1997) had started to conduct life history research with people with intellectual disability, thus for the first time exploring recent history from their hitherto forgotten perspectives.

Mick Finlay, Charles Antaki and colleagues also started publishing in this field. Using conversation analysis, they continue to produce an interesting body of research on communication techniques of and with people with intellectual disability, for instance examining questioning of this population in police interviews (Antaki, Richardson, Stokoe, & Willott, 2015) or in mundane interactions with care staff (Finlay & Antaki, 2012). Their close analysis of discourse offers unique insights into disparities that may occur in conversations and an awareness of these issues can enable researchers to pre-empt them. This body of knowledge is referred to throughout this paper.

Moreover, there is now an immense body of evidence available on a vast range of methodological tools that can be used to engage people with intellectual disability and enhance research interviews, such as the use of participatory photographic research methods (Aldridge, 2007) or visual and metaphorical devices (Nind & Vinha, 2016). Many recent

projects are furthermore underpinned by the principles of inclusive research. According to Walmsley and Johnson (2003, p. 16) such research is based on the notion that it 'must address issues which really matter [to the research population] and ultimately leads to improved lives for them'. 'It must access and represent their views and experiences' and people with intellectual disability 'need to be treated with respect by the research community'. This paper focuses on means by which just one key ingredient of inclusive research can be achieved, that of engaging respondents with intellectual disability so that they become 'more than just subjects of research. They [become] actors, people whose views are directly represented in the published findings in their own words' (Walmsley & Johnson, 2003, p. 61f).

This brief summary aimed to give a flavour of recent advances. It did not do the developments in the field justice, nor did it intent to give a complete historical overview of the key authors in each era. What should become apparent is that all of this progress towards methodological innovation that accommodates people with intellectual disability is exciting, but it can also be daunting. This author is often approached by researchers who are new to working with less articulate subjects. They tend to ask for a concise guide that summarises some useful techniques that can help them to achieve successful interviews. The purpose of this paper is therefore to summarise not only the tools and techniques developed for the study from which this paper arose, but also the advice found across the literature that was particularly helpful. The aim is to create a useable catalogue of techniques that other researchers will be able to adapt and build on for their own projects.

The study: Conversations about sex, risk and daily living

This paper is based on a study that explored to what extent risk of sexual violence against people with intellectual disability is shaped by social processes (author's own). Risk is an abstract concept, as perceptions of who is at risk and from what are based on the anticipation of threatening future events. They therefore 'initially only exist in terms of (…) *knowledge* about them. They can thus be changed, magnified, dramatized or minimised within knowledge, and to that extent they are particularly *open to social definition and construction* [original italics]' (Beck, 1992, p. 23). Nonetheless, the perception of people with intellectual disability being at risk from harm has an immense impact on informal family interactions and formal social care planning (e.g. Curryer, Stancliffe, & Dew, 2015; Gilbert, Lankshear, &

Petersen, 2008; Harkes, Brown, & Horsburgh, 2014), which is why this study sought to explore this notion further. It did this by taking a social model stance.

The social model of disability makes a distinction between disability and impairment. Whilst impairment is a personal characteristic of mind, body or senses, disability is a social condition, which is imposed on a person on top of their impairment. It 'is the disadvantage or restriction of activity caused by the political, economic and cultural norms of a society which takes no or little account of people who have impairments and thus excludes them from mainstream activity' (Oliver, Sapey, & Thomas, 2012, p. 16). Applied to the material presented in this paper this means that people with intellectual disability may have difficulties with literacy, with understanding abstract concepts and they may have a limited vocabulary and articulateness (impairment related factors). This in itself does not preclude them from participating in social research. Further barriers may be introduced if researchers take no or limited account of the diverse access needs of respondents, resulting, for instance, in questions being posed in inaccessible formats (disabling social factors). In line with the social model, this paper will direct the gaze away from the respondent's alleged 'limitations' when exploring some inconsistencies that occurred during interviews towards facilitator style and techniques.

Moreover, this research incorporated some aspects of inclusive research. A group of eight women and seven men who met weekly at an independent self-advocacy agency were involved as consultants. Group members helped to decide what topics should be covered in the interviews. They corrected the researcher when words and phrases they considered to be too complex were proposed and they critically examined the picture cards that were drafted to accompany question categories. Self-advocates also helped to write and produce three risk perception vignettes, as discussed in the section on 'concrete prompts and props'. Before fieldwork commenced, the final questionnaire was piloted with three volunteers from the group. The research advisors helped to recruit some of the participants and they were then again involved at the data analysis stage.

The narrative accounts of adults with intellectual disability were used as the main source of information in this study. Semi-structured interviews were conducted with twelve men and 17 women in the north of England. Respondents were between 22 and 68 years old and labelled with 'mild' to 'moderate' intellectual disability. Here, 'intellectual disability' describes a person who has an IQ below 70 and social and adaptive difficulties, with onset before adulthood (World Health Organisation, 2010). About half of the respondents lived with their parents or other family members. About a quarter lived in residential group settings

and another quarter lived independently. They were accessed at two day centres and two advocacy services, where participant observations were furthermore conducted. Due to the method chosen, one presumption for inclusion in the sample had to be the presence of some expressive language.

Researchers may at times shy away from broaching sensitive issues with populations who are considered 'vulnerable', due to concerns about complications in receiving ethical permission. Such difficulties are as vividly illustrated by Hays *et al.'s* (2003). This researcher had a very different experience when applying for access through two local authorities, who processed the application jointly. The process of seeking ethical approval was completed in about two months. As part of the resulting research agreement a link person within each local authority was named. The researcher was obliged to contact them if actual or suspected violence was disclosed during the course of the research. In addition, the researcher was required to obtain an enhanced Criminal Record Bureau check (HMSO, 2000).

Achieving successful interviews

Researchers who work with less articulate subjects are advised to get to know respondents prior to the interview (Arksey & Knight, 1999). In this research most respondents were met several times during participant observations at day centres and advocacy groups. This contributed to the researcher becoming acquainted with part of respondent's daily routine, as well as with ways in which they communicate. People with intellectual disability might not be able to concentrate for lengthy periods. To make interviews less demanding, these were stopped when the respondents became tired of talking. Most interviews were conducted in two parts, each normally lasting between 30 and 60 minutes.

Interview parts were usually conducted in consecutive weeks, to ensure that as little time as possible elapsed between meetings, because individuals might otherwise forget about the project (The Learning Difficulties Research Team, with Bewley, & McCulloch, 2006). The first session was usually transcribed prior to commencing the second one. This helped to identify any communication difficulties. Questions that arose from the dialogue could be address in the second meeting. It also meant that many non-verbal cues could still be recalled by the researcher whilst transcribing.

The remainder of this paper explores in detail how successful interviews were achieved by using adapted and flexible techniques. The discussion is divided into four main

sections: a description of how depth of questioning was adjusted for each respondent, an introduction to some tools that cane help to create a concrete frame of reference, a section that takes a new look at three concepts that have previously been used to put blame for interview errors on the respondent and a brief discussion of triangulation.

Adjusting the depth of questioning

The label 'intellectual disability' is most usefully understood as an umbrella term, which brings together individuals with a diverse range of communication preferences. The following discussion uses the example of expressing preferences and opinions, to distinguish different levels of depth that may be achieved in conversations with respondents from such a disparate group. Response styles of three participants are compared.

Respondent 1 (R1) provided the least detail. The extract below explores whether he helps his mother with preparing meals:

R1:   No, I don't. .. I don't use the c… I don't use the coo..ker.. Not
                 allowed to.

Interviewer (I):   Why is that?

R1:   ... I'm not allowed to. That's why.

R1 was clear about his limits: He knew an informal rule, which he routinely follows, but he could not clarify why this rule exists. This does not invalidate his response. R1's response might imply that his immediate *preference* is *not to break the rule*, but this would need to be explored with further questioning.

R2 provides an explanation when she is asked to justify a similar restriction:

R2: We can't go in the kitchen. … We've been warned about going in the kitchen. If
        we get burned, staff are getting into trouble at our home.

I: [...] Would you like to go into the kitchen?

R2: *(eyes widen, immediate response, loud)* NO.

I: Why not?

R2: *(immediate response, loud)* You mustn't get told off by the staff.

R2 is able to provide a rationale for the restriction. She also expresses a *preference* in the last line of the exchange. However, she does not express a full *opinion*. This would make further sense of the advantages and disadvantages of the rule at hand.

R3 was one of the most articulate respondents. Four years prior to the interview, she had moved from sheltered accommodation to a residential home with 24h staff support.

I: Do you like living in the home?

R3: No.

I: Why not?

R3: It weren't that, it's not the right place for me. I'm too independent […] Before I came into [area] I did all my cooking and everything myself, but now I'm in [area] I can't do me own cooking, I can't do a bit of anything I need to do independently. [...] All me independent skills have gone out of the window.

The second line of this exchange provides limited information. Here, R3 stated a *preference*, but she then goes on to describe a fully rationalised opinion. It would have been a shame not to prompt further and not to allow R3 to express her views. On the other hand, it would have been at best intimidating to insist that respondents like R1 provide such detailed reflections. At worst, this can introduce interview errors, as discussed later on. Moreover, it would have been a loss to disregard R1's and R2's interesting and insightful accounts as comparatively 'incomplete'.

Creating a concrete frame of reference

People with intellectual disability are more likely to use a concrete, rather than an abstract frame of reference (Booth & Booth, 1994). Metaphors and similarly ambiguous expressions should be avoided, to accommodate those who possess a literal rather than a figurative mode of expression. For instance, questions that enquire how a person thinks others view them involve a complex level of social understanding. Informants would have to infer the internal emotions, attitudes or beliefs of another person from their behaviour (Finlay & Lyons, 2001). This is an extremely difficult task for some. The question: 'What do others like about you?' did not return any answers at the pilot stage. Such socially reflexive questions were

consequently removed from the interview guide. Questions should furthermore be relevant to respondent's experiences, relatively direct and specific and concentrate on one point at a time.

The fact that questions about time and frequency are best avoided or when they are essential replaced by reference points that are more relevant to the individual was already explained in the introduction. During the course of this study there was only one situation when information about time was crucial: R4 stated that she has been 'bullied' by her father. The way in which she spoke could have suggested that this was still ongoing. In that case R4 and the researcher would have needed to explore how she could be supported to prevent further incidents. R4 however had little concept of time. It was hard to understand when exactly events have taken place. After suggesting a number of reference points it was eventually established that the 'bullying' went on while R4 was at school. That means that this must have stopped at least ten years prior to the interview.

Concrete reference tools

Concrete reference tools can help to make conversations more tangible, thus enabling those who find abstract thought difficult. They can also help to make interviews more accessible for less articulate respondents, as they can provide prompts and words. In this study, picture cards accompanied all of the question categories. These were put together using images from CHANGE (2016) *General* and *Health Picture Banks, Photosymbols Ldt* (2016), *Valuing People Clip Art* (Inspired Services Publishing, 2016) and the sex education package *Sex and the 3 R's* (McCarthy & Thompson, 1998). There were altogether 36 picture cards for 23 question categories.

For example, line drawings from *Sex and the 3 R's* were used to discuss body parts. A laminated A4 card with 14 colourful pictures displaying a range of activities or settings was used for discussions about leisure activities. These included walking a dog, playing a board game, watching TV, dancing, listening to music, drinking in a pub, reading a paper, a picnic, playing basketball, a theatre, a beach, a paint set, horse riding and shopping. Even though this did not present an infinite list of options, pictures provided some basic prompts.

Respondent's use of the picture cards varied. Some barely noticed them, but others relied heavily on the pictures as reference points. They would work their way through them to talk about a subject. R5, for example, looked at the pictures, pointed at them and stated: 'Like

that … don't like that.' She seemed to find it hard to think of words and concepts when unsupported, but the inclusion of pictures facilitated communication.

Photo story vignettes

As discussed earlier, the notion of risk, which was central to this study, is an abstract concept. This makes it difficult to discuss this with people who have a more concrete frame of reference. However, some picture cards were interpreted as prompts for discussing risk by several respondents, most notably a *Photosymbol* (2016) that depicted a man opening an oven, which a number of individuals perceived as 'dangerous'. Some ensuing discussions were explored earlier on. Risk of sexual violence is even harder to imply in a single picture. To make this more concrete, three risk perception vignettes were developed. The research advisors helped to write the story lines and some posed for the accompanying photographs. The vignettes were presented as a whole, on a laminated A3 sheet. Researcher and respondent would usually sit together for this part of the interview. The interviewer would point at each picture and read out the text underneath. In figure 1, a sample vignette is reproduced.

Insert figure 1 about here.

The first two stories featured an incident of unsought touch and implied a risk of further intrusions. The third one was a case study about 'stranger-danger'. Respondents were asked to advise the individual who had been approached by the other actor what they should do by the end of each vignette. The vignettes prompted many respondents to reflect on potentially unsafe situations they encountered in their own lives, as evident in R2's response:

I:	What should Jill do?
R2:	Tell him to stop it.
I:	Is there anything else she could do?
R2:	*(mumbles)* Hit him across face.
I:	Sorry?
R2:	Hit him across face. I did it once. A lad tried to get hold of my boobs, so I kicked him.

Nonetheless, R1 and R6 found the vignettes difficult and were unable to imagine what would happen next and to articulate an elaborate response. One of R1's answer is discussed in the next section. Below, it initially appears that R6 articulates a preference:

I: What should Jill do?

R6:   It's… very bad, that.

I: Mmh. Why is that?

R6:   I don't know.

The 'why' question proves to be too difficult for R6. As R6 has taken little ownership of the preference he articulated, it is less clear whether this is his own view or what he assumes to be the 'correct' response the interviewer wants to hear. These uncertainties resulted in this exchange being excluded from the final data set.

So far it was shown that working individually with the respondent and adjusting expectations in line with what they want to or can offer, as well as further enabling communication by using concrete reference tools, can help to facilitate effective dialogue. The focus was on interviewer techniques. The next section will initially pick up three concepts, which focus on the respondent.

A new look at acquiescence, unresponsiveness and recency

Difficulties in interviewing people with intellectual disability have in the past been described in individualising terms, blaming respondents for allegedly 'lacking skills' needed to communicate effectively. This section discusses three such concepts; acquiescence, unresponsiveness and recency. However, the arguments presented here suggest that it might be the facilitator who should examine whether they have the skills needed to accommodate successful dialogue.

Acquiescence

The first concept, acquiescence, also referred to as 'yeah-saying', describes a bias towards affirmative responses (Sigelman et al., 1981). Supposed causes include a person's intellectual

disability per se, but also the fact that so many aspects of their lives are controlled by others that many people with intellectual disability become socialised into compliance (Stalker, 1998). To counter these claims, Rapley and Antaki (1996, p. 219) maintain that the literature that substantiates the 'acquiescence' phenomenon does so 'in the absence of detailed transcripts of the interactions between interviewers and interviewees'. They argue that this phenomenon lacks coherent evidence and also demonstrate that people with intellectual disability are capable of *anti*-acquiescence. Antaki et al. (2015) highlight such incidents even during police interviews. This study found similar occurrences of respondents disagreeing with or challenging what the interviewer has suggested.

However, if we were to run with this concept for now, difficulties with 'yeah-saying' first emerged in one of the pilot interviews. The respondent had just described that support staff chose the clothes he will wear every morning.

I: Are you happy **with that**?
R7: I am quite happy, yeh…
I: Or would you rather pick your own clothes?
R7: I'd rather pick me own.

This could be interpreted as acquiescence. R7 agrees with both statements suggested by the interviewer, thus contradicting himself. However, a closer look at the transcript suggests at least one alternative explanation. Finlay and Lyons (2001) warn that *modifiers and negatively worded questions* should be avoided in interviews with people with intellectual disability. A modifier can be a single word or clause that changes the sense of a question. In this example it is possible that the first question was phrased in an ambiguous format. The sense of the entire question changes if 'with that' was erased from the first line. Respondent and interviewer may not be talking about the same issue. From his response, there is no indication that R7 has picked up on the meaning of the modified question. All he says is that he is 'quite happy'.

Questions were therefore rephrased into less ambiguous formats for the main interviews. As negatively worded questions can also mislead, these were substituted for unmistakably negative expressions, for example, asking: 'Do you **hate** broccoli?' instead of: 'Do you **not like** broccoli?' Talking like this felt strange, as this is a rather harsh way of referring to broccoli, which the interviewer was not used to, as they tend not to express food

preferences in such extreme terms. Nonetheless, it was deemed more appropriate to ask clear questions than to be pedantic about all of the possible nuances of discourse.

The following exchange is a further example in which a respondent looks to be contradicting himself when he goes along with suggestions made by the interviewer. It describes R1's response to a vignette:

I: What should Frank do?

R1: Don't know.

I: You don't know?

R1: No.

I: Could he go and listen to that man's music?

R1: Yeah.

I: Or should he not go?

R1: Not go.

Finlay and Lyons (2002) assert that alleged 'acquiescence' may arise when the answer is not known or when questions are too long or too complex. In other words, saying 'yes' could be a way of disguising a lack of understanding. This could be what R1 was doing here. He had already asserted that he did not know the answer and as he was nonetheless pressed further, he went along with the suggestions. In other words, the error here may again lie with the interviewer: Perhaps they should have stopped putting R1 on the spot like this.

Unresponsiveness and recency

The extracts presented thus far support Finlay and Lyons's (2002) claim that communication difficulties that initially appear to be caused by 'acquiescence' may be caused by inappropriate questioning. A similar assertion can be applied to 'unresponsiveness'. Booth and Booth (1994) remind us that some people with intellectual disability have a responsive rather than a proactive communication style and an instrumental rather than an expressive vocabulary. They therefore require persistent prompts to tell their stories. However, there is also a risk of mis-attributing a person's silence to their impairment. At times, respondents may simply be un*willing* to participate or to elaborate, rather than un*able* to do so (Lesseliers, Van Hove, & Vandevelde, 2009). For instance, R8 seemed nervous when he was asked

questions about sex. His communication style and body language changed: He moved into the furthest corner of his seat, away from the interviewer, slouched, started fidgeting and gave monosyllable responses, whereas before he had answered in short sentences. The interview was thus brought to an end, as R8's mostly non-verbal cues were interpreted as signs for his embarrassment by this line of questioning.

For those respondents who are genuinely less articulate, Booth and Booth (1996) demonstrate that the exclusive use of closed-ended questioning can be useful. While this research did not solely rely on this question type, closed-ended questioning was increased for less expressive respondents. Many questions in the interviewing schedule included options for phrasing them in either an open-ended or closed-ended format. To provide an example, the following extract demonstrates how R9 worked her way through multiple-choices answer alternatives to an open-ended question about appropriate behaviour in a sexual relationship. Note that R9's responses were loud and immediate. The first four responses were accompanied by what could be interpreted as enthusiastic nodding. R9's facial expressions changed by her fifth response. She stopped smiling and nodding.

I: Do you think that it's okay to hold hands-

R9:   -YEAH. YEAH.- […]

I: Do you think spending time together is a good thing?

R9:   YEAH. YEAH.

I: Do you think people can cuddle?

R9:   YEAH. YEAH. [...]

I: Is it okay to kiss?

R9:   YEAH. YEAH. [...]

I: Do you think if two people love each other they can have sex?

R9:   NO. I can't. *(Stifled laugh)*

I: You can't?

R9:   No.

I: Why not?

R9:   No. I don't want to.

This is an example of a successful dialogue. Instead of leaving the question open, which R9 found difficult to respond to, the following multiple choice question was posed, broken down into multiple yes/no questions:

How can you show your boyfriend that you love him? [Choose as many as apply.]

a) hold hands;

b) spend time together;

c) cuddle;

d) kiss;

e) have sex.

The yes/no format in the exchange with R9 was used to avoid a questioning error that could have given rise to recency. This concept refers to respondents always picking the last option from a list of multiple-choice question alternatives (Sigelman et al., 1981). Finlay and Lyons (2001) explain why recency may occur. When literate respondents are asked multiple-choice questions, these are usually presented in written format, which limits recency. The fact that such questions are typically posed orally in research with participants with limited literacy demands a high memory load of respondents and recency should therefore not come as a surprise. It is likely that R9 would have forgotten answer alternatives that were listed earlier on, had the question not been broken down as demonstrated. Yet, Sigelman et al. (1981) further suggest that the yes/no question format used instead introduces an increased risk of 'acquiescence'. In the extract cited earlier R9 could indeed be suspected to be acquiescing at first. What speaks against this is the fact that her affirmative responses were very keen: She laughed and spoke loudly, which indicated that she genuinely meant to say 'yes'. She also eventually said 'no' firmly when she meant it, accompanied by a significant change in her non-verbal communication.

Whenever it was not clear whether respondents had systematically picked the last option of two alternatives, this was checked by rephrasing the question and by changing the order of response alternatives, as suggested by McCarthy (1999). Furthermore, short responses were checked by probing respondents to give more detail (Finlay & Lyons, 2001). Responses were then closely examined during data processing. Data arising from a participant merely answering 'yes' or 'no' or picking an option from a list was generally discharged, unless it was supported by further qualitative evidence. This could sometimes be non-verbal cues, like R9's smiles, laughs and nodding. The fact that unsubstantiated data was removed before analysis increased the reliability of the data that was retained. This meant that some data from at times less expressive respondents, like R1, R6 and R8, was retained, which was preferred to disregarding a person's whole account.

Triangulation

Even after the strategies described so far were employed, occasionally, respondents told interesting stories, but without providing enough context, which would allow the listener to make complete sense of the situation. This section describes the use of triangulation in such instances, which refers to the cross verification from additional sources. The first technique is asking another person to add contextual information on an issue that warrants further clarification. The second technique is to draw on other field observations.

Using secondary confirmatory sources

The paragraph below summarises a section from R5's interview. Prompts by the interviewer are cut out of what would otherwise be a lengthy dialogue. However, R5's account is presented in her own words.

> Staff's stopping me going to see me friends on a Fridays. […] And I like, I like going to the pub. Who are me friends on a Fridays and … the staff said: 'No, no, you can't do this. Can't, you can't do that!' Because your social worker said you're barred from it. … And I didn't do anything wrong. … And the staff behind the bar say… the, the, the lad who goes […], is to get drunk. To get too drunk and they take the micki out of me. And saying stuff behind my back and I don't like that. Should say it in me face what you wanna say.

The researcher was unable to piece together exactly what had happened. With R5's consent, a staff member was able to provide further context. Below are some field notes on what she said:

> R5 likes clubbing and going to pubs, where she apparently approaches men 'inappropriately', including blowing kisses, dancing 'provocatively' and seeking body contact. This has caused offence on numerous occasions, especially when men's partners were present. Two working men's clubs have asked for R5 'not to

come back for a while'. Each time it is reported that other customers have been

hostile towards R5; her social worker will instruct support staff that R5 should no

longer be supported to visit that particular club.

At times, some researchers may refer to the accounts of more articulate subjects, in order to
verify another person's account (e.g. Courtney, Rose, & Mason, 2006). Conversely, due to its
alignment with the social model, this study referred to the accounts of others only to
contextualise what people with intellectual disability were saying. Caldwell (2014) confirms
that supplementing data gained from interviews with people with intellectual disability in this
way, using others as secondary confirmatory sources, is now a widely used approach.

R5's account appears to verify the staff's, whereas the staff's description of an
ongoing adult protection intervention can help to contextualise what R5 was trying to make
sense of. However, at the data analysis stage, there was no shift towards the key worker's
version of events. For instance, R5's behaviour was not labelled as 'inappropriate'. The focus
remained on aiming to understand R5's perspective, i.e. that R5 did not fully understand what
was going on, found this restrictive and felt that she was being stopped from seeing 'friends'.
The advantage for the researcher was that they now had a clearer understanding of the context
that made R5 feel that way.

Referring to field observations

The final case study demonstrates how it was possible to string together enough evidence to
support R1's account of his views on sexuality with reference to his own narrative, participant
observations and also a comparison to the interview with his 'boyfriend'.

I: Have you got a girlfriend or a boyfriend?

R1:   *(mumbles)* He don't know.

I: Sorry?

R1:   Not at home. Here.

I: [...] Who is that?

R1:   Eh.. [R10]

I: [...] So, R10 is your boyfriend?

R1:   Yeah.

R1 did not elaborate further and the interviewer was not sure whether they had understood what R1 was trying to say. R10 is another day centre attendee. During participant observations it was noted that R10 and R1 spend the majority of their time at the day centre sitting together, away from the others. R10 was also interviewed for this study. In his interview, he claimed to be heterosexual. He mentioned a girlfriend and spoke about R1 as a 'friend'. This contextualises R1's account. R10 was indeed not aware that he was R1's 'boyfriend', but he was someone R1 spent a significant amount of time with. At a different point of the interview, R1 offers an explanation for his secrecy:

I: Do you know what love is?

R1:   Don't.. kissing. Don't kiss boys.

I: [...] Why is that?

R1:   Get into bother.

I: [...] Who would you get into bother with?

R1:   [day centre manager].

As discussed earlier, some of R1's responses, such as his answers to the risk perception vignettes, had to be discharged from the data set, as they seemed to entail interview errors. Here is an example that shows that he was nonetheless still able to express some of his experiences. Triangulation with other sources helped to clarify and add more substance to what he was saying: R1 feels that he has to keep his sexuality secret, even from his 'boyfriend', due to fears of 'getting into bother'. The implication is that this happened before, which opens a whole new line of questioning. Going into detail with this would be beyond the scope of this paper. What is of interest is that R1 did indeed have some experiences to share, which were highly relevant for this project. Simply discharging all of the data from R1's interviews, due to errors occurring in parts, would have silenced his already marginalised voice.

Nonetheless, respondents like R1 highlight that, no matter how much effort is made to enhance accessibility, the choice of the interview method will disadvantage or exclude entirely the least articulate subjects. In the field of disability studies this includes those with multiple and profound intellectual disability. For such groups, adapting a range of more interactive qualitative methods, including for example, graphic facilitation (e.g. Chapman,

2014) and drama (e.g. Garbutt, 2009), would be more suitable. A discussion of such methods is however beyond the scope of this paper.

Discussion

This paper has shown that successful dialogue with people with intellectual disability can be achieved by adapting interview content and style to suit the communication preferences of each individual in this highly diverse population. Taking the time to get to know respondents prior to the interview will pay off, as this will give researchers a better idea of the adaptations that may be required. One such alteration may be to adjust the depth of questioning, in order to work with the response styles of the participants.

Keeping the interviews too basic, in order to ensure that even the least responsive participant can answer all the questions would be a shame, as the accounts of those who have more to say on a particular topic would be lost. The more articulate respondents may also be at risk of feeling patronised if questions are kept too simplistic. Prompting beyond what a less articulate respondent has offered can also have negative effects, as this can introduce interview errors. In other words, getting the balancing act of prompting for more or less detail right for each respondent will enhance the quality of data obtained.

This researcher found the use of concrete reference tools particularly useful. These can help to make conversations more tangible, thus enabling those who find abstract thought difficult. They can provide words to less articulate respondents and enable them to have some control in selecting what to discuss. In research about sensitive issues the discussion of vignettes can take the focus away from the potentially embarrassed respondent. In this study vignettes have also helped respondents to make sense of an abstract concept. Yet, as with all aspects of the methods discussed, 'one size did not fit all' and two of 29 respondents did not find the vignettes helpful, necessitating the use of alternative methods.

One such technique discussed was triangulation. Here, this refers to the use of secondary confirmatory sources to contextualise what respondents were discussing, as well as drawing on information from other aspects of the research, such as participant observations. It was explained that drawing on such supporting accounts should not act to discredit what the person with intellectual disability is saying. This method is merely used on occasions where a little help is needed to contextualise issues that may not make full sense to the person themselves.

Finally, this paper offered a new look at acquiescence, unresponsiveness and recency. These concepts have in the past been used to blame respondents for 'lacking skills' needed to communicate effectively. However, the arguments presented here point to errors in question phrasing and suggest that it might be the facilitator who should examine whether they have the skills needed to accommodate successful dialogue. For instance, a researcher's awareness that modifiers and negatively worded questions may alter the sense of a question should encourage them to phrase less ambiguous questions.

Conclusion

The label 'people with intellectual disability' brings together individuals with a vast range of communication styles and preferences. Researchers who wish to get the most out of such respondents should approach fieldwork from the stance that people with intellectual disability can speak for themselves and that it is the researcher's task to facilitate this process, rather than focussing on what a respondent may not be able to do. Some of the information in this paper may help to rule out techniques which are more likely to fail, but this does not mean that doing the exact opposite will be enough. In fact, it has become apparent that removing one predicament (such as risk of 'recency') can often introduce another (such as risk of 'acquiescence').

Many of the issues discussed in this paper will be of help in research with other intimidated or less articulate respondent groups. For instance, children, people who have difficulties expressing themselves in the language in which the interview is being held or people with dementia may benefit from the use of concrete reference tools to assist their communication. Triangulation can be helpful with respondents who cannot make full sense of a situation they find themselves in. Flexibility in responding to communication preferences and the ability to adjust expectations in line with what a respondent has to offer will be useful in interviews with most groups. For instance, a businessman may only have a short amount of time to engage in an interview and may refrain from giving lengthy responses.

But overall the most important general points to take away from this paper are that interviewers will be able to get the best out of their respondents if they are willing to adopt a flexible approach to interviewing, to get to know how each respondent best communicates, respect what they have to offer and have faith in their ability to give the most accurate and meaningful account of their own subjectivity.

References

Aldridge, J. (2007). Picture this: the use of participatory photographic research methods with people with learning disabilities. *Disability & Society, 22*(1), 1 - 17.

Antaki, C., Richardson, E., Stokoe, E., & Willott, S. (2015). Can People With Intellectual Disability Resist Implications of Fault When Police Question Their Allegations of Sexual Assault and Rape? *Intellectual and Developmental Disabilities, 53*(5), 346-357.

Arksey, H., & Knight, P. T. (1999). *Interviewing for social scientists: an introductory resource with examples*. London: SAGE.

Atkinson, D. (1997). *An auto/biographical approach to learning disability research*. Aldershot: Ashgate.

Atkinson, D., Walmsley, J., & Jackson, M. (1997). *Forgotten lives : exploring the history of learning disability*. Plymouth: BILD Publications.

Beck, U. (1992). *Risk society: towards a new modernity*. London: Sage.

Booth, T., & Booth, W. (1994). *Parenting under Pressure: Mothers and Fathers with Learning Difficulties*. Buckingham: Open University Press.

Booth, T., & Booth, W. (1996). Sounds of silence: Narrative research with inarticulate subjects. *Disability & Society, 11*(1), 55-69.

Caldwell, K. (2014). Dyadic interviewing: a technique valuing interdependence in interviews with individuals with intellectual disabilities. *Qualitative Research, 14*(4), 488-507.

CHANGE. (2016). Homepage.   Retrieved from http://www.changepeople.org/

Chapman, R. (2014). An Exploration of the Self-Advocacy Support Role Through Collaborative Research: 'There Should Never be a Them and Us'. *Journal of Applied Research in Intellectual Disabilities, 27*(1), 44-53.

Courtney, J., Rose, J., & Mason, O. (2006). The Offence Process of Sex Offenders with Intellectual Disabilities: A Qualitative Study. *Sexual Abuse: A Journal of Research and Treatment, 18*(2), 169-191.

Cummins, R. A., & Laraine Masters, G. (2002). Proxy responding for subjective well-being: A review. *International Review of Research in Mental Retardation, 25*, 183-207.

Curryer, B., Stancliffe, R. J., & Dew, A. (2015). Self-determination: Adults with intellectual disability and their family. *Journal of Intellectual and Developmental Disability, 40*(4), 394-399.

Doody, O. (2012). Families' views on their relatives with intellectual disability moving from a long-stay psychiatric institution to a community-based intellectual disability service: an Irish context. *British Journal of Learning Disabilities, 40*(1), 46-54.

Finlay, W. M. L., & Antaki, C. (2012). How staff pursue questions to adults with intellectual disabilities. *Journal of Intellectual Disability Research, 56*(4), 361-370.

Finlay, W. M. L., & Lyons, E. (2001). Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychological Assessment, 13*(3), 319-335.

Finlay, W. M. L., & Lyons, E. (2002). Acquiescence in interviews with people who have mental retardation. *Mental Retardation, 40*(1), 14-29.

Flynn, M. C. (1986). Adults who are mentally handicapped as consumers - issues and guidelines for interviewing. *Journal of Mental Deficiency Research, 30*, 369-377.

Garbutt, R. (2009). Let's Talk about Sex: Using Drama as a Research Tool to Find Out the Views and Experiences of Young People with Learning Disabilities. *Creative Approaches to Research, 2*(1).

Gilbert, A., Lankshear, G., & Petersen, A. (2008). Older family-carers' views on the future accommodation needs of relatives who have an intellectual disability. *International Journal of Social Welfare, 17*(1), 54-64.

Goodley, D. (1996). Tales of Hidden Lives: a critical examination of life history research with people who have learning difficulties. *Disability & Society, 11*(3), 333 - 348.

Harkes, M. A., Brown, M., & Horsburgh, D. (2014). Self Directed Support and people with learning disabilities: a review of the published research evidence. *British Journal of Learning Disabilities, 42*(2), 87-101.

Hartnett, E., Gallagher, P., Kiernan, G., Poulsen, C., Gilligan, E., & Reynolds, M. (2008). Day service programmes for people with a severe intellectual disability and quality of life: Parent and staff perspectives. *J Intellect Disabil., 12*(2), 153-172.

Hays, S.-J., Murphy, G., & Sinclair, N. (2003). Gaining ethical approval for research into sensitive topics: 'two strikes and you're out?'. *British Journal of Learning Disabilities, 31*(4), 181-189.

HMSO. (2000). *Care Standards Act 2000*. London: Her Majesty's Stationary Office.

Inspired Services Publishing. (2016). Welcome to the Valuing People Clipart Collection.   Retrieved from http://www.inspiredservices.org.uk/

Lesseliers, J., Van Hove, G., & Vandevelde, S. (2009). Regranting identity to the outgraced - narratives of persons with learning disabilities: methodological considerations. *Disability & Society, 24*(4), 411-423.

Lloyd, V., Gatherer, A., & Kalsy, S. (2006). Conducting qualitative interview research with people with expressive language difficulties. *Qualitative Health Research, 16*(10), 1386-1404.

McCarthy, M. (1999). *Sexuality and women with learning disabilities*. London: Jessica Kingsley.

McCarthy, M., & Thompson, D. (1998). *Sex and the 3R's: rights responsibilities and risks. A sex education package for working with people with learning difficulties*. Brighton: Pavilion Publishing.

Nind, M., & Vinha, H. (2016). Creative interactions with data: using visual and metaphorical devices in repeated focus groups. *Qualitative Research, 16*(1), 9-26.

Oliver, M., Sapey, B., & Thomas, P. (2012). *Social work with disabled people* (4th ed.). Basingstoke: Palgrave Macmillan.

Photosymbols Ltd. (2016). Welcome to Photosymbols.   Retrieved from http://www.photosymbols.com/

Rapley, M., & Antaki, C. (1996). A conversation analysis of the 'acquiescence' of people with learning disabilities. *Journal of Community & Applied Social Psychology, 6*(3), 207-227.

Sigelman, C., Schoenrock, C., Winer, J., Spanhel, C., Hromas, S., Martin, P., . . . Bensberg, C. (1981). Issues in Interviewing Mentally Retarded Persons: An Empirical Study. In R. Bruininks, C. Meyer, B. Sigford, & K. Lakin (Eds.), *Deinstitutionalization and Community Adjustment of Mentally Retarded People*

(pp. 114-129). Washington, DC: Monograph No.4. American Assiciation of Mental Deficiency.

Stalker, K. (1998). Some Ethical and Methodological Issues in Research with People with Learning Difficulties. *Disability & Society, 13*(1), 5-19.

The Learning Difficulties Research Team, with Bewley, C., & McCulloch, L. (2006). *Let me In - I'm a researcher! Getting involved in research*. London: The Department of Health.

Walmsley, J., & Johnson, K. (2003). *Inclusive Research with People with Learning Disabilities – Past, Present and Futures*. London: Jessica Kingsley Publishers.

World Health Organisation. (2010). ICD-10.   Retrieved from http://apps.who.int/classifications/icd10/browse/2010/en

Index of transcription signs

(italics)	Summary of context/ actions, non-verbal and non-lingual cues
..	Short pause (under 3 seconds)
…	Longer pause (3 seconds or more)
[…]	Part of the dialogue has been deleted.
[staff]	If non-italic words are used in brackets, they provide further information or clarifications or they replace a name, place or other identifier, to preserve anonymity.
NO	Louder/ respondent raised their voice
Is -	Speaker gets interrupted (overlap)
- I do	Speaker interrupts (overlap)
bold	Not a transcription mark. Text highlighted to enable analysis.

Appendix - Figure 1: Sample vignette*

John and Jill are good friends. They work together.

Here are John and Jill. They work together in an office.

John and Jill spend their free time together. They visit each other at home.

John makes Jill laugh.

One day Jill makes a cup of tea.

John comes up behind Jill. He puts his arm around her waist. He pulls her close.

Jill is shocked. She says: "What are you doing?"

John says: "We are friends. I am allowed to touch you. I like it! You are sexy."

What should Jill do?

*Faces have been blanked out to preserve anonymity of the research advisors.
Please note that I aim to ask the two actors whether they consent to vignette 1 being published once the paper is accepted for publication. If they decline I may use another one of the study's vignette (with the actor's consent) or I will blank the actor's faces out more effectively.