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Successful interviews with people with intellectual disability

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Abstract:	<p>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.</p>

Successful interviews with people with intellectual disability

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.

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

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18 In the UK alone the 1990s saw some exciting developments. As part of their in-depth
19 research with parents with intellectual disability Booth and Booth (1994) published some
20 detailed accounts of techniques they found useful. For instance, following on from Flynn's
21 (1986) point about difficulties with questions about time, they recommend the use of
22 alternative reference points, such as events, like Christmases, birthdays or holidays, to
23 establish when an event has taken place. Authors such as Goodley (1996) and Atkinson,
24 Walmsley, and Jackson (1997) had started to conduct life history research with people with
25 intellectual disability, thus for the first time exploring recent history from their hitherto
26 forgotten perspectives.

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28
29 Mick Finlay, Charles Antaki and colleagues also started publishing in this field. Using
30 conversation analysis, they continue to produce an interesting body of research on
31 communication techniques of and with people with intellectual disability, for instance
32 examining questioning of this population in police interviews (Antaki, Richardson, Stokoe, &
33 Willott, 2015) or in mundane interactions with care staff (Finlay & Antaki, 2012). Their close
34 analysis of discourse offers unique insights into disparities that may occur in conversations
35 and an awareness of these issues can enable researchers to pre-empt them. This body of
36 knowledge is referred to throughout this paper.

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39 Moreover, there is now an immense body of evidence available on a vast range of
40 methodological tools that can be used to engage people with intellectual disability and
41 enhance research interviews, such as the use of participatory photographic research methods
42 (Aldridge, 2007) or visual and metaphorical devices (Nind & Vinha, 2016). Many recent
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3 projects are furthermore underpinned by the principles of inclusive research. According to
4 Walmsley and Johnson (2003, p. 16) such research is based on the notion that it ‘must address
5 issues which really matter [to the research population] and ultimately leads to improved lives
6 for them’. ‘It must access and represent their views and experiences’ and people with
7 intellectual disability ‘need to be treated with respect by the research community’. This paper
8 focuses on means by which just one key ingredient of inclusive research can be achieved, that
9 of engaging respondents with intellectual disability so that they become ‘more than just
10 subjects of research. They [become] actors, people whose views are directly represented in
11 the published findings in their own words’ (Walmsley & Johnson, 2003, p. 61f).

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

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42 This paper is based on a study that explored to what extent risk of sexual violence against
43 people with intellectual disability is shaped by social processes (author’s own). Risk is an
44 abstract concept, as perceptions of who is at risk and from what are based on the anticipation
45 of threatening future events. They therefore ‘initially only exist in terms of (...) *knowledge*
46 about them. They can thus be changed, magnified, dramatized or minimised within
47 knowledge, and to that extent they are particularly *open to social definition and construction*
48 [original italics]’ (Beck, 1992, p. 23). Nonetheless, the perception of people with intellectual
49 disability being at risk from harm has an immense impact on informal family interactions and
50 formal social care planning (e.g. Curryer, Stancliffe, & Dew, 2015; Gilbert, Lankshear, &
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3 Petersen, 2008; Harkes, Brown, & Horsburgh, 2014), which is why this study sought to
4 explore this notion further. It did this by taking a social model stance.
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6 The social model of disability makes a distinction between disability and impairment.
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8 Whilst impairment is a personal characteristic of mind, body or senses, disability is a social
9 condition, which is imposed on a person on top of their impairment. It 'is the disadvantage or
10 restriction of activity caused by the political, economic and cultural norms of a society which
11 takes no or little account of people who have impairments and thus excludes them from
12 mainstream activity' (Oliver, Sapey, & Thomas, 2012, p. 16). Applied to the material
13 presented in this paper this means that people with intellectual disability may have difficulties
14 with literacy, with understanding abstract concepts and they may have a limited vocabulary
15 and articulateness (impairment related factors). This in itself does not preclude them from
16 participating in social research. Further barriers may be introduced if researchers take no or
17 limited account of the diverse access needs of respondents, resulting, for instance, in
18 questions being posed in inaccessible formats (disabling social factors). In line with the social
19 model, this paper will direct the gaze away from the respondent's alleged 'limitations' when
20 exploring some inconsistencies that occurred during interviews towards facilitator style and
21 techniques.
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31 Moreover, this research incorporated some aspects of inclusive research. A group of
32 eight women and seven men who met weekly at an independent self-advocacy agency were
33 involved as consultants. Group members helped to decide what topics should be covered in
34 the interviews. They corrected the researcher when words and phrases they considered to be
35 too complex were proposed and they critically examined the picture cards that were drafted to
36 accompany question categories. Self-advocates also helped to write and produce three risk
37 perception vignettes, as discussed in the section on 'concrete prompts and props'. Before
38 fieldwork commenced, the final questionnaire was piloted with three volunteers from the
39 group. The research advisors helped to recruit some of the participants and they were then
40 again involved at the data analysis stage.
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48 The narrative accounts of adults with intellectual disability were used as the main
49 source of information in this study. Semi-structured interviews were conducted with twelve
50 men and 17 women in the north of England. Respondents were between 22 and 68 years old
51 and labelled with 'mild' to 'moderate' intellectual disability. Here, 'intellectual disability'
52 describes a person who has an IQ below 70 and social and adaptive difficulties, with onset
53 before adulthood (World Health Organisation, 2010). About half of the respondents lived
54 with their parents or other family members. About a quarter lived in residential group settings
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3 and another quarter lived independently. They were accessed at two day centres and two
4 advocacy services, where participant observations were furthermore conducted. Due to the
5 method chosen, one presumption for inclusion in the sample had to be the presence of some
6 expressive language.
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10 Researchers may at times shy away from broaching sensitive issues with populations
11 who are considered 'vulnerable', due to concerns about complications in receiving ethical
12 permission. Such difficulties are as vividly illustrated by Hays *et al.*'s (2003). This researcher
13 had a very different experience when applying for access through two local authorities, who
14 processed the application jointly. The process of seeking ethical approval was completed in
15 about two months. As part of the resulting research agreement a link person within each local
16 authority was named. The researcher was obliged to contact them if actual or suspected
17 violence was disclosed during the course of the research. In addition, the researcher was
18 required to obtain an enhanced Criminal Record Bureau check (HMSO, 2000).
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27 ***Achieving successful interviews***

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30 Researchers who work with less articulate subjects are advised to get to know respondents
31 prior to the interview (Arksey & Knight, 1999). In this research most respondents were met
32 several times during participant observations at day centres and advocacy groups. This
33 contributed to the researcher becoming acquainted with part of respondent's daily routine, as
34 well as with ways in which they communicate. People with intellectual disability might not be
35 able to concentrate for lengthy periods. To make interviews less demanding, these were
36 stopped when the respondents became tired of talking. Most interviews were conducted in
37 two parts, each normally lasting between 30 and 60 minutes.
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44 Interview parts were usually conducted in consecutive weeks, to ensure that as little
45 time as possible elapsed between meetings, because individuals might otherwise forget about
46 the project (The Learning Difficulties Research Team, with Bewley, & McCulloch, 2006).
47 The first session was usually transcribed prior to commencing the second one. This helped to
48 identify any communication difficulties. Questions that arose from the dialogue could be
49 address in the second meeting. It also meant that many non-verbal cues could still be recalled
50 by the researcher whilst transcribing.
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56 The remainder of this paper explores in detail how successful interviews were
57 achieved by using adapted and flexible techniques. The discussion is divided into four main
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sections: a description of how depth of questioning was adjusted for each respondent, an introduction to some tools that can 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.

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3 R2 is able to provide a rationale for the restriction. She also expresses a *preference* in the last
4 line of the exchange. However, she does not express a full *opinion*. This would make further
5 sense of the advantages and disadvantages of the rule at hand.
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8 R3 was one of the most articulate respondents. Four years prior to the interview, she
9 had moved from sheltered accommodation to a residential home with 24h staff support.
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13 I: Do you like living in the home?

14 R3: No.

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16 I: Why not?

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18 R3: It weren't that, it's not the right place for me. I'm too independent [...] Before I
19 came into [area] I did all my cooking and everything myself, but now I'm in
20 [area] I can't do me own cooking, I can't do a bit of anything I need to do
21 independently. [...] All me independent skills have gone out of the window.
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26 The second line of this exchange provides limited information. Here, R3 stated a *preference*,
27 but she then goes on to describe a fully rationalised opinion. It would have been a shame not
28 to prompt further and not to allow R3 to express her views. On the other hand, it would have
29 been at best intimidating to insist that respondents like R1 provide such detailed reflections.
30 At worst, this can introduce interview errors, as discussed later on. Moreover, it would have
31 been a loss to disregard R1's and R2's interesting and insightful accounts as comparatively
32 'incomplete'.
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41 **Creating a concrete frame of reference**

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44 People with intellectual disability are more likely to use a concrete, rather than an abstract
45 frame of reference (Booth & Booth, 1994). Metaphors and similarly ambiguous expressions
46 should be avoided, to accommodate those who possess a literal rather than a figurative mode
47 of expression. For instance, questions that enquire how a person thinks others view them
48 involve a complex level of social understanding. Informants would have to infer the internal
49 emotions, attitudes or beliefs of another person from their behaviour (Finlay & Lyons, 2001).
50 This is an extremely difficult task for some. The question: 'What do others like about you?'
51 did not return any answers at the pilot stage. Such socially reflexive questions were
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3 consequently removed from the interview guide. Questions should furthermore be relevant to
4 respondent's experiences, relatively direct and specific and concentrate on one point at a time.
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6 The fact that questions about time and frequency are best avoided or when they are
7 essential replaced by reference points that are more relevant to the individual was already
8 explained in the introduction. During the course of this study there was only one situation
9 when information about time was crucial: R4 stated that she has been 'bullied' by her father.
10 The way in which she spoke could have suggested that this was still ongoing. In that case R4
11 and the researcher would have needed to explore how she could be supported to prevent
12 further incidents. R4 however had little concept of time. It was hard to understand when
13 exactly events have taken place. After suggesting a number of reference points it was
14 eventually established that the 'bullying' went on while R4 was at school. That means that
15 this must have stopped at least ten years prior to the interview.
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24 25 26 **Concrete reference tools**

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28 Concrete reference tools can help to make conversations more tangible, thus enabling those
29 who find abstract thought difficult. They can also help to make interviews more accessible for
30 less articulate respondents, as they can provide prompts and words. In this study, picture
31 cards accompanied all of the question categories. These were put together using images from
32 CHANGE (2016) *General and Health Picture Banks*, *Photosymbols Ltd* (2016), *Valuing*
33 *People Clip Art* (Inspired Services Publishing, 2016) and the sex education package *Sex and*
34 *the 3 R's* (McCarthy & Thompson, 1998). There were altogether 36 picture cards for 23
35 question categories.
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42 For example, line drawings from *Sex and the 3 R's* were used to discuss body parts. A
43 laminated A4 card with 14 colourful pictures displaying a range of activities or settings was
44 used for discussions about leisure activities. These included walking a dog, playing a board
45 game, watching TV, dancing, listening to music, drinking in a pub, reading a paper, a picnic,
46 playing basketball, a theatre, a beach, a paint set, horse riding and shopping. Even though this
47 did not present an infinite list of options, pictures provided some basic prompts.
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52 Respondent's use of the picture cards varied. Some barely noticed them, but others
53 relied heavily on the pictures as reference points. They would work their way through them to
54 talk about a subject. R5, for example, looked at the pictures, pointed at them and stated: 'Like
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3 that ... don't like that.' She seemed to find it hard to think of words and concepts when
4 unsupported, but the inclusion of pictures facilitated communication.
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8 9 **Photo story vignettes**

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

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37 The first two stories featured an incident of unsought touch and implied a risk of
38 further intrusions. The third one was a case study about 'stranger-danger'. Respondents were
39 asked to advise the individual who had been approached by the other actor what they should
40 do by the end of each vignette. The vignettes prompted many respondents to reflect on
41 potentially unsafe situations they encountered in their own lives, as evident in R2's response:
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46 I: What should Jill do?
47 R2: Tell him to stop it.
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49 I: Is there anything else she could do?
50 R2: *(mumbles)* Hit him across face.
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52 I: Sorry?
53 R2: Hit him across face. I did it once. A lad tried to get hold of my boobs,
54 so I kicked him.
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3 Nonetheless, R1 and R6 found the vignettes difficult and were unable to imagine what would
4 happen next and to articulate an elaborate response. One of R1's answer is discussed in the
5 next section. Below, it initially appears that R6 articulates a preference:
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10 I: What should Jill do?
11 R6: It's... very bad, that.
12 I: Mmh. Why is that?
13 R6: I don't know.
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18 The 'why' question proves to be too difficult for R6. As R6 has taken little ownership of the
19 preference he articulated, it is less clear whether this is his own view or what he assumes to
20 be the 'correct' response the interviewer wants to hear. These uncertainties resulted in this
21 exchange being excluded from the final data set.
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24 So far it was shown that working individually with the respondent and adjusting
25 expectations in line with what they want to or can offer, as well as further enabling
26 communication by using concrete reference tools, can help to facilitate effective dialogue.
27 The focus was on interviewer techniques. The next section will initially pick up three
28 concepts, which focus on the respondent.
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36 **A new look at acquiescence, unresponsiveness and recency**

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

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54 The first concept, acquiescence, also referred to as 'yeah-saying', describes a bias towards
55 affirmative responses (Sigelman et al., 1981). Supposed causes include a person's intellectual
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3 disability per se, but also the fact that so many aspects of their lives are controlled by others
4 that many people with intellectual disability become socialised into compliance (Stalker,
5 1998). To counter these claims, Rapley and Antaki (1996, p. 219) maintain that the literature
6 that substantiates the 'acquiescence' phenomenon does so 'in the absence of detailed
7 transcripts of the interactions between interviewers and interviewees'. They argue that this
8 phenomenon lacks coherent evidence and also demonstrate that people with intellectual
9 disability are capable of *anti-acquiescence*. Antaki et al. (2015) highlight such incidents even
10 during police interviews. This study found similar occurrences of respondents disagreeing
11 with or challenging what the interviewer has suggested.

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

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25 I: Are you happy **with that**?

26 R7: I am quite happy, yeh...

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28 I: Or would you rather pick your own clothes?

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30 R7: I'd rather pick me own.
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33 This could be interpreted as acquiescence. R7 agrees with both statements suggested by the
34 interviewer, thus contradicting himself. However, a closer look at the transcript suggests at
35 least one alternative explanation. Finlay and Lyons (2001) warn that *modifiers and negatively*
36 *worded questions* should be avoided in interviews with people with intellectual disability. A
37 modifier can be a single word or clause that changes the sense of a question. In this example
38 it is possible that the first question was phrased in an ambiguous format. The sense of the
39 entire question changes if 'with that' was erased from the first line. Respondent and
40 interviewer may not be talking about the same issue. From his response, there is no indication
41 that R7 has picked up on the meaning of the modified question. All he says is that he is 'quite
42 happy'.
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49 Questions were therefore rephrased into less ambiguous formats for the main
50 interviews. As negatively worded questions can also mislead, these were substituted for
51 unmistakably negative expressions, for example, asking: 'Do you **hate** broccoli?' instead of:
52 'Do you **not like** broccoli?' Talking like this felt strange, as this is a rather harsh way of
53 referring to broccoli, which the interviewer was not used to, as they tend not to express food
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3 preferences in such extreme terms. Nonetheless, it was deemed more appropriate to ask clear
4 questions than to be pedantic about all of the possible nuances of discourse.
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6 The following exchange is a further example in which a respondent looks to be
7 contradicting himself when he goes along with suggestions made by the interviewer. It
8 describes R1's response to a vignette:
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13 I: What should Frank do?

14 R1: Don't know.

15 I: You don't know?

16 R1: No.

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

18 R1: Yeah.

19 I: Or should he not go?

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

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44 The extracts presented thus far support Finlay and Lyons's (2002) claim that communication
45 difficulties that initially appear to be caused by 'acquiescence' may be caused by
46 inappropriate questioning. A similar assertion can be applied to 'unresponsiveness'. Booth
47 and Booth (1994) remind us that some people with intellectual disability have a responsive
48 rather than a proactive communication style and an instrumental rather than an expressive
49 vocabulary. They therefore require persistent prompts to tell their stories. However, there is
50 also a risk of mis-attributing a person's silence to their impairment. At times, respondents
51 may simply be *unwilling* to participate or to elaborate, rather than *unable* to do so (Lesseliers,
52 Van Hove, & Vandeveldde, 2009). For instance, R8 seemed nervous when he was asked
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3 questions about sex. His communication style and body language changed: He moved into the
4 furthest corner of his seat, away from the interviewer, slouched, started fidgeting and gave
5 monosyllable responses, whereas before he had answered in short sentences. The interview
6 was thus brought to an end, as R8's mostly non-verbal cues were interpreted as signs for his
7 embarrassment by this line of questioning.
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11 For those respondents who are genuinely less articulate, Booth and Booth (1996)
12 demonstrate that the exclusive use of closed-ended questioning can be useful. While this
13 research did not solely rely on this question type, closed-ended questioning was increased for
14 less expressive respondents. Many questions in the interviewing schedule included options
15 for phrasing them in either an open-ended or closed-ended format. To provide an example,
16 the following extract demonstrates how R9 worked her way through multiple-choices answer
17 alternatives to an open-ended question about appropriate behaviour in a sexual relationship.
18 Note that R9's responses were loud and immediate. The first four responses were
19 accompanied by what could be interpreted as enthusiastic nodding. R9's facial expressions
20 changed by her fifth response. She stopped smiling and nodding.
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- 29 I: Do you think that it's okay to hold hands-
30 R9: -YEAH. YEAH.- [...]
31
32 I: Do you think spending time together is a good thing?
33 R9: YEAH. YEAH.
34
35 I: Do you think people can cuddle?
36 R9: YEAH. YEAH. [...]
37
38 I: Is it okay to kiss?
39 R9: YEAH. YEAH. [...]
40
41 I: Do you think if two people love each other they can have sex?
42 R9: NO. I can't. (*Stifled laugh*)
43
44 I: You can't?
45 R9: No.
46
47 I: Why not?
48 R9: No. I don't want to.
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55 This is an example of a successful dialogue. Instead of leaving the question open, which R9
56 found difficult to respond to, the following multiple choice question was posed, broken down
57 into multiple yes/no questions:
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5 How can you show your boyfriend that you love him? [Choose as many as apply.]
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- 7 a) hold hands;
8 b) spend time together;
9 c) cuddle;
10 d) kiss;
11 e) have sex.
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16 The yes/no format in the exchange with R9 was used to avoid a questioning error that could
17 have given rise to recency. This concept refers to respondents always picking the last option
18 from a list of multiple-choice question alternatives (Sigelman et al., 1981). Finlay and Lyons
19 (2001) explain why recency may occur. When literate respondents are asked multiple-choice
20 questions, these are usually presented in written format, which limits recency. The fact that
21 such questions are typically posed orally in research with participants with limited literacy
22 demands a high memory load of respondents and recency should therefore not come as a
23 surprise. It is likely that R9 would have forgotten answer alternatives that were listed earlier
24 on, had the question not been broken down as demonstrated. Yet, Sigelman et al. (1981)
25 further suggest that the yes/no question format used instead introduces an increased risk of
26 'acquiescence'. In the extract cited earlier R9 could indeed be suspected to be acquiescing at
27 first. What speaks against this is the fact that her affirmative responses were very keen: She
28 laughed and spoke loudly, which indicated that she genuinely meant to say 'yes'. She also
29 eventually said 'no' firmly when she meant it, accompanied by a significant change in her
30 non-verbal communication.
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41 Whenever it was not clear whether respondents had systematically picked the last
42 option of two alternatives, this was checked by rephrasing the question and by changing the
43 order of response alternatives, as suggested by McCarthy (1999). Furthermore, short
44 responses were checked by probing respondents to give more detail (Finlay & Lyons, 2001).
45 Responses were then closely examined during data processing. Data arising from a participant
46 merely answering 'yes' or 'no' or picking an option from a list was generally discharged,
47 unless it was supported by further qualitative evidence. This could sometimes be non-verbal
48 cues, like R9's smiles, laughs and nodding. The fact that unsubstantiated data was removed
49 before analysis increased the reliability of the data that was retained. This meant that some
50 data from at times less expressive respondents, like R1, R6 and R8, was retained, which was
51 preferred to disregarding a person's whole account.
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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

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3 come back for a while'. Each time it is reported that other customers have been
4 hostile towards R5; her social worker will instruct support staff that R5 should no
5 longer be supported to visit that particular club.
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10 At times, some researchers may refer to the accounts of more articulate subjects, in order to
11 verify another person's account (e.g. Courtney, Rose, & Mason, 2006). Conversely, due to its
12 alignment with the social model, this study referred to the accounts of others only to
13 contextualise what people with intellectual disability were saying. Caldwell (2014) confirms
14 that supplementing data gained from interviews with people with intellectual disability in this
15 way, using others as secondary confirmatory sources, is now a widely used approach.
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19 R5's account appears to verify the staff's, whereas the staff's description of an
20 ongoing adult protection intervention can help to contextualise what R5 was trying to make
21 sense of. However, at the data analysis stage, there was no shift towards the key worker's
22 version of events. For instance, R5's behaviour was not labelled as 'inappropriate'. The focus
23 remained on aiming to understand R5's perspective, i.e. that R5 did not fully understand what
24 was going on, found this restrictive and felt that she was being stopped from seeing 'friends'.
25 The advantage for the researcher was that they now had a clearer understanding of the context
26 that made R5 feel that way.
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36 Referring to field observations

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38 The final case study demonstrates how it was possible to string together enough evidence to
39 support R1's account of his views on sexuality with reference to his own narrative, participant
40 observations and also a comparison to the interview with his 'boyfriend'.
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45 I: Have you got a girlfriend or a boyfriend?

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

47 I: Sorry?

48 R1: Not at home. Here.

49 I: [...] Who is that?

50 R1: Eh.. [R10]

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

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

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

21 I: [...] Why is that?

22 R1: Get into bother.

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

24 R1: [day centre manager].
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31 As discussed earlier, some of R1's responses, such as his answers to the risk perception
32 vignettes, had to be discharged from the data set, as they seemed to entail interview errors.
33 Here is an example that shows that he was nonetheless still able to express some of his
34 experiences. Triangulation with other sources helped to clarify and add more substance to
35 what he was saying: R1 feels that he has to keep his sexuality secret, even from his
36 'boyfriend', due to fears of 'getting into bother'. The implication is that this happened before,
37 which opens a whole new line of questioning. Going into detail with this would be beyond the
38 scope of this paper. What is of interest is that R1 did indeed have some experiences to share,
39 which were highly relevant for this project. Simply discharging all of the data from R1's
40 interviews, due to errors occurring in parts, would have silenced his already marginalised
41 voice.
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49 Nonetheless, respondents like R1 highlight that, no matter how much effort is made to
50 enhance accessibility, the choice of the interview method will disadvantage or exclude
51 entirely the least articulate subjects. In the field of disability studies this includes those with
52 multiple and profound intellectual disability. For such groups, adapting a range of more
53 interactive qualitative methods, including for example, graphic facilitation (e.g. Chapman,
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3 2014) and drama (e.g. Garbutt, 2009), would be more suitable. A discussion of such methods
4 is however beyond the scope of this paper.
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8 ***Discussion***

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12 This paper has shown that successful dialogue with people with intellectual disability can be
13 achieved by adapting interview content and style to suit the communication preferences of
14 each individual in this highly diverse population. Taking the time to get to know respondents
15 prior to the interview will pay off, as this will give researchers a better idea of the adaptations
16 that may be required. One such alteration may be to adjust the depth of questioning, in order
17 to work with the response styles of the participants.
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22 Keeping the interviews too basic, in order to ensure that even the least responsive
23 participant can answer all the questions would be a shame, as the accounts of those who have
24 more to say on a particular topic would be lost. The more articulate respondents may also be
25 at risk of feeling patronised if questions are kept too simplistic. Prompting beyond what a less
26 articulate respondent has offered can also have negative effects, as this can introduce
27 interview errors. In other words, getting the balancing act of prompting for more or less detail
28 right for each respondent will enhance the quality of data obtained.
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33 This researcher found the use of concrete reference tools particularly useful. These
34 can help to make conversations more tangible, thus enabling those who find abstract thought
35 difficult. They can provide words to less articulate respondents and enable them to have some
36 control in selecting what to discuss. In research about sensitive issues the discussion of
37 vignettes can take the focus away from the potentially embarrassed respondent. In this study
38 vignettes have also helped respondents to make sense of an abstract concept. Yet, as with all
39 aspects of the methods discussed, 'one size did not fit all' and two of 29 respondents did not
40 find the vignettes helpful, necessitating the use of alternative methods.
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45 One such technique discussed was triangulation. Here, this refers to the use of
46 secondary confirmatory sources to contextualise what respondents were discussing, as well as
47 drawing on information from other aspects of the research, such as participant observations. It
48 was explained that drawing on such supporting accounts should not act to discredit what the
49 person with intellectual disability is saying. This method is merely used on occasions where a
50 little help is needed to contextualise issues that may not make full sense to the person
51 themselves.
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3 Finally, this paper offered a new look at acquiescence, unresponsiveness and recency.
4 These concepts have in the past been used to blame respondents for 'lacking skills' needed to
5 communicate effectively. However, the arguments presented here point to errors in question
6 phrasing and suggest that it might be the facilitator who should examine whether they have
7 the skills needed to accommodate successful dialogue. For instance, a researcher's awareness
8 that modifiers and negatively worded questions may alter the sense of a question should
9 encourage them to phrase less ambiguous questions.
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17 ***Conclusion***

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20 The label 'people with intellectual disability' brings together individuals with a vast range of
21 communication styles and preferences. Researchers who wish to get the most out of such
22 respondents should approach fieldwork from the stance that people with intellectual disability
23 can speak for themselves and that it is the researcher's task to facilitate this process, rather
24 than focussing on what a respondent may not be able to do. Some of the information in this
25 paper may help to rule out techniques which are more likely to fail, but this does not mean
26 that doing the exact opposite will be enough. In fact, it has become apparent that removing
27 one predicament (such as risk of 'recency') can often introduce another (such as risk of
28 'acquiescence').
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36 Many of the issues discussed in this paper will be of help in research with other
37 intimidated or less articulate respondent groups. For instance, children, people who have
38 difficulties expressing themselves in the language in which the interview is being held or
39 people with dementia may benefit from the use of concrete reference tools to assist their
40 communication. Triangulation can be helpful with respondents who cannot make full sense of
41 a situation they find themselves in. Flexibility in responding to communication preferences
42 and the ability to adjust expectations in line with what a respondent has to offer will be useful
43 in interviews with most groups. For instance, a businessman may only have a short amount of
44 time to engage in an interview and may refrain from giving lengthy responses.
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51 But overall the most important general points to take away from this paper are that
52 interviewers will be able to get the best out of their respondents if they are willing to adopt a
53 flexible approach to interviewing, to get to know how each respondent best communicates,
54 respect what they have to offer and have faith in their ability to give the most accurate and
55 meaningful account of their own subjectivity.
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For Peer Review

Index of transcription signs

<i>(italics)</i>	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.

1
2
3 **Appendix - Figure 1: Sample vignette***
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6 **John and Jill are good friends. They work together.**



17 Here are John and Jill. They
18 work together in an office.
19



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



42 John makes Jill laugh.



55 One day Jill makes a cup of
56 tea.



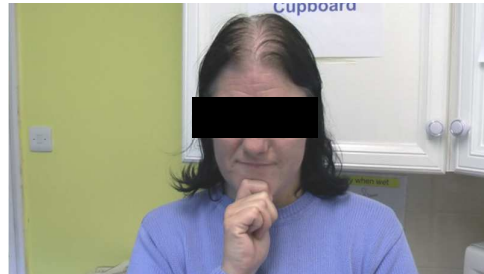
John comes up behind Jill. He
puts his arm around her waist.
He pulls her close.



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.