# Facilitating qualitative research interviews for respondents with intellectual disability

Hanne Marie Høybråten Sigstad<sup>a\*</sup>, and Veerle Garrels<sup>a</sup>,

<sup>a</sup> Department of Special Needs Education,

University of Oslo.

\*Corresponding author:

P. O. Box 1140 Blindern,

0318 Oslo,

Norway,

Tel: +4722858127

e-mail: h.m.h.sigstad@isp.uio.no

Keywords: Intellectual disability, qualitative research interviews, communication techniques,

methodological challenges

#### Abstract

Qualitative interviews form an efficient tool when wanting to access the subjective experiences of an individual. For respondents with intellectual disability, facilitation of the interview may be necessary to help them provide rich descriptions. In this article, the authors discuss several communication techniques from counselling practice (silence and encouraging prompts, rephrasing questions; repeating, paraphrasing and summarizing responses) as a means to improve the quality of the interviews. Examples to illustrate these techniques are provided. Further, possible threats to validity that may occur as a result of the facilitation are discussed, and ways to counter these threats are suggested.

#### Introduction

Intellectual disability (ID), characterized by impairment of cognitive and adaptive skills, is estimated to have a prevalence of 0.05 to 1.55 % (McKenzie et al. 2016). Depending on their level of cognitive impairment, persons with ID may experience communicative difficulties in terms of language comprehension, memory, ability in abstraction, understanding turn taking, and processing speed (Corby, Taggart, and Cousins 2015; Finlay and Antaki 2012). An inadequate linguistic comprehension may also imply an impaired ability in understanding long and complex grammar structures (Antaki 2013; Finlay and Lyons 2001, 2002). Further, difficulties formulating themselves may limit their ability to express themselves adequately in context and to provide relevant responses in a conversation (Finlay and Antaki 2012). These cognitive limitations and communicative difficulties may pose challenges during qualitative research interviews.

Whilst research interviews by nature may constitute an uneven power balance between researcher and respondent, this is often amplified if the respondent has ID, as the cognitive and

communicative impairment may influence their participation during the interview (Emerson et al. 2004; Heal and Sigelman 1995). Questions have been raised concerning the extent to which people with ID are able to provide rich descriptions in interview situations due to their cognitive and communicative limitations (Corby, Taggart, and Cousins 2015). Limited responses to interview questions may be either a result of inadequate expressive abilities or a lack of understanding and insight, and the exact cause may be difficult for the researcher to determine (Lloyd, Gatherer, and Kalsy 2006). Indeed, the cognitive and communicative difficulties that persons with ID face may pose methodological challenges in research interviews and this may threaten the validity and reliability of the research results (Hartley and MacLean 2006; Heal and Sigelman 1995; Sigelman et al. 1981; Sigstad 2014).

Whilst it is important to acknowledge that not all persons with ID will be able to provide valid descriptive accounts of their own experiences, thoughts and sentiments, we argue that it is desirable to include persons with ID in qualitative research especially because of three reasons. Firstly, when researchers want to investigate complex and subjective matters, as is often the case in qualitative research, self-reports may be more reliable sources of information than proxy reports (Cummins 2002). Even though information provided by parents or caregivers may have its own value in providing additional information and a different perspective, these proxy reports may have poor agreement with self-reports, and therefore, they are not considered valid substitutes for self-reports (Claes et al. 2012; Emerson, Felce, and Stancliffe 2013; Huus et al. 2015; Schmidt et al. 2010; Zimmerman and Endermann 2008). When wanting to assess a subjective experience, the principal source of information should be the person who is at the centre of this experience. In their systematic review of studies using phenomenological research

interviews with persons with ID, Corby, Taggart, and Cousins (2015) also emphasized the importance of giving persons with ID the opportunity to describe their own experiences.

Secondly, excluding persons with ID from research based on their cognitive impairment or communication disorders may violate the principle of non-maleficence. As stated in the Helsinki Declaration, ethical research shows respect for all human subjects, prevents harm and protects the health and rights of research participants (WMA 2013). However, in their efforts to protect persons with ID from possible harm, ethical boards may overestimate disability and underestimate the competence of persons with ID, and, in this way, create barriers that prevent their research participation (Brooker et al. 2015; Feldman et al. 2014). McDonald and Kidney (2012) argue that the exclusion of persons with ID from research studies may lead to certain interventions not being accessible to them, and key aspects of their lives may be left unexamined. As such, there may be a social injustice and possible harm in excluding persons with ID from research participation (Feldman et al. 2014). Whilst the protection of vulnerable groups from exploitation in research studies is imperative, Northway (2014) makes a strong point when stating that this vulnerability is not a consequence of having ID itself, but rather that it occurs when others fail to acknowledge their right to autonomy and freedom from harm. Additionally, the ability or inability to respond for oneself is not a fixed trait, but it will instead depend on context, maturation, topic, accommodation, etc. (Claes et al. 2012). The need to include persons with disabilities in research is further expressed in the UN Convention on the Rights of Persons with Disabilities, §31, which encourages the collection of research data on persons with disabilities to identify and address barriers they may face in exercising their rights (UN 2006). Unfortunately, individuals with intellectual disability remain a segregated group in society, and research may play an important role in their inclusion.

Thirdly, persons with ID want to have their voices heard. McDonald, Kidney, and Patka (2013) found that persons with ID want to participate in research when they are given the chance in order to make a difference. Many adults with ID show a strong sense of civic interest and altruism, and they may be motivated by the opportunity to help others with ID. Participating in research can make them feel valued members of the community, and they may appreciate being given the chance to contribute (McDonald, Conroy, and Olick 2016).

Thus, despite certain challenges and barriers due to cognitive and communicative impairments in persons with ID, there is ample reason for researchers to aim to include persons with ID in their studies. Qualitative research interviews may prove to be especially useful for empowering participants with ID (Walmsley and Johnson 2003). However, the inclusion of respondents with ID and communicative challenges in research interviews demands a number of careful considerations. Several previous research studies have pointed to essential methodological challenges regarding interviews with respondents with ID. Sigstad (2014) addressed challenges related to the obtaining of voluntary informed consent and the conducting of interviews with informants with ID, and how the researcher may deal with such issues. In particular, the article focused on specific issues concerning acquiescence and inconstancies. Finlay and Lyons (2001) further discussed threats to validity in interviews and self-report questionnaires for persons with ID. In a systematic review of 28 qualitative research studies that used interviews with persons with ID as a means of data collection, Corby, Taggart, and Cousins (2015) found that many of the researchers made significant attempts to maximize the success of the interviews, e.g. by spending sufficient time building rapport, using clear and simple vocabulary, using picture support, etc. Strategies such as expansion, modification of content and format, the use of preliminary questions and the use of physical prompts also contributed to more adequate responses from the

respondents. It has also been demonstrated how good facilitation and supplementary questioning techniques may contribute to overcome some of the challenges and produce increased participation of the informants (Antaki 2013; Finlay and Antaki 2012).

Essentially, these studies have displayed useful examples of alternative approaches to help strengthen the communication between the interviewer and the respondents. A willingness to adapt the ordinary methods that are traditionally used in this kind of research may be a prerequisite to bring out the uniqueness of each individual's descriptions, and a less structured approach to the data collection is recommended. A more flexible approach may have the potential to bring out important aspects of experiences that are of particular importance for people with ID.

# Aim of the article

Whilst much of the previous research literature focuses on issues such as ethical considerations, rapport-building with the informants, the use of augmentative and alternative communication, and flexible approaches to functional adaptations of the interview guide to improve communication, less attention has been given to how appropriate communication techniques may enhance the interviewer's communicative competence, and how this may strengthen the conversation more directly.

In the present article, the authors aim to present suggestions as to *how* researchers can facilitate communication between interviewer and respondents, in order to help respondents with ID provide rich descriptions that present their points of view in the best possible way. For this purpose, our focus is on three specific communication techniques from counselling practice; 1) *silence and encouraging prompts*, 2) *rephrasing questions*, and 3) *repeating, paraphrasing and summarizing responses*. Based on this presentation, the authors also discuss different ways in

which such an approach to interviews may help strengthen or weaken the validity of the results that emerge. This article has a particular focus on suitable communication techniques, without including use of additional means, such as augmentative communication techniques. However, we add that this kind of interviews presupposes such supplementary techniques to succeed in obtaining valid descriptions. Because of the diversity that exists in the population of persons with ID, the emphasis of this article is on adolescents and adults with mild intellectual disability. Mild intellectual disability is defined according to the International Statistical Classification of Diseases and Related Health Problems, 10<sup>th</sup> revision (WHO 2016).

This article is based on the authors' own studies with individuals with ID (Sigstad 2017; Garrels forthcoming), in which the objective has been to achieve good quality communication between researcher and respondents, and also to ensure the most complete descriptions from the respondents as possible. Examples from specific calls in our own research are referred in order to illustrate the choice of appropriate strategies during the interviews.

Whilst this article focuses on the inclusion of respondents with ID, the authors assume that the described communication techniques may also be of use for conducting interviews for other target groups, such as individuals with language impairments, mental health problems, or individuals with minority background.

# Communication techniques suitable for enhancing conversation

Due to cognitive limitations and communicative difficulties, people with ID may have difficulties in conversation, which can pose challenges in qualitative interviews. With the intention of ensuring the most complete descriptions from the respondents, a more flexible approach to data collection is suggested (Corby, Taggart, and Cousins 2015). In this context, the authors present and illustrate three different communication techniques derived from counselling practices (Conte 2009; Egan 2014; Lassen 2014), that may be appropriate in interview situations with respondents with ID: i) silence and encouraging prompts, ii) rephrasing questions, and iii) repeating, paraphrasing and summarizing responses.

## Silence and encouraging prompts

Most persons with ID experience communication difficulties due to limitations in verbal comprehension and working memory (Corby, Taggart, and Cousins 2015; Finlay and Antaki 2012). In interview situations, there may be a longer latency between the interview question and the answer provided by the respondent, as the respondent may need extra time to process the question and formulate an appropriate answer. For the interviewer, it may be difficult to know whether this latency occurs because of a slower processing pace, or whether it is due to a lack of understanding of the interview question. In case of slow processing pace, repeating or rephrasing the question may interrupt the respondents thought process, and it may hamper the formulation of an adequate answer (Carr and O'Reilly 2016; Sigstad 2014). Thus, this type of interview requires a high level of sensitivity to the respondents (Antaki 2013). In preparing for the interview, it is important that the interviewer formulates the interview questions as straightforward as possible, to maximize the likelihood that the respondent gets a clear understanding of the interview questions. The language of the interview questions should be sufficiently simple, so that the respondent knows how he/she can respond (Finlay and Lyons 2002). Persons with ID are better able to understand phrases with simple sentence structure, and with terms linked to specific conditions or concrete objects (Finlay and Lyons 2001). Similarly, questions that require abstractions may be mostly unsuited for this kind of interview (Caldwell 2014). A functional facilitation of the interview should thus include simple and concrete questions, as this may

improve the overall quality of the interview. When these precautions are taken, it may be more likely that the respondent's response latency stems not from comprehension difficulties, but rather from a slower information processing pace. Then, it is important for the interviewer to adjust the time frame of the interview, so that the respondent gets sufficient time to respond in an appropriate manner (Lloyd, Gatherer, and Kalsy 2006). Hence, the interviewer should dare to allow silences during the interview, by posting pauses after each question to let the respondent think about what has been asked and to let him or her formulate an answer. This silence provides the respondents with time to think and to process the situation (Conte 2009). Encouraging verbal and nonverbal probes, such as small interjections (e.g. 'hm') or simple nods, may signal to the respondent that it is okay to take time to think before providing an answer (Rogers 1990). In the following example, taken from a goal-setting intervention for students with mild intellectual disability (Garrels forthcoming), it is illustrated how the interviewer's (I) silences and encouraging probes are used actively to give the student (S) sufficient time to think, so that an adequate answer can be formulated:

I: Is there any particular goal that you would like to work on during the next couple of weeks?I: (*pause; nonverbal probes: eye contact, smiling and nodding*)

S: (*silent*)

S: Hm, I'm thinking.

I: That's okay, we've got plenty of time.

S: (silent, thinking)

S: Actually, I would like to learn some English, because I have a friend in England. Maybe start with numbers or something.

In this example, the interviewer provides a small pause after the question, in order to give the respondent time to think. To make the silence more comfortable, the interviewer uses nonverbal communication such as a friendly smile, encouraging eye contact, and a nod with the head. This nonverbal communication provides a reassuring atmosphere for the interview, and the respondent experiences that there is time to think. When given this additional time, the respondent is clearly able to formulate an adequate answer.

# **Rephrasing questions**

Whilst silence and encouraging prompts are useful techniques to gain more elaborate responses from the respondent, it may sometimes still be necessary to rephrase the question, possibly expand the question, or ask the same question more specifically during the course of the interview (Finlay and Antaki 2012). By rephrasing the question, the respondent is allowed to hear the same question again with a different wording, which may help in understanding what is being asked for. More expansion of the question includes not explicit information in the original question. An expansion of the question may be about establishing a clearer link between the question and a concrete context (Finlay and Antaki 2012). A description of the context may thus contribute to a better understanding of the content of the question. The following example from a friendship study (Sigstad 2017) demonstrates how expansion of the question contributes to a deepening and better understanding of the student's perspective:

I: Do you know what a secret is?

S: Yes.

I: What is a secret?

S: A secret is something you can do with friends.

I: It is something you can do with your friends? (repetition of the response)

S: Yes.

I: Can you tell Isabella a secret? (a clearer link to the context)

S: What?

I: Can you tell Isabella something that you want her to keep a secret? (*rephrasing of the question with some expanding*)

S: I don't want to do that.

I: You don't want to tell her secrets?

S: Then Sue will know.

I: Sue will know if Isabella knows?

S: Yes, if Sue is listening.

The call above exemplifies how the expanding of the question contributes to a fuller response from the student.

Similarly, a more specific question may provide a clarification for the respondent. Changing of question-formats may be another useful strategy to succeed in getting responses. The following example from Sigstad's (2017) friendship study demonstrates how an open-ended question was made easier to respond to by changing it into a single alternative yes/no – question (Finlay and Antaki 2012):

I: But, if you're not friends anymore, what is stupid if you fall out with each other?

S: Then we argue.

I: Yes, what do you argue about? (open question)

S: There are slightly different things.

I: Yes.

I: You disagree? (changing open question into yes/no-format)

S: Yes.

The conversation above is also a demonstration of how more specific questions may contribute to an elaboration of the theme; a more defined question serves as a further follow-up of the original question.

Respondents with ID may typically provide relatively short answers, which makes it especially important for the interviewer to follow up with more specific questions, so that richer answers can be obtained (Finlay and Antaki 2012). This also becomes clear from the following example from a goal-setting intervention (Garrels forthcoming):

I: Usually it is the teacher who sets goals for the students, but this time it was you who got to do so. How did you feel about that?

S: Nice!

I: Nice, what was nice about it? (more specific question)

S: That I could choose my own goal.

I: Hm, was that kind of important to you, to be able to choose your own goal? (*more specific question*)

S: Yes.

## I: Why was that? (more specific question)

S: Because then I can say which goal I want to work on, and I can avoid these boring goals that the teacher chooses.

In this example, the continuous asking of more specific questions helps the respondent to express a more thorough answer that gets to the core of the topic. Each time, the respondent's answer is used to formulate a new and more specific question, which helps the respondent to reveal more personal thoughts.

# Repeating, paraphrasing and summarizing responses

During the course of an interview, it may be useful for both interviewer and respondent to repeat, paraphrase and summarize what the respondent has said. Repetition is known from counselling practice as a way of responding to the clients' descriptions (Egan 2014; Lassen 2014). In a counselling context, repetition is used as a technique for reflecting on the responses. The repetition becomes a further support in the conversation; by repeating the response of the clients, he/she gets an opportunity to hear own responses, then reflect about these responses, give a correction, and possibly complement the answer. In the same manner, repetition may be a useful technique in a qualitative interview.

In a qualitative interview study among students (S) with intellectual disability (Sigstad 2017), repetition had such a function in a call concerning a football competition:

S: Sometimes he wins, and sometimes I win.

I: Hm.

S: Yes.

I: How would you feel if he wins?

S: Eh, I don't know.

I: But, if you win?

S: That's good.

I: That's good? (repetition of the response)

S: It's no big deal if you lose.

I: It's no big deal? (repetition of the response)

S: Everyone loses.

A conversation technique that is closely related to repetition is paraphrasing. Paraphrasing is used as a suitable strategy for reflecting the client's own themes in counselling practice, to make the client aware of the main theme of what he/she communicates (Egan 2014; Lassen 2014). The counsellor's reflective act functions as a way of clarifying the main themes in the client's descriptions, and at the same time it provides the client with feedback on how the counsellor interprets the client's statements. The purpose of paraphrasing the interviewees' statements may resemble the aim of repetition. Based on the respondent's answer, the interviewer attempts to formulate the responses in other words (Lassen 2014). To reframe what the respondents say, the interviewer has to reflect what the respondents say in a different way from how the respondents presented it (Conte 2009). Thus, the respondents receive feedback on their own responses, they listen to the interpretation, and they get opportunities to make corrections and complement their statements. However, if such paraphrasing is to have an actual value, the interviewer needs to be aware of the way in which this is done; the responses of the interviewer need to be reproduced in short sentences with a simple language. In the following example (Sigstad 2017), the interviewer

makes use of some minimal responses and paraphrasing, which contributes to more elaboration and clarification of the respondents' statements:

I: When you are together with Allan and Roy, what do you like to do?

S: We like to walk together and things like that, we also really like, and sometimes we go to the woods.

I: Do you?

S: Yes.

I: What do you do in the woods then?

S: What we like is to chop and push down trees and so on.

I: Oh yes?

S: I'm not involved.

I: Okay, you do not like to join them? (paraphrasing, reflective response)

S. Yes, I like to be with them, but I prefer to watch. (clarification)

This way of providing reflective responses may thus be relevant in an interview context. When we spend time and resources on qualitative interviews with informants with ID, it is precisely to give the respondents an experience that their contributions are of value to us who are listening (Finlay and Lyons 2002; McDonald, Conroy, and Olick 2016). Such an emphatic understanding requires sensitivity to the respondent in the here and now (Rogers 1990). By reflecting the respondents' responses, we show that we are listening actively, and that we are interested in obtaining the content of their descriptions, which may help them further to provide even more detail than they have already done. Reflection by paraphrasing may start with: 'I hear you say that ...', 'You mean that ...', 'You feel that ...', which is then followed by the statements the respondents used. The interviewer reflects what has been said by repeating the content in other words. The reflection process often provides a clarity that is effective for gaining a deeper understanding of the respondent's experiences and thoughts (Kokkersvold and Mjelve 2003).

In the following example from a goal-setting intervention (Garrels forthcoming), paraphrasing is used to clarify a response from the respondent and to avoid misunderstandings when the respondent experiences difficulties in expressing herself:

I: Was there anything you thought was difficult about choosing your own goals?

S: I thought it was a bit difficult, yes, to figure out which goal I wanted to set.

I: Yes. What was it that made it kind of difficult?

S: Well, it was that, eh... what am I actually able to do, that I want to learn what is hard and that I cannot do [sic].

I: Hm, yes. So, do you mean that it was a bit scary to set a goal for something that you hadn't learned yet? (*paraphrasing*)

S: Yes. (clarifying, confirming)

In a similar way, summaries of the respondent's answers may function as a reflection and feedback to the respondents (Egan 2014; Lassen 2014). Such kind of summaries may function as abstracts of previous given statements in the responses (Conte 2009). Along the way, the interviewer provides short summaries as feedback to the respondent. The summaries help to focus on the topic of the conversation and provide assistance in structuring the conversation,

while also providing assistance for those interviewed to better remember what the interviewer asked about, and, in the same manner, provide a new opportunity to correct and supplement earlier descriptions. Summaries used in this context, are made by brief recaps of the respondent's responses along the way, and based on these, the interviewer may ask for additions to their descriptions. An example from the friendship study (Sigstad 2017) shows how summary was used as a technique to expand the respondent's descriptions:

I: Now we have talked a lot about whom you call a best friend and how you characterize a good friend. *(summarizing)* Possibly, you had something in mind when you were invited to this talk about friendship?

S: Yes.

I: Is there anything you want to tell me about friendship that we have not already talked about?

I: Any questions or something you want to say? (more specific question)

S: No.

I: When you think of friendship, is there anything you think is important to tell? (*rephrasing the question*)

S: You could also talk about those who are not only my best friends.

I: Those who are not only your best friends? (paraphrasing the response)

S: Yes, those usual friends, yes.

I: Okay, did you think about the others you hang out with?

S: Yes, Martin and Dee.

I: Oh yes.

I: Is there anything you want to tell about them? I appreciate you saying that.

S: Yes, that's fine.

I: It is nice to have some other friends too?

S: Yes, it is.

S: It's nice; they are so funny, cool and happy people, yes.

I: How do you think about having more friends, not only one?

S: It's fun and even nicer.

I: That's good.

I: You missed that I did not ask about the others?

S: Yes, but its fine.

Whilst qualitative interviews with respondents with ID and communication difficulties may pose particular requirements for facilitation of the interview situation, the goal of such interviews is the same as for ordinary interviews, namely to bring about the voice of the respondents in relation to a specific phenomenon that is being researched. So far, we have demonstrated how these interviews may require more untraditional means and a stronger awareness of communication techniques to enhance communication. Despite this being unconventional in research, the interviewer must adapt his way of communicating to fit the purpose. However, it is important to be aware of some threats to validity that may occur when using these communication techniques.

# Threats to validity in facilitated interviews – A discussion

Validity in qualitative interviews is all about whether we can feel confident about our interpretations and conclusions (Creswell 2013). From collecting data to analysing and interpreting our findings, the central question concerning validity in qualitative research is 'Did we get it right?' (Stake 1995, 107) – do our interpretations and presentations of the findings match the experiences of the informants? As such, we want to provide plausible and trustworthy findings, with a high level of credibility, which capture the informants' experiences as much as possible (Kazdin 2014).

When doing research with informants with ID, the researcher's effort to capture the informant's experiences may bring bias into the study, and the study's validity may be under threat. One aspect that needs particular consideration is the tendency of researchers to find results that are in line with their own conceptual views (Kazdin 2014). As with all research, interpretations of qualitative interview data may be tainted by personal experiences, views and beliefs, and the researcher's conceptual views may play a role already during the course of the interview, for example when paraphrasing or summarizing the respondent's statements. When paraphrasing what a respondent has said, the researcher's pre-understanding may bring nuances in the respondent's answers that were originally not intended by the respondent, or the paraphrase may not capture the essence of the respondent's experiences. These nuances may either go unnoticed by the respondent, or he or she may find it easier to acquiesce than to correct the differences. To avoid putting words in the mouth of the informant that are not reflecting his or her own experiences accurately, we suggest two approaches, namely 1) using as much as possible the same type of vocabulary as the informant, and 2) prolonged engagement with the informants. Firstly, by using the same type of vocabulary as the informants when paraphrasing or summarizing, it may be easier for the respondents to determine whether they have been

understood correctly, and whether they agree with the researcher's paraphrase. When the meaning of the informants' statements is conveyed in a simple and straightforward language that matches their own communicative level, the researcher can be more confident that the paraphrase has been understood correctly, which makes it easier for the respondent to provide the necessary clarifications. When used in this way, paraphrasing may fill the role of 'member-checking', i.e. a strategy to improve validity. Here, the researcher shares his/her interpretation of the informant's statements, so that the informant can check whether these interpretations reflect his/her own experiences correctly (Creswell 2013). Secondly, prolonged engagement may help broaden the conceptual views of the researcher, and align these more with the experienced world of the informants. The conceptual views of a researcher may differ rather substantially from those of informants with ID, and hence, the meaning of getting to know the world of the informants cannot be overstated. Prolonged engagement is also a good way of building rapport with the informants and of getting to know their communicative styles better (Bedoin and Scelles 2015). Taking time to observe the verbal and nonverbal language of the informants may help later in the interview situation, as it may make it easier for the researcher to detect misunderstandings and uncertainty in the informants. This knowledge of the informants and their communicative style may improve the researcher's confidence that the data are being interpreted appropriately. As Creswell (2013) states, the researcher's knowledge of and closeness to the participants in the study add to the accuracy of a research study.

The communication technique of rephrasing questions may also bring bias into the data, as it in some cases may result in leading questions, where the researcher rephrases a question so that the answer matches the researcher's opinions and ideas, rather than those of the respondent. Also, the use of yes/no-questions may lead to a social bias in the respondent, who may perceive one of the

two options as the 'expected' answer. Whilst it may be easier for participants with ID to answer yes/no-questions, the researcher should take care to follow up this type of questions with more open questions to get to the depth of the participant's experiences. This way, with richer descriptions obtained, the validity of the findings is strengthened. Also, it is paramount for the quality of the research study that several voices are heard, so that a fuller picture can be obtained. With more informants providing answers to the same questions, the authenticity of the study is safeguarded, and the researcher can be more certain that the data form an adequate representation of the experiences of the informants.

Whilst the use of encouraging prompts in general is a good communication technique to put informants at ease and to indicate that the researcher is listening actively, these prompts may also introduce social bias in the interview situation. When used inattentively, encouraging prompts might give informants the impression that some answers are better received than others, and they may influence how the informants respond further throughout the interview. Here, Egan (2010) argues that, in order for communication skills to contribute to authentic communication, it is important that these skills become second nature to those who use them. When the communication skills become part of the researcher's natural communication style, the researcher will be more aware of how his or her own communication influences the participants, and measures to increase validity can be undertaken. Therefore, it is recommended that researchers who intend to use qualitative interviews in research with informants with ID practice these communication skills as often as possible, e.g. by audio-recording conversations and analysing the use of the different communication techniques.

Threats to validity are unavoidable in research studies, and there is no such perfect study where there is total absence of bias. The communication strategies that were presented in this article can

contribute to richer descriptions when performing interviews with informants with ID. However, as discussed previously, these communication strategies may also introduce threats to validity in the research study. Therefore, researchers need to proceed with care and use validation strategies to counter these threats. Also, it is important that possible threats to validity are reported in the presentation of the research study, so that readers can assess the quality of the study.

#### Conclusion

In the present article, the authors have focused on facilitating research interviews for respondents with intellectual disability. The authors argue for the need to include people with intellectual disability in research for three reasons. Firstly, research on intellectual disability from a subjective perspective requires descriptions from the ones concerned, namely those with an intellectual disability. Secondly, excluding people with intellectual disability from research based on their cognitive impairment or communicative challenges may violate the principle of equal treatment. Thirdly, people with intellectual disability seem to appreciate getting the opportunity to participate in research in order to contribute to the expansion of the existing knowledge base.

However, inclusion of people with intellectual disability requires facilitation. The focus in this article is directed towards the researcher as interviewer, with the purpose of strengthening the interviewer's expertise in conducting interviews with respondents with intellectual disability. On this basis, the authors have chosen to highlight examples of appropriate communication techniques that they experience contribute to more detailed descriptions from the respondents. Three different communication techniques derived from counselling practice are discussed and exemplified: silence and encouraging prompts; rephrasing questions; and repeating, paraphrasing and summarizing responses.

However, it is emphasized that this facilitation and adaptation of the research interview may involve methodological challenges, as it may pose a risk to the study's validity and reliability. As with all other research, both the implementation of the interview and the interpretation of interview data may be influenced by personal experiences and perspectives, and the conceptual views of the interviewer may thus play a crucial role. These threats to validity may need extra consideration in research based on qualitative interview data that is obtained from respondents with intellectual disability. The authors suggest that, by using as much as possible the same type of vocabulary as the respondents, for example when paraphrasing or summarizing, it may be easier for the respondents to recognize their own statements, provide corrections when needed, and specify their answers with more detailed descriptions. Prolonged engagement with the respondents is considered to be of value for broadening the conceptual views of the researcher, and thus making it easier for the researcher to get hold of the experienced world of the respondents.

Increased competence in the abovementioned communication techniques requires regular practice of these skills in interviews with respondents with intellectual disability. When these communication skills develop into a 'second nature' of the interviewer's communication style, the researcher becomes more aware of how his or her own communication affects the respondents, and this may contribute to a more critical assessment of the study's validity. Whilst using participants with ID in qualitative interview research may pose extra threats to the soundness of a study, the authors wish to emphasize the importance of including individuals with ID in research studies, so that their voices can be heard and their interests be addressed.

## References

Antaki, C. 2013. "Two conversational practices for encouraging adults with intellectual disabilities to reflect on their activities." *Journal of Intellectual Disability Research* 57(6): 580-588. doi: 10.1111/j.1365-2788.2012.01572.x

Bedoin, D. and R. Scelles. 2015. "Qualitative research interviews of children with communication disorders: methodological implications." *European Journal of Special Needs Education*, 30(4): 474-489. DOI: 10.1080/dx.doi.org/10.1080/08856257.2015.1035884

- Brooker, K., K. van Dooren, C. Tseng, L. McPherson, N. Lennox, and R. Ware. 2015. "Out of sight, out of mind? The inclusion and identification of people with intellectual disability in public health research." *Perspectives in Public Health* 135(4): 204-211. doi: 10.1177/1757913914552583
- Caldwell, K. 2014. "Dyadic interviewing: a technique valuing interdependence in interviews with individuals with intellectual disabilities." *Qualitative research* 14(4): 488-507. doi: 10.1177/1468794113490718
- Carr, A., and G. O'Reilly. 2016. Lifespan development and the family lifecycle. In *The Handbook of Intellectual Disability and Clinical Psychology Practice*, edited by A. Carr,
  G. O'Reilly, P. N. Walsh, and J. Mcevoy, 45-78. Hove and New York: Routledge.
- Claes, C., S. Vandevelde, G. Van Hove, J. van Loon, G. Verschelden, and R. Schalock. 2012.
  "Relationship between Self-Report and Proxy Ratings on Assessed Personal Quality of Life-Related Outcomes." *Journal of Policy and Practice in Intellectual Disabilities* 9(3): 159-165. doi: 10.1111/j.1741-1130.2012.00353.x

- Conte, C. 2009. Advanced Techniques for Counseling and Psychotherapy. New York: Springer Publishing Company.
- Corby, D., L. Taggart, and W. Cousins. 2015. "People with intellectual disability and human science research: A systematic review of phenomenological studies using interviews for data collection." *Research in Developmental Disabilities* 47: 451-465. doi:10.1016/j.ridd.2015.09.001
- Creswell, J.W. 2013. *Qualitative Inquiry and Research Design. Choosing among Five Approaches.* 3th ed. London: SAGE Publications Ltd.
- Cummins, R.A. 2002. "Proxy responding for subjective well-being: a review." *International Review of Research in Mental Retardation* 25: 183-207. doi:10.1016/S0074-7750(02)80009-X
- Egan, G. 2014. *The Skilled Helper. A Client-Centred Approach*. Europe, Middle East & Africa Edition. Hampshire: Cengage Learning.
- Emerson, E., D. Felce, and R.J. Stancliffe. 2013. "Issues Concerning Self-Report Data and Population-Based Data Sets Involving People With Intellectual Disabilities." *Intellectual and Developmental Disabilities* 51(5): 333-348. doi: 10.1352/1934-9556-51.5.333
- Emerson, E., C. Hatton, T. Thompson, and T. Parmenter. 2004. *International handbook of applied research in intellectual disabilities*. Chichester: Wiley.
- Feldman, M.A., J. Bosett, C. Collet, and P. Burnham-Riosa. 2014. "Where are persons with intellectual disabilities in medical research? A survey of published clinical trials." *Journal* of Intellectual Disability Research 58(9): 800-809. doi: 10.1111/jir.12091

Finlay, W. M. L., and C. Antaki. 2012. "How staff pursue questions to adults with intellectual disabilities." *Journal of Intellectual Disability Research* 56(4): 361-370. doi: 10.1111/j.1365-2788.2011.01478.x

- Finlay, W. M. L., and E. Lyons. 2001. "Methodological Issues in Interviewing and Using Self-Report Questionnaires With People With Mental Retardation." *Psychological Assessment* 13(3): 319-335. doi: 10.1037/1040-3590.13.3.319
- Finlay, W. M. L., and E. Lyons. 2002. "Acquiescence in Interviews With People Who Have Mental Retardation." *Mental Retardation* 40(1): 14-29. doi:10.1352/0047-6765(2002)040%3C0014:AIIWPW%3E2.0.CO;2
- Garrels, V. Forthcoming. "'Jeg fikk utfordret meg selv' elevsentrert læring for elever med utviklingshemming.» ['I got to challenge myself – student-directed learning for students with intellectual disability]. *Spesialpedagogikk* 2018 (1).
- Hartley, S. L., and W. E. Jr. MacLean. 2006. "A review of the reliability and validity of Likert type scales for people with intellectual disability." *Journal of Intellectual Disability Research* 50(11): 813-827. doi: 10.1111/j.1365-2788.2006.00844.x
- Heal, L. W., and C. K. Sigelman. 1995. "Response biases in interviews of individuals with limited mental ability." *Journal of Intellectual Disability Research* 39(4): 331-340. doi: 10.1111/j.1365-2788.1995.tb00525.x
- Huus, K., M. Granlund, J. Bornman, and F. Lygnegård. 2015. "Human rights of children with intellectual disabilities: comparing self-ratings and proxy ratings." *Child: Care, health and development* 41(6): 1010-1017. doi: 10.1111/cch.12244

- Kazdin, A. E. 2014. *Research Design in Clinical Psychology*. 4<sup>th</sup> ed. Essex, England: Pearson Education Limited.
- Kokkersvold, E., and H. Mjelve. 2003. *Mellom oss. Trening av kommunikasjon i* gestaltperspektiv [Between us. Training of communication in the gestational perspective].
  Oslo: Gyldendal Akademisk.
- Lassen, L. M. 2014. Rådgivning. Kunsten å hjelpe og sikre vekstfremmende prosesser [Counselling. The art of helping and ensuring growth-promoting processes]. Oslo: Universitetsforlaget.
- Lloyd, V., A. Gatherer, and S. Kalsy. 2006. "Conducting Qualitative Interview Research With People With Expressive Language Difficulties." *Qualitative Health Research* 16(10): 1386-1404. doi: 10.1177/1049732306293846
- McDonald, K. E., N. E. Conroy, and R. S. Olick. 2016. "Is It Worth It? Benefits in Research
  With Adults With Intellectual Disability." *Intellectual and Developmental Disabilities* 54
  (6): 440-453. doi:10.1352/1934-9556-54.6.440
- McDonald, K. E., and C. A. Kidney. 2012. "What is right? Ethics in intellectual disability research." *Journal of Policy and Practice in Intellectual Disabilities* 9 (1): 27-39. doi: 10.1111/j.1741-1130.2011.00319.x
- McDonald, K. E., C. A. Kidney, and M. Patka. 2013. "You need to let your voice be heard': research participants' views on research." *Journal of Intellectual Disability Research* 57 (3): 216-225. doi: 10.1111/j.1365-2788.2011.01527.x

- McKenzie, K., M. Milton, G. Smith, and H. Ouelette-Kuntz. 2016. "Systematic Review of the Prevalence and Incidence of Intellectual Disabilities: Current Trends and Issues." *Current Developmental Disorders Reports* 3(2): 104-115. doi: 10.1007/s40474-016-0085-7
- Northway, R. 2014. "To include or not to include? That is the question." *Journal of Intellectual Disabilities* 18(3): 209-210. doi: 10.1177/1744629514543863
- Rogers, C. 1990. Client-Centered Therapy. In Carl Rogers Dialogues. Conversations with Martin Buber, Paul Tillich, B. F. Skinner, Gregory Bateson, Michael Polanyl, Rollo May, and others, edited by H. Kirschenbaum, and V. L. Henderson, 9-38. Boston: Houghton Mifflin.
- Schmidt, S., M. Power, A. Green, R. Lucas-Carrasco, E. Eser, E. Dragomirecka, and M. Fleck.
  2010. "Self and proxy rating of quality of life in adults with intellectual disabilities:
  Results from the DISQOL study." *Research in Developmental Disabilities* 31: 1015-1026.
  doi:10.1016/j.ridd.2010.04.013
- Sigelman, C. K., E. C. Budd, C. L. Spanhel, and C. J. Schoenrock. 1981. "Asking questions of retarded persons: a comparison of yes-no and either-or formats." *Applied Research in Mental Retardation* 2: 347-357. doi:10.1016/0270-3092(81)90029-1

Sigstad, H. M. H. 2014. "Characteristic interviews, different strategies: Methodological challenges in qualitative interviewing among respondents with mild intellectual disabilities." *Journal of Intellectual Disabilities* 18(2): 188-202. doi: 10.1177/1744629514523159 Sigstad, H. M. H. 2017. "Qualities in friendship – Within an outside perspective – Definitions expressed by adolescents with mild intellectual disabilities." *Journal of Intellectual Disabilities* 21(1): 20–39. doi: 10.1177/1744629516631682

Stake, R.E. 1995. The Art of Case Study Research. London: SAGE Publications Ltd.

UN (United Nations). 2006. Convention on the Rights of Persons with Disabilities (CRPD). Accessed September 29 http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

- Walmsley, J., and Johnson, K. 2003. Inclusive Research with People with Learning Disabilities:Past, Present and Futures. London and New York: Jessica Kingsley Publishers.
- WHO (World Health Organization). 2016. International statistical classification of diseases and related health problems (10th rev., Version 2016). Accessed September 29 <u>http://apps.who.int/classifications/icd10/browse/2016/en#/F70-F79</u>.
- WMA (World Medical Association). 2013. Declaration of Helsinki Ethical Principles for Medical Research Involving Human Subjects. Retrieved from https://www.wma.net/
- Zimmerman, F., and M. Endermann. 2008. "Self-proxy agreement and correlates of healthrelated quality of life in young adults with epilepsy and mild intellectual disabilities." *Epilepsy and Behavior* 13: 202-211. doi:10.1016/j.yebeh.2008.02.005