Guidelines for Researchers when Interviewing People with an Intellectual Disability

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A Note of Caution
These Guidelines are intended for researchers carrying out interviews with people with an intellectual disability. The guidelines are not intended to be definitive, as further research may offer greater insights on this topic. Equally researchers should have regard to their own organisations' policy guidelines on interviewing when planning research interviews.

We hope that you will find this document helpful. Any questions or comments regarding this document are welcome and can be forwarded to: National Federation Research Sub-Committee, National Federation of Voluntary Bodies, Oranmore Business Park, Oranmore, Galway or email secretariat@fedvol.ie
(Please insert "Interviewing Guidelines" on the subject line of your email).

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when Interviewing People with an Intellectual Disability

1.   Introduction

Many international declarations of recent times have stressed the universality of human rights and emphasised the values of human dignity, autonomy, bodily integrity and equality. The *European Convention for the Protection of Human Rights and Fundamental Freedoms* formally codifies freedom of expression, freedom of thought, conscience and religion, respect for private and family life and liberty and security. Similarly, the *United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities* (1993) directs the responsibilities of national governments under headings such as: support services and family life and personal integrity (Harris, 2003). The increased acceptance that rights for people with an intellectual disability are, in fact, fundamental human rights leads inexorably to an expectation that they will be active participants in their own lives to the fullest extent.

People with intellectual difficulties have over the past ten years or so, become increasingly seen as '*reliable informants who hold valid opinions and have a right to express them'* (Stalker, 1998). Such individuals are now accepted to be the best authority on their own lives and on their own feelings and opinions (Godley, 1996). Service users are in a unique position to comment on their personal experiences and feelings about the services they are involved with (Taylor & Devine, 1993). In this regard, the National Disability Authority (2002) developed G*uidelines for Including People with Disabilities in Research,* which should be read in conjunction with these interviewing guidelines.

However, well-documented deficiencies do exist in our capacity to ascertain the views of all people with an intellectual disability. The extent to which these difficulties will arise and will impact depends upon the capacity of the interviewer to be skilled and knowledgeable in communicating with people with an intellectual disability taking into account individual levels of intellectual disability, the topics under investigation, and the extent to which potential difficulties have been considered and addressed. There is an obligation on interviewers to be sufficiently prepared, aware and trained before embarking on the interview process. Failure to do so will not only undermine the validity of the interviews but will demean the person with an intellectual disability who has consented to be involved in the process. Below are some issues for consideration.

2.   Setting the Scene

Interviewing has three important stages (before the interview, during the interview, and after the interview), which will require careful planning by the interviewer. Issues such as access to interviewees, consent by interviewees, the content and duration of the interview, support required by interviewees, accessibility of the venue and transport arrangements, where necessary, will need to be considered. In these guidelines we will concentrate primarily on the issues that arise at the time of the interview.

When meeting the interviewee, it is important that the interviewer clearly identifies themselves. They should establish a good rapport with the interviewee, using incidental conversation to break the ice (e.g. weather), before embarking on the interview proper, thereby encouraging the interviewee to trust and share accurate information on the topic to be discussed. The interviewer should explain the purpose of the interview, address terms of consent, confidentiality and

anonymity, and indicate that there are no right or wrong answers. People with an intellectual disability have the right to remain anonymous and to have their privacy and confidentiality respected. The interviewer should make it clear to the interviewee that they can withdraw from the interview at any time without consequence.

The interviewer should also inform the interviewee that they are free to ask or clarify any questions being asked of them. It is also important that the interviewer provides sufficient time at the end of the interview to allow the person with an intellectual disability to ask the interviewer any questions they may have. Interviewers should provide the interviewee with their contact details, following the completion of the interview, in case the person wishes to clarify any other concerns at a later date.

3.   Communication Strategies in the Context of Research Interviews

Dealing with Abstract Concepts
People with an intellectual disability often have great difficulty dealing with abstract concepts. Therefore, questions must be phrased as simply as possible using concrete concepts. Sentences should be kept short and each sentence should clearly deal with only one topic. Questions concerning time or numbers can be problematic and therefore questions such as: 'how much?' 'how often?' or 'since when?' should be avoided. The following websites, www.easyinfo.org.uk and www.bris.ac.uk/Depts/NorahFry/PlainFacts, may provide some additional guidance on making information more accessible and easy to understand.

The Wording of Questions
The language used in both the questions and in any given response option must be familiar and pitched at a level that will be understood by the individual. Negatives should be avoided; all questions should be phrased positively and where possible open-ended questions should be used. However, when options are presented they should be two or three in number and should be in randomised order to counter the tendency of some people with an intellectual disability to take up the last option mentioned. It is preferable to avoid questions that trigger a yes or no response.

Avoiding Response Bias
People with an intellectual disability have a greater tendency to acquiesce, nay-say and select the last mentioned option (recency). An individual with a tendency to acquiesce will answer all or most questions in the affirmative; those with a tendency to nay-say will answer in the negative; and individuals with a propensity to recency will select or agree with the last or most recent option or suggestion. Cummins (1997), among others, suggests some strategies to minimise the effect of these tendencies but all interviewers should be aware of these issues and test for them. Of course, biases in the phrasing of the questions will exacerbate these problems.

Avoiding Induced Acquiescence
People with an intellectual disability at times have a desire to please others perceived to be in an authority role, including, possibly, the interviewer. Therefore, individuals may not answer questions truthfully, instead they may respond to questions in a certain way because they think that it is the "desired" response.

Rapley & Antaki (1996) first reported a form of induced acquiescence where an interviewee changed their response when their initial answer was not immediately accepted by the interviewer. A delay in accepting the response or a rephrasing of the question following a

response was interpreted by the interviewee as an indication that their initial response was unacceptable or incorrect and this response was changed.

Redesigning Questions
Interviewers should be aware of the extent to which they 'redesign' a question during an interview. Discussing the meaning of the question may amount to a reinterpretation of the question and may impact on the study as a whole. However, in discursive interviews, rephrasing or asking questions in more than one way can work to ensure the accuracy or consistency of answers to questions raised (Rodgers, 1999).

Asking About Satisfaction
When people with an intellectual disability are asked to evaluate services or indicate their level of satisfaction, the validity of their responses is mediated by the level to which they have experienced alternatives and choices. Typically, some people will not have the same breadth of experience as a member of the general population of the same age and sex and may also have low expectations. In addition, it is important to acknowledge people with an intellectual disability may feel pressure to respond in appropriate ways (e.g. respond with satisfaction when in fact they may be dissatisfied), with the desire to please others perceived to be in power.

4.   Who Should Interview?

A Neutral Party?
People with an intellectual disability availing of any service may consider their responses to questions about services or life satisfaction in terms of the effect any answers may have on the services that they receive. Brown & Lumley (1993) and Meredith & Wood (1995) are among those who recommend that a neutral party should conduct interviews to reduce 'gratitude responses' and any fear of repercussions due to critical answers. The individual's perception of the balance of power between the interviewer and themselves may affect their interview.

A Familiar Person?
The key to successful interviews with people with an intellectual disability is flexibility and sensitivity to the requirements of the individual. Therefore, notwithstanding the previous paragraph, a person known to an individual with an intellectual disability may be the best interviewer as a greater level of communication and trust may already exist between them.

An Interviewer with an Intellectual Disability?
People with an intellectual disability will be of invaluable assistance in the development of any questionnaire particularly in their evaluation of the appropriateness of the concepts, the questions or the language (see www.easyinfo.org.uk for further guidance on the use of language). They may also have a role as interviewers where the respondents have an intellectual disability and may perceive them as more sympathetic, less threatening and having more understanding of their situation, leading to fuller and better quality responses. Interviewer's intellectual disability may find that it gives them credibility with the interviewee (Knox et al, 2000). Schalock (2002) reported that using consumers with intellectual disabilities as surveyors reduced the need for proxy respondents.

Experience of Interviewers
Interviewers should possess interviewing skills as well as professional competence. They should have experience with carrying out interviews with people with an intellectual disability, and of the subject at hand, before they embark on the interview process. The principle investigator has a responsibility to ensure that the researcher carrying out the interviews has the necessary skills.

5.   The Use of Proxies

Despite a diverse range of strategies that have been developed to enhance communication with people with a more significant level of intellectual disability, situations still exist where we are unable to understand a person's choices. One solution is to explicitly or implicitly exclude people with severe or profound disabilities from the process or extrapolate the views of those people with an intellectual disability who can communicate for themselves.

Alternatively, it can be approached using proxies – with parents, advocates or supporters responding on behalf of the person with an intellectual disability. The extent to which proxy responses accurately reflect the views of the individual with an intellectual disability are disputed and the subject of some debate, although Stancliffe (1999) states that: "*a well-informed guess may be preferable to no information in cases where the person is unable to communicate her/his own views*".

Concerns also exist, when the person with an intellectual disability is non-English speaking. Ideally, the interviewer should be able to speak the individual's language. However interpreters will generally have to be used and the training in interviewing skills of interpreters should be considered by the interviewer. As noted earlier, the use of proxies can result in the loss or misinterpretation of information and the same principle applies when using interpreters. Thus the guidelines on proxies might be equally applied to interpreters.

When proxies have been used to respond on behalf of people with an intellectual disability, this fact must always be made explicit in any report or article. Responses and data collected from proxies must always be reported or analysed separately from responses and data collected from the target respondents themselves.

Proxy interviewing is strengthened when:

(a) the person in question is present during the interview, ideally sitting beside the proxy; and

(b) the proxy speaks for the person who is the focus of the interview (e.g. "John likes ……", rather than "I think it would be good if he ……").

The presence of authority figures may intimidate the interviewee and 'higher' authority figures such as managers, administrators etc may especially intimidate. The proxy should be the person who knows the person best. However, Rodgers (1999) recommends that the validity of a carer's answer should always be tested and that probing the responses to answers, asking for examples and concurrent observation are all useful in this regard. Additionally, the proxy might be asked 'How do you know?' or 'Why do you think that?' to elicit some supportive evidence.

Instruction to Proxies
If a proxy is used, they should be well briefed. The interviewer should meet the proxy to clarify their role (for example, to help the interviewer to understand what John is saying in reply to the interview questions) and to agree procedures. We also recommend that the interviewer explain the procedures in an understandable way to the person with an intellectual disability. An example of such a briefing might be:

> I want you to sit beside John and opposite me; your role is to tell me what John is saying and if you don't know what John is saying, you should make this clear. If you only think you know what John is saying you must say "I think John is saying that he likes...." and

not "John likes....." I will address each question to John and wait for him to reply. If he cannot reply verbally I will wait to give him time to express himself in another way (e.g. he may smile, become agitated, nod his head, look away etc). When I am satisfied that I am ready to hear your interpretation, I will glance in your direction to indicate that you should speak. When you are speaking, I will be looking at John in order to acknowledge him and his answer and to look for further corroborating clues in his reaction to your interpretation.

6.   Enhancing Communication

Verbal Communication
It is important to look and speak directly to the person being interviewed and if the interviewee has communication difficulties, the interviewer should avoid correcting or completing sentences for the interviewee. If the interviewer does not understand the response given by the interviewee, the interviewee should be asked to repeat their response.

Where necessary, the interviewer should restate what they have understood and ask the interviewee if the information is correct. However, remember that the person with an intellectual disability may not feel comfortable correcting the interviewer. In order to verify the interviewees understanding, it is advised that the interviewer should observe the person's body movements, gestures and facial expressions.

Interviewers should use his/her usual tone, rate and volume of voice, unless asked to slow down or speak up. Every effort should be made to keep the language simple and clear (e.g. plain and concrete), however, it is important to treat each person in an age-appropriate manner.

Non-Verbal Communication
As mentioned above, the interviewer should be aware of, and alert to, body movements, gestures, and facial expressions as a means of communication, particularly when interviewees have severe levels of communication difficulties (Guess et al, 1985). Preparation is essential to ensure an understanding of the person's preferred means of communication. Guidance should be sought from those who are familiar with the person with an intellectual disability.

Aids to Communication
Creativity and flexibility in the manner of questioning will empower people with a more significant level of disability to express opinions and make choices. Clearly worded and simple text can be reinforced with visual aids such as symbols or pictures. Stories, photos, and playing games as well as open-ended discussions can also facilitate the exchange of information. When interviewing children, it may be appropriate to use 3-D figures such as dolls and toys.

Alternative systems of communication such as Lámh and PECS may be the respondent's only or preferred means of communicating. Some symbol sets are capable of being used to communicate quite complex ideas (Detheridge, 2000). People with an intellectual disability often find it easier to understand visual input rather that auditory communication. Signs may help a person to clarify what he/she is trying to say and relieves guesswork and frustration.

Pictures can also assist people who are less articulate to communicate their ideas - when Rodgers (1999) asked people with intellectual disability who were not able to express their ideas verbally to draw pictures of what health meant to them, she was encouraged by the level of sophistication with which they conceptualised health through their art work.

7.   Other Considerations

Language
The type of language used in interviews can sometimes cause offence to people with an intellectual disability (e.g. the use of the expression 'mentally handicapped'). It has long been accepted that the person should be referred to first and not their disability. Interviewers should strive to be considerate of the individual needs of the person they are interviewing, without being patronising (see '*Appropriate Terms of Use'* at www.nda.ie for further guidance).

Allowing More Time
Ascertaining the views of people with an intellectual disability may take more time then a similar exercise with people without an intellectual disability. This should always be borne in mind when scheduling interviews. Interviewers should exercise patience and not attempt to speak for the person with an intellectual disability; instead the interviewer should ensure that sufficient time is given to allow the individual respond and they are not pressed unduly. In the situation where the interviewee has not previously met the interviewer, it is important that time is taken to get to know the person before the interview (Simons et al, 1989; Atkinson, 1988).

Disclosure
Issues of a serious nature may be disclosed during an interview. There are both legal and moral imperatives which impel researchers to act where risk or danger is revealed. The researcher should anticipate and plan for such disclosure. Interviewers should refer to the following publications for further guidance, before carrying out interviews with *children*:

• Department of Education and Science (2002). Code of Good Practice – Child Protection of the Youth Work Sector. Dublin: Stationery Office.

• Department of Health (1999). Children First: National Guidelines for the Protection and Welfare of Children. Dublin: Stationery Office.

In addition, we recommend that interviewers refer to the organisation's policy in managing disclosure with children and adults during the interview process. In this regard, interviewers should use their discretion to appoint an identified external person in advance of the interview process, where applicable, to support the interviewee. The interviewer should also consider any negative impact that the proposed interview may have on the respondent. Certain topics may provoke strong or emotional reactions and therefore appropriate information, counselling or other supports should be available. The presence of a peer or advocate in the interview may also provide support to the interviewee.

Refusal to Participate
The interviewee has the right to refuse to participate or to continue to participate at any stage of the interview. The respondent should be made aware that consent is an on-going process. According to Waltz et al (1991), 'a generally accepted ethical position is that the respondents should be free to participate or withdraw from participation without recrimination or prejudice'.

The interviewer should always look for signs of their willingness to participate, particularly among people with communication difficulties, rather than expecting it to be expressed in words. Such refusal techniques might include: "*declining to stay in the room with me or falling asleep"* (Rodgers, 1999).

Venue

Consideration should be given to the venue in which the interview takes place. The venue should be accessible, comfortable and familiar to the interviewee (e.g. Is there a ramp? Are there accessible toilets? Is the interview room accessible?). Interviews should be carried out in a quiet place away from possible distractions (Cummins, 1997) and this may often mean that each interview takes place in a different location.

However, it is important that regardless of location, the person with an intellectual disability should feel safe and comfortable to provide answers to what may be personal, difficult or awkward questions without the fear of being overheard. Communication may be enhanced when the venue is relevant to the discussion (e.g. discussing job tasks in the setting where they occur).

8.   Conclusion

People with an intellectual disability should be treated with respect and dignity, and in a manner appropriate to their age before, during and after interviews. These guidelines have highlighted and discussed a wide range of issues to be considered by interviewers. In particular, these guidelines identified some of the practicalities interviewers need to consider on the day of the interview, including dealing with abstract concepts, the wording and/or redesign of questions, avoiding response bias and/or induced acquiescence, and asking about satisfaction levels. These guidelines have also explored who should interview, the use of proxies and/or interpreters, and methods for enhancing communication. Other considerations such as language, allocation of time, disclosure, refusal to participate and the venue of the interview have also been highlighted and discussed.

9. Reference List

Atkinson D. 1988. Research Interviews with People with Mental Handicaps. *Mental Handicap Research,* 1, 75-90.

Brown S. & Lumley J. 1993. Antenatal Care: A Case of the Inverse Law? *Australian Journal of Public Health,* 17, 2, 95-103.

Cummins R. A. 1997. *Comprehensive Quality of Life Scale – Intellectual/Cognitive Disability*. 5th Edition. School of Psychology. Deakin University.

Detheridge T. 2000. Research Involving Children with Severe Learning Difficulties. In *Researching Children's Perspectives.* Eds Lewis, A. & Lindsay, G. Open University Press Buckingham.

Department of Education and Science. 2002. *Code of Good Practice – Child Protection of the Youth Work Sector*. Dublin: Stationery Office.

Department of Health. 1999. *Children First: National Guidelines for the Protection and Welfare of Children*. Dublin: Stationery Office.

Godley D. 1996. Tales of Hidden Lives: A Critical Examination of Life History Research with People who have Learning Difficulties. *Disability and Society,* 11, 333-348.

Guess D., Benson H. & Sigel-Causey E. 1985. Concepts and Issues Related to Choice-Making and Autonomy among Persons with Severe Disabilities. *Journal of the Association of Persons with Severe Handicaps,* 10, 79-86.

Harris J. 2003. Choice and Empowerment for People with a Learning Disability. *A Review Conducted on Behalf of APEMH.*

Knox M., Mok M., & Parmenter T.R. 2000. Working with the Experts: Collaborative Research with People with an Intellectual Disability. *Disability and Society*, 15, 49 -61.

Meredith P. & Wood C. 1995. The Development of the Royal College of Surgeons of England's Patient Satisfaction Audit Service. *Journal of Quality in Clinical Practice,* 15, 67-74.

National Disability Authority. 2002. *Guidelines for Including People with Disabilities in Research.* Dublin: NDA.

Rapley, M and Antaki, C. 1996. A Conversation Analysis of the 'Acquiescence' of People with Learning Disabilities. *Journal of Community and Applied Psychology*, 6, 207-227.

Rodgers J. 1999. Trying to get it Right: Undertaking Research Involving People with Difficulties. *Disability & Society,* 14, 4, 421-433.

Schalock, R. L. 2002. The Concept of Quality of Life: What We Know and Do Not Know. *IASSID Europe Conference Plenary Session*.

Schalock, Robert., Brown, Ivan., Brown, Roy., Cummins, Robert A., Felce, David., Matikka, Leena., Keith, Kenneth., Parmenter, Trevor. 2002. Conceptualisation, Measurement and Application of Quality of life for persons with Intellectual Disabilities: Report of an International Panel of Experts *Mental Retardation,* 40, 6, 457-470.

Simons K., Booth T. & Booth W. 1989. Speaking Out: User Studies and People with Learning Disabilities. *Research, Policy and Planning,* 7, 9-17.

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

Stancliffe R.J. 1999. Proxy Respondents and the Reliability of the Quality of Life Questionnaire Empowerment Factor. *Journal of Intellectual Disability Research,* 43, 3, 185-193.

Taylor B. & Devine T. 1993. *Assessing Needs and Planning Care in Social Work*. Aldershot: Ashgate.

Waltz, C.F, Strickland, C.L & Lenz, E.R. 1991. *Measurement in Nursing Research*. 2nd Edition. Philadelphia: F A Davis.