Counted but rarely consulted: The involvement of people who have an intellectual disability as research respondents.

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BACKGROUND

A survey of five major journals in the intellectual disability field (American Journal on Mental Retardation, Journal of Intellectual and Developmental Disability, Journal of Intellectual Disability Research, Disability and Society, Mental Retardation) for 1992 and 1996, identified 211 articles focusing on people with an intellectual disability. While results of this survey should be viewed cautiously (e.g., different research methodologies require specific forms of data gathering), the survey found that people with an intellectual disability were: interviewees to tests or formal questionnaires in 43% of the studies; subjected to physical assessment in 21% of studies; and, in 32% of the studies, significant others in their lives were the main source of data concerning them. People with an intellectual disability were questioned: using a yes/no response format in 1.5% of the studies; using forced-choice, structured interviews in 9.5% of studies; and, using open-questions in 6.6% of the studies.

It appears not much has changed to disprove Bogdan and Taylor's (1982) contention that:

> Seldom are those labeled 'retarded' approached with the idea that they have important insights to offer about their own situations in particular and the field of mental retardation in general. Instead, the mentally retarded have been studied as a separate category of human beings. Special theories have been developed to explain their behaviour. This has made it difficult to get to know those so labeled with any degree of intimacy or depth (p. 17).

Studies which one would expect to involve consultation with people with an intellectual disability (e.g: Stancliffe & Abery's 1997 study of deinstitutionalization and choice) may, in fact, not do so. Observations of individuals in various settings and activities give an impression of their daily life (Edgerton, Bollinger, & Herr, 1984) however, the meaning individuals give to those experiences cannot be deduced simply by observation (March, 1992). People with an intellectual disability are valid sources of information concerning their own experiences. Indeed they alone can supply some information, and it may only be obtained by some form of direct questioning (Wyngaarden, 1981). The issue in such cases for the researcher is, 'How may I best obtain that information?'

Involving people who have an intellectual disability as research interviewees raises a number of ethical, practical, and methodological issues. This paper will identify major common concerns in this regard.

CONTEXT

The author has recently interviewed a number of people who have an intellectual disability as part of a phenomenological study on the meaning of home. This was done using a combination of two major interview strategies, namely, the general interview guide approach and the standardised, open-ended interview (Patton, 1990). In this way, the basic framework of the interview was determined in advance, while the opportunity to follow emergent information fully remained uninhibited. The purpose of the interview was to identify the perspectives, meanings and experiences each interviewee had of the concept of 'home'.

Initial Contact

All initial contact was through a third party so that the initiative for further contact and involvement remained with the prospective interviewee. This independent third person explained the nature of the research to potential interviewees using a researcher-provided plain language statement and asked if they were willing to meet the researcher. The advantages of this approach were: the research was first explained by someone known to the potential interviewee; confidentiality was maintained until and unless the person agreed to participate; the person did not feel pressured or obligated to participate; and, stress at the initial interview was reduced as it only proceeded at the request of the interviewee. There were however, disadvantages to this approach which required consideration (i.e., the third person's relationship with the potential interviewee influencing their response; the lack of full researcher control over the initial presentation of the research; the researcher's absolute reliance on the intermediary to actually present and faithfully convey potential participant's responses to the researcher; and, where the third person was a staff member of an agency used by the potential interviewee, the risk of the research being identified in the minds of the potential interviewee as conducted by that agency).

Consent

Informed consent is a critical and sensitive issue. Where the researcher had any doubts about the interviewee's level of understanding of consent, the interviewee was asked to describe what she understood of the nature and purpose of the research and her role in it, and rights in this regard. Only after the researcher was reasonably confident that the interviewee understood what it was to which she was consenting did the interview commence.

CONDUCT

Interviews with two interviewees occurred at their respective places of residence. The remaining interviewees were all recruited through their day programs and individual interviews were conducted there in private at a time and date mutually convenient to all parties. No other person besides the researcher was present during any of the interviews.

All interviewees, with one exception, were as previously unknown to the researcher as he was to them. Unfortunately, due to time constraints it was not possible to spend time establishing anything other than a superficial, but adequate, rapport with interviewees during the preliminary stages of the interview. The researcher dressed so as to minimise any perceived status differential between himself and the interviewee and to avoid looking like a staff member of any agency associated with the interviewee or any sort of authority figure.

The interview preamble was very brief as it was felt that a prolonged general conversation would be of limited value. This was because many people with an intellectual disability have poor social skills in developing and maintaining a conversation or are shy or hesitant in spontaneously conversing with someone they've only just met. Furthermore, such a conversation could give rise to confusion in the interviewee's mind as to why they were there and what it was all about. For these reasons it was felt prudent to get to the interview as soon as seemed appropriate.

The interview began with the researcher introducing himself, thanking the interviewee for his or her time and willingness to assist, and explaining where the researcher was from and why he was interested to talk with them. The researcher's independence from any service agency with which the interviewee might be involved was stressed as was the confidentiality of anything said to the researcher by the interviewee. The purpose of the research and its potential outcomes were simply explained. The issues to be discussed were broadly identified and the willingness of the interviewee to be interviewed was re-confirmed. Interviewees were then reassured that they did not have to undertake the interview or answer any questions, if they did not wish to do so. They were told it was “their interview” and that, as far as the researcher was concerned, they were “the boss” of the situation.

THE INTERVIEWEES’ CHARACTERISTICS

Intelligence

Only adults with an intelligence level somewhere in the moderate to mild range of intellectual disability were targeted as potential interviewees to this study as they were considered, “... more able to answer questions, ... and less likely to acquiesce in response to yes-no questions than are lower IQ persons” (Sigelman et al., 1980: 511-512). The researcher has worked with people who have an intellectual disability for some 25 years and therefore felt confident to assess the degree of structure each interviewee might require in order to have a reasonable understanding of the interview questions. The interviewee’s ability was assessed during the preliminary remarks and fine-tuned by the researcher during the early stages of the interview.

Interviewees’ background

The researcher found that the interviewees with an intellectual disability were no more or less cautious in volunteering information than non-disabled interviewees (Bogdan & Taylor, 1982). Whether or not the individual had lived in a residential service setting for any significant period of time appeared to make no difference to their willingness or reluctance to talk nor to promote any discernable tendency to please the researcher. Questions regarding hypothetical future homes were always introduced by emphasising their hypothetical nature.

Responsiveness

The responses of interviewees covered a wide range (i.e., no response; unintelligible response; irrelevant response; ‘don’t know’, ‘don’t remember’, ‘not sure’; vague or inadequate response; request for clarification of question; minimally appropriate answer which met the formal demands of the question only; and, expanded response which provided qualifying or additional information beyond the formal demands of the question (Sigelman & Werder, 1975)). Sometimes the interviewee was asked to describe how a third party might experience things (e.g: “How would someone know this was Bill’s room? What would they see that would tell them that?). A mixture of semi-structured informal and conversational interviewing and more direct questioning was used to elicit answers to questions according to the needs of the interviewee as perceived by the interviewer.

Inarticulateness

Interviewing inarticulate interviewees proved extremely difficult with the interview sometimes taking the form of an interrogation. The researcher also had great difficulty in distinguishing between a silence which is waiting to be broken (an expressive silence) and one which is waiting until the conversation moves on (a closed silence).

To assist inarticulate interviewees, the interviewer consciously used: an instrumental rather than expressive vocabulary; a present orientation; a concrete rather than abstract frame of reference; a literal rather than figurative mode of expression; a focus on people and things rather than on feelings and emotions; and a responsive rather than proactive style. Where interviewees appeared to have a concrete frame of reference questions were reworded to probe the informant’s own experience directly rather than requiring their interpretation of experiences. Silences encountered when interviewing were addressed by:

re-phrasing and re-asking the question; or, approaching the topic in a less direct or challenging fashion; or, moving on to some other topic; or posing a leading question requiring a yes/no response.

Speech problems occasionally disrupted or distorted the communication between researcher and interviewee during the interview despite the use of a less structured approach allowing discretion in seeking information from the interviewee. In order to minimise this problem, and to make it easier for the person transcribing the tape recording of the interview, the researcher frequently summarised or repeated the answer given by the interviewee. Even so, several times when this technique was used the interviewee made no attempt to clarify the researcher's possible misunderstanding.

Issues of interpretive bias.

There was a risk of bias in interviewing several inarticulate interviewees who were unable to tell their story in their own words. Here the researcher became an interpreter or biographer thereby running, "... the risk of ... imposing (his) own assumptions, understandings and ambitions upon the stories that emerge" (Goodley, 1996:345). In at least one case, where the informant did not articulate much about what he did do, but was very clear about what he didn't do, the researcher was able to build an understanding of the person's use of home almost as clearly as if the interviewee had said directly, 'I never do any ironing, cooking, cleaning, or gardening, at home. All I do is sleep and watch television'.

Issues of time and frequency

A number of interviewees were found to be oriented to the present, rather than the past or future, and therefore had difficulties with dates and numbers (Booth and Booth, 1996). Where such information was required the use of an approximation or a chronological marker (e.g: before or after you moved house) was found to be the best solution.

Truthfulness

The question of the innate truthfulness or otherwise of interviewees was not considered important as the major concern of the research was to understand how people perceived their home and the meanings they attached to it, not why they did so. The interviews, by their very nature, covered a mixture of subjective and objective aspects of people's residences. Some potential major influences on the informant's subjective responses were to be avoided however. These included: the informant's ulterior motive(s); the presence of any real or imagined bars to spontaneity; the informant's desire to please or impress the interviewer; or, other idiosyncratic factors such as mood, question wording, individual connotations of specific words or concepts (including parallel associations), and the presence and strength of any extraneous distracters. These potential influences were minimised by: carefully structuring the interview; sensitively conducting the interview and being aware of the factors identified above; staging the interview so as to minimise distractions; reducing ulterior motives by emphasising the researcher's inability to apply influence which could assist the interviewee in some fashion; reducing bars to spontaneity by emphasising the confidentiality of the interview; and, minimising idiosyncratic factors by being aware of their possibility and by asking questions on a given topic in a variety of ways (Dean & Whyte, 1978).

The issue of acquiescence

The tendency for people with an intellectual disability to acquiesce when given a question seeking a yes/no answer was always in the back of the researcher's mind when the interview became limited to such responses. However, the use of cross checking through reversed questions and the interviewees' level of intelligence coupled with their variations in yes/no responses in a seemingly appropriate fashion suggested that they were more taciturn than lacking in understanding of the questions.

INTERVIEWEES' PERCEPTIONS OF THE STUDY AND THE RESEARCHER

Because involvement as an interviewee in this research was facilitated by a professional, interviewees may have had concerns that the researcher was part of the formal human service system or specific agency serving them. Therefore, they may have been hesitant in answering questions fully or harboured a fear of negative consequences resulting from any answers given, or concern about the confidentiality of the interview and the use of any information volunteered (Atkinson, 1989). Use of a tape may have added to the interviewee's concerns. These issues were addressed by reassuring interviewees (repeatedly, if appropriate) that the interview was confidential and that they did not have to answer any questions or continue the interview. Conversely, interviewees may have regarded the interviewer as a 'potential helper' with various problems in their everyday lives. The researcher therefore took care to stress his independence from the service system, and subsequent inability to act as an effective helper (Wyngaarden, 1981).

OTHER FACTORS AFFECTING THE INTERVIEW

Environment

The interview environment can have a significant effect on the interviewee's responses (Sudman & Bradburn, 1974). The informant chose the interview site wherever possible (Biklen & Moseley, 1988) or else they were asked if they felt comfortable talking there before the interview began. An interviewee's need to be listened to, and taken seriously seemed best met by conducting interviews in interviewee's home (Atkinson, 1989). Where this occurred, care was taken to ensure that that only the interviewee and interviewer were present (Card, 1983; Sudman & Bradburn, 1974), and that the interviewee was satisfied with the degree of privacy afforded (Wyngaarden, 1981).

Open-ended questions.

There are a number of specific issues surrounding the use of open ended questions requiring consideration, besides those described elsewhere. Open-ended questions receive a poor response from people with an intellectual disability in comparison with yes/no response or pictorial choice questions or other means of asking questions more directly (Booth & Booth, 1996; Flynn, 1986; Sigelman et al., 1981, 1982). Open-ended questions are "… unanswerable by many (intellectually disabled) persons and supplementing them with clarifying examples and probes for additional information only exacerbates response bias" (Sigelman et al., 1982:511). However, a mixture of open-ended and short, closed questions, some seeking a yes/no response, proved effective in recording the subjective reality of interviewees in this case (Neumayer & Bleasdale, 1996).

Yes/no questions.

The researcher's experience confirmed that as the interviewees had a mild or moderate level of intellectual disability they were less likely to acquiesce in response to yes/no questions than people with greater levels of intellectual disability (Sigelman et al., 1982). These types of questions were mixed with other types of questions and the yes/no questions framed in both positive and negative terms to minimise acquiescence bias (Chadsey-Rusch et al., 1997, Heal & Sigelman, 1995, Neumayer & Bleasdale, 1996). Other ways used to minimise the problem of acquiescence with yes/no questions included adding a 'not sure' answer to the range available, and asking questions requiring a reverse response for consistency with another answers (Seltzer & Seltzer, 1978).

The Relationship Between Both Parties

Much of the preceding advice impacts upon the nature of the relationship between the interviewer and the interviewee in addition to the other considerations encountered in any research involving human beings. The research act can, and does, significantly effect both the researcher and the researched and therefore sensitivity and the ability to anticipate the other's reactions are important in minimising any harm which might be done. In this regard, perhaps the best advice to researchers when contemplating a number of possible research strategies involving people with an intellectual disability, is to identify the likely harm which might be done to the person or group under study and choose that strategy which will result in the least harm to them (Gaylin, Glasser, Marcus, & Rothman, 1978).

SUMMARY

Two factors of immediate concern to the researcher wanting to involve people with an intellectual disability are: the extent to which this involvement can be structured; and, the degree of disability of the potential informants. Some approaches are suitable for all people despite the extent of their disability (except in the most exceptional cases); some are suitable for people with severe and profound levels of intellectual disability but less appropriate for those less disabled; some are suited primarily to people with mild to moderate levels of disability only.

In arguing for the development by researchers of more imaginative ways of capturing the perspectives of people with intellectual disabilities, Booth and Booth, (1996) make the following powerful observation:

> Too often the problems of interviewing inarticulate subjects are seen in terms of their deficits rather than the limitations of our methods. Such a 'deficit model' of informant response is rooted in a view of disability as a problem of the individual. It serves to legitimate the exclusion of, for example, people with learning difficulties from a participatory role in … research in ways that mirror their exclusion from the wider society. The emphasis of research should be on overcoming the barriers that impede the involvement of inarticulate subjects instead of highlighting the difficulties they present. Conventional research methods can create obstacles for inarticulate subjects in terms of the demands they make on their inclusion. The lesson to be drawn ... is that researchers should attend more to their own deficiencies than to the limitations of their informants (p. 67).

The social model of disability argues that people are disabled by the refusal or lack of effort by society to make provision for their inclusion. Too much research to date appears to continue to disable people by excluding them from having input to society's research agenda. The inclusion of people with disabilities in all research concerning them, in all possible roles, and at all stages of that research, is long overdue. Let us listen carefully to them.

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