Good research should be relevant and useful, it may even be enlightening or symbolic, but it can also be emancipatory. Qualitative research can be useful in challenging structures, policies and practices that disempower and marginalize segments of the population. However, could it be that the empowerment of the participant ends where the weakness of the researcher begins? In qualitative studies the researcher seems to have a number of favourite interviews. In a study on the relational and sexual experiences of 46 people with learning disabilities, 12 interviews were withdrawn from the general data on the basis of lack of relevance. It is important to re-examine why the voice of some people fell out of the in-depth analysis and whether this was justified. In this article some methodological opportunities and pitfalls to re-grant identity to these silenced narratives are considered and discussed.

Keywords: qualitative research; re-examination of data; empowerment; selection of participants; silenced narratives; communication difficulties

Introduction

Research methodologies, quantitative or qualitative, each have their own strengths and weaknesses. In relation to this, it is important not to impose the rules of one particular research tradition upon another. In seeking guidance on how to judge qualitative research, the initial consideration of guidelines essentially proposed a set of criteria which resembled those that guided conventional inquiry: ‘researchers separately code field notes and interview transcripts and then count up agreements and disagreements as though the goal was to reduce the data to an agreeable compromise of interpretation, or at least a summary’ (Ferguson and Ferguson, 181). However, an imitative approach limits the contribution of interpretivist methodology to a reflection of quantitative methodology (Ferguson and Ferguson 2000).

Booth and Booth (1996) noted a reaction against the ‘over-determined’ view of reality brought about by methods that impose order in a messy world; they saw a creeping disenchantment with research that subordinates the realm of personal experience to the quest for generalization (Faraday and Plummer 1979, cited in Booth and Booth 1996; Abrams 1991, cited in Booth and Booth 1996). Whittemore, Langness,
and Koegel (1986, cited in Booth and Booth 1996) marked a growing frustration over the problem of the ‘disappearing individual’ in sociological theorizing. McCarthy (1999) – whose research fits into an ethnographic tradition which is essentially interpretive – stated that much traditional research terminology misses the point of a lot of what goes on in these studies.

Qualitative research is conducted to contribute to a process of continuous revision and enrichment of understanding of the experience or form of action under study (Elliot, Fisher, and Rennie 1994, cited in Lincoln 1995).

It is scientific inquiry that embraces a set of new commitments: first, to new and emergent relations with respondents; second, a set of stances (personal, professional and political) toward the uses of inquiry and toward its ability to foster action; and finally, to a vision of research that enables and promotes social justice, community, diversity, civic discourse, and caring. (Lincoln 1995, 277)

Good research should be relevant and useful, it may be of instrumental utility, even enlightening or symbolic, but it can also be emancipatory. Qualitative research can empower participants often simply by letting them tell their stories about a particular aspect of their lives. ‘Beyond the immediate participants, such research can be useful in challenging structures, policies and practices that disempower and marginalize entire segments of the population’ (Ferguson and Ferguson 2000, 184). Researchers believing in the paradigm of critical special education are conscious of the need for change – for liberation from social relations that hinder development (Broekaert et al. 1997).

The research discussed below is situated within a disability rights perspective that rejects labelling (stigmatizing) and deficit (pathologizing) thinking (of people with learning disabilities). Giving people with disabilities the opportunity to voice their opinions and talk about their experiences meets an important criterion of good disability research: it appeals for respect for the personal perspective of people with disabilities by addressing their own ideas about a quality life (Taylor and Bogdan 1996; McCarthy 1999; Van Loon and Van Hove 2001). However, to what degree are research methods in general, and narrative studies in particular, influenced by the researcher’s skills and previous experiences (cf. Owens 2007)? Or, in other words, could it be that the empowerment of the participant ends where the weakness of the researcher begins?

Objective

Heshusius (1987) critically noted that little attention had been paid to the documentation of how persons with learning disabilities experience their own sexuality. Although there has been an increase in sex education materials (e.g. Kempton 1988; McCarthy and Thompson 1998; Spanjer et al. 1994), little attention has been paid to how people with learning disabilities personally experience their need for intimacy, sensuality and sexuality in their daily lives (Jurkowski and Amado 1993; Lamers-Winkelman and Sterkenburg 1997; McCarthy 1999; Kersten 2003). It was in this spirit that we undertook a research study in which we provided a forum for people with learning disabilities to speak for themselves regarding their relational and sexual experiences (Lesseliers and Van Hove 2002). Forty-six persons with learning disabilities took part in the study. Responses of 34 of the 46 were analysed deeply, however,
the other 12 interviews were perceived as containing insufficient relevant material to be included.

The focus of this article is, however, not on the in-depth analysis of these 34 interviews (for this see Lesseliers and Van Hove 2002), the main question here is whether it was really necessary to withdraw 12 interviews from the general data. In a way, the selection of these 12 interviews is associated with difficulties often mentioned with regard to qualitative research. Apparently, the interviewees whose data was excluded were not the most ‘narratively competent’ persons in this study. Their stories were classified as failed when compared with the 34 interviews that were used. It is important to re-examine why the voice of some people with learning difficulties fell out of the in-depth analysis and whether this was justified. Therefore, the main objective of this article is to examine and discuss methodological opportunities and pitfalls to disclose narratives of people with learning disabilities, with a focus on those stories of persons with whom it seems difficult to communicate.

Method

This study is part of a more comprehensive project regarding the relational and sexual experiences of persons with learning disabilities in Flanders (Lesseliers and Van Hove 2002). The participants involved were asked to speak about various topics relating to personal relationships and sexuality (e.g. being in love, having a boyfriend/girlfriend, being loved by somebody, getting married, having children, sexual education, having sexual contact and being sexually abused). These topics were designed by the interviewers/researchers with reference to the literature on sexuality and relationships, which generally focuses on these themes (Bosch 1995; Craft 1979; Denekens 1992; International Association for the Scientific Study of Intellectual Disabilities 1996; Jansen and Stael-Merkx 1979; McCarthy 1996a; Thompson 1994; Van Zijldeveld and Sweere 1974; Young Adult Institute 1997). In keeping with the principles of semi-structured, in-depth (face to face, private) interviews (McCarthy 1996b; Bogdan and Biklen 1998; Maso and Smaling 1998), pre-planned topics served as stepping stones to start up a conversation.

In order to fulfil research to a certain methodological standard, researchers agree with all kinds of restrictions. This often implies the inclusion and exclusion of respondents. A critical revision of these methodologies implies a clear display of the reasons why respondents are excluded. In this article issues related to rendering the sample more homogeneous, the selection of the facilities and participants, communication difficulties and issues on ‘time spent’, ‘responsiveness’, ‘suggestion and unreliability’ are taken into reconsideration. The 12 interviews were re-read with the intention of obtaining a critical perspective beyond the obvious and to extract elements left in the shade. A conscious revision of these (restricting) methodologies provides opportunities to look more freely at what initially remained hidden.

Results – where and why did it go wrong and how do we deal with it?

Where did it go wrong: homogeneity in heterogeneity?

The selection of the people that were interviewed initially was far from homogeneous. A lot can be said about the personal characteristics of the interviewees: their age and
cognitive abilities varied greatly. Some were also physically impaired, while a number had a somewhat anomalous background in terms of support.

A very heterogeneous group of respondents sometimes worries scientists. Without making too many compromises, the aim is to obtain to some extent a generally applicable result. In itself, there is nothing wrong with the registration of individual stories (Whittemore 1991, cited in Booth and Booth 1996; Abrams 1991, cited in Booth and Booth 1996), but in the end a researcher does not intend to produce an isolated study. It is preferable to create a kind of balance, whereby the individual retains the right to express his or her individual experience against the background of generally observed conclusions and/or tendencies. Thus, the study can actually contribute to science, while science, in its turn, can contribute to (improvements in) society.

In what way is this heterogeneous group sufficiently homogeneous to yield results that can be placed in a wider context? What are the criteria on the basis of which attempts are made to render the group more homogeneous, in order to obtain results from the interviews that have a greater general value?

In the first instance, there is the fact that all of the respondents live in – or, through a day-care centre, have a connection with – officially recognized ‘group homes for adults with a moderate learning disability’. All of the participants were described as needing support on a 24 hours per day schedule. This labelling results in support services that are provided through facility-based programmes. Under the Flemish system of service delivery they are supposed to be ‘kept occupied’, because they are perceived as not being able to work in paid situations nor at supervised community work sites.

Admittance to a group home (or to similar day-care) only happens after a long series of tests and selection; in short, the labelling and placement of a disabled person occurs after a history of care and referrals spanning years. In itself, because of this, each respondent living under such conditions may be regarded as belonging to a common group (the same label, more or less the same potential/problems, the same need for care). Essentially, this is a sufficient theoretical and empirical criterion for homogeneity, which implies that none of the interviews needed to be excluded from an extensive analysis and that all of the interviews could be taken into consideration when formulating the overall conclusions.

Why then were 12 interviews not analysed extensively?

Globally speaking, the reasons fall into the following two categories:

- concerns about the validity of the research sample, resulting in the withdrawal of persons with additional physical impairments (n = 3);
- communication difficulties with implications for the content of the interviews (n = 9).

Self-evidently, it is open to debate that these two criteria have led to the elimination of 12 interviewees. The two criteria cannot be seen as strict enough to reject the interviews from a thorough analysis. As the aforementioned criteria are ‘elastic’ concepts: individuals with an invisible additional physical impairment were not removed from the selection, and neither were people with additional medical problems, such as diabetes, epilepsy, etc., whereas these conditions obviously affect their general physical constitution, and thereby the experiences, needs and expectations of that person.
Whether respondents were included in the ‘homogeneous group’ was predominantly linked to the fact that ‘additional physical impairment’ affects the mobility of the individual in question. Due to this criterion, and more specifically the consequences of mobility on their relational and sexual experiences, people who were confined to a wheelchair were not included in the overall selection. Without reducing a relationship, or rather the sexual experiences within this relationship, too simply to a matter of mobility, it has to be said that limited mobility inevitably has implications, not just for the person in question and their partner, but perhaps particularly for the way that staff at a facility handle this aspect. For 3 of the 12 interviewees that were excluded this criterion was the decisive factor.

In 9 of the 12 eliminated interviews communication between the interviewer and participant appeared to be so difficult that it had substantial implications for the information gathered. When analysing the data these interviews were removed on the basis that communication difficulties resulted in ‘unreliable or insufficient information’.

As regards the criterion ‘physical impairment’, there is not much more that can be said, although it is relevant to pose the question whether it has really affected the outcome of the survey (see below). At the same time, we think it is important to describe the so-called ‘communication difficulties’ in more detail below. With respect to the criterion ‘communication difficulties’, the main parameter was to what extent this had implications for the content of the interviews.

**Where did it go wrong: selection by staff members?**

It is difficult to imagine an alternative approach to understanding the sexuality of men and women with learning disabilities other than by listening to how they experience and understand sex and relationships (Thompson 1994; Brown et al. 1996; Booth and Booth 1996; Smith and Sparkes 2008).

There is no doubt that in most cases researchers are only able to reach this group of respondents in an indirect way. To recruit participants service providers were requested by the researchers to ask the people they were supporting whether they would be interested in being interviewed on sexual topics. People were also selected – or rejected – by staff and/or social workers on the basis of their ability to communicate and understand (Brown et al. 1996). Apparently, some of the individuals whom the staff considered able enough to be involved in the research did not come through in the end. Out of the 9 interviews that were seen as containing insufficient accessible information, 7 turned out to be with people from 5 out of 9 participating facilities. This raises questions about the way in which staff members implemented the initial selection of the participants: is this connected to the (emancipatory?) culture of the facility, implying that a willingness to take part in the survey was the main reason for selection, rather than their ability to communicate? Was this a coincidence, or are the abilities of the clients in those facilities more limited in general? Could the staff members have been too optimistic about the communicative skills of their clients when dealing with outsiders?

It would be advisable to ask management and employees involved in the setting up of the study their opinion on this. In any case, this matter shows clearly that the researchers were, with respect to this study and especially with respect to the outcome of the research, partially dependent on factors that played a part in the selection of potential interviewees by staff members of the facilities.
**Why did it go wrong: time spent; responsiveness; suggestion and unreliability?**

**Time spent**

Qualitative techniques to obtain correct interpretative truths— and, perhaps more importantly, not completely incorrect ones – may vary, but one constantly emerging method in the literature is to spend a sufficient (or long) time in the field, to have more than a few participants or a few pages of data and/or to combine several techniques or analyses (Wolcott 1990, cited in Ferguson and Ferguson 2000; Smith and Sparkes 2008; Susinos 2007).

Clearly, the outcome of this research was significant. Also, one year after the initial interviews 26 of the 34 (thoroughly analysed) participants were interviewed again to see whether situations, feelings, desires and concerns had changed. Although this second round of interviews resulted in additional material, it did not substantially enrich the results of the first series of encounters. Thus the information gathered was sufficient and in relation to the amount of time spent with these respondents (Lesseliers and Van Hove 2002).

However, the issue of ‘time spent’ remains a weak link in the research with regard to the 12 eliminated interviews, in particular to the 9 transcripts discarded for reasons of ‘communication difficulties’. They did not get a second chance to express themselves on the changes or lack of in their lives in the second round one year later, as after the first series of interviews communication difficulties had been accepted as a reason to withdraw the interviews.

In many of the 9 interviews that we decided not to use it was difficult to sufficiently understand the person in question. Was ‘time’ an important aspect in this? Was the researcher able to get to know the participants well enough, so that they were likely to really say what they thought? Was there enough of a relationship to move beyond the official story that informants might offer a casual inquirer? How did the researcher establish a satisfying level of communication? How did the interviewer explore the efficacy of different modes of questioning in order to find ways of helping the interviewee to respond without, however, influencing their answers (cf. Antaki, Young, and Finlay 2002)? In what way could the researcher have established a good rapport (Booth and Booth 1996; McCarthy 1999; Ferguson and Ferguson 2000)? More time spent, including a longer preparation period before doing the interviews, would probably have made a difference in relation to all these questions.

**Responsiveness**

One question is whether laborious communication was not in the first place a matter of willingness, in this case attributable to the issue of selection. One respondent was very sparing with words. Initially the researcher was under the impression that this was due to a lack of communicative skills, but eventually the interviewee confirmed that he would rather not talk. At first glance this case seems clear: not a matter of ‘cannot’, but rather of ‘wish not’.

Nevertheless, we need to be cautious: perhaps the interviewee was sensitive to the fact that the researcher had the impression that communication was difficult and, therefore, he chose to end the conversation, at least on this subject. If so, it is not an issue of willingness after all, but of communicative problems, essentially about the impact of the interviewer on the interviewee. The researcher must establish a level of
communication that facilitates a rapport without making people feel inadequate. ‘Too often talking to people with a learning disability involves talking down to people, as if their lack of words denotes a lack of comprehension’ (Booth and Booth 1996) – a similar attitude appears in relation to elderly people and children (Kuczynski 2003). In addition, it is worth mentioning that the respondents in the study did not exclude the possibility of ‘another time’.

Communication with one particular individual was awkward because she was in the grip of a certain ‘fear’. It was unclear whether she felt a fear of talking in the context of this study or whether this fear was embedded in a much broader feeling of uneasiness and/or specific problems or whether it was connected to the person of the interviewer. The respondent indicated several times that she was not allowed to speak to the interviewer, that a another inhabitant at the facility had said so:

they say that I should not talk to you, talk to you …. X has said so, she does not like it, she can’t stand me, nobody … she’s going to go to the courts … she will go to the police because I do not want to work, because I do not want to do anything.

It was impossible to find out from the respondent what was really going on. Eventually, the conversation was broken off.

**Suggestion and unreliability**

In a number of cases the main communicative problem was credibility, not just in relation to the story told by the respondent, but also resulting from/induced by interaction with the interviewer.

One person started the interview by telling stories that the interviewer knew absolutely to be untrue as they referred to the interviewer’s personal life. Potentially the interviewer could have an effect on the participant, more specifically because of the gender of the interviewer. Self-evidently, this greatly undermined the relevance of all other information supplied by this interviewee:

How is it that your heart is broken?
Because of you.
Because of me?
Yes.
...
Do you know what ‘being in love’ means.
Yes, being in love, with you.
...
I have a relationship with you.

A number of interviews were to some extent discredited because the interviewer caught herself posing leading questions. It is not always clear how to allow a person with a disability complete freedom when it comes to formulating an answer to a question. On the one hand, it is important that the questions are as neutral as possible (‘How does that feel?’ , Can you explain that?’ or ‘What do you mean, can you say more about this?’) instead of ‘did this feel like this, or rather like that’ or ‘is this because of this or because of that’? The interviewer thought it important to create an atmosphere for each conversation that was as relaxed as possible, leaving a lot of scope for the respondent to contribute as he or she wished. It is generally
agreed that interviews should be ‘open and fluid in order to enable the subject to take the lead’ (Plummer 1983, cited in Booth and Booth 1996, 56). Good examples of interpretivist research engage the participants in helping define the questions to be asked and the way in which the answers should be communicated (Ferguson and Ferguson 2000). It is normal for much of the material in the interview to be narrated independently of direct questions (Thompson 1981, cited in Booth and Booth 1996).

On the other hand, Booth and Booth (1996) stated that the reverse is more likely to be true in the case of inarticulate subjects. Sigelman and her colleagues (cited in Booth and Booth, 1996) found that open-ended questions received the poorest response. Booth and Booth (1996) stated that the problem with an inarticulate informant is ‘that he does not provide any clues about what the interviewer should be asking: unlike more fluent subjects whose responses generally contain the seeds of the next question’ (p. 62). ‘The lack of responsiveness to open-ended questioning by informants with learning disabilities usually requires the researcher to adopt a more direct style of interviewing’ (p. 56). This puts the burden on the skill of the researcher, who must work harder (by asking more questions and probing more fully to elicit information). Consequently, there is a realistic chance that interviewers get their fingers burnt because they ask leading questions.

In some of the interviews, the balance – between a neutral and a too subjective approach (cf. Antaki, Young, and Finlay 2002) – seems to have tipped towards the latter:

You miss her?
Yes.
You would like to be with her always?
Yes.

In the last question the researcher volunteers an option, which may influence the way the respondent replies. Not just with respect to the possible answer that may be given, but also the manner in which the entire interview evolves from that point onward, as the respondent may presuppose that he is expected to continue along those lines. It equally has a potential impact on the perspective that the respondent may acquire in the longer term regarding his life and environment. Self-evidently, a response to the suggestion could also be solicited in a more neutral manner. Just by asking when the respondent would tend to miss that person could provide the researcher with an insight into how the interviewee would prefer to deal with this need.

On the other hand, a leading question does not necessarily have to pose insurmountable problems (see above). The technique of constructing a narrative on the basis of creative speculation – by suggesting certain responses and the elimination of alternatives – may be very illuminating (Booth and Booth 1996). To what extent this is risky depends on the veracity of the respondent in question. Sometimes it is sufficient to ask the same question later, or in the course of the interview itself, formulated differently or set in a different context to verify whether the reply matches what was said earlier. This is equally a current method in surveys that follow the quantitative research paradigm, often with the purpose of checking whether the respondent is sensitive to ‘acquiescence’ (Swanborn 1987). A remarkable feature of the Flemish study was the impression that only a few respondents tended to say ‘yes’ to every-
thing. When acquiescence was suspected this could fairly quickly be circumvented by changing the method of questioning. However, generally those with a disability do say ‘no’ or they fall silent when they do not wish to reply or if they simply do not have an answer. Booth and Booth (1996) arrived at the same conclusion during their own research: the inability of the participant ‘to put himself into hypothetical situations stripped him of the capacity to deceive. … His only alternative to telling the truth was to remain silent’. Nevertheless, in order to obtain more detailed answers in cases of a ‘yes’, a ‘no’ or silence(s) sometimes the only option, according to the authors, is to offer a range of suggestions which the interviewees may or may not concur with.

Some leading questions could equally be regarded as an example of the empathic approach by the interviewer(s), allowing the respondent to overcome a certain discomfort. To pose a leading question that is nonetheless direct with respect to a potentially embarrassing subject could make the interviewer feel uneasy, but it could also be a relief because it suggests that the issue is less unmentionable than the participant initially suspected (Booth and Booth 1996). This is certainly true for the topics of the Flemish study.

In short, according to Booth and Booth (1996) this technique – of putting suggestions to a respondent – does not conform with the recommendations in standard textbooks in relation to proper interviewing methods. It can be seen as ‘putting words into the mouths of informants’. The position of the authors that ‘the challenge of interviewing inarticulate subjects calls for unorthodox methods’ may be a bit exaggerated. Saying that the only way of collecting their stories may be ‘to loan them the words’ could well be a more nuanced way of putting it. At the same time, the better the researcher knows the respondent – in this debate also ‘time spent’ is an issue – the better he/she can afford to pose leading questions. One thing is certain: a leading question does not necessarily imply that the answer is untruthful.

Results – how difficulties reveal the bright side: learning from what went wrong?

Twelve interviews were perceived as containing insufficient relevant material to be included. Three respondents were removed from the selection on the basis of an additional physical impairment, 9 respondents due to communication problems. When undertaking a second revision of these interviews the reasons for withdrawal become more explicit. A raised consciousness of the way some narratives are treated in a stepmotherly fashion is a major gain for researchers. Yet, it also produces opportunities to reveal information that was initially not taken into account. It appears that the results of these narratives are not that different from those who initially survived selection. Similar to the initial research findings (Lesseliers and Van Hove 2002), some people liked where they lived while some expressed distress and loneliness:

I had to, where else could I go? I cannot get out …
I don’t have any friends, I am all alone.

To these respondents too, romance offers an ambiguous world of unattainable loves, rejected love or love submitted to conditions:
Interviewer: Would you like to be with someone?
Interviewee: As a lover, mmm, yes, I don’t know, I am not easily pleased. I asked another staff member, to say to that person ‘Elliot likes you very much’, … and then they said: ‘I don’t want that invalid, see’.

The respondents described love and loving someone in terms of concrete expressions of these feelings:

When you were in love with him, can you describe those feelings?
Then I feel happy, what, much more relieved you are, you hold each other tightly and all.
And can you explain to me, X, how does it feel to be in love?
Well you’re in love, aren’t you
What do you feel?
You give each other kisses, eh, kisses.

In the group of excluded respondents someone related a story of a satisfying relationship. The partner, who lived in another facility, came to stay every other weekend. They felt good about this situation because it was not stressful, but still satisfying. This story matches the narratives of other couples in the intensively analysed interviews who had satisfying sexual relationships with the opportunity to spend enough time together and with sufficient privacy. It confirms that these conditions are important:

At the start it was, like, you exchange kisses, but if you know each other better you do more things …Yes, I think it is a good decision [living apart together]. Yes, for I think if you see each other every day in the end you don’t know what to say any more, and now, yes, he is away for fourteen days and then there is more to tell, isn’t there ….

Analogous to the results from the general analysis, the limited sexual knowledge of the 12 respondents was apparent.

Conclusion

Limitations of the study reconsidered: potential pathways to overcome the aforementioned difficulties

Järvinen (2000) questioned whether ‘conceptions of interviewee competence do lead us to unwittingly encourage some representations of experience and silence others’ (p. 371). Among all potential ‘givers of meaning’ (interviewees), researchers treat some as useful respondents, i.e. as interesting and competent conveyers of thoughts and feelings, whereas others are classified as narratively irrelevant or incompetent. Perhaps the ‘unsuccessful interviews’ can teach us something about the successful ones, i.e. the interviews that dominated the content of the final research report (Ferguson and Ferguson 2000; Järvinen 2000). This paper revealed some of the procedures behind the final interviews in this study. Re-analysing the data on the excluded interviews shows that the information was more relevant than initially thought.

Why did the researchers allow communication difficulties between the interviewer and interviewee to have such an impact that some of the results were not included in the study? If certain actions had been taken this could have been avoided or the damage could at least have been limited to some extent.

Would it not have been useful, in the first instance, to ask management and staff how they (theoretically) handled the way their clients experienced relationships and
sexuality at their facility, what impact this had on policy and on concrete plans of action and how staff deals with these issues in practical terms?

Second, would it not have made sense to ask management and staff how they viewed the living environment of potential respondents, before talking to the clients? If this background story is known, it is easier to put the replies into context, to pose more detailed questions and to discard some elements and add others.

Third, would it not have been logical to enter the world of the interviewees by means of participatory observation, and in this way gain a better insight into their daily activities and concomitant contacts, experiences and emotions? Participatory observation of the living conditions of the (future) interviewee obtains information within a more informal context which would undeniably add value to this study.

Fourth, would it not have been meaningful to become familiar with the way in which the future respondents talked, to get to know their vocabulary, in order to cross this communicative barrier before the interviews took place? In addition, allowing an intermediary, a personal supervisor or an interpreter, during the interview would, to a greater or lesser extent, have influenced the outcome on the basis of the data gathered.

Finally, would it not have been logical to question management, staff and specialist workers (and relatives?) again once the interviews were over, in relation to additional doubts and (in)consistencies? Dependent on the degree to which they were involved with the respondent on a daily basis they could have provided a context for certain replies.

In short, there are many advantages to triangulation and support by third parties during the actual interview and to participating in the life of the respondents before the interview took place. The fact that the interviewer approached the respondents without any prior knowledge or only partially prepared had a significant impact on the eventual results of each interview.

Limitations of the study reconsidered: some caveats

There are, on the other hand, also important disadvantages: not least the likelihood that in the presence of an intermediary or interpreter the narratives could have had equally significant shortcomings as they had under the present conditions, if only because the interviewees may not have felt that they could speak freely.

Also, triangulation of the sources of the interview, before or after the interview, carried the risk that the interviewee’s story would largely be overwritten by what management and staff said on the subject.

It was considered important that all participants told their own story without distortion by preconceived ideas or impressions on the part of staff. Therefore, staff members were asked not to reveal the life story of the interviewees. One could argue that a stranger is not the best person to interview others about their personal relationships and sexuality. On the other hand, a stranger may have the advantage that participants may feel less inhibited when talking to someone they do not know (and will not see again) about personal experiences. Moreover, as a stranger the interviewer was less biased by the culture of the facility and, as a consequence, there were more opportunities for the interviewer to approach the participant with a free and open mind. Rather than verifying the participants’ interviews with staff, we believed that it was better not to have all of the information than risk losing their authenticity and the confidentiality that was promised to the participants (Lesseliers and Van Hove 2002).
There is also a lot to be said in favour of the individual impact of researchers who install themselves in the formal and informal environment of the participants in order to gain their confidence and thereby obtain more relevant and correct data. The question is, do such actions not additionally extend the objectification of a participant in a study, which always takes place to a greater or lesser extent? The presence over a prolonged period of researchers in the participant’s world probably makes it easier to establish a more personal and less scientific relationship. But where does it leave the person with a disability when the research is completed? Does the participant really benefit from the pertinent, but temporary, presence of a researcher in his or her life?

There are important solutions to this problem. Lincoln (1995) stated we have to ‘come clean’ about the claim that we, and not the respondents, are the genuine knowledge producers: ‘imagine an academic world in which judgements about promotion, tenure, and merit pay are made on the basis of the extent of our involvement with research participants, rather than on our presumed objective distance!’ (p. 285). Ferguson and Ferguson (2000, p. 183) looked at studies where both the researchers and the participants were present as co-constructors of the study: ‘The importance of relations extends beyond establishing enough of a relationship to elicit information that is not all wrong to honouring the role of the participants in research’. In view of a participating role of individuals with learning disabilities in the set-up and outcome of the study itself, long-term involvement would be justified. It would provide equality to disabled people as co-constructors of the study. However, as far as this study is concerned, even though the voice of the respondent played an important part, it would be impossible to designate it as a ‘co-constructive study’.

References


