In discourses on the sexuality of people with learning disabilities, there is one voice that goes unheard: that of people with learning disabilities themselves. Hence the motivation for the study described here. The author went to ask people with learning disabilities to enquire about the way they perceive their relationships and their sexuality, what they think of these topics and what is important to them in this respect. There is one major constant in all this information: that the circumstances of people's lives shape their perceptions of sexuality and relationships. Many service facilities have too many structural and organisational problems to allow relationships between service users, let alone value them. Professionals should be creative in finding ways to minimise the structural pressures exerted by the service facilities on the personal needs and wishes of people with learning disabilities.

Introduction

In the 1970s, Van Zijderveld & Sweere (1974) noted that the dominant view in our society is extremely prejudiced regarding the sexuality of people with learning disabilities. People with learning disabilities have long been denied the right to be themselves, because the expression of their sexuality did not fit well with our cultural and historical conceptions of what is good and bad sexual behaviour. As professionals, we needed to critically evaluate the ethical framework which denies the sexuality of people with learning disabilities, instead of integrating it as a part of their sexual reality. Such a denial has historically been the case in Flanders (Nijs & Christiaens, 1981), The Netherlands (Douma et al., 1998), the US (Kempton et al., 1982) and the UK (Brown et al., 1996).

Now in 1999, 20 years after the first pioneering and emancipatory steps of Van Zijderveld & Sweere (1974; see also Craft & Craft, 1979), professionals might like to honour the 'right to sexuality' of people with learning disabilities in theory (UNO, 1994), but many do not quite know how to go about doing this in practice. More often than not, parents and professionals are still endlessly discussing the extent and degrees of permissiveness, responsibilities and consequences of sexual behaviour involving people with learning disabilities (Denekens, 1993; YAI conference, 1997). In all these well-intentioned discourses, what is unheard is that one important voice: that of those with learning disabilities. The perceptions and opinions of people with learning disabilities still play little role either in theory or in practice. Neither in The Netherlands, as Lamers-Winkelman & Sterkenburg (1997) have observed, nor in Belgium is research undertaken where people with learning disabilities describe their sexual experiences. This imbalance requires redressing. Hence the motivation for the study described here. I went to ask Flemish people with learning disabilities about the way they perceive their relationships and their sexuality, what they think of these topics, what their desires are and what is important to them in this respect.

Methodology

With the advantages of semi-structured, in-depth, one-to-one private interviews in mind (see McCarthy, 1996), 46 people with learning disabilities from nine different service facilities in Flanders were interviewed. (Four residential facilities and one day care centre, each accommodating about 60 persons, and two group homes and two day care centres with an ability to care for ten to 40 people were chosen.) From among them, 34 interviews have been selected. The interviews appear in an interim report (and feature in this paper), and more interviews are planned for the author's doctoral research. The interviews with the remaining 12 people did not contain sufficient material to be included in this paper. Of these, 34 subjects between the ages of 20 to 65, 23 are women and 11 are men.

The staff at these facilities selected people with learning disabilities depending upon whether the latter were interested in being interviewed on these topics and, as Brown et al. (1996) suggest, upon their ability to communicate and understand. Confidentiality with respect to the interviews was guaranteed in the sense that the information acquired by the interviewees was not passed on to the staff. In a couple of cases, however, because of the wishes of the interviewees, some issues were discussed with staff. The participants were asked to speak about various topics relating to personal relationships and sexuality, e.g. being in love, having a boy/girlfriend, loving somebody, getting married, having children, sexual education, sexual contact and sexual abuse. The rational given to them by the author was 'in order that I might write a book about how people feel and think about these things'. People with learning disabilities are vulnerable during such interviews. The interviewer needs to understand that the way s/he communicates will influence the interviewee. Here it is essential that the interviewer actively listens and does not confuse the interviewee by bombarding him or her with suggestions (Brown et al., 1996). During the interview, it was made clear the interviewee was free not to answer the questions s/he did not want to. However, it is not completely...
true to suggest that people with learning disabilities have this freedom of choice because of the asymmetrical power relationship with the professional (Thompson, 1994). While it is quite possible that some did not tell me everything — nor would I wish them to — it is also probable that my gender (female) has had some effect (both positive and negative) on the interviews. The issue of reciprocity in the exchange of information was carefully considered (McCarthy, 1996) and I was, therefore, prepared to answer personal questions as well. Considerations of space do not permit full consideration of the ethical problems in this kind of research (but see McCarthy, 1999). However, citing Thompson (1996), one could say: it is difficult to imagine an alternative approach to understanding the sexuality of people with learning disabilities other than by listening to how both men and women with learning disabilities experience and understand sex and relationships.

What the interviews revealed

The overall impression was that most participants did not distinguish between the feeling of being in love and its expressed behaviour. Being in love was described by several participants as ‘having butterflies in your tummy’, ‘something that makes your heart beat faster’, ‘something that stirs up feelings of excitement (in the sense of anxiety)’ while other participants described it as ‘giving hands, hugging each other and caressing’. As to why they are in love with this particular person, they reported that they ‘love talking about everyday things with that person’. They loved doing things together, they wanted to be nice to each other and take care of each other ‘because love is the nicest possible thing on earth’, or because their partner is the source of their happiness: ‘true, I am happy, but it is X who gave me hope, and made me happy. Without X I felt so weak’.

Three women recently experienced difficulties in their relationships because they had just been abandoned by their partner which they found very hard to cope with. One woman concluded bitterly that her boyfriend was untrustworthy: ‘I had known him for a year. Now I am angry with him because he lied so much. I can’t bear that. I have suffered badly’. Most of the time they did not know why their relationships broke down and, it seems, there was hardly any counselling available to them regarding this: ‘I am not angry with him, you know, but he is angry with me. I have not wronged him. If I haven’t done anything wrong, he shouldn’t be angry with me. He shouldn’t do that — making me sad and annoyed, causing me such heartache when I think about it. But he doesn’t want to tell me what’s wrong’.

Several of the participants were in love with an unattainable person. For example, one person described the physiotherapist of the institution as ‘a prince on a white horse’. All she wanted was ‘the love of a married man’, and therefore expected no more than just a hug. The fact that he was unobtainable because he was a professional did not appear to enter into her considerations. Five participants reported to never being in love with anybody. Some put this down to their age; they felt too old for romance now: ‘Those things used to be very strict. Things like that were never discussed, you know. We were not allowed such things. If I am allowed to start all over again, if I were young again, I think I would do things differently.’ Another participant said he had never been in love, because he could not afford it: ‘boyfriends or girlfriends cost too much. You have to keep on buying all sorts of things for them’. One participant gave the impression that she had completely cut herself off from her own emotional life. She lived in a residential facility, did not like it very much, but realised that she could not change anything. Apparently, this made it difficult for her to create space for relationships, especially intimate or loving ones: ‘because I like to be on my own. That is easier, it’s better that way’. One woman said she would rather not fall in love ever again, because, having lost contact with the person she was in love with due to rehousing, she was still sad about that. Separation due to re-housing seemed a recurring feature in the lives of many participants.

Most of the time, love and the feeling of being in love were expressed in a way that did not go further than what is described in the Dutch literature as ‘the sexuality of the middle area’ (Bosch, 1995). This means that their intimate activity involved caressing, kissing, cuddling and hugging each other. It is striking that many of them answered the question whether they go further than mere caressing and kissing with a ‘we don’t do that sort of thing’. Many of the older subjects thought they were too old for sexual relations: ‘I think that it is not appropriate for me anymore, I am 60 you know’. Others thought that sex is disgusting and dirty.

Thirteen participants indicated that they did not want anything more than kissing and cuddling yet. Although in some cases more would not be allowed by their parents, they did not object to this restriction. Women and men felt they ‘should take it easy at first’, ‘prefer waiting a bit longer’. Four women indicated that they did not want their boyfriends to rub their breasts, for the fear of pain: ‘it can hurt when they squeeze that’. In general, women indicated that they expected tenderness and gentle manners from their boyfriends. In this respect, intercourse was perceived as rather aggressive and thus to be avoided.

But six other participants, while answering with a ‘we don’t do that sort of thing’, nevertheless explicitly expressed the wish to go to bed with their boy or girlfriend, stroke their breasts, etc. However, we found that most couples did not reach this stage because they were never alone. They were never allowed the necessary privacy for sexual intimacy to develop and physical gestures of love were frowned upon: ‘We are not allowed to do that, we would be punished and I’m not risking that’. Even though some of them had not directly experienced censure by the staff, they were afraid that intimate or sexual behaviour would not be tolerated within the premises. Consequently, they did not dare mention their desires in this respect.

Nine people had sex with their partner (friend). One woman did have sex with her female room-mate and described it as pleasurable. Three women were not very enthusiastic about their heterosexual experience. The women played a rather passive role or had sex because their boyfriend liked it: ‘I did not really like it. I did it more as a game. He liked it, I didn’t’. One woman described how she had some pain when they started
Although some of the participants had received sex education—from their parents, the authorities (at school or specific training programmers) or the staff—they lack of sexual knowledge was striking. Most of those who answered the research questions were not capable of naming their genitals—not in their own terms and definitely not in (basic) biological terms. Quite a few assumed that women and men were different from each other, but were not able to say why. One person had a very good explanation for her lack of knowledge: 'You read all these books and magazines, so you know all those things. I do not read any of those, you know.' When people with learning disabilities have difficulties even in naming the genitals, it should not be surprising that knowledge of their functions is absent. Concepts like masturbation or orgasm were foreign to them. Very few could say how babies are made; most were confused in this regard; the origin of egg cells and sperm was mostly mixed up as well. Questions about how a baby is born were answered by 'children come from the man's penis, which is very tense then and has an urgency'. However, it was noticeable that couples who had a regular sex-life in a lasting relationship were better informed. Despite their lack of practical experience, some older women, who seemed to have read some literature on the subject, also knew more about it.

**Reflections**

During the course of this research, I met different people, each with his/her own story, needs and wishes. Some of them had never been in love and did not feel the need for it; some were in love but did not see the need for profound sexual perceptions, while others explicitely expressed their wish to go further than cuddling and kissing their partner. Our research has many similarities with previous research in the UK: those how have had sexual contact are not always unreservedly happy about it, partly because of abuse in some cases. Positive emotions such as tenderness and care are frequently absent (Burns, 1998). Women with learning disabilities tend to be the passive partners, 'their sexual pleasure is conspicuous only by its absence' (McCarthy, 1996). Only those couples who have a lasting relationship have found an extra dimension and pleasure in sex. They seem to have stable and loving relationships, exhibiting respect for each other's feelings and wishes, experiencing and experimenting on the basis of mutual consent. In this regard, it is very important to give such people the time and the space to grow in their relationships (Van Hove, 1999).

Unfortunately, one major constant feature emerged from all this information: when one examines why a relationship (or its absence) is perceived in a certain way, the institutional way of life seems to be greatly responsible for such a perception. One can ask oneself whether the needs and wishes expressed by the people with learning disabilities actually corresponds to their personal perception—perhaps as a result of having a learning disability. Alternatively, it might have something to do with their life story, the way they are approached by others and the (institutional) position they take with respect to other people. Constant shifting of the staff, support-workers or the people they are living with, creates the possibility that they no longer want to
become attached to some particular person. Nevertheless residential facilities and day care centres are characterised by 'live-in groups'. Living constantly in a group environment makes it practically impossible to have a normal relationship (McCarthy & Thompson, 1998). Not allowing expressions of passion because they do not fit within the group raises questions about privacy and the individual's rights to have physical relationships. Many residential or day care centres have too many structural and organisational problems to even allow relationships between subjects, let alone value them. One could agree with McCarthy & Thompson (1998) when they state that time and place affect sexual relationships: when sex takes place hurriedly in a non- or semi-private place, it tends to be limited to quick penetrative sex and therefore not (always) satisfying for both partners. Due to financial and structural reasons and, perhaps, an unjust attitude, the staff still provide little or no practical or emotional support to people with learning disabilities. Professionals should be creative in finding ways to minimise the structural pressure exerted by the care facilities on the personal needs and wishes of people with learning disabilities. Staff, parents, and society at large should be aware of how the environment can shape a person's sexuality, for better ... or for worse.

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References

RESPOND TRAINING COURSE
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Following a grant award from the Department of Health, Respond is pleased to offer a unique training opportunity for Spring 2000. This 10 week training course will enable professionals from a variety of disciplines (e.g. social workers, psychologists, student counsellors, occupational therapists, etc.) to develop their understanding of and skills in, one-to-one psychodynamic counselling for people with learning disabilities who have experienced sexual abuse.
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- Emotional impact of a learning disability
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Memoranda of Agreements
Applicants must be actively engaged in one-to-one work with clients and have at least two years post qualification experience working with people with learning disabilities.
Time commitment
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