

SEXUALITY OF CLIENTS WITH SPECIAL NEEDS

‘Touching people in relationships’: a qualitative study of close relationships for people with an intellectual disability

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Aims and objectives. To explore the experiences and perceptions of close and sexual relationships of people with an intellectual disability.

Background. Positive interpersonal relationships are beneficial for people with an intellectual disability, acting as a protective barrier against, social stigma and negative outcomes such as physical and mental health problems. The social networks of people with an intellectual disability are, however, often more restricted than those of the general population. There has been very little research exploring the views and experiences of people with an intellectual disability about social and sexual relationships.

Design. Exploratory study using a qualitative research design.

Methods. Semi-structured interviews were conducted with 10 (6 male, 4 female) participants. Data were analysed using interpretive phenomenological analysis.

Results. ‘Touching other people in relationships’ was identified as a superordinate theme. The theme was represented by five subthemes: ‘Is wrong’; ‘Unsafe to talk about’; ‘Suggesting is safe’; ‘No freedom or fun’; and ‘Being touched’. The findings presented are drawn from a larger qualitative study.

Conclusions. The findings highlight the importance of touch and sexual behaviours in the close relationships of participants. Negative perceptions were observed to surround sexual behaviours. Rules and restrictions regarding physical contact were also described.

Relevance to clinical practice. Disseminating these findings may increase awareness of the importance of physical contact in the close relationships of people with an intellectual disability and promote positive support arrangements.

Key words: experiences, intellectual disability, qualitative, relationships, sexuality

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Introduction

It has been well documented that the social networks of people with an intellectual disability (PWID) are often more restricted than those of the general population (Wiener & Schneider 2002, Pockney 2006). As such PWID do not have the same opportunities to develop and engage in interpersonal relationships and are often socially isolated

(Department of Health 2001, A. Lafferty, University of Ulster, Ulster, unpublished PhD Thesis). This is concerning as an individual’s interpersonal relationships are considered to be protective (Heiman 2001) and an indicator of quality of life (Brown 1993, Cummins & Lau 2003, Power *et al.* 2010).

There is debate surrounding the cause of the difficulties PWID encounter regarding interpersonal relationships. Some

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discuss internal factors, such as social skills (Wiener & Schneider 2002), communication and emotional literacy difficulties (McKenzie *et al.* 2001, Brackenridge & McKenzie 2005). Others highlight the role society plays in the diminished social networks and relationships of PWID. L. Mills (University of Edinburgh, Edinburgh, unpublished PhD Thesis) described society's 'lack of acceptance', experienced by PWID through lacking opportunities or negative attitudes (Pockney 2006). A combination of these factors has also been proposed, which suggests that PWID are less able to defend themselves against others' prejudice and preconceptions 'regarding what they think, want and feel' (Lesseliers & Van Hove 2002, p. 69). A dominant discourse was identified by R.D. Wilson (The University of Leeds, Leeds, unpublished DCLinPsy Thesis) that PWID are naïve and dependant and those who support them are knowledgeable and responsible. Potentially, this understanding, in combination with a poor ability to defend themselves, has contributed to PWID's limited interpersonal relationships. This has occurred as parents and professionals tend to define the boundaries of PWID's responsibilities, freedom (Lesseliers & Van Hove 2002), and in turn, their interpersonal relationships.

Most people with mild or moderate intellectual disabilities (ID) are capable of, and show, a desire for sex and sexual contact (Craft 1987). However, the false assumptions of others have had a negative influence upon their sexuality and sexual relationships. Historically, two contradictory assumptions were particularly influential. The first, that PWID needed protecting from sexuality as they were considered to be 'eternal children' (McCarthy 1999, Yau *et al.* 2009) without sexual feelings (Bunyan *et al.* 1986, McCarthy 1999, Taylor Gomez 2012). The second, that society needed to be protected against PWID's pronounced sexuality (Lesseliers & Van Hove 2002, Taylor Gomez 2012). These perceptions resulted in the sexual relationships of PWID being considered controversial and distasteful by many (Bunyan *et al.* 1986). Consequently, any interest in sexual relationships or signs of sexual behaviours were repressed, discouraged or misunderstood (McCarthy 1999). Also, many PWID were placed in gender segregated institutions, to prevent heterosexual behaviour.

The adoption of the normalisation principle in the 1970's led to deinstitutionalisation and an end to segregated living. It also signified a general shift in attitudes and beliefs. Alongside these changes came the hope and aim of enabling PWID to live as normal a life as possible, including sexuality (McCarthy 1999). These principles

were also reflected in later policy documents including 'The same as you?' (Scottish Executive 2000) and 'Valuing People' (Department of Health 2001). Although services no longer denied or explicitly repressed the sexuality of the people they supported, they developed a role managing the sexuality of PWID (McCarthy 1999), based upon the preconceptions and views of nonintellectually disabled individuals. This management did not prevent sexual behaviour, but did discourage it through rules and restrictions, or a lack of education and support required to develop psychosexual maturity (Taylor Gomez 2012). Such discouragement could stem from the prejudice of those who directly support PWID or from a lack of direction and confidence in the normalisation reforms (Löfgren-Mårtenson 2004). Whilst the principles promoting the rights of sexuality for all have been adopted, it is proposed that a lack of consideration regarding how these principles are translated into practice (Johnson *et al.* 2002) has resulted in a lack of support for parents, carers and PWID (Change 2010, Pownall *et al.* 2012, A. Lafferty, University of Ulster, Ulster, unpublished PhD Thesis). As such, those directly supporting PWID frequently generate barriers to sexuality, even though the old assumptions have been challenged and institutional barriers have been removed (Löfgren-Mårtenson 2004).

However, it has been observed that PWID are starting to take control of their sexual lives (McCarthy & Thompson 1995, Department of Health 2009) and are more commonly being seen as agents in their own lives (Lesseliers *et al.* 2010). This is reflected in an increase in the positive promotion of sexuality (McCarthy & Thompson 1995, Scottish Executive 2000, Department of Health 2001, 2009, Mental Welfare Commission for Scotland 2011), alongside campaigns by PWID themselves (Learning Disability Coalition 2012). It has also been documented within the growth of the self-advocacy movement (McCarthy 1999) and an increase in the prevalence of qualitative research, both of which facilitate PWID to express their views about sexuality and sexual relationships. These developments enable the voices and opinions of PWID to replace the previously dominant assumptions and opinions of nondisabled individuals. They also enable PWID to begin to influence practice, policy and, most importantly, their own relationships. However, there has been very little research which has explored the views and experiences of PWID about their social and sexual relationships (Knox & Hickson 2001; A. Lafferty, University of Ulster, Ulster, unpublished PhD Thesis; R.D. Wilson, The University of Leeds, Leeds, unpublished DCLinPsy Thesis).

The current study aims to extend the limited previous research by addressing the gap in the qualitative literature regarding PWID experiences and perceptions of close relationships in general. This wider focus has been chosen to provide PWID with the opportunity to describe relationships that are important to them. The study adopts an exploratory position and is not hypothesis driven. However, it is hoped that the process will facilitate the exploration of close relationships for these individuals, which may highlight valued and difficult aspects of interpersonal relationships.

Methods

Aim

The research aimed to explore the experiences and perceptions of close relationships in PWID.

Design

A qualitative design using interpretive phenomenological analysis (IPA: Smith & Osbourne 2003, Smith & Eatough 2007, Smith *et al.* 2009) was selected to explore participants' views and perceptions in an area where there was limited previous research. IPA was considered more appropriate than other qualitative methods as it is 'concerned with experiences which [are] of particular significance to the person' (Smith *et al.* 2009, p. 33), and it acknowledges other influential aspects such as historical and cultural factors, social norms and practices (Eatough & Smith 2006). The interpretative component and transparency of the researcher's context were also aspects that contributed to its selection.

Sample and setting

Participants were recruited in central Scotland, through People First Scotland (PFS), a nationwide advocacy organisation for individuals with ID. It was considered beneficial to recruit from an advocacy organisation as members would be better placed to make decisions about consent (Nind 2008) and express their experiences and opinions with a professional. Participants self-elected to take part in the study following an invitation to participate provided by PFS Development Workers. As IPA calls for sample homogeneity, participants were recruited using a purposive sampling method. Inclusion criteria detailed that participants should be adults (aged 18 and over), who were willing to be interviewed independently and considered themselves to have ID, as indicated by their membership

of PFS.¹ Participants had to be able to provide informed consent and have English as their first language and expressive language abilities sufficient to allow them to participate in the interview process. Individuals were also required to live in the community, with a maximum of three other adults, excluding individuals living in large group accommodation. Potential participants were excluded if they were currently experiencing severe mental health difficulties or were involved in ongoing adult support and protection procedures or other proceedings relevant to relationships or sexual activity.

Prior to interview and obtaining written consent, an accessible document detailing the project and procedure was provided and presented by the PFS Development Worker and researcher, to ensure that participants understood what participation would entail. This also provided an opportunity to ask questions.

Ten participants were recruited. All were White and Scottish. A table summarising participant characteristics is presented in Table 1.

Data collection

Interviews were arranged at a time and place of participants' choosing. Venues included day centres ($n = 7$), homes ($n = 2$), PFS premises ($n = 1$) and a local community venue ($n = 1$). Interviews were semi-structured, facilitated by an interview schedule. This was developed prior to interview in line with IPA methodology, using open questions and prompts, as PWID often find open questions problematic (McCarthy 1999). Questions focused on participants' experiences of close relationships, what these meant to them and what they valued in close relationships. Interview length average 53 minutes. All interviews were digitally recorded and transcribed verbatim.

Data analysis

Transcripts were analysed by the first author using the procedure described by Smith *et al.* (2009), outlined in

¹It is important to note that members of PFS choose to be referred to as having 'learning difficulties' rather than 'learning disabilities' as is commonly used amongst professionals (e.g. British Psychological Society 2000, Department of Health 2001, 2009). Their chosen term emphasises that people have the capacity to learn when difficulties in the learning process are overcome (Harris 1995), which is in line with the social model of disability and also emphasised that these difficulties are not only located within individuals but also within their social environment (Hollomotz & The Speakup Committee 2008). As such, all documents used with participants used the term 'learning difficulties'.

Table 1 Demographic information relating to participants

Participant pseudonym	Gender	Age group	Living arrangement	Number of adults living in accommodation	Daily activities
Lesley	F	41–50	Own Home	1	VW
Lucy	F	31–40	Family Home	3	DC
Chloe	F	31–40	Family Home	2	DC + VW
Keith	M	51–60	Own Home	1	I + E (past)
John	M	31–40	Own Home	1	I
Tim	M	41–50	Family Home	3	DC + VW
Guy	M	41–50	Family Home	3	DC
Oliver	M	51–60	Family Home	3	DC + E
Jane	F	51–60	Family Home	3	DC
Ben	M	51–60	Family Home	2	VW

DC, day centre; E, employed; VW, voluntary work; I, spends time independent of services and employment.

Table 2 Summary of interpretive phenomenological analysis analytic process

Stage	Description
Stage 1: Reading and rereading	Researcher becomes immersed in the data through repeatedly reading transcripts and listening to audio recording of interview
Stage 2: Initial noting	Initial notes made which highlight the content of the account, use of specific language and potential conceptual and contextual elements
Stage 3: Developing emergent themes	Identify emergent themes through exploration of patterns across the original text and initial notes
Stage 4: Connections across emergent themes	Connections across emergent themes explored to produce higher level superordinate themes by looking for connections across emergent themes
Stage 5: Moving on to the next case	Steps 1–4 were repeated for each transcript, allowing new themes to emerge from each case, whilst not being influenced by previous analysis findings as far as is possible
Stage 6: Looking for patterns across cases	Superordinate themes from each transcript are examined to identify recurrent and isolated superordinate themes. A constant iterative process leads the movement from individual to overarching themes, which lead to integration and production superordinate themes that represented the whole cohort

Table 2. Exploring the meaning of the experiences (or phenomena) for participants is key, but IPA also requires the researcher to interpretively engage with the data (Smith 1996), facilitated by the use of a reflective diary and supervision throughout data collection and analysis.

Validity

The analysis process and resulting themes were validated by triangulation with the second author. Participant feedback was also obtained from seven participants who all reported general agreement with the research findings, with one exception. The original theme title, 'Physical Intimacy', was not found to be an accessible phrase for participants and was subsequently changed to the current title, 'Touching people in relationships', suggested by one of the participants.

Ethical considerations

The project and materials were reviewed and approved by PFS's Chairs Committee and The University of Edinburgh, according to the guidelines of the School of Health Research Ethics Committee. A number of ethical issues were addressed through the use of an accessible information booklet. This highlighted that participation in the project was voluntary and that people could withdraw or not answer questions at any time. It also outlined the researcher role, what would occur if participants became distressed, confidentiality procedures and when these might be broken.

Results

Five superordinate themes were identified: 'Relationships feeling safe and being useful'; 'Who's in charge?'; 'Struggling for an ordinary life'; 'Hidden feelings'; and 'Touching people in relationships'. This article describes and explores the latter theme. 'Touching people in relationships' was discussed by eight participants. The main areas discussed were, kissing, hugging, holding hands and sexual behaviours such as sleeping in the same place as their partner, touching other's private areas and having sex. The researcher observed that these

descriptions were often associated with some embarrassment, suggesting that the topic was seen as 'taboo'. It was considered that the challenges participants experienced when discussing the area highlighted its importance. Further, when it was broached, it was accompanied by an emotional intensity which had a very powerful impact on the interviewer. Whilst not all respondents talked explicitly about physical touch and intimacy, the accounts were sufficiently rich to enable analysis of the content. Five subthemes were found to relate to touch and physical intimacy: 'Is wrong'; 'Unsafe to talk about'; 'Suggesting is safe'; 'No freedom or fun'; and 'Being touched'. Each will be discussed and illustrated using verbatim extracts. The source of extracts is indicated by participants' pseudonyms. To maintain confidentiality, all identifiable information has been changed. Where quotes have been edited for succinctness ellipses [...] indicate omitted material and [] indicates additional information added by the researcher.

Is wrong

Where touch in the form of sexual behaviours was explicitly discussed, it was often considered that such behaviours were seen by others as wrong and a negative thing to do:

My friend...I said to my mother, um, I'm going to invite her to stay with at my house and she turned around and said well if you're going to do that don't come back to the house...I phoned her mother to say that, um, I'll have to ask her to leave because my mother says if I'd if I have her in the house then she's going to disown me. (Keith)

Somebody said we were having sex, but we weren't having sex at all, we were just chatting [...] and they took us down and put us in detention together. (Lucy)

Both Keith and Lucy encountered negative reactions at the mere possibility of sexual behaviours occurring. The participants seemed aware of the potential for further negative judgement during the interview and appear to distance themselves from sexuality in their descriptions, illustrated by Keith's mislabelling of the couple relationship and Lucy's presentation of a very acceptable alternative behaviour. Both experiences convey a clear message that sex is a bad thing, also illustrated by Jane who feared others' reaction to the extent that she did not tell her family about her experience of being raped:

I was in hospital for ten days, I was in hospital for ten days [...] I didn't tell my family [...] because I was too scared to tell them.

Choosing to conceal the rape suggests that even though sexual intercourse was experienced as the result of a violent

act this was perceived as unlikely to lessen the negative views of others. All of the participants' experiences also convey a powerless position, where others' opinions were dominant and must be followed.

Unsafe to talk about

When circumstances occurred that could be interpreted as times where sexual behaviours may have taken place, it was observed that participants were anxious to defend against this possibility. For example, prior to this extract, Chloe described that close relationships involved sexual intercourse:

Int.: ...have you got any close relationships?

Chloe: No [quick response, definite tone].

Int.: Have you ever had a close relationship in the past?

Chloe: I've got a relationship with a boy here [...] but he doesn't do nothing like that [clear tone].

Chloe makes it very clear that her relationship is nonsexual. The tone and speed of her response to clarify the nonsexual status of her relationship emphasises the importance of not being misunderstood and suggests that sexual behaviours would not be acceptable within their relationship. Others were also observed to defend against such interpretations:

Well I used to go to his house, and he used to invite me to tea, and then I used to go home at night. (Jane)

So I took her up to the house, two or three hours. We had our dinner, we went and done a couple of things had a chat up the stairs. So that was fine, quite happy. (Ben)

Um, she makes me a coffee, I make her a coffee, we have a coffee, we'll listen to a CD in the bedroom or we'll go for a lovely walk. We'll have lunch together. (John)

Spending time together as a couple seems important to all participants. The specification of locations commonly associated with sexual behaviours by Ben and John may be related to a wish to be viewed as adults who have freedom and are trusted to spend time alone in these locations. However, their clarification of these times as nonsexual suggests the importance of defending against such behaviours. This was even observed when participants were able to stay in the same room as their partner overnight:

I used to stay overnights. I used to, first I used to sleep on the floor in the room, she had a double, a single bed and then her sister got a camp bed and I used to stay overnight. (Ben)

The significance of staying at his girlfriend's overnight is clearly conveyed by Ben. However, anxiety that the situation could be misinterpreted is indicated by his clarification that they slept separately. The involvement of others being required for the couple to stay together suggests a public development and external management of the relationship. Further, the purchase of a camp bed rather than double bed could be interpreted as others' residual discomfort and a fear of promoting sexual behaviours in a couple with ID. All of which are likely to have influenced the couple's behaviour and feelings about sexual behaviours.

Suggesting is safe

In the light of the negative context in which sexual behaviours were viewed, participants often made indirect reference to physical relationships:

Int.: Does that mean your relationship will be different if you get engaged?

Tim: It means it will still be the same [...] until Sarah gets used to it [...] until Sarah gets into the relationship.

Um, well we, we, we went and cuddled and we kissed each other [...] and then things developed and we've always seen each other since. (John)

Both Tim and John describe that the development of their relationships would lead to a change in the couple's behaviour, but neither openly states what this means. The language and descriptions are akin to what one would expect of adolescents in a relationship where sexual behaviours are going to be experienced for the first time. Such vague descriptions may have been used due to embarrassment at discussing such an intimate area with the interviewer who was a relative stranger. However, it may also have been used to self-protect against potential negative judgments, as hesitation and suggestive language were observed even when participants felt comfortable discussing sex:

I did have a brief um affair with May which was, um, that was just a sort of, kind of I don't know what you would. A natural thing. (Keith)

Here, Keith refers sexual behaviour as a 'brief affair', which only implies a sexual experience. Interestingly, this term is commonly used in a negative way. Although this is his label, the connotations it implies seem to be defended against later, when he describes the experience as a 'natural thing'. This could reflect an inner conflict between the understanding of sex being wrong and sex being a natural process.

No freedom or fun

Throughout the interviews, restrictions and negative experiences were strongly associated with sexual behaviours, which seemed to influence the participants' ability, perception of and desire to engage in them. This association could be derived from the behaviour and information provided by others or from participants own experiences:

No, I'm not allowed. I can't [...] they don't let me [...] it's just the rules in the place. They don't let anybody stay overnight. (John)

The involvement of third parties in relationships limited John's ability to stay overnight. The power others hold over relationships is clearly conveyed alongside the message that sexuality is wrong, indicated by the blanket rule regarding overnight stays. All of these aspects appear to result in infrequent opportunities to engage in sexual behaviours in complete privacy. The power of others was also observed through the provision of information about sexual relationships. For example, Chloe described receiving teaching about relationships; however, the information she provided indicates that what she was taught or what she had retained had left her with a skewed perception of sexual behaviours within relationships:

Int.: ...what do you think close relationships are?

Chloe: I think they just make love, ken, man and wife and he just makes love to her [...] it's all about like, how to make babies and how like that. And how the, how the man puts his penis in the, the lady's vagina and then makes the egg and then there's a baby.

It seems that sexual relationships were understood to only occur within marriage only for the purpose of procreation. This perception could be related to some religious understandings of sexuality or information provided to inhibit sexual behaviour. However, the absence of contraception or pleasure from Chloe's description suggests the latter is true. This is also supported by sex being presented as male dominant and mechanistic. Conversely, this simplistic presentation could be contributable to expressive language difficulties (Lloyd *et al.* 2006).

Participants' were also influenced by their own negative experiences. Three of the participants had experienced rape or sexual assault, within and outside of relationships:

...I don't think I'll be ready for that because, um. But I did say to the person that I was raped when I was sixteen and I thought about especially women, um, what they get, well not in the same sort of, kind of way but [...] you have to think about your own safety as well as the other person, because you're doing it [...] and

about, um, your responsibilities [laugh] [...] And also, um, about the persons responsibilities... (Keith)

Keith's experience of rape had focused his attention on risks and potential responsibilities that come with sexual relationships. The impact of rape was also discussed by Jane:

I had to go to the hospital to get an abortion as well. I had to get rid of it as well and it wasnie, it wasnie my doing, but I just had to get it done [...] because, um, I was surely, I should say raped. Really bad. Really bad. It was horrible. (Jane)

It is clear by Jane's use of language that she did not perceive that she had a choice regarding the abortion. It is possible that the abortion was advised due to the conception occurring within rape. However, Jane later explained that she would never be able to have a child; as such, it seems that not having children was the choice of others:

...I can't have babies or anything like that. I can't have any more, that's why I had an abortion because I couldn't have any. (Jane)

Being touched

Half of the participants interviewed made no reference to sexual behaviours, but it was still made clear that touch was an important aspect of relationships:

Int.: ...do you think that it's important to have a close relationship?

Guy: Aye.

Int.: What's, what's important about it?

Guy: herrr, holding her hand.

Lucy also described the significant value and meaning of physical contact, relating it to emotional closeness within a relationship:

I felt closer to William than I did, than I did to Ben [...] because he used to, he used, he used to put his two arms around me [...] instead of just one it was two [...] It made me feel more secure. (Lucy)

It is possible that the closeness Lucy described is actually physical closeness, and the security referred to describes the feeling of being held by another. However, both forms of touch described would also act as a clear sign to others of intimacy within a relationship. Thus, the attachment that these overt symbols represent may also be a key factor in the positive feelings described.

Discussion

There has been an increasing emphasis on the importance of promoting positive relationships, including sexual relationships for PWID, as reflected in the policy document 'Valuing people' (Department of Health 2001) which noted the need for services to 'help people with learning disabilities develop opportunities to form relationships, including ones of a physical and sexual nature' (p. 23). The results of the current research suggest that this recommendation has only been partly successful in changing the experiences of PWID in relation to sex.

Participants predominantly discussed physical intimacy in the context of boyfriend-girlfriend relationships. Behaviours such as kissing, hugging and holding hands were discussed openly, and touch was described as an important aspect in close relationships. Sexual behaviours were referred to much less frequently and were generally referred to indirectly by participants. This is interesting given that the cohort were all in a stage of life where sexual relationships would typically be developing or established (DeLamater & Friedrich 2002). Previous research regarding close and couple relationships of PWID also found that sexual behaviours were only spoken about directly by a few participants (A. Lafferty, University of Ulster, Ulster, unpublished PhD Thesis) or not at all (R.D. Wilson, The University of Leeds, Leeds, unpublished DCLinPsy Thesis). Both authors discussed the impact of cultural constraints upon participants' accounts, which were considered to be influenced by participants' limited opportunities to engage in such behaviours and potential disapproval from others (A. Lafferty, University of Ulster, Ulster, unpublished PhD Thesis). This is echoed in the current study by the interpretation that participants may have felt unsafe discussing sexual behaviours, which were perceived to be wrong. R.D. Wilson (The University of Leeds, Leeds, unpublished DCLinPsy Thesis) also suggested that participants may feel uncomfortable talking to an unfamiliar person. This was discussed by two participants in the current study during the feedback session. Both described feeling shy talking about the area, but also described that the topic should be kept private and should not be talked about outside of the relationship. These comments could reflect a natural desire for privacy or embarrassment (Change 2010, Bane *et al.* 2012) at discussing such a personal area with a relative stranger. However, they could also reflect the interpretation proposed by the authors and several other researchers (Yau *et al.* 2009, Change 2010, Fitzgerald & Withers 2011) that sexual behaviours are understood by PWID to be something that is wrong and that should not be spoken about

at all. This was illustrated in the current research by sexual behaviours being concealed and participants defending against being associated with such behaviours.

The basis of negative perceptions surrounding the sexuality of PWID has also been examined in the literature. Areas discussed have included, sex education that only focused on biological or negative aspects of sexuality (Yau *et al.* 2009, Change 2010), others negative perceptions of sexual behaviours in PWID (Johnson *et al.* 2002), others negative reactions to couple relationships in PWID (Thompson 1994, A. Lafferty, University of Ulster, Ulster, unpublished PhD Thesis), being punished for intimate behaviours (Kelly *et al.* 2009) and negative sexual experiences (Thompson 2001, Yau *et al.* 2009, Fitzgerald & Withers 2011). All of these were described by participants within the current research.

A 'high level of supervision and external control' was described by R.D. Wilson (The University of Leeds, Leeds, unpublished DCLinPsy Thesis, p. 110) in relation to couple relationships, which was mirrored by a lack of freedom within the current research. A review of the literature highlights that restrictions and regulations are dominant factors in the couple relationships of PWID. Participants in several studies described a lack of privacy (Knox & Hickson 2001, Lesseliers & Van Hove 2002, Yacoub & Hall 2008) and being monitored by others (Löfgren-Mårtenson 2004, Kelly *et al.* 2009, A. Lafferty, University of Ulster, Ulster, unpublished PhD Thesis). Some had been told that sex was not allowed (Wheeler 2007, Change 2010, Fitzgerald & Withers 2011), others were warned against sexual behaviours (White & Barnitt 2000, Yau *et al.* 2009) or told such behaviours were only acceptable in marriage or when living independently (Yau *et al.* 2009). Many of these issues were also presented within the current research. This highlights the need for support and guidance for families and staff groups regarding the translation of principals and policies (Scottish Executive 2000, Department of Health 2001) into reality regarding the facilitation of safe and positive sexual relationships for PWID, which is necessary to address the human rights of this population.

Despite the restrictions, barriers, negative perceptions and negative experiences of this population, this research and several other studies (Craft 1987, Kelly *et al.* 2009, Yau *et al.* 2009) have found that PWID value and desire touch and sexual behaviours in their close relationships, which clearly highlights its importance in their lives.

Limitations

The current study has limitations. IPA recommends a homogenous sample so that the findings may be more gen-

eralisable to a specific population (Smith *et al.* 2009). Although the current sample was generally homogenous, variation was present regarding their age, living arrangement and support services. Further, members of PFS do not have to be diagnosed as having an ID as defined by the British Psychological Society (2000). It was not considered to be ethically appropriate to conduct formal diagnostic assessments with potential participants which means that some may not have met the criteria for ID.

Measures were taken to ensure that the process of the research project and the limitations of the researcher role were made clear to participants prior to their participation, as this is a common area of difficulty experienced when conducting research with intellectually disabled participants (Nind 2008). However, several individuals made comments regarding the number of meetings or the role of these meetings which indicated that this information had not been fully comprehended. Although the procedure developed with PFS to manage such situations worked well, the experience highlights the importance of researchers reiterating information and being sensitive to potential misunderstanding and misinterpretation.

Finally, as the study required that participant's expressive language abilities were sufficient to participate in an interview process, many members of PFS were excluded from taking part and sharing their experiences. As such, future research should seek to develop new strategies to allow individuals with more impaired language abilities to participate.

Relevance to clinical practice

The findings clearly indicate the importance of close relationships and the physical contact that occurs within these to PWID. Highlighting the negative impact that rules, restrictions and negative attitudes have on the close relationships of PWID may encourage changes in services and supports.

Participants also experienced a lack of support when developing, maintaining and dealing with difficulties within their relationship. As such, services should consider providing training and supervision to staff (A. Lafferty, University of Ulster, Ulster, unpublished PhD Thesis; R.D. Wilson, The University of Leeds, Leeds, unpublished DCLinPsy Thesis) and materials and support for parents of PWID (Change 2010, Pownall *et al.* 2012). This could change perceptions and increase confidence, which may enable the provision of appropriate support.

This research and other projects (Change 2010, Pownall *et al.* 2012) found that the information being provided regarding sexual behaviours and relationships is often limited (Change 2010). It may be helpful for services to con-

sider whether their relationship and sex education provisions are sufficient. It is suggested that sex education should focus upon PWID's right to sexual relationships. They should also present a representative picture of relationships and provide information about desire and pleasure (Kelly *et al.* 2009), as the general message conveyed by participants was that sexual behaviours were wrong and should not be spoken about. Further, as information acquired during sex education is not always translated into practice (Thompson 1994, Yacoub & Hall 2008), the efficacy of supports also needs to be considered.

Finally, the study found that opportunities to develop close relationships and engage in sexual behaviours were limited. As such, services need to consider how they can assist PWID to experience more freedom and increased privacy in relationships.

Contributions

Study design: FS, KB, KM, EQ; data collection and analysis: FS, KB, EQ and manuscript preparation: FS, KB, KM, EQ.

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