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Intellectual disability, sexuality and sexual abuse prevention

A study of family members and support workers

Background

People with intellectual disability experience difficulty forming intimate relationships and are prone to sexual exploitation and abuse. This study sought information from people involved in the care of adults with intellectual disability regarding how they supported them in the areas of sexuality, relationships and abuse prevention.

Methods

Semistructured interviews and focus groups were held with 28 family members and paid support workers caring for adults with intellectual disabilities. Interviews and focus groups were audio recorded, transcribed, coded and analysed qualitatively.

Results

Major themes emerging included views on sexuality and intellectual disability, consent and legal issues, relationships, sexual knowledge and education, disempowerment, exploitation and abuse, sexual health and parenting.

Discussion

People with intellectual disability were described as lonely, disempowered and vulnerable to abuse. The sex industry, internet and mobile telephones were identified as new forms of risk. While this study looked at the views of both family members and support workers, the sample was too small to identify any meaningful differences between the two groups.

Keywords

developmental disabilities; education, health (to lay people); sexuality; vulnerable populations; contraception; women's health In recent decades, people with intellectual disability have moved from institutional to community living,¹ with a resultant increase in the use of mainstream housing and social and health services including general practitioners. General practitioners recognise that people with intellectual disability have specific needs and face particular problems, but may experience difficulty addressing these needs.²

Many people with intellectual disability live in supported accommodation,¹ or with family, and many lack jobs, meaningful activities or close relationships in their life.^{3,4} Unrecognised health problems,⁵ mental illness^{6,7} and psychotropic prescribing⁸ are more frequent in people with intellectual disability than in the general population, and challenging behaviours can also be a problem for some.⁹

Sexual relationships in people with intellectual disability present a particular challenge. Attitudes have shifted from viewing people with intellectual disability as asexual 'innocents' or 'oversexed' potential sex offenders to recognition of their sexual needs and rights.^{10–12} However, attitudes toward sexual expression may remain restrictive.^{13,14} People with intellectual disability express desires for intimate relationships¹⁵ but report limited opportunities^{16,17} and difficulty negotiating relationships.¹⁸ Sexual knowledge in people with intellectual disability has been shown to be poor^{19,20} and access to education limited despite the development of appropriate programs.^{21,22} Capacity to consent to sex may be limited or difficult to assess,²³ and social and legal rules regarding sexual behaviour may be confusing.²⁴ Laws addressing sexual exploitation^{25,26} may be interpreted as prohibition of relationships.

People with intellectual disability are prone to physical, psychological and sexual abuse.²⁷⁻³⁰ These problems may present to GPs as mental illness and/or challenging behaviours. Perpetrators may include family members, support workers, intimate partners and co-residents.15,31-33 People with intellectual disability may lack the assertiveness to report abuse or the verbal skills to describe it. When abuse is reported, responses may be inadequate. Lack of sexual knowledge, relationship experience and protection skills³⁴ may increase the risk of abuse and impair the ability to recognise an experience as abusive.^{31,35,36} Innovative and successful support programs have been developed, such as the Australian 'Living Safer Sexual Lives' initiative,37 but availability of these programs is often limited.38

We have previously interviewed women with intellectual disability about sex, relationships and sexual abuse.³² This study aims to add the perspective of those involved in the care of people with intellectual disability.

Methods

Semistructured interviews and focus groups were conducted between August and October 2010 with family members and paid support workers caring for an adult (aged 18 years or over) with intellectual disability. A participant was eligible if they provided significant support, was aged 18 years or over and was able to participate in English. Four community organisations and a clinic providing services to people with intellectual disability were invited to circulate information about the project to support workers and family members.

An outline was used to prompt discussion about relationships, sexual knowledge and education, consent and legal issues and protection skills. Interviews and focus groups lasted 40–75 minutes and were audio recorded and transcribed. Coding was carried out using NVivo[®] software. Initial themes emerging were coded and revised as more data was added and subthemes emerged. Themes identified in the first study³² were reviewed and the current transcripts examined looking for similar themes. The initial coding was carried out by the interviewer (GE), reviewed by a co-author (ES) and modified to reconcile differences.

Ethics approval for the study was granted by Bond University Human Research Ethics Committee.

Results

Twenty-eight participants agreed to participate in either an interview or a focus group. Ten individual interviews and three focus groups were conducted. Interviews were held with seven family members, all female (five mothers and two sisters) and three support workers, one female and two male. Focus groups were held with 18 participants, five family members (all mothers) and 13 support workers (10 female and three male). Two family members also worked as support workers. Focus groups with family members were held separately from those with support workers. However, as the sample was small and the study exploratory, participants were considered as one group for analysis. There were no new themes in the later interviews, suggesting data saturation was reached.

The main themes emerging from the interviews and focus groups follow.

Views on sexuality

Participants agreed that people with intellectual disability had the right to healthy sexual relationships, including same-sex relationships:

'What gives us the right to deny (sexuality) to a group of people?' (Interview 7)

However, participants also expressed discomfort regarding sex and intellectual disability.

'It raises all these kinds of fears in us ... opening up a Pandora's box ... It's probably ... an unfounded fear.' (Interview 9)

Regarding a possible relationship, a family member said:

'Somebody was interested in E ... but E's always said, 'no' ... so I thought, phew, thank goodness for that.' (Focus group 2)

Regarding a dating agency for people with intellectual disability, a support worker said:

'Tabooness ... of setting people up where they're going to have sex.' (Focus group 1)

Consent and legal issues

Consent to sexual activity was described as a difficult and complex process:

'There may be a verbal consent actually when all the other messages people are putting across is no ... you need to look at what people's body language is saying.' (Interview 9)

'It's not completely informed consent if you're not able to understand all the ... possible repercussions of that action.' (Interview 5)

Participants raised concerns about legal restrictions relating to sexual activity with a person with intellectual disability:

'Is it a crime in Queensland to actually have a sexual relationship with someone with an intellectual disability?' (Interview 9)

However, other participants perceived the laws as being aimed at prosecuting perpetrators of exploitation rather than outlawing mutual relationships.

Relationships

Participants perceived a strong desire for relationships among people with intellectual disability:

'People would desperately love intimate, sexual, caring relationships ... the romantic idea of marriage.' (Focus group 1)

However, some people with intellectual disability were reported to have simplistic and sometimes unrealistic ideas of relationships, often from television shows:

'She watches Home and Away, and Neighbours ... I mean, her relationship has got to be like that. And it's so false.' (Focus group 2)

When it came to real-life relationships, people with intellectual disability were seen to fare poorly. Isolation and lack of social opportunities limited the choice of partners, or even friends. This lack of choice was seen to encourage and perpetuate unhealthy relationships:

'We've had a few problems. And I've said to S, "Maybe you would be better off if you weren't in a relationship" (but) ... it's like, "But where else am I gonna find somebody?"' (Focus group 2)

The process of forming and maintaining a relationship was reported to be problematic. Poor awareness of social cues, lack of interpersonal skills and lack of assertiveness were described.

'S pursued him relentlessly ... we had a call from his family saying, "Stop S ringing up because

we're all going bonkers".' (Interview 4)

Concern was expressed about people's ability to negotiate sexual activity:

'If ... the girl wants to stop halfway ... you've got an aroused male ... [who] is intellectually impaired? Hooley dooley. It's a terrible, terrible mess.' (Focus group 2)

Disempowerment

Disempowerment emerged as a strong theme underpinning the difficulties people with intellectual disability experienced in negotiating relationships, consenting to sexual activity and protecting themselves against exploitation:

'I think she would just want to make that person happy and do whatever they want her to do ... she does things to please people.' (Interview 3)

Disempowerment was viewed as having an important role in increasing the risk of exploitation and abuse:

'It was clear that [he] didn't want [sexual activity] ... but... he felt impelled [sic] to ... because of his inability to say 'no' ... passive in the face of people who are seen as more verbal, more accomplished, more confident.' (Interview 10)

'They've also got that fear ... 'We might get into trouble if we say anything.' (Focus group 3)

The sex industry

Participants expressed concern that some people with intellectual disability were accessing unhealthy and possibly exploitative sexual activities by means of bars, prostitution and pornography:

'One of the young guys ... had been to this place ... 'wild girls', or something ... he paid for a strip snooker game with a girl ...' (Interview 10)

'He'd like to ... go down to the strip club ... or peep show and ... he's ... talked about ... hiring prostitutes ... this is his way of experiencing sex ...' (Interview 5)

Technology and exploitation

Participants also expressed concern about sexual exploitation via the internet and mobile telephones:

'Pornographic videos, internet ... mobile phone sites where people share pictures ... of genitalia with each other, share pictures of people engaging in sexual acts ...' (Interview 10)

'[She] does a lot of internet dating ... she will come across men who try to pressure her for sex ... when ... she's feeling really lonely ... she often chats to people on the internet ... sometimes she'll go straight to the person's house ...' (Interview 8)

Exploitation and sexual abuse

Participants identified sexual abuse as including a range of unwanted behaviours. This included situations where consent was given for some sexual activity but further, nonconsensual activity occurred, often involving coercion and manipulation:

'Her partner took an image of them having sex and has distributed that to other people. It's unclear ... how engaged she was in agreeing to make the video ... she certainly didn't want [it] released.' (Interview 10)

'They took her back in their car to the hostel, and both of them had sex with her there ... she said, 'I didn't want to do it Mum, but they said they were my friends.' (Interview 4)

Participants discussed a range of ways in which abuse had been disclosed or identified:

'All of a sudden her moods changed ... one day ... she just come out ... what he'd asked her to do.' (Interview 3)

'She rang us ... and said, 'Come and get me Mum ...' So we did, and then we found out.' (Interview 4)

Participants reported dissatisfaction with the responses to reports of abuse:

'[Another worker] ... touched her on the breast ... the supervisor ... said, 'Well N could have stopped it.' (Interview 2)

Attempts to report to the police or take legal action had also met with limited success:

'Because S had let him in, because she had sex with him without jumping up and screaming, there's nothing [the police] could do.' (Interview 4)

Participants reported that following abuse incidents, the people they cared for remained confused, hurt and sometimes resentful that the contact had been stopped:

'She ... sees my [intervention] ... as my attempt to deprive her of companionship ... "You don't want me to have a boyfriend". (Interview 4)

Participants reported some successful use of refusal or self-protection strategies, but this was inconsistent, even in those who had been taught protection skills.

Sexual knowledge and education

Participants gave accounts of gaps and misunderstandings in sexual knowledge:

'She's got to 50 ... if you think babies come out of your belly button there's probably a few other things you don't know.' (Focus group 1)

Poor understanding was identified as a risk to people with intellectual disability and other people:

'The person approaches younger people ... gets into all kinds of difficulties ... they just don't have a great awareness of what they're doing.' (Interview 9)

Participants commented that while basic knowledge was important and often lacking, knowledge alone was not sufficient for sexual safety:

'Information is only a small part of it ... if people are really going to understand that stuff ... needs to be an ongoing thing.' (Interview 10)

A participant expressed concern about educating people while attitudes toward sexual relationships remained negative:

'I see that as a bit unfair ... to teach them the right way to have sex...and about relationships ... but saying, 'No, you can't do that' ... It's like having chocolate put in front of you but you can't eat it.' (Focus group 3)

Support for sexual relationships

Supporting safe, constructive sexual relationships was acknowledged to be a challenging and complex task. Family members were recognised as important in facilitating relationships:

'I really would support him in [a relationship] ... and he may need it too, to have the confidence.' (Interview 5)

Participants described their role as ambiguous and their legal position as uncertain. It was noted to be difficult to intervene in relationships that were seen as damaging:

'You say anything to S, and it's, "My choice" ... she acts like a teenager. But, yeah, it's all her choice, you don't have a say.' (Focus group 2)

Participants saw paid support workers as having an important role in relationship support and protecting from and responding to abuse:

'We can let people know that there are people looking out for this person ... put the neighbours on watch.' (Focus group 1)

Participants described some tensions when families and support workers did not agree on the best response to a situation:

'We can't make it difficult for them even if the

parents don't support it because our loyalties are to the client and not to the parents. They are but they're not.' (Focus group 3)

Support organisations had policies regarding sex and relationships. Workers reported positively about these.

Sexual health issues

Participants described involvement in obtaining contraception for those they cared for, generally with the understanding of the person:

'C, she knows what it's about, in her arm ... the baby stopper.' (Focus group 2)

Participants also mentioned sterilisations, despite being aware of legal restrictions:

'She wouldn't take the pill, and I was terrified that I would have a houseful of little kids that I would be looking after. So in desperation, I sought the help of a doctor and I got her tubes tied.' (Interview 4)

'[She] had a hysterectomy at age 12 ... she constantly talks about being a mum, and I don't know if she actually understands that that's happened.' (Interview 7)

Condom use and prevention of sexually transmissible infections were mentioned as areas of concern:

'I would be giving out safe sex messages ... how would I know if he was having unprotected sex?' (Interview 1)

Parenting

Participants spoke of the right of people with intellectual disability to have children, despite awareness of the need for support with parenting:

'Do you think B was capable of having a baby? She ... did and now she's married ... good on her. So whose call is it?' (Focus group 3)

Not all people with intellectual disability wanted children:

'She said 'No, I can't look after myself so I'm not going to, why should I try and look after a baby?' (Interview 2)

Unrealistic expectations of parenthood were discussed:

'[A] client fell pregnant ... who thinks that a baby's a toy ... she was wanting it because I think she felt it would bond them.' (Focus group 3)

Some participants, particularly family members, found the thought of supporting parents with intellectual disability quite overwhelming: 'I wouldn't be prepared for E to have a child, and then couldn't cope with it, and then you're left as a grandmother ... raising up, at my age.' (Focus group 2)

Discussion

Participants in this study supported the needs and rights of people with intellectual disability to form healthy, mutual sexual relationships. However, they described the actual relationship experiences of those they cared for in strongly negative terms. People with intellectual disability were described as overwhelmingly lonely, with limited social circles and few opportunities for either friendships or sexual relationships. They were seen as disempowered, lacking assertiveness toward those perceived as more able or more powerful, and fearful of negative consequences if they refused a request. Many examples of sexual abuse and exploitation were described. This echoes what people with intellectual disability have said in other studies.16,32

Vulnerability to exploitation was seen to be heightened by new technologies including internet pornography, online 'dating' and mobile telephone chat rooms. While these technologies have been implicated in many cases of sexual abuse of children and adolescents,^{39,40} the authors could not find any studies addressing this phenomenon in relation to adults with intellectual disability. Further investigation of this emerging risk is warranted.

Concern was raised about involvement in the sex industry. While acknowledging that people with intellectual disability accessed peep shows, topless bars and prostitutes, participants expressed reservations about the associated risks and unhealthy views of sexuality. While one study has examined the dynamics of people with intellectual disability who perform sex work,⁴¹ there appear to be only anecdotal accounts of people with intellectual disability as sex industry consumers.⁴²

When discussing real-life mutual relationships, participants admitted to considerable discomfort despite their stated views. Of note was strong concern from family members about their family member with intellectual disability having a child they could not raise.

Participants struggled with the complexities regarding capacity to consent to sexual activity.

If this is the experience of carers, it is hardly surprising that people with intellectual disability also experience difficulty in this area.^{23,24}

Previous research has indicated differences in attitudes toward sexuality between family members (more protective and restrictive) and support workers (more liberal and rights focused).¹³ While a range of attitudes was expressed in our study, the sample was too small to identify a trend.

Participants described glaring holes in sexual knowledge, relationship skills and self-protection skills, consistent with previous findings.^{16,17,19,32} This is likely to reflect limited real-life exposure to potential relationship situations^{16,19} and lack of social skills training.²²

When discussing what was needed to improve relationship experiences and safety, participants were clear that knowledge was important but not sufficient. They voiced a need for comprehensive, ongoing support including education, facilitation of contraception and assistance in self-protection.

Participants spanned a wide age range. The majority were female, consistent with the preponderance of women in both family and paid roles. Importantly, participants were recruited from a limited number of sources, and may have held more liberal attitudes than those who declined to participate.

Conclusion

Our study demonstrates the range and complexity of issues faced by those who support people with intellectual disability. New technologies mean that people with intellectual disability – like other people in the community – are exposed to more information than ever before. Information about sex from these sources may involve highly sexualised imagery or ideas or connection with persons who may abuse. Limited education and ability to process such information places people with intellectual disability at increasing risk of exploitation from exposure to these sources.

Further research is needed to explore these new risks and inform developments in education and support programs. There is a large unmet need for well designed, properly evaluated education for people with intellectual disability, families and support workers. There is also a need for clarification of legal and ethical issues. Family members and professionals alike need to remain aware of the risk of abuse and its effect on the health and lives of people with intellectual disability.

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