

Sexuality, Sexual Abuse and Protection Skills in Women with Intellectual Disabilities



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Why research sex and intellectual disability?



- ▶ Sex is for everyone...

...except if
you have
a
disability



Sex and intellectual disability: the evidence

- ▶ High rates of sexual abuse in people with ID
- ▶ Sexual abuse is associated with psychiatric and behavioural disorders, sexual dysfunction and revictimisation
- ▶ Sexuality training and support benefit people with ID
- ▶ Improved sexuality education is associated with improved ability to negotiate appropriate relationships
- ▶ Education programmes tailored to the needs of people with ID have been developed

Sex and intellectual disability: the reality (1)

- ▶ People with ID seen as 'asexual', 'childlike' or 'hypersexual'

That should stop
you boys having those
unnatural urges!

Special School
for Spastic Boys
and Girls



Crippen

Sex and intellectual disability: the reality (2)

- ▶ Sexual behaviour seen as normal for other people may be seen as inappropriate for people with intellectual disability

PHARMIST

Are you sure that you're allowed to have sex?!



Crippen

© XXI. 2.09

What do you mean you're a lesbian - we thought you were disabled!



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CRIPPEN

Sex and ID: the reality (3)

- ▶ Limited access to sex education
- ▶ Poor understanding of sexuality, sexual abuse and self protection
- ▶ Many believe that others control whether or not they have sex
- ▶ Limited opportunities for relationships

No lads - the
drinks machine is
further down
the hall!



Study aims

- ▶ To gain first-hand information about the knowledge and experiences of women with intellectual disability regarding sexuality, sexual abuse and protection skills

Study design

- ▶ Qualitative study: in-depth interviews
- ▶ Women recruited via community support organisations
- ▶ Pre-interview session: explanation of the project, brief assessment of capacity to consent and participate
- ▶ Formal interview on a different day
- ▶ Qualitative analysis using NVivo software programme

Results

▶ Interviews

- 21 women approached
- 12 pre-interview sessions
- 9 completed interviews

▶ Themes

- Sexual knowledge and its sources
- Sexual relationships
- Declining unwanted sex
- Sexual abuse and its sequelae

Sexual knowledge

▶ From simplistic...

- 'When you haven't got any clothes on and the person lies on top of you'

▶ To relatively sophisticated...

- 'in a girl, I think that every couple months or something there is an egg release... And the guy's sperm basically goes up them into the girls eggs and basically makes a baby... the guy ejaculates his semen into the girl's vagina...'
- (sex is) basically from head to toe like with your lips, your breasts, your vagina'

Sources of sexual knowledge: School

- ▶ From a 42 year old:
 - 'we did not talk about anything about sex at school cos I think we couldn't, I dunno was it illegal for us to talk about it'
- ▶ From a 21 year old:
 - '... we had to learn how to put a condom on so we basically do it on a banana or a zucchini
 - how a male injects like the sperm into a girl's, I mean a woman's vagina... your eggs and how you get your monthlies and everything, how it all works'

Sources of sexual knowledge:

Other

- ▶ 'Mum had sex books lying around... so I looked at the pictures and thought oohh that seems great'
- ▶ 'My foster mum did take me to another lady... some of it was about sex and some of it was about a woman's body and how a female's body works and how where the places you do it, private and non private'
- ▶ (With a counsellor) 'we used to do drawings... what is good and what is bad and who hurt me and who did not hurt me and who you can trust and that kind of stuff'
- ▶ 'Because I was raped'

Declining unwanted sex- with an established partner

▶ Successful

- ▶ '...you turn over and then you've got your bum and then your breasts in the way and... couldn't get to my vagina and my breasts and that'
- ▶ 'My husband accepts that I said no and so he's pretty happy with it, and just keep saying no, no'

▶ Unsuccessful

- ▶ 'It's really really hard to say no...'
- ▶ 'Threatening with violence and I didn't want to a few times, and then he shoved me on the bed and ripped my shirt, so after that I just had sex with him, because I didn't want to get hurt any more than that'

Declining unwanted sex- with a non-partner

■ Successful

- ▶ 'he thought I was the perfect come-on but I wasn't interested, and... if they don't accept no's no then just call the police and they'd put a stop to it'

■ Unsuccessful

- ▶ '(A 'friend') just woke me up in the middle of the night wanting to have sex and I just didn't really want it, and in the end I enjoyed it, I shouldn't have it was a bad mistake'

Experiences of sexual abuse

- ▶ 'A bloke that... I worked with...he had one hand on one side of my head and the other on the other side of my head and so I couldn't move... then his hands started to go up my uniform and stuff like that'
- ▶ '(My grandfather) touched my breasts... my vagina'
- ▶ 'Mr J used to touch me all the time'
- ▶ 'My brother... I was twelve... He put his finger, his pizzle, he was on me he put it in me'
- ▶ '(My uncle) was piggy backing me... he... would somehow get his hand round... (in my vagina)'
- ▶ 'A boy at school raped me'

The impact of sexual abuse



'Sorrow' by tjlinds
www.tjlinds.com

Experiences of reporting abuse: unsuccessful

- 'I had to go back to work... and face him...I had to... tell the boss... and he said OK, you've got two choices, you can either resign or I can fire you'
- 'I said mum I don't want to go and see grandpa because pop touched me, and then, then my mum talked to my grandma and... my gran said I was a liar'
- 'I used to run away because Mr J used to touch me all the time, and everybody could not find me and I didn't want to go back'
- 'I told my mum, I screamed out when I was twelve, I screamed out and all I got is bashed up by my mum'

Experiences of reporting abuse: successful

- ▶ 'I rang mum and dad, I went to hospital for a while and while I was in hospital dad called the police'
- ▶ 'I had the phone number, gave it to the police, they... told him to back off or else... and he said tell her I won't harass her anymore'
- ▶ 'I told my teacher... she didn't believe me... so I went to the principal... the police came...'

Sequelae of abuse

- ▶ 'Ever since (abuse)... I tighten up down there before he gets full penetration'
- ▶ 'Even with my husband I turn him down on sex and that... He knows what my brother has done to me and he just backs off'
- ▶ 'Soon as my grandfather did it to me I just hate (sex)'
- ▶ 'How do you stop being scared?'

Discussion

- ▶ Direct information from women with intellectual disability indicates:
 - Patchy sexual knowledge
 - Inadequate education, training and support
 - Difficulty declining unwanted sexual advances
 - Difficulty reporting abuse
- ▶ The women interviewed for this study all had decision making capacity and verbal skills and could be expected to benefit from improved training and support if this were available

**It might be a while before we
see affirmative action...**



Thanks to the team

▶ Bond University:

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▶ QCIDD, University of Queensland:

- A/Prof Nick Lennox
- Ms Lyn McPherson

▶ Community Organisations:

- WWILD
- Community Living Programme
- Rural Lifestyle Options
- Spiritus Alina

The future



- ▶ Study of families and support workers in 2010
- ▶ Interviews and focus groups
- ▶ Data collection currently in progress

'Growth' by tjinds
www.tjinds.com

Thanks to the artists



- ▶ Tjinds is a Brisbane artist who has posted her own website visually documenting her recovery from sexual abuse
- ▶ Details: www.tjinds.com



- ▶ Dave Lupton (aka Crippen) is a British cartoonist working from the comfort of his wheelchair
- ▶ Details: www.daveluptoncartoons.co.uk