Relationships and sexuality – developing a positive approach to education and support

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Introduction

• Women and girls with an intellectual disability still undergoing forced sterilization (WWDA, 2001) and have limited choices re contraception and reproductive decisions (Areschoug, 2003)

• People with an intellectual disability are at the highest risk of abuse of all people with an intellectual disability (Horner-Johnson & Drum, 2006)

• Parenting seen as a problem for people (in particular women) with an intellectual disability (Kroese, et al., 2002)

• People with an intellectual disability living in group homes not allowed privacy to conduct intimate relationships – risk averse culture (Hollomotz, 2008)

• Sexuality and relationship education limited – narrow focus - needs to be comprehensive and involve people with an intellectual disability in development and delivery (Barger et al., 2009)

Abuse by carers 'covered up'
The Age Newspaper - July 16, 2012
MORE than 100 intellectually disabled people in state-funded care are alleged to have suffered sexual abuse and other harm at the hands of their carers, amid accusations that senior public servants are trying to cover up incidents.

The Department of Human Services recorded 112 cases of alleged "staff-to-client" abuse in 2011-12 in government and community managed housing for the intellectually disabled across Melbourne...

One of the most serious unresolved Melbourne east cases involves a male carer who has been the subject of several sexual assault and misconduct allegations.

Call to ban forced sterilisations

MICHAEL INMAN
PHOTO's editor and chief of the disabled are regularly shown shopping and getting ahead to have their children sterilised illegally, according to the Australian Human Rights Commission. Under current Australian law, only the Family Court or a guardianship tribunal can authorize the irreversible medical procedure. But national Disability Discrimination Commissioner Graeme Innes said anecdotal evidence suggested non-comprehensive, non-therapeutic and forced sterilisations appeared still common in Australia.

Mr Innes is seeking to have the practice criminalised, with penalties of at least six months in prison for those found guilty. He recently wrote a letter to federal Attorney-General Nicola Roxon saying current law had failed to protect women and girls with disability from non-therapeutic and forced sterilisation. While exact figures in relation to non-therapeutic sterilisation within the health sector are difficult to obtain, Mr Innes said the commission had attempted to gather data on the practice but had only managed to collect figures from New South Wales, Tasmania, Victoria and Western Australia.

The data collected showed permission was granted for 12 procedures over the past five years, including one in NSW for a child under 16. Mr Innes said the commission suspected many more procedures were carried out without court consent.

"I'm resisting the criminalisation of forced sterilisations," Mr Innes said. "It should be a criminal offence for any adult to be sterilised without consent and for any child at all, apart from life-saving circumstances.

But Mr Innes said he would also seek a broader public awareness campaign on the issue. "We've got to do more than criminalise it, that's just the legal remedy," he said.

"There's got to be a lot of public education to support families to realise there are other alternatives to sterilisation, there are various methods of non-surgical management that are available.

The plan comes after the Senate Community Affairs Committee recently announced an inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia, enquiry architect Queensland Liberal Senator Sue Boyce—who has a daughter with Down syndrome—said institutional management and preventing pregnancy appeared to be the major reasons families and carers sought to sterilise their disabled child.

The Senate inquiry is currently receiving submissions on the issue.
Marginalisation and regulation

“Policy and provision around disability often neglect to consider sexuality as one of the basic human needs. While housing, transport, education and other needs are dealt with, albeit inadequately, consideration of social and sexual factors is not high on the welfare agenda. Disabled people in day centres or residential homes are often denied privacy, or the opportunity to form emotional or sexual relationships. This failure to prioritise matters which are highly significant to most adults, reflects a failure to consider disabled people as fully human” (Shakespeare, 1996. p. 87)

“The reasons for the marginalisation and regulation of the sexuality of people with intellectual disabilities are both historical and contemporary and are closely related to ....the fears associated with the increased rights of people with intellectual disabilities and to prevailing attitudes towards people with intellectual disabilities” (Johnson, Hillier, Harrison, Frawley, 2001)

Not human - High risk - Not competent - No insight or feelings - “Not like us”
Genderless
**Dominant attitudes**

General population – stigma towards the sexuality of people with an intellectual disability. In particular, less favourable views about the sexuality of people with an intellectual disability than people with a physical disability (Katz et al, 2000)

Scotti et al (1996) found that students (without disabilities) viewed the sexual behaviour of people with intellectual disabilities as being less acceptable than their own sexual behaviour

Karellou (2003) – attitudes of staff - age and level of education were the main factors; older less liberal & lower education level more negative. Oliver et al (2002) also found age to be an influence on attitudes

Variable attitudes in relation to level of disability of people and type of expression of sexuality ;— liberal attitudes towards masturbation, less liberal regarding sexual intercourse, homosexual relationships (Yool et al, 2003; Valios, 2002) & involvement of people with intellectual disabilities in determining their sexual expression (Yool et al, 2003)

Attitudes of staff supporting people with an intellectual disability; less institutional setting more liberal attitudes – correlates with attitudes towards people with higher support needs, homosexuality. Most conservative views are about males living in more institutional settings and homosexuality. (Grieve et al, 2008)

Parents attitudes are reported to be more conservative than paid carers (Brown, 1994; Rose & Jones, 1994) with older parents being most conservative
Shifting attitudes - rights

People with disabilities have the right:

To have privacy and be respected at home

People with disabilities have the right:

To be sexual

People with disabilities have the right:

To make your own decisions about relationships
Shifting attitudes – ‘listening to’ and being informed by the lived experience of people with an intellectual disability

Living Safer Sexual Lives (Johnson, et al 2001; Frawley et al., 2003) Research with 25 people with an intellectual disability in Victoria, Australia – developed stories of their lives – focus on relationships and sexuality

<table>
<thead>
<tr>
<th>Aims</th>
<th>Findings</th>
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<tr>
<td>• to identify key issues around sexuality and relationships for people with learning disabilities</td>
<td>• Stories are complex, emotional, passionate, painful, joyful – tell about adults struggling with issues about sexuality and relationships</td>
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<td>• to place sexuality and relationships in the broader context of the lives of people with learning disabilities</td>
<td>• Secret sexual lives – risk and abuse</td>
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<tr>
<td>• to develop, trial and evaluate workshops and other resources based on stories contributed by people with learning disabilities</td>
<td>• Leading unsafe sexual lives</td>
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<tr>
<td>• to develop, trial and evaluate workshops and other resources based on stories contributed by people with learning disabilities</td>
<td>• People wanted/aspired to long-term intimate relationships</td>
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<tr>
<td>• to develop, trial and evaluate workshops and other resources based on stories contributed by people with learning disabilities</td>
<td>• Isolation, rejection</td>
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<tr>
<td>• to develop, trial and evaluate workshops and other resources based on stories contributed by people with learning disabilities</td>
<td>• Limited access to information about relationships and sexuality</td>
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<tr>
<td>• to develop, trial and evaluate workshops and other resources based on stories contributed by people with learning disabilities</td>
<td>• Balancing protection and rights</td>
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What the people in the stories SAY

• **Other adults treat me like a child** ‘Well I just asked mum and dad if I could get married to Peter. And me mum said “No”. I was nearly 30. Me mum said “You’ve only got one hand, you can’t cook, you can’t do ironing, you can’t do anything”. I said “Well, I’ll find a nice man”. I said “He will do it”. Mum said “No”.’ (Elaine)

• **People think I shouldn’t have sex** “I can’t talk about stuff like that with my family” (Molly)

• **There’s no privacy** ‘Before we shared our room, a staff member knocked on the door and found us together. She said ‘Get into your own bed’. I didn’t like her that much doin’ that. (Hanna)

• **Fertility is taken out of my control** “There was a time when I would have liked to have children, but I never had the chance...well it would have been nice to at least have the choice”

• **I learned about sex through abuse** ‘There was no messages about safe sex. If my stepfather couldn’t get sex or my brother in law, they would come to me. The message was, ‘come here’. (Gina)
LSSL: RR model

- **Research and Evaluation** – Social change
- **Learning Partners**
  - Resourcing natural supports
- **Co-Facilitation**
  - Sector Development
- **Peer Education**
  - Respectful Relationships program ran by and for people with an intellectual disability
## Developing the LSSL:RR program

<table>
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<tr>
<th>Engagement with mainstream - Community based Model</th>
<th>Building capacity/sector development</th>
<th>Inclusive program development with people with an intellectual disability</th>
<th>New comprehensive program for people with an intellectual disability – resources /research/ evaluation</th>
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<td>Situated in 5 sites (3 Vic; 2 Tasmania)</td>
<td>Trained 20 people with an intellectual disability as peer educators</td>
<td>Project team – 3 women with an intellectual disability; 2 project workers</td>
<td>LSSL:RR program: 4 sessions; Talking about relationships and sexuality; Having rights and being safe; Respectful Relationships; Men and respectful relationships</td>
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<tr>
<td>Planning with representatives from disability and community sector, including people with an intellectual disability</td>
<td>Trained 20+ community professionals as co-facilitators</td>
<td>Used accessible program as basis (LSSL, 2003 – stories of pwid and relationships)</td>
<td>Research Peer education model – findings about involving people with an intellectual disability as educators in a violence and abuse prevention program</td>
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<td>Engaged local organisations – auspice and coordinate the program, using existing resources</td>
<td>Facilitated educators to promote the program locally</td>
<td>Prolonged engagement – fortnightly for 6 + months</td>
<td>Model evaluation Barriers and enablers to developing a community based cross sector violence and abuse prevention program for people with an intellectual disability</td>
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<td>Developed LSSL:RR network</td>
<td>Linked people into community prevention activities</td>
<td>Pwid as trainers</td>
<td>Papers and presentations – broad dissemination</td>
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LSSL:RR Program 4 key ideas: Respectful relationships; Not putting up with violence and abuse; Values – equality, fairness and respect; Rights

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<th>Four Stories</th>
<th>Four Themes</th>
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<tr>
<td>Molly’s story “My dream is to get married”</td>
<td>Talking about relationships and sexuality</td>
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<td>Angela’s story “I like to ride on trains”</td>
<td>Having rights and being safe</td>
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<tr>
<td>Hanna’s story “It’s hard to get privacy”</td>
<td>Respectful Relationships</td>
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<tr>
<td>Kevin’s story “I’ll spend my life with her”</td>
<td>Men and respectful relationships</td>
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**Peer educator’s motivation, aims outcomes**

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<th>Why people got involved – motivation to be peer educator</th>
<th>Personal experience of relationships – good basis for being a peer educator</th>
<th>Already have skills – program good opportunity to develop these further</th>
<th>Self advocacy – link for peer educators to program; place where they have learned to ‘speak up’ and share experiences</th>
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<tr>
<td><strong>How they saw their role – aims</strong></td>
<td>Helping peers so they can have better experiences in relationships</td>
<td>To share own experiences, help people talk about relationships through the stories and own experiences</td>
<td>Can be an educator because I am “in their shoes” Being a role model</td>
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<tr>
<td><strong>What people got out of it - benefits</strong></td>
<td>Helping others and self</td>
<td>More confidence and being respected</td>
<td>New knowledge and skills – about relationships, support services and being a facilitator</td>
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Peer educators are credible sources of information...

Link between peer educators’ experiences, the stories and the experiences of the program participants....

“Well, some of my story could affect, like, go good with their stories as well sometimes... Like, like certain bits in my story could help them. They might, they might think it - they’re like what I’ve been through....Like if, like some, like if it’s a woman it, they might think, like after they’ve had a kid or something, they might think how I feel, how they’ve, how I lost my daughter and I can only see her monthlies..”.(P4).

“Like talking, like when we show stories to ‘em they think they’re like, like Molly’s story and that....And they talk about – when we talk about Molly’s story they talk something about really about their own self and that.: (P4)

“They ripped it [private sign] down on them. Like these [people with an intellectual disability] are grown adults, consenting adults. They don’t need to be treated like they’re children. And yeah, that really got on my nerves. I had to go home and cool down after hearing that. Yeah, I was quite grrr (P1).
Peer educators are role models...

Despite concerns about capacity to ‘handle the job’ peer educators managed and lead by example and experience

“Hey, look at them! They can do it; we can do it too!” .... And that’s what got me going. (P2)

“Personally it’s better with people with disabilities. As I said, you can reflect. So you’re going to listen, you’re going to be interested because, “Hey! They’re just like me.” And I think that’s a big draw card is, “Hey look, if they can do it, I can do it too.” (P 6)

Evaluation question –”What was a good thing about the program”?

Participant –”[names the peer educator] I want to do what she is doing” (ER 0411)

• Peer education is beneficial for peer educators with an intellectual disability
• People with an intellectual disability can manage the complexity of facilitating a relationship program – with collegial support, an experiential learning program and rigorous training
• Shared experiences between peer educator and program participants – strong learning –empowerment
• Relationship programs enhanced through peer education
Where to for relationship and sexuality education with people with an intellectual disability?

• Based on lived experiences – acknowledges reality of people’s lives – “same as me”

• Make clear the disabling nature of attitudes and practices that do not acknowledge the sexuality of people with an intellectual disability – identify these and focus for change

• Gendered understanding of relationships, sexuality and disability

• Inclusion of people with an intellectual disability in shaping
Frawley, P., & Bigby, C “I’m in their shoes” Experiences of Peer Educators in Sexuality and Relationship Education (in press)


