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Supporting the socio-sexual needs of young men and women with intellectual disability

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Background

- No consistent National policy: education/sexual health – mainstream or targeted for people with IDD
- Some State based curriculum in schools – not consistent in mainstream and often not present in Special Education/Education programs for young people with IDD
- Flow-on effect young people with IDD is ad-hoc support and education
- Young adults with IDD are at a critical life transition where counter-productive outcomes can have a lifelong impact.

Young Adults with IDD

- Disparity between what we know about sexuality, relationships, sexual health and sexual behaviour for young people with and without disabilities
- 5th national survey of secondary students and sexual health (Mitchell et al 2014) – over 2000 respondents in years 10 – 12: none reported having a disability, no data about education for or experiences of young people with a disability
- Research of sexuality, sexual health, sexuality and relationships of people with IDD focussed on:
 - Behaviour and behaviour change
 - Attitudes of staff and families
 - Knowledge of people with IDD
- Very little research with young people as respondents that has asked about:
 - Their experiences of gaining and using information and education
 - Their ideas about how best to provide education and support

Starting point: what is known from the literature

- Increased risks: **young women** with IDD – unwanted/unplanned pregnancy; sexual assault by someone they know; limited knowledge of and increased experience of forced or coerced use of contraception; limited knowledge of sexual health
- **young men** with IDD – sexual offending; low level of sexual health awareness
- **Sex ed** – focus on biological discourse, risk reduction, behaviour change, rules; found to be ineffective
- **Conservative views** of the sexuality of people with IDD held by disability support staff, family and carers; particularly held by older female family, carers and staff and particularly about pregnancy/reproduction and same sex relationships

Methods

- Qualitative study – explorative with view to expand
- Ethical approval by University of Sydney HREC
- Focus Group Interviews with young people with IDD who attended TTW programs in NSW and staff of these TTW programs
- Approach to interviews/focus groups: Narrative semi structured – (Booth & Booth, 1998) – build picture of person ; exploration of experiences; evaluative questions/reflection

Young adults: experiences of sexuality education, quality of that education, best modes for that education, access to information and support

(Consulted with NSW CID re questions for young people with IDD)

- Gathered some demographic information – ages, cultural background, education, family, living situation
- Analysis: constant comparative approach guided by constructivist GT: Open coding– selective coding – core themes – development of short collective narratives: (NW young men; PF young women)

Staff – findings presented at IASSID 2014 – not focus of this presentation

TTW Program - NSW

- Two-year program operating in NSW
- Approximately 63% participants have ID
- The majority of TTW clients in NSW are young men (approximately 56%) between 16 and 21 years of age
- In 2010 62.5% of participants ended up in some form of employment (supported / open)

Participants

- Focus groups separated by gender plus x1 individual interview
- Young adults with ID: (n = 25)
 - Female (n = 11)
 - Male (n=14)
 - Mean age 18.7 years

What young people knew/had heard about

Young men	Young Women
Wet dreams Masturbation (wanking) Orgasms (some uncertainty) Oral sex	Menstruation Contraception Should say 'no' to unwanted touching

What they had experienced

Young men	Young women
None reported being sexually active with a partner Watched pornography Masturbated Got 'in trouble' for 'inappropriate' behaviour	One reported being in sexual relationship All using some form of contraception Some kissing and touching with boys

Emerging finding

Young women and men with IDD

- Limited knowledge – biological & gendered
- Limited and mainly ‘physical/biological’ sexual experiences – very little sexual activity-sexual relationships reported
- Restrict and control urges, interests, behaviours– gendered ; young men control themselves; young women - others

'Lilly'

- Lilly is 18 years old. She has gone to a couple of different schools the last one was a high school where she was in a 'special unit'. She has had some education about sexuality but it was really mainly about menstruation and keeping safe with boys. She was also taught about the 'mechanics' of sex but she has never had sex, she is using contraception though. When people like teachers and her mum have talked to her they have told her about keeping safe, nobody has talked to her about what to do if you like a boy (or girl), and nobody has talked to her at all about what it is really like when you have sex. She is pretty scared about it – scared it will hurt, scared she won't know how to do it, scared she will get pregnant or a disease. But she is really interested in it, thinks a lot about having a boyfriend but doesn't really talk to anyone about it. She has had a boyfriend, they went out on weekends to a club with other young people with disabilities and sometimes the pictures together but they have not spent much time on their own – she has kissed a boy and let him touch her breasts but that's all.

Focus of formal and informal education

Young Men	Young Women
Rules about sex - consent, privacy, respect for women How to use a condom – verbal instruction + banana	Menstruation and menstrual management Pregnancy/reproduction – how to avoid Stranger danger How to use a condom- verbal instruction + banana

- Biological – rules based
- Gendered – men self control; women protect yourself and be clean

Provided by; parents, some at school, some TTW

Outcomes; not retained, embarrassed, confused, some 'self education' – mixed outcomes;

Fear: young men – abusing; young women – of sex, being abused, pregnancy

Regulation/Protection

Capacity

- Capacity of people with an intellectual disability to understand and decide about sexuality and relationships questioned

Incapable of doing this –

Not Like Me

Manage For

This is something we have to **manage for** people with an intellectual disability

Incapable of doing this –

At Risk

Rules and Behaviour

- What not to do
- Teaching/training a set of rule
- Restricting/managing 'problem behaviour'
- Biological and behavioural discourse

The 'nuts, bolts and rules'

Restrict and Manage

- Biology of sex - menstruation, arousal
- Sociology of sex and relationships – limit relationships, suppress /limit sexual expression

Limited & controlled experiences



'Angus'

- Angus is 17 years old, he went to a Special School and now he is at a program to help him get a job. He learned a bit about sex at school but it wasn't very good, mainly 'the facts'. He has also been told a lot about how to behave in a relationship – to respect girls, don't force them to do things, and always wear a condom if he is having sex with a girl. But Angus does not really know how you get a relationship – he is full of questions. He lives a really solitary life – goes to the program, goes home, watches TV, spends time on the internet looking at porn, occasionally hangs out with some other young men who drive their cars around a parking lot. He never has a chance to talk to anyone about his ideas and thoughts about sex and relationships. He has got in trouble at school for asking a girl to 'suck his dick', he thought she was a bitch for telling on him. He's had a girlfriend at the program but they hardly ever see each other in private – mainly they muck around at lunch time, sometimes he gets turned on when she sits on his knee – he thinks she is leading him on.

What is missing – what is needed: young peoples' perspectives

- **Chance to talk** – with each other/with 'informed other' – someone knowledgeable, approachable, a mentor , ' someone like you' (NW & PF)
- **Focus of education/information** - How to have an intimate relationship – socio/sexual
- **Support** – to access information from range of services; to understand experiences; to be able to conduct an adult, private intimate relationship; to make informed decisions

What's possible - Amy

- I live with Mum and Dad I am 19 years old. I love having sex and having a boyfriend. Mum tried to talk to me about sex, I thought it was disgusting talking to Mum about it. She found out that I had a boyfriend and that I was having sex so she decided to try to make it Ok for both of us. She told my counsellor about it and now I talk to her about it every time I see her, but she also told Dad and he wasn't that happy. She wanted me and my boyfriend to be able to sleep together and have sex at home, Dad wasn't sure about that but as usual Mum won. Me and my boyfriend were both shown how to use condoms but then it was practice – “we just got straight into it”. It's great. We love going out together to Karaoke, and the club where we dance and sing too.

Young adults with ID:

- **Are sexual**, they experience the complexity of feelings, the breadth of dreams/hopes/aspirations and the usual myriad of questions
- **Can Love and Live** the way they want –acknowledge their sexuality, understand it within a socio-sexual framework
- Like other young people their sexual health and socio-sexual development is important and will **not be without problems/issues/challenges**
- Like other young people they **need education, information and support** that is tailored to them and is accessible, applicable, ongoing.

Discussion

- Post-school years are critical for socio-sexual development and a TTW program is often the ONLY disability program these young adults are in contact with.
- Compared to non-disabled peers – less sexually active; less access to socio-sexual information and education
- Strong biological focus – suggests notion that they could not understand / comprehend complex socio-sexual reality of intimate relationships – “not like me/us”

Gendered Messages

- Not much progress from late 19th early 20th century
- **Young women** - “A feeble-minded girl is exposed as no other girl in the world is exposed. She has not sense enough to protect herself from the perils to which women are subjected’ (Cummings, 1902 in Butler & Parr, 1999);
- **Young men** – control your steed – poster from 19th century used with men in institutions
- No longer segregating young men and young women from each, but sending them the same strong messages and controlling what they ‘can know’ and how they ‘should act’

Conclusion

- More first hand knowledge of what young people with disabilities think, feel , know, experience and want to know and experience- survey and in-depth case studies
- More knowledge about what families as key supporters of yp with id know, want to know feel and experience that underpins their approaches
- Develop and use knowledge to inform approaches in education, sexual health promotion, counselling – mainstream and targeted with an early intervention aim and socio-sexual framework.
- Drawing on best practice in the mainstream and emerging knowledge about how to bring mainstream and targeted together (Frawley & Anderson, 2014)

Thanks

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- References available on request