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Experience, Wisdom and Education

**Young adults with ID and
transition staff reflect on
sexual health needs**

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Background

- Australia does not have a coherent biopsychosocial sexual health policy
- State-based single-issue programs and policies (e.g. HIV, STDs, fertility)
- Flow-on effect for disability sector is ad-hoc policies and service responses
- Young adults with IDD are at a critical life transition where counter-productive outcomes can have a lifelong impact.

Young adults with ID:

- **Are sexual**, they experience the complexity of feelings, the breadth of dreams/hopes/aspirations and the myriad of questions that come with sexual expression and relationships.
- **Can Love and Live** the way they want –acknowledge their sexuality, understand it within a socio-sexual framework, recognise need to explore sexuality and enabled range of intimate and social relationships others have.
- 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 – little is known about their current use of information and education in their lives

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 rules
- 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



Caregiver literature – 3 key themes

- factors that influence paid caregiver's willingness and perceived competence to provide support
- the gendered attitudes of paid caregivers toward the sexuality of men and women with IDD, and
- the types of sexual issues where paid caregivers are required to provide support

Literature – factors that influence caregiver responses

- If paid caregivers perceived the inappropriate sexual behaviour to be **temporary** and viewed the efficacy of their likely response **optimistically**, then they were **more likely to provide support** (Willner & Smith, 2008)
- Factors for providing sex education included **reacting to a socio-sexual problem** (schaafsma et al., 2014).

Literature – caregiver gendered perceptions

- women and girls with IDD were viewed as **sexual innocents**; men and boys with IDD were perceived to have sexual motivations based on **sexual gratification** (Young, Gore & McCarthy, 2012)
- Positive attitudes, but men and boys with IDD were perceived to have **less self-control** and that **less sexual freedom** was desirable for women and girls with IDD (Gilmore & Chambers, 2010)

Literature – types of sexual issues

- Narrative review by Rushbrooke, Murray and Townsend (2014): (1) fear and uncertainty, (2) impact of perceptions of sexuality, (3) the same and different, (4) balancing the roles of protector and facilitator, and (5) conditionally sexual/conditional support.
- caregivers felt a clear responsibility, but they also had to **balance the tension of risk versus the right** to socio-sexual independence

Background – Australian disability sector

- Do disability transition staff have a role as sexuality educators?
- Most policy focuses on **providing information when it is needed** not direct education or education that is ongoing, holistic.
- Raises the question about the role of mainstream services in providing sexuality education and sexual health information and support to people with IDD

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)
- Anecdotal evidence – sexuality can be problematic and staff not skilled in area.

Research aims

- To explore how Transition to Work (TTW) staff currently saw their role in providing sexuality education and information
- To explore with young men and women with ID their experiences of sexuality education.

Methods

- Ethical approval by University of Sydney HREC
- Focus Group Interviews with TTW participants and staff
- Semi-structured interviews:
 - 1) Staff: range of sexual issues where staff have provided support, what was effective / ineffective
 - 2) Young adults: experiences of sexuality education, quality of that education, best modes for that education

Methods

- Staff Participants (n=17) were TTW staff from x3 agencies in Sydney; Female (n=15); male (n=2); Mean age – 38.5 years; Mean experience – 8 years
- Young adults: (n = 25); Female (n = 11), male (n=14); Mean age 18.7 years

Findings - staff

Selective Code	Subjective Code	Core theme
TTW = job skills	Meant to be promoting employment skills	"Reluctant Counsellors"
Mimics the workplace		
The asexual child	Family struggles facing sexuality of their child	
Delayed reality about their child's sexuality		
Seeking help from TTW program		
Social problems	TTW Program fills a social gap	
Social opportunities		
Life experiences	TTW staff as socio-sexual educators	
Skill deficits		
In-house solutions		
Referring on when "too hard"		

Findings

- Meant to be providing employment skills

I don't think it is within the boundaries of what we are meant to do, I think we are here as an employment program

with the relationships again it comes back to if you are at work and you are in a relationship you can't be going up and kissing each other so that is why we draw that line here

Findings

- Meant to be providing employment skills

I saw that our client was hugging several of her co-workers and I actually thought right ok and spoke to her support person about that and also I spoke to her about the rules around the workplace

Findings

- Family struggles facing the sexuality of their child

this is my worst nightmare, I have been dreading this ... just hoping it wasn't going to happen

we gave all the information and referrals to the Mum and Dad and it was not her fault at all ... she ended up being exited out of the program

Some parents don't even think ... she wouldn't be interested

Findings

- TTW Program fills a social gap

a lot of them don't mix in social groups with other people who are obviously in similar situations

I think social media too has now come into play we just recently had a young lady who, she says "I fell for him" ... and she was just requesting for him to be her friend on Facebook

Findings

- TTW Program fills a social gap

he only has to look at you and he is in love with you and he is passionate in love and you will be the love of his life

regular friendships can continue but more common is the blurring of lines and that brings us to, we have a need here that has to be addressed, this guy or woman needs a life

Findings

- TTW staff as socio-sexual educators

a young girl last year who came in and told me she had not been on contraceptives but had just had sex with this guy that morning

he has just come out talking about how he loves women's clothing ... well confided to a couple of us, that he likes to put his mum's clothes on when they are not home and I find it really hard because they don't know

Findings

- TTW staff as socio sexual educators

She was saying she was having sex with her boyfriend, that is fine, but how she was getting bladder infections so I sat down and told her after you have sex go to the toilet so we have to take on that role anyway

There have been staff over the years who have been uncomfortable with dealing with any issues remotely in that sexuality area

Findings – young adults

- 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.

Findings – young men with an intellectual disability: **Fear – Abuser -**

• ‘Knew /Heard about’

- Wet dreams
- Masturbation
- Orgasms
- Oral sex

Messages from parents/ staff

- Don’t abuse women
- Don’t give/get diseases
- Don’t watch pornography
- Masturbate in private

Formal Education

- ‘Rules’ about sex – consent, respect , privacy
 - How to use a condom
- From Dad’s, school, TTW staff

Experiences

- Watched pornography
- Had masturbated
- Got in trouble for ‘inappropriate’ behaviour

(Frawley & Wilson, in preparation)

Findings – Young Adults

- 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.

Fear – Abused/Victim - Pregnant

Knew/Heard about

- Menstruation
- Contraception
- Saying ‘No’ to unwanted touching

Messages from parents/staff

- You are not ready until...
- Don’t get pregnant
- You are likely to be abused
- You are not safe

Formal Education

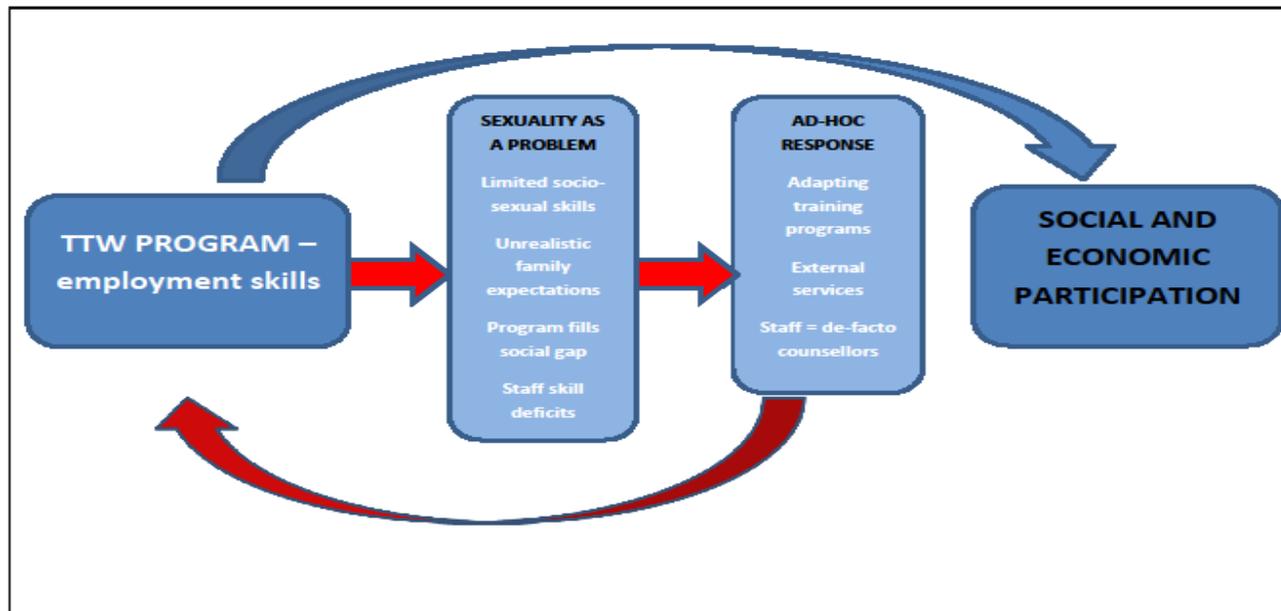
- Focussed on the physical aspects – menstruation, body parts, women’s health and hygiene, pregnancy
- How to use a condom

Experiences

- One woman sexually active
 - Some kissing and touching
 - Looking at internet sites about sex – mixed success/ some R rated sites
- (Frawley & Wilson, in preparation)

Discussion

RELUCTANT COUNSELLORS: "if we are not dealing with it, and the family don't deal with it, then who is dealing with it?"



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.
- Three socio-sexual pathways:
 - 1) counter-productive outcomes – e.g. pregnancy and sexual offending
 - 2) ignored and regulated until there is a problem – problematised discourse
 - 3) productive and healthy outcomes

Who can young adults talk to?

- Peers: Interviewer: Would you talk to your friends about it: Young women in unison “Yes”
- Parents: Interviewer: Would you ask your Mum: Young woman “It would be awkward”
- TTW staff: Interviewer : Would you talk to staff here? – Young women “Yes (in unison) – about relationships and stuff like that yes. Interviewer: Do you think it is important for TTW staff to know how to talk to you about it? “Yes definitely”
- Best way to talk and learn
- In group – single gender: Interviewer: Boys and girls together? Young woman “No these boys are not exactly mature”
- Facilitated by someone ‘trusted’ – “someone like you [the female interviewer]”

Conclusion

- TTW staff should be focussing on employment-related skills
- BUT socio-sexual issues will remain while there is a social and sex education gap
- What can be done to fill these gaps?
- Need for evidence-based, relevant, responsive and health-promoting sex education programs that TTW staff can access
- Need for structured social opportunities outside of TTW program

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.

Future Research

- Examination of immediate and longer-term **counter-productive outcomes** for young men with socio-sexual difficulties
- Feasibility of socio-sexual education programs – focus on gender
- LGBTIQ needs
- Design and pilot a socio-sexual education program

Thanks

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- References available on request