

Young People with Intellectual Disability Talking About Sexuality Education and Information

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Abstract When young people with intellectual disability (ID) begin to explore their sexuality they face a number of challenges accessing information and support. Unlike most of their non-disabled peers, young people with ID face the challenge of developing their sexuality and relationships within a narrow and regulated social and private life. For young men with ID their sexuality is often pathologised and for young women there is a focus on hygiene, self-protection, and pregnancy. For both young men and young women, their education is dominated by a biological focus and taught as ‘rules’. Mainstream sexuality education curriculum has progressed to a more holistic approach. This holistic approach is missing from programs experienced by young people with ID. In this study we spoke to young people with ID about their experiences and opinions of the effectiveness of sexuality education. Gender-specific focus groups were conducted with 14 young men and 11 young women with ID attending transition programs in Australia. Qualitative data were analysed using a constant comparative method informed by Grounded Theory and highlighted three issues: (1) the young people knew facts and rules but not the ‘how to’ of relationships and sex (2) access to information was limited and mediated by risk averse informants (3) the young people were full of unanswered questions - they wanted to know more and do more.

Keywords Intellectual disability · Sexuality and relationships · Young people · Transition to · Adulthood · Sexuality education · Gender

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Introduction

Emerging adulthood raises similar challenges for young people with intellectual disability (ID) as it does for other young people, including issues with developing a sexual identity, sexual expression and development and navigation of intimate relationships. Sexuality and social relationships research with young people with ID in transition to adulthood, highlights the additional complexities they face [1]. These include having difficulties forming social and intimate relationships, finding a partner and having social lives and social experiences independent from their parents [2]. For young people with ID, paid and unpaid caregivers are closely involved in planning for the young person's adult life, determining how this transition will occur and mediating learning and social opportunities within this transition time. These 'mediators' face their own challenges in supporting young people with ID through transition, in particular in relation to sexuality and relationships [3–5]. The evidence strongly suggests that the values, attitudes and actions of these 'mediators' are conservative and risk averse, leading to restrictive approaches that limit the young person's access to information, education and opportunities to develop their own social and sexual identity. Less is known though about how young people with ID perceive the education, information and guidance they receive and how they understand and use it to inform exploration of their emerging adult social and sexual selves; this study seeks to fill this gap in knowledge.

Background

Young people have an entitlement to sexuality education which is globally recognised by UNESCO's *International Guidelines on Sexuality Education* [6]. These guidelines acknowledge that few young people receive the sexuality education they need stating that, "Many young people approach adulthood faced with conflicting and confusing messages about sexuality and gender" (6, p. 2). Although these guidelines call for more appropriate sexuality education for all young people they overlook the particular issues relating to providing this education for young people with disability.

Sexual health, safety in relationships and a full and meaningful social and intimate life are articulated rights for people with disability embedded in the UN Convention on the Rights of Persons with Disabilities [7]. In particular, State Parties are mandated to ensure the rights of people with disabilities are upheld in all matters relating to marriage, family, parenthood and relationships and that people with disabilities are ensured the highest standard of health without discrimination, including sexual and reproductive health [7]. For many young Australians with intellectual and other disabilities these rights are often not upheld or considered until there is a real or perceived problem, often in relation to reproduction or sexual behaviour. A national audit of Australian disability research found that the experiences of people with disability in the areas of 'sexuality, personal relationships, and family' and 'health and education' were significantly under-researched [8], however what exists strongly suggests that young people with ID are not faring well in this area.

Reported Sexuality and Relationship Experiences

People with disabilities are reported to experience all forms of violence and abuse at increased rates compared to the general population, however reliable data is lacking.

Research in the US highlights that women with disabilities are at particularly high risk [9], with one study that reviewed national survey data reporting women with severe disabilities were four times more likely to be sexually assaulted than women without disabilities [10]. In Australia a study of reported rapes of women found that 26.5 % had disabilities with 22.1 % being identified as women with intellectual disabilities [11]. Women with ID also experience increased rates of unwanted and unplanned pregnancies and levels of child removal from parents with ID is reported at 40–60 % [12]. Reproductive rights violations are also significant for women with ID who are more likely to be sterilised than non-disabled women [13–15], more likely to be prescribed long acting contraceptives and less likely to be involved in decisions about contraception than women without disabilities [16, 17].

A recent review of the literature about men with ID noted an overtly pathological focus on their sexuality and sexual health with calls for a shift to a more positive starting point [18]. The available population data about men with ID shows that they have a significant risk of poor sexual health with rates of STIs eight times greater than their non-disabled peers [19]. Another concerning outcome for young men with ID is sexual offending; although there is a lack of clarity about prevalence, due largely to methodological difficulties, research undertaken two decades ago suggests an increased prevalence [20]. Despite the gap in reliable data, research on recidivism of sexual offenders with ID suggests those men with ID who are sexual offenders are between 3.8 and 6.5 times more likely to reoffend compared to the general population [21]. Lambrick and Glasser point out that the key issue is a lack of appropriate services for sex offenders with an ID and their exclusion from treatment programs where the presence of ID is used to exclude.

Young people with ID are faring poorly in a range of outcomes associated with sexuality and relationships. They are missing out on opportunities to develop knowledge about sexuality and relationships and to pursue their social and sexual aspirations as emerging adults. Some research suggests that this is due in part to their contested adulthood where they are seen as “...living in suspended adolescence” ([22], p. 33). Slater in her research on the question of contested adulthood of people with ID expands on this noting how discourses of ableism and adulthood interact to inhibit the ‘becoming adult endeavour’ [23] of young people with a disability. Although young people without disabilities can also struggle with transition to adulthood and with adult surveillance of their social and sexual lives, for young people with ID questions of their capacity to be sexual and be self-determining about their sexuality and intimate relationships is a strong theme. International research with caregivers and staff has found that they hold conservative values and attitudes and that these underpin how they mediate the young people’s access to sexuality education, information about sexuality and relationship opportunities [24–26]. This research also suggests that there is a translation from restrictive attitudes of staff and caregivers to restrictive outcomes for the young people including limiting their access to sexuality education and relationship opportunities.

Young People with ID Informing Sexuality Education—the Gap

Current best practice in sexuality education for young people has shifted away from ‘moral-panic’ approaches to approaches that recognise the agency of young people, are based on ‘real life’ experiences and enable young people to learn how to negotiate ethical sexual lives [27]. Importantly this research is informed by the voices of young people where insights into their experiences are used to inform education approaches [28, 29]. While policy and practice in disability is increasingly being informed and shaped by people

with a disability, research and practice in sexuality education is still primarily informed by others. Research by Azzopardi-Lane and Callus [22] in Malta with self-advocates, and research by Lofgren-Martenson [30] in Sweden and CHANGE in the UK [31] are notable exceptions. These studies acknowledged the importance of asking people with a disability directly about their views about the education and information they received, and what their experiences had been in developing their sexual identity. In Australia there has been very little research of this nature apart from the work by Hillier, Johnson and Harrison [32] in 2002, and the later work on peer education by Frawley and colleagues with ID [33]. More needs to be done to align what is happening with and for young people with and without disabilities in this area. The research reported here aimed to begin this process with a small group of young adults with ID who were involved in transition to adulthood employment support programs in Australia.

Method

Ethical Considerations

Ethical approval was granted by the Human Research Ethics Committee at The University of Sydney (Approval ID: 2013/159). Researchers were aware that some participants might struggle talking about sexuality with peers so additional time was spent ensuring options for participating or ceasing their participation were known. This extended to information about support during and after the focus groups if needed given the sensitive nature of the research. No significant issues arose although one young man did cease to participate in one of the focus groups in relation to a health matter and was given appropriate support immediately following his withdrawal from the group.

Data Collection

This research took a view that the young people were knowledgeable, able to talk about and reflect on their experiences of sexuality education and accessing information about sexuality and could provide a critical lens to their experiences. In this way it was a departure from other research that has failed to engage directly with young people based on an assumption that this topic would be too difficult for them. Participants were offered the opportunity to participate in a focus group or an individual interview; one participant chose an individual interview. The focus group approach was chosen as a way to involve young people together so they could draw on and engage in the social context of the research [34]. A semi-structured interview schedule of open ended questions was used to guide all interviews. The key questions were designed to explore what information and education the young people had received about sexuality and relationships, how and from whom they received this information and education, how useful this information was to them and how this could be improved. Reflecting both the gendered approach of this study and addressing issues of comfort and safety in data collection, young men were interviewed by a male researcher (NW) and young women were interviewed by a female researcher (PF). While in this study this decision was based on assumptions by the researchers, future research could ask research participants their preferences about who they would be comfortable to talk to in research considering sexual identity and sexual orientation.

Participants

Four focus group interviews were conducted with 25 young adults with ID. The age range was 17 to 20 years, the mean age 18.6, 14 participants were male and 11 female. Twenty three of these young people were born in Australia primarily to Australian born parents (14 fathers born in Australia, 15 mothers born in Australia). Table 1 provides a summary of participant demographic data.

Participants were recruited through the transition program where staff disseminated information about the research to the young adults who used the service. In some instances parents were involved in negotiating the participation of the young adult in the research through providing their consent in addition to the young person also providing consent for participation. Using best practice approaches in research with people with intellectual disability, plain language statements were developed in easy English with pictures and verbal and written consent were given by the young person.

Data Analysis

Utilising both inductive and deductive reasoning, the constant comparison method of grounded theory [34] was used to analyse data. Interviews were analysed initially by the first author where a line-by-line analysis yielded a range of preliminary memos in the margin of the transcript. Initial coding of the data from the men's interviews was undertaken by NW and the initial coding of the data from the women's interviews was undertaken by PF. Next, both authors, with different professional backgrounds—nursing and education—worked together where memos were collated first into open codes and then into axial codes. The first author then developed a range of selective codes which corroborated the relationships between categories and the literature of the topic. Finally, credibility was addressed after both authors refined a draft conceptual framework that was presented to peers at international and national conferences ($n = 4$) and to a sub-sample of participants ($n = 6$) for member-checking. These analyses were brought together under the following three themes: (1) the young people knew facts and rules but not the 'how to' of relationships and sex (2) access to information was limited and mediated by risk averse informants (3) the young people were full of unanswered questions—they wanted to know more and do more.

Findings

The focus of this research was to gain evaluative information from young people about the sexuality education they had received and ideas about how to improve it, however the focus groups also yielded information about what young people felt they knew and the questions they had. While there were some similarities between what the young men and young women said and reflected in the focus groups, in particular the strong view that they were not in control of what they learned and when, or decisions about sex and relationships, there were clear differences that are outlined below.

Table 1 Demographic data young adults with ID

Variable	Participants
Level	<i>N</i> = 25
Gender	
Male	14
Female	11
Age (years)	
Range	17–20
Mean	18.7
Country of birth	
Australia	23
Asia/Pacific	1
UK	1
Fathers country of birth	
Australia	14
Other	11
Mothers country of birth	
Australia	15
Other	10

Young Men—What They Knew

The young men had pockets of knowledge about sex devised mainly from pornography magazines and were full of questions. They used the interview as a place to rehearse what they knew, check it with the interviewer and to learn from each other as this conversation about masturbation reflects.

Can I ask a question, wouldn't you have to masturbate to get an erection before you could put one [a condom] on?... I never learned about masturbation... I think we might of.... We learned that at certain times, it depends on where you are, it is ok because you are a male, you got to do that sort of thing... It is in your hormones, a natural thing. You do it in private places, you never do it in front of anyone... I just masturbate when I watch porn on the computer.

I want to learn about wet dreams. When you have an orgasm during your sleep you don't realize it because you have too much sperm produced-do you know anything about it or not?

If you want to have a huge orgasm does it, you don't want to straight away you want to take your time before you ejaculate? Interviewer: Hang on a sec, so when you masturbate, you never have an orgasm? FG member: No never Interviewer: Do you know what an orgasm is? FG member: Yes when you scream. Interviewer: Do you know what happens? FG member: Maybe, not sure, well it is to do with sexual intercourse, it is a feeling, people describe it as a very good feeling. Interviewer: So if you masturbate and it feels good and then normally when you have an orgasm normally you ejaculate, which means you "come". FG member: And all the milk comes out, it isn't really milk but it is all the sperm coming out, well orgasm is if you

keep masturbating all the time you are not going to have full orgasm, you will run out of sperm, you need about 72 h to recover?

They also used the interview as a place to air their thoughts and ideas about moral and ethical issues about sex and relationships, in particular in relation to how to treat women, respect, the place of women in pornography and the ethics of pornography.

Pornography is just people making money... It is not exactly consensual but they do it for the film... I don't watch that stuff because I find it a bit immoral and I am not religious or nothing but it is a bit degrading to women... When it comes to me I have ultra-respect for women... My father, he taught me always to respect women. Everyone used to say you shouldn't be watching it [pornography] but whenever I had my door locked there would be a smart arse comment, he [my dad] would walk in and say "you watching porn" and I would say maybe and he would ask if he could join me. He always taught me about respecting women... This guys [the one who called women bad names] got no respect for women, he told a girl to suck his dick.

In their life experiences they did not have places or relationships they could ask questions or rehearse their ideas about sex and relationships within. The young men reported having no or limited social networks and lacked regular contact with other young men in places where they could talk about these things. One young man spoke about a mate he saw at drag races who "told him stuff" but he was unsure of the reliability of this information.

On Friday and Saturday everyone takes their nice cars down there [shopping centre car park] and they flash them off and there are all these hot chicks there and my mate all he does is get in his car and does a burn out to impress the chicks. Sometimes he tells me things and I don't answer so I ask him and what did you do, he says he had a wank, he tells me things I don't want to hear.

Sometimes they talk about [sex]my mate is a horny bastard and it is all he talks about, he goes on a girl website and he went to a brothel, Yes told me what he did, how much he paid for it and all he wants is a girlfriend.

The young men had the vocabulary for talking about their questions but nowhere to do this; on reflection the researchers saw that the focus group provided this 'men's space' to talk about wet dreams, masturbation, how to get an erection. They also lacked 'practice' of the things they learned about however one young man shared his experience of learning about how to use a condom in class by putting a condom on a banana, recognising this was not adequate he told of stealing some condoms to take home and practice with.

Knowledge and practice of having a relationship was also limited, they knew the rules about how to treat women but had very little practice in relationships.

[Should you] tell her to suck your dick?... Maybe if you were having sexual intercourse it would be alright and if they say yes it would be ok, but don't force them... Because it is not consensual.

Their questions were less about the 'mechanics' of sex and more focussed on how to get a girlfriend, keep a girlfriend how to relate to a girlfriend intimately and emotionally.

Perhaps we could take advice from you from any experience you might have had and it could reflect on us somehow. Maybe starting a relationship with someone and developing it also maybe giving insight into things that people might be embarrassed about and self-confidence as well. I want to find out about [how] to have a

relationship with a girlfriend and how to communicate and socialize with them. How to keep a girl for longer, how to keep a relationship.

Well there is a difference between knowing about something and doing something, Like doing something is a very different experience from learning it.

Talking to a girl when I see movies and see guys talking to girls I wonder why they are embarrassed and then when I do it and I talk to a girl then I see the reason, yes because I can't find the right words to say.

I want to talk to girls, rather than just staring away, let the girl talk to me, I don't know maybe I don't stare [I could say] "How are you, hello and how has work been and how is your job going?"

I do [have a girlfriend] since last year, Yes we just talk and stuff I put my arm around her I put my arm on her leg and she puts her hand on top we hold hands. She is beautiful.

I think really the only way to help other people is to talk about it, talk it through. If there is something you are not sure about or there is something that you feel uncomfortable with just talk to someone who can actually help you and I think that is the only way really. I personally think it is better to talk to someone who has actually experienced it than just simply reading about it, your problems and what not.

Some young men reflected that without guidance and opportunities to think through how to put relationship information into practice, they might revert to negative 'stereotypical' ideas about girls and respond aggressively.

I had one girlfriend cheat on me and one used me for my money and one just decided to turn into a real bitch, the problem was first her mother didn't approve our relationship, she thought because of my cultural background which is Lebanese that I would rape her and bash her which is bullshit because I am not like that...about a year she started being a real bitch and I turned around and said you know what I don't want you anymore I am sick of your bullshit... now I can't stand the bitch.

To tell you the truth, I don't have her now because she turned out to be a bitch but when I had my ex-girlfriend she seemed like she wanted to be around me all the time, always wanted to sit on my lap, not certain parts of her body but certain parts would show when she was around me, her underwear would always show around me and I felt like she wanted me to have sex with her but if she had asked I would have said no.

Despite their self-reported 'readiness', for some it seemed that those around them had either deemed they are not 'ready' or that they are only ready or perhaps capable of knowing rules rather than having a deeper understanding about sex and relationships.

One group of young men were less aware and able to talk about sex and relationships. This group had also had some factual information about sex, mainly at school but did not talk as openly about what they knew or any questions they had as the other group. They did not seem to have the vocabulary, but it was clear they had been 'taught' some rules

Interviewer: What did you learn about it?

FG member: Willie, penis

Interviewer: And what did you learn about your penis?

FG member: Pills, up, wee wee.

Interviewer: So you learned about your penis, pills and your willie going up, what else did you learn?

FG member: Finish penis.

But the condom freaks me out, I laugh when I see the condom packet. On the pack of the condom the penis grows and what it would look like?

Young Men—How They Formed the Knowledge

While almost all of the young men involved in the interviews indicated that at school they had some sex education, it seemed that family, including siblings, were a key source of information—however only a few talked about having got information or advice directly from these sources. Most relied on formal education from school and some limited education at the TTW but more on their own ‘research’ and what they picked up from movies, pornography and some said talking with others. However apart from one person mentioning a friend who talked a lot about sex, nobody gave any detailed information about who they would talk to beyond their parents and friends.

I talk to my parents about it and I have a brother as well so I talk to him.

One young man did mention professionals like a Psychologist or Specialist.

Well I know it is not something to be embarrassed about but I used to see a Psychologist, I have seen her for two or three years or something and she has been a lot of help. I would bring up things to the person because that what they try to help and understand people with problems and what not, they are very good with that sort of thing, about talking to girls, what I should do.

Another young man talked about using the internet in preparation for his formal learning at school.

When I was at high school during my physical education (PE) class, well before I did some research on it, just out of interest and back in primary school we did this hormones programme, we went onto a web site and it would tell us about sex and that sort of thing, just like Wikipedia. Well, it is just information, not pictures or anything but just sexuality in general and also diseases and the chances of getting a disease.

Interviewer: Ok so if you need to get some advice or help where do you go to get help, where have you gone to get help?

FG member: From guardians or parents or Psychologist or doctor, I think doctor or maybe PE teachers.

Although the young men were interested in issues beyond the rules of sex, most of what they knew and had been told was about ‘the rules’, in particular about safe sex and not abusing women. Much of the focus group transcripts were dotted with words like, “don’t force them”, “sometimes you don’t want to have sex with a girl because they might have a disease”, “I don’t think having a child is a good idea for boyfriend and girlfriend who are not married”, “they [girls]don’t want to hear about sex all the time”.

Young Women—What They Knew

The young women spoke mostly about contraception and safety in sexual relationships. When contraception was mentioned in the focus group in unison the women tapped their arms, pointing to their contraceptive implants. The key reason they gave for using contraception was pain relief for and management of periods. The young women knew that the contraception prevented pregnancy but could not describe how, and for most the decision about using contraception was made by others.

Interviewer: Who decided you should have (rod implanted for contraception)... FG member: Mum.. Interviewer: So you had a boyfriend at the time? FG member: Yes. Interviewer: And were you having sex? FG member: No because she [Mum] would go off her head.

Interviewer: So your Mum helps you out with that by keeping your schedule so that she can say your period is coming up. FG member: Yes and I am also on a pill because I get aches. Interviewer: So who told you about getting the pill? FG member: That was the doctor. Interviewer: Can you remember what the doctor said? FG member: He just gave me the prescription, I have to take it every morning...it prevents “a certain thing” not to mention in this room...pregnancy.

While these young women had a good knowledge of the basics about their own bodies they were not so clear about men and sex and had no practical experience of sex. Like the young men, they had questions about how to have a sexual relationship and how sex worked. One woman noting she was scared about it and another making the comment that she wanted to know “...how to control a sexual relationship”.

Like the young men the young women had been taught about condoms at school by putting condoms on bananas. Their responses to questions about the effectiveness of this approach to learning about sex and safe sex indicates great confusion about it and again questions the effectiveness of this approach to learning about safe sex.

When I was at school they showed us bananas and stuff...we didn't have that, I never had that (all talking at once), we had to put oranges in [laughter]. Interviewer: Is that what condoms are for? [laughter]... FG member: No they are for protection...Interviewer: Did anyone talk to you about safe sex...FG member: My Mum...she just said use protection...Interviewer: And did she show you what protection meant, did she show you how to use a condom...FG member: No we saw them at school with the banana.

The one woman who spoke about being in a sexual relationship recounted how she learned about safe sex and using a condom,

Interviewer: Tell me what you know about safe sex...Interviewee: My Mum said if you don't have a condom you will die...you can get chlamydia, STD and die a painful death... Interviewer: So you use condoms...Interviewee: Yes...Interviewer: Who taught you how to use condoms? ...Interviewee: My Mum...Interviewer: How did she do that...Interviewee: She just gave me a condom and said use it on my boyfriend, slide it on...too much public hair.

There was a strong sense among the young women that others felt they were not ‘ready’ to learn about sex or to have sex until they met a set of conditions.

Interviewer: Do you think you have enough information about contraception and having babies...FG member: Maybe in the future...if you want to have sex you have to be in love with the person...or married. Interviewer: Do most people wait until they are married? FG member: No...they have it at 16.

Interviewer: What about if you were to go to start a sexual relationship with someone, say you have found a boyfriend or girlfriend and you want to start a sexual relationship with them, do you think you would need to know anything more than you know now? FG member: Yes I think we would need to know everything there is to know about sex and stuff... Basically my Grandad told me you have to know about the person for years.

Young Women—How They Formed Their Knowledge

Hygiene and menstruation were the focus of most of the education and information the young women had received. They recounted many facts about these topics.

My periods go for four days...I hate it when it soils your knickers...Bleeding means your body is healthy...Stress can stop you from having your periods...I don't get my periods any more...because I had really bad ones...well I take a needle every four weeks.

The young women who said their mothers had given them information noted they were embarrassed talking to their mother, although where mothers had talked to their daughters the young women were likely to refer to them as their first 'port of call' for more information.

Interviewer: The thing I am interested in is the people in your life who have said to you, you are growing up to be a woman so I need to tell you about getting your periods so who has that been for everyone? FG members: Mum (in unison).

Interviewer: Did anyone else help you with information about growing up and being a woman?...FG member: Dad's girlfriend because I was living with him. Interviewer: So Dad wasn't that comfortable with talking to you about it. FG member: It was a bit weird and uncomfortable. Interviewer: Do you remember what she told you? FG member: No

Interviewer: What did your Mum talk to you about? FG member: The birds and the bees (group laughs).

Interviewer: Did you ever ask your Mum (about sex). Interviewee: Yes and she said when you are older we can have a talk. Oh no "the talk"... Interviewer: So tell me about that, tell me about the talk. Interviewee: It was the most disturbing thing in my life, I had to sit down with her and she went through all the sexuality things and I learn how to research it myself.

Sexuality education that had been provided at school was not seen as very useful by the young women with focus group participants in one focus group answering "no" in unison to a question about whether school sex education was useful. Some also indicated that the 'kids in mainstream' got more education and information. One young woman who went to a special school noted they did not do any sex education there even though she was 12 and she felt she needed it.

FG member: All we did, when I was in high school, the teacher put a video on something about sex education but it was a cartoon version of it and I was in Yr.11... Interviewer: So who thinks the schools did a good job at telling you about sex? FG members: No way (everyone talking at once)... The kids were not mature enough because they always mucked up and laughed about it and then they stopped it because we didn't really learn much... No they didn't actually teach up properly... Except for mainstream classes, they give you heaps of information then. Interviewer: So you were in a Special Education stream at school... did you need the same information? FG member: Yes... half the stuff I don't know about sexual intercourse and stuff.

The young women had strategies for finding out more about sex on their own. Some noted that the internet was helpful, particularly when they did not understand the words that were used in books or in other written information they accessed. Others talked about using books from the library and books they had when they were kids being useful. However this was all self-directed learning and was a bit 'hit and miss'.

Interviewer: So who wants to tell me about a place... where they have got information from, have you looked at the internet about stuff on sex and relationships and has it been useful? FG member: Yes.. Kind of most words I don't understand... I agree. Interviewer: Do you remember any of the particular places you have looked for information about sex on the internet? FG member: Wikipedia-books in the library. Interviewer: Can you remember what the book was called. FG member: I think it was sex and pregnancy... Yes because they were showing you how to have sex and have a child.

Another strong theme from the young women's' focus groups was being told how to say 'no' to sex. There was no discussion about the pleasure of sex or sex and relationships being a positive experience, leaving women a bit scared about the whole topic. Despite the education they had and information they accessed they were still left with many questions about 'how to have a sexual relationship' and how to 'control' a sexual relationship. They saw the focus groups as an opportunity to find out more and rehearse their own ideas. They wanted to have 'girls' chats' facilitated by someone like the interviewer. They noted that they would like their information to be provided in a group like the focus group, by another woman who was someone they thought had more knowledge than them but was not a teacher or a parent. They wanted access to information in formats that they could understand. But most importantly they wanted to have a 'girl's space' to 'talk about things'.

The young women noted that the education they received at the transition program was better than at school because it was provided in smaller groups, the trainers were more approachable (particularly the younger trainers), and they used information that had easy words and pictures. However this was all part of a training module about appropriateness in the workplace which also included some information about sexuality and sexual health. Placing sexuality and relationship information in this context was seen to be somewhat confusing by the young women. It was also clear by the way the young women talked about this education that staff, or more likely the work training curriculum dictated what was taught, how and when.

Learning from each other informally was something the young women noted was a good thing about being in the transition program. They noted that they had more breaks to

'hang out' together than they had at school and these were times they talked to each other about common experiences.

Interviewer: Are your friends good people to talk to? FG members: Yes (everyone agreed)... Because they keep secrets. Interviewer: Does anyone want to share with me something you might talk to your friends about. FG members: Not really (laughter and general chat again)...Interviewer: And would your friends sometimes know more than you? FG member: Because they care about us or probably because we have disabilities... Yes I find that people around me that don't have a disability they act funny... They probably think you are weird or something... [friends with disabilities]...they can understand each other.

For the young woman who had a stable sexual relationship, this relationship had been the impetus for her education provided primarily by her mother and supported by a counsellor. Her account of learning about sex was that she received a talk from mum that embarrassed her, was told how to use a condom, she did some further research of her own on the internet and then 'practiced'. She also talked to her boyfriend to plan and negotiate what each other wanted to do.

Interviewer: Do you-do you ever talk to your boyfriend about it [sex]... Interviewee: We chat about it on Facebook or phones. Interviewer: So when you are with your boyfriend how do you work out what you are going to do, you just ask...Interviewee: Yes and then we get right to it...to the sex.

In addition this young woman also received some counselling to talk about the more complex issues of having a relationship. However others noted that counselling had not been helpful to them.

Discussion

This research with young men and women with ID highlights that this cohort were inquisitive and ready to find out more about having sexual relationships and wanted what other young people have; ways of exploring this in actual relationships. It confirms some of what other research undertaken with young people with ID has found including that young people with ID have some knowledge about sexuality and relationships [35] and can and do find out some things for themselves despite the barriers they face accessing information [30, 31]. It also found that young people with ID are sexual if not as sexually active in the same way as other young people. In particular they think about and have sexual interests and desires and are sexually explorative. Overall they also reported that they did not have enough information or opportunities to learn and explore. They wanted to talk with each other but wanted these 'talks' facilitated by someone other than parents or staff and wanted the 'permission' and opportunities to experience a sexual relationship as a way of growing this knowledge.

Information that was 'given' to these young people was mediated by staff and parents and revised in accordance with what they deemed the young people could understand and could use. Often this left the young people with more questions than answers and there were large gaps in this information. There was a strong focus on 'rules based', factual, and biological education. However for these young people this linear almost clinical approach did not meet their needs. They reflected a more explorative and chaotic engagement with questions, interests and feelings about sexuality and relationships, and apart from the

regulated transition service environment, they largely lacked the social opportunities where they could explore these relationships. The transition services did not see it as appropriate that these young people conduct their relationships ‘at work’ [36]. This was evidenced by the lists of rules that lined the walls; no touching, no kissing, no two people alone together. For some of these young people the transition service was the only time they were together with other people their own age.

Education provided to these young people was also clearly gendered and had a strong heterosexual focus; the young men were taught to be careful not to abuse young women, spread disease or get someone pregnant, and the young women were taught to be clean, stay safe and to not get pregnant which was ‘ensured’ by placing them on contraception. While for both young men and young women there was a focus on avoiding pregnancy, for the young women there was a lack of involvement in contraceptive decisions. For both the young men and the young women the overwhelming message was that sex and sexual relationships were something to be concerned or scared about. One young woman asked “How do I control a sexual relationship?” while one young man asked how he would really know what a girl wanted. These are very good questions, however the education and information they had received, coupled with the lack of social opportunities and private places to conduct an intimate relationship, particularly in the heavily regulated environment of the transition service, made the development of the deep knowledge needed for a safe, informed and pleasurable sexual relationship very difficult.

Sources of information reported by the young people with ID in this study had some similarities and some differences to what young people without disabilities report as trusted and reliable sources. A recent Australian report of non-disabled young people found that they rated their friends and the internet as key sources of information [29]. Similarly the young people with ID in our study used these sources, albeit with some difficulty, particularly given their friends were potentially as information poor as themselves and they lacked the literacy skills to read and understand some of the information they found in the public domain. While formal sex education primarily at school was mentioned as a source of information for the young people in our study they reported it was not very accessible or useful. Conversely young people without disabilities rated school programs as a key and valued source of knowledge [29].

Conclusion

A key message then is that accessible sexuality and relationship education and information is needed for young people with ID. This needs to be available in a range of places, facilitated by a range of people including families, peers and teachers and also be independently accessible by young people with ID. Further, that as with young people without disabilities, the young people with ID need to be engaged in shaping this education and how the information is developed and delivered. Peers are an important part of all young people’s lives. The young people in this study, in particular the young women, reported that they did ask their friends and felt comfortable talking to other young people with disabilities. This suggests that peer education could be a worthwhile approach. While little work has been done in this area there is some evidence that it can be used successfully in sexuality and relationship programs with adults with ID [33]. Importantly both the young men and young women in this study reported value in the opportunity they had through the research to talk as a group, facilitated by the researchers who were seen as knowledgeable

and approachable. As researchers we valued this opportunity although we knew it was only fleeting. The research opened a line of communication that worked for the groups and they wanted more, recognising that talking about their questions and getting some answers was better than the didactic approach they had experienced at school and with parents. It is not ideal however that research like this is seen as an alternative to or substitute for formal education.

More research is needed to bring the sexuality and relationship and sexuality education experiences of young people with ID into sharper relief so holistic approaches that are informed by young people with ID and potentially facilitated by them, can be developed to address the gap that exists for this cohort. Partnership and inclusive research design used in other areas of research in ID need to be employed to ensure the voices and experiences of young people with ID are heard and used to shape and co-produce this education and information, in line with work being done with their non-disabled peers. While gaps between the knowledge and experiences of disabled and non-disabled young people may always be evident, in this area of sexuality and relationships there needs to be at least the same effort to inform and empower.

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Compliance with Ethical Standards

Conflict of interest No conflicts of interest are declared.

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