



Visibility Podcast



## Opening the door on sexual relationships episode transcript

Fiona

Hi everyone. And thanks for listening to Visibility, the monthly podcast produced by CID, the Council for Intellectual Disability.

Fiona

Here, we will be telling our stories, and exploring some of the issues that impact people with intellectual disability. To find out more about our work visit [www.cid.org.au](http://www.cid.org.au).

Now, settle in and enjoy.

Music

[CID's podcast tune]

Adele

In the spirit of reconciliation, the Council for Intellectual Disability acknowledges the Traditional Custodians of country throughout Australia and their connections to land, sea and community. We pay our respects to their elders past and present and extend that respect to all aboriginal and Torres Strait Islander peoples today.

Hi. I'm Adele and I work for the Council for Intellectual Disability. Visibility is a podcast where people with intellectual disability tell their stories. Today's episode is a little different though. We're joined by Jono. Jono has cerebral palsy and is non-verbal, but he doesn't have an intellectual disability. Jono is a passionate advocate for the rights of people with disability. When it comes to self-pleasure and access to sex therapies and



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services many of the challenges Jono discusses are shared by people with intellectual disability. So, we're really excited to hear what he has to say.

Jono uses a tablet to communicate so you will hear an electronic voice that is representing Jono's words. You also might hear a few longer pauses and this is just naturally how long it can take for Jono to input information into his tablet and for us to listen back. So please be patient and inclusive. And welcome to the Visibility podcast on sexuality Jonathan.

Welcome. Hi Jono. You are going to be speaking today through your tablet and we've got a series of questions so that we can unpack the interesting yet controversial idea that people with disabilities are sexual beings and have a sex life.

So, Jono I understand that you have a physical disability have you got an intellectual disability as well?

Jono

No, I have cerebral palsy and I am non-verbal. Because of this people often assume I also have an intellectual disability, but this is not the case.

Adele

And so, Jono thanks for taking the time to chat with us today. I'm really interested to hear your thoughts. I know that you're an incredible disability advocate based there in Melbourne. I'm high from Sydney to Melbourne I'm so pleased you guys are out of lockdown as well.

Jono there is the perception among some people that people with disability whether that's physical or intellectual disability are not sexual beings. What are your thoughts on this?



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Jono

A word biology if that is not enough. I will clarify. The flow of testosterone estrogen and other hormones which drive sexuality are present and active in most people. There is no stopping that that drive is coupled with our basic social needs in which sexuality is well established by science as a critical component to general well-being. Not to mention a basic human right to assume people with any kind of disability would be different from anyone else's. In my opinion they're either vignettes. It is biology and it is a simple fact of life.

Adele

Thanks Jono. Yeah, it's very interesting, isn't it? We are all different, but we do have those same basic human rights and those needs and just because we express them differently to the next person doesn't mean they're just not as important.

Jono tell me what are some of the challenges for people with disability in meeting someone or maintaining a sexual relationship whether that's like a one-night stand hook-up or a long-term relationship?

Jono

The challenges people with disability face could be broken up into three categories. These include challenges for the individual, for the prospective partner and finally challenges with necessary supports from workers for individuals seeking romantic encounters or partners.

The first hurdle is self-doubt and lack of confidence. Experience is of course a big player in this and people with disability may not have a lot of experience to start with. That is a catch-22 situation as it takes positive experience to develop confidence in the absence of experiences to build on encouragement from surrounding.



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Support networks become essential. That can be particularly difficult if not impossible for family members and it is questionable if that is even appropriate really. Who would want their mother to be involved with anything surrounding sexuality?

Another really important factor is that people with disability can sometimes be much more vulnerably. Whether that be to abuse, rejection or exploitation that vulnerability can be compounded if there are no emotional support networks available. Again, this comes down to the presence and quality of the individual's support network.

If so, called supports for whatever reason have a bias everything glides to a halt.

I have had support workers try to stop me from doing both sexual and non-sexual activities simply because those activities were against their personal beliefs. Differences between prospective purpose physical attributes can be another massive hurdle. For instance, if an individual is non-verbal, partially verbal or even carrying a simple speech impediment they can easily be dismissed.

As a non-verbal person myself I see people make assumptions about my capacities and abilities based solely on my inability to speak as they do. Even the extra time it takes me to type out my words on a device can be too much for some people and often means I will not be given any consideration as a romantic candidate. People can be so very quick to dismiss people with disabilities as romantic partners.

Physical considerations can also include other more profound differences whether that be paralysis, spasticity, chronic health conditions or any of the many other conditions that might be presenting both physical and non-physical.

Sexual encounters can hinge on the person's knowledge or familiarity of disability or alternately the ignorance or fear they may hold, real or perceived. Some people present physical characteristics that identify them as having an intellectual disability, such as people with Down syndrome.

There is often an automatic presumption that these people are not intelligent. For so many it just takes extra time to form thoughts and ideas.

Most people without disability assume that these people are incapable of profound or intelligent thought, but this is not true. In so many cases this form of discrimination is widespread and is a massive barrier to meeting people and exploring sexuality. And then of course the complexities of human relations can be compounded further for those with hidden disability.



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People are so often intimidated by things and do not understand or quick to judge others on the smallest thing that may seem odd. If a person says something wrong swipe left. If they seem to think or talk in unconventional ways swipe left. If they attempt the moon that misfires swipe left.

If they say something that seems weird swipe left. For the most part people tend to avoid those who they perceive are different to them. It can be very hard for a person with a hidden disability to carry things forward when they are dismissed so quickly and so out of hand.

Adele

Jono thank you. You are so right. I think you've captured the idea of the way that society works at the moment and the simplest of things that if someone doesn't make the grade you know in two seconds in your mind. It's just swipe, left. Yeah, it is very strange, isn't it?

And I think that it is important what you were saying about how taking the time to be able to understand one another and if we express ourselves differently or our communication is unusual to just take the time out with each other because you never know what's underneath.

That can be about who you live with and who you spend time with and stuff.

So, what if any barriers exist within the family for people with disability who wish to begin a sexual relationship? Do you or do people with disability feel like they need to be secretive because of like fear of disapproval or anything?

Jono

I was 21 when I decided I was ready to try out sex. I cannot self-stimulate so it was going to be a completely new experience for me. A trip to Sydney came about and since my support worker was coming with me and my mum was staying home, I took the opportunity to arrange a session with a sex worker. It was certainly not something I could do with my mum around. I googled disability friendly sex workers, chose someone



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I liked and booked an appointment. It was a fantastic experience, and I was really fortunate to see a woman with the right attitude and understanding.

Afterwards I told my mum about it since she was responsible for my personal care at the time. I didn't want her to be shocked if I somehow contracted a sexually transmitted infection disease and she found it while showering me. She completely shut down.

That was not a conversation she was able to have with her son. I imagine it is like this for most family members. I also imagine many people with disability are equally unwilling or uncomfortable to explore ideas with family. For many it's just too weird.

Adele

You're absolutely right Jono. And I think that you know for people out there who are listening whether you be a person with disability or whether you be a family member or a friend just remembering that no one really wants to chat with their parents about sex.

But often times you know your parent is going to be your closest person to you as a support. So that's really difficult to navigate as well both for the parents and for the persons themselves with regards to dignity and all those sorts of things.

I'm so pleased that you had a positive experience as well with a sex worker and just wondering, Jono, for people out there with disability or any of us who are supporters of family members and friends with disability that there are some really great sex workers out there too who can help you out and be sympathetic and understanding to ensure that you have a good experience.

Can you tell us Jonathan have you ever lived in a group home environment and other specific challenges in that environment?

Jono

We used to live in the cluster of units with people and live independently. However, the agency running the complex have a policy whereby their support workers are prohibited from assisting with sexual activity. Including assisting with the setup and use of adult devices. This meant I had to get one of my personal support workers in which depleted my house for personal assistance.



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Assisting me in this area takes less overall time than going to the toilet so I see no reason for this policy to exist. It almost seems it is just because it's in the "too hard" basket.

Adele

That is often the case, isn't it Jono? It's just complex and people don't want to have to deal with it. I understand now that you've moved into another environment and you live by yourself in a sort of cluster of units and you have the support there when you require it.

Let's just go to a short break and talk about this more when we get back.

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[Music].

You're listening to the Visibility podcast with the Council for Intellectual Disability.

My guest today is Johnathan Bredin, and we are chatting about sexuality and disability.

So good to have you with us Jono. Speaking of support workers and other people's influence over the idea of whether you should have sex or not and the level of assistance that occurs and sex workers having different values and all that kind of stuff it must be a really interesting thing to navigate with people. So, do you know what role do support workers play?

Do you think in helping people with disability to navigate those sexual relationships? And you know if there is that resistance and disapproval particularly where there might be a need for physical support what do you what do you do to kind of navigate this?



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Jono

Another important factor particularly for people who require complex supports are the support workers themselves. For instance, if I'm out on the town with my support worker and I meet someone and hit it off with them, but my support workers shift ends at 11 p.m. with us that leave me. Unless I have supports that can be very flexible with their time it can be very difficult.

They also need to be willing to assist me in the way I want I might need them to stand aside and allow me the space to communicate with people in my own way. I need them to follow my lead regardless of whether they feel something is appropriate or not. What if I decide that I don't want to go clubbing and instead choose to hire a sex worker? I have had support workers tell me paid sex is wrong or unsafe.

From my perspective it is safer to engage with sex through a paid sex worker than it is to find some random unknown person who may well have ulterior motives. At least I know a professional sex worker will perform their tasks, respect my dignity and needs and leave without fuss or risk to my personal or material safety. I make specific arrangements with my support workers where I can. I have a couple of workers who have set up a series of protocols for various scenarios.

For example, if I meet someone at a nightclub and we want to go back to a hotel room or her place for the night my support worker will settle in nearby and wait on standby for my call. This will allow me to experience an evening of spontaneity which I may not have heard otherwise. I have developed a good understanding around these issues with all my support workers nowadays.

When I go out, they are effectively acting as my wing person. We have a lot of fun with that. I do have a couple of workers who are uncomfortable with aspects of my sexuality and I am careful not to impose anything on those particular workers.

I think it's important to be fair as well. I should say that it's vital for the person with disability to draw the line and for the support workers to state whether they are able to provide support under those terms or not. If they are unable or unwilling to assist with sexuality, I would simply put them on another shift.





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Adele

That's such an understanding and sensible approach Jono because you're right. I mean just the subject of sex for most people you know draws so many different types of reactions and it's really important to be able to respect and honor people's values so just being able to sort of talk to your workers and choose which workers are going to be the cool ones are going to be down with being your wing person and then ones who are probably better off helping you with cooking and things.

We say there is a lot of controversy around assisted sex and pleasuring for people with disability and lots of controversy around the NDIS either supporting that or covering that. I know there has been a good amount of controversy around whether a person's NDIS funding should be allowed to be used for sex services. You've been really vocal about this which is incredibly important and we're just so happy to have you on the show today, Jono.

Can you tell us what your thoughts are on the matter of the NDIS funding being used for sex workers and sexual aids?

Jono

In relation to this a woman won her case against the NDIS allowing her to use NDIS funding to buy self-stimulated devices and pay sex workers. This rule meant that people who can't self-stimulate due to profound disability can now access NDIS funds for sexual activities provided it is written into their NDIS plan.

As a girl the moment I heard this I contacted my occupational therapist and we have added to my plan. I can now use my NDIS funding for sexual release via adult toys and sex worker. While I am able to obtain satisfaction through the use of adult toys there is nothing that can substitute intimate person to person contact. For me it is deeply nourishing and an integral part of my life.

However last week NDIS once again made up their own rules and said NDIS funding can't be used for sex workers and purchasing of self-stimulation devices. This is appalling and it needs to be challenged again. I am looking into this and I will be fighting it. The NDIS is set up to help people with disabilities to live ordinary lives. Self-stimulation is a part of ordinary life just like walking and eating so why shouldn't people with disabilities be able to explore.



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This sexuality is a basic human need and people with disabilities should be able to apply for funds to support this need just like they can apply for train to help support them to stand.

As I stated earlier there are additional barriers that prevent people with disabilities from having the same sexual opportunities or relationships as people without disability that should also be taken into account and the current restrictions should be brought into account them. I would also like to see more manship made available for people to develop their social skills and understanding of sexuality, so they are better equipped to navigate this most complex and important area.

Adele

Jono, thank you so much for that. It's just so important that everybody has equal opportunity to be able to explore all parts of our lives and we're here maybe just one time around and why wouldn't you want to have all of the pleasure and all of the good things in your life available to you. And the idea that at the moment the NDIS is not allowing that to happen it's just great to have advocates like yourself who are speaking out about this.

Jono, thank you so much for chatting with us today. You obviously have really strong views on this really important subject and just like everybody else people with disability are no different to anyone when it comes to wants, needs and desires.

If you want to chat to Jono more about this you can contact him on [www.grabcontrol.com.au](http://www.grabcontrol.com.au) or on Facebook [u g r a b c o n t r o l](#) or on twitter [Grab Control](#).

Thanks everyone so much for listening. Please make sure that you join us again next month when we talk to Jack about the relationship dynamics between support workers and their clients when you're a person with intellectual disability.

Until then, take care.

You can support our podcast by leaving a review on apple or your listening app of choice.

Until next month.



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