



Visibility Podcast



Shopping, showers and sharing time episode transcript

Fiona

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

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.

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.

You're listening to Visibility, the Council for Intellectual Disability's podcast. I'm Adele, and today we'll be talking with Jack, about his experiences as a person with both intellectual and physical disability who relied on the services of support workers on a day-to-day basis. Welcome, Jack. How are you today?



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Jack

Good, how are you Adele?

Adele

I am good. We're starting to see a little bit of sunshine aren't we?

Jack

Yes we are.

Adele

[laughs]. So, Jack, we're starting to talk about different relationships in our Visibility podcast, so thank you for taking the time to chat with us today.

Jack

No worries at all.

Adele

You've got a lot of experience with support workers and it would be really great to get some insights into that really unique relationship. Jack, can you just tell the listeners what you set up is? So maybe where you live and what sort of support you may need on a daily basis?

Jack

I am within a supported independent living. It's sort of like a festivity in my local school area so it's like a big complex and we cater for at least twenty people a day. So, that can be very intense with working out support workers with rosters and stuff that we do in a very wide caseload.



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Adele

It sounds like a lot and as you say, a lot of co-ordination of different people. So, Jack do you get a lot of say in who works with you each day?

Jack

To be honest with you, I don't get much of a say at the moment because they do it just so everyone has a say so one part of my accommodation we have a ten bed facility in one part of the property, so I'm living in the ten bed section and then they have a section that reads east side or west side and the support workers get allocated to either east or west or up in our villa section.

Adele

Wow. That sounds like quite a set-up, doesn't it? And so, I guess this is a new situation for you Jack, so I'm wondering if you can tell us when you do have the opportunity to choose your support workers, what sort of characteristics or interests or personality types do you think suits you? What do you look for in a worker?

Jack

I look out for a support worker who looks out for ideas namely to engage the people with whom their supporting because there's so many in this industry, there's so many support workers in this industry who aren't engaging their clientele and that gives the industry a bad rap because they're just right for me and come and I know that getting a job depending on your situation is hard but at the end of the day you do need to give these people a good quality of life because it's important because you have quality of life, why can't the disability sector get some quality of life?



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Adele

Yeah, most definitely, and like you just pointed out Jack, it's interesting because support work can be an entry-level job. You don't necessarily have to have a degree, you don't necessarily have to have a certificate. A lot of support workers have a certificate IV in disability which is great, but there's not that sort of necessity. So I guess Jack, do you find that a lot of the time, you're just trying to find the things that you have in common with your support workers and trying to sort of make a relationship?

Jack

Yeah, I think it's really important because you do especially in accommodation you do see these people like for multiple days at a time or with different shifts so it can't be like a 'How are you doing?' "that's good" or it can't be like a small talk situation because they're dealing with either medication, cooking or even the most delicate of cares, personal care that might be assisting a person going to the bathroom, or putting a personal care item on that person.

Adele

Yeah, which must be, I mean, that's an unusual relationship, isn't it? I mean, most people would be in that situation when we're in hospital, or when we're at home unwell and maybe we have a family member or partner caring for us where we might have that sort of more intimate interaction with people. So, Jack, how do you sort of manage that strange relationship when you might have only known someone for a couple of hours and next thing off we go to the toilet or, you know, do you find that you have ways of dealing?

Jack

Off we go for a shower, well, [laughs], I just ask them icebreaking questions and what I've found before is you need to be less awkward, I like to pump some music into my shower so I will say 'All right, I can do my time, bring my phone with my little speaker and we'll just play some music', so that might be something from the early 2000s to the 90s, to a musical soundtrack.



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Adele

That's a great idea

Jack

But even that can break the awkwardness because you're even bonding while you're in the shower where I'm saying 'Oh, I'm liking this musical.' It just doesn't make it feel weird.

Adele

Yeah, yeah and music is a bit of a social leveler, isn't it? And if you kind of can both bop a tiny bit along to the same piece of music there might just be that connection as you say. That sort of takes away from the weirdness that can occur. To me it sounds like there's a professional relationship because the person is required to support you and see to your requirements during that shift but also from what you're saying that there's a bit of responsibility on your side to be able to make them comfortable so that you're comfortable and to try and sort of gain a connection. What do you think, how would you describe the relationship between a support worker and a person requiring that support? Do you think it's more professional more like a friendship or is it sort of something in between?

Jack

Yeah it's definitely something in between because you want to keep it professional but I know for conversation piece I say to some support workers I say 'Oh how's your mum?, how's your dad?, how's your dog?, what did you get up to on the weekend?'

I had a support worker who recently came off a two week holiday and so I'm like "how did you enjoy your two-week holiday?"



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Adele

I guess you're doing that sort of making small talk but you're trying to ensure that there's a comfort level there and you're trying to ensure also that they feel comfortable. And that they feel seen because just those questions around 'how are you' and 'how was your weekend' and 'how's your family' or whatever it might be those sorts of things mean that you're interested in them as well which hopefully makes them a bit more interested with you if you have that connection and so I wonder like you know Jack you just described um that you're in quite a large sort of home and living facility so there must be a lot of situations where you would like a bit more privacy or a bit of space. How do you negotiate that with your worker? If you say for the day you plan to do certain things and on that day you think 'I just need a bit of time to myself I'd prefer to do something else' or 'I actually just really need some privacy'. How do you negotiate that with workers?

Jack

Before the coronavirus I was very active in the way of going out in the back so when I flew around I can say to the support workers just going for a walk or just something as nice and simple of hopping to your room and just watching a movie on a streaming service or just listening to music and just having your own time in your room just to step away from. As you say. It's always hustle and bustle how have my accommodation and you're like 'why would this belong?'. So, it's nice to come into your room or go outside and... and collect your thoughts. Because as we all know that there's different shifts over the disability sector and even though they do give you some reasoning we really want them a shower well when you want to get out of bed yourself. They do have certain requirements that they have to fill in and shift per day, per week. So just to step away from that and say 'okay I need a break from this' because it can be a lot. Because you may have someone saying for like the tenth time that week 'All right Jack I'm not rushing you but you have to have a shower probably in the next half an hour' like you want one or like when is **your peg feed conditional** or even the background noises of people talking when you've got your door shut and they're really in a good conversation and you feel like I just need to step out for a minute and just be with myself.



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Adele

Yeah, thank you Jack I mean that's it. Sounds really difficult because when I think about it you know if somebody told me when I had to have a shower hmm I'm not sure I'd be so calm about it and I guess it's I guess you've had to yeah learn negotiation because you understand there's professional obligations with a support worker and they have to you know make sure that you're safe and clean and fed and all that sort of stuff but there's also that um that consideration around, 'Well Jack what do you want to do?' and 'how do you want today to look' and 'Are you comfortable doing this?' And 'Oh dude you need some time to yourself great... I'm... I'm going to you know ensure that you have that time' but it really sounds a lot Jack like it needs to come from you that you have to kind of sort of stamp your space a little bit or kind of you know ensure your own privacy?

Jack

Even working with people that you don't normally work with because the facility like this there is like still a high majority that kind of works with me and then when you when you're living in a place like how big my accommodation is it can be exhausting even explaining what your routine is. And even on top of that for agency staff that comes in and floats in and out we do have our regulars. But there are some support workers that you're like 'Oh I have to do it all over again' So basically you feel like you're going back to the drawing board probably multiple times during the week all like every like week and a half. You're just going back to the basics on how to do your care.

[Music]

Adele

Yeah and that sounds quite intense and repetitive. I'm really enjoying this conversation. We're going to take a quick break but we'll be right back to hear a little bit more about your thoughts on the support worker relationship for people with intellectual disability.



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Fiona

You're listening to visibility the podcast produced by the Council for Intellectual Disability. If you're enjoying this episode you can support us by viewing us through apple podcaster or your favorite listening app.

Adele

Welcome back everyone you're listening to CID's podcast visibility and today we're chatting with jack about his relationship experience with support workers as a person with both intellectual and physical disability.

Adele

So jack we've been talking about what it's like to be in a big accommodation, as you are having to share workers not necessarily or always knowing or getting a choice of your workers and sometimes as you just mentioned before the break you feel like you're going back to the drawing board when you have to sometimes you explain things to people. So with that and that idea of turnover, when you you've had a you've been with a support worker for a little while you guys have a really nice bond how do you deal with the fact that you know people move on from their jobs and they might get new roles or get promoted and I imagine that probably happens quite a bit do you just want to talk to us a little bit about how... how that feels for you when your workers move on especially if you have a nice bond?

Jack

It's really hard because you do get that special connection and you're just sad that they're leaving but that's the beauty of in a traditional sense when they're leaving that you can if they allow you, you can still keep in contact via social media and stuff.

And I had one support worker a couple years ago who really wants to stay in contact with me and talk to about six years later and we're still checking in to how each other is going and what we're doing in our lives. That's very nice and very special to me that a support worker could evenly transition being **inspected** their own life.



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Adele

Yeah it's interesting, isn't it? I think because you know as human beings we naturally bond hopefully and then and then when something is official as a change of job comes into it you still think well I'd really like to spend time with you.

So I'm really pleased to hear Jack that you're able to negotiate that sort of landscape because oftentimes people may not want to ask their support workers if they want to remain friends they might not have the capacity to ask if they'd like to do that and certainly I think that sometimes support workers might feel a bit uncomfortable because they're like 'Oh is this is this a breach of um you know any kind of like policy that we might have' or 'Is this something that's deemed unprofessional'.

So Jack it sounds to me like um you're someone who's quite proactive in your relationships and that maybe you know if you're getting along with someone then you'll kind of you'll probably chase them up right.

Jack

Yeah I am definitely with the one that I'm still keeping contact with today. I am at **our text work to** keep that momentum going on our first six years because in that case.

We all know that friends can get different priorities in their lives and stuff like that so yeah so it's really nice that that one particular example I definitely see where it could be like 'oh you're a good person but like I don't think it's a good idea for me to keep professional relationship with you because I might be moving overseas or might be moving states' and stuff like that.

Adele

Yeah that must be that must be hard when I guess some circumstances sometimes change your relationship as opposed to just the relationship changing and as you say it could be moving jobs it could be moving out of the state and then I guess it's up to you to and the other person if they want to... to try and keep that um relationship and you just mentioned um social media as well so I imagine that that's probably been has that been a helpful platform for you to continue relationships sometimes?



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Jack

Yeah just to see how they're going when most of the support workers I have worked with want to keep in contact with me

Adele

Popular. I think that's a really good note to end on because you're talking about how important it is to be able to connect with people when you're a person with disability who requires support. And you've really spoken a lot about how important it is that you know support workers are able to tune in to you and that you're able to if you would like when you have a really nice connection be able to um keep up a friendship with them after the fact as well and it sounds to me like you mentioned that you use music to kind of break the ice with things but it sounds to me and knowing you that having a sense of humour is probably um a really important way to sort of um to get to know people and get through the awkward stuff?

Jack

Yeah well, I just around with my support workers on a regular basis. It just keeps it a nice working relationship and for them to say 'Oh I'm going work with Jack today. I am going to have a good day today'



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Adele

That's what you want, isn't it? That is what you want. Well thanks Jack for joining us today and sharing some really great insights into a relationship between support workers and a person with intellectual disability.

For those of you listening thank you as well. So please join us next month for our episode on LGBTQIA plus relationships from the perspective of a person with intellectual disability until then take care.

Fiona

You can support our podcast by leaving a review the apple or your listening app of choice. Until next month.

Music