

Visibility Podcast – Life My Way

Leonie's Story

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

Adele

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

Raylene

In this series, we talk to people with intellectual disability about the decisions and choices they make in their lives. Leonie lives and works in regional New South Wales. Today she is going to tell us about living independently, working in a job she loves, her relationships and how she is showing other people that with the right support they can do the same. My name is Raylene Griffiths. I will be your host today.

Raylene

With me is my co-host, Tom Parker.

Tom

Thanks Raylene.

Raylene

Welcome, Leonie and thanks for joining us to talk about your life. You live in Wagga. Can you tell us a bit about what it's like living there?

Leonie

I like being in Wagga most of the time. I like socialising and going out for food and for my work.

Raylene

Have you lived in Wagga your whole life?

Leonie

I was born at The Rock which is about a half an hours drive from Wagga Wagga and then I have moved into Wagga stay there most of the time and then sometimes I stay out at Junee. My house in Wagga I have lived in there for nearly 30 years.

Raylene

How does it feel to live independently?

Leonie

It feels really good to live independently on my own. I can do things for myself most of the time. You havent got people every 5 minutes telling you what you can do and what you cannot do.

Tom

Did you ask for support to live independently? Who supported you?

Leonie

I think it was my mum. She said she was not going to be around forever. I think I was in my thirties when I moved out.

Tom

Leonie, can you tell us about your childhood and some of your experiences growing up?

Leonie

My childhood was not really good. When I was little I could not talk properly so I was sent away to the Far West Home in Sydney. That was a bit frightening.

Tom

How old were you when you went to the Far West Home?

Leonie

About 4 and a 1/2 5. So I would have come back when I was about 5 and a 1/2 6. And when I went to high school just got picked on all the time. I did my school certificate and I got it but it was a hard time and I was doing my school certificate because my dad had just passed away the week before.

Tom

That would have been pretty rough.

Leonie

Yeah it was.

Tom

So when you were growing up Leonie were you able to make your own decisions or were other people making decisions for you?

Leonie

Other people were making them for me and like even learning how to cook. Yeah, I was told by my brothers and sisters that my mum, made all my decisions for me. Kind of babying me and would not let me have a go. And that is why I until I started working I just used to use the word dumb.

Tom

So that's how you felt about yourself did you? Or was that what other people sort of told you?

Leonie

Yes, I told me I was dumb and then that had stuck in my head ever since.

Tom

How big is your family?

Leonie

I did have a real brother and a real sister. And then I had two half sisters.

Tom

Were you brothers and sisters supportive?

Leonie

When I got older they were, and when my mum was gone they were more supportive.

Tom

So what did you dream of doing when you left school Leonie?

Leonie

I was hoping to work with kids. I love kids.

Tom

So what kind of work did you do?

Leonie

I did cafe work for a while and then I did a nanny at Melbourne and also worked at a preschool in Wagga as a volunteer.

Tom

Did anyone support you to help you find work?

Leonie

I think it could have been my mum and then I went around looking for a bit myself.

Raylene

What was your favourite as all of these jobs Leonie?

Leonie

Looking after the kids at the preschool. But then they said no I could not get a job there. They said I could only be a volunteer because I think they picked it up that I had a disability.

Tom

How long did you work there for?

Leonie

About 2 or 3 years.

Tom

When did you decide to stop volunteering there?

Leonie

After they kind of told me that I would never get a paid job there.

Tom

And how did that make you feel?

Leonie

Yeah I felt that it was unfair because they should have gave me a go. And then after that I just did volunteer work at a daycare centre with elderly and the disabled.

Tom

So Leonie you looked in the newspaper and found a job for a nanny. You applied and were offered a job with a family in Melbourne. That was a pretty brave thing to do for a young woman from a small town. Can you tell us what your experience was like?

Leonie

That was a bit frightening because my mum had to take me on the train and that was just an eye opener because I was working for a lawyer. But the kids were good. 2 little boys.

Tom

What did that job involve?

Leonie

Cleaning the house. Setting the table. Making sure the kids have a meal. Changing their nappies. Giving them food and entertaining them.

Tom

And how long were you down there for?

Leonie

Not quite 12 months. And then they said I was not fit for the job because a couple of things that happened while I was looking after the kids. They went away once and I could not get the gas stove to light. It kept going out. I had to go and ask the neighbour what to do. And then one of the boys got diarrhoea and I could not keep up with the nappies. So I had to go and ask the neighbours next door again. What do I do? I am running out of nappies. And they said haven't you been in this job very long and I said no.

Tom

What did you do once you finished that job?

Leonie

Come back home to my mum til I found something else.

Tom

You now have a partner. Len. How did you two meet?

Leonie

At TAFE doing literacy and numeracy and sewing. We made our own clothes. I have done a few dates and I have thought he is the one I want.

Tom

What do you two like to do together?

Leonie

We like to go out and have meals with people without a disability and people with a disability. And we like going for trips in the car. And we like playing 10 pin bowling.

Tom

In what ways does Len support you?

Leonie

Len supports me like getting me to work. He takes me to medical appointments and sits in to see what the doctor says. Takes me shopping. Helps me support the shopping. Except he does not like going bargain hunting.

Tom

Does not like bargain hunting. But he likes expensive things does he?

Leonie

Yes and he does not like shopping for dolls.

Tom

Now you have got quite an extensive doll collection I hear Leonie.

Leonie

Yes over 200.

Tom

How are some of the ways that you support Len?

Leonie

Waking him in the morning. Helping him use his computer. Help him with medical appointments.

Tom

You also wanted to have children of your own. What did the doctors say to you?

Leonie

That was a risky decision. Because it could turn out like me with an intellectual disability. Or I could die while I was having it. Or it could turn out like my partner.

Tom

So does your partner also have an intellectual disability?

Leonie

Yes. I decided I did not want to risk my life and I do not want to risk the baby's life. I felt relieved but I was pretty sad.

Tom

And who supported you to make that decision?

Leonie

Len his mum was alive and I also think my sister was.

Tom

What sort of age were you when you were going through that process?

Leonie

In my middle thirties.

Tom

And had you just recently met Len or had you been with Len for a little while?

Leonie

I had been with Len for a long time before that.

Tom

I see though that you hang out with your nieces and nephews quite often. Does that bring you joy?

Leonie

Yeah they do. Every time they see you down the street can we come? Can we come? We love you Auntie Leonie and Uncle Lennie can we come?

Raylene

Thanks Leonie for sharing your story with us. We will now take a short break before returning to hear more of Leonie's experience as a woman with an intellectual disability living independently.

Fiona

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Raylene

Welcome back everyone.

Tom

You also have a support circle of friends, family and support workers?

Leonie

The support workers are really top. They let us make their own decisions. What we cook and if you cannot think of something they give us an idea what we could have. So they only assist us. We have got two favourite ones.

Tom

What makes them such great support workers?

Leonie

Well, they listen to you. They do not boss you around. They only help is if you cannot think of something yourself.

Tom

So is it sort of a genuine support there?

Leonie
Yes.

Tom
And trust?

Leonie
And trust.

Tom
So how recently did you start getting paid support?

Leonie
Since NDIS came in.

Tom
So before the NDIS came in how did you sort of survive? Who are you asking for support?

Leonie
Just lived on my pension and going into debt. Like I owed money to shops. I just used to waste it. Like it was hard. I was asking my family and at that stage I had a lovely art teacher i would be ringing up to say I need your support how do I cook this? What do I do now?

Tom
Say if they didn't pick up the phone what would you do?

Leonie
Ring the next person in line. It might be 10 phone calls. I would try my auntie across the paddock. I would try my niece who has got the kids out at the Rock. I just keep ringing and ringing till I found someone to say how do I do this? I am stuck.

Tom
How does that make you feel that you know you sort of felt the need to constantly ask people for support in those areas?

Leonie
It felt bad as if I was silly and I did not know what to do.

Tom
And then now that you have got those supports in place what does that look like now?

Leonie

It looks a lot better. I am not in debt any more. Cause I had family draw me to set up payments to come out of my Centrelink payment. Now I just don't miss it. Yeah I have gained more confidence at lighting the stove. I am not walking away leaving it. They let me cut the food up. But they can pick out sometimes if we are not on track. If I am having a bad day. Or I am a bit tired. They might say would it be safer for me to finish the cutting for you?

Tom

Have you ever had something that you call sort of bad support?

Leonie

One staff member would not let me food prep. Just because I had an incident with a knife once. I was opening packets with a knife instead of a pair of scissors and I cut my finger and it bled. She said ah I do not like blood. I better put a Band-Aid on. I better ring your boyfriend to come back. He had better take you up to the hospital for stitches. It was a big ordeal. All they said it does not need stitching love.

Leonie

It needs just to wash and a Band-Aid. Off you go.

Tom

And did you work with that support worker again after that?

Leonie

For a little while and then another bad support worker came in. And she said, Oh no you just watch. I won't let you do anything. And I said well how am I going to learn? I said to her I feel really bad I want to have another go. I rang up the boss and said I am not happy with the support worker. She would not give me a go and she was not really supportive.

Leonie

She just wanted to prepare the meal herself. Or just read books. Or this girl that I got rid of there was her and another lady and the other lady I have still got.

Tom

So when you were younger Leonie did you feel you had that same confidence to be able to make those decisions?

Leonie

No I did not. When I was younger I did not have much confidence to make decisions for myself.

Tom

So when did it click for you that hang on I do have these rights?

Leonie

As I got older and moved started getting support.

Fiona

What are some examples of good support you have had?

Leonie

At Junee Medical you cannot be happier because they are willing to listen to you. If I need to fill out forms they try and fit time in. And then if you want to know results they will either show you on a picture on the screen or they draw a picture and explain it to you. And if you don't understand it, I say, can you use plain English not big words. They take an interest and they say well what is the problem today? And then they say you got any more issues? And they just sit there until you finish all your things that you want to say to them.

Tom

And do you see that as being a big difference to sort of what you find in hospitals?

Leonie

A big difference. I have had bad support at the Wagga Hospital filling out forms. They say can't you do it yourself? And I say no I have an intellectual disability. And they say can't you find someone.? And I say no this is your job. You should be doing it for me. And if feel really put down.

Raylene

Now you are using all your life experiences to create training that helps other people learn new skills. How does that feel for you?

Leonie

It feels really good to me that I have learned a lot of skills and I can help my friends. They can stick up for their rights. Like sometimes one particular girl wants a certain meal and the carer says no you have to have this. It should be that young girls decision. One group home they see nearly every fortnight I was told by a support worker that they let the guys try and make your own decisions. But in one of the other homes I was going to before COVID clients were not really given very much choice. If the resident can make decisions the staff should be letting them do it.

Tom

So you work with us at the Council for Intellectual Disability and you have cofacilitated training for supported decision making. What sort of skills do you teach people?

Leonie

You can speak up for yourself and everyone has got rights. It is your choice. Give it a try. Try and give them enough information as possible.

Tom

And what are some of the barriers that support workers have been talking about?

Leonie

Restrictive practice. Communication. Financial.

Tom

So there's lots of different barriers that are in place that hamper decision making in general?

Leonie

There is. Because a person might be non-verbal and you have to work out a way to communicate to them. Not everyone can use sign language and if you can sign that is a good advantage.

Tom

Are you able to sign?

Leonie

Yes.

Tom

Have you learned some new skills yourself Leonie?

Leonie

Learning how to speak up. Learning how to use a computer. Learning how to text messages.

Tom

The work that you are doing now is that something that you saw yourself doing when you're younger?

Leonie

No. I did not think I would ever be in an office.

Tom

What is your favourite thing about working at CID?

Leonie

The money. And the different staff and their characters.

Tom

So why does why is the money such a big thing?

Leonie

Because you have to have money to live on and where I was working before I was pretty poor.

Tom

So while you were working at an ADE the money was not so great?

Leonie

No like 6 dollars an hour.

Tom

Can you explain what an ADE is Leonie?

Leonie

Is it Australian disability enterprise?

Tom

Yeah I think that is correct. And what sort of work do they do there?

Leonie

In the sheltered workshop. We work at recycling. When I first started there I used to sort the rubbish which is pretty gross. And then I started in the security building. They sort coloured paper from white paper and squashing dirty old milk bottles.

Tom

How long did you work in an ADE for?

Leonie

It is coming up to 20 years.

Tom

Yeah. When did you sort of hear about mainstream employment or open employment?

Leonie

They talked about it at the ADE and they said anyone that thought they were confident to go out they could try a job. I thought oh well I may as well go and have a go at open employment and see if I liked it and I like it.

Tom

So how long have you been in open employment now?

Leonie

Nearly 4 and a 1/2 years.

Tom

What do your family members say to you now when they say you are achieving all these goals?

Leonie

They say we are really surprised Leonie how far you have come in life now.

Raylene

What do you wish you had known when you were younger?

Leonie

That I could have had the confidence and if I would have had the skills I would have been a much happier person.

Raylene

What advice do you have for other people with disability who want to live independently?

Leonie

If they want to try and go independently there is no rule saying they cannot do it. They could listen to more training and more support from their support workers. They could go and talk to the NDIS. The advice I give them. If they want to have a go, let them have a go.

Raylene

Thanks Leonie for sharing your story today.

Leonie

Thank you.

Raylene

And for everyone listening thank you as well. Join us next month when we will share more stories from people with intellectual disability about the decisions and choices they make in their lives.

Fiona

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