```
[music playing]
[Narelle] Good morning,
and welcome to this episode
of the Digital Access Show,
where we focus on communication,
accessibility, digital
accessibility in particular,
and disability.
What is the link
between the three?
Interaction.
Communication provides an
interaction between people.
People with disability often
have problems with communication
```

because the digital

content is not built for this.

Now, my guest today is a lady with the difference,

and I am really excited to have her on the show.

What's the difference?

Well, this is Shiralee's first time she's on a podcast.

So ladies and gentlemen, please meet Shiralee McKitrick.

Shiralee, thank you so much coming on.

[Shiralee] Thank you for having me.

I'm really excited to be here.

[Narelle] Shiralee,

can you tell us a bit about yourself and your family?

[Shiralee] Yeah.

I have, I have two boys. They're teenagers now, and our disability is quite a hodgepodge. We have chromosomal deletions. So basically, we have our chromosomes, and I like to explain it as a library. Each chromosome is a library, and it teaches... it teaches your body how to build things, brains, eyes, body parts. Our library is incomplete. So in that library, we're missing books,

and because we're missing books,

our bodies did not make things in our brains

that we need to function.

My boys are missing 12 books

that makes it sometimes difficult to live their lives,

and I'm missing 27 books.

So that makes it more difficult to live our lives.

So we've got things like autism and ADHD.

We also have, um,

hypermobility, joint problems,

heart problems, eye problems,

you name it,

because... the, the books weren't there. The books weren't there to, um, build the bits that we need. [Narelle] Shiralee, how do they diagnose that? That's really interesting. [Shiralee] Yes. What happened was, is when I had my first son, he had a difficult birth. They thought that his problems were due to a difficult birth. And I did ask them if it was chromosomal, and they said, no,

it's a difficult birth.

And I was like, okay, so I had my second son straight after,

And he had the same problems.

And they were like, this doesn't look right.

And when I went to physiotherapy with them,

they said, we think they've got Ehlers-Danlos syndrome.

And I said, oh, how do you test for that?

And they said, oh, well, you need to do a DNA test.

And so we did the DNA test.

And they came back,

and they said, you don't have Ehlers-Danlos syndrome,

but you do have something. And I'm like, Oh, what is it? And they said, Well, you get to name it. -[Shiralee] Because... -[Narelle] What? [Shiralee] Yeah, they put all the deletions into the world, the worldwide data bank, and usually that will, that will spit out a syndrome. Of chromosome or deletions. There is no, nobody else in the world has our... specific set of chromosomal deletions.

My set, or the boys' set,

because they had to test us as well

to make sure that it was a familiar thing

and not just an environmental thing that just popped up.

So we've been walking down the road of...

working out why things happen when things happen.

Is it a chromosomal thing?

Is it an environmental thing?

They can't tell us anything...

about anything,

life expectancy and all that kind of stuff.

It's just based on our familiar

patterns, which is normal. And so we just truck along as we truck along. And when things pop up, we just... deal with them as they come along. So there's a lot of physical problems, which you can't see. Boys needed braces and jaw realignments, because our brain's... chromosomes didn't know how to make our faces properly. So there's hearing problems as well, which you can't see because it's all in, inside the brain.

From what we can gather,

it's mainly in the face and the brain,

as well as hypermobility and, um, low collagen,

which makes us very stretchy and, um,

prone to fall down a lot if we're tired.

[Shiralee laughs]

[Narelle] Okay, this is getting really interesting,

because you have a background in science as well, don't you?

[Shiralee] I do.

I do. It's one of my hyper fixations.

I do like it. I didn't do a lot about genetics, though,

but I, I do have a science degree,

[Narelle] Yeah.

[Shiralee] And so this is all very fascinating for me.

It does help a little bit with trying to explain things,

like the library's,

the library with books.

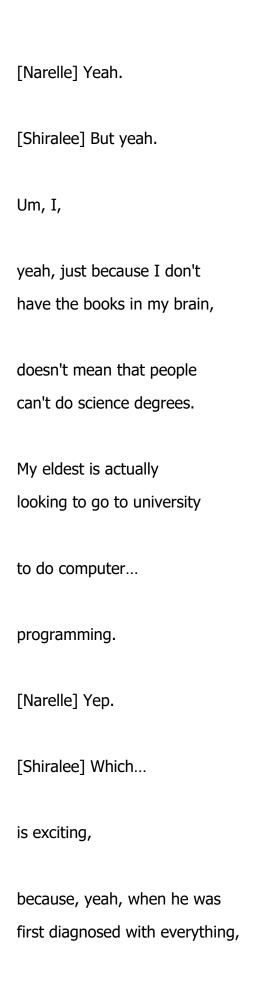
You know, if you don't have the book, you...

can't make the thing.

-[Narelle] Yeah.

-[Shiralee] You know?

[Shiralee] It seems to make it easier to explain to people.



they said he wouldn't even live really,

he'd be a vegetable.

-[Narelle] My gosh.

-[Shiralee] They...

They told me to don't worry about the therapies.

Don't worry about anything. Just...

love him as he is, kind of thing. And...

they suggested that I needed psychiatric support

because the first time they told me that,

I looked at him and said, this boy's going to go to university.

And they said, this...

boy can't even hold his head up at three.

You know, he can't even hold his own body weight.

-[Narelle] Yeah.

-[Shiralee] What do you mean?

You know, he hasn't even made a noise, um, of any description.

[Shiralee laughs] What do you mean he's going to university?

[Narelle] Yeah.

And I said, yeah, he's going to go to the university.

And yeah, he has a normal IQ.

[Narelle] Yep.

[Shiralee] You couldn't pick him out in the crowd,

besides the fact that his voice is a little muffled

because of his auditory processing,

everything is muffled to him, so that's how he speaks,

um, which does make people think that he's...

not always all there,

but he has a higher vocabulary than most...

teenagers of his age.

-[Narelle] And he's 16 or 17?

-[Shiralee] So...

[Shiralee] Um, he's 16, turning 17.

-[Narelle] Yeah.

-[Shiralee] My youngest is 15,

turning 16.

He was diagnosed with autism

when he was two,

which is, well, actually 18 months,

but that which is quite unusual,

but he was so classic...

that they just went, yeah.

And the way I found out about him was actually,

his eldest went to a special daycare,

and, and he would come with and they went,

would you like to bring him in for daycare as well?

And I was like, why?

Because when your firstborn is different, you don't know what's normal and what's not normal. [Narelle] Yeah, that's true. [Shiralee] No reason, no reason. Would you just like... to bring him in? And I'm like, Yeah, sure. And yeah. He's diagnosed with the highest level of autism, they do the scales now. So the social, the interactive, the daily living, the... his is off the charts.

Absolutely off the charts. But he is a very articulate, social, bubbly, he's got a huge group of friends. You could not pick him out... in a, in a lineup. In fact, the government tried. [Shiralee laughs] [Narelle] What happened? Tell me this. [Shiralee laughs] When he was younger, they had a thing down here where they wanted, um, people with disabilities,

more support in the schools.

So they were bringing out what's called the Gowan act,

and they wanted to do a big PR thing,

and they wanted, they selected...

his school,

and they asked, they said, oh, we need the most disabled child,

because we want to do this big PR thing,

about how disabled children can get into schools.

-[Narelle] Yeah.

-[Shiralee] They were like,

he's exactly who you want.

You want,

you want my child,

because he's so, like, top of the chart for autism.

I mean, you know, never met another autistic child like him,

And they're like, oh, brilliant.

Bring him here, we'll come down.

They came down with their cameras,

and like, the politicians were there.

[Narelle] Even the politicians?

[Shiralee] Even the politicians.
They wanted this,

it was going to be in the papers, in the,

you know, online, on the news kind of thing. They all came down,

and it was a school assembly.

And they were searching for the wheelchairs,

they were searching for, the the canes

and the teacher's aides and all this kind of stuff.

They're like, where is he?

And they said, we'll bring him up to you.

I got him.

And here's my child bopping along.

And he put out his hand, and he's like, hi.

You're looking for me?

And they were like... we need the disabled child. [Narelle laughs] And I went... he's the most disabled child in our school. And they went... No, no, we wanted a disabled child. And he's like, yeah, that's me. And he rattled off all these things, and he's like, I hear you want to interview me. I'm really excited about it, and they were like, no.

- -[Shiralee] They left.
- -[Narelle] They refused?

[Narelle] Left, and

left him hanging?

- -[Shiralee] And they left.
- -[Narelle] Oh my gosh.

[Shiralee] They went to another school with somebody else,

[Narelle] My gosh.

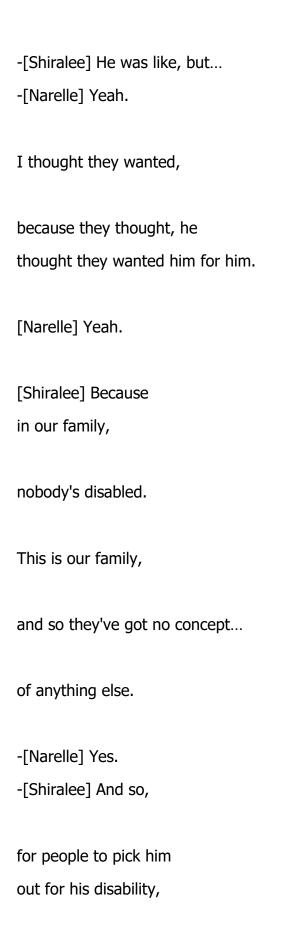
[Narelle] What was the effect on your son then?

[Shiralee] He thought it was funny as heck.

- -[Narelle] I bet.
- -[Shiralee] He was like...

[Shiralee] Yeah, no bruise to his ego whatsoever.

- -[Shiralee] He was confused.
- -[Narelle] Yeah.



it's just a foreign concept to him,

because he's just like, well, they want me for me.

They don't want me for my disability, because everybody's...

you know, got their own issues.

And whilst other people might not have as many as us,

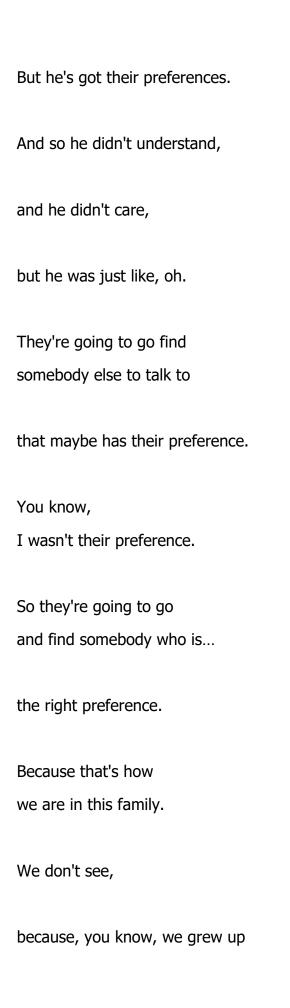
I mean, everybody's got a preference for cars.

Everybody has a preference tying their shoes.

Everybody's got a preference for how they get from A to B,

whether it's a wheelchair, or it's a car,

whether it's walking, whether it's...



and they grew up going to...

a different daycare,

which had different things in it,

and it had, you know,

kids in wheelchairs,

and kids that didn't like crust on their sandwiches,

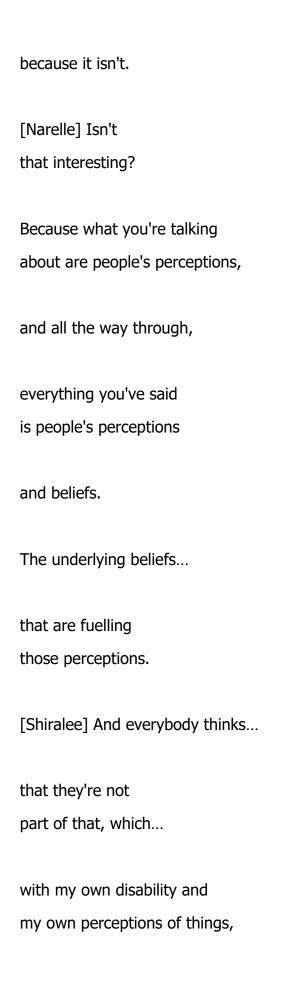
and kids that couldn't touch the blue block,

and, you know, kids that could only go to one sort of toilet,

that's normal for them.

So they don't see the world,

and I don't teach them that the world's any different,



I find fascinating, because,

there has been times where we have been discriminated against

or the perception has been different,

because teachers will read these huge,

I mean, they've got mountains of paperwork about...

the things that these children can and can't do.

And then they see them and they're like, oh.

You're a functioning human being.

And we've had people come at us that might...

what they consider themselves to be neurotypical

or normal or whatever,

and, you know, they're like, but your children, you know,

only like chicken nuggets or whatever.

But then they're what they call normal,

and they'll be like, I don't. Like sauce on a burger.

Oh, I don't like, you know, potato.

I only like sweet potato fries, you know?

I only,

and it's like, what's the difference?

-[Narelle] Yeah.

-[Shiralee] Just because...

[Shiralee] Just because I got a label attached to mine,

because I need medical help and things and stuff.

I'm no different to you,

I like a different food and you like a different food,

I have a way of doing things.

You have a way of doing things.

I found it fascinating with the physiotherapist, actually,

because the boys struggle tying their shoes.

And I was trying to teach them to tie the shoes my way,

I thought there was a certain amount of ways to tie shoes.

And the physiotherapist

said to me, do you know that every single person on this planet has a different way of tying their shoes? [Narelle] Really? [Shiralee] Yeah. Nobody ties their shoes the same way. They might look the same, but where they place the fingers on the length of the lace, which hand they start with first, which bow goes first?

Whether they use a bow,

whether they use a knot,

whether everybody's different. I was like, that is fascinating. -[Shiralee] Like... -[Narelle] How can it? [Narelle] This is getting more and more fascinating, because, okay, we've looked at that part. What about on the IT side? The digital content side? What type of issues do you have yourself? You, Shiralee, because you're saying you've got these 27 chromosomal issues. -[Narelle] What type of issues... -[Shiralee] Me? Internet is... [Shiralee] Interesting.

```
-[Narelle] Yeah?
-[Shiralee] Computers are...
fascinating.
[Narelle] Yeah.
[Shiralee] I have to get a
lot of help from the boys.
Because and even
they have trouble...
deciphering things.
-[Narelle] Yeah?
-[Shiralee] Like...
[Shiralee] Yeah. I mean,
my eldest is...
the biggest computer
nerd known to mankind,
```

and my youngest is following

eagerly in his footsteps.

```
But like...
colours?
Why do people have
a click now and it's red?
That, that signals
danger in my head.
-[Narelle] Yeah.
-[Shiralee] And I...
[Shiralee] I don't know
where to do this thing,
and sometimes you'll
hit the next button,
but you didn't need
to hit the next button.
It'll just do its thing.
And other times, like,
people will send me stuff,
and they're like, oh,
```

Shiralee, you just, you know,

send me an email or whatever, and I'm like...

I don't know, like,

how do I. I just take photos of things.

Like I worked out now on the computer, how to, how to, like,

photo it and share it.

But, like, even starting this Zoom call...

took me, I had to, like, prepare,

you know, 30, 40, minutes beforehand,

because evidently I had Zoom
but I didn't have Zoom Workshop,

and then I had to, like,

reload Zoom Workshop,

and then it didn't want to work properly.

And I was like, do
I shut this down,

because it's got the wheel going?

But if I shut it down, do I have to start all over again?

And then do I need to bring up another one? And...

-[Narelle] Oh my gosh. So... -[Shiralee] It's...

[Narelle] How do your sons manage their school work?

How do you work with your sons with the school work?

And because I know teachers will say, yeah,

I want you to write an assignment about...

Japanese history.

How does your sons manage that? How do you manage that?

-[Narelle] Yeah.

-[Shiralee] They'll leave it.

If it's just like that,

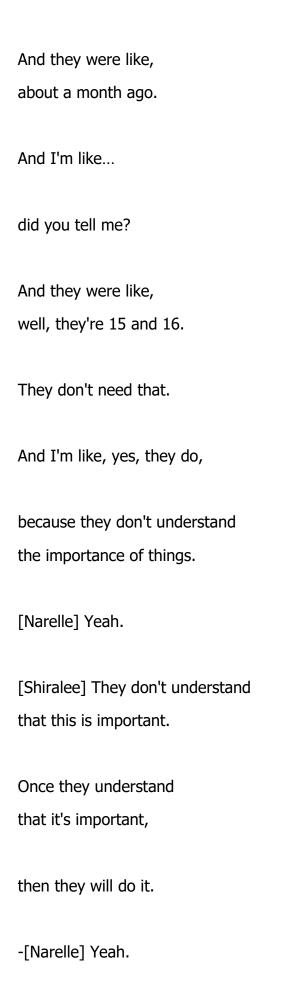
they will leave it.

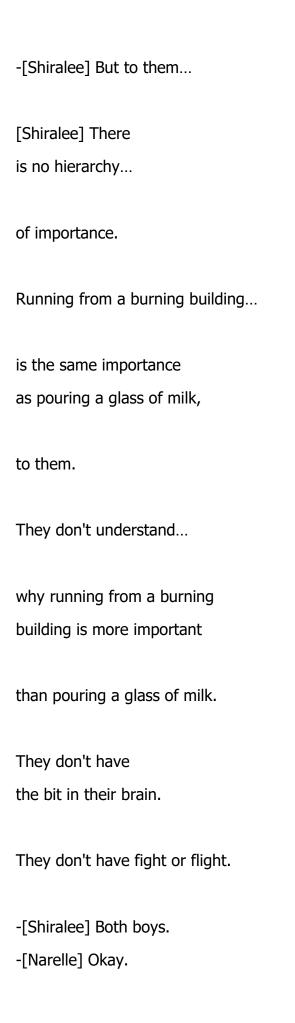
They will leave it until, yeah, they will ignore it.

And I won't know, because the teachers won't tell me,

until I get a call saying they didn't do their assignment.

And I'd be like, when was that supposed to start?





They don't have reflexes.

You know, when you fall down

and you get arm out because you automatically like,

they don't have that.

They will just face plant straight into the ground.

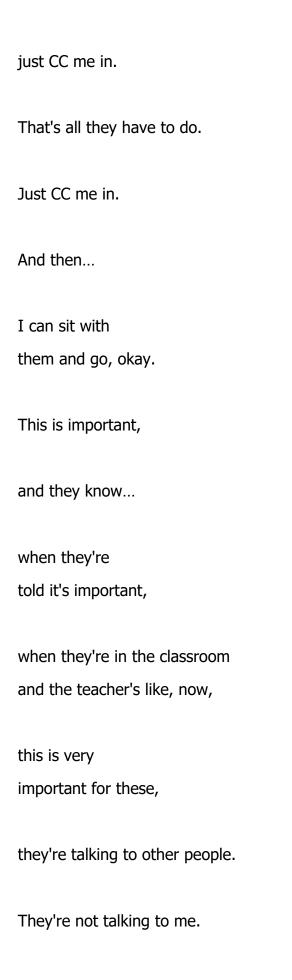
[Narelle] Wow. So what can the teachers do?

How do you manage that as a parent?

What should the teachers be doing

considering this world of digital technology?

[Shiralee] I ask the teachers to let me know when they,



They didn't use my name. So, if they want, because this is where we're at now with 15 and 16. So the teachers usually make... an appointment with them at lunch time, and sit them down and go, this is important. And they will give them a, a a countdown list, [Narelle] Yeah. [Shiralee] And instead of handing the whole assignment in, hand in your introduction on this date.

Hand in your body on that date. Hand in your conclusion on that date. And then they can also go, this is the rubric. The kids now know what a rubric is, and they can tick the bits off. Have I done this bit? Tick. Have I done that bit? Tick. So, and then they know they're on track. Yeah. Usually it's like, A, B, C, D, and like, if you need, if you want an A, this is what you must include.

If you want a B, is this is what you must include. It's what the teachers use to, to mark. They market against what's called a rubric, And each... each A, B, C, D, like grade, has what needs to be in the assignment to get that mark. So for them, it's extremely logical. There is no... thought put in it.

If they want an A,

and this is why I can happily get mad at them,

because I'm like, you picked B.

I know you picked the

B because you got a B.

Because that's all they do,

is just follow the rubric.

And it doesn't matter...

what words they use, what fancy words they use,

what little words they, if,

if they say in the rubric,

you must include...

the trade route from Japan to China,

and they include the trade route from Jan, you know...

[Narelle] Yeah?

[Shiralee] To China,

they get the mark.

If you include the trade route from Japan to China, it's a C.

If you include the trade route from Japan to China

and you include the boat,

you get a B.

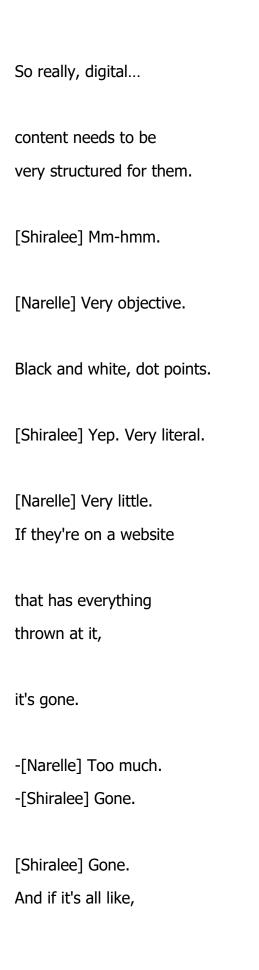
If you include the, the trade route from Japan to China

and you include the boat,

what was on the boat and why it was significant,

tick, tick, tick, tick, A.

[Narelle] Oh my God.

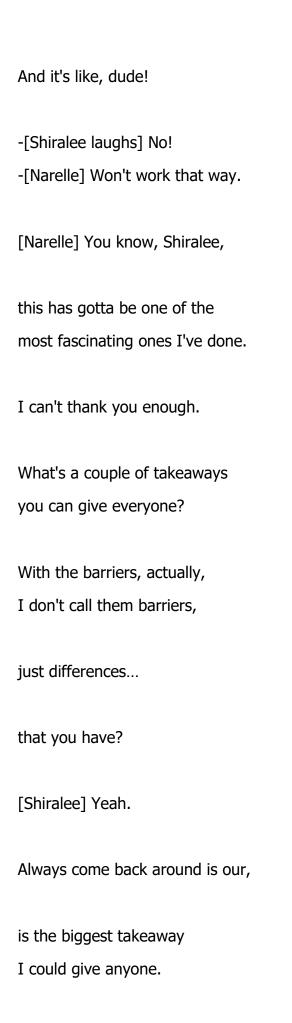


```
you know, this will
make you feel like,
like a superhero, they're like...
that's not logical.
-[Shiralee] Click, you know,
-[Narelle] Yeah.
[Shiralee] But
it's also a case of,
if you, you know, stop smoking,
you'll add 10
years to your life.
And they're like, well,
how do I stop smoking
when I never started smoking?
```

Maybe I should start smoking,

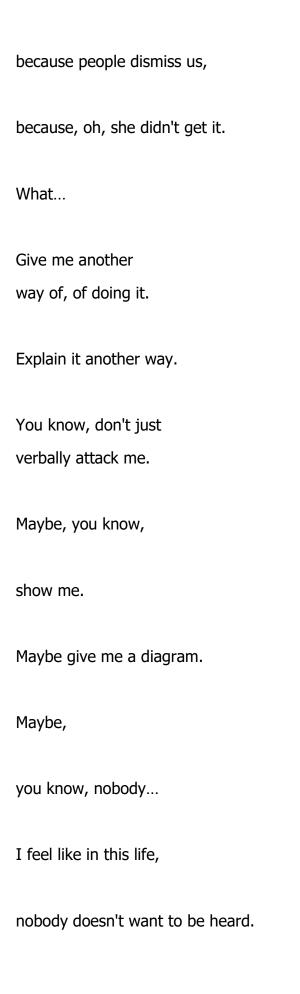
because then I can stop it,

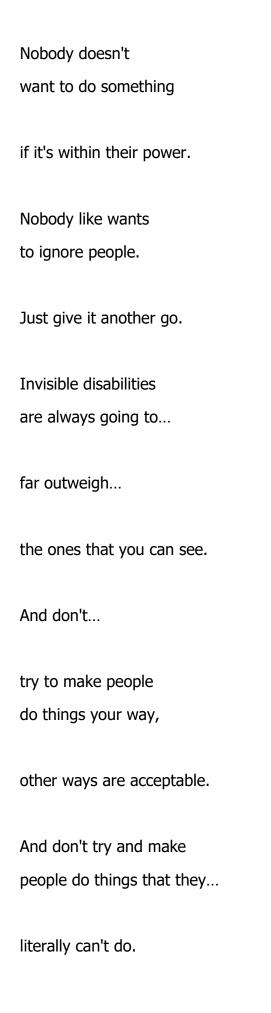
and add 10 years to my life.



If you're talking to somebody, and they just don't seem to be getting it, or you've asked them to do something and they didn't do it, or, always come back around. Don't think they didn't do it because they didn't understand. Or they didn't do it because they don't like you. Don't think they didn't do it because... Give it another crack. -[Narelle] Yeah. -[Shiralee] You know, I'm...

constantly feeling disheartened

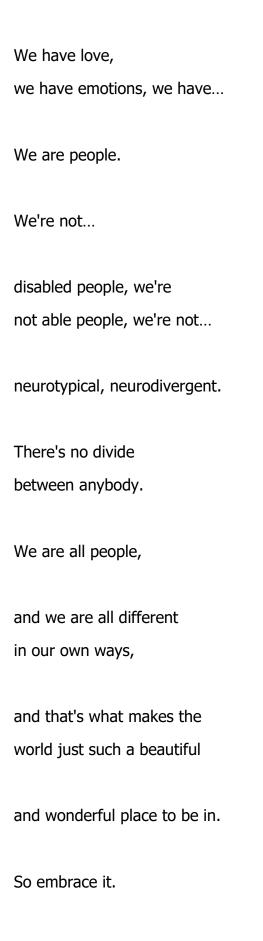




If I don't have the bit in my brain, my brain can make other ways... to get around it, but I don't have that bit. I... It would be like asking a paraplegic to get up and dance. [Narelle] Yeah. [Shiralee] Find another way. And we're all the same, like we're literally all the same. We have the same blood,

we have the same thoughts and feelings.

we have the same heart,



```
Embrace it,
and find out new
ways to do things
that you never thought
you could do before.
[Narelle] Shiralee, thank you.
-[Narelle] That was awesome.
-[Shiralee] That's okay.
[Narelle] Shiralee, how can
people contact you to keep...
talking to you?
[Shiralee] I love
talking to people
and finding new ways
to do different things.
You can contact me on my email,
which is helloshiralee,
```

S-H-I-R-A-L-E-E, @gmail.com And I specialise in finding... ways for people to do things that they've always wanted to do but never thought they could. [Narelle] Fantastic. Thanks. I will make sure that's on the end of our podcast. Shiralee, it's been a pleasure. I have learned so much 15, 20 minutes. -[Narelle] My God. -[Shiralee laughs]

[Narelle] Just wonderful, and...

have a great 2025.

