[music playing]

[Narelle] Hi.

Welcome to this week's episode

of the Digital Access Show.

We talk about what it's like to

have a severe vision impairment,

or to be deaf,

or we've talked to people

with dyslexia, dyspraxia.

I'm lining up some

people with autism.

There's a group of people that

are always going to struggle

to come on a website,

a podcast, I should say.

Actually, they struggle

to get on websites as well.

I cannot tell you what

their lives are like,

because I don't know.

It's people that

are born deafblind,

or become deafblind

as they get older.

Now, that's an issue that is,

I'm not sure of the

population base in Australia,

but there are many

people that have that issue.

We all know the story

about Helen Keller,

and the remarkable

work that her governess…

did to help her become

part of the community,

and to live the

life that she led.

Here in Australia, there are

people with deafblindness,

and I want to introduce

you to Meredith Prain.

Meredith herself

is not deafblind

but she's going to

tell you what she does.

Welcome, Meredith.

Thank you so much

for coming on the show.

[Meredith] You're

welcome, Narelle.

Good to be here

and speak with you.

[Narelle] Meredith, can you tell

us a little bit about yourself,

and what you do?

[Meredith] Sure, happy to.

So, I have a vision

impairment myself.

I lost my vision when I was 17.

I have Leber's Hereditary

Optic Neuropathy.

And I studied speech pathology,

which was really challenging

with the vision impairment,

but I did get through.

And so, I've been working

as a speech pathologist

with people with

deafblindness for 30 years now.

It was 30 years this month

July, yeah, 1995 I started.

And I still have

a tiny caseload,

but I predominantly work in

projects and research now.

So, I completed my

PhD studies in 2012,

looking at interactions

between people born deafblind

and their support workers.

But my current roles are…

managing the Deafblind

Information Australia project.

And I also work as the

National Head of Research,

and Centre of Excellence

in Deafblindness,

with Able Australia.

I also have a job as a research

fellow with Melbourne Uni,

where we're

working on a project…

of family members of

people with deafblindness

or other complex disability,

looking at individualised

supported living training.

So, lots of things

going on there.

But I mean, in

all of those jobs,

there's a lot of digital access

that's required and that goes on.

And I guess I learned the

most about digital accessibility

and the needs of people

with deafblindness,

in our DeafBlind

Information Australia project,

because we had thought our

website was pretty accessible.

We prided ourselves

on it being accessible.

And then in

undertaking an audit,

we're pretty shocked by

the level of fails that we had.

So, we've all learned a lot and

been on that access journey.

[Narelle] Can you tell us a bit

more about the Deafblind project

that you're working on,

what are you looking at there?

What are some of the findings

that you're coming out with?

[Meredith] Sure.

So, it's an NDIA-funded project,

under the National

Information Program.

So, the aim is to be

getting information out

to people with deafblindness,

to their families and

to service providers,

and supporters about

basically all things deafblind.

[Narelle] Yeah.

[Meredith] We've got a bit of a

focus on people born deafblind,

because they often

fly under the radar,

and are not picked up as well…

by some of the peer support

groups around Australia.

But really there should be

information on that website,

that's sort of your DeafBlind

101 go-to as a resource.

We run regular

face-to-face training

for service providers

and family members.

And also, webinars

and develop resources,

so there's fact sheets.

But lots of videos, webinars,

like a range of information…

sources all found

on that website,

that DeafBlind Information

Australia website.

[Narelle] One of the

things that people…

do say is,

"There's not many people with

deafblindness in Australia."

What would your response be?

[Meredith] I'd say there's

definitely more than you think.

So a study done back in 2013,

just using government data,

found that there was

just under a 100,000,

so enough to fit in the MCG.

But I mean, this is a

huge issue in the field,

is that most people

with deafblindness…

don't identify as

having deafblindness,

and we don't have good ways of

capturing them and finding them.

So, I'll give you a

classic example.

Our ageing population…

with the high incidence

of age-related vision,

and hearing conditions,

most people sort of

over the age of 80,

you would probably

consider deafblind.

Because deafblindness,

people think Helen Keller,

total deafness, total blindness.

Most people with deafblindness

have some functional…

vision and or hearing.

So,

just as there's such a spectrum

with people with low vision,

blindness and low vision,

so too deafblindness,

like you can be fully deaf,

right through to mild

hearing impairment.

If you're blind with a

mild hearing impairment,

you can't fully compensate

for the loss of one distal sense

with the other distal sense.

Like, they're our two main

ways of accessing the world,

and they lie

heavily on the other.

If one is reduced,

and then if you've got

reduction in the other,

we say it's a

multiplicative effect,

that it's not one

plus one equals two,

that it's not deaf plus blind,

but that the challenges and

the complexity is much greater,

and that it is a unique…

disability in its own right.

And I guess the common features,

people with deafblindness

vary incredibly.

They have many different

communication methods,

and it depends on when they

lost their vision and hearing,

what level of functional

vision and or hearing they have,

what's their environment,

who's around them,

who their communication

partners are.

So all of these things

will influence what…

their primary

communication method is.

But that is one of the primary…

effects of deafblindness,

is that you'll have

communication challenges,

you'll have challenges

with mobility,

orientation mobility,

and challenges with

access to information.

So, that's where you

get your digital access.

Any person with

deafblindness is going to have…

information access requirements.

[Narelle] Wow.

And, you know, I'll

add something in,

because it occurred

to me as we were,

you know, you were

mentioning all that.

A person that starts

to lose their sight

and their hearing older in life,

their fingertips are

not as sensitive.

They've had a

lifetime of working.

I know for me,

gosh, help me if I ever

start to lose my hearing,

I can't learn Braille.

My fingertips are

not sensitive enough…

to feel the

difference in the dots.

And that's a big issue.

So suddenly it's not

just deaf and blind,

because their fingers

are not sensitive enough,

they don't have that really

good sense of touch as well.

[Meredith] That's right. And I

guess cognitive decline as well,

having to learn new

skills or techniques.

So, yeah, there's often,

it's often not just

deafblindness,

but other…

other issues as well.

So, I guess if you're

wanting some statistics,

the World Federation

of the Deafblind,

in their global report in

2018 and then in 2022 as well,

are saying that

across the globe,

it's estimated that

0.2 to two percent

in any population

will be deafblind.

[Narelle] Yeah.

And as you said,

that's not really counting…

That's, yeah, not counting age.

That's a huge number.

In this day in ageing,

it becomes a very big number.

[Meredith] That

is counting older…

[Narelle] It is counting age.

[Meredith] When you get to

two percent of the population,

that's a big chunk.

But certainly, the numbers

increase as you get older.

[Narelle] Yeah.

So, when we talk about

digital communication then,

because a person that is blind,

like you or myself with our

severe vision impairments,

we're heavily reliant

on screen readers.

I don't know Braille because

I lost my sight later in life,

but we are very

heavily reliant on sound.

A person that has a

hearing impairment,

a severe hearing impairment,

is very reliant on sight.

So when you suddenly

haven't got either,

your world becomes very limited,

even in what you can

do with a computer,

a phone, anything like that.

[Meredith] That's right.

So for, and I mean,

I certainly know quite

a few people who…

have sort of Helen Keller

level of deafblindness,

so severe vision or

hearing impairments or loss.

So, yeah, tactile,

that's your only means.

So, Braille is the

only way they've got.

So, you know, any video

content needs to be transcribed.

You need a transcription,

because they won't access any

audiovisual sort of material.

But refreshable

Braille displays,

and portable devices have

been an absolute game changer,

just for access.

And being able to

communicate with each other

when they leave the home rather

than needing the TTY at home.

But yes, with refreshable

braille displays,

and those little portable

ones are fantastic,

so they can access the internet

when they're out and about,

but the bigger ones for

at home for the desktop.

So, that's for that group.

[Narelle] Yeah.

[Meredith] But then, yes,

you would have people

with deafblindness using…

screen magnification,

screen readers.

So, the same things that

vision impaired people use.

[Narelle] Yeah.

[Meredith] But I guess

the other thing that…

One thing we did get big

ticks on our website for,

was that we don't develop

any video information

that doesn't have

Auslan interpretation.

So Auslan is the

Australian sign language,

which a lot of, there's a

condition called Usher syndrome.

So if they are born

deaf, signing deaf,

and then develop

retinitis pigmentosa,

so get tunnel

vision later in life,

lose their peripheral vision.

And so, those users

will need Auslan videos

to follow any video content,

or audio content,

you would put it

into Auslan as well.

But we also have

to be really mindful

that they have a

vision impairment,

and so keeping dark backgrounds,

that the interpreter has

high contrast for their hands,

to their clothing

and the background.

So, if you've got a white

or pale-skinned interpreter,

you're wanting them to

be wearing dark clothes,

so their hands are contrasting.

And just to minimise glare

from the screen with the video,

and not have animations

or any other stuff,

and just position them, you know,

centrally and facing forward.

All of these sorts of things

are things to be mindful of

for that deafblind…

population who have

sufficient vision to access…

print and access Auslan, but

you still need to be mindful.

The other thing with

that group is being mindful

of the level of language.

Cause they're from a culturally

and linguistically diverse group,

Auslan is their first

language, not English.

We make sure that all of our…

print content is at grade

9 reading level or below,

because 44 percent of

the Australian population…

can only read, like not higher

than grade 9 reading level.

So going for grade 9,

or going as low as

you possibly can,

is the best tip but making

sure it's not over grade 9.

And there's a great free app

called the Hemingway Editor

that I use all the time

to check reading level.

So, there's a few apps

you can use, free apps.

So that's just a free way of

making stuff more accessible,

for everybody immediately.

Just using plainer language,

using bullet points instead of

long sort of rambling sentences.

If you're going, oh,

we went to, you know,

or if you're talking about

technologies, you might say,

Braille readers,

this, that, the other,

but put them in point form

rather than in a long sentence.

So, just a few tips like that

that simplify it for people.

[Narelle] And this is it.

While I was thinking about that,

you were mentioning Auslan,

I don't think people realise the

number of actual sign languages…

in the world is what,

about 300, isn't it?

So, if…

we here in Australia use Auslan.

However, you go to America and

they use American Sign Language.

There will be some similarities.

So, the captions are

still incredibly important.

[Meredith] Yes, the

captions, you're right, Narelle.

Everything has to be captioned.

And I tend to have

open captions,

partly as sort of an

accessibility prompt

to encourage people to use it,

but I think sometimes people

don't know how to turn them on,

so having them

just there all the time.

We find lots of people

benefit from captions,

all sorts of people

with access issues.

Even hearing impairment,

missing a word,

but not just fully deaf,

but people from from culturally,

linguistically

diverse backgrounds,

who might not pick up the

accent or understand the word,

to have it there in

print is really valuable.

So yeah, great point, Narelle.

[Narelle] Yeah. It's

an interesting area,

because I hadn't thought anything

really of it until I met you,

and we started talking

about the work you do.

One of the things that…

interests me is,

people will think that people

that are deafblind don't work.

I would say that's

probably another myth.

[Meredith] Definitely.

I know plenty of people

with deafblindness with jobs,

that do government work.

I've had colleagues

with deafblindness,

doing project officer roles.

I'm just trying

to think, there's…

There's, yeah,

an educator employed at Senses

that runs a lot of training.

But even working in a variety

of government departments.

Over in Western Australia,

I knew a few people with

deafblindness employed.

So, certainly it's

more challenging.

I know there's some great

deafblind artists as well.

But it is possible.

Like it's just having

an employer who can,

you know, be a bit creative

and open, work with the person.

What's going to

work best for them?

[Narelle] Yeah.

And that's it, isn't it?

Because, you know,

they don't think twice…

about employing a

person in a wheelchair,

or a person that might

have a missing arm,

or a missing leg.

[Meredith] I think

they do think twice.

I think people do think

about being diverse.

I don't know, but I think…

a lot of people are very

uncomfortable with disability

and think of all these

issues that aren't issues.

I know for me,

there's all sorts of issues

I have in the workplace,

but it's never ones that all

the employers come up with

that they think

could be a problem.

They're so worried about OH&S

that you're gonna trip over.

It's like, no, that's the

least of your worries.

So, I think anyone

with a disability,

they're always really

concerned about OH&S.

So, but, yeah,

certainly I think,

people with blindness as well,

are really underrepresented

in the workplace,

relative to the

number of employable…

people at employment age.

[Narelle] And I, what…

What advice or what

tips can you give people,

when considering deafblindness,

whether it's the

hospitality industry or…

the medical industry?

I know for me, I

often get so frustrated.

They will say to me,

oh, we need you to fill out

this form, and it's on paper.

And I'll look at them and they

say, we'll fill it out for you.

And they take you to one side

and they say in a loud voice,

what is your first name?

What is your birth date?

And I think, where's my privacy?

In all this, what tips

can you give people?

[Meredith] So I guess one is

for anyone with any disability,

but definitely deafblindness,

is ask the person, don't assume.

And ask, would

you like assistance?

If so, how can I

best assist you?

So, and you know,

we're talking

about access today.

What access needs do you have?

What can we do to make

this situation accessible,

to make this website accessible,

make our information accessible,

make this forum, this meeting,

this whatever accessible to you?

So, asking the question straight

up and asking the person,

cause people have

different preferences.

And just because

you've met one person,

even if they've got a similar

condition or level of vision,

they still may have different

preferences to the other person.

So, always ask the person.

And the second is

budget for access.

Accessibility does cost.

So, build access

into your budgets,

build money in for

proper captioning

not just relying on

the auto captioning,

to really get it done properly.

For Auslan interpretation,

for taking the time to make

the reading level lower.

It takes time.

It's free. You can

have someone do it,

but you've still got to

pay that person to do it.

[Narelle] Yep.

So, definitely ask the person,

and budget for access

would be my two top tips.

[Narelle] Meredith.

I actually think they're the

two best tips you could give.

I know,

for me,

where I've worked previously,

it was always a disappointment

when I couldn't do something.

I knew technically

I could do it.

I had the knowledge to do it.

The problem was the environment

wasn't going to let me do it.

And that's sad.

I really appreciate

having you on, Meredith.

How can people keep

in contact with you,

find out more about your work?

I do think it is important work,

so I'd love people

to be able to find you.

[Meredith] Thank you.

Thank you for asking.

Go to, if you Google DeafBlind

information, we will pop up.

So DeafBlind

Information Australia,

there's just a wealth of

information on that site,

and you can keep track

of upcoming webinars,

or face-to-face training

sessions that we're running,

which are always

all free of charge,

so, because it's

government funded,

That's a good thing.

But also on Able Australia's…

Centre of Excellence

DeafBlind page,

there's lots of

research projects,

or communication guide training,

video guidance training,

there's some training that

we run out of there as well.

So, yeah, people can

follow both of those,

or follow me on LinkedIn.

Yeah, I guess those would be

my top three places to find me,

and the work that we're doing.

[Narelle] Yeah.

Thanks, Meredith.

Thanks for your time today.

[Meredith] Thanks, Narelle.

It's been a pleasure.

[Narelle] It is a real pleasure.

-[Meredith] Thank you.

-[Narelle] Well…

[Narelle] When we originally

sort of broached it,

I think one of my

favourite books I've read,

and I've read it,

I actually wore the book out,

was the Helen Keller story.

Because to me,

yeah, she was born with

no hearing and no sight,

but I think more

it's about resilience.

It's about Helen's resilience.

It's about the resilience of

her governess, and that belief…

that people can do it.

You just have to find the way

that's going to work for them.

Actually, I'll amend that.

People themselves have to find…

the way that's going

to work for them.

[Meredith] So, just

one point there.

[Narelle] Yeah.

[Meredith] When I started working

in the field of deafblindness,

I couldn't understand why

people born deafblind had such…

complex and

profound disabilities,

because I thought Helen Keller

was born deafblind as well.

Helen Keller could see

and hear until she was two.

And so you learn an

awful lot about the world,

and you have an awful lot of

language by the age of two.

So, that is a lot of the reason

why she was able to develop,

she already had a map

of the world in her mind,

and an understanding

of the world.

Still huge challenges,

incredible challenges

to overcome.

But quite different to having

no vision or hearing from birth,

which is some of the

people that I work with.

But you're right as well,

needing that really skilled,

sensitive and dedicated…

communication partner

that's willing to take the time,

and effort to work with you in

a way that's meaningful to you,

to develop the skills.

So, yeah, amazing

woman for sure.

[Narelle] Yeah,

just so important.

So if you like what we do,

please like, share,

subscribe, review.

We really do love feedback

and we don't care if it's ugly.

If it's ugly, it means we're

going to change things,

and we're going to learn.

And really that's what
the whole world is about.

The more we learn, the more we
learn how to change our lives,

to improve our lives,
the better off we are.

And maybe it's something that we
can pass on to others as well.

So, this is The
Digital Access Show.

We will catch you next week.

See you later. Bye.

[music playing]