[music playing]

[Narelle] Good morning!

And welcome to The
Digital Access Show.

My guest today and I met at
the Brisbane Disability Expo,

and we had a really great
conversation…

…about communication.

And I'm really thrilled that
Bianca said yes straight away,

when I said, would you come
on the podcast to talk about it?

Everyone, please
meet, Bianca Saez.

Bianca, thank you

for being on the show.

[Bianca] You're so

welcome, Narelle.

Thank you so much

for having me here.

[Narelle] Bianca, tell

us a bit about yourself.

[Bianca] So, I've had severe

Tourette's Syndrome my whole life,

from the mddle, the age

of four, diagnosed at five.

Pretty sure after

that, we worked out,

that was I was one of the worst

people in the world with Tourette's,

when I was younger.

But as I've gotten older, my
Tourette's has kind of calmed.

Still got see Tourette's, but
it's calmed to the point where…

I can walk down the
shopping aisle without ticing,

and breaking things with my
Tourette's like I did as a kid.

So I've had a big, big life
with Tourette's Syndrome,

all different avenues of things
that have happened to me,

but as I've gotten older,

all I do is just want to
work like everyone else.

But no one would hire me
because of my swearing.

So I'm like, "Alright,
let's make my own job".

So I just decided…

to do stuff on my social media
platform, which was amazing.

But previously,
back in my childhood,

I've got three 60
Minutes stories in it,

60 Minutes Australia to
be able to boost my career,

so that I've been
on social media.

After that, created a platform
for disability advocate.

And then after that, I got a job
at a place called Designer Life,

that basically wanted
me to talk to their students,

to uplift and tell them what I
had to do before I come to work,

trying to uplift so
they get jobs too.

And then from there,

I found out that I have a passion
for motivational speaking,

but also it's the educationa; of
side of Tourette's that I need…

to get across to people.

Like un, another person in my
Tourette's community…

went and took
himself to the park,

just so he could be
away from other people,

so he could tic freely.

And then there was a
lady and a child there,

and there was police,
and she went over,

and complained to
the police about him.

About him being too aggressive
or yelling or something. So.

And the way the
police handled it.

They don't know how to approach
someone with a disability,

or how to go about it.

There's so much education needed
done in all walks of life,

from hospitals,
ambulance staff, police,

teachers at school.

There's so much education

needing to be done.

So that's why I dedicated
my life to do that.

Yeah.

[Narelle] Bianca,
that's awesome.

Bianca, I don't know
much about Tourette's.

I've only heard
about it socially.

And to be honest, I
think from memory,

you might've been the first
person I have met with Tourette's.

What is Tourette's?

[Bianca] So Tourette's Syndrome
is a neurological disorder,

characterised by
controllable movement,

and vocalisations
called Tourette's.

So basically, our tic is like,

someone says,
stop your Tourette's.

It's like saying to them, stop
breathing or stop blinking.

Tourette's Syndrome is
more common in boys too.

You don't come out as
baby, but it comes out later.

You could be 21 and you
could wake up with Tourette's,

or you could be any age and
develop Tourette's, you know?

[Narelle] Oh my gosh.
I didn't realise.

[Bianca] it's very
rare in older people.

But yeah, there's people
that I know who've had…

been 21 and woke up and started
ticing and it never stopped.

[Narelle] Can people get
it through having strokes,

or other conditions like that?

[Bianca] I think it's a

neurological disorder.

So genes passed down from your

parents or something like that.

[Narelle] Yeah.

-[Bianca] Yeah. Pretty much.

-[Narelle] Okay.

[Narelle] So what affect…

…does Tourette's have

on communication?

I imagine it must

have a massive one.

How does it affect you?

[Bianca] I'm a very

good communicator.

It's just people in public
that don't understand.

So, a couple of Saturdays ago,

I was at a pub with friends,

just having some
drinks and some dinner.

And then I decided to go
home early, around 6:30, 7.

So I organised the courtesy
bus to drive me home.

Then not even two minutes down
the road, I tapped the window.

This man said,
what are you doing?

I said, remember, I
have Tourette's Syndrome.

He goes, I know. Do it again, and
I'll have to kick you out of my car.

[Narelle] Oh my gosh.

[Bianca] I couldn't help doing
it again, and so I did it again.

He goes, that's it. I'm boint to put
you out on the side of the road.

I said, no, please,

Like, I, I'm, I have a disability,

and I'm worried
about getting home.

Could you just please

take me back to the pub,

so my friends there can
help me ring someone,

to help pick me up or something?

And I just, he kept saying,
I didn't care what you got.

I don't care what
you have to deal with.

I just don't want you in my car.

So, then he ended up lying
to the boss and everything.

But a good things
come out of it.

So now that…

something's been
happening in that place,

I did a video on it saying, hey,

I was just trying to get home.

Anyway, now this place
has done disability training,

and they're going to get
me to come and have a chat.

So, it's really good.

So, now that awful thing
that happened to me,

now, good change
has come out of it.

People have realised
that they need to be…

being there and understanding
about people with disabilities,

so this pub will be much better,
better equipped in the future,

after my encounter.

[Narelle] That's awesome.

What about as a child at school?

I mean, children with Tourette's
must have a hard time at school.

[Bianca] To be honest,

a lot of people in my
Tourette's community have...

awful times with
teachers and stuff.

I had bullying…

from kids my whole
schooling career.

But other than that, the
teachers were so good with me,

and so understanding
when I was at school,

which I was lucky enough
to have a good experience.

But a lot of people don't.

Another friend of mine
has now been traumatised.

He has fear of open
spaces, that he can't…

leave the house,

because it terrifies him due to…

the way the teachers
treated him at high school,

when he was at high school.

And now he's mentally and…

physically scared…

to go out in public,
because of these…

how they treated
him at primary school.

And so, I think people
should be ashamed for that.

To put a kid through that…

[Narelle] A big issue
with all of this is…

lack of communication
about Tourette's,

and that is the
bottom line, isn't it?

If people knew it was just
something you can't control,

accept it for what it is,

and it's just everyone
has the education about it,

which is done by communication.

-[Narelle] We'd be a lot better off.
-[Bianca] Yeah.

[Bianca] This is, this is what
makes me really sad.

I'm lucky enough to
receive NDIS funding,

but my community
can't receive anything,

because Tourette's is
classed as psychosocial.

So it's with schizophrenia,
bipolar and stuff.

So it's not classed
as a proper disability.

It's in the psychosocial tab.

So, if the NDIS isn't
listening and understanding,

how are we supposed
to help people?

The Tourettes Community,
The NDIS doesn't want to…

…give people funding
to help them. You know.

[Narelle] Actually, I didn't
realise it wasn't on the NDIS.

[Bianca] No, it's not. It
hasn't been ever on the NDIS.

Cause, I was in the disability
service before the NDIS came about.

So I think that's why
I went over to NDIS.

I think we need to communicate
with the government and stress,

I'm not saying for every person
with Tourette's Syndrome,

that has the tic disorder,
but for people in my situation,

that was when I was younger.

I destroyed my parent's homes.

Every aspect of
daily life gets affected.

So, if you got one tic, you don't
necessarily funding for that.

But people in my
situation where…

they're breaking
homes, suicide attempts,

all these awful
things happening.

A lady came to me in the
expo a couple of years ago,

and wrote something
to NDIS to get…

her client funding

and the stuff that she
wrote was horrendous.

And the NDIS said, no, you
don't get it. You don't need it.

[Narelle] Yeah.

[Bianca] So, that's
what I'm trying,

and why people with severe

Tourette's struggles every day,

why they can't
access NDIS funding,

because it benefits
my life so much.

I have a better life.

I get to do so many amazing things,
and without my NDIS funding,

I wouldn't be able to do
the motivational speaking

and the educating that I've
need to do in this world.

So, NDIS makes my world
go round and have a better life.

And I can't believe people with

Tourette's Syndrome don't get it.

It makes me want
to cry, to be honest.

[Narelle] Oh, Bianca.

What…

When you're looking at
websites and things like that,

is there anything that triggers?

Like if you're looking at
movement on websites, videos,

is there anything that
will trigger the tics?

Or are they just…

under control?

[Bianca] So, with my
Tourette's Syndrome…

So, with my Tourette's Syndrome,

I can't use computer mice,
keyboard or computers,

because I've just broken
so many over my life.

[Narelle] Okay. Yeah.

[Bianca] Or I can
only use on my phone,

because I got a, you saw my
pillow invention that I made,

to put up my phone so it
stops breaking my phones?

Yeah. So basically, it's the
only thing that I can do it on.

There's a lot of platforms,

or things that you need to do to
make things better on a computer,

but I don't have
access to a computer.

Another thing that
I struggle when…

…I'm on websites is little words,

So if they're bigger, I
can read them better.

Yeah.

[Narelle] I never
realised that. That is.

And there are a lot of apps
and things out there where,

if you're looking at it on a a phone,
you don't get all the information.

It is actively not available,

so your communications
even affected,

by not having…

Wow.

[Bianca] Can I say,
for about…

seven years,

I didn't have a phone.

So I couldn't keep in
touch with my friends.

I couldn't do anything
until I made this invention,

but that was when I was younger.

So when I was young…

probably 17 to 21,

probably before that,

before 17 to 21…

What am I saying?

[Narelle] You didn't have a phone to
be able to communicate with people,

because of the
affects of Tourette's.

[Bianca] Yeah, so I
didn't have a phone,

so I couldn't keep
up with anything.

I couldn't see where my friends
were or what was happening.

So that was
incredibly debilitating,

and being cut off from world,

not knowing,

because I just kept
breaking phones.

[Narelle] Yeah. And
you love rock music.

I follow you on Facebook,
and you're into rock music.

And you're a social person.

Not being able to
keep up socially,

because of the
effects of Tourette's,

really is an issue.

But even more than
that is too, the issue of…

if you haven't got a computer,

and everything is
around computers today.

[Bianca] Yup.

[Narelle] You're
reliant on a phone.

Oh my gosh, what
are you missing out on?

[Bianca] Imagine in the future,

if they start to put things
inside our body like...

There's this movie that they
put a phone inside their hands,

so all they have
to do is do that.

So in the future, if things
start to happen like that,

I can't have things inside my
body due to my staph infections,

from 16 deep brain stimulation
surgeries to help my Tourette's.

What else?

I just mind blanked again.

[Narelle] There'd be so much,
because it'd even be paying bills,

cos some bills are harder
to pay on the phone.

There's no doubt about it.

I've run into one now.

So, you'd be relying
on other people…

…actually knowing
your bank details,

so you can pay bills.

[Bianca] But I got really good when I
didn't have a phone with directions,

and where the car was parked.

So yeah, actually I
adapted, and it made me…

more equipped to find
my way around and stuff,

and have other skills,

because I couldn't have a
phone in the palm of my hand.

My carer goes,
B, you're amazing.

You remember everything.

You can even get
there without maps.

It's because I've
had to for so long.

-[Bianca] So, yeah.
-[Narelle] Yeah.

And simply, for a
person to wear glasses,

that is such a big problem,

I can't wear glasses,
cause I'll break them.

I can't do contacts.

Imagine trying to put
a contact in every day,

and the only way my eyes can be

fixed in the future is surgery,

and you have to
be awake for that,

so I can't be doing
this during the surgery.

And if I did this to my eye
once, I'll lose my eyesight,

and I'll go blind.

And then I'm also losing
hearing in my ear here.

That's a dramatic sign.

So, now,

I'm getting hearing loss,
but I can't wear hearing aids,

because I just push
them out of my ears.

So I don't want to be
blind and deaf in the future,

just because of my disability,

we can't have
the right surgeries,

or be able to do
things to help me.

[Narelle] And add to that, if
the videos don't have captions,

and you're deaf,
and you can't see properly,

what are you to do?

[Bianca] Yeah, my disability

stops me from wearing glass,

and have hearing help.

If I'm blind, I'll come and
hang out with you, Narelle.

We can just talk and hangout.

[Narelle] Sounds great.

[Bianca] We'll have
no eyes together.

[Narelle] Yeah. And
do you know the thing,

I never, I'm gobsmacked,
Bianca, cause I didn't…

because I don't
know about Tourette's,

I didn't realise that, yeah,
they are massive issues,

not being able to wear
glasses, contacts, hearing aids,

[Bianca] This is
what I'm trying...

[Narelle] Yeah.

It'll even be down to things
like, you can only use a phone,

but you can't use
computers, and it's...

you know, your
communication is, you know,

the digital communication world
is not going to be fully open to you.

[Bianca] For such a
long time, I kept breaking,

before I could have a phone,
befpre I invented my phone pillow,

I had to have communication because I
was living in my house on my own.

and I didn't have
any communication.

So we bought like
15,000 house phones,

and I broke them all.

And a man in Sydney made me,

you know the intercoms
to let in, like a hotel?

Oh, let me in.

He made a phone like that for me,

but eventually it
just broke over time.

But there has been a lot of
adaptions in my life to help me,

but a lot of them just haven't
worked out for the best.

But, anyway.

[Narelle] Bianca, can I
just summarise all this?

Because I'm absolutely…

astounded, is
probably the best word.

Tourette's is a neurological…

Go on.

[Bianca] Can I just say one more
thing and you can wrap it up?

Another thing that people don't
realise for me to live in a home,

so I've broken bones,
I break chip rock.

I break so much.
I've broken kitchens.

So, my whole house has
been modified for my needs.

So I've got hard wooden
walls, plastic windows.

So that's what I'm saying.

And I have to have
certain furniture that works,

like there's so many problems
in my life that I have to face,

and get around each day.

To simply to live in a normal
house, I could never do that.

[Narelle] So to sum all this up,

Tourette's is a neurological
condition that is genetic,

and you're not sure which.

It's either an overproduction
of dopamine or seronine …

which causes tics.

They're uncontrollable tics,

and it can be anything from
swearing to sudden movements,

to breaking things.

And the effects for you is down
the street with communication,

the, the way people
think about you.

And then, the next step is also you
cannot use a computer or keyboard,

mouse.

You cannot use any of that.

You've had years where
you couldn't even use a phone.

And so, upir dogota;. the ability to…

be like myself or
anyone else that uses…

…phones for
everything that we do,

like for me, it's voice over,
and all the tools that I use.

That's even limited,

and you now are
dependent on a smartphone.

And you've invented a pillow
to keep the smartphone safe.

But even with a smartphone,
there is issues there,

because there

are things that can…

cause physical reactions
for you with the smartphone.

[Bianca] Yes.

I can't imagine…

how many other disabilities
get affected by communication too,

and access, being able to
access things on the internet.

Yeah.

[Narelle] What message do
you want to give people, Bianca?

I mean, what can we do…

on this podcast, and with

the tools that we've got,

to help get the message out?

[Bianca] It'd be great if the
NDIS listened to start off with,

because then that can
create society understanding.

But I feel like…

all we need to keep everyone with
disabilities getting together,

advocating, discussing, doing
podcasts like this, because…

the day that everything changes
to help people with disabilities,

there'll be more money
coming into the economy.

There'll be more
people coming out. So,

I just feel like everyone
just has to start…

…working together
as a whole to get there.

Hopefully the government
will look at Tourette's…

as something that's
needing funding,

which is very much needed.

And then all I ever
need, everyone,

any disability, any
mental disorder,

compassion and kindness
is always key, you know?

If you see when someone's struggling
on the street, help them.

You know, do that. Are you okay?

Would you like me to help your bags,
put your bags in the car for you?

If the world was more
understanding like that,

and everyone comes together
and helps each other,

I think it'd be a
different world.

But I don't know
how we get there,

but we can only do it one
foot at a time, I believe,

[Narelle] Oh, my
God, you're so right.

I so agree with you. And,

yeah, Bianca, thank you so much.

Bianca, how can people keep in
contact with you,

and follow you?

Because I think your
message is just so important.

[Bianca] If you'd like to
follow me on Facebook,

my Facebook, Facebook group, B

Breaks Barriers, on Facebook.

And then you can
follow me on Instagram,

B__Tourette's.

And then, I have a YouTube
channel called B With Tourette's.

[Narelle] That…

Bianca, thank you.

I have learnt so much,
and I keep saying it.

Every time I do an episode,

I learn something new.

So, Bianca's phone
might have died,

and that's okay.

Look, please follow Bianca.

And if you like what we do,

like, subscribe, review, share.

Tell people about Tourette's.

Can you imagine not being
able to use a computer at all?

And being reliant on
just a mobile phone?

Or not even being able to
use a phone in this digital age?

It's a massive issue for
people with Tourette's.

And I like what Bianca

said, empathy and kindness.

It's going to make

a better world.

We'll see you next time.

[music playing]