

voice

Breaking Down Barriers



Down Syndrome
Australia

June 2024



Artwork by Rachael Young
Read her story on page 22





Down Syndrome
Australia



Supporting positive change for our community

As non-profit organisations, Down Syndrome Australia and its members are dedicated to supporting, informing and advocating for the needs of people with Down syndrome and their families across Australia.

Our teams work diligently to support people with Down syndrome through developing resources, advocating for positive change, engaging with the community and implementing innovative programs focused on creating an inclusive future for all.

Your ongoing support enables us to continue with this important work and together, shape the future for people with Down syndrome throughout Australia and beyond.

Your donations help us make a real difference.



All donations, no matter the amount, help us to continue our important work.

To make a donation, scan the QR code or visit:

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Editorial



Hello everyone,

Welcome to this issue of *Voice* magazine.

In the pages that follow, we hear from people with Down syndrome who are breaking down barriers and overcoming assumptions about what they can and can't do.

Inspired by this year's World Down Syndrome Day theme "End the Stereotypes," the stories that follow show us what's possible when we support a person's potential, rather than boxing them in with preconceived ideas.

We read about people with Down Syndrome going to university, making art, learning new skills at work, even becoming social media celebrities! A big thank you to everyone who shared their experience with us.

Also in this issue, we talk about the World Down Syndrome Congress, and hear from the five recipients of the "Together We Can" scholarship about the leadership training they've been doing and what they're excited about for the big event.

Enjoy this issue of *Voice*!

Warm wishes,
Nathan



Too much importance is given to perfection, intelligence, gifted and productivity. We all have value and society needs to start looking within and how they can create capacity for us all.



Rachael Young
(read more about her story on page 22.)

Cover photo by Stephanie Rodden from Celebrate T21.

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Breaking Down Barriers – Easy Read



The theme of this magazine is Breaking Down Barriers.

Breaking down barriers means doing things that people don't think you can do.



People with Down syndrome can experience barriers when it comes to education, getting a job, living independently, finding love, as well as other life experiences.



Many people with Down syndrome are showing the world that they can do more than what others think they can do.



It is important not to make assumptions or stereotypes of people so that everyone can be who they are.

My story



An end to stereotypes

By Stephanie Papaleo

When I was three years old I started talking with ABBA music. My mother did not know that I could sing, but I knew all the words by heart, and sang them for 24 hours every day over and over.

My mum's side of the family comes from an Italian background. I spoke Italian to my grandparents when I was a child (because they did not understand English). Some people may not know that I speak two languages, but I can.

When I was at school, I learnt lots of things, speaking Italian, learning how to sing and dance, learning about religious backgrounds, acting, etc.

Now that I'm an adult, I'm challenging myself to do things that I didn't know how to do. For example, at my job at Down Syndrome Victoria (DSV), Zoe (my supervisor) taught me to create animated videos on PowToon, and I also regularly update the DSV website with Lucy.

I am also a personal assistant to our CEO, which includes tasks like organising events with other DSV staff, hosting staff monthly meetings, and creating articles for the DSV website.

When I was a child it was very different to now, because people did not know what people with Down syndrome could achieve.

My whole family believed that I could do things that I did not know how to do, and that has always been important for me, (as my mum would say, you are a role model for people with Down syndrome). Having people believe in me has helped me achieve my goals.

Generally speaking, it's not a good idea to stereotype other people, eg. why did you become blonde or actually blondes have 'lots more fun'. Believing in people as individuals will help people be the best they can be.

Message from the CEO



Welcome to the latest edition of *Voice*, which comes at an exciting time for the Down syndrome community as we make the final preparations to host

the World Down Syndrome Congress in Brisbane from 9-12 July.

This event has been many years in the making and will bring together people with Down syndrome, families, advocates, professionals and researchers to meet, share knowledge, insight and experience with others from different countries around the world.

In other exciting news, we are very proud of the fact that Down Syndrome Australia has recently been recognised as one of 11 National Disability Representative Organisations, leading a new consortium, representing people with Down syndrome and similar chromosomal differences. We will be working alongside the Australian Government to promote equality and accessibility, ensuring the views and experiences of people with disability are heard.

We have previously been funded as a member of a broader group of disability organisations, so it is a significant achievement to be recognised as a Disability Representative Organisation in our own right. This role comes at a timely point as we await the Government's response to the Disability Royal Commission and NDIS Review where we continue our advocacy to ensure that the outcomes of these landmark reports are implemented so that people with Down syndrome in Australia live in an inclusive society with full participation.

This issue of *Voice* tackles one of the biggest challenges facing people with Down syndrome, and with any form of disability in 2024: the barriers and stereotypes of the broader community. These barriers and stereotypes play a significant role in excluding people with disabilities from various aspects of society, and arise when people focus on a person's disability rather than seeing them as a whole.

Instead of focusing on a person's disability and how that person can change to fit in with society, the focus should be on changing the barriers created by society (attitudinal, physical, systemic, verbal and technological), and increasing the responsibility of society to accommodate people with disabilities rather than expecting individuals to adapt.

DSA takes a systemic approach to breaking down these barriers. We aim to highlight system changes that would better accommodate people with Down syndrome as well as promote awareness and education, encouraging positive interactions and dispelling misconceptions about Down syndrome.

Remember, everyone has a role to play in promoting inclusion and breaking down barriers for people with disabilities. By fostering understanding, empathy and proactive change, we can build a society where everyone can participate fully and equally.

I look forward to meeting many of you at Congress and wish you and your families all the best.

A handwritten signature in black ink, appearing to read 'Darryl Steff'. The signature is stylized and cursive.

Darryl Steff
CEO DSA



DSAN update



Hi, I'm Lauren, and I am the Canberra representative of the Down Syndrome Advisory Network (DSAN).

Over the past five months, the DSAN has been on lots of Zoom meetings to talk about the NDIS and meet new people.

We have also been talking a lot about inclusion and rights, and living independently.

At our meetings, we all have the chance to speak. We have an agenda, and we all talk about how we can help people with disabilities.

We did a face-to-face meeting in Queensland. It was great. We were working on lots of topics, mostly about the World Down Syndrome Congress in Brisbane.

I am going to be speaking at the Congress and I'm excited. My presentation is about inclusion and rights. I want to help more with the big events with Shannon and Gemma.

I would like to do more public speaking in the jobs I do.

We made a video with all the DSAN members, which is on the Down Syndrome Australia website.

We have also been doing some workshops and I would like to do more. They have been a good way to meet people and learn things.

I went to the World Down Syndrome Day event in Canberra and I met all the ministers.

My passion is to share my voice, be heard, and be more in the media with what I do. I also want to do more in the DSAN.

Over my birthday, I donated \$308 to Down syndrome associations. I want to help more through the year and for a long time to come.

Lauren Murray
ACT DSAN member

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You can also let us know if you'd prefer to receive a digital copy of the magazine, rather than the printed version.



Two of us



Pranks, friendship and fame Meet The Brother Boys

Bill Cooper met his best friend and brother-in-law Kyran O'Donnell 12 years ago, when Kyran started dating Bill's sister, Lucy.

They had an instant bond, and started making videos of their antics together for social media.

Now known as "The Brother Boys", the duo is an internet sensation, with millions of followers across TikTok, Facebook and Instagram.

Kyran is a Barkindji man working as a landscaper in Mildura, Victoria. Bill is a man with Down syndrome based over the border in Wentworth, NSW, and works at a supermarket.

The videos they make are hilarious, and spread an important message about diversity and inclusion.

The Brother Boys won the Best Social Media Creator in the Family, Pets and Parents category at the 2022 Australian Influencer Marketing Awards. They have amassed nearly 70 million views for their videos.

Kyran and Bill share their story of meeting each other and becoming famous.



Kyran

We've been Brother Boys for 12 years now.

I had never met someone with Down syndrome and didn't know what to expect with Bill. I had seen video clips and heard what Lucy said about him, but I still had no idea.

I remember Bill walking in the house and instantly he was protective of his sister and sizing me up. Straight away, he was giving it to me. That caught me off guard.

Then he made me laugh and we had a bond instantly. From that moment we have always had this strong connection.

The pranks started early on – long before we put them on social media.

I remember one of the first pranks Bill did. I was asleep on the couch and I had a fluffy beard then. And Bill came up and put a wax strip on it. I woke up with a slap. Then this massive strip pulled from my beard!

One of my favourite pranks was early on in Covid. It's the bag prank that women were doing to their blokes at the time. We were in the front car seats and I grabbed a bag from the back and swiped it across his head to grab something out of it. And the whole prank is to pretend like nothing happened.



But straight away, Bill wasn't going to have it. He just said: "Really? You really just did that? Are you right?" It was brilliant.

We say that Bill is unprankable. Once I put a fake spider above the sun visor on the car dashboard. He gets in the car, takes the visor down and no reaction. Smooth.

It means a lot to us to be able to represent our people as Brother Boys.

When we started posting the videos, we weren't concerned about the inclusion and diversity aspect. It was just fun.

Then we started getting feedback and realised what we were doing was powerful.

We get to show people who we are. We break down barriers and stereotypes that people have about Aboriginal folks and folks with Down syndrome.



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Two of us



We once had a girl message us and say: “Your videos are so awesome. I’m pregnant, and we just found out we’ve got a child with Down syndrome on the way. We weren’t going to go ahead, but thanks to you guys, we’re definitely keeping it.” Wow.

Bill always brings the vibes, especially in a social setting. He’s high energy.

I remember thinking he’s already a superstar in the community. Everything he does, whether he’s at his football club or job, he’s got superstar energy.

The first time we got recognised for being Brother Boys was on the streets of Sydney. We didn’t know what to do when this dude came up to us! He was like, “It’s you from social media! Can we get a photo?”

I would love to see Bill keep being a superstar, and educating the world about how smart, positive and fun people with Down syndrome can be.

I’d love to see Brother Boy smash any goals he wants to.

Bill

When I first met Kyran, I was a bit shy and awkward. I was 16, pretty fresh back then. He started dating my sister, Lucy.

He had long hair and was beefed up. He had just started his lawn mowing job.

It all started from there, when he came into the family. We loved him the most, and he was family.

Me and Kyran started going to the cinema together, going to pubs and bars and all that.

We started doing pranks to get reactions out of each other.

I don’t need a book. I’m funny. I’m the prankmaster. I always get Kyran. I always have the last laugh.

We are just two brother-in-laws having fun on TikTok. It’s not work. We love our fans, and we have a lot of fun.



It's been amazing being a person of disability. It can be a tough day and we make a thing that puts smiles on faces.



I'm very proud of people with disability and it's been great to do this with Kyran.

I learned about Kyran's family and his culture. He is in the Barkindji tribe. We went to the NAIDOC event in Victoria and I learned all the stuff they did, their art, their food, everything they have, music. We did a dance there.

I love my dancing. Dancing is a whole part of me because I had one inspiration when I was young and his name was Michael Jackson. I was a big fan of his.

One of my favourite things is karaoke. We went on a cruise and I did a song called Take It Easy by the Eagles. It was an old song that my Dad and Mum love. I smashed the whole song. I was singing the, "Ooh, ooh. Cause it's so good. Yeah, it's so good."

We love being celebrities and superstars. Sometimes people recognise us on the streets.

We went to Sydney for the TikTok awards. Luke and Sassy Scott were there, all the celebrities.

My dream is to get to New York one day.

You can follow the Brother Boys on social media. @the_brotherboys on Instagram and TikTok. The Brother Boys on Facebook and YouTube.

Finding support at pre-natal diagnosis

Mum Sarah Smithies tell us about the community she discovered that helped her see the wonderful parts of having a daughter with Down syndrome.



“Tonight Zariah and I wrestled on the mat for about an hour. Her laugh and giggles light up the house and my whole world. A noise I never thought I would hear again in my life – another child of mine laughing and giggling, and her extra chromosome just makes it all the more sweeter.”

Sarah Smithies

At just one year old, Zariah Smithies is bringing a lot of joy to her big brother Braxton and mum, Sarah.

Last year Sarah went through IVF to have a much-wanted baby and sibling for Braxton.



Photos on this page by Celebrate T21

Sarah's IVF journey, and discovery of her daughter having Down syndrome, were featured on the TV show, *Big Miracles* (which you can watch on 9now.com.au).

During Sarah's pregnancy with her last remaining embryo, prenatal screening showed the baby would have Down syndrome.

Although the news was a shock, Sarah was determined to continue with the pregnancy.

In her words at the time: “scary, sad, but then I think about how much she'll be loved and how much love she'll bring to the family”.

Sarah's experience of receiving the prenatal testing results was not very helpful.

She did not feel there was much compassion or reassurance shown by the medical staff. Nor was there

any information given to her about Down syndrome. "There has to be a way to deliver this news and show it's not a death sentence," she says.

Fortunately, support and help were not far away through the group, Celebrate T21.

Celebrate T21 is an organisation that brings together families in the Down syndrome community, and provides a platform for them to share stories and inspiration.

Sarah and Braxton attended sessions organised by Celebrate T21 and felt welcomed and embraced by parents in similar situations.

Sarah says: "I was always going to keep the baby, but Celebrate T21 made it more joyous. Being around other people with the same condition helped me see the good and joyous parts".

Sarah found a whole new community through Celebrate T21, and received a lot of support and advice through their Facebook page. Being able to read other parents stories and get answers to her questions was an important resource for her.

She says: "When you first receive the diagnosis, you can't see much further than what's in front of you. You grieve the loss of the child you thought you were going to have. But knowledge is power. All I can do is get the knowledge I need to handle each hurdle that comes."

Zariah was born six weeks early, and after some anxious weeks in hospital, Sarah and Braxton were thrilled to bring her home, just in time for Mother's Day.

She is now thriving, and Sarah says: "I am blessed to have her".

Sarah adds that since coming home with Zariah, she has also found countless support and information from those living the journey via the T21 Mum Australia Network.

When Sarah looks around at the Down syndrome community she is connected with, and the barriers people with Down syndrome are breaking down, she sees a bright future ahead for her daughter.



Photos courtesy of Sarah Smithies

Entering a mainstream high school

Sienna and her mum Kerry McVittie share their experience of going to an inclusive school.

A common misconception is that young people with Down syndrome should go to segregated schools. But many are breaking down that barrier by having positive learning experiences in mainstream education.

One such person is 13-year-old Sienna, who has been at mainstream school in her hometown of Ballina since pre-school.

She recently entered secondary school and has been navigating the transition with some of her primary school friends by her side.

“There is a big hall at the new school,” she says. “More teachers. It’s a lot of walking around.”

Sienna’s mum Kerry says it was important to follow Sienna’s friendship base from pre-school through to secondary school, and for her to have a familiar environment with teachers that had been around her from an early age.

Sienna says her best friends are Indie, Tommy and Issac, and she likes to play basketball with them.

She also enjoys learning new things, and her favourite subject is science with Mrs. Jukes.

“I love being at school, it’s so fun,” she says. “Last week I did a geography presentation on New York. I put some cars in there and big buildings. We’ve been to New York.”



Kerry, who was a teacher with a degree in Special Education and taught in support settings, says she hadn’t originally thought of sending Sienna to a mainstream school. But then she started researching and hearing more about families who had positive experiences of inclusive education.

“I started to think that she would do better in mainstream,” says Kerry. “I figured I’d give it a go – and it worked for us.”

“We applied to four schools and all of them would have accepted her. I liked the feel of the one she is at the most.”

“The Principal was lovely. He did say to me, ‘I don’t know that we can meet her needs.’ I said ‘I would be surprised if you couldn’t meet her needs’, and that was the last time I ever heard anything slightly negative from them.”

“The Principal will now tell you what a wonderful job they’ve done together and how much they enjoy having Sienna there.”



A common concern for parents is that having children with Down syndrome in an inclusive classroom will take away “teacher time” from other students.

But Kerry says feedback from the parents of Sienna’s classmates over the years has been largely positive.

“They’ve seen it as a bonus for their kids to have Sienna in the classroom,” she says.

Kerry says there needs to be a mindset shift when it comes to schooling children with Down syndrome.

“It’s just assumed that they should be in segregated schools, but that’s not always the best option,” she says. “Some will thrive in a mainstream setting, and others will do better with specialised support. It’s about seeing the possibilities, and having faith in your child.”

Some of the WhatsApp messages Kerry has received from parents include:

“We’re all grateful (parents and kids) to have learned from Sienna. I’m sure all her Year 6 crew will keep an eye on her at high school.”

“Thank you beautiful girl for showing us diversity can be so powerful, positive and inclusive. How wonderful to celebrate everyone for who they are.”

“Sienna has brought out the best in our kids.”

“Sienna has taught all the kids so much and they’re all sure to be better humans for having her in their lives.”

Thriving at work

Brodie Leslie and his mum Lorna talk to us about Brodie's job in hospitality with Emirates Leisure.



At Launceston Airport, in Tasmania, you'll find Brodie pouring drinks at the bar, preparing food in the kitchen or having a cheery chat with customers and work colleagues.

As part of his kitchenhand position with Emirates Leisure, he gains valuable experience in creating and delivering freshly prepared snacks and meals to a range of venues within the airport, and gains confidence in a front-of-house role.

"I make food and do the bar and serve. My job in the kitchen is a six-hour shift. I go twice a week," Brodie says.

"I've got nice friends; my boss chef Rickie, Liz and Katie. They're the best team."

Brodie's mum Lorna says the close-knit team are "very hands on deck" and cook a variety of food on the premises using local produce where possible.

"I have learned how to cook pies and really big biscuits and love to help make croissants, toasted sandwiches and yoghurt cups," says Brodie.

In 2017, Brodie and his brother started a gardening business together. His brother wanted Brodie to have meaningful employment.

Brodie's first choice was making coffee, but his brother wanted to do something different. Gardening was Brodie's second choice.

Brodie and his brother ran a successful business, and Brodie learned lots about providing professional client services and gardening.

But his interest in making coffee stayed, so he continued in hospitality training within a commercial kitchen at the Tailrace on Monday afternoons, with support from Northern Occupational Support Service Tasmania.

He began volunteering for the community Christmas lunches where he would scrape food plates and stack the dishwasher. He also volunteered with The Salvation Army community lunch program and as assistant camp chef with Scripture Union Tasmania.

When Emirates Leisure approached Down Syndrome Tasmania about employing staff at the local airport, Brodie's name came up.



Brodie joined the Emirates Leisure team and has been mentored largely by the chef, who also assigns various staff members to assist with his training and customer service.

Brodie is determined to upskill towards using an Eftpos machine, and further develop his favourite role: making coffee.

"From what I have observed, he's had a really solid learning experience," says Lorna. "There is no additional support person assigned, as the team wanted to bond with Brodie directly and they clearly have been able to work through any communication barriers themselves.

"He's got good people around him and they're willing to do everything to keep him learning and make sure that he's having a good work experience."

Brodie says some of the challenges he had to overcome for the job was doing an interview and meeting the team for the first time.

"The big bosses come and everybody in the staff group meet me and know me," he says.

Adds Lorna: "I witnessed that for them, it was about putting aside the stigmatised expectation of working with someone with Down syndrome and letting themselves see the person behind the disability as somebody that they can develop a friendship with."

"Now they go out together socially as a team, which puts Brodie in mainstream settings. He's one of them. And all the work conditions are the same for him, same wage, allowances, camaraderie."

"In many ways, he's categorically not different from the other staff members. That has had a big impact."

Living Independently – Easy Read



When we are children, we usually live with our family. When we are adults, we usually think about moving out and living somewhere else.



As an adult, you have the right to choose the way you want to live.



Everyone makes choices. Some choices can be harder, like deciding:

- Who you want to live with
- Where you want to live

You could make a list of what is good and bad about each choice.



Here are some questions to help you think about where you want to live.

- Do you want to live near your family?
- Do you want to live near your activities?
- Do you want to live near public transport?



Here are some options of who you could live with.

- Your family.
- By yourself.
- A friend, or a few friends.
- A partner.
- People you haven't met before.



Here are some other things to think about:

Costs – how much will it cost to live the way you want? Think about rent and bills. Are there things you need to buy, like a television or refrigerator?



Cleaning and taking care of yourself – will you be able to keep your home tidy? Can you cook?

Support – everyone needs support in their lives. What do you need help with?



It's a good idea to make a plan once you've decided how you want to live.

Ask a support person or family member to help you make a list of the things you need to do and know.

Smashing the higher education ceiling



Colby Hickey shares his experience of going to university and overcoming other obstacles and assumptions about his learning capacities.

I am Colby and this is my story.

Over my life I've faced many challenges, mainly due to my disability and the stigmatism that comes with it. Having Down syndrome is not something to be judged, there is an intelligence in Down syndrome people that may not seem obvious, and people assume because of physical appearance we are not capable.

My story spans over many years of my life. I was first told that I would not be able to go to school with my disability. The teachers didn't think I could read or write and thought it would be too hard to have me in the class. So challenge accepted, I went on to complete higher education in my twenties and thirties.

I studied a subject called Theology. I was interested in this because I am curious about how we use religion and faith. I found this subject to be quite compelling as it gave me insight into how we relate to the idea

of God. I am fascinated by the use of religion in our modern day. It was useful to gain an understanding of this for my own life and I enjoyed learning this subject in relation to my own situation as someone with Down syndrome.



I received accolades for my efforts at university, including an Edyth Rawson scholarship, an award based on academic excellence, involvement and contribution to the university and community.



My first memory of experiencing negative stereotypical behaviour as a person with Down syndrome was when I was at primary school. I was treated like I was dumb. Everyone in the classroom assumed I didn't understand what was going on around me. It was like they thought I was deaf and couldn't hear them. It was awful not being treated like everyone else. That was a difficult time, but I became very resilient because of the experience.

Throughout my twenties I was treated like a child by everyone. It was difficult to grow and mature in this environment, but I have done what I can to overcome this by keeping an open perspective and remaining very tolerant. This is an ongoing obstacle with continual assumptions being made from people I interact with day to day.

Having a team of support workers is an interesting way to view the judgement of others. Often people in the community assume I am not being cared for correctly – there is a judgement made that I am not comprehending and perceiving my surrounds, however my support workers understand my capabilities. People who make these assumptions are the ones unfairly judging me by my physical appearance and perceived disability.

Currently I'm on the advisory network board for Down Syndrome Victoria. There are ten of us that meet to discuss important topics involving people with



Down syndrome and ways they can be supported by their community to live a fulfilling and happy life. Fortunately, this ongoing role has equipped me with a deep understanding of the importance of inclusivity and diversity.

This experience has not only honed my skills but has also reinforced my commitment to contributing positively to the community.



My purpose is to advocate for the diverse and unique perspective that people with Down syndrome have and their contribution to society. I will continue to shed light on this topic and live a purposeful life.





The artist's way

Rachael Young is a 32 year-old woman with Down Syndrome who loves art and singing. She recently performed at the Celebrate T21 Connecting my Communities event, where she also showcased her vibrant artworks. She speaks with us about her passions.

Tell us about your artwork.

I love my art and the freedom of using vibrant colours to brighten up everyone's day.

I guess it really started when I was little because I loved colouring in and was very particular about it.

I started exploring art as a high school student at St Mary's College Wollongong and further developed my passion with regular art classes.

I am developing my own distinctive bright style using pastel on a textured medium using bold primary

colours. Colour is very special to me as it can brighten up everyone's day including mine.

My artworks are abstract, quirky and graphic in nature, looking at things from a different perspective and relating to memories, experiences and a sense of joy for nature.

Why is art important to you?

Art creates the perfect creative outlet for me as there is really no right or wrong and if I am not happy with my artwork, I can just go over it again using all the bright colours.

What was your involvement in the Celebrate T21 Connecting My Communities event?

I was asked by Celebrate T21 founder Stephanie Rodden to sing and present some of my artworks.

It was an awesome day where I was able to meet many different people from different organisations both from here in the Illawarra and also from out of the area.

It was fantastic to speak with them and they were very happy to see my artworks and they all loved them.

What songs did you sing?

I sang a song called "What a difference a Day Makes." I love this song as it makes people think that every day is different and better than yesterday.

Do you get nervous when you perform? How do you overcome that?

I get very nervous when I am in front of strangers as I get stressed that I will make a mistake.

I really practice so much before the event and it's great to have people around me that care about me that tell me it's going to be ok and I have got this. It makes me feel so much better.

It is also fantastic and makes me feel better when I have someone that cares about me in the audience.



What do you love about music?

I love music so much. It makes me feel happy and relaxed. I love the music sessions I have with Steph from Celebrate T21 as they are so much fun and help me to speak more clearly.

This is so much better than speech therapy for me because I practice it as it is so much fun. My speech is improving and my tone has improved.

I also love to dance and practice my moves nearly every day. I think I can be a stand in for Michael Jackson.

What barriers does society need to break when it comes to people with Down syndrome?

I never knew I had a disability. I have two brothers and my mum and dad expected the same from us all.

It wasn't til I was in high school that I realised I was different as the others didn't need the help I did. I looked different and I was treated differently by the other girls.

I didn't want to be different but my family encouraged and supported and cared so much for me and told me that we are all different and we all have different gifts to share with each other.

They told me to try hard always and give everything a go and it's ok to get it wrong sometimes as long as we learn from that.

It would be great that society would be like that too. Too much importance is given to perfection, intelligence, gifted and productivity. We all have value and society needs to start looking within and how they can create capacity for us all.

Assume That I Can

ff I discovered that in psychology there is a concept called “self-fulfilling prophecy”, whereby a teacher who thinks that a student cannot understand would just act accordingly and therefore they would not teach the student. And there you go: the prophecy self-fulfills.

But in my opinion, there are no difficult or easy concepts, there is always a simple way to explain things. If I think of all the things that were not explained and taught to me, well I really get angry. **ff**

These are the words delivered by Marta Sodano, a 29-year-old Italian woman with Down syndrome, during the World Down Syndrome Day Conference at the United Nations to describe the hurdles she had to overcome in her school experience.

On World Down Syndrome Day, CoorDown – Italy’s National Coordination of Associations of People with Down Syndrome – launched the international awareness campaign “Assume that I Can.”

It calls for an end to the stereotypes, biases and low expectations that limit the potential of people with Down syndrome.

Inspired by the words of Marta Sodano (above), the video campaign sees the lead character – a young woman with Down syndrome played by Canadian actress Madison Tevlin – challenge the low expectations others have of her and offers a different perspective.

She challenges people who believe that she cannot drink a cocktail, be a boxer, study Shakespeare, live alone, achieve important goals.

Halfway through the film there’s a twist: the character invites us to think outside the box and use the self-fulfilling prophecy positively: **if you believe in me, if you trust in me, you can have a positive impact, and then, maybe, I will achieve goals, even unexpected ones.**

You can find the video on the CoorDown YouTube channel – it’s fantastic. We spoke with the lead actress, Madison Tevlin.



Credit:
Sam Jackson

We loved the Cooldown campaign! What were some of your highlights filming it?

I was so excited to be part of this campaign, but I had no idea what to expect! We shot in Barcelona and that was amazing. The crew and everyone on set were so encouraging and so nice. I had no idea that I was going to be the main star for the whole ad!

Shooting the “bar” scene was my favourite because I love going out dancing. The response has been overwhelming in the best way, and seeing the impact it’s made on so many people has been incredible. We still have a lot of work to do for people with disabilities, but this was a big step in the right direction!

Why is “assume that I can” such an important message in your opinion?

When some people look at me, all they see is Down syndrome. I want people to know that I am so much more than that. Down syndrome is the least interesting thing about me.

Every person is unique and shouldn’t be judged on just one thing. We are all made up of so many different things and that’s what makes us special. This campaign started a conversation about not judging people based on assumptions.

What barriers have you personally had to overcome to build your career as an actor, presenter and model?

I think the biggest thing is exactly what the campaign was all about. People assuming that I can’t do certain things, or putting limitations on me before I even get a chance to try.

Sometimes I get treated like a little kid, but I’m 22 years old! Proving people wrong is really fun though, so I’m always up for the challenge!

In what ways do you challenge people’s misconceptions about having Down syndrome?

By going after my dreams! I put myself out there and I try new things. Sometimes it’s scary and sometimes it doesn’t turn out the way I hoped, but I’m always proud for trying.

Credit:
Charlotte McBride



I also just want people to see me living a ‘regular’ life, like everyone else. Some people are surprised at the things I do – just because I have Down syndrome, and I think it’s important to show the ordinary as well as the extraordinary.

What’s been your career highlight so far?

I’m so lucky, there have been so many. Shooting “Champions” is definitely at the top of the list. Meeting and interviewing Ryan Reynolds was a dream come true. Being honoured with the Quincy Jones Advocacy Award last year and being the first person with Down syndrome to be nominated for a Canadian Screen Award was so special. If I have to choose one, I’d say hosting my own TV show is my career highlight so far!

What are you working on now and what are you excited about in the future?

I just won 3 Webby Awards and was in New York for their awards ceremony! It was so exciting to walk the red carpet and be on stage. I am grateful to have been part of it. I’m really hoping to shoot a second season of my show, WHO DO YOU THINK I AM? I’m also doing lots of talks at schools and different events. You can follow everything I’m up to at [@madisontevlin](#) on IG and TT and at my website [madisontevlin.com](#).

Self-advocacy Guide – Easy Read



People with Down syndrome often have a limited voice in the decisions that affect them.



You have the right to make your own choices.



Self-advocacy is speaking up for yourself and other people with Down syndrome or disabilities.



Speaking up is about saying what you want to happen.



You can speak up to your family and friends – tell them what is important to you.



You can share your thoughts on social media. Make a video and share it online, e.g. YouTube or DownTV.



You can speak up for your human rights.



You have the right to be fully included in society. You should not be discriminated against.



It can be hard to speak up. But you need to speak up if you want to say what happens in your life.



Speaking up gets easier the more you do it.

Congress is here!



The 2024 World Down Syndrome Congress is taking place in Brisbane from July 9-12, 2024.



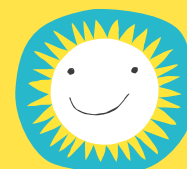
There might still be time to register. Visit <https://wdsc2024.org.au> to find out.



Congress is where the global Down syndrome community gathers – including families, advocates and professionals.



The theme is: “Together we can: celebrating diversity and inclusion”.



Many people with Down syndrome will be presenting. Some of the topics include:

- Health and wellbeing
- Advocacy
- Employment
- Family life



There will also be social functions to meet and connect with other people.

- Self-advocates forum meet and greet – 8 July
- Welcome reception – 10 July
- Congress dinner – 12 July



Congress is a great opportunity to learn about Down syndrome and meet people from around the world.



On the next page, the Congress co-chair Rhonda Faragher tells us more about what's in the program.

Congress is here!



Professor Rhonda Faragher is the 2024 World Down Syndrome Congress co-chair. She has been part of the committee developing the three-day Congress program (and pre-congress self-advocates and health days). She tells us what's in store.



Congress theme

The theme for this Congress is “Together we can: Celebrating diversity and inclusion”.

We wanted a theme that acknowledged the broad interest in Down syndrome, and a depth of talent and strengths in the community, as well as a range of support needs — because we don't want it to be a Congress that's just about some people with Down syndrome. We want it to be for all.

Engaging people with Down syndrome

The truth is: researchers, scientists, clinicians, teachers and all sorts of folk in this space cannot do their work without doing it alongside the people who will benefit from their work. And that's people with Down syndrome. That's what the focus of this Congress is all about.

We have had people with Down syndrome in all our Congress committees, and lots who have offered to be part of the program by giving presentations or performances.

What's in the program

We could have run a film festival with all the video submissions we've had! There are going to be films in the program. There will also be live performances, visual art displays and a few surprises. I'm particularly looking forward to the closing ceremony.

The presentation topics will explore health and therapeutic advances, education and employment, advocacy and social inclusion, family life and personal development.

You'll hear from people with Down syndrome who have developed a business or have a performing arts background, people who are engaged in sport and various activities.

The topics will also explore moving into different accommodation, supportive employment, smashing ceilings – essentially, the presentations will reflect the richness of people's lives.





Things to get excited about

I can't wait to connect with the community in person again. It's been a while since the World Congress has had an in-person event, and we get to welcome people from around the globe to beautiful Brisbane.

I also can't wait for the gala dinner. You have a whole group of people who dance as though no one's watching. It's sensational.

The third thing that I'm really looking forward to is showing off our city and our association. I think Down Syndrome Australia is fabulous, and to show it off to the world is a terrific opportunity.

My daughter was only three when I went to my first Congress, and I learned so much. It opened my mind to what was going to be possible. It then introduced me to a worldwide family, and that's why I keep going. It is a chance to connect, see friends and contribute.

Pre-program events

There are pre-program events beginning on the Monday. There is the Meet and Greet, which is a social function for adults with Down syndrome.

There is also the advocacy event, where adults with Down syndrome discuss priorities that they want the research community to take on. It's a facilitated conversation about issues that are affecting them. This year we have Professor Roy McConkey who will lead a conversation with self-advocates to communicate their views to the wider congress.

Important information

We've got a fantastic Congress app, that people can download soon, if they have access to a smartphone. You'll find the full program there plus lots of other useful information.

Congress is fully accessible, so people don't need to be worried or anxious about anything. There'll be lots of volunteers to help them find their way and make a great time of it.



Learning to be leaders

Late last year, applications opened for the “Together We Can Scholarship”, which would see five recipients undergo leadership training and head to Congress to present and participate as emerging leaders.

Funded by the Sherry Hogan Foundation, the scholarship was awarded to Ethan Perry from Queensland, Jerry Richter-Nguyen and Mia Johnston from South Australia, Joseph Salt from Western Australia, and Annalise Haigh from Tasmania.

For the past five months, the group has met regularly on Zoom and undergone training to develop their leadership and public speaking skills.

They are now getting ready to head to Congress where they will give presentations and meet a range of people from the international Down syndrome community.

Here, the five emerging leaders tell us who they are, what they’ve been learning in the training program, and what excites them about going to Congress.

Why did you apply for the Sherry Hogan scholarship?

Mia Johnston: I saw the scholarship and I got excited. I got accepted and I look forward to Congress.

Annalise Haigh: Because it is important to us being a leader to other leaders. And be brave and supportive to others. Being in a Sherry Hogan Scholarship means to me is that other girls and boys are different and we don’t know who has disabilities around the world.

Jerry Richter-Nguyen: I applied for the scholarship to learn more about advocacy and leadership. I like to grow as a person and help other people. I love new experiences, meeting people, travel and learning.



FF I will be the best leader, and mentor. I am caring to others, cheerful, brave and hopeful.

Mia Johnston



I believe my background, attitude, personality, desire to help and inspire others and my training make me a great leader.

Jerry Richter-Nguyen



What have you been learning in the leadership training?

Mia Johnston: I have been learning to be caring to others, someone in need of support, and we should help them.

Ethan Perry: I learned about respecting people and listening to others, my rights to have a voice, and equal opportunities.

Annalise Haigh: It is important to know things like meetings, rights, public speaking, leadership units to be worked on, together we can.

Jerry Richter-Nguyen: I have been learning about meetings – what they are and how to participate to talk about issues, making decisions, share ideas, plan things and learn new things.

What makes you a great leader?

Ethan Perry: I'm a good person and make good choices. I encourage people to be good.

Annalise Haigh: I am a good leader. Public speaking to others is important, and to be responsible and respectful to others. I am also a great at teamwork with others and Down Syndrome Australia helps me with the program they run during with Zoom with Liz and Claire and others too.

Jerry Richter-Nguyen: I believe I am a great leader because of my will to try new and challenging things and “can do attitude”. I try to live a happy, fulfilled and meaningful life. My biggest contribution to leadership is my outgoing personality and interest in others. I talk to anybody and have introduced my family to many people.

Joseph Salt: I really enjoy being around people, and taking an active role in bringing people together; uniting them. As individuals we can strive for excellence but together we can be amazing.



I have to stand up for any issues and things I think are important, be more of an advocate.

Annalise Haigh



What excites you about going to Congress?

Mia Johnston: I feel positive energy, and am excited to be studying to be an ambassador. I am a little bit excited to fly to Brisbane, and see my best friend Owen.

Ethan Perry: Doing activities with my friends. I would like to be on stage talking to everyone.

Jerry Richter-Nguyen: Everything about it! Travelling there, meeting people, showcasing what I can do, inspiring others and waiting to have a dance with Liz!

Joseph Salt: Learning from others and having fun being involved in all the activities.



ff I want to be a good leader and show others that they can try to do new things. I want everyone to know that they can be treated the same.

Ethan Perry



What does this scholarship mean to you?

Ethan Perry: It is special because I get to tell everyone my message and I get to be a leader and learn more. I want help everyone understand how to treat people with a disability. I want to be treated the same as everyone else.

Joseph Salt: It is a chance to meet new people from all over the world and show them how awesome Australians are. It is an opportunity to learn new skills throughout the program, give back and serve my community and develop as a leader.



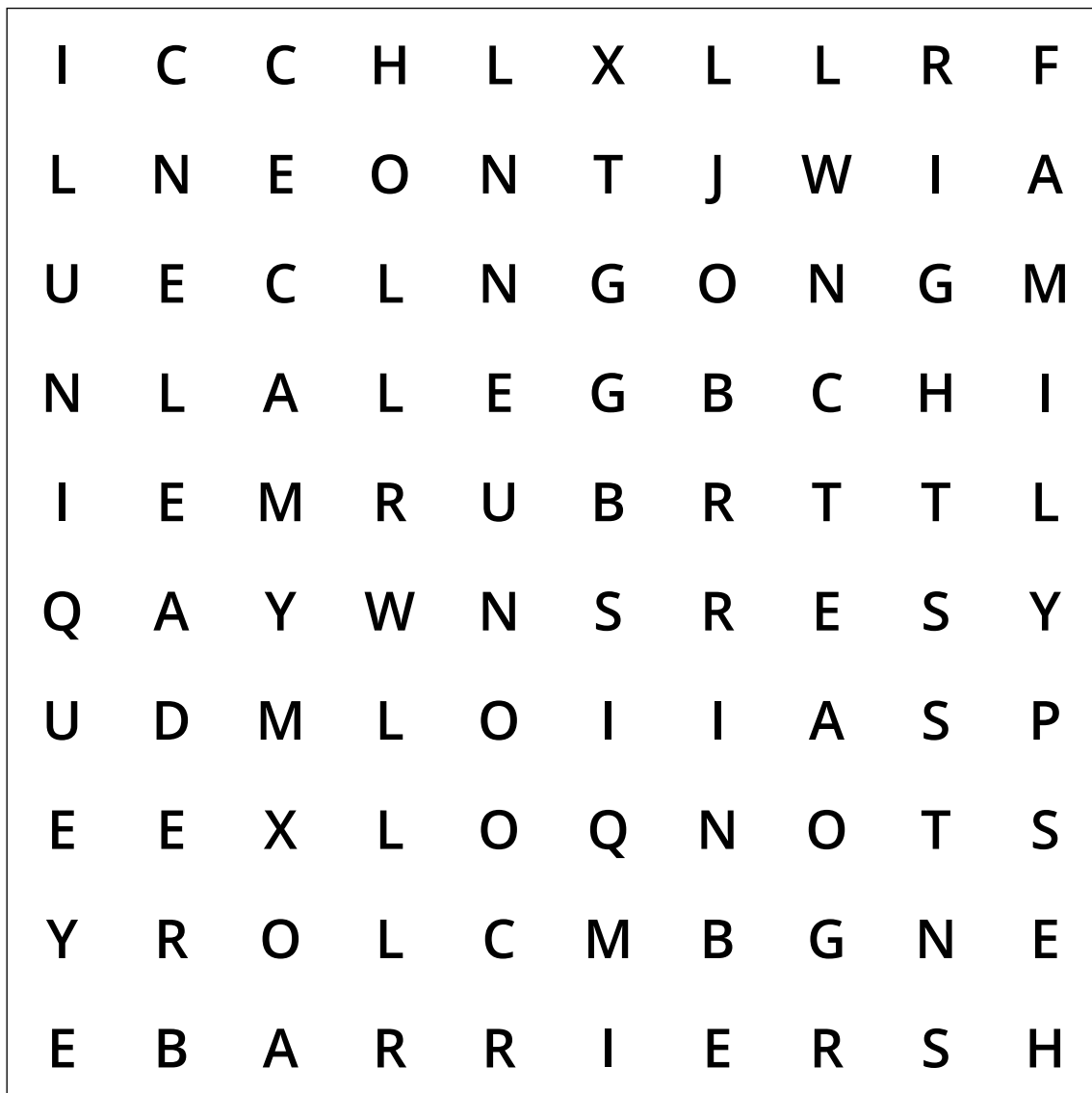
ff As individuals we can strive for excellence but together we can be amazing.

Joseph Salt



Find a word

Can you find the ten words listed below? They could run in a straight line down, across or diagonally.



celebrate

family

learning

inclusion

rights

barriers

congress

leader

unique

job

I'm loving it



With Trent Potter

Celebrate T21 Ambassador Trent Potter has been busy with public speaking events for Harmony Day and World Down Syndrome Day. We ask him about public speaking, and the things he's loving at the moment!

Tell us about the Celebrate T21 events you've been speaking at.

I spoke at Mt Keira public school. The school kids and the teachers did dancing and so did I. We talked about Down syndrome and how I thought Down syndrome was "dance syndrome". Everyone had odd socks to celebrate World Down Syndrome Day.

What do you enjoy about public speaking?

Meeting new people. Learning a lot about new things

Photos by Stephanie Rodden from Celebrate T21

Do you find it challenging, and how do you overcome those challenges?

I sometimes find it hard say to the right words properly and sometimes it's hard for people to understand me. I practice at home all the time. I repeat myself when people don't understand, and go a little slower.

What messages do you think are important to share about living with Down syndrome?

Down syndrome is a learning disability and sometimes I don't speak properly or I say the wrong thing.



Now for the fun bit! Favourite movie right now?

I'm a big fan of superhero and car movies and I currently have two fav movies. One of them is *Fast and Furious* because of the cars and the backstories of the people, and the other is *Avengers Endgame* because they have a lot of superheroes in there. My favourite is *Captain America*.

Favourite book

Captain Underpants

Favourite hobby

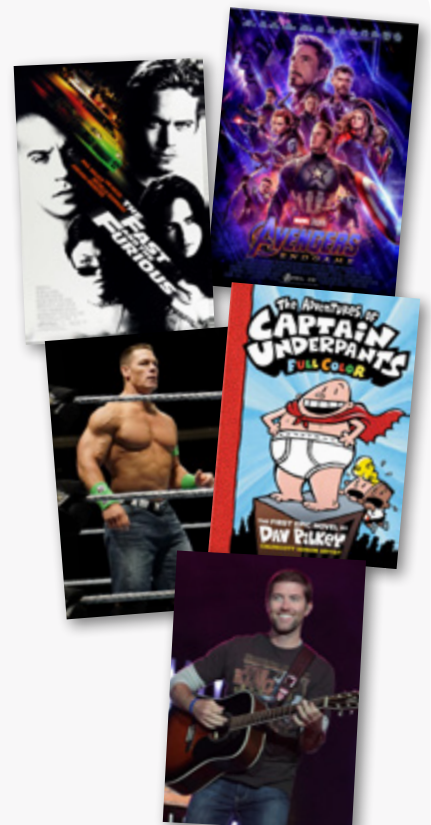
Vlogging

Favourite TV show

WWE wrestling. My favourite wrestler is John Cena and I like the back stories of the wrestlers and watching the matches to see who wins and who loses.

Favourite song

"Your Man" by Josh Turner. The song is saying that I love you so much and I want to be with you and I feel that way about my girlfriend.



Out and About

Conferences, social outings, workshops, and of course World Down Syndrome Day! It's been a busy start to the year across the country.

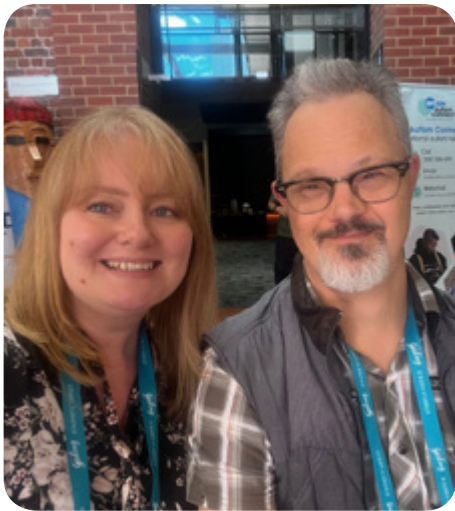


Left: DSA Health Ambassadors Emily and Amelia at Melbourne University in April to speak to nursing students about inclusive communication. **Right:** Employment Ambassador Charlotte advocating for the rights of people with Down syndrome in Melbourne as part of the NDIS participant reference group in February.



Left: In February, DSA CEO Darryl and the Advocacy team – Rachel, Erin and Alyssa (with team mascot, Aura the dog) got together in Melbourne to plan our important advocacy work. **Right:** DSA Senior Advocate Rachel (right) with ten-year work award-winner Holly and her mum at Jobsupport's 2024 Award Ceremony at Sydney's Shangri-La in February.





Left: DSA Health Ambassador Rohan and Project Coordinator Gemma at the VALID conference in Geelong in February. The VALID conference is an important annual event for people with disabilities. It's a time to connect, learn new things and actively take part in delivering the event. **Right:** Self-advocate Matt doing a solo presentation at the VALID Having a Say Conference 2024 in Geelong in February. Matt also ran the Community Participation workshop.



Left: Self-advocate and DSV Advisory Network Chair Matt, with DSV Adult Support Manager Debby and DSA Project Coordinator Gemma at the VALID conference in Geelong in February. **Right:** DSA Health Ambassador Naomi presenting on health equity to the UN for the 13th World Down Syndrome Day Conference in New York in March.



Left: DSA Health Ambassadors Olivia and Rohan outside Royal North Shore Hospital in Sydney in February. They presented on inclusive communication to doctors, nurses, allied health practitioners and medical students. **Right:** DSA Health Ambassador Olivia speaking to over 1000 people at the annual DSC NDIS conference in Sydney this March.

World Down Syndrome Day



Down Syndrome QLD: Queensland celebrated WSD for a whole week, starting with a gala in Townsville on 16 March and ending with the Everton Park Neighbourhood Day and Easter Hunt on 24 March. They served DSQ Brew coffee at Parliament House and lit up Government House to raise awareness. So many photos and wonderful memories; 2024 was one of their best celebrations yet!



Down Syndrome WA: Down Syndrome WA organised a range of events for their community, including a morning tea, family picnic and stakeholder gatherings, ensuring everyone could join in the fun!



Down Syndrome VIC: Families in Victoria had a blast at Werribee Open Range Zoo on 24 March. They enjoyed live music, magic shows, safari tours, and much more. It was a fantastic chance for families to connect with others while having fun. Down Syndrome VIC also enjoyed a delightful morning tea hosted by Minister for Disability, the Honourable Lizzie Blandthor, at Parliament House.

Down Syndrome TAS: School children taking part in "Lots of Socks" for World Down Syndrome Day.





Advocating for change in the Capital!

World Down Syndrome Day 2024 saw DSA back in Canberra! Team members Rachel Spencer and Erin Papps tell us what happened.

The events we hosted at Parliament House and attended at Government House gave us a great opportunity to advocate for change, increase awareness, celebrate and connect, and increase skills and confidence.

Let's take a look at each of these areas and hear what our team got up to.

Advocate for change

DSA works hard to make change in policy, in society and in the lives of people with Down syndrome. Key advocacy areas include education and employment. Our Parliament House Breakfast event on 21 March focussed on ending discrimination in schools and workplaces.

The Minister for Social Services and Assistant Minister for Employment attended and spoke.

Our CEO Darryl and ACT team member Charlotte met with the Assistant Minister for Employment Andrew Leigh and encouraged the government to develop a roadmap for inclusive employment. We want the plan to include fair pay and working conditions.

We met Western Australian Senator Jordon Steele-John, a disability advocate. We talked about barriers people with Down syndrome face.

DSA Health Ambassador Olivia said: "one of the greatest challenges that we face is people's attitudes." She explained that people with Down syndrome have the right to make their own health decisions.

Andrew, Down Syndrome WA's Advocates Network Chairperson was excited to meet Jordon. He said education and health systems are the areas people experience the most discrimination in WA. He said children with disability should get the opportunity to go to their local school.

We also met with the Minister for Social Services' Advisor, Jaimee Hunt. Darryl talked about:

- The Disability Royal Commission
- Priorities for the Minister
- How DSA can help the Minister and the Department of Social Services.

Our self-advocate Michael Cox asked about how people with disability will be involved in putting the recommendations in place.



Increase awareness

Being in Canberra, meeting with ministers and government staff meant we got to make people more aware of the strengths of and challenges faced by people with Down syndrome. Having our self-advocates involved in all the meetings and events helped us end some of the stereotypes.

DSA shared lots of posts on social media about WDS. People enjoyed seeing photos and reading the messages we took to Canberra. Thanks for liking, sharing and commenting, and helping get our message out there.

Celebrate and connect

Governor General Sir David Hurley and his wife Linda Hurley hosted an afternoon event at Government House. A great chance to relax and celebrate while sharing key messages.

A great thing about bringing DSA team members together is the time we spend chatting and connecting over meals, coffee and in transit.

Our State and Territory member organisations also celebrated with some great events that saw people connect across the country.

Increase skills and confidence

Self-advocacy is about speaking up for yourself and other people. Our self-advocates from across Australia bring a range of skills and experience to our work. Being well supported and prepared, and being together, means we all learn from each other.

Thank you to everyone who travelled to Canberra and those behind the scenes who helped bring us together. We have collected feedback from all involved. If you have ideas on how we could celebrate WDS next year, please email Lyn admin@downsyndrome.org.au



World Down Syndrome Day – Easy Read



Down Syndrome Australia went to Canberra for World Down Syndrome Day.

The events gave us a chance to:

- Advocate for change
- Increase awareness
- Celebrate and connect
- Increase skills and confidence



The breakfast event at Parliament House was about ending discrimination in schools and workplaces.



DSA self-advocates met with government ministers and staff. They talked about barriers they face and ways to make things better.



Being in Canberra gave people a chance to catch up and celebrate. It also helped us build our skills in self-advocacy and speaking up.



Thank you to everyone who helped make World Down Syndrome Day a great one.

If you have ideas for next year, email Lyn

admin@downsyndrome.org.au

DSA board welcomes new member!



Earlier this year, Down Syndrome Australia welcomed new members to the board. One of them is Gemma Namey, a mother of two and an experienced lawyer who has worked with clients with intellectual disability, including people with Down syndrome.

She tells us about her background and what she's excited to contribute to the DSA board.

Tell us about some of your background and experience.

I'm a lawyer, and I currently advise the Cabinet Office in the NSW government. I've been a government lawyer for over 10 years. I provide advice to the premier and ministers on different matters. I really like it because involves cutting edge policy and legal issues, and the politics of the day.

Before I joined the government sector, I worked in the community legal sector. I had an interest in disability law. I worked at the Intellectual Disability Rights Service, a NSW Community Legal Centre for people with intellectual disability.

I have two girls, and my eldest, Isabelle, has Down Syndrome. She's nine-and-a-half, and in a mainstream school with her younger sister, who's in year one.

What drew you to join the DSA board?

The organisation has a lot to offer. It's a critical time with the large number of reviews happening at the Commonwealth level into the NDIS and Royal Commission.

There's some real opportunity for fundamental changes in government policy. I want to share my skills in governance and law with the organisation.

When Isabelle was born, I said to my partner, it's the best time to be born with a disability because the NDIS was being introduced, and community attitudes were becoming more accepting. There's still a long way to go, but I think the support is there and the NDIS is here to stay.

What are you excited to contribute to the board and mission?

I have a particular interest in governance. I will assist in making sure the organisation has the right policies and procedures in place. I also have a strong commitment to human rights and want to continue this focus of the organisation in guiding its advocacy work.

What do you feel are the important issues facing people with Down syndrome?

Education continues to be a real issue. The Royal Commission was divided on the question of segregated settings, but they were united in saying that more needed to be done in making mainstream schooling more inclusive.

I would like to see the end of segregation. The evidence shows that everyone does better when each child is learning alongside their peers.

There's also work to be done in terms of schools equipping people for employment. The employment levels of people with disability are generally much lower compared with other parts of the world.

The importance of work is undervalued. It's not just about economic participation. It's also about connections with community, and having relationships outside of your immediate family or other people with Down syndrome.

How would you like to see DSA evolve over the next few years?

I would like DSA to be seen by government as the leading voice for people with Down syndrome across Australia. I'd like to see the organisation set some of the agenda with government, especially around the recommendations from the Royal Commission.

I think we need to work closely with our states and territories and continue developing those relationships.

I'd like to see us continue to help improve the lives of people with Down syndrome – particularly things like employment levels, and more children being able to attend the school they want to attend.

Our Voice



Australian Capital Territory

In late 2023 we changed our name to ACT Down Syndrome & Intellectual Disability. This name change enhances our commitment to promoting and supporting inclusivity across the ACT and reflects our mission to advocate for and support people with Down syndrome, people with Intellectual Disability and their families.

In March we celebrated World Down Syndrome Day at a breakfast at Parliament House and afternoon tea with the Governor General. Minister for the NDIS, Bill Shorten visited our member Charlotte Bailey at work at Eastlakes Gungahlin where she spoke to him about the need for NDIS plans to support people with Down syndrome in mainstream employment.

In addition to our current groups, we created an Inclusive Dance Fitness class that runs on a Wednesday afternoon from our office in Pearce.

In April we hosted an all abilities disco and danced the night away with over 100 friends and community members! The Xtreme Stars performed for the crowd and everyone had a terrific night!

Our community was lucky enough to attend a special Q & A screening of the movie 'What About Sal' and met the actors Gerard O'Dwyer and John Jarratt.

We look forward to seeing everyone at World Down Syndrome Congress in Brisbane in July where many of our members will be presenting. Check out the details at <https://wdsc2024.org.au/>

Shannon Kolak

CEO ACT Down Syndrome & Intellectual Disability



Queensland

The proposed NDIS Amendment Bill 2024 will introduce major policy changes to the NDIS that will alter how current or future participants access supports.

In Queensland, the Department of Child Safety, Seniors and Disability Services has engaged Queensland Treasury Corporation (QTC) to work with them and the sector to undertake some targeted early input into the design of the disability foundational supports strategy in Queensland. QTC are working with peak disability organisations which includes Down Syndrome Queensland (DSQ).

Following celebration of World Down Syndrome Day where we raised awareness and support within the broader community, DSQ proceeded to deliver several great initiatives.

- On the back of successful *Relationships Workshops* in Brisbane and Gold Coast, a workshop will be delivered on the Sunshine Coast in the coming weeks.
- MyTime Program cohorts are now operating in Rockhampton and Gladstone and soon to be in Bundaberg.
- ID:8 Consults, QEST Observations & Consultations and Kindy Consults have increased.
- Workshops delivered include: Inclusive Unit Planning Workshop for Educators and PTC with the topic Key Word Sign.
- Possibilities Pathways Program (employment preparation program) has its third cohort underway.

Chris McMillan

CEO Down Syndrome Queensland





South Australia

On behalf of DSA, we would like to recognise the contribution of Sam Roach, who provided information services to SA for just under four years. Sam provided great support for people with Down syndrome in SA, and we want to recognise her contribution to the community.

With Sam's resignation, DSA approached Down Syndrome WA to provide service delivery to the SA community to leverage their experience and connections. We hope to appoint someone on the ground in SA in the coming weeks. If you have an interest in providing casual family support in SA, we would love to hear from you and work with you. In recent weeks we have updated the database for SA families and will be shortly commencing an ENews for the community.

In March this year, the team from DSV presented the Teacher Professional Development day, and followed this with an education day for parents. Nikki Schwagermann, Senior Family Support Coordinator from DSWA, also attended and met families and educators.

DSWA has a family support team that can be contacted via email InfoSA@downsyndrome.org.au. We can offer family support meetings by video link or phone. We will soon be sending a short survey to those families on the database. Please feel free to share this widely among the Down syndrome community in SA so that we can reach as many as possible.

We hope to meet some of you at the World Down Syndrome Congress in Brisbane in July. I will also be visiting SA in late July.

Cassandra Hughes
CEO Down Syndrome WA



Tasmania

Down Syndrome Tasmania is excitedly entering its 40th year of operation this year! To celebrate we had a cake at our annual camp to celebrate and will be offering another celebration at our annual general meeting.

It has been a quiet first half of the year here in Tasmania with lots of planning and discussing fundraising options for our organisation. Our board has been focusing on the strategic planning preparation for the next 3-5 years, we are busily reviewing the member survey responses to guide us in this planning process.

We held our annual family camp at Camp Clayton in February welcoming new and old families, it was a wonderful, relaxing weekend.

Our members got to experience pony rides, bike rides, a guided paint session, a musical sing along by a local Music Therapist, rock painting and ending one of the nights with a disco!

We also held a well awaited relationship workshop (which included speed dating practice!) hosted by the local ladies, and Gemma and Kylie at DSA.

Stacey Jackson
EO Down Syndrome Tasmania



Victoria

A fabulous celebration of World Down Syndrome Day was had at Parliament House Melbourne on 21 March. DSV's Advisory Network employees joined a worldwide call to end the stereotypes to an audience including the Honourable Jacinta Allan, Disability Minister Lizzie Blandthorn, members, families, friends, and DSV staff. It was a wonderful mix of celebration versus highlighting to state government the challenges that remain for people with Down syndrome to live the lives they choose.

World Down Syndrome Day celebrations continued at our annual Family Fun Day event at Werribee Zoo, where over 500 people came together for a day filled with fun, activities, music and connection.

Whilst we look ahead to FY25 with optimism, the excitement for the expansion of additional services and supports in regional Victoria is offset by several significant and successful projects concluding on June 30. This will see some much-loved members of the team finish up at DSV and leave a significant gap in supports and budget. Whilst we will continue to work alongside and advocate with and for people with Down syndrome and families, the breadth of information, services and supports we provide will be restricted by reduced funding.

If you would like to support DSV, there are multiple ways to get involved this end of financial year, including our *Hole in one for T21* campaign or you might like to get behind the *Five Peaks Challenge* team who are tackling Mt Kosciusko this November. You can find out more on our website, downsyndrome.org.au/vic.

Dan Payne

CEO, Down Syndrome Victoria



Western Australia

We celebrated World Down Syndrome Day with three events: a stakeholders evening, community morning tea and the annual family picnic on a glorious sunny day.

The family support team have been busy, with 10 births so far this year in WA.

Down Syndrome Regression Disorder continues to be a major focus for WA. We are working with students and researchers to bring further awareness of the condition and the best way to support families. WA's Regression Support Group welcomes new family members and we have a national pilot data survey underway to collect key primary data to help inform future research and education <https://forms.office.com/r/L07pN7Z9ts>.

The Dementia support group is also active and we are looking at ways to further positive aging in people with Down syndrome.

As a close-knit community, when we lose members, it touches us all, and this year we have lost three members of our community. We pay tribute to Roisin (20), George (9 months) and Aimee Clarke and their families; we feel your loss and recognise the importance of your presence in our membership. We will always be here to support your loved ones and families.

As CEO I recognise the outstanding contribution of the DSWA team, it has been a challenging year, and their commitment to and compassion for our members, and the association, is heartwarming and inspiring.

Cassandra Hughes

CEO, Down Syndrome WA





voice

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