

voice



Advocacy



Down Syndrome
Australia

June 2023



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:

www.downsyndrome.org.au/get-involved/donate/

All donations over \$2 are tax deductible.



How to use this digital edition



How to navigate

You can scroll through and read page-by-page or jump ahead using the contents page.

Jump to a story

Tap or click on the story title you wish to read from the contents page.

Return to contents

Tap or click on the DSA icon in the bottom right corner of any page to return to the contents page.

Open a website link

If the story you are reading contains any links to websites, simply tap or click the link to open in your web browser.



Editorial



Welcome to the latest edition of *Voice* magazine. I'm excited to be stepping in as the new Managing Editor and what an issue we have lined up!

In this issue, we celebrate the power of voices united, as we explore the incredible efforts being made to promote awareness, understanding, and inclusivity for individuals with Down syndrome.

Advocacy is close to all our hearts at Down Syndrome Australia (DSA), so alongside exploring stories of celebration and triumphs taking place in communities around Australia, we're also sharing the changes we're calling for in DSA's new advocacy strategy – Advocacy Asks.

Advocacy plays such a crucial role in shaping society's perception of Down syndrome and ensuring equal opportunities for all. Through inspiring stories, insightful interviews, and thought-provoking articles, we aim to shed light on the advocacy initiatives making a profound impact on the lives of people with Down syndrome and their families.

In these pages, we will meet individuals who have taken up the mantle of advocacy, challenging stereotypes and championing the rights and potential of people with Down syndrome. Their unwavering dedication and tireless efforts are reshaping attitudes, breaking down barriers, and fostering an inclusive society that values diversity.

Together we'll take you on a journey through topics including advocacy in action, accessibility and inclusion, education and workplaces, health and wellbeing, and of course a behind-the-scenes look at some community highlights from World Down Syndrome Day 2023 events (including a surprise visit by Prime Minister Albo!) and checking in with what our state and territory member organisations have been up to recently.

As you navigate through the pages of this edition, we hope you will be inspired by the extraordinary advocacy initiatives taking place around Australia and beyond. Together, let us celebrate the accomplishments, amplify the voices, and contribute to the ongoing progress towards a more inclusive and accepting society for individuals with Down syndrome.

Pop the kettle on and make yourself a cuppa, find a comfy spot and let's dive in!

Mel van Deventer
Managing Editor

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Message from the CEO



This is my first edition of *Voice* since starting as the new CEO of Down Syndrome Australia and it's great to begin with an issue dedicated to Advocacy, which is at the heart of what

we do. I am honoured and excited to be working with such a great team and leading the organisation at this time to build on the achievements of recent years.

We work to create change in social and public policy and to make sure that people in communities around Australia understand the experiences of people with Down syndrome and their families, and we do that with the active involvement of people with Down syndrome.

All of our advocacy work is informed by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which is an international agreement that aims to protect the rights and dignity of people with disabilities. It recognises that people with disabilities have the same human rights as everyone else and should be treated equally under the law. The UNCRPD covers a wide range of issues, including accessibility, education, employment, healthcare, and political participation. It also emphasises the importance of involving people with disabilities in decision-making processes that affect their lives. The UNCRPD has been ratified by over 180 countries, and its principles are used to guide policies and practices that promote inclusion and equality for people with disabilities around the world.

As the national peak organisation for people with Down syndrome and their families, we are recognised by the Federal Government as one of the key Disability Representative Organisations which means that we are invited to provide input and feedback on public policy and issues faced by people with Down syndrome. We leverage the input of our Down Syndrome Advisory Network, our state and territory members, and our

self-advocates in our advocacy work. You will read in this issue of *Voice* about a number of the important issues we continue to engage on with key decision makers including politicians and senior bureaucrats – from the NDIS Review to the Disability Royal Commission, migration and employment amongst many others.

One of the key highlights for me since joining the DSA team was the self-advocacy work that we were able to do in Canberra in conjunction with World Down Syndrome Day. With the support of the Sherry Hogan Foundation, and under the theme of "With Us Not For Us", we facilitated 12 self-advocates and their support people to attend a Parliament House morning tea in Canberra for World Down Syndrome Day (that the Honourable Prime Minister Anthony Albanese dropped into!), face-to-face meetings with ministers and department staff and a self-advocacy forum.

We also worked with our self-advocates to create our Advocacy Asks document outlining our key advocacy asks. At the Parliament House morning tea, and in separate meetings with ministers and departmental staff, the self-advocates had the opportunity to discuss our advocacy asks. In particular, Minister Bill Shorten and Minister Amanda Rishworth spent considerable time talking with the self-advocates.

Feedback received from our self-advocates and their support people was positive in relation to the respect and engagement they received from ministers and department members as they shared advocacy asks. Our self-advocates felt listened to and that their conversations would lead to positive outcomes for people with Down syndrome and the broader community of people with disability.

I hope you enjoy reading about the important advocacy work that is happening across Australia and I look forward to working with our members, partners and supporters to continue making a positive impact in the lives of people with Down syndrome. Thank you for your ongoing support of our work.

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

Darryl Steff
CEO, Down Syndrome Australia

DSAN update

When it comes to advocacy, our Down Syndrome Advisory Network (DSAN) are always eager to prepare and share their voice on important topics and issues facing people with Down syndrome, disability and the wider community.

In this edition of *Voice*, DSAN member Jenny Bowden shares with us why it is important for people with Down syndrome to be self-advocates, and some important issues for people with disability, along with some highlights from celebrating World Down Syndrome Day in Canberra which Jenny attended.

Self-advocates get up to lots of important advocacy work across the year. When we asked Jenny what she's been up to recently, she spoke of how she voted in the State and Federal elections last year. "It is important for me to have a say. I want to choose a government that looks after people, especially disadvantaged people and also to choose a government that will look after the environment."

"I like to make decisions about what I do in my life. It is really important to me to have opportunities to make new friends and to follow my passions e.g. singing in a choir, dancing, drama, keeping fit. I also really enjoy being able to socialise and be in the community independent of my family. My parents help me to achieve this. I volunteer in a Red Cross Op Shop and I like being helpful to other people in the community. It makes me feel happy that I can do things to help".

"When I go to the doctor, dentist etc., I like to speak for myself and have the doctor talk to me in ways that I can understand. I want to be listened to. I like my parents to help me. It is very important to have support to advocate for myself."

Jenny also shared about some important issues for people with disability that our DSAN members often discuss, including "Community access – I have friends in a wheelchair and they need support to have access in the community. E.g., make sure there are ramps



– the government needs to support this. Health and Wellbeing and Mental Health – we need good information about how to have a healthy lifestyle and we need support to achieve this. We need good and informed health services for people with a disability".

Jenny believes it is important for people with Down syndrome to be self-advocates, "It is important to speak up and be heard. We have a right to have choices and lead a full life". When it comes to advocacy and speaking up, Jenny advises practising speaking up for yourself, get to know your rights and find support to help with these things.

Reflecting on World Down Syndrome Day in Canberra, Jenny said "the best part for me was meeting Bill Shorten at Parliament House. I was able to tell him what a difference the NDIS has made to my life. I told him that the NDIS has made it possible for me to do a lot more things in the community and to be more independent. I said thank you, but please don't cut the NDIS."

"I also really enjoyed going to Government House and meeting the Governor General and his wife."



At Down Syndrome Australia, we work to influence social and policy change and provide a national voice for people with Down syndrome.

Our Advocacy Approach.

Our approach to advocacy is a mix of proactive and reactive work, we are flexible and dynamic. Our approach is informed by our values of inclusion, collaboration, trust and respect. We proudly:

- ensure people with Down syndrome are at the centre of our work
- support people to make choices, build self-advocacy skills and take on leadership roles
- work in partnership with government, disability representative organisations and the broader community
- collaborate with our state and territory members to advocate for issues that are important to people with Down syndrome in Australia



At our World Down Syndrome Day morning tea event at Parliament House on 21 March 2023, we launched our revised Advocacy Strategy and Advocacy Asks.

We are asking the Australian Government to act on six key areas to ensure the rights of people with Down syndrome and their families are realised. Our asks in these areas will continue to be informed through consultation with people with Down syndrome and their families, and input from our state and territory member organisations.

As a well-recognised and highly regarded organisation we will continue our advocacy work that makes change and contributes to us achieving our vision.

You can access our full Advocacy Asks document and Easy Read summary here:

www.downsyndrome.org.au/advocacy/

“ We face barriers to being involved. Sometimes we don’t get the support we need. But when we are supported, we can make a big difference. ”

Claire Mitchell, Board Member



Our Advocacy – Easy Read



Down Syndrome Australia is the national voice for people with Down syndrome in Australia.

We are called DSA for short.



We want people with Down syndrome to

- be valued
- be included
- reach their potential.



DSA wants to make things better for people with Down syndrome.



DSA does advocacy work to make changes to laws, services and the community.

Advocacy is speaking up to make things better for people with Down syndrome.

How we work



People with Down syndrome are at the centre of our work.



We support people with Down syndrome to:

- make choices
- build self-advocacy skills
- become leaders.



We work with:

- the government
- other disability organisations
- people in the community.



On World Down Syndrome Day we asked the government to make changes to

- Prenatal screening
- Health
- NDIS
- Education
- Employment
- Migration.

We will work hard to make this happen.



Advocacy in the Capital

By Rachel Spencer, Senior Advocacy Manager

On March 21, Down Syndrome Australia hosted a morning tea at Parliament House in Canberra to celebrate World Down Syndrome Day and to raise awareness of the issues on which Down Syndrome Australia is advocating for at a national level.

Our guests got a real surprise when Prime Minister of Australia, Anthony Albanese, popped in to watch the presentation!

After the presentation, our ambassadors had the opportunity to meet and speak directly with the Prime Minister alongside Bill Shorten MP, Amanda Rishworth MP, Tania Lawrence MP, Libby Coker MP, Luke Gosling MP and Dr Mike Freeland MP who also attended the event.

The DSA team, alongside self-advocates, made the most of our time in Canberra by meeting with several ministers and government department staff to further discuss our Advocacy Asks. We met with:

- Minister Shorten
- Minister Rishworth's Advisor on Disability
- Minister Giles
- Department of Education staff
- Matt Wright, Stakeholder Engagement NDIA

Ministers are very busy while Parliament is sitting in Canberra; a lot of advocacy went into securing these meetings and a lot of effort went into our preparation. When you get thirty minutes with a minister, you need to make the most of every minute!

Our keys to success in the Capital

All meetings included self-advocates with Down syndrome, family advocates, DSA Board and staff members. This meant we could share a range of issues and ideas related to our key areas of Prenatal screening, Health, NDIS, Education, Employment and Migration.

All team members were briefed on DSA's position in a key area. Self-advocates with Down syndrome were well supported to ensure they were able to share their own experiences and messages. Preparation is key and often includes:

- Supporting self-advocates to understand the context and purpose of the meeting, who will be attending and what it might be like.
- Having several conversations to support self-advocates to develop their key messages.
- Participation support on the day to ensure people have their say.

Messages from self-advocates

While preparing for World Down Syndrome Day, self-advocate Jenny said "I really want to meet Bill Shorten. I have a question for him about the NDIS."

On the day Jenny got a chance to meet and ask the minister, "Are you going to keep the NDIS? The NDIS has made a huge difference, please don't cut it."





While Minister Shorten was slightly surprised by a question that was accompanied by a compliment, he assured Jenny that the NDIS is here to stay and that they are working to make it better.

The DSA team had other opportunities to raise issues with the NDIS and share ideas on how to make it better. A common issue that is raised about the NDIS is the planning process, and how it does not include people with Down syndrome and other intellectual disability well.

Lauren said...

“People need to be included and involved in making the decisions in their plan. Preparation before my NDIS meeting with my plan coordinator and my family help me to go into the meetings prepared and knowing what I want. People with Down syndrome should be supported to help other people to learn about the NDIS and making their own decisions.”

Self-Advocacy Forum

DSA also held a self-advocacy forum, where people with Down syndrome from all over Australia came together to:

- ✓ Share what was good about World Down Syndrome Day 2023 and ideas on how to make it better next year.
- ✓ Learn about Australia’s Disability Strategy and talk about how the government can improve community attitudes.
- ✓ Continue to build leadership skills and mentor others.

To end the forum, we did a breathing exercise and discussed connection. A common theme among self-advocates and supporters was the value of connecting in person. It allowed people to make new friends, build more respectful relationships and contribute to discussions around our advocacy work. We acknowledged and are thankful for the funding provided by the **Sherry Hogan Foundation** for making the forum possible.

Taking on New York City

Thanks to many who generously supported Kylie Scott, she was able to join other self-advocates from around the world on 21 March 2023 to celebrate World Down Syndrome Day at the United Nations in New York.

While in New York, Kylie presented at the UN Convention on the Rights of Persons with Disability (UNCRPD) about legal rights, decision making and easy-to-understand communication. She did an amazing job!

This year's WSD message was 'With Us Not For Us', which is key to a human rights-based approach to disability.

Down Syndrome International is committed to moving on from the outdated charity model of



disability, where people with disability were treated as objects of charity, deserving of pity and relying on others for support.

A human rights-based approach views people with disabilities as having the right to be treated fairly and have the same opportunities as everyone else, working WITH others to improve their lives.

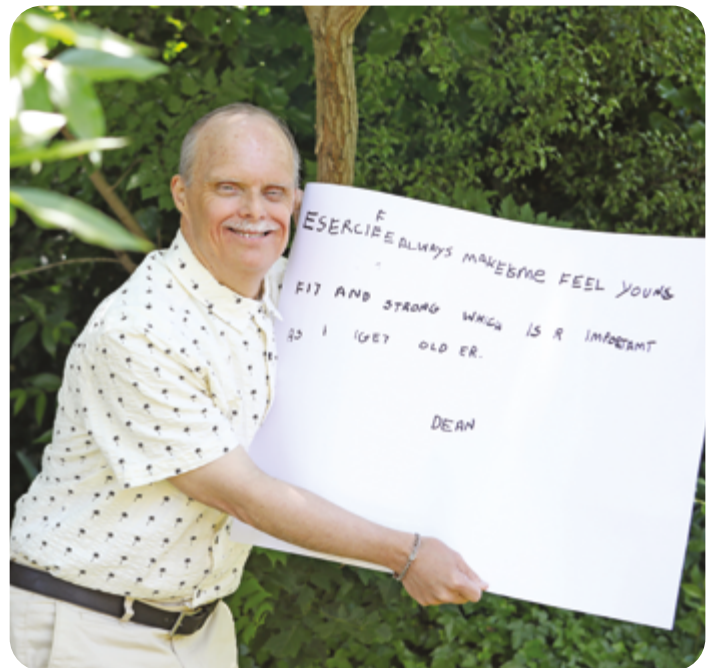
It was an exciting but exhausting week for Kylie with her support person as they walked and walked the streets of NYC, visited many famous sites and saw two Broadway shows!



Our messages for WDSD 2023

For World Down Syndrome Day this year, we asked individuals with Down syndrome what advocacy messages they would like to share with the world. Here are some of the highlights.

Images by Lisa Clarke



Top left to right: Hannah and Isla, SA, Dean Whettenall, ACT. **Bottom:** Joanna and Justin Moran, QLD, Charlotte Roach, SA.



Top: Waiata Johnson, WA. **Bottom:** Rachel Freeman, Tasmania.



Top: Jackson Barnswell, ACT. Bottom: Lisa Tiernan, NT.



Top: Lauren Murray, ACT. Bottom: Joshua Firrel, QLD.



Top: Charlotte Bailey, ACT. **Bottom:** Finn Hilder, TAS.

Technology is life

Interview with Ruth Faragher, Queensland Down Syndrome Advisory Network (QDSAN) member.

We reached out to Ruth Faragher – member of the Queensland Down Syndrome Advisory Network (QDSAN) and committee member of the World Down Syndrome Congress 2024 (WDSC2024), for some insights into this important area.

Accessible technology for Ruth includes things like using a smartphone or iPad for social media and getting in contact with family and friends, using Telegram X for sharing photos, using a computer or iPad for learning and at school, and Google Chromecast to TV. She also enjoys using PlayStation and games like Minecraft, as well as staying in touch with friends around the world through Facebook messenger chat. These digital technologies help Ruth stay connected to her community and are a vital part of her wellbeing and independence.



Technology assists Ruth in her day-to-day life, for example, using the Uber app to get around, using her smart phone for public transport timetables and other essential information. Ruth shared with us that she believes it is important for technology to be accessible for people with Down syndrome and all people with a disability. Like everyone, they rely on technology for so many things and Ruth believes teaching people with Down syndrome how to use technology is essential to making it more accessible.

Ruth participates in regular online meetings with the QDSAN and WDSC2024 committee which are held on Zoom, a meeting technology she finds to be accessible. Challenges she has experienced in using digital technology include things like learning newer platforms (e.g. Microsoft Teams) or when the internet drops out during meetings!

People with disability have a right to access technology. Access to new technology, especially digital communication technology, is an enabling right for people with disability because it is critical to the enjoyment of a range of other civil, political, economic, social and cultural rights.

Australian Human Rights Commission

Improving the NDIS experience

Down Syndrome Australia (DSA) is pleased to see that the recent Federal budget announcement included an investment of more than \$720 million over 4 years from 2023-24 to fund reforms to lift the NDIA's capability, capacity and systems to better support NDIS participants.



We understand that the Government and the NDIA are committed to undertaking the detailed design and implementation of these reforms through a co-design process in conjunction with National Disability Representative organisations such as DSA. We continue to advocate for a number of key changes to the NDIS to ensure that it can better support people with Down syndrome. These measures are a step in the right direction but further change is needed.

DSA's CEO, Darryl Steff, also commented regarding the community response to the proposed growth moderation targets – "We understand and share the concerns of our community and the broader disability sector regarding the uncertain impact of the recently announced NDIS reboot and the 8 per cent target to moderate Scheme growth by 2026. It is important that the conversation moves away from focusing purely on the cost of the NDIS and also discusses the benefits and returns of the investment that has changed thousands of lives for the better."

We look forward to working with Minister Bill Shorten, his team and the NDIA through the co-design process to ensure that the reforms meet the needs of our community.

We asked Claire Mitchell, DSA Board Director and member of Queensland Down Syndrome Advisory Network (pictured), to share some reflections on her NDIS experience.

Why is the NDIS important for people with Down syndrome?

My NDIS plan gives me the opportunity to access supports which assist me to be more independent and lead a fulfilling life. All Australians with intellectual disabilities have the right to have access to appropriate support through the NDIS which enables people to have a better quality of life.

How was your experience applying to join the NDIS?

I believe it is important that I know what is in my plan and for me to be involved because I want ownership of my life and I also want my voice to be heard. Mum supports me through the NDIS process. In the beginning she attended workshops and collected information materials and we followed some of the strategies to involve me. For example, we created a picture of all the areas of my life, we drew up a diary of everything I do in my life, and because I prefer to write things down, I wrote my story about what I do and don't like and what is important to me, what I find difficult and what type of support I want. I have attended every meeting and we request the meetings to be face-to-face and my involvement has increased over time.

How does the NDIS support you in your daily life?

Through the NDIS, I have supports in place that allow me to live the life that I choose. I lead a happy and fulfilling life that includes all the things that are important to me, such as having a job, being involved in my community and my family and friends. My independence has increased since I became an NDIS participant and that is very important to me and my family.

What could the NDIS do better for people with Down syndrome?

I think they are trying to get it right but the NDIS could learn more about living with intellectual impairments, like Down syndrome, and to follow guidelines that are recommended like the 'Listen, Include, Respect Guidelines'. People with intellectual disabilities all have different needs and the appropriate supports need to be put in place for people to be involved in their planning. The system needs to be set up to offer information and plans in easy-read formats and meetings need to allow people time to process the information and focus on the person to ensure that they feel included and understand what is being said.

What advice would you give to people with Down syndrome who are thinking about applying to join the NDIS?

My advice is to firstly create a very clear and very detailed picture of your life. To list your priorities and to decide what is important to you. Secondly, you need to have good support, there is a lot to take in and understand. For me, good support involves a lot of discussions and looking at the details of the decisions I need to make and allowing me time to process what has been discussed. Also be patient and have confidence.

The National Disability Insurance Scheme (NDIS) was established to provide individualised support for eligible people with permanent and significant disability, their families, and carers.

On the DSA website, you can find information about how the NDIS works and key links and resources to use. To learn more, visit:

www.downsyndrome.org.au/resources/ndis/

If you need assistance, you can get in touch with Down Syndrome Australia via phone **1300 344 954** or email **info@downsyndrome.org.au**

If you'd like to learn more about the NDIS or apply to join, visit: **www.ndis.gov.au**

Advocating for meaningful work at full pay

By Cassandra Hughes, CEO, Down Syndrome WA

Life is meaningful when we are nurtured, supported and independent and where we have an ability to choose the life we want. Employment provides us all with the opportunity to grow, to learn, to socialise and to earn. Earning provides us the opportunity to make choices for our life that require income, to participate in the community, buy a home, and to travel, being just a few. This is essential to our success as people, and employment is key. Advocating for the right to work for our members is pivotal to successful engagement.

Advocacy does not always look a particular way. We don't have to be sitting at a table full of suits, pressing our case. Sometimes, it is more likely that we are advocating 1:1 with an employer, introducing them and supporting them to understand employing people with Down syndrome and then advocating for each individual that we seek to place in open employment.

Finding the skills and talents unique to every employment candidate has been the key to the success of the appointments, then matching them with an employer who shares the same values and enthusiasm. It is also important that the tasks and role an individual is matched with, offer our candidates opportunities to utilise their skills.

Advocacy in its true sense is a process to support a cause, and by carefully advocating for each individual in open employment, we are, step-by-step, advocating for broad systemic change to the way we employ all people. Advocacy by its nature is not easy, or short lived, it is an ongoing process to ensure that the rights and dreams of candidates are met, and more importantly embraced.

In Western Australia, our employment program has continued to grow. We have focussed our attention on understanding our candidates' strengths and interests, while ensuring we understand any challenges they may face. Understanding the challenges provides valuable insights that help us to make the right connections for them. The program has been very successful, however not without its failures and challenges. The goal will always remain that our candidates are supported in their employment until, and only until, they are capable of working independently on meaningful, rewarding tasks that meet and develop their skills and provide them with challenges and growth.

Here are some of our recent employment stories.

Brayden

Brayden was impacted by the decision last year that his employer of 15 years would close. With concern for what the future might hold for Brayden, Down Syndrome WA (DSWA) worked with Brayden and his family to find a suitable role. Now working at Wire Aid in the factory producing and packaging their handwoven, steel hose restraints and stockings, which are critical safety products in the mining and industrial areas, Brayden is thriving.

Deeply enthusiastic, warm, and friendly, Brayden commenced at Wire Aid four (4) days per week. Brayden has been exposed to a range of tasks trying several tasks in the production and packaging areas. Over time, Brayden's workdays changed to three (3) days per week, to better suit his and the employer's needs. Through a process of trial and test, his strengths and areas for genuine growth were identified.

Brayden currently packs large industrial products, sorts them by code and prepares them ready for despatch. He is now working on producing labels for the products with the support of his mentor, who assists by producing Easy Read procedures to improve the ease of the task.

We have worked closely with the employer through advocacy via our DSWA mentor and Employment Coordinator, and in doing so, identified that with additional practice and development, Brayden would be able to participate in a greater range of tasks.

Brayden is a highly valued member of the Wire Aid team. His warmth and humour are appreciated by the team, as is his willingness to learn and try new skills. When asked, Brayden shared his love of his new role and being included. "I love working here, with the guys".



Jack

Jack works at The Boxman, a Perth company manufacturing cardboard boxes and other products. This is a long-established business with a sales team, office and factory/warehouse team.

The key to supporting Jack in his role was creating and implementing effective tools and procedures, to allow Jack to use his strengths and minimise challenges. Jack works in the showroom, stacking shelves and ensuring product is available for sale, as well as in the factory, packing boxes from individual items on large pallets to retail packs that suit customer needs.

The Boxman team reached out for support and ideas to find ways to change their procedures, reducing the reliance on high numeracy skills and finding out ways that tasks could be completed. With Jack's employment mentor, they changed their systems from counting to have a physical measure that allows Jack to pack products effectively and very efficiently.

Jack too, has had the opportunity to try other tasks and has excelled at working on one of the cutting machines, which means lifting large and cumbersome sheets of cardboard, carefully placing them on a table and setting the machine to run and cut the product. The use of colours and symbols allows Jack to complete the task of operating the machine, and starting and stopping the process without support. Jack is currently working two days a week – one day with a mentor and one day fully independently.

Both Jack and Brayden have excelled in their new roles. The key to the success of the program has been the advocacy with the employer and the individual one-on-one work with the candidates.

Working together to make inclusive schools a reality for all

By Queensland Collective for Inclusive Education, with edited contributions from Shalee Gregson-Quinn and Natalie, Lilly, and Bella Terry-Bedwell

On Wednesday 26th October 2022, Queensland families and allies rallied outside Parliament House calling for 'Inclusion NOW!'. The rally demanded that the Queensland government and Education Minister honour its own policy by committing to genuine inclusive education reform.

The rally was organised by the Queensland Collective for Inclusive Education, a group of parents who advocate for their own children's inclusion, support each other, and work together to make inclusive schools a reality for all.

The rally heard from people with disability, parents, academics, advocates and siblings of current students with disability, on their hopes for inclusion, current systemic failures and the actions needed to ensure every student's human right to an inclusive education is upheld.

Shalee Gregson-Quinn, a mother of two from Central Queensland, spoke to the rally.

"If my youngest, Violet (age 8), who has Down syndrome were able to self-advocate, she would love to be speaking here for herself. She is a confident self-advocate in our home and an enthusiastic participant in the organised chaos that is family life. She is also clear about her desire to be educated amongst her peers – learning, having fun, being challenged to explore her potential. Our family are fortunate to belong to a school that values diversity and supports Violet's inclusion, but I am here today because EVERY student in Australia has a fundamental right to be included, welcomed, and supported at their local school, without question. That is the non-negotiable heart of a true, well-funded and holistic inclusive education system.

Violet and all children deserve the same education opportunities – the unchallenged right to enrol at the school of their choice, access to a rich curriculum delivered alongside same age peers, those with and without a disability. Where the education resources that



Left: Shalee Gregson Quinn – Rally Speaker and Violet's mother. **Right:** Violet and school friend.





Left: Violet Gregson-Quinn and friends. **Right:** Archie Terry-Bedwell, inclusive education advocate and son of Natalie and Wade.



are currently split between mainstream and special settings are finally combined to create a learning environment where **every** child's learning and support needs are expertly recognised and accommodated, just as Queensland's inclusion policy promises.

We are here because the cost of inaction is high. Too many students with disability are turned away from their local schools or can only attend minimal hours, adjustments are not provided, and students are denied access to the same learning, playgrounds, camps and opportunities other students get automatically. Our students deserve better. By perpetuating the idea that disabled people belong in segregated spaces, we teach the next generation that people with disability are less than and limit their ideas of what disabled people can achieve. We send the message that difference is something to be hidden and we deny children the opportunity to be educated alongside their disabled peers who have so much to offer."

Natalie Terry-Bedwell and her husband, Wade, also attended with their seven children, including son Archie, age 7 who has Down syndrome and friends.

"Our family's wish is for our children to enjoy rich full lives, with social value, employment, independence and all the same opportunities and experiences as each other, whether they have a diagnosis or not. It doesn't define them; it doesn't limit them. We value their voices, we value their human rights, and we value inclusion.

Inclusion is messy, parenting is messy, it's not about perfection or ego. It is about acceptance, collaboration, respect, and a shared understanding that it may involve change in processes, a shift in mindset, and a willingness to truly listen to our young people.

Our children attend Catholic schools, and we are passionate advocates for ensuring all students have access to the same rich schooling experience.

A school principal once told us that parents and students being welcomed into the school community is like 'having a seat at the table.' My question was why do some students get handed a set menu rather than the full a la carte menu others get, or automatically get seated at a different table solely for students with disability? The 'Special education hub' or 'separate table' at my children's high school recently closed because the school is recognising that inclusive education isn't exclusion, segregation or integration but all students being in the same classrooms with the supports they need. They recognize that inclusion works just as well in high school, and that classroom peers are a great asset to inclusive classrooms.

After the 'Inclusion Now' rally, our high school Principal invited our family in to discuss what inclusion means to our family and asked Bella and Lilly to write for the school newsletter. They jumped at the chance to share why inclusion matters and the negative impacts they saw for friends with disability only offered a 'set menu' or 'different table'."



Lilly, Archie and Bella at the rally

Lilly, age 17 and Bella, age 15 are high school students and siblings to younger brother, Archie, who has Down syndrome. They shared their perspectives as both students and siblings.

Lilly shared:

“Our family recently attended the ‘Inclusion Now’ Rally outside Parliament House. This is our little brother Archie, age 7, handing over the rally demands and family stories to the representative from the Department of Education at the ‘Inclusion Now’ rally.”

We get asked all the time “what special school does Archie go to”? He doesn’t, he goes to the same primary school that we all attended. Why? Because it’s his right to be included in the same school, same classes, learning the same curriculum. Archie is a visual learner and his teacher says that since he has been implementing multimodal class work, he has seen improvements for many students, not just Archie.

The QLD Department of Education has an Inclusive Education policy, but they fail to support teachers and schools and are still significantly funding the construction of special schools instead of making all schools accessible!

Bella shared:

“Since closing the Special Education Hub, our high school is becoming more inclusive. The ‘Inclusion Now’ Rally was asking Queensland’s Minister of Education to ensure all students can attend inclusive schools.

When we leave school, we will all be in the same community, so to have friends with all different skills, needs, strengths and weaknesses is what life is all about.” We need our schools and classrooms to be places where we can all learn from each other and build friendships. 60 years of research evidence proves that inclusive education is better for all.

“My favourite speaker at the rally was Marlena Katene, an entertainment journalist with Cerebral Palsy who uses a wheelchair and communicates using ACC (Augmentative and Alternative Communication). Marlena has a Communications degree and has interviewed hundreds of celebrities, including Ed Sheeran, Robbie Williams, and the Dalai Lama. She owns her own business, has published books and was the first person in the world with CP to Base jump 421 metres. I’ve been privileged to attend workshops with Marlena and hear about her Mum’s advocacy and how inclusion made her who she is today.”

Natalie Terry Bedwell also said, “Our family was proud to support the Inclusion NOW rally. We will continue to advocate for our own children, but we also need to work together to make genuine inclusion a reality for all students – no set menus and no separate tables!”

Links

Family advocacy stories from Shalee and Marlena Katene are available here: <https://cru.org.au/wp-content/uploads/2020/08/CRU-Dreaming-Big-Standing-Strong-Interactive.pdf>

Other inclusive education resources are available at: <https://cru.org.au/our-work/inclusive-education/resources/>

To learn more about the Queensland Collective for Inclusive Education and the rally, visit: www.qcie.org

QCIE, together with Down Syndrome Australia, is a member of the Australian Coalition for Inclusive Education who have a roadmap for inclusive education reform. <https://acie.org.au/acie-roadmap/>

Inclusive workplaces

Zoe Shearer, Health Project Manager at Down Syndrome Victoria recently interviewed Daniel Harrowell about his experience of open employment in a supportive workplace culture. Zoe provides support and training to Daniel in his workplace role.



Daniel lives in Albury with his girlfriend Alannah and his dog, Ralph. He has been employed since October 2022 as Health & Education Ambassador at Albury Wodonga Health in Victoria where he helps run workshops at the hospital on Disability Awareness training. He is also a participant at Purple Chicken, as part of their hospitality training program and café in Albury for young adults with disabilities.

When Daniel is not working, he enjoys a diverse range of leisure activities like hip hop dancing, bike riding, colouring, tie dye, playing basketball and ten-pin bowling. In his words “I have a great life!”.

Daniel likes to have something on every day of the week and says, “It’s important for me to have a weekly routine because this helps me understand what I’m doing.”

Daniel loves his job at Albury Wodonga Health. He enjoys meeting new people at the hospital, chatting with them, and helping teach about communication with people with intellectual disabilities. His presentation, ‘Communication with people with Intellectual disability’, covers helpful tips about how to talk about Down syndrome or a disability and how he likes people to communicate with him.

Albury Wodonga Health, as Daniel’s employer, and Purple Chicken as his training provider are both supportive and inclusive organisations where Daniel and his contributions are recognised and valued.

Here is Daniel’s advice for people with Down syndrome looking to find a job:

“When you are looking for a job you should make your own decision about what kind of job you want. I would advise that you try a couple of different jobs to see what you like. Find something that you like to do.”

People with Down syndrome have the right to work in meaningful jobs with equal pay and conditions as people without disability. People with Down syndrome want to work for the same reasons as everyone else – so that they can earn their own money, learn new skills, meet new people, be more independent, contribute to society and feel valued.

(DSA Advocacy Asks)



Opening doors and improving health outcomes

By Jenny Crosbie, Swinburne University Researcher

A behind-the-scenes look at how Down Syndrome Australia's (DSA) Health Ambassador Program is opening doors, starting conversations and making a real difference towards inclusive communication in health professions.

An independent evaluation conducted by The Centre for Social Impact at Swinburne University is finding that DSA's Health Ambassadors program is changing health professionals understanding about communicating with people with Down syndrome, while building meaningful work opportunities for people with Down syndrome themselves.

The Inclusive Communication program aims to educate health care workers and health students about Down syndrome, intellectual disability, and inclusive communication. It has a novel design in that it utilises a team of people with Down syndrome, known as 'Health Ambassadors', who are employed by DSA as trainers and advisors to build the capacity of the health sector workforce.

Health Ambassadors deliver training to tertiary students studying in diverse health fields and health professionals already employed in the health sector right across Australia. As well as delivering training presentations about inclusive communication in health contexts, Health Ambassadors also promote inclusive communication messages to a wider audience, including policy makers, and advise on the design of resources and other issues relevant to the disability sector.

The evaluation found that being employed as a Health Ambassador contributed to four main outcome areas:

1 Personal development

Health Ambassadors reported feeling more confident and they saw the role as opening up new opportunities. Health Ambassadors had learned a range of new skills, including travelling for work, using technology and public speaking. Their family members noted increased independence and confidence, self-esteem and readiness for the future.

2 Sense of purpose

The Health Ambassadors felt that the work they were doing was important because it helped others with Down syndrome. The role itself was highly valued due to the opportunities made available. For example, meeting politicians at Parliament House in Canberra and presenting to auditoriums full of people, meant that the Health Ambassadors were immensely proud of the work they were doing and saw it as important in changing people's lives.

3 Having employment and financial reward

Health Ambassadors were paid a full wage for their work and enjoyed other benefits associated with paid employment. The payment of real wages added to the sense of importance of the role. The role was also flexible enough to enable Health Ambassadors to take on other roles and to balance other commitments.

4 A sense of collegiality and finding a 'tribe'

Health Ambassadors worked as part of a team, meeting regularly face to face and online. They were supported by a Health Program Manager during meetings and when giving presentations. The team structure enabled Health Ambassadors to feel supported by a group of colleagues with similar goals and to make new friends.

In the second half of 2022, over 1700 health professionals received training through the Health Ambassador program. Nearly one third completed a feedback survey after receiving training, with the evaluation finding that health professionals benefited from the program in several key areas:

Health professionals found the information about disability of most interest (199 identified this theme), with people commenting on prevalence of Down syndrome, learnings about continued prejudice and barriers, poorer health outcomes, and the importance



of a human rights lens including affirming the capabilities of people with Down syndrome. A similarly large number (191) found learning about better provision of health care of most interest, particularly noting the gaps in current healthcare education about people with intellectual disability and diagnostic over-shadowing. Many valued learning directly from people with Down syndrome and hearing about their experiences in the healthcare system.

Overall, audience members expressed newly awakened awareness of strategies to mitigate exclusion for this group, particularly in relation to communication. In addition, a high number of health professionals stated they would use more inclusive and adaptive communication strategies when treating people with Down syndrome and would apply inclusive communication in their healthcare practice, as well as addressing accessibility issues and using person-centred care principles.

Overall, the critical elements of the model include its specific focus on health settings, the employment of people with lived experience in real jobs to deliver the training, and the program manager's own experience both in health settings and supporting people with Down syndrome.

All these things contributed to the success of the program. It is hoped that the positive results of the evaluation will result in the continuation and expansion of the Health Ambassador program into the future.

The 'Inclusive Communication: Improving Health Outcomes for People with Down syndrome' program was funded by the Department of Social Services, within the Mainstream Capacity Building stream of the Information, Linkages and Capacity Building grant scheme. Since the program launch in March 2021, the Health Ambassadors have educated over 3000 health professionals and health students.

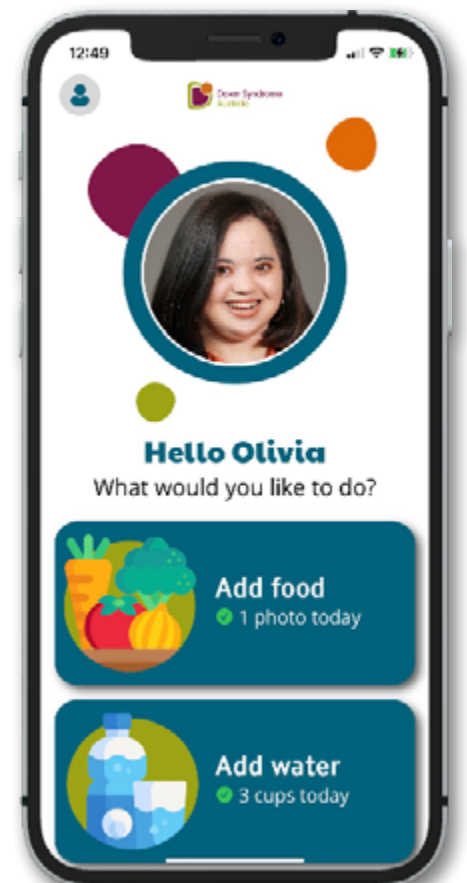


Good health, in the palm of your hands

In December 2022, Down Syndrome Australia (DSA) released two exciting new apps – the Down Syndrome Good Health App and the Down Syndrome Health Record App. Our apps aim to support well-being and inclusion for people with Down syndrome in their own health journey. Let's take a closer look at what each app has to offer.

Note – our apps are currently available on iOS only, however we are actively looking to secure funding to enable us to produce the Android version of both apps for people with Down syndrome.

Image (left to right): DSA Health Ambassador Kimberley Adams, DSA Health Program Manager Natalie Graham and DSA Health Ambassador Amelia Sloan.



Down Syndrome Good Health App

This app was developed for people with Down syndrome in mind as the primary user. It was designed with the knowledge that visual aids support learning and understanding for people with Down syndrome. The app encourages people with Down syndrome to be a part of their own health decisions and lead a healthy life.

There are 4 areas within the app that assist a person with Down syndrome to monitor their health by keeping a record of:

- diet by taking photos of meals
- water intake
- exercise and physical activities
- the things a person does and how they make them feel

The app encourages regular use and includes mini-games that are unlocked by daily diary entries.

What our users say

FF Looks really useful, lots of people will benefit **JJ** **FF** It helps me to keep fit **JJ**



The Down Syndrome Good Health App can be downloaded from the Apple Store <https://apple.co/3XkZ2QP>

Down Syndrome Health Record App

This app was developed with parents/support people and carers in mind.

The Down Syndrome Health Record App assists parents and support people of people with Down syndrome to record and monitor their child's growth, development and health as they grow. It's as simple as entering the relevant information and it is all kept in the one easy-to-access place.

With the Down Syndrome Health Record App, you can:

- Record information relating to medical diagnoses, allergies, medications, vaccinations, hospital admissions and healthcare providers
- Record and monitor a child's weight, length/height and head circumference, as well as developmental milestones and compare to the Down Syndrome Growth Chart
- Track active symptoms to share the information with healthcare professionals
- Record information for healthcare appointments
- Easily create a pdf summary of a person's medical conditions, allergies, medications, and healthcare providers
- Scan documents into the app so they too can be stored in one place

The Down Syndrome Health Record App can also be downloaded to a person with Down syndrome's device. This allows them to be able to access information about themselves on their own device, to share with health professionals.

What our users say

FF It looks great. It forms a very helpful record and repository of referrals and reports etc. **JJ**
FF Would have loved it from when my son was born **JJ**



The Down Syndrome Health Record App is available now on the App Store to download: <https://apple.co/3TX3AtV>

Going digital – introducing our new e-Learning short course



'Down Syndrome: The Essentials' online short course is part of a National Mainstream Health Program run by Down Syndrome Australia and funded by the Australian Government through the Information Linkages and Capacity Building (ILC) Grant program.

As part of our ongoing advocacy work, Down Syndrome Australia is proud to share the launch of a new online short course – **‘Down Syndrome: The Essentials’** which is accredited by the **Royal Australian College of General Practitioners (RACGP)** for **6 Continuing Professional Development (CPD)** points.

Since 2021, when Down Syndrome Australia was awarded ILC funding to improve health outcomes for people with Down syndrome, DSA has been working hard to educate health professionals about Down syndrome, the benefits of inclusive communication and how reasonable adjustments to practice make a difference. The Health Ambassadors have been on the road and online, educating health professionals and now we are pleased to release our online learning package – *Down Syndrome: The Essentials*.

This e-learn provides the learner with a single place to access much of what is needed, to be able to provide the best health care to people with Down syndrome. The e-learn also invites and equips the learner with information and tools to challenge bias and stigma towards intellectual disability and to advocate for a more inclusive society. *Down syndrome: The Essentials* is an action towards positively influencing the current appalling health statistics for people with intellectual disability in Australia.

This short course is designed for and useful to anyone who is working or studying in health. Most health professionals in their career will care or treat someone with Down syndrome or intellectual disability more broadly. The benefits of this course are multi-faceted:

- 1 Health professionals will gain knowledge and confidence when working with and caring for people with Down syndrome.
- 2 People with Down syndrome will receive more informed and inclusive care from health professionals who have completed this course.
- 3 People with Down syndrome will therefore have better health experiences.
- 4 People with Down syndrome will have better health outcomes.

Although this course is designed with health professionals in mind, family members, support workers and organisations who work with people with Down syndrome will also find this course interesting and educational.

***Down Syndrome: The Essentials* is hosted on The University of Melbourne’s Mobile Learning Unit online education portal and is completely FREE.**

To learn more about this exciting new online course, please visit: <https://study.unimelb.edu.au/find/short-courses/down-syndrome-the-essentials/>



The winds of change

In this article we hear from Michael Cox, member of the Queensland Down Syndrome Advisory Network, about the importance of physical and mental health and some thoughts around diversity and inclusion.



Physical health and fitness

Physical health and fitness are important. It's what keeps us going through life. It drives our bodies to move around and be able to do the things we love to do whether it's going to the gym to hanging around with friends and family, to be having an independent life. Eating and drinking healthily also helps our bodies to function properly, it also helps us to stay in good shape. Our fitness plays a huge part in our life and staying fit helps us to live longer and to stand, sit and to be moving around. It helps our heart to keep a beat that we can all dance to. Our sleep and recovery also plays a massive factor for our bodies to heal from sickness, overuse, soreness and tiredness.

Mental health and fitness

Mental health and fitness is important because it's what drives our minds and our brains to full function. A strong body and a strong mind help us to live life to the fullest and enjoy ourselves. We may wonder why our mental health and fitness is so important to us as well as physical health and fitness. To truly be healthy and fit our minds and bodies need to be on the same page as each other. Having a strong mind can help you to do anything that you set your mind to. In today's society, people lack the knowledge of how important our mind is. It keeps us motivated and helps us to have a purpose in life. It should be our best friend. Eating and drinking healthy foods and drinks affects our minds. Eating and drinking unhealthy food and drinks also has an effect on our minds as it can make us sick, tired, sluggish and worse, it can make us feel depressed. It can make us feel lonely by being depressed. The more unhealthy things we put in our bodies the worse it can make us feel, which is why we need to stay on top of mental health and fitness.



The truth behind diversity and inclusion

Diversity and inclusion are just fancy words that we use to make people feel valued and included but that is a load of rubbish. It does not matter how people view us at all, it's how we feel inside ourself. To be true to our own beliefs we may be different in all sort of ways whether it's our heritage, age, gender or different shade of skin, we all are amazing in our own ways. It doesn't matter if some people have a disability, we are all human and should all be seen as and treated as human and the same way there is a saying 'treat people like you want to be treated', be nice to each other.

To be included and to feel included are two different things in life. In a world where we want to be more involved in things and to be accepted by others, it is important to be accepted and to feel accepted as well.

To be accepted we need to put in the hard work to be likeable and to be trusted by the people around us. If you are not trustworthy how can people accept you and want to be around you? You have to build trust and companionship so you can be accepted for who you truly are. We are all here to help each other and sometimes people need a bit of an extra push to be more accepting of others.

My advice

My advice is to be you and enjoy your life and embrace it. Life is amazing and you don't know what's around the corner so live it up, have fun and yes, we all have things we need to work on, but we will get there in the end. We will be stronger if we all work together as a team whether it's finding an inclusive way or to have more diversity in world, but we all need to do our part to help change the world.



If you want to be valued, then we all must put in that hard work ourselves and look inside our dreams and our hearts and value our self as a person. When you value yourself people will see the real you.



A platform to be heard

Q&A with DSNSW Member Tara Elliffe

The Disability Royal Commission (DRC) was established in April 2019 in response to community concern about widespread reports of violence against, and the neglect, abuse and exploitation of people with disability. These incidents might have happened recently or a long time ago. The DRC has been gathering information through research, public hearings, personal experiences from people, submissions, private sessions, and other forums. A final report will be delivered to the Australian Government by 29 September this year. The report will include recommendations for how to improve laws, policies, structures and practices to ensure a more inclusive and just society.



What is it like to be heard by the DRC?

Hear a first-hand experience of what it's like to make a submission to the DRC from Down Syndrome NSW Member Tara Elliffe who kindly shared her experience with us.

Tell us a little bit about yourself

I'm 35 years old and I have Down syndrome. I volunteer with the SES, I'm a blood donor and I love my parents. I have three brothers and I'm a proud aunty to my two nieces.

Why did you want to make a submission to the Disability Royal Commission and what was your submission about?

I wanted to do a submission for two reasons – I wanted to talk about my experience in hospital which wasn't positive compared with great experience I have with my GP. I wanted my voice to be heard.



Back row (left to right): Hon. Ronald Sackville AO KC, Stein Boddington, Christine Regan, Ms Barbara Bennet PSM.
Front row (left to right): Erin Sheehy, Tara and Dr Rhonda Galbally AC.

I feel that sometimes I am not listened to, I felt this at the hospital where staff spoke to my parents and not me. I wanted to make sure that good news stories were shared, also. My GP experience is so positive, I still see the same one. I think it's important that we share the good news as well as the challenges.

How was your experience providing a submission to the DRC?

My barrister Kate was wonderful and I had a great experience developing my submission with her. I felt well supported by Kate and her amazing team in my preparation, as well as being supported by my parents. I did a preliminary interview that prepared me for the day run by Kate, which was really helpful. I was well prepared because I met Kate before the day, so because I knew her, I felt comfortable to share my views. The format was good too because Kate asked me questions that I could answer.

Would you change anything about the process to make it easier for people with Down syndrome to make a submission to the DRC?

Using Easy Read information would be great. I hope that people reading this can see that it is possible to have a voice. Try things. Get the support you need to participate.

What does it mean to you to have the opportunity to have your voice heard by the DRC?

I felt really proud of myself for presenting to the Commission. It was also great to spend time with others making submissions and hearing their stories. We all got along well and there was a lot of support in the room. When I spoke to the Commission, I felt they understood me. Being heard is a good start but it's more about being listened to. At the end, I said "we need to be heard" and the Commissioner replied, "Miss Elliffe, you have been heard".

A time for change

When it comes to advocating for change, one issue that's been gathering a lot of attention recently is the Australian Government's immigration policy. We invited Down Syndrome Australia's Migration Advisor, Dr Jan Gothard to share with us some insights about the conversations and work going on surrounding the 'Welcoming Disability' campaign.



Left to Right: DSA Board Member Dr Rhonda Faragher, DSA Migration Advisor Dr Jan Gothard, Hon Andrew Giles MP – Minister for Immigration, Citizenship and Multicultural Affairs, Self-advocate Lexi Livingstone, DSA Board Chairman Angus Graham and Shelby Livingstone.

DSA gratefully acknowledges Dr Jan Gothard, our Migration Advisor and author of this article, for the valuable and vital service she provides to the broader Down syndrome community.



Below are just some examples of the dozens of letters the DSA Migration Advice service receives regularly from families wanting to migrate to Australia with a family member with Down syndrome. The Australian migration system is very selective and sometimes I have to tell families it's not the disability that's the issue – they simply don't have the skills or the family connections required for an Australian visa. Too often though, families do have the skills and even a job offer, but a family member will fail to meet the migration health requirement.

I am a research chemist from Brazil, my wife is a dentist, and I have a permanent job offer in Australia, but my 8-year-old daughter has Down syndrome – can we get in?

My son is two years old and has Down syndrome. There are no facilities for his support in Kenya and he has no future here. Can you help us migrate?

My mother in India has dementia and can no longer care for my 25-year-old sister with Down syndrome. We want her to live with us in Australia. She has no other family anywhere.

We have been working in Australia on a temporary visa, but now my son is born with Down syndrome here, we can't get a permanent visa because of his disability.

The migration health requirement is designed to protect Australia against public health issues such as TB, but also to protect community resources. If a visa applicant or family member is regarded as representing health or community costs which exceed a threshold of \$51,000 over the duration of the visa, or over 10 years for a permanent visa, they will fail the health requirement.

Depending on which visa they are applying for, applicants may be able to request a waiver of the health requirement, which means they are given the chance to argue that the benefits they and their families bring to Australia outweigh the notional community costs. To do so is expensive and time-consuming, but the majority of applicants who are eligible to apply for a waiver are successful. However, more than half the visa applicants who fail the health requirement cannot apply for a waiver and regardless of their skills and employment opportunities, their visa will be refused.

The Down Syndrome migration service offers free advice to all inquirers on Down syndrome-related migration matters. Is there any hope? Are they on the right path? Too often there is no hope, or, perhaps worse – they have already set out on a path that is a dead end, at great personal and financial cost. While our service cannot deliver miracles, it can help steer people in the right direction, if there is one, or prevent them from wasting their time and money if the way is barred.

As part of our advocacy in the migration area, DSA is a founding partner in the 'Welcoming Disability' campaign, which is calling for the following changes (amongst other things), to the migration health requirement:

- make applying for a waiver possible to all visa applicants
- waiving the migration health requirement for all children with disability or health issues born in Australia
- removing 'education support' from assessment of community costs when assessing the migration health cost
- making the Migration Act subject to the Disability Discrimination Act (it is currently exempt)
- ending the attitude which sees disability purely as a cost

Overall, *Welcoming Disability* believes people with disability can and do 'contribute' to society, and we want to see an end to the attitude which only values 'contribution' when it is measured in monetary terms. To learn more about the Welcoming Disability campaign or become a supporter – find us on social media or send us an email.

Website: www.welcomingdisability.com

Email: welcomingdisability@alhr.org.au

Facebook: [@welcomingdisability](https://www.facebook.com/welcomingdisability)

Twitter: [@welcomingdisab](https://twitter.com/welcomingdisab)

Instagram: [@welcomingdisability](https://www.instagram.com/welcomingdisability)

To contact DSA's Migration Advice service, please email migration@downsyndrome.org.au

Our Voice

In each edition of *Voice*, we invite our state and territory members to tell us about what they've been up to in their local communities around Australia.

With World Down Syndrome Day (WDSD) and lots of events happening recently, let's take a look!



Australian Capital Territory

In March ACTDSA presented 'Diversity in the Classroom' to local school teachers. Sharon Moore, Karen Garrity and Kelli Gowland presented inclusive classroom strategies and resources, and shared stories about teaching children with Down syndrome in a mainstream classroom.

We kicked off World Down Syndrome Day celebrations alongside DSA with functions at Parliament House and the Governor General's residence. ACT Employment Ambassador Charlotte, spoke at an event at Aspen Medical and alongside members Lauren and Kim, met with ACT Government Ministers to discuss issues that are important to people with Down syndrome in Canberra. We also hosted a disco and invited Xtreme Starts dance troupe to perform.

We rely heavily on the generosity of the community to raise funds for our association. In 2023, we have participated in the Hands Across Canberra – Canberra Day appeal, with over \$11,000 in donations. We assisted the Lions Club of Belconnen in hosting the breakfast tent at the Canberra Balloon Spectacular and were given \$5,000 from the group. GoBoat raised funds for us during the Balloon Spectacular, and we received \$5000 from the Labour Club Belconnen in their Marble Run promotion. We receive ongoing donations from the Canberra Southern Cross Club Community Rewards Program, and Aspen Medical asked us to participate in their Hack4Good program where they donated \$2000 plus their volunteer's expertise in creating a corporate sponsorship program!

Shannon Kolak
CEO Down Syndrome ACT



New South Wales

We have been busy on all fronts with membership growing alongside our team. Policy and advocacy have been particularly busy, attending Minister Shorten's National Press Club Speech on the NDIS in April, the Federal Budget night in Canberra in May as well as stakeholder meetings with the NSW Minister for Disability Inclusion, Kate Washington and NSW Parliamentary Secretary for Disability Inclusion, Liesl Tesch.

DSNSW made submissions to the NDIS Review, Early Years Strategy, the Capability and Culture of the NDIA and were excited to be invited to speak at DSC's Annual NDIS Conference in Sydney in June.

WDSW saw us interviewed by Channel 7 News, alongside our partners the Sydney Swans who held a private training session as well as an exclusive screening of the Champions film with the players.

Our CEO Commentary and In Brief series launched in April, providing key insights on policy and advocacy issues impacting our community with positive feedback from our members. To join our mailing list, email admin@dsansw.org.au

We are thrilled to be shortlisted and progress to the next stage of submissions as part of the AFR's Most Innovative Companies awards for 2023, thanks to our new 'Congratulations Initiative' aimed at improving health professionals' delivery of a diagnosis and supporting families.

Emily Caska

CEO Down Syndrome NSW



Queensland

2023 has commenced with many positive activities. In March we held an Educators Conference with the theme of *Endless Possibilities*, focused on supporting educators in inclusive practices. A Parents Conference was also held providing an opportunity to interact with our professional team sharing information on the array of DSQ support services, education opportunities, advocacy work and a range of resources.

World Down Syndrome Day (WDSW) was celebrated through several events including an awareness activation at Parliament House, afternoon tea hosted by the Governor of Queensland at Government House and on the Saturday prior to WDSW, a Broncos NRL match at Suncorp Stadium had DSQ as the Charity Partner for the 50/50 Charity match.

The successful *Now and the Future Podcast* series has continued with Season 8 now scheduled for recording including topics such as employment, Kindy program and travel training.

Play Matters (peak body for playgroups in Queensland) has worked with DSQ to commence an inclusive playgroup at our Ascot office. This initiative fills a unique peer support void for families in the greater Brisbane area who have a young child with Down syndrome.

To round out a great first half of the year, in a few weeks' time we will celebrate our first Latch On program graduation!

Chris McMillan

CEO Down Syndrome Queensland



South Australia

The week of World Down Syndrome Day (WDSO) saw some fantastic celebrations for the South Australian community. It was wonderful to see so many families enjoying our WDSO event at the Adelaide Zoo. We were very thankful for funding received from the Liquor Industry Charity Golf Association and the City of Adelaide Council which enabled us to provide this event to our community.

A small group of representatives from South Australia headed to Canberra to take part in the WDSO events at Parliament House and Government House. Back in Adelaide, on Wednesday 22nd March, our community members were invited to morning tea at South Australia's Parliament House, hosted by MP, Nat Cook.

Our first morning tea for new parents and those with young children in the early years was held at the beginning of April. The morning incorporated a session by speech therapists and parents, Lara and Jen, who talked about communication in the early years and ways to support babies and young children. It was a lovely session, and we are looking forward to our next one later in term 2.

For those with older children, we had an informative workshop for parents on puberty, where we discussed how to talk about puberty and those changes with children and what to expect.

To keep up to date with events coming up, you can follow our Facebook page or email our Information officer, Sam at InfoSA@downsyndrome.org.au

Samantha Roach

Information Officer for South Australia



Tasmania

It has been a busy first half of the year here in Tasmania with continued growth of our events and opportunities for our members.

We kicked off the year with three social pool days including the waterslide! They were beautiful days, and it was fabulous to see our members enjoying the last of summer.

To celebrate World Down Syndrome Day we set sail on the Sailability boats in Hobart for an amazing experience with our members having a go at steering the boats. The day ended with a friendly competition of cornhole (also known as beanbag toss!).

We held our annual family camp at Camp Clayton this year welcoming new and old families. It was a wonderful, relaxing weekend. Our members got to experience their first pony ride, tie-dye socks, have a go at the taiko drummers' drums, create fabulous woodwork creations and end the night with a disco! We also held some well awaited relationships workshops hosted by Sexual Health Victoria.

In May we held our annual educational professional development days. These workshops are in their 13th year and continue to be successful, interactive days.

This year each term we are running our BrightStars dance groups and a social bowling group in our three locations around the state: Hobart, Launceston, and Ulverstone. Sign up to receive our quarterly newsletter to stay up to date for all days and times by emailing info@downsyndrometasmania.org.au.

Down Syndrome TAS Board and Staff



Victoria

We hit the ground running in 2023 with a number of exciting initiatives and events... how is it mid-year already?! In March we enjoyed celebrating World Down Syndrome Day (WDSD) via our annual Family Fun Day at Werribee Zoo, a morning tea hosted by our Advisory Network at OC House, a trip to Canberra for national events at Parliament House, and our inaugural 4Peaks challenge raising an incredible \$32,000 for DSV. One of the best parts about WDSD 2023 was being able to share the first two impactful videos in our *Now You See Me* series, a collection of videos illustrating the authentic and contemporary voices of people with Down syndrome and their families. Visit www.downsyndrome.org.au/vic/now-you-see-me/.

We are mid-footy season here in Victoria and this year that has meant the reinstatement of the AFL Umpire Association's (AFLUA) Fiona McBurney Match Day Experience, which aims to connect sport and disability by providing a unique experience for individuals with Down syndrome to undertake an official guest AFL umpire trainer role on match day. After a few years' hiatus due to the pandemic, we are thrilled to once again be working with the AFLUA and hope to be able to expand this program to other states in years to come. We would like to extend our gratitude to the AFLUA for this wonderful opportunity.

Lastly, DSV is now running MyTime across Victoria. Jump over to www.mytime.net.au/groups/ to find your closest group and connect with local parents and carers.

Dan Payne

CEO, Down Syndrome Victoria



Western Australia

DSWA moved into beautiful new premises in March, providing the perfect backdrop for our World Down Syndrome Day event. Members and other guests were treated to morning tea, and were entertained and moved by our speakers Sian King, Gabrielle Coles and Brayden Wake.

Our younger years groups, Playgroup and Kids club have continued to thrive with growing numbers, and a range of wonderful events and activities over the past few months. We have also undertaken a review of the Teens and Adult social groups after our coordinators moved to other roles. In reviewing these programs and employing a new coordinator we have introduced a greater focus on achieving participant goals, improving communication and social skills and both seeking and providing feedback post event. Numbers are steadily growing in both groups with a fantastic turnout at the recent Friends for Life disco.

With our social programs well established and the employment program continuing to gain interest and traction, we have increased our attention on Down Syndrome Regression Disorder and working with families with recent dementia diagnosis. Importantly we are seeking out the most appropriate resources for our families and ensuring that we commence support networks to bring parents together.

There was also lots of optimism and excitement in the air for our 4th Annual Gala Dinner.

Cassandra Hughes

CEO, Down Syndrome WA

World Down Syndrome Day Showcase



2023



Top left: ACT members with the Governor General (GG). **Bottom left:** Lexi and Rachel with Minister for the NDIS, Bill Shorten. **Bottom middle:** ACTDSA Member Nathan ringing the bell at the GG's. **Right:** To celebrate WDSO, Down Syndrome Australia Employment Ambassador Charlotte Bailey met with ACT Deputy Chief Minister Yvette Berry to discuss issues concerning people with Down syndrome in Canberra.



Left: Self-advocates, family and DSA team members outside Parliament House ready for our WDSO Morning Tea. **Right:** ACT Members Cheikh and Kura at Parliament House.





Top row, bottom left and middle: World Down Syndrome Day at the Zoo! The South Australian community had a great day celebrating WDSO at the Adelaide Zoo. **Bottom right:** DSNSW held an exclusive screening of Champions with the Sydney Swans.



Left and middle: DSTAS celebrated WDSO on the water this year in Hobart with Sailability. **Top right:** Sydney Swans and Down Syndrome NSW Training Day. **Bottom right:** Lots of Socks at Northmead Public School celebrating WDSO and fundraising for DSNSW.



Top left: The Down Syndrome Victoria community gathered at Werribee Open Range Zoo to celebrate World Down Syndrome Day. **Top right:** Behind the scenes with the team at Down Syndrome Victoria. **Bottom left:** Down Syndrome Victoria's morning tea was hosted by staff from their Advisory Network: Emily Porter, Matt O'Neil and Colby Hickey. **Middle:** Taking to the field with the Brisbane Broncos to mark WSDS. **Right:** Afternoon tea at Government House in Queensland to celebrate WSDS.



Top left: Showing off our 'Lots of Socks' at the WA WSDS morning tea. **Bottom left:** Sian King speaking about her SLES journey at the WSDS morning tea in WA. **Middle:** Families enjoying the WSDS picnic in WA. **Right:** Down Syndrome Victoria's inaugural 4Peaks adventure team hiked over 50km to raise awareness and funds for DSV this March.



voice

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