



Down Syndrome Australia

Annual Report 2021/22



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Our Patron

The Governor-General
of the Commonwealth
of Australia, His Excellency
General the Honourable
David Hurley AC DSC (Retd)

Down Syndrome Australia

is registered as

*Down Syndrome Australia Pty Ltd
ABN 65 150 209 224*

Who we are

Down Syndrome Australia (DSA) is the national peak organisation for people with Down syndrome and their families. Since establishment in 2011, DSA has advocated on a national scale to influence the Federal Government to provide better policies, legislation and supports to people with Down syndrome and their families on prenatal screening, inclusive education, equitable health care, and the NDIS.

DSA supports people with Down syndrome to be strong self-advocates and build skills to live an independent life. DSA also develops national resources in partnership with the state and territory Down syndrome associations to support and inform families and professionals.

Our work is informed by the UN Convention on the Rights of Persons with Disabilities, and people with Down syndrome are at the centre of all the work that we do. We work to create change and make sure people understand the experiences of people with Down syndrome and their families.

Our goal is to ensure that people with Down syndrome have full inclusion in our community, get the support they need, and have their rights respected. People with Down syndrome deserve to be valued, reach their potential, and have equality across every aspect of society.

See the Down Syndrome Australia Strategic Framework 2021 – 2024 [here](#).

Our Vision

An Australia where people living with Down syndrome are valued, reach their potential and enjoy social and economic inclusion.

Our Purpose

To influence social and policy change, provide a national profile and voice for people living with Down syndrome, and to build resources and knowledge capacity of the state and territory Down syndrome associations. We work collaboratively with the state and territory Down syndrome associations to achieve our mission.



Highlights of our Year



Speaking at the
General Debate
at COSPI5

Launch of the
Right to Work
pilot project



Right to Work
exhibition at the
Canberra Centre

DRC prenatal
discussion paper
published



20,216 resources
downloaded from our
national website



Facebook reach of
2.7 million



426,541
total website
page views

13
new fact sheets
produced



Production of
COVID-19 resources
in partnership with
the Aus Gov Dept
of Health

ABC Federal
Election Forum
partnership



Presenting to the
United Nations
for WDS

Presenting at
the World Down
Syndrome Congress



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A Message from our Chief Executive Officer

The past year has been a year of change and opportunity for Down Syndrome Australia and the community we serve.

We faced ongoing challenges with the COVID-19 pandemic, frustrations with cuts to NDIS plans, and ongoing fights against barriers to inclusion. But at the same time, we have had a change in government, a new focus on co-design in the NDIS reforms, and new opportunities to advocate for inclusion.

One of my highlights from this year has been the increasing involvement of people with Down syndrome in the work of Down Syndrome Australia as advocates at the local, national, and international level. This advocacy has taken many forms including sharing information with professionals, involvement in government committees, participating through submissions, and various forums. Some of the key opportunities have included:

- The valuable work of our Health and Employment Ambassadors
- The ABC Election Forum we held with the ABC

- Our first Right to Work exhibition
- Claire Mitchell (DSAN member and Board Director) attending COSP and speaking on the floor of the General Assembly about inclusion
- The continued involvement of people with Down syndrome as co-facilitators in our Pathways to Independence workshops.

Families have also played a key role in supporting our advocacy work. This year DSA released a paper which outlined the experiences of families who received a prenatal diagnosis. This work was based on the experiences shared with us by more than 300 families across Australia.

Down Syndrome Australia continues to engage with key decision makers about a range of issues of importance to our community. We have also continued our strong partnerships with the other disability peak organisations and have collaborated on joint advocacy on the NDIS, inclusive education, access to appropriate health care, the Disability Royal Commission, and COVID-19.



Our work is also supported by our strong connection to our members, the state and territory Down syndrome associations. Over the last year, we have had the opportunity to collaborate on a range of projects and initiatives.

I want to thank the team at Down Syndrome Australia and the DSA Board for their work, enthusiasm, and support. I would also like to thank my colleagues in the state and territory organisations for all their collaboration and support.

A handwritten signature in black ink, reading 'Ellen Skladzien'.

Dr Ellen Skladzien
CEO DSA

A Message from the DSA Chairman

It is my pleasure to provide this Chairman's report for Down Syndrome Australia. The financial year of 2021/2022 has been another year of growth and opportunity for DSA.

This year we had the opportunity to participate in the Conference of State Parties (COSP) at the United Nations in New York as part of the Australian delegation where we were able to advocate internationally for better inclusion for people with intellectual disabilities. We have been involved in other international presentations as part of World Down Syndrome Day and our work with Down Syndrome International. Even more importantly we are leading by example, with people with Down syndrome involved in every aspect of our organisation including on the Board, as employees, co-facilitating workshops, and as participants in our leadership programs.

In April this year, I was pleased that we were able to hold a face-to-face planning meeting with all our member organisations. At this meeting we focused on ways to work collaboratively together and develop new partnerships, strengthen the involvement of people with Down syndrome, develop our approach to measuring impact, and ensure we are meeting the information needs of our community. It was a great opportunity to reflect on all that we have achieved through our collaborative approach to the Federation over the last decade, and how we can build on that success over the coming years.

Over the past decade, DSA has established itself as a leader in human-rights based advocacy and inclusion for people with intellectual disabilities. Some of the key highlights from this year for DSA include:

- The advocacy work on prenatal screening which included national media coverage of the report we released in October 2021



- The launch of our Employment Ambassador Program and the Employment Awareness Campaign
- Taking a leadership role relating to the NDIS reforms including having membership on the NDIS Co-design Advisory Group, the Intellectual Disability Advisory Group, and the Information Gathering, Access and Planning Co-design Advisory Group
- A collaboration with Good Things Foundation on promoting digital literacy for people with intellectual disabilities including co-hosting a national roundtable on digital inclusion



- Work with the Department of Health to develop resources and information for our community on COVID and vaccinations
- The Election Forum we held with the ABC to support people with Down syndrome to share their views about voting
- Collaborations with Australian Lawyers for Human Rights on advocacy relating to migration through our Welcoming Disability Campaign
- The continued work of our National Health Ambassadors in supporting health professionals to develop skills around inclusive communication.

The DSAN continues to play an important role in the work we have been doing at DSA, by providing information and advice to the DSA Board and DSA team. Members of the network have been involved in a range of other activities including engaging with media and sharing their experiences through public speaking. It is with great thanks to the support from the Sherry Hogan Foundation that we can continue to support this network.

I would also like to thank the significant contribution of the members of the Board of DSA as well as state and territory Board members and staff for their input, advice, and support in the important work of DSA. In addition, I want to thank Dr Jan Gothard who volunteers her time to work as DSA's probono Migration Advisor. Lastly, I want to take this chance to recognise and thank the DSA team. Their hard work, dedication, and passion for DSA is evident in everything they do. As DSA has grown in its reach and impact, we have been fortunate to have such a strong, dedicated team to support our work.

Angus Graham OAM
Chairman

Down Syndrome Advisory Network report

The Down Syndrome Advisory Network members have had another big year, advocating for the rights of people with Down syndrome on both a national and international level.

"It has been another busy year for our group. With COVID-19 still increasing in most states our DSAN meetings have always included the need to keep in touch and discussing new ideas on how to keep busy during periods of lockdown," DSAN member Lauren Murray says.



On the day of the Federal Election, DSAN members shared why it was so important for people with Down syndrome to have their say.

Jenny Bowden told our community:

FF *I put my ballot paper in the box.
I love voting and having my say as
to who should be in government.*

*The issues that I care about are
I want action on climate change
and the environment.*

*People with a disability should have the
same opportunities as everyone else.
That means supporting the NDIS.*

*Good health care and quality education
that is accessible to everyone.*

*People with disabilities need to have a
say and be heard. Voting is my way of
having a say. JJ*



The Network provide direct advice to the Down Syndrome Australia Board, and make sure Down Syndrome Australia receives direct input from Australians with Down syndrome on issues that affect them.

"There has been a strong focus on inclusion, employment and self-advocacy this year," Lauren says.

"We have also done workshops online on how to do your resume and tips on self-advocacy and decision making."



As the Australian representative for Down Syndrome International (DSI), Andrew Domahidy attended and presented at the World Down Syndrome Day Congress which was held virtually in Dubai.

"I gave a presentation about what inclusion means to me. Robin from DSI pre-recorded my presentation but I did it live on the day," Andrew says.

"I spoke about being welcomed as a participant in my workplace, in sport and in my local community. I spoke about positive examples of inclusion in Australia like the NDIS and what we need to do to improve inclusion in Australia – especially by providing more open employment."

The Network continues to be a space of both leadership and advocacy.

"The best thing I have worked on this year is attending the meetings regularly and getting ready for the DSA leadership program. I am looking forward to that before the end of 2022," says Kylie Scott.

Down Syndrome Advisory Network members

Andrew Domahidy, Western Australia

Appointed November 2017

Claire Mitchell, Queensland

Appointed November 2017

Elise Romaszko, Tasmania

Appointed August 2020

Jenny Bowden, Victoria

Appointed August 2020

Kylie Scott, New South Wales

Appointed November 2017

**Lauren Murray,
Australian Capital Territory**

Appointed March 2020



What I love about being part of the DSAN is that I belong and I can feel part of a like-minded community, I can advocate for the rights of people like myself and contribute to make everyday life better for those with Down syndrome. It is a chance for me to speak up about CRPD rights and make a few steps towards improving the lives of people with disability.

Kylie Scott, Down Syndrome Advisory Network Member





Advocacy

Advocacy is at the core of everything we do.

Our team works with decision makers across the country to advance the rights of people with Down syndrome and their families to have full inclusion in society.

Down Syndrome Australia at the Conference of States Parties

In June 2022 Down Syndrome Australia representatives Dr Ellen Skladzien, Claire Mitchell and Lisa Clarke attended the 15th session of the Conference of States Parties to the CRPD at the United Nations Headquarters in New York.

Board Director Claire Mitchell had the opportunity to present a three-minute speech at the General Debate on the first day of COSP15. Not only was she the only member of the Australian Delegate to present on day one, but she was also the only member of the Australian Delegate with an intellectual disability to present at the Conference.

Her speech addressed the lack of opportunities people with intellectual disability have to participate at events in their communities, including in international events such as COSP. She talked about barriers to participation, including the use

of jargon and lack of accessibility, and the need for appropriate supports to be in place for inclusive practices.

We face barriers to being involved.

People use jargon.

Meetings go too quickly.

Sometimes we don't get the support we need.

But when we are supported, we can make a big difference.

Claire Mitchell, General Debate speech at COSP15

Claire's speech was well received by the Assembly and gained a large round of applause, with many people coming up to congratulate her in person. She also received wide support from the Australian community via Down Syndrome Australia's social media channels.



Having the opportunity for Claire to speak at the General Debate enabled Down Syndrome Australia to share the important message of inclusive practices on a global scale, which in turn will influence organisations to consider making reasonable adjustments to their own practices to ensure true equality for all.

Attendance at COSP15 was also an opportunity to further develop relationships with international organisations for future collaborations on the development and integration of wider inclusive practices to ensure the full participation of people with intellectual disability in society.

Attending the 15th session of the Conference of States Parties to the CRPD

by Down Syndrome Australia Board Director Claire Mitchell

On the first official day we met with people from the Department of Foreign Affairs (DFAT) and the Department of Social Services (DSS) who organised a big room for members of the Australian Delegation to meet to watch the Civil Society Forum.

The Forum was very structured, as support people were needing to translate for the people with different languages and to talk about where they were from. I listened to all the information with Ellen and Lisa's support.

Unfortunately, there wasn't information in Easy Read, which would have been so much easier to follow. It is important for people with intellectual disabilities to be able to understand what they were reading.

On the first day we also met with Down Syndrome International and Inclusion

International to talk about the new Listen, Include, Respect guidelines.

The Guidelines have been thought out very well and this is how it should look, so everyone can understand and have a voice. It is important that we can all be heard. The Guidelines have been broken down into sections using different colours which really helps, and I think there is enough information on each page.

After the meeting I was able to talk to Bryan Russell from Peru with his translator, as Bryan speaks Spanish. Bryan is the first person with Down syndrome to campaign for a publicly elected seat in a government. We gave each other our business cards and I gave him a small koala and showed him postcards of Brisbane and invited him to attend the World Down Syndrome Congress in 2024.



The General Assembly

Being at the General Assembly at the United Nations headquarters in New York felt like being in the Green Room of the House of Representatives at Parliament House in Canberra.

I followed the process for the election of new members to the Committee on the Rights of People with Disabilities. The Australian Delegation were confident that Rosemary Kayess would be voted back onto the Committee. Everyone was very excited when her name was drawn out and celebrated her great achievement.



Before I spoke in the General Assembly, Ellen and I moved to the floor and we sat at a table with a built-in microphone. This is where I delivered my presentation.

This was an experience of a lifetime.

It was my first time in New York at the UN and I was excited and very happy. I felt so proud and honoured to be representing Australia, especially in something that I am very passionate about.

I thank Ellen and Lisa for giving me this opportunity to be involved and for supporting me to participate. I am very appreciative of their assistance.

Meeting people from across the world

On Wednesday and Thursday we went back to the UN to hear from different organisations about other issues at the Round Tables.

Over the week we were able to meet with other organisations and advocates from across the world to discuss some important issues.

One of these meetings was with Anna Fedewa and Kayla McKeon from the National Down Syndrome Society (NDSS) in America. Kayla is the Manager for Grassroots Advocacy and Anna is the Manager of Public Policy. We invited them to join in an online meeting with the DSAN, to tell our members about the different ways they talk to their local politicians to change laws.

We talked about her work to make things better and about inclusion for people with Down syndrome and the World Down Syndrome Congress in Brisbane.

We also met with people from Down Syndrome International, the Asia Pacific Down Syndrome Federation, Inclusion International and Humanity and Inclusion.

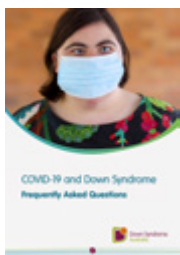
At these meetings we talked about what we do as an international community and how important it is for people no matter what type of disability they have, to be included to participate and to be involved in their communities and to be just like everyone else.



COVID-19 and people with Down syndrome

Into the second year of the pandemic there was still a great need from our community to get factual and timely information, particularly when vaccines were approved for use in the country.

To address this need, Down Syndrome Australia collaborated with the Australian Government Department of Health to produce a series of resources for people with Down syndrome and their families about the COVID-19 vaccine rollout.



Frequently Asked Questions guides

Our community had many concerns about the level of risk for people with Down syndrome if they caught COVID-19 and wanted to know what the best options were to prevent their loved ones from contracting the virus.



As a result, we developed two guides to answer some of the most frequently asked questions from our community:

- A Frequently Asked Questions guide about COVID-19 and Down Syndrome
- A Frequently Asked Questions guide about COVID-19 and Children with Down Syndrome

These two guides addressed issues around vaccines, risk of hospitalisation, needle fear, supported decision making and COVID safe practices. Working directly with the Department of Health to share factual information we aimed to dispel misconceptions about vaccinations and support our community to remain healthy during the pandemic.

Video content

Providing accessible resources for our community is always a key priority for Down Syndrome Australia, and as an organisation we aim to put the voices of people with Down syndrome front and centre.



As part of our COVID-19 vaccination collaboration we worked with nine Federation members from across Australia to produce a video in which they encouraged our own community and the wider population to get vaccinated.

In the video Down Syndrome Queensland member Ruth Faragher shared that she wants everyone to get the vaccine so we can all go back to normal life.

DSA Health Ambassador Olivia Sidhu said she wants “to keep my family safe”.

However, needle fear was a big factor in people with Down syndrome not wanting to get vaccinated. To support



families through this, we produced a video resource with tips about how to assist their loved ones with Down syndrome who are afraid of getting needles.

Health Ambassadors Caitlin Woolley, Naomi Lake and Kimberley Adams also created their own videos sharing some personal tips on how to get the vaccine even when you're scared of needles.

The power of positive storytelling

Because some parents had concerns about having their younger children vaccinated, we worked with a South Australian family to share their own personal story about why they were getting their son vaccinated when he turned 5 years old and how they came to that decision.

Mum Jennifer said, "It was the advice from other families and medical staff that helped us know that we're on the right path, know that we're doing the right thing."

Sharing personal stories of people with Down syndrome getting their vaccines from across the country was an important

way to show our community what other families were experiencing and how they had overcome concerns and fears.

When 12 to 15-year-olds were eligible to get the COVID-19 vaccination in Australia, Levi's story struck a chord with many families.

His mum Wendy shared that her 12-year-old son Levi had many procedures throughout his life, so he understood that needles can help you stay healthy. Levi has had pneumonia and chest infections before, so his family felt it was important to protect him against COVID.

They didn't shy away from reality and knew he was a bit nervous before his first COVID-19 vaccination, but said he handled it like a champion and had no side effects afterwards.

Levi also knew as a bonus to staying safe, if he got vaccinated then he could soon return to Hawaii for a holiday when the borders reopened.

13-year-old Moya didn't really like needles either, but came up with a great way to distract herself when she got her first



COVID-19 vaccine by watching YouTube clips of her favourite bands on her phone, followed by getting a hug from her sister.

"It feels like a sharp pain, but then it's over. It was quick," Moya said. "The nurse in the hospital was my favourite, she was blonde like me and gave me a sticker."

Moya made 12 phone calls in 10 minutes after she got her first COVID-19 vaccination because she was so proud to let all her friends and family know that she got the jab. Some even got woken up in the UK to hear her news.

"I'm brave. I made lots of phone calls afterwards. I phoned my sister, my father, my friends, my carer, my gran gran, my aunties and my cousins."

Our DSAN members and Health Ambassadors also happily shared their personal vaccination stories and photos to encourage the community to roll up their sleeves.

These personal stories from our community resonated far and wide, with a reach on social media of over 400,000 people.





Right to Work

Down Syndrome Australia received funding from the Department of Social Services (DSS) to deliver Right to Work, an employment project addressing the barriers people with Down syndrome face when trying to get a job in open employment.

This project has been delivered nationally in collaboration with the local state and territory Down syndrome associations.

The main components of the Right to Work project are:

The Work Readiness Program

DSA developed a Work Readiness Program for young adults with Down syndrome to identify their skills and strengths, develop confidence when applying for jobs by learning to create a resume and doing interview practice, and learn about workplace expectations. This program has been piloted in Brisbane, Canberra, Melbourne, Sydney and Perth, and was tailored to the learning style of people with Down syndrome, including the use of Easy Read materials and visual supports such as videos.





The Employment Connection Service

The Employment Connection Service has been run locally by Business Connectors in the state and territory organisations with national coordination from DSA. DSA developed guidelines and resources with information on how to best support people with Down syndrome wanting work in open employment and how to customise jobs through job carving.

The Employment Connection Service placed 28 people with Down syndrome into jobs and provided information to 232 employers.

Right to Work Awareness Campaign

The Right to Work Awareness Campaign showcased some of the many successful employment stories from across Australia. The stories DSA shared throughout the year directly challenge negative misconceptions about what it means to hire a person with Down syndrome by showing the reciprocal benefits of employing them to be part of the team.



Employment Success Stories in numbers

32
employment
success stories

384,689
Total reach
ACROSS FACEBOOK,
TWITTER, LINKEDIN
AND INSTAGRAM

35,666
Total engagement
ACROSS FACEBOOK,
TWITTER, LINKEDIN
AND INSTAGRAM

51,777
Total
video views



“I think it’s important to be included in the workplace to show people that everyone has gifts and talents. Even if I need more help to learn new things, I am good at my jobs.”

**Rachel Parker, WA
Administrative Assistant and
Dental Assistant**





Vision for an inclusive Australia

f *Employing someone with a disability in a meaningful job can make their dreams come true.* **f**

Charlotte Bailey, ACT

On World Down Syndrome Day, we shared ACT Employment Ambassador Charlotte Bailey's *Vision for an inclusive Australia* video, in which she addressed the barriers people with Down syndrome face when trying to get a job. Charlotte talked about what we need to do as a society to make Australia more inclusive, including providing supports and training so people with disability can build skills that will help them to succeed.

Her speech reached over 30,000 people on social media and was shown at the United Nations Virtual World Down Syndrome Day conference with the Asia Pacific Down Syndrome Federation.

Right to Work exhibition, Canberra Centre

Down Syndrome Australia teamed up with ACT Down Syndrome Association in March to hold the Right to Work exhibition at the Canberra Centre.

The exhibition featured four local employment stories and had foot traffic of approximately 350,000 people over the week.

Dozens of people attended the launch on World Down Syndrome Day and the exhibition was covered by WIN News TV.

Employment Ambassadors

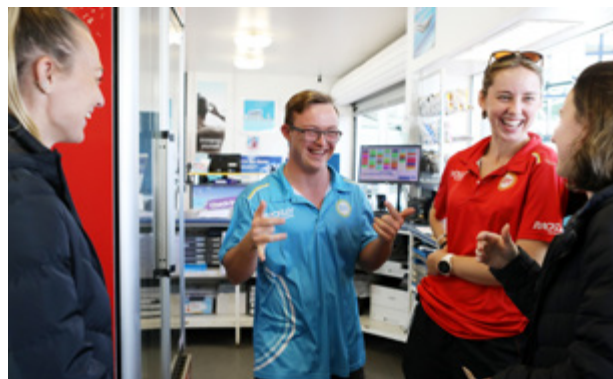
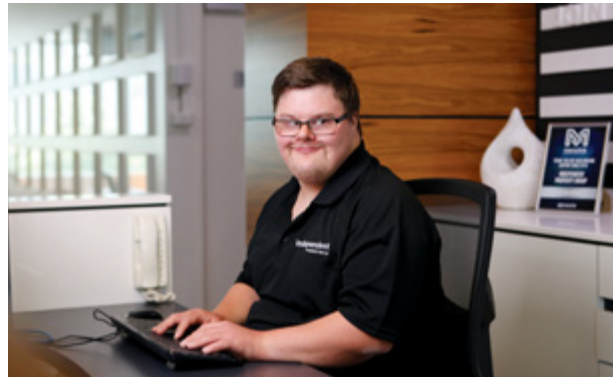
As part of the Right to Work project, Down Syndrome Australia hired an exceptional team of Employment Ambassadors from across the country to share their personal employment stories with organisations and talk about the benefits of hiring people with Down syndrome. They also co-facilitate the Work Readiness Program and help to train other people with Down syndrome looking for employment.

“ When I was picked to be an Employment Ambassador it made me feel very proud and important. I like working with and gaining new experiences from working with staff. I loved how we did Zoom meetings during COVID. I had the best day talking about my work at Harris Scarfe at the disability conference with Kylie and Debbie. I liked to talk to the people who were there. And I met some again the next morning when I had breakfast. And I had fun at the Carers Solution filming program about inclusion. That made me feel special. **”**

Keziah Glenane, VIC

Over the 12 months the Ambassadors were involved in a range of presentations and events, including:

- Presenting to Baker Hughes (Charlotte and Ellen)
- Presenting at the 2022 Disability at Work Summit (Ellen)
- Presenting to PricewaterhouseCoopers on World Down Syndrome Day (Ellen)
- Presenting at two screenings of ‘Chef Antonio’s Recipes for Revolution’ in WA
- Working at the Australian Network on Disability Conference stall (Keziah)
- Presenting on a Chatability panel for Carer Solutions (Keziah)





Some of the new Employment Ambassadors shared the highlights of their first year in the job:

"I liked helping employers to understand employing people with Down syndrome because they are good workers."

Kirrin Pereira, QLD

"I like giving presentations and sharing my story. I think it is important to show people with Down syndrome the possibilities of open employment. I also think it is important for potential employers to understand the benefit of employing someone with Down syndrome and how it promotes inclusion. I was very pleased to present to prospective employers at PricewaterhouseCoopers."

Naomi Lake, WA



"I love my role as an Employment Ambassador! I get to meet with EAs from other states. I also got to learn new skills for public speaking, such as how to stand and how to dress to impress."

Ellen Maher, NSW

"I am proud that I can show other people that I have been a staff member in my job as office assistant for over 8 years, through photos and newsletter articles."

Jessica Toster, WA

"I enjoyed learning all the new skills and I loved talking to all the people."

Eoin Gibson, QLD

"I loved doing the speeches for the workshops for the other people who want to get a job. I hope it helped them to get a job that makes them happy."

Claire Robinson, WA

Employment Ambassadors

Charlotte Bailey,
Australian Capital Territory

Claire Robinson,
Western Australia

Ellen Maher,
New South Wales

Eoin Gibson,
Queensland

Jessica Toster,
Western Australia

Kenichi Gray,
Western Australia

Keziah Glenane,
Victoria

Kirrin Pereira,
Queensland

Naomi Lake,
Western Australia

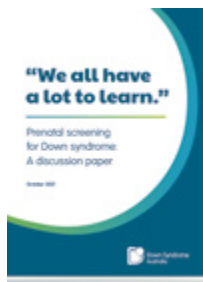
Rachel Freeman,
Tasmania



"We all have a lot to learn."

Prenatal screening for Down syndrome: A discussion paper

Over the last decade, families of children with Down syndrome have told us many stories about not receiving the right supports during pregnancy. We have heard horrific stories about doctors telling people that their child would have a lifetime of suffering. We have also heard of terminations being booked before a family has been able to process the possibility of having a child with Down syndrome.



In July and August 2021, Down Syndrome Australia undertook a survey to understand contemporary prenatal screening experiences. The survey received 320 responses from parents who have a child under the age of 10 with Down syndrome. Disturbingly, the experiences shared reveal that it is still commonplace for prospective parents to be given misinformation about life with Down syndrome as they navigate prenatal screening decision making. Nearly



Image by ABC

half of the parents surveyed felt pressure from health care providers to terminate their pregnancy.

Information shared with families in the context of prenatal screening decision making rarely reflects the experiences of those living with Down syndrome and their families. Nearly half of parents who

responded to the 2021 survey felt that the information presented to them by health care professionals did not give them an understanding of Down syndrome or a clear understanding of the lived experience of people with Down syndrome and their families. Very few families were given the opportunity to meet a person with Down syndrome.



Our research showed that nearly half of families surveyed felt pressure from medical professionals to terminate their pregnancies, and more than 40 per cent felt that they had received negative or inaccurate information about Down syndrome from a health professional when they were trying to make their decision.

The release of the report raised national awareness of this issue and was covered by ABC News.

Read the report here:
https://www.downsyndrome.org.au/wp-content/uploads/2021/10/DSA_Prenatal-Screening-Experiences.pdf

Case studies

Zoey's experience

When Zoey received a call from her obstetrician with her amniocentesis results, she expected to be asked to attend his office.

The call came when Zoey was at school teaching a room full of four-year-olds, when he stated over the phone *"It's not good news. Your baby has Down syndrome... and I've scheduled a termination for tomorrow."*

With twenty children watching on, Zoey had no chance to process what she had just been told. She made an appointment to see him in person later that day to talk further.

"We were in there for five minutes, it was awkward, we were in shock," Zoey says.

"He gave us an information sheet and from that point, it was neglect."



Julia's experience

Julia described the amniocentesis experience as horrible, and if she had been given a choice by her obstetrician, she wouldn't have done it because the result wouldn't have changed her decision to go through with her pregnancy.

When they found a hole in her baby's heart, the cardiologist said *"Considering the diagnosis of Down syndrome and the heart condition, we highly recommend termination. This is not a pregnancy we think should go ahead."*

Julia made it clear that having a baby with Down syndrome was not a concern to the couple but asked whether the heart condition was repairable. They responded: *"I can fix his heart but there is no way I can fix that he has Down syndrome."*

Moya's experience

Like nearly half the survey respondents, Moya* felt pressure to terminate her pregnancy.

Moya had received a high chance of Down syndrome after non-invasive prenatal screening. Despite declining further invasive diagnostic testing, Moya was provided information about termination based on her screening result, saying, "I got the impression that the doctor felt they needed to give me a way out."

The most unhelpful thing Moya found throughout her whole pregnancy was that even though she had clearly indicated she would not be terminating; she was asked to confirm that she was happy with that decision on every subsequent visit to her obstetrician and at ultrasounds.

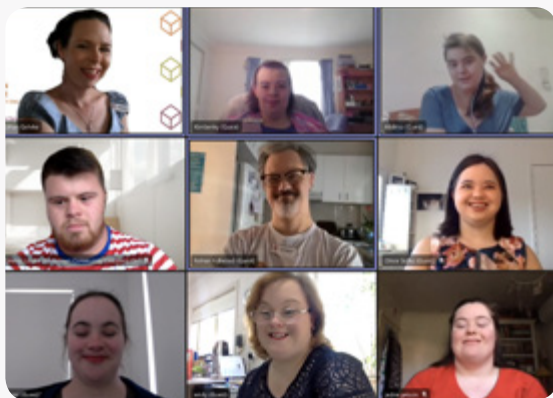
"I lost count in the end, but the number of times I had to reiterate or confirm my decision was ridiculous.' She questioned this at the time, asking whether her decision could be noted in the file and that it not be revisited at each appointment but was told 'we just need to cover our bases, and this is something we need to check.'"

"Having to so frequently confirm our decision not to terminate the pregnancy felt like our decision as a family was being questioned and invalidated each time, rather than respected."

**Name changed to protect privacy.*

Inclusive Communication in Healthcare

Into its second year, the Down Syndrome Australia Inclusive Communication Project has become a recognised and respected program showing healthcare professionals the importance of including people with Down syndrome in conversations about their own health.



I am proud to be helping people with Down syndrome get better healthcare
Caitlin Woolley, Down Syndrome Australia Health Ambassador

The project aims to amplify the voices of people with Down syndrome to change inadequacies in the healthcare system and break the cycle of stigma, misinformation, and lack of awareness about intellectual disability.

Headed up by Health Program Manager Natalie Graham, the Project was implemented mid-2020 to address the issue of improving health outcomes for people with Down syndrome and the barriers people with Down syndrome face in accessing good health care.

As Australia slowly began opening up to domestic travel at the end of 2021, the Ambassadors have been able to reach a wider audience with their in-person presentations, making even more of a direct impact with students and healthcare professionals:

"I'll work hard to understand what specific communication styles and needs each of my clients prefer"
– Mental Health professional.



Health Ambassador Amelia Sloan says, *"I am proud for the opportunity to speak to health professionals and be paid for the work I do."*

Improving inclusive communication practices from the ground up, the Health Ambassadors presented to hundreds of allied health students to ensure that the future clinicians were learning best practices through sharing personal stories of their own experiences in the healthcare system.



"Learning about the human rights of people with an intellectual disability... was very interesting and I would like to find out more so I can advocate for my future clients," shared an Occupational Therapy student from the University of Sunshine Coast after participating in an online presentation about inclusive communication with Ambassador Gillian Gehrke.

Ms Gehrke says, *"After presenting to the allied health students I felt full of energy, jumping for joy!"*



Inclusive health in numbers

From July 2021 to June 2022, the DSA Health Ambassadors:

- Presented 20 times on inclusive communication to 800+ university students and clinicians in allied health, nursing, medicine, and Primary Health Networks
- Participated in 6 steering and advisory committees, including for the National Roadmap for Improving the Health of People with Intellectual Disability and on the University of Queensland's 'We need to talk' project
- Presented virtually at the World Down Syndrome Congress in Dubai
- Had a Federal MP share their speech on the importance of inclusion in Parliament
- Gave valuable input in 2 research advisory committees.

DSA Health Ambassadors

Alishia Lindsay, Northern Territory

Amelia Sloan, Victoria

Caitlin Woolley, Tasmania

Emily Porter, Victoria

Gillian Gehrke, Queensland

Hugo Taheny, South Australia

Kimberley Adams, ACT

Naomi Lake, Western Australia

Olivia Sidhu, New South Wales

Rohan Fullwood, New South Wales

Down Syndrome Australia's Inclusive Communication Project is funded through a 3-year Information, Linkages and Capacity Building (ILC) grant, which pays to employ 10 Health Ambassadors across the country who work to educate health professionals on the importance of inclusive communication.

Pathways to Independence

Down Syndrome Australia's Pathways to Independence workshops are still proving to be popular across the country for both adults with Down syndrome and their families.

Led by ILC Project Manager Kylie Preston as part of our Individual Capacity Building grant, the 3-year project empowers people with Down syndrome to develop independence and make choices about their lives, as well as create sustainable networks of community support.

People with Down syndrome have been employed as peer facilitators and are involved with delivering the workshops in each state and territory. Employing peer facilitators has not only made an impact with the attendees of the workshops, but it has also positively affected the facilitators themselves and their confidence to use their skills to connect with their wider community.

Down Syndrome Victoria Health Program Manager Zoe Shearer says facilitator and former DSAN member Matthew O'Neil is proud to be a role model for other people with Down syndrome and is now running other events for his community:



f *After delivering the Pathways to Independence Community Participation workshop Matt decided that he wanted to organise a social event in his own community because he wanted to be a role model to other people with Down syndrome to show them that they could do this. He also wanted to showcase and share community activities that he enjoys to other people with Down syndrome.*

With the support of the DSV Club 21 facilitator, he organised a dinner at a local pub for the Club 21 group. He wanted to book the venue and help organise transport there, and then asked the facilitator to help support him to do this. He booked the venue himself and told everyone which tram to get and how to get there from Federation Square.

He hosted the evening, met Club 21 participants at the pub and was the last one to leave. The night was a huge success.

Now other Club 21 participants want to organise their own events in their local communities. This is a massive change for some of these adults with Down syndrome. It impacts not only people with Down syndrome but also their family members.



The Down Syndrome Advisory Network has also reviewed workshop content to provide feedback.

Workshop topics covered this year include:

- Becoming a Leader: Learn about meetings, rights, public speaking, and leadership
- Staying Healthy
- Relationships
- Self-Advocacy
- Housing Options
- Decision Making
- Community Participation



- Building and Supporting Independence
- Circles of Support
- Supported Decision Making.

Housing Options

At our Housing Options workshops 92 per cent of attendees said they felt more confident to help their family member with Down syndrome make future housing decisions, and 83 per cent of attendees had a better understanding of what housing supports are provided through the NDIS.

One family member shared, “It’s great to know about more options and a starting place to achieve them. Everyone was so friendly, welcoming and helpful. I enjoy being in a non-judgmental arena.”

Staying Healthy

80 per cent of attendees with Down syndrome said they had a better understanding of ways to stay healthy after coming to this workshop, and 60 per cent of respondents said they felt more confident talking to their doctor after this training.

“I will be able to participate more in decision making in my life!”

Rights

73 per cent of attendees at the Leadership workshops on Rights said that they know more about what their rights are after this training, and 100 per cent of attendees said that they have learnt new skills.

Attendees said:

“I have better leadership skills.”

“I feel like a leader.”

“I have learnt new skills in advocacy.”

Pathways to Independence in numbers

- **68** Pathways to Independence workshops were held, with **28** face-to-face and **40** online
- **23** of these workshops were facilitated nationally by Down Syndrome Australia and **45** workshops were ran by the state and territory Down Syndrome Associations
- **55** workshops were for people with Down syndrome
- **13** workshops were run for families
- **254** people with Down syndrome attended
- **185** family members attended.

ABC Election Forum

In the lead up to the Federal Election Down Syndrome Australia partnered with the Australian Broadcasting Corporation's Specialist Reporting Team and 5050 Equality Team in hosting a community engagement forum to find out what issues were most important to adults with Down syndrome.

This forum was collaboratively designed by both organisations as an opportunity for ABC journalists and producers to hear directly from people with Down syndrome about their key issues of concern, and what was guiding their decision on how they were going to vote in the 2022 Federal Election.

14 self-advocates from across the country shared their ideas and opinions during the forum, which helped to inform the way the ABC reported about election issues.

Living independently, health and employment were discussed, as well as other issues that influenced voting.

One advocate who took part in the forum was Brooke Canham from WA, who said, "I have already made a very strong decision about who I am voting for, based on how things were handled during the lockdowns."

With support from four DSA staff members and eight ABC staff, the self-advocates shared the following insights:

- Adults with Down syndrome are career driven and passionate about employment, with great aspirations for their dream jobs
- They are keen to challenge businesses to employ more people with disabilities because they have a lot to offer and want to contribute
- It would help people with Down syndrome if there were specific education courses on topics such as healthy eating
- People with Down syndrome may experience more health issues than people without Down syndrome, so access to health insurance is important



- Support for reforming the NDIS was a key concern that might help decide how someone votes
- Most people with Down syndrome want to live independently and have control and choice over their own lives.

Down Syndrome Australia will continue to work with the ABC's Disability Affairs Specialist Reporting team to share more stories that showcase the experiences of people with Down syndrome.

Voice

Voice is about people with Down syndrome, for people with Down syndrome, by people with Down syndrome. Under Managing Editor Lisa Clarke, we have continued to include more stories about people with Down syndrome and by people with Down syndrome than ever before.

We hit a new record over the latest three issues, featuring content from over 100 Australians with Down syndrome, and many more families and community supporters.

Our issue themes over 2021/2022 have covered money and skills, with our May 2022 issue published as a special double issue covering employment.

Our August 2021 issue broke with our usual format and featured stunning cover artwork from Georgia Bartlett for the theme of money, as well as cut out and keep money cards on the back cover which were designed with input from the Down Syndrome Victoria Advisory Network.

For this issue we wanted to share lots of practical advice about the world of money and show what steps can be taken for

everyone to become more financially literate, including a fantastic Easy Read guide from Council for Intellectual Disability about managing your money and budgeting for things you need and want.

Talented ACT photographer Sam Chapman also contributed a photo essay on the financial literacy course run by the ACT Down Syndrome Association.

Our skills issue in December 2021 showcased the wide range of skills our members and own staff have, including Voice in Brief Editor Stephanie Papaleo, who taught us some words in Italian. We wanted to show that whether you are learning a life skill or wanting to get better at your hobby, improving at anything starts with a goal, creating a plan to reach your goal, and then following through with your plan. This could cover any skill at all, from earning your black belt, getting your driver's licence, or even learning to ride a bike.

The May 2022 double issue on employment was published as a companion issue to our new pilot project Right to Work, featuring many of the great exercises covered in the Work Readiness Program and success stories from our Employment Awareness Campaign.



Employees nation-wide were proud to share their tips to getting and keeping a job that you love, and our cover model and ACT Employment Ambassador Charlotte Bailey shared her vision for an inclusive Australia.

We will continue to provide a platform for people with Down syndrome to share their stories and advice on issues important to the community in 2022/2023.

Digital Engagement

 **426,541**

total webpage views

across the national and Federation websites

 **20,216**
resources

were downloaded from
our national website and
resource hub

WE SHARED 

650

posts on Facebook,
with a total reach of

2,775,533



WE BEGAN WORKING ON
two health apps

for people with Down
syndrome and their families



OUR TWEETS HAD
3,642
LIKES 



OUR TWEETS HAD

375,400

impressions



Our Facebook

posts had a total of

102,964

reactions

Our newsletters
reached over

10,000

people



Our most successful
month was **March**, with
a Facebook post reach of

507,788 USERS

27,682 REACTIONS

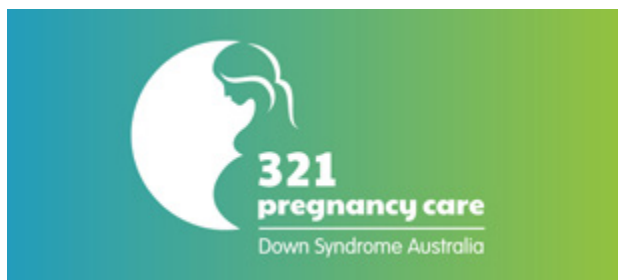


321 Pregnancy Care

"Thank you for all your support and encouragement over the past few months. This group has been enormously helpful to me, especially being able to connect in person with [other mums]. I feel so lucky to have found you all." – new mum in the 321 Pregnancy Care group.

This past year Down Syndrome Australia was entrusted to take over the 321 Pregnancy Care public Facebook page and private Facebook group.

The page and group were initially established to give on-going support to expectant parents who were given a high chance diagnosis or confirmed diagnosis of Down syndrome in their unborn child. This support has continued with Information SA Officer Samantha Roach providing



"I look back to when I was pregnant and found out about our little guy having T21. All the stress, all the unknowns that just went out the window as soon as I looked at him for the first time. I cannot wait to watch him grow up and see all of his achievements. He already has made me a proud mum with how strong and brave he has been."

information about local contacts, leading discussion, and welcoming new parents along with over 20 parent mentors and state association staff.

The parents in the group help provide support and encouragement during the pregnancy journey by sharing their

personal experience with new families and letting them know they are not alone. It is often a very emotional time when parents are first given a diagnosis of Down syndrome or high chance diagnosis, and the invaluable group provides a safe place for parents to talk about and share their concerns in a supportive space.

Digital Inclusion



Down Syndrome Australia has partnered with Good Things Foundation and Down Syndrome Queensland on a pilot project to support young people with intellectual disability and their supporters to improve their digital literacy skills.

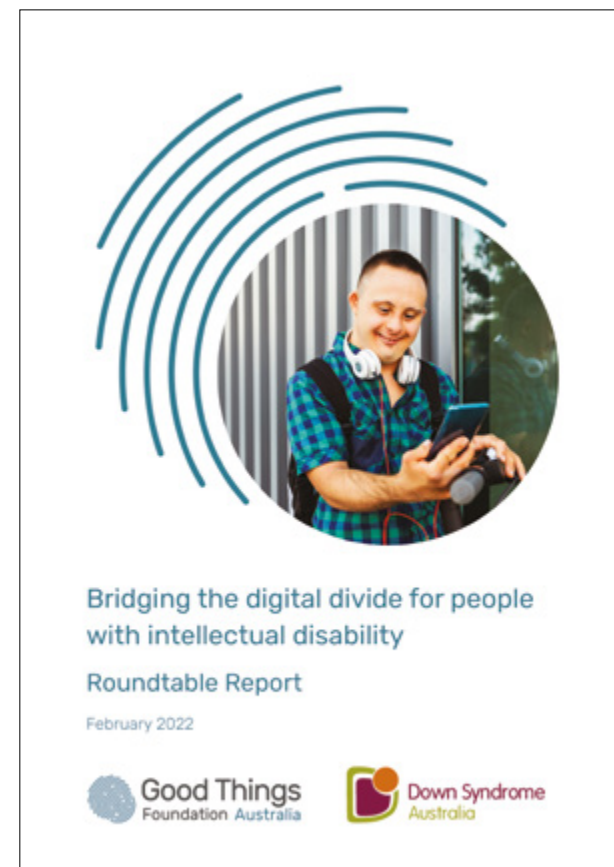
As a collective we have looked to address what the key barriers are for people with intellectual disability using technology, what would help to overcome these barriers, and what the critical next steps are to ensure that people with intellectual disability can equally access technology.


This on-going project is focused on developing new resources, training digital mentors and supporting young people with an intellectual disability to improve their digital skills and confidence.

In October 2021, Down Syndrome Australia and Good Things Foundation held the Bridging the Digital Divide for People with Intellectual Disability Roundtable, which brought together people with intellectual disability, family members, government representatives, disability workers, and digital inclusion experts to gain a greater understanding of the digital divide and the online safety risks for people with intellectual disability, and the current research and programs to address these needs.

The Roundtable was co-chaired by Jess Wilson, Chief Executive Officer of Good Things Foundation Australia, and Ellen Skladzien, Chief Executive Officer of Down Syndrome Australia.

Read more about the key recommendations to address barriers to access in our report with Good Things Foundation.





"StepUP! and the WDSO picnic are events that our family really looks forward to every year! The connections we've built with other families is so important to us. I remember back to our first event and just feeling overwhelmed with the love and support from those walking the same path as us and now I know that new families that come along experience the same support that we did, and I love that. Already looking forward to next year!"

Information Service South Australia

The Information Service in South Australia continues to link parents, professionals, and service providers to specialised services and up-to-date information. Enquiries in the past financial year have included those from expectant parents with a new diagnosis to migration and visa enquiries, and requests from schools for professional development and resources.

The highlights of the year for Information Service SA were our two major community events: StepUP! #21YourWay and our World Down Syndrome Day family day. The culmination of time spent connecting to local families cements how important an active community is and highlights how these connections strengthen support among families.

Both events are growing in attendance since our first year, and it is encouraging to see new people are finding out about

the events and the Information Service in South Australia. The feedback from families has been fantastic and makes us even more determined to build on our work to support the community.

In the coming twelve months the Information Service is exploring ways in which we can better connect with hospitals and medical staff to ensure parents with a prenatal and post-natal diagnosis are being linked in with DSA resources and the community. We are exploring ways we can help South Australian educators become better equipped at including students with Down syndrome in their classrooms and learning environments.

**Samantha Roach, Project Officer for
Information Service in South Australia**



Michael Sullivan appointed as a Member of the Order of Australia

This year Michael Sullivan was appointed a Member of the Order of Australia (AM) in the Queen's Birthday 2022 Honours List.

The Order of Australia recognises Australians who have demonstrated outstanding service or exceptional achievement, and Michael has been recognised for his significant service to people with disability in a range of roles.

Michael has been a long-time advocate for people with intellectual disability. He was appointed as the first Chairperson of the Down Syndrome Australia Network in 2018 due to his extensive experience and dedication to making the world a more inclusive place for people with Down syndrome.

Michael has been breaking barriers for our community from an early age. Michael commenced his education at a mainstream school and as a teenager

gained work experience at the NSW Teachers Federation. When he finished his education, he travelled through Europe for over two years before returning to Australia and commencing work with the NSW Teachers Federation. He continued in this role for over three decades.

In 1999 Michael was nominated to the National Disability Advisory Council for the Department of Family and Community Services, and in 2014 became the Chairperson of Council for Intellectual Disability.

Michael has always taken his role as an advocate seriously, and says, "Speaking up for other people makes me feel good, it is an honour and a privilege to meet ministers and people in government and speak up for others."

Down Syndrome Australia thanks Michael for his tireless work on behalf of our community. His years of service have



shone a light on important issues, and because of his dedication, we are moving towards a more inclusive and accessible society for all.

We are so happy that his efforts have been recognised at the highest of levels and he is truly deserving of this honour.

Angus Graham OAM,
Chairman
Down Syndrome Australia

Dr Ellen Skladzien,
CEO
Down Syndrome Australia



Our Organisation – staff

Dr Ellen Skladzien

Chief Executive Officer

Lisa Clarke

Communications and
Engagement Manager
Managing Editor of Voice

“There have been so many highlights from the past 12 months that it’s hard to choose just one. In April I had the privilege to travel to regional South Australia and spend some time with the McCullough family to film their experience of living through the pandemic with a child with Down syndrome and share their thoughts and advice to other families around vaccines. Connecting with families to share their experiences with our community is the reason I love my job so much, and I was so grateful that this family trusted us to share theirs during this incredibly tough year.”

Natalie Graham

Health Program Manager

“This year has once again been full of highlights for DSA’s health program. We have supported families and health professionals by making information about health and Down syndrome more accessible on our website and the Health Ambassador program has gone from strength to strength. There are two highlights that stand out for me. Firstly, the Health Ambassador Program being included in the National Roadmap for Improving the Health of People with Intellectual Disability, as a ‘model for health system navigators to help guide and support’ health professionals. Secondly, it would be the Health Ambassadors featuring at the World Down Syndrome Day event in New York.”

Kylie Preston

National ILC Project Manager

“It’s been a year of highlights, but two things in particular stand out for me. Firstly, seeing our Employment Ambassador Kez participate in a panel discussion on what disability inclusion means to her through her employment. Kez did such a great job of sharing her insights on how her work helps her to be a valued member of her work team. Secondly, I received some feedback from one of DSTas that a young woman who attended our Becoming a Leader training in late 2021 recently co-presented a workshop with DSTas on relationships. She was really proud to have used her skills to be a co-presenter. It is so fulfilling to see the confidence and skills that develop from our Leadership training and that this led to a paid employment opportunity!”



Zoe du Cann

National Website and
Inclusive Information

FF *My highlight of the past year has been working alongside other people who are passionate about supporting people with Down syndrome. Being a part of this team of staff members, family and supporters has been such a rich experience and I enjoy the drive and commitment of everyone involved in the Down syndrome Federation. It has been rewarding to work together on our common goals and see some great projects come to life.* **JJ**

Samantha Roach

Information Officer South Australia

FF *My favourite moment of the year was the World Down Syndrome Day family picnic in March this year. It was well attended and was great to catch up with families, and to meet some of our new families.* **JJ**

Yuka Yamoaka

Employment Project Officer

FF *The two biggest highlights for me this year was becoming a part of the DSA team and being involved in the employment project. It has been so exciting to see how this project has progressed with the delivery of the WRP, the impact of the employment awareness campaign, and having the Employment Ambassadors and the Business Connectors on board to do the fantastic work that they do. Although there is still so much that needs to change in the employment space, I feel that the outcomes of the employment project have helped to increase community awareness about the positive impacts that open employment can have on the employee with Down syndrome, but also the employer.* **JJ**

New staff members

Shaena Jones – Events Coordinator, commenced October 2021

Jessica Jones – Grants and Partnership Manager, commenced May 2022

Rachel Spencer – Senior Advocacy Manager, commenced June 2022

Board

Angus Graham – Chair, Director

Grant Lindsay – Director, Deputy Chair

David Fuller – Director, Treasurer

Claire Mitchell – Director

Dr Rhonda Faragher – Director

Alicia Flack-Koné – Director

Katrina Enos – Director

Catia Malaquias – Director

Dr Rebecca Kelly – Director

Rene Pennock – Director

Read more about our Board Directors [here](#).

A Message from the Treasurer

2021–2022 has been another year of growth and development for Down Syndrome Australia.

DSA believes that strong governance leads to the most efficient and effective use of funding and leads to the delivery of the highest impact. This year, Down Syndrome Australia has continued to build on its strong governance, risk management and project controls including:

- Full review of all organisational policies and procedures and the implementation of new policies such as the Whistleblower policy and updates of financial delegations
- Review and update of the DSA Board processes and Board nomination process to ensure a diverse and strong board composition based on our board skills and diversity matrix
- Work to improve accessibility of Board documents including developing Easy Read policies and more accessible Board documentation including budget

- Planning day with the DSA Federation to identify key areas of collaboration and innovation
- Review of the DSA risk policy and matrix.

During 2021/2022, we received funding from the Department of Social Services (DSS) for Information Linkages and Capacity Building (ILC) grants, work on the Royal Commission, as well as funding for Disability Representative Organisations. We also received new funding from NDIA to support our work with the NDIA on co-design and input on reforms. All the grants we have received have been in line with the strategic objectives of the organisation.

Through the support of a grant from the Sherry Hogan Foundation, we continue to support the Down Syndrome Advisory Network. This network is made up of people with Down syndrome across Australia who come together monthly to provide Down Syndrome Australia with advice and support on our advocacy. Funding from the Sherry-Hogan Foundation also supported us to



appoint a dedicated part-time Grants and Partnership Manager.

Revenue for 2020/21 was \$2,828,000, mostly derived from Government Grants which is an increase on the 2020/2021 revenue of \$2,080,000. In line with this and the expenditure required to complete projects, expenses for 2020/21 increased from \$2,038,000 (2019/2020) to \$2,064,000. It should be noted that a significant amount of that expenditure (\$1.6 million) was provided to the State and Territory Down syndrome organisations to deliver projects at a local level which enables the most effective and efficient project delivery.



At year end, our 2020/21 assets were \$2,191,000 compared to \$2,247,000 in 2020/2021. And our final total equity was \$411,000 compared to \$231,000 in 2020/2021.

Finally, what is not reflected in our financial reports is the contribution of the many volunteer hours that are given by those who generously contribute their time and energy to make a difference to the organisation, and to people with Down syndrome and their families.

This includes our Board Members, the members of our Down Syndrome Advisory Network, as well as other individuals who have volunteered their time and expertise over the last 12 months. Our most sincere thanks for their generous contributions to the organisation.

David Fuller
Treasurer



Donors, Sponsors and Supporters

We would like to acknowledge the following individuals and organisations for their valued support in the 2021–2022 financial year. We would also like to sincerely thank the many donors whose names we have been unable to list. Every donation goes towards supporting our advocacy work on behalf of people with Down syndrome and their families.

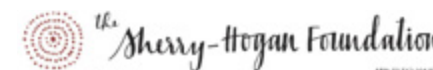
Individuals and Organisations

ATJS Earthworks Pty Ltd	HVCCC
Aussie Slots QLD	James Willoughby
Axis Toys	J Grassick Mechanical
Bonds Babes Australia	Jodi Cooper
Brian Reaby	Joel Deane
Clayton Rigby	J Taheny
Daniel Chrisp	Moe Kadhon
Darryl Gowlett	Shellcove Landscaping & Maintenance
Dave Fenlon	Stevenson
David Read	T Smith
Glen Wickens	Trigg
Graham Gibson	Unity College
Hue Duong	Xuan Huynh



Trusts and Foundations

Sherry-Hogan Foundation



Fundraising Initiative

Flora & Fauna

Perry Gilsenan and Scrapheap
Adventure Ride

Government Funding

Department of Health
Department of Social Services
National Disability Insurance Agency



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Australia