



# Down Syndrome Australia

Annual Report 2022/23



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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 voice for people with Down syndrome in Australia. DSA and its member organisations come together to represent and progress the needs, interests and aspirations of people with Down syndrome and those that support them.

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.

Down Syndrome Australia provides systemic advocacy on behalf of people with Down syndrome and their families. We work to create change and make sure people understand the experiences of people with Down syndrome and their families. We play an active and public role in engaging with a range of relevant groups, including government, disability

representative organisations, decision makers, the media, partners, families, and the broader community.

Our work delivers and facilitates change and contributes to us achieving our vision. We support people to make choices, build self-advocacy skills and take on leadership roles. Our approach is informed by our values of inclusion, collaboration, trust and respect.

## Our Vision

*People living with Down syndrome are valued and have full access to social and economic inclusion in order to achieve their full potential.*

## Our Purpose

*Our purpose is to influence social and policy change and provide a national profile and voice for people living with Down syndrome.*



# Highlights of our Year



**4** formal presentations at **COSP and the Civil Society**

Release of DSA's **Advocacy Asks** on World Down Syndrome Day



**Consortium member** of the National Centre of Excellence in Intellectual Disability Health

Involvement in the **NDIS Review** and **Disability Royal Commission**



**372,837** total website page views

**15** submissions made or contributed to



**10** new fact sheets produced

Involvement with over **30** advisory groups and committees



Launch of the online learning package **Down Syndrome – The Essentials**

**14,851** resources were downloaded



**Partnership with Kmart** for their dolls with Down syndrome

Launch of the **DSA Health Record App** and **Good Health App**



# A Message from our Chief Executive Officer

It is my pleasure to provide my first message as Down Syndrome Australia (DSA) Chief Executive Officer as part of the Annual Report for the 2022/2023 financial year.

I have been a part of the Down syndrome community for the past 13 years since the birth of my third child, Bella who has Down syndrome. I started in the role as CEO of DSA in January of 2023, and prior to that had been involved in Down Syndrome Queensland both on the Board and as CEO for the previous seven years. It is a constant source of pride and fulfilment to have the opportunity to do work that truly makes a difference for people with Down syndrome and their families and support networks.

The past year has seen continued growth for DSA along with increased advocacy opportunities for DSA to stand alongside self-advocates as the national voice of people with Down syndrome and their families across Australia. Our newly released Advocacy Asks document informs our approach to advocacy and outlines

6 key areas of advocacy, to ensure the rights of people with Down syndrome and their family members are realised.

One of my highlights from this year has been representing DSA at the 16th session of the Conference of States Parties (COSP) to the CRPD at the United Nations Headquarters in New York and advocating on behalf of all people with Down syndrome and their families. I was honoured to give a speech at the UN Meeting on the Resolution on Easy to Understand Communication regarding the importance of considering the needs of people with intellectual disability and their need for easy to understand communication and how that is approached at DSA.

I've also had the privilege to work alongside our DSA staff, Board, Member organisations, self-advocates and other National Disability Representative Organisations at the local, national and international level, through the involvement in government committees, advisory groups, contributions to submissions, presentations, events and conferences.



This past year, DSA has been actively involved in what are probably two of the biggest opportunities for change in the lives of people with Down syndrome in a generation, the Disability Royal Commission and the NDIS Review. DSA has made numerous submissions, recommendations and participated in consultations for these two critical reviews, involving people with Down syndrome and their families throughout the process. Going into the latter part of 2023 and into 2024, the focus switches to working with Government on the outcomes and recommendations in these reports to ensure that they are implemented effectively and actually change the lives of people with Down syndrome for the better.



## Some other highlights from the year include:

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- Our involvement as part of the successful consortium that will operate the Australian first National Centre of Excellence in Intellectual Disability Health. This Centre brings together strong advocacy, clinical and research experience in intellectual disability health, and will be a catalyst for action to ensure people with intellectual disability have improved access to quality, timely and comprehensive health care.
- Our celebration of World Down Syndrome Day which saw the release of our Advocacy Asks document at Parliament House to community and government representatives, and the attendance of the Prime Minister as well as Ministers Rishworth, Shorten and other key members of parliament.
- DSA Health Ambassador, Olivia Sidhu attending COSP and making a presentation at the Civil Society and COSP, on the importance on self-advocacy and inclusion.
- The launch of our partnership with Kmart Australia on their dolls with Down syndrome and continuing the conversation about the importance of representation.
- The continued involvement of people with Down syndrome and their family members as co-facilitators in our pathways to independence workshops.
- The Scrapheap Adventure Ride which raises money for regional initiatives.
- The ongoing involvement of the Down Syndrome Advisory Network in a range of projects, and opportunities.
- Down Syndrome Advisory Network member, Kylie Scott presenting at the United Nations in New York as part of World Down Syndrome Day about legal rights, decision making and easy to understand communication.
- The valuable work of our Health and Employment Ambassadors who are working in these sectors to raise awareness, build skills and understanding of Down syndrome.

Our work is strongly supported by our Member organisations. Over the last year we have had the opportunity to collaborate on a range of projects and initiatives, providing services, support and information nationally for Australians with Down syndrome and their families. I would like to thank our Member organisations for their commitment to our shared vision, their collaboration and continued support.

I would also like to thank the previous CEO, Dr Ellen Skladzien, on her significant contribution to DSA over her 6 year term, and for her support as I transitioned into the role. Ellen's tireless commitment to DSA has been critical in ensuring DSA is a well-recognised and respected national voice for people with Down syndrome and their families. Lastly, I would like to thank the DSA staff and Board for their work, enthusiasm, and support.

**Darryl Steff**  
CEO DSA

# A Message from the incoming DSA Chair

It is my pleasure to provide my first report as Board Chair for Down Syndrome Australia (DSA). I feel honoured to have been appointed as Chair and excited for the opportunity to continue to contribute to the important work of DSA. As the mother of Ryan, a delightful and attitude-filled tweenager with Down syndrome, I understand deeply the importance of the work we do to improve the lives of people with Down syndrome.

The 2022/2023 financial year has been a busy and exciting for DSA. We all mourned the departure of our CEO Dr Ellen Skladzien in late 2022. It's hard to put into words the immense contribution Ellen made to the work of DSA and our growth as an organisation. We miss her and wish her well in all her future endeavours.

January saw the commencement of Darryl Steff as our new CEO. Darryl was previously the CEO of Down Syndrome Queensland. He's done an excellent job hitting the ground running and has

quickly proven himself as an exceptional manager and leader. He has provided a seamless transition that has allowed us to continue our leading role in national advocacy, maintaining and strengthening our partnerships and collaboration with a broad range of organisations and within our Down Syndrome Federation, and has steered our successful delivery of a range of ILC funded projects. Welcome Darryl!

This year we launched our Advocacy Asks campaign during our celebration of World Down Syndrome Day at Parliament House. Self-advocates did a fantastic job leading the delivery of six key messages we have urged the Australian Government to act on to ensure the rights of people with Down syndrome and their families are realised. The event was well attended by self-advocates, ministers, MPs and department staff including the Honourable Prime Minister Anthony Albanese, Minister Bill Shorten and Minister Amanda Rishworth. Our Advocacy Asks document guides our systemic national advocacy for which we are recognised as a leading Disability Representative Organisation (DRO). Our



advocacy activities include contribution to 15 submissions and involvement with over 30 advisory groups and committees this year as well as providing direct advice to Commonwealth Government Ministers and staff on issues that are critical to improving the lives of people with disability and their families and carers.

DSA again 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. Our involvement included 4 formal presentations and the co-delivery



of a side-event with Down Syndrome International. DSA Health Ambassador Olivia Sidhu was a member of the Australia delegation and gave a powerful speech calling for more accessibility of processes and participation from different groups of persons with disabilities in United Nations processes.

*Since its creation, DSA has established itself as a leader in human rights-based advocacy and inclusion for people with intellectual disabilities.*

People with Down syndrome are at the heart of everything we do, with people with Down syndrome involved in every aspect of our organisation including on the Board, through our Down Syndrome Advisory Committee (DSAN), as employees and co-facilitators of workshops, and as participants in our leadership programs. Some of the key activities where the contributions of people with Down syndrome have been pivotal to the work of DSA this year include:

- Significant involvement and contribution to the NDIS review.

- Continued development and improvement of resources and fact sheets for people with Down syndrome and their families.
- Launch of two Apps to support the health of people with Down syndrome and their families.
- Continued delivery of capacity building workshops for people with Down syndrome and their families, which are co-facilitated by peers with Down syndrome.
- The continued work of our National Health Ambassadors in supporting health professionals to develop skills around inclusive communication.
- Numerous presentations and committee involvement by our self-advocates at conferences and meetings across the country and internationally.
- The continued work of our team and Employment Ambassadors in addressing the barriers to employment people with Down syndrome face and assisting in placing people with Down syndrome into open employment.



- Launch of our free online course *Down Syndrome: The Essentials*, designed to empower healthcare professionals in providing the best care and support for individuals with Down syndrome.
- Continued collaboration with Good Things Foundation on promoting digital literacy for people with intellectual disabilities.
- Delivery of workshops and events in South Australia to address gaps in support to people with Down syndrome in that State.

The Down Syndrome Advisory Network (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. I would like to thank them for their contribution and leadership, in all that they do.

I would also like to offer my thanks to of the members of the Board of DSA as well as board members and staff of our Member organisations. I strongly appreciate the significant contribution they make to the important work of DSA

through their advice, collaboration and support. I'd like to offer special thanks to Angus Graham and Grant Lindsay, DSA's outgoing Chair and Deputy Chair. Their leadership has been integral to the growth of DSA from an idea to the strong and successful organisation that is DSA today. They leave a legacy to be proud of and very large shoes for David and I to fill. I also want to thank Dr Jan Gothard who volunteers her time to work as DSA's pro bono Migration Advisor.

*Lastly, I want to recognise and thank the DSA staff. Their hard work, dedication, and passion for DSA is evident in everything they do.*

Finally I'd like to encourage everyone to register for the World Down Syndrome Congress being hosted by Down Syndrome Australia which is being held from 9-12 July 2024 in Brisbane. This Congress will bring together people with Down syndrome, their families and supporters and a range of professionals from all over the world to

share knowledge and build the capacity of people and organisations to improve the lives of people with Down syndrome. We hope to see people from every part of Australia take advantage of this opportunity to engage with such an interesting and exciting group of people.

**Dr Rebecca Kelly**  
Chairman



# A message from the outgoing Chair

It has been an extraordinary privilege to be the Chair of Down Syndrome Australia (DSA) for the past 12 years.

In the 12 years since we founded DSA, the disability landscape in Australia has changed dramatically. Without a doubt, the most impactful change was the introduction, in 2013, of the National Disability Insurance Scheme (NDIS), which has been life changing for people with disability. DSA was, when the NDIS started, a new, small, unfunded organisation.

As a Federation of State and Territory organisations who all had their own logos and websites, we recognised we needed to identify as one national voice while delivering much-needed services at the local level. That's why we collaboratively created a national logo that was adopted by the Federation Members – so we would be recognised in Canberra and around the country as a collective of Member organisations working as one. As a result, DSA ensured the voices of people with Down syndrome were

heard at all levels of Government through our lobbying, campaigning, and continued advocacy.

*The bottom line was – and is – this: the purpose of the DSA is to improve the lives of people with Down syndrome.*

That's why, in the years before the NDIS was established, we were early supporters of the Every Australian Counts campaign – lending our support and voice to the whole disability sector at a State and Federal level. And that's why, despite the organisation being in its infancy, we quickly became recognised as an important advocacy and policy group within the disability sector, bureaucracy and Government. This achievement was in no small part due to the exceptional early leadership of our founding CEO, Catherine McAlpine, who laid the important foundation stones for DSA by building relationships with government agencies. This work resulted in funding from Government that allowed the organisation to grow and expand – and better serve



the interests of people with Down syndrome. DSA also made international connections – becoming an active member of Down Syndrome International (DSi) and founding members of the Asia Pacific Down Syndrome Federation (APDSF). Importantly, our work and resources have been invaluable to fellow members of the APDSF in the Asia Pacific, as they have been translated into multiple languages – providing important information to families that had not been previously accessible in the region.

This early work was followed up by the impressive policy skills of our second CEO, Dr Ellen Skladzien. Ellen took DSA to a level

that saw us not only 'punch well and truly above our weight', but also gave us a seat at the table for all the important decisions around the rollout of the NDIS. Under her leadership, we also became an accredited Non-government organisation at the Conference of States Parties to the United Nations to the Convention on the Rights of Persons with Disabilities.

Ellen was also instrumental in assisting me with reforms to ensure DSA practiced best governance and constitution change. These initiatives included the formation of the Down Syndrome Advisory Network (DSAN), which saw people with Down syndrome advising the DSA Board on issues that directly impacted them. For example, the DSAN said wanted a person with Down syndrome on the Board. As a result, we ensured the structure and supports were in place and the DSA Board appointed Claire Mitchell as a director in 2020. Claire is the first person with Down syndrome to be appointed to the DSA Board but won't be the last. She has made an extraordinary contribution and brings an important perspective to the Board

table and reminds us constantly of the guiding principle of the disability rights movement: 'with us, not for us'.

DSA recently appointed our third CEO, Darryl Steff. Darryl has continued to build on the legacy of Catherine and Ellen, ensuring DSA is the national voice for people with Down syndrome and their families and a go-to organisation for Government funding and advice. Thanks to the dedicated work of both Ellen and Darryl, DSA has been a key contributor to the successful consortium that will operate the National Centre of Excellence in Intellectual Disability Health. The Centre is an Australian first, bringing together the best minds in advocacy, clinical and research experience in intellectual disability health to ensure people with intellectual disability have improved access to quality, timely and comprehensive health care.

*Looking back, we have achieved a lot together. Personally, it has been more than a privilege to work with so many dedicated, collaborative, passionate people – it's been inspiring.*





Nationally and internationally, DSA has made an impact, delivering better outcomes for people with Down syndrome at home and abroad. I am so proud of everything our organisation and our people have achieved. In saying goodbye, there are too many people for me to thank everyone personally. However, in addition to those I have already mentioned, there are some individuals who deserve singling out. Thank you to Prof Kirsten Deane OAM, who has been a constant support since day one and I simply say that DSA would not be where it is today without her. Thank you to Grant Lindsay as well. As Deputy Chair since the beginning, Grant's friendship, advice and pragmatism has been enormously appreciated. Grant, it has been a great pleasure to have worked alongside you. Finally, we can never fulfil these roles with the support of our families; to mine I say thank you for all your love, patience and understanding.

The new leadership team – led by Dr Rebecca Kelly as Chair and David Fuller as Deputy, with Peter Murray as Treasurer and the very hard working and talented Darryl Steff as CEO – will take DSA to

the next stage in its development and continue its trajectory as a world-leading advocacy body for people with Down syndrome and intellectual disability.

*Great advocacy is about hard work, great policy and authenticity. DSA is doing this important work extremely well and I am immensely proud of the organisation it has become and the real impact it makes in the lives of people with Down syndrome and their families.*

I look forward to seeing you all at the World Down Syndrome Congress in Brisbane next July, to celebrate, learn, share and connect with the international Down syndrome community.

**Angus Graham OAM**  
Outgoing Chairman

# A Message from the Treasurer

The 2022/2023 financial year has been another year of growth for Down Syndrome Australia, in revenue, staff and impact as the national voice of people with Down syndrome and their families.

During 2022/2023, 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 funding from NDIA to support our work with the NDIA on co-design and input on reforms. DSA is proud to receive funding as the peak body for people with Down syndrome and their families in Australia and be one of the few peak bodies that receive federal funding. All the grants we have received have been in line with the strategic objectives of the organisation, as the national voice of people with Down syndrome and their families.

Through the support of a grant from the Sherry Hogan Foundation, we held a well-

attended national self-advocates forum and are progressing with a development of our fundraising strategy to continue to diversify our revenue streams. The Scrapheap Adventure Ride continues to raise significant funds for Down Syndrome Australia, which will be used to deliver projects to people with Down Syndrome and their families in rural and remote Australia.

Revenue for 2022/23 was \$3,150,815, mostly derived from Government Grants which is an increase on the 2021/2022 revenue of \$2,828,227. In line with this and the expenditure required to complete projects, expenses for 2022/23 increased from \$2,647,358 (2021/2022) to \$3,009,059. It should be noted that a significant amount of that expenditure (\$1.8 million) was provided to our Member organisations to deliver projects at a local level which enables the most effective and efficient project delivery.

At year end, our 2022/23 assets were \$3,158,257 compared to \$2,190,934 in

2021/2022. And our final total equity was \$553,539 compared to \$411,783 in 2021/2022.

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 across Australia. 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**  
Outgoing Treasurer



**Peter Murray**  
Incoming Treasurer

# Financial information



## Balance Sheet

Balance Sheet as at	30-Jun-23 \$	30-Jun-22 \$
<b>What we own</b>		
Money in the bank	2,867,203	2,109,166
Money and services owed to us by other organisations and people	283,831	78,759
Office equipment we own	7,223	3,009
<b>Total</b>	<b>3,158,257</b>	<b>2,190,934</b>
<b>What we owe</b>		
Money we owe other organisations and people	261,184	65,014
Money we need to spend on delivering grant activities	2,308,460	1,680,844
Money we owe our staff when they take leave	35,074	33,293
<b>Total</b>	<b>2,604,718</b>	<b>1,779,151</b>
<b>How much money would be left if we sell everything we own and pay all the money we owe:</b>	<b>553,539</b>	<b>411,783</b>



## Income Statement

Income Statement for the year ended	30-Jun-23 \$	30-Jun-22 \$
<b>How much money we earned</b>		
Donations from people and organisations	209,276	235,518
Money we earned for grant activities	2,845,554	2,506,491
Money we received from Member organisations	61,200	61,150
Other money we have received	34,785	25,118
<b>Total</b>	<b>3,150,815</b>	<b>2,828,277</b>
<b>How much money we spent</b>		
Money we paid for accounting and audit services	34,064	31,756
Money we paid for marketing and communications	41,523	123,349
Money we reimbursed the Board for expenses and travel	33,809	26,564
Money we paid to go to conferences, meetings and events	36,994	964
Money we paid for travel and accommodation	131,325	43,575
Money we paid for fundraising	20,638	16,507
Money we paid for publication, design and printing	43,483	40,855
Money we paid to Member organisations to deliver grants and other activities	1,820,604	1,739,470
Money we paid to our staff	706,368	550,269
Money we paid for IT services	45,956	23,014
Other money we spent	94,295	51,035
<b>Total</b>	<b>3,009,059</b>	<b>2,647,358</b>
<b>How much money we have left</b>	<b>141,756</b>	<b>180,919</b>

# World Down Syndrome Congress



On behalf of the Local Organising Committee of the World Down Syndrome Congress (WDSC) 2024, it is our great pleasure to invite you to attend WDSC 2024 in Brisbane, Australia.

This international conference brings together people with Down syndrome, family members, researchers and service providers to showcase the latest research and best practice as well as the lived experience of Down syndrome from around the world.

The Congress supports the ongoing agenda of Down Syndrome International: to improve quality of life for people with Down syndrome worldwide and promote their inherent right to be accepted and included as valued and equal members of their communities.

To find out more about Congress, including registration for tickets or submitting an abstract for a presentation please visit the Congress web page <https://wdsc2024.org.au/>.

We look forward to seeing you in Brisbane!



**Angus Graham OAM**  
Congress Co-Chair



**Rhonda Faragher, AO**  
Congress Co-Chair

## World Down Syndrome Congress Sponsorships and Scholarships

Thanks to the generosity of the Sherry Hogan Foundation DSA has a Celebrating Diversity and Inclusion sponsorship program and a Together We Can Scholarship program, to assist people with Down syndrome to attend the Congress.

Both programs cover the travel costs for deserving individuals and their support people to attend Congress, who would otherwise be unable to attend due to financial limitations.

The Together We Can Scholarship program will also offer recipients mentoring from DSA and training in public speaking to assist with the delivery of a presentation at Congress. Recipients will also go through DSA's leadership program, Becoming a Leader, to further support personal and professional development.

To find out more about these programs visit our website <https://wdsc2024.org.au/>.



# Down Syndrome Advisory Network

The Down Syndrome Advisory Network (DSAN) gives advice to the Down Syndrome Australia Board. This makes sure DSA receives direct input from Australians with Down syndrome on issues that affect us. We continue to advocate for the rights of people with Down syndrome on both a national and international level, building and demonstrating our leadership in all that we do.



## Key achievements for the financial year



Completed the **DSAN review** to ensure continuous improvement for its members and DSA.



DSAN contributed to the **NDIS Review** with a focus on improving planning meetings.



Kylie Scott presented at the **United Nations in New York** as part of World Down Syndrome Day.



DSAN did other work for the NDIA on **protecting the NDIS and participants** from fraud and scams.



Lauren Murray represented DSAN at DSA's **World Down Syndrome Day** events in Canberra and met with NDIS Minister Shorten.



Some DSAN members attended **VALID's Having a Say conference** and did a presentation.



## Down Syndrome Advisory Network members

**Claire Mitchell, Queensland**

Appointed November 2017

**Kylie Scott, New South Wales**

Appointed November 2017

**Lauren Murray, Australian Capital Territory**

Appointed March 2020

**Andrew Domahidy, Western Australia**

Appointed November 2017

**Jenny Bowden, Victoria**

Appointed August 2020

**Elise Romaszko, Tasmania**

Appointed August 2020

**Bella Kobayashi, South Australia**

Appointed September 2023

**Lisa Tiernan, Northern Territory**

Appointed September 2023

**“ I want them to ask me what is important for me to live a good life and I want them to listen to me. ”**

Jenny Bowden, VIC

# Advocacy

**Our advocacy works makes change and helps us achieve our vision.**

We ensure people with Down syndrome are at the centre of our advocacy work.

Our approach is informed by our values of inclusion, collaboration, trust and respect.

We support people to build self-advocacy skills and take on leadership roles.

We work in partnership with our member organisations, government, disability representative organisations and the broader community.



## Key Advocacy Areas

We have asked the Australian Government to act on six key areas to ensure the rights of people with Down syndrome and their families are realised:



**Prenatal screening**



**Health**



**NDIS**



**Education**



**Employment**



**Migration**

To read more about our Advocacy Asks and our advocacy work, visit our website <https://www.downsyndrome.org.au/advocacy/>.



## Key Achievements

- Advocacy Asks released on World Down Syndrome Day
- Ongoing meetings with key Ministers and Advisors
- Self-Advocacy Forum held in Canberra
- National Centre of Excellence for Intellectual Disability Health funded
- Continued collaboration with Good Things Foundation on promoting digital literacy for people with intellectual disabilities
- Building stronger relationships and partnering more with other organisations including Disability Advocacy Network Australia (DANA), Australian Federation of Disability Organisations (AFDO) and Inclusion Australia.
- Membership of Down Syndrome International, Inclusion International, Asia Pacific Down Syndrome Federation, Australian Federation of Disability Organisations and Australian Council of Social Service

## DSA Submissions

DSA made a range of submissions to government departments to let them know what is important to people with Down syndrome, including:

- Early Years Strategy submission to Department of Social Services
- Early Childhood Statement to Children and Young People with Disability
- National Health Literacy Strategy Framework and Intellectual Disability Health Capabilities to Department of Health and Aged Care.
- Universal access to reproductive healthcare, focusing on prenatal screening to Senate Enquiry
- NDIS Platform Providers to NDIA
- National Care and Support Economy Strategy 2023 to Office of Prime Minister and Cabinet
- NDIS Review



## Joint submissions

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We also worked with other Disability Representative Organisations (DROs) on joint submissions and contributed to some of their submissions:

- Provision of Access to Dental Services in Australia
- NDIS CALD Strategy plus Culture and Competence of NDIA
- Review of the Transport Standards 2022
- Assessment and Support Services for people with ADHD
- Administrative Appeals Tribunal Enquiry; for a new system of federal administrative reviews including NDIS appeals
- Joint Standing Committee on Electoral Matters
- Disability Services and Inclusion Act
- Australia's Disability Strategy 2021 – 2031 Consultations to inform the guide for Guiding Principles.

Working with other DROs brings a united voice from people with disability and ensures the voices of people with Down syndrome and their families are included and heard.



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**Thank you to everyone from DSA and our Member organisations for your contributions to these valuable submissions.**

DSA are also involved in over 30 advisory groups and committees. Some of these groups are with the Department of Social Services, Department of Health, NDIA and Services Australia. Having a seat at the table contributes to our advocacy work by giving us direct links with decision makers.

# Down Syndrome Australia at the Conference of States Parties

In June 2023 Down Syndrome Australia representatives Board Chair Angus Graham OAM, CEO Darryl Steff, Health Ambassador Olivia Sidhu and Health Program Manager Natalie Graham attended the 16th session of the Conference of States Parties (COSP) to the CRPD at the United Nations Headquarters in New York.

## Key highlights from DSA's attendance at COSP:

- Delivering 4 formal presentations across COSP and the Civil Society
- Delivering a side event in conjunction with Down Syndrome International and National Down Syndrome Society
- Attending more than 10 other side events and networking events
- The opportunity to engage with other organisations working with people with intellectual disability
- The ability to showcase and share some of the great work going on around the world in self-advocacy, by the self-advocates
- The ability for delegates to see self-advocates in action talking about their work and the importance of them being supported to be self-advocates
- The benefits of learnings from other countries on matters we are familiar with



- Improving our understanding of the challenges that people with disability face in other countries
- Increasing our knowledge into UNCRPD implementation
- Increasing our knowledge of different approaches to inclusive practices
- Increased awareness and visibility of DSA internationally

To read more about our attendance at COSP visit our web page (<https://www.downsyndrome.org.au/blog/2023/06/30/dsa-attends-cosp16/>)





It is so important that the person who has Down syndrome should go to COSP and speak because they have a powerful and motivational message to get the message across. It is so important and we are making a difference in everyone's lives and raising awareness for people who are living with Down syndrome.



*Olivia Sidhu, DSA Health Ambassador*



*Down Syndrome Australia received funding to attend COSP as part of the Australian delegation from the Department of Social Services. DSA is grateful for the support provided by the Department to attend such an important event.*



As part of the project DSA employs 10 people with Down syndrome to work as trainers, educators and advisors to build the capacity of the health sector workforce. These 10 Health Ambassadors deliver training to tertiary students studying in diverse health fields and health professionals already employed in the health sector and they undertake a range of broader advocacy focused activities.

### Project Achievements for the Financial Year

- Finalist in the 2022 HESTA Disability Services Awards – Team Excellence
- Further education and capacity building for the Health Ambassador Team with a 2-day conference in Melbourne
- Evaluation of the Health Ambassador Program by Swinburne University of Technology, Centre for Social Impact
- Delivered over 30 education sessions to over 2,200 students studying in diverse health fields, health professionals already employed in the health sector and Primary Health Networks

## Inclusive Communication in Healthcare

The 'Inclusive Communication: Improving Health Outcomes for People with Down syndrome' program is funded by the Department of Social Services, within the Mainstream Capacity Building stream of the Information, Linkages and Capacity Building grant scheme. The project educates healthcare professionals and students of health about Down syndrome, intellectual disability, and inclusive communication.



- Launch of the DSA Good Health App <https://www.downsyndrome.org.au/resources/apps/down-syndrome-good-health-app/>
- Launch of the DSA Health Record App <https://www.downsyndrome.org.au/resources/apps/down-syndrome-health-record-app/>
- Launch of the free online learning package Down Syndrome: The Essentials, designed to empower and enable healthcare professionals to provide the best care and support for people with Down syndrome. The e.learn is accredited by the Royal Australian College of General Practitioners for 6 CPD points. <https://study.unimelb.edu.au/find/short-courses/down-syndrome-the-essentials/>

**“ I’m a confident speaker and communicator. I’m good at making connections and getting other people’s voice heard too. ”**

**Gillian Gehrke,  
DSA Health Ambassador**



- The Health Ambassadors participated in national steering and advisory committees including:
  - The National Roadmap for Improving the Health of People with Intellectual Disability
  - The Lived Experience Reference Group for the Department of Developmental Disability Neuropsychiatry
  - Presentation to the Australian Government Department of Health and Aged Care Disability and Health Sector Consultation Committee (DHSCC) Primary Care Division
  - Participation in NHMRC Partnership Project: Preventive healthcare for People with Intellectual Disability Department of Developmental Disability Neuropsychiatry (3DN) and University of NSW
  - Co design and advisors to resources for the NSW Statewide Intellectual Disability Mental Health Outreach Service (SIDMHOS)



## DSA Health Ambassadors

**Alishia Lindsay**, Northern Territory

**Amelia Sloan**, Victoria

**Caitlin Woolley**, Queensland

**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

“A big thank you. I thought this was an extremely valuable presentation. There needs to be more of this in hospitals, to create better awareness to ensure health care workers are giving people with a disability a better voice to give them power over their own health and health outcomes.”

Nurse



“Thank you for taking the time to come and talk to us, it was a great presentation and I look forward to implementing this into my future practice as a nurse.”

Nursing student

“I love giving the presentation and talks and speeches to the other health professionals, doctors, students and the public.”

Emily Porter,  
DSA Health Ambassador

“I like working for DSA because we get to make choices and to help get better health outcomes for others.”

Hugo Taheny,  
DSA Health Ambassador



# Pathways to Independence

Down Syndrome Australia's Pathways to Independence project delivers workshops across the country for both adults with Down syndrome and their families, as part of our Individual Capacity Building grant.

People with Down syndrome have been employed as peer facilitators and are involved with delivering the workshops in each state and territory through our Member organisations.

**ff** *I have never been away with my work colleagues before and that means a lot to me.*

*It was a new experience and I have never had that opportunity before and that made feel proud.*

*It also meant a lot to me because I could be independent.* **ff**

Co-host with Down syndrome after travelling to regional Australia to present

## Project Achievements for the Financial Year



**27**  
**Pathways to Independence**  
workshops were held



**14**  
**workshop topics**  
delivered



**17**  
face-to-face



**10**  
online



**17**  
workshops were  
for people with  
Down syndrome



**10**  
workshops  
were run  
for families



**89**  
people with  
Down syndrome  
attended



**112**  
family  
members  
attended



**5**  
workshops were facilitated nationally  
by Down Syndrome Australia



**22**  
workshops were run by the state and  
territory Down Syndrome Associations



# Right to Work

Down Syndrome Australia's Right to Work project addresses the barriers people with Down syndrome face when trying to get a job in open employment.

The project includes four key components which are delivered in conjunction with our Member organisations:

- 1** Delivering the DSA developed **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.
- 2** DSA has 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.
- 3** The **Employment Connection Service** which assists in placing people with Down syndrome into jobs and providing information to employers.
- 4** The **Right to Work Awareness Campaign** which showcases employment stories from across Australia to directly challenge negative misconceptions about what it means to hire a person Down syndrome by showing the reciprocal benefits of employing them to be part of the team.



## Project Achievements for the Financial Year



**57**

people with Down syndrome placed in employment



**11**

**Employment Ambassadors** employed to assist with the delivery of the project



**1**

Employment ambassador presentation at **Speak Out Conference**



**32**

**Employment success stories** developed and shared



**38**

people with Down syndrome have completed the **work readiness program**



**71**

**families supported** through the project to learn more about employment for people with Down syndrome



**6**

employment stories were developed for our **World Down Syndrome Day awareness campaign** in March 2023



Information and resources provided to

**256 EMPLOYERS**



**Jobs and Skills Summit** attended by **2** employment ambassadors



National awareness campaign on employment

**OVERALL REACH**

**490,260**

**ENGAGEMENT RATE**

**41,445**

through our social channels



AND REACHED OVER

**45,200**

accounts across

**Facebook and Instagram**



## Case Study

Through this grant, ACT Down Syndrome Association (ACTDSA) supported a young man with Down syndrome to obtain employment with a local company, GoBoat. The role that was advertised was customer service with the plan that as the employee grew more confident, more hours would be offered, and the role tailored. ACTDSA provided extensive support to GoBoat to prepare for the young man's start and GoBoat staff were provided with training in Easy English to create task cards.



GoBoat's training and expectations of their employee has gone above and beyond the expectations of the role. The young man is now completing all customer service tasks, including assisting customers to dock their boat which involves turning and tying the boat independently.

The skills that both the employee with Down syndrome and GoBoat have gained, have been substantial. GoBoat are now able to cater to a wide variety of customer needs, and the employee has developed not only employment skills but life skills that he will take with him.

## 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

**Lisa Tiernan,**  
Northern Territory

# Digital Engagement

 **372,837**  
total web page views  
across the national and  
Federation websites

 **14,851**  
resources  
were downloaded from  
our national website and  
resource hub

**voice**  
OUR FIRST FULLY DIGITAL COPY  
of *Voice* was issued to  
**3,741**  
subscribers


 Our posts  
on Facebook  
had a total reach of  
**427,701**

 OUR TWEETS HAD OVER  
**107,891**  
impressions

 Our posts  
on Instagram  
had a total reach of  
**5,290**

Our newsletters  
reached over  
**93,500**  
people 

 OUR  
website  
upgrades  
reached their final stages  
prior to launch in  
**August 2023**

Our national **parents and  
carers survey** had over  
**100** responses  
**84%** FOUND DSA'S  
RESOURCES RELEVANT  
**92%** FOUND DSA'S  
RESOURCES EASY TO USE 

# Information Service South Australia

The Information Service in South Australia continues to bring together the South Australian Down syndrome community, by linking parents, professionals, and service providers to specialised services and up-to-date information.

## Achievements for the Financial Year



OVER  
**170**

attended our **World Down Syndrome Day** Celebration at the Adelaide Zoo



Commencement of the **Primary Kids** play sessions



**Puberty workshop**

delivered to  
**16** PARENTS



**StepUP!**

picnic in celebration of **Down Syndrome Awareness Month**



COMMENCED  
**new parents and early years**

morning tea and information sessions, held once per term



**300**

Facebook followers



**ff** Events such as World Down Syndrome Day at the zoo are especially vital for us as they provide an opportunity to connect with other families, our siblings to connect with other siblings and our child to connect with other children with the same diagnosis. We have met many other families and made lifelong friends in doing so.

As a family we find it particularly special to have the opportunity to see and meet people with Down syndrome and their families from all ages across the lifespan. Having that opportunity to see a glimpse into the future, especially as new(ish) parents, provides great comfort, reassurance and hope unlike anything we would find elsewhere.

We cannot thank Down Syndrome Australia – South Australia Information Service for giving us this opportunity and providing our whole family such a positive, heart-warming experience that we are sure to remember for a long time to come. **ff**

**Jennifer and Daniel McCullough**



# Our Organisation

## Our Board

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**Dr Rebecca Kelly** – Chair

**David Fuller** – Deputy Chair

**Peter Murray** – Treasurer

**Angus Graham**

**Grant Lindsay**

**Claire Mitchell**

**Dr Rhonda Faragher**

**Katrina Enos**

**Catia Malaquias**

**Rene Pennock**

Read more about our Board of Directors

<https://www.downsyndrome.org.au/national/our-board/>

## Our Life Members

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Dr Ellen Skladzien



*In recognition of her significant contribution to DSA, Dr Ellen Skladzien was awarded Life Membership to Down Syndrome Australia on World Down Syndrome Day 2023 at a presentation at Government House, with our Patron the Honourable David Hurley.*

## Our Member Organisations

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ACT Down Syndrome Association

Down Syndrome New South Wales

Down Syndrome Queensland

Down Syndrome Tasmania

Down Syndrome Victoria

Down Syndrome Western Australia

## Our Memberships

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Down Syndrome International

Inclusion International

Asia Pacific Down Syndrome Federation

Australian Federation of  
Disability Organisations

Australian Council of Social Service

# Donors, Sponsors and Supporters

We would like to acknowledge the following individuals and organisations for their valued support the in 2022/23 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

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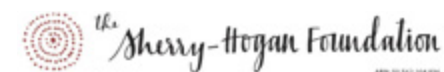
Axis Toys	Kmart Australia
Bill Wilkin	Kerry Hall
Brendon Campbell	Kevin Irwin
Chia-Lung Tai	Les and Jane Johnston
Chris Marsh	Liquor Industry Golf Club of SA Inc
Clare Coyle	Marian Gavin
Colin Meacham	Mark Neuer
Damian Rinaldi	Moe Kadhom
David Bailey	Patrick Cooper
Denise Ladwig	Peter Donkin
Gaetano Turrisi	Sandra Woods
Glen Wickens	Sharon Cashen
Graham Gibson	Sonya Hough
Illume Learning	Timothy Childs
Joe Thompson	Tony Woods
Judy Anderson	RB Sellars
Karen Gargalis	



## Trusts and Foundations

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Sherry-Hogan Foundation



## Fundraising Initiative

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Perry Gilsenan and Scrapheap  
Adventure Ride

## Government Funding

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Department of Health  
Department of Social Services  
National Disability Insurance Agency  
City of Adelaide  
Tourism and Events Queensland  
Brisbane Australia

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 [www.downsyndrome.org.au](http://www.downsyndrome.org.au)



Down Syndrome  
Australia