

DSA Country Update

2022 has been a productive and busy year for Down Syndrome Australia. We have continued our focus on advocating to Government for greater inclusion, supporting and developing the capacity of our members to be self-advocates as well as providing evidenced-based national information to people with Down syndrome, our families, and the community.

National Disability Insurance Scheme

In Australia the main funding source for services for people with disability is through the National Disability Insurance Scheme. DSA has been working hard to make sure that the Government Agency responsible for the scheme (NDIA) are considering the needs of people with Down syndrome in all the work that they do and the reforms they make to the Scheme. DSA has been involved in a range of different ways including through involvement in reform work on Information Gathering and Planning as well as a Co-design advisory group. In addition, we have had the opportunity to run a range of focus groups for the NDIA with people with Down syndrome to ensure that the experiences of people with Down syndrome are heard by the government agency.

Health

Down Syndrome Australia has been advocating for better health care for people with Down syndrome in Australia. This has included:

- Involvement in the implementation of the National Roadmap on Intellectual Disability and Health
- 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 and videos for people with Down syndrome and their families about the COVID-19 vaccine rollout.
- The DSA Health Ambassadors continue to raise awareness about the needs of people with Down syndrome in the health system through presentations and workshops with medical students, health professionals and international forums including in regional areas. The Health Ambassadors have presented to more than 1000 university students and clinicians in allied health, nursing, and medicine. They have also been involved in a range of Government committees. The Health Ambassadors were nominated as finalists in the 2022 HESTA Excellence Awards for their efforts to inform and educate health care professionals on how to include people with Down syndrome in their own healthcare decisions.
- DSA is developing high-quality evidenced based e-learning for GP's and other Health Professionals which will be hosted on the University of Melbourne Platform and will be RACGP accredited.
- In the 2022 October Budget, the Government has committed \$23.9 million over four years from 2022-23 for the National Centre on Intellectual Disability and Health, with funding to continue beyond those four years. There will be a tender process for the Centre in early 2023. DSA has started discussions with partners around the possibility of a consortium approach to the tender.

- DSA has developed two new Health-Apps for people with Down syndrome and their families.
 - The Down Syndrome Good Health App is available now on the App Store to download: <https://apple.co/3XkZ2QP>. This new health app is for adults with Down syndrome to keep a diary of daily meals, water, exercise, and activities.
 - The Down Syndrome Health Record App is available now on the App Store to download: <https://apple.co/3TX3AtV>. This new health record app is for parents and support people of children with Down syndrome. The Down Syndrome Health Record App assists parents and support people of children with Down syndrome to record and monitor their child's health, growth, and development.

Employment

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.
- **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 more than 30 people with Down syndrome into jobs and provided information to 232 employers.
- **Right to Work Awareness Campaign**
 - The Right to Work Awareness Campaign highlighted 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.

DSA was also pleased to be able to attend the NDIS Jobs and Skills Forum which was held in Canberra to provide NDIS participants and their families the opportunity to discuss how to increase economic participation of NDIS participants and explore solutions for people to join the workforce. DSA Employment Ambassadors Keziah Glenane, Charlotte Bailey and Kenichi Gray attended the Forum with DSA CEO Ellen Skladzien to give their own insights into what needs to be done to improve the system.

Involvement at the United Nations

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 COSPI5. 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. Attendance at COSPI5 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.

Information/Resources

DSA has continued to develop our range of resources on the National Resources Hub ([Resource Hub – Down Syndrome Australia](#)). Some of the key new resources in 2022 include:

- New resources on Covid-19 and vaccinations ([COVID-19 – Down Syndrome Australia](#))
- Translations of Relationships guide into 8 languages- [Translations – Down Syndrome Australia](#)
- New resources on Voting (Plain English and Easy Read)
- Information for New Zealanders on community services
- New webpages on statistics on Down syndrome ([Population Statistics – Down Syndrome Australia](#))

Our CEO also worked with international colleagues on a published research report regarding the prevalence of people with Down syndrome in Australia and New Zealand. A fact sheet about that report can be found here: <https://go.downsyndromepopulation.org/australia-factsheet>

Congress

Down Syndrome Australia is also busy starting our planning for the World Down Syndrome Congress in 2024 which will be held in Brisbane. We hope to be able to welcome many of our APDSF colleagues to the Conference- and would appreciate any support in promoting the event. [World Down Syndrome Congress \(wdsc2024.org.au\)](#)

Staff Changes

At the end of this year, we will have a change in our CEO of Down Syndrome Australia. After 6 years of leading DSA, Dr Ellen Skladzien has decided to resign from her role. We are very pleased to be welcoming Mr Darryl Steff into the role at Down Syndrome Australia in July 2023. Darryl is currently the CEO of Down Syndrome Queensland and will come into the position with a great deal of background and experience. [New Down Syndrome Australia CEO appointed – Down Syndrome Australia](#)