



Impact Report

2024-2025

DOWN SYNDROME
NEW SOUTH WALES



>>> President's Report



Looking back over the last year of our work together for members of Down Syndrome NSW and my first year having the privilege of serving as President,

my overall feeling is of appreciation, gratitude and pride at what we have been able to achieve together in this short time. After the previous period of challenge and loss, together we have renewed our focus on our main purpose, strengthened and broadened relationships to support that purpose, doubled down on strong governance and collective accountability, and done the hard work of reflection, change and renewal. The Board and team of DSNSW have pulled together united in our collective focus on supporting and advocating for the needs of members and elevating the diverse voices and interests of members.

Some key achievements in this period of renewal include completing the joint work for our new Constitution which members resoundingly supported and adopted; conducting a thorough governance and accountability review; turning around DSNSW financial position from 2023/24 deficit to a 2025 surplus setting our association up for the next year of exciting plans and refreshing our genuine commitment to outreach to members across the state.

The work of the last year has included laying the foundations for greater inclusion of members in the governance

of the organisation. We have begun renewal of using sub-committees to more formally bring member contributions into governance, such as the Constitution Sub-committee and soon to be established Sub-committee on Ageing. Importantly the new Down Syndrome NSW Constitution now formalises leadership roles of people with Down Syndrome in the organisation's governance. It guarantees three Board positions to be held by adults with Down Syndrome elected by the soon to be launched Down Syndrome Network. The Network will bring together young people and adults with Down Syndrome to network, share ideas and learn, build self-advocacy capacity, set priorities important to them and shape the agenda and policies for the organisation.

It is with great appreciation that we acknowledge that whilst facing the challenges and change of the last year of renewal, the team at DSNSW has continued to deliver amazing results across our programs and services.

- » More than 450 health care professionals were educated in best practice pre and post natal diagnosis communication for parents and future parents of people with Down syndrome. This included midwives, nurses, doctors, genetic counsellors, OTs, speech, social workers, paediatricians, obstetricians.
- » Information, referral and support was provided to over 1600 people who made contact via phone, email and the website.

- » Down Syndrome NSW delivered a significant expansion of its Inclusive Education Program, with more than 90 school support services delivered, including 30 training sessions delivered in schools and support for 47 families.

We particularly appreciate the support and leadership of Deb Begg, General Manager Strategy and Change who with skill, commitment and grace took on the complex tasks set for her to refocus and renew the organisation and its operations.

With great sadness we express our deep gratitude for Lorraine Clark AM our past Down Syndrome NSW President who passed away this year. Lorraine was a passionate advocate, a trailblazer, and a cherished member of the Down Syndrome NSW community.

Lorraine dedicated much of her life to improving opportunities for people with intellectual disability. Her tireless advocacy and unwavering belief in inclusion made a profound and lasting difference to so many families.

Lorraine volunteered with Down Syndrome NSW over many years in a range of roles, with her most recent being as President from 2021 to 2024. In every role, she brought fierce commitment to ensuring people with Down syndrome and their families had a strong voice.

Her experiences as the mother of Gabrielle led to a lifelong passion for upholding the rights of people with intellectual disability, and promoting

the role of sport and community participation in building meaningful, healthy lives. During her time with Down Syndrome NSW, Lorraine played a key role in bringing the World Down Syndrome Congress to Sydney. She championed the development of a volunteer-led social program for adults with Down syndrome, advocated for improved health outcomes, and consistently worked to elevate the voices and needs of families. She was also a strong advocate for ensuring people with intellectual disability had meaningful opportunities to lead, speak, and be heard in their own right.

In 2019, Lorraine was awarded a Member of the Order of Australia (AM) for significant service to people with intellectual disability through her work with Special Olympics Australia.

It has been a big year for Down Syndrome NSW. I greatly appreciate the commitment and collaborative hard work of the Down Syndrome NSW Board to achieve so much in a short time. Now renewed and refreshed we are ready for a strong, invigorated and focused future of meaningful member inclusion, delivering support in ways that are needed, led and valued by members and a strong organisation to support achieving members' directions.

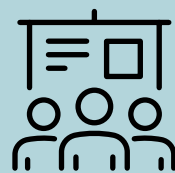
I thank you for the privilege of working with you.

Carolyn Quinn

>>> Workshop/Events

This year, Down Syndrome NSW proudly delivered a diverse calendar of events and workshops that brought our community together, celebrated inclusion, and shared knowledge. A standout moment was our first-ever Donor Recognition Event at Government House, where we honoured the generosity of our partners and supporters in a remarkable setting. Our flagship UP! For Fun event, once again created a space for families to connect, enjoy inclusive activities, and celebrate the vibrancy of our community.

Our workshops, offered both online and in person, were another highlight of the year. These sessions covered a broad range of topics relevant to families, people with Down syndrome, educators, and professionals, providing practical strategies and resources to support individuals with Down syndrome across all life stages. The flexibility of online workshops increased accessibility for families across NSW, while in-person sessions provided opportunities for connection and collaboration. Together, these programs equipped parents, carers, and professionals with tools to build confidence, inclusion, and stronger pathways for people with Down syndrome.



31

Workshops and member events

700

Total attendees at workshops and member events

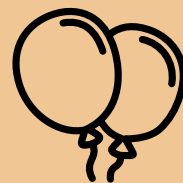


“

The webinar we attended the other day was fantastic, we were scribbling notes, discussing as a team and gave us future food for thought. We can not wait for more. ”

Workshop Participant

>>> Social Programs



94

social program events
– online and in person

250

participants
and families



UP! UP! and Away & UP! Club

After almost a year's break, UP! UP! and Away returned this April with a School Holiday Easter Event, proudly funded by the CUW grant, giving families the chance to come together at no cost and share in Easter crafting and activity fun.

UP! Club Camps continued to foster growth, with the peer mentor and supervisor program providing valuable spaces for leadership, self-advocacy, and problem-solving. Parents shared that time away on camps and Travel Clubs has led to noticeable improvements in their children's independence, social skills, and confidence.

“

DSNSW have been instrumental in supporting and guiding me with my brother, since 2018. Through assistance with transition from his group home of 20 years to an independent living apartment... they have provided information, education and encouragement.

”

Family Member



The Congratulations Initiative



The Congratulations Initiative continued to be a cornerstone of support for families this year, providing resources, connection, and care during the prenatal and early parenting journey. Our Congratulations initiative webpage that hosts family and health professional digital information packs was accessed on average 140 times a month, while 30 physical prenatal and new baby packs were distributed. Thirteen families received personal visits in hospital or at home, giving parents the chance to ask questions, access resources, and receive face-to-face encouragement.

Four New Babies Days brought together 33 families and 150 participants across Sydney, offering expert presentations from speech therapists, occupational therapists, and early childhood professionals, as well as vital opportunities for families to connect. Alongside this, fortnightly Online Catch Ups proved a consistent source of peer connection, with 97 participants attending across 22 sessions.

The initiative also strengthened partnerships with health professionals, delivering nine in-service presentations at hospitals, health networks, and professional seminars, reaching more than 450 practitioners. These sessions focused on best practice in prenatal and postnatal diagnosis, emphasising lived experience and the importance of respectful, supportive language when speaking with families.

Feedback has been overwhelmingly positive, with health professionals valuing both the practical resources and real-life insights shared. Stories from families whether navigating loss, celebrating new life, or finding reassurance through peer support highlight the profound impact of the Congratulations Initiative in fostering confidence, resilience, and community for new parents across NSW.

“

Brilliant presenter very useful information and so informative. ”

Midwife, North Shore Private

Support for Families and Health Professionals

Links to digital copies of pre-natal family, new baby family, and health professionals packs are sent out to all callers on request for information.

Support for Families	
Prenatal and new baby packs	Prenatal = 6 New baby packs = 24
New parent Home and hospital visits	13
New babies days	4
Prenatal and new baby support calls and emails	90
Online Catch Ups	22 sessions with 97 attendees

Support for Health Care Professionals	
<i>Presenting on best practice pre and post natal diagnosis: midwives, nurses, doctors, genetic counsellors, OTs, speech, social workers, paediatricians, obstetricians.</i>	
In services delivered	9
Total attendees at in-services	452
Healthcare professionals pack (physical and digital)	120
Prenatal and new babies support calls and emails	41



140

average
page views
per month

“

Good to meet people I've only seen online, in person connections are way better.”

Workshop Participant

“

A great introduction to DSNSW.”

Family Member



>>> General information



432

website forms
submitted

884

direct phone calls to
the main phone line



**Plus Congrats direct
calls/emails/texts**

18

prenatal

62

new babies

41

health care
professionals

In FY24/25, the Information Services team continued to be a trusted first point of contact for families, professionals, and community members seeking guidance and support. With over 1,600 direct enquiries through phone calls, emails, and website submissions, the team provided personalised advice and resources on a wide range of issues from supporting new parents through our Congratulations Initiative to assisting families navigating complex health, mental health, and ageing concerns.

Alongside this frontline work, the program continued its long-standing educational contribution, presenting to first-year medical students at Notre Dame University for the eighth year in a row. The positive feedback reinforced the importance of sharing lived experience, with students inspired to explore meaningful careers and even volunteer with Down Syndrome NSW.

A significant milestone this year was the launch of the Knowledge Hub on the DSNSW website, which brings together all our resources in one central location, making it easier for families and professionals to find reliable information quickly. In total, 11 new resources were developed across education, employment, volunteering, and partnerships, strengthening the depth and reach of information available to the community. The introduction of the new Contact Us website form also proved highly successful, generating 432 enquiries since launch and streamlining support for new parents, disability organisations, educators, and health professionals. Together, these initiatives have enhanced accessibility, responsiveness, and the impact of our Information Services program ensuring individuals with Down syndrome and their families have the knowledge, tools, and connections they need at every stage of life.

“

Support for regional students like ours is so needed. This was specific, practical, and incredibly helpful. **”**

Workshop participant



“

A wonderful opportunity to enjoy the ‘fellowship’ of parents/carers of a child/ now adult with Down syndrome...I learned – and thoroughly enjoyed being able to laugh at – some of our hurdles and how we accommodated them. ”

Face-to-Face Workshop Participant



>>> Inclusive Education



In FY24/25, Down Syndrome NSW delivered a significant expansion of its Inclusive Education Program, providing support to 92 schools across the state, including through new regional outreach in areas such as Nowra and Lismore. The program was strengthened through Fugen and government grant funding, which enabled the introduction of free support for schools removing financial and geographical barriers to accessing tailored expertise. The cohesive program now offers a full range of services, from behaviour support and curriculum guidance to teacher training and specialist resources. This year, 30 training sessions were delivered in schools, and 16 regional schools received face-to-face support, many for the first time. Positive feedback highlighted the impact of professional learning in transforming teaching practices, particularly in schools within lower socio-economic areas and for educators supporting students from non-English-speaking backgrounds.

Alongside direct school engagement, the team supported 47 families with education-related needs, helping them navigate systems and advocate effectively for their children. Strong demand for online workshops grew, with six sessions delivered exceeding the original target of four including highly successful sessions on literacy, occupational therapy, and numeracy.



92

Support provided to schools
(including multiple provisions of supported within the same school)

47

Parent support re: Education

27

New schools engaged
(Target 20)

30

Training sessions in schools

6

Online workshops
(Target: 4)

16

Regional schools supported

5

New resources
(Target: 4)

>>> Employment Connections



12

placements

6

High School Meetings

2

Regional/Remote
engagement

21

people with Down
syndrome supported

21

family members and
friends supported

3

people with Down
syndrome engaged to
support grant activities

24

meetings with
potential employers

40

meetings with people
with Down syndrome

44

promotion of
Employment
Connections

In FY24/25, the Employment Connections program at Down Syndrome NSW achieved strong outcomes, supporting 21 people with Down syndrome into meaningful pathways, including 12 paid placements well above the original target. This included employment opportunities with the State Theatre, Collective Leisure, and paid roles within DSNSW's own UP! Club, where members gained confidence and new skills.

Partnerships were strengthened with organisations such as the Sydney Swans, with further collaborations confirmed into 2025 and 2026, and outreach extended to major employers including RSPCA, Officeworks, and Chemist Warehouse. The program also engaged with high schools and families, supporting transitions from school to work through meetings, workshops, and tailored visual employment profiles. Importantly, regional outreach expanded, ensuring families outside metro areas could access pathways and support.

A highlight this year was the appointment of Ellen Maher as Employment Ambassador, whose story has inspired employers and families alike. Ellen presented at Parliament House, employer engagement sessions, and donor events, helping shift attitudes around inclusive employment. Other members, such as Taylor Hansen and Ellen Hester, also contributed through grant activities and short-term roles, with Taylor gaining the confidence to pursue more work opportunities. Success stories shared on social media and through the Employment Connections Facebook group sparked wider community interest and increased program enquiries. Innovative collaborations, such as with Sydney University, opened new pathways with people with Down syndrome employed as medical actors and in health advocacy roles. Together, these achievements demonstrate the growing impact of Employment Connections in building inclusive workplaces, strong partnerships, and brighter futures.

>>> Fundraising, Partnerships and Campaigns



30

Partnerships

9

Champions for Change

47

partnership meetings

6

Ambassadors

9

Ambassador activities

4

campaigns and appeals



In FY24/25, partnerships and philanthropy played a vital role in strengthening Down Syndrome NSW's impact. We secured 30 active partnerships which contributed to just under \$240,000 in donations or opportunities for members. The launch of our Champions for Change donor recognition program formalised this support, with nine organisations recognised across Platinum, Gold, Silver, and Bronze levels..

Our Lots of Socks campaign secured 12 new partnerships, reached 3.75 million people on social media, and achieved a donor conversion rate of 12.5% well above industry averages showcasing the power of collaboration, ambassadors, and creative engagement.

“

Since your visit, our student now joins most class activities and now no longer needs 1:1 support at recess and lunch. Thank you again for your support – your visit made a real difference! ”

Face-to-Face Workshop
Participant

Champions for Change

This year marked the first official year of our Champions for Change program, recognising the incredible generosity and commitment of our major supporters. We were proud to celebrate these partners at our inaugural Donor Recognition Event at Government House on World Down Syndrome Day, a memorable occasion to thank them for their leadership and impact.

Bronze

The Haddock Family



Silver



Gregorius Trust



Gold

Platinum



The Davies Family Foundation



 www.downsyndromensw.org.au

 www.instagram.com/downsyndromensw/

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