



Down Syndrome
New South Wales

Impact Report

2023



In Celebration

HONOURING TOM HANCOCK

Tom Hancock's work was most often highly detailed and utilised confident mark making to create intricate webs of lines and personal symbols. It also often incorporated text from favourite songs and movies, incorporating not just titles but actors and characters and sportspeople into the piece.

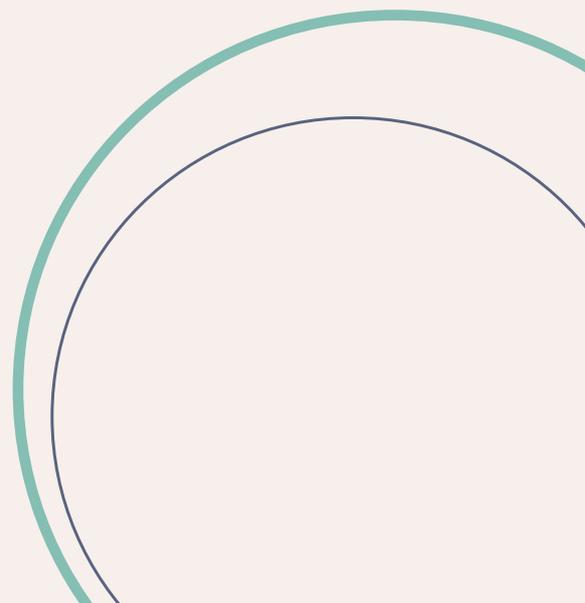
For me it felt like he was mapping his world, linking his interests. It felt a little bit like the American painter Jean-Michel Basquiat, who also incorporated pop culture references in text and image throughout his work. Tom always relaxed and became quite meditative when he worked on his pictures.

He would seem to dive into the detail and become deeply involved in the process of passing the pen or pencil over the paper. If someone else was nearby, sometimes he would break out of that concentration and make an often hilarious comment about what he's drawing; 'It's you!!' he might say of a fun little character with a huge head.

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PRESIDENT'S *Letter*

Over the past year Members of the Board have been successful in governing the organisation known as Down Syndrome New South Wales, Inc. The year 2023 has presented the Board of Directors with some very emotive, yet challenging issues to navigate through to ensure that the needs of our members and families with Down syndrome are prioritised in every representation the board makes.

Down Syndrome NSW Inc was founded in 1980. Our founding members were adamant that parents of people with Down syndrome would benefit greatly by sharing their knowledge and experiences with other families and they worked tirelessly to achieve the recognition we enjoy today.

All members of our board are volunteers who have lived experience which certainly enhances the level of expertise that contributes to the operations management of DSA NSW.

I would like to acknowledge Rene Pennock, Margot Elliffe, Nicholas Gotsis, Lynne Legge, Charles Burfitt and Chris Herbert for sharing their knowledge, enthusiasm, different opinions and new ideas to work with the staff at DSA NSW to ensure the best decisions continue to be made in the best for the benefit of all our members.

As President of DSA NSW Inc I sincerely believe that we have the right mix of individuals on our board to satisfy the needs of our membership with the following skills -

- The ability to commit tapping, on lived experience
- The ability to prepare
- Effective networkers
- Open-mindedness
- Awareness of their impact and input
- Bravery, diligence and patience
- Management of team mentorship
- Being dispassionately 'passionate'

Unfortunately, we do experience at times negative emotion which is normal when the outcome doesn't match up to our plans. However, disappointment is an unavoidable part of the process we are bound by as a board.

There is much more work to be done in the Succession Planning for People with Down syndrome and their families. 2024 we will extend our "Wisdom Lunches" to regional areas to give people the opportunity to gather and discuss the important issues that growing older presents.

I would like to sincerely thank all members of our board for their total support and dedication for people with Down syndrome and their families. You are all "Champions for Change".

The staff at DSA NSW have achieved so many firsts for our association in the past 12 months.

Under the leadership of our CEO Emily Caska, the benefits to members are unprecedented.

Emily will take you through the list of staff achievements in her CEO's report.

A huge THANK YOU to all our dedicated staff and members.



Lorraine Clark AM, President Down Syndrome NSW

CEO Message

Oh what a year we've had in 2022-23. Central to all we do is the best interests of our members, most notably our loved ones with Down syndrome. Following our significant success last year across all metrics, it is pleasing to see another year of upward motion, energy and connection. Our membership continues to grow at a rapid pace, our diversified revenue has increased from last year as has our equity which in short means that we are thriving, sustainable and innovative.

This year marked a significant increase in our engagement, service delivery and influence at all levels of government - local, state, national and international. Our focus this year has been to be there for our members at every stage. The reinvigoration of our Congratulations Initiative is a natural highlight, as is the introduction of Travel Club opportunities for our adults with Down syndrome. We also held not one but two camps this year for teens and adults. Our capacity building workshop series gained much momentum, with our local and international expert partners sharing their knowledge.

Most significantly, our policy and advocacy work has seen a positive shift which in some ways is a return to our influence of years' past as well as new, innovative approaches to ensuring that the voice of people with Down syndrome and their families are heard. We are now an accredited NGO with the United Nations, having attended the Conference of State Parties to the CRPD this year, and we have played a key role in the NDIS Review, Disability Royal Commission and other key policy priorities. This thought leadership by Down Syndrome NSW has seen us be invited as keynote speakers to a range of national conferences, which has served to shine a light on the triumphs and challenges our community face.

My deepest gratitude goes to our Board and our incredible team, the vast majority of whom have lived experience of disability. It often surprises people to know that all we do is made possible by our small but mighty team. Our suppliers too form an important part of our tight knit ecosystem, which means we can direct as much funding as possible to the delivery of services, supports, information and advocacy to our members.

We know there remains more to do and we are more enthused and energised than ever to continue on our trajectory. We are passionately committed to enhancing our support for regional, rural and remote members, as well as strengthening our advocacy and services in the important realms of inclusive education and employment.

Here's to another fabulous year.

This year marks our highest revenue ever, as well as our largest equity. This is a significant achievement and speaks to our sound financial acumen, reputation as a credible organisation and diverse support. This also ensures we continue to thrive and grow long into the future.

Thank you for having me as your CEO. I am beyond humbled to work for you and stand beside you.



Emily Caska, CEO Down Syndrome NSW





Our Impact

Our Expertise

Our Reach

Our Impact in the Past Year

43 years
in operation



290
babies

are born with
Down syndrome
each year



We employ:

- People with Down syndrome
- Parents of children with Down syndrome
- People with lived experience of disability

Facebook

86,473 followers /
5,300,000 reach



Instagram

12,100 followers /
1,739 reach

People with
Down Syndrome
8,000+



Families,
Carers and
Siblings
10,000+



**76 events +
workshops**

283 community
activities

**19 policy
submissions**

4.2 star average
rating for events
+ workshops

**4 star average rating
for satisfaction with
DSNSW**



34 consultations
conducted

**79 government
and interagency
meetings**

1,791 social
media posts

**42 new partnerships
+ ambassadors**

31 memberships to
national, international
and local peaks

**21,072 emails +
phone support**

81 new resources
developed

**83% of staff have
lived experience
of disability**

7 new programs
implemented



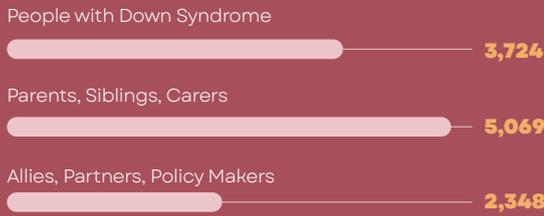




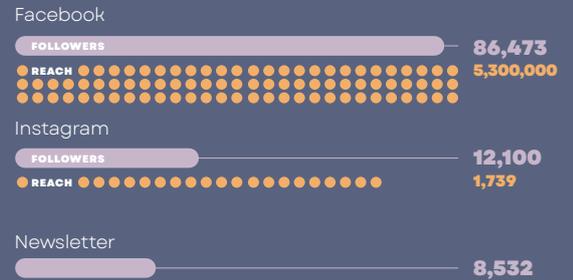
Key Highlights

KEY HIGHLIGHTS

Our Reach



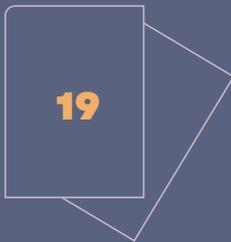
Our Reach



In the past year

19 policy submissions

712 member survey responses



In the past year

76 events + workshops + conferences

283 community activities



In the past year

4.2 star average rating for events + workshops



4 star average rating for satisfaction with DS NSW



In the past year

26 consultations with people with Down Syndrome



79 government and interagency meetings



In the past year

42 new partnerships + ambassadors

31 memberships to national, international and local peaks



In the past year

2,192 social media posts

14 tv + radio + media interviews



In the past year

21,072 emails + phone support

81 new resources developed



In the past year

100% increase in staffing capacity



83% of staff have lived experience of disability



In the past year

Representation on 28 advisory and research groups

Financial sustainability, diversification of revenue and equity increased



In the past year

6 successful fundraising campaigns

7 new programs implemented



KEY HIGHLIGHTS

PARTNERSHIPS

- Our valued partnership with the Sydney Swans has gone from strength to strength, as part of their Diversity Action Plan.
- As part of this, we enjoyed an Exclusive Training Session for our members, as well as an Exclusive Movie Screening of Champions with over 200 people.
- Our CEO Emily Caska and our members were also featured on Channel 7 News as part of World Down Syndrome Day.
- We have worked closely with and support the great work of a range of wonderful organisations this year, including Bus Stop Films, Right Start Foundation, NSW Council for Intellectual Disability, Special Olympics Australia and more.

POLICY AND ADVOCACY

- We are now accredited with the United Nations, as party to the Conference of State Parties to the Convention on the Rights of Persons with Disability.
- Our CEO, Emily Caska, attended the Conference of State Parties to the CRPD in New York in June as part of the Australian delegation. This was also attended by Minister for Social Services, the Hon Amanda Rishworth and a reception held by the Hon Mitch Fifield, Australian Ambassador to the United Nations, alongside key peaks and advocates.
- Down Syndrome NSW joined the NSW Government Disability Stakeholder Reference Group, advising on key policy and advocacy priorities affecting people with disability across the state.
- We have met numerous times with a number of key government representatives to ensure the voices of people with Down syndrome are heard, understood and acted upon, including:
 - Federal Minister for the NDIS, the Hon Bill Shorten
 - NSW Minister for Disability Inclusion, the Hon Kate Washington
 - Parliamentary Secretary for Disability Inclusion, the Hon Liesl Tesch
 - NSW Shadow Minister for Disability Inclusion, the Hon Natasha Maclaren-Jones
 - Federal Member for Campbelltown, Dr Mike Freelander
 - Federal Minister for Social Services, the Hon Amanda Rishworth
 - Former President of the Legislative Council, the Hon Matthew Mason-Cox
- This year, our CEO Emily Caska conducted a study tour of the US to investigate research and medical care solutions and contemporary best practices. On this trip, she met with a range of esteemed experts including Dr Brian Chicoine, Dr Brian Skotko, Dr Dennis Maguire, Dr Joaquin Espinosa, National Down Syndrome Society, National Down Syndrome Congress, Down Syndrome Association of Florida, National Down Syndrome Association, Advocate Health Adult Down Syndrome Center, Down Syndrome Clinic at Massachusetts General Hospital, Gigi's Playhouse and more.

- Our Step UP! event this year was our biggest on record - in terms of attendance as well as funds raised to support our important work.
- We held a special event at NSW Parliament House, hosted by the President of the Legislative Council and attended by over 120 members in the Fountain Court to celebrate Down Syndrome Awareness Month.

INFORMATION, SERVICES AND SUPPORTS

- This year, as the metrics show, we reached more people with Down syndrome and their families across a variety of platforms.
- Other innovative new deliverables we so proudly achieved this year include:
 - Publication of our first ever Easy Read Recipe Cards
 - Release of our Extraordinary Pocket Guide on Down Syndrome for primary school students
 - Launch of Travel Club weekend getaways
 - Highly successful Housing and Accommodation Conference
 - Launch of our CEO Commentary and In Brief series
 - Weekly Newsletter format, to keep members up to date and engaged with all happenings
 - Finalist in the AFR Most Innovative Companies 2023
 - Leadership Award at the National Disability Organisations Gala awarded to CEO Emily Caska
 - Reinvigorated our New Babies Days, with huge success
 - Enhanced our Up Up and Away offering, with great attendance across the year
 - Saw the successful employment of a number of members as part of our Employment Connections program
 - Ran our first play.gro.UP! groups as a pilot for future sessions
- We enjoyed our biggest Annual Members Christmas Party to date, with so many old and new faces connecting.
- Our CEO Emily Caska visited Mudgee, Dubbo, Wollongong, Orange, Gosford, Ballina as part of our regional engagement, with much more to follow in coming years.

OUR MIGHTY TEAM

Our Miriam celebrated a mighty 18 years with Down Syndrome NSW this year, an incredible milestone and indication of her commitment to our loved ones with Down syndrome and their families. Miriam is truly like no other – her knowledge is broad, her approachability valued and her passion unwavering.

We warmly welcomed more experts to our team, many of whom bring with them lived experience of disability. Through this, we also increased our engagement of employees with Down syndrome.

We were so humbled this year to re-engage with a number of staff who have played a key role in the history, growth and success of our organisation.





Our Programs

Our Vision

All people with Down syndrome in NSW live meaningful lives as valued and contributing members of their communities.

Our Mission

At Down Syndrome NSW:

- (i) advocate for change to achieve social transformation by building systems that promote self-determination;
- (ii) create opportunities for people with Down syndrome that promote connection, capacity and autonomy; and
- (iii) provide information and support to families, carers and supporters, informed by best evidence and lived experience.

OUR CURRENT PROGRAMS

You can be a part of our story and make a difference for generations to come in one of these areas:



The Congratulations Initiative – This initiative aims at educating medical professionals in their delivery of a diagnosis, providing up to date information about Down syndrome through our Medical Professionals Packs, linking Down Syndrome NSW as key support partner and most importantly saying congratulations not sorry.



play.gro.UP! – We hope to offer a range of therapy, play, and music-based playgroups specially designed for toddlers with Down syndrome and intellectual disabilities. These playgroups are available both online and in person, providing flexibility and accessibility to families.



The Inclusive Education Initiative – We look to introduce our comprehensive Primary and Secondary School Support Program, designed to benefit both mainstream and special schools. The program's core objectives are to strengthen the capacity of schoolteachers, principals, and SLSOs (School Learning Support Officers) and to foster strong connections among key stakeholders, including families, therapists, and behavior support specialists, all with a focus on putting the student at the center.



Up! Up! and Away – Specially curated for kids and teens with Down syndrome and intellectual disability. This program is designed to promote active engagement and offers enriching experiences through a series of capacity-building workshops. Additionally, we have integrated mental wellbeing workshops to ensure holistic development and emotional support for all participants.



Employment Connections – Supporting prospective employees with Down syndrome to be job ready and secure meaningful placements, alongside inclusion and diversity capacity building for employers.

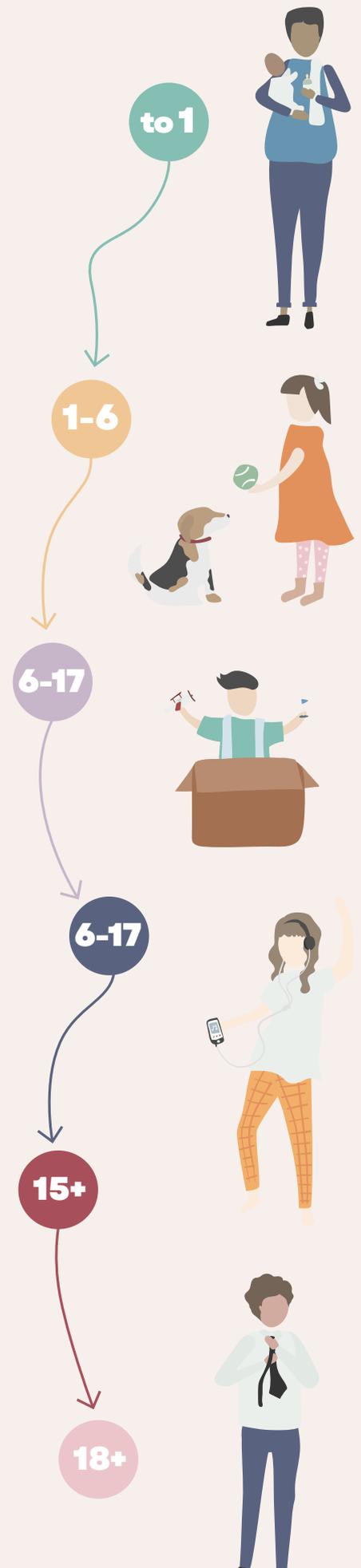


UP! Club – We are dedicated to providing capacity building and community participation opportunities for adults with Down syndrome, enabling them to learn, engage, and connect. Our programs focus on reducing isolation, fostering further education, skill-building, promoting independence, and assisting with future planning.



The Inclusion Institute – We are committed to providing a wide range of support and resources for all individuals with Down syndrome, their families, carers, professionals, students, and the community at large. Our offerings include information, fact sheets, books, as well as access to our helpline via phone and email. Additionally, we maintain a comprehensive website and private social media groups for ongoing engagement and support.

Our mission is to create a nurturing and empowering environment for everyone affected by Down syndrome. By fostering connections, providing resources, and promoting advocacy, we aim to empower individuals with Down syndrome and their families to lead fulfilling lives.



PROGRAMS IMPACT



100%

of new parents said
that our New Parent Packs and
hospital/home visits were helpful

130 medical professionals
attended our in-services



30 people attended our
Up! Up! and Away events

1 event was facilitated by one
of our celebrity ambassadors



238 capacity building
activities held per year

3 camps per year with
150+ participants

Average evaluation rating of Medical Professionals Information Pack and In Service



100%

recommend our Medical Professionals Information Pack and In Services

Requests for more training, information, resources and support:



100% yes



27

people with Down Syndrome placed in employment

51

employers engaged and upskilled on inclusive employment



68

workshops held

1,634

participants attended





Financial Report

FINANCIAL REPORT

OUR FINANCIAL REPORT FOR THE 2022-23 FINANCIAL YEAR SHOWS:

- Our largest revenue on record for the Down Syndrome Association of NSW.
- Our largest total equity position, almost doubling our equity position from 2020 to 2023.
- Revenue of \$1,330,810, an increase of \$58,497 on the previous 2021-22 Financial Year revenue of \$1,272,313, and an increase on our 2020-21 Financial Year revenue of \$1,105,847.
- Once expenses are deducted, this results in a surplus of \$85,726 for the 2022-23 Financial Year.
- This follows a surplus of \$278,518 in the 2021-22 Financial Year.
- Our sustained surplus position in 2022-23 Financial year is a great result albeit lower than the previous 2021-22 Financial Year, especially as we have made strategic investments in our capacity, services, supports and technology to provide better outcomes to our members.

**Revenue**

How much money we got

\$1,330,810**Expenses**

How much money we spent

\$1,245,084**Surplus**

How much money we were in surplus

\$85,726**Total Assets**

How much money we have

\$1,647,867**Total Liabilities**

How much money we own

\$179,763**Equity (net assets)**

How much money would be left if we sell everything we own and pay all the money we owe

\$1,468,104





Strategic Plan

Strategic Plan 2021 - 2023

DS NSW is proactive, contemporary, representative and engaged, with its members firmly at the centre

- develop and implement a strategic member engagement framework that includes:
- an Advisory Council comprising of people with Down syndrome
- optimisation of digital engagement
- engaging and meeting the needs of rural and remote members
- diversity of representation
- meaningful internal consultation mechanisms in place
- social media policy
- capture and understand our membership skills, capabilities and opportunities over time
- encourage an active and engaged membership and volunteer base to build internal capital
- deliver exceptional services, education and support that are responsive to need, innovative and evidence based

DS NSW promotes systemic, individual and self advocacy

- develop self advocacy partnerships and resources, with a focus on enhancing leadership capability and capacity building and opportunity pathways through the Advisory Council and other bodies
- develop individual advocacy partnerships and resources
- develop systemic advocacy partnerships, submissions, representation, partnerships
- structure an annual policy agenda on key topics (housing, succession, screening, education, NDIS etc)
- collaborate with the federation of Down Syndrome Associations to inform and contribute to the national policy and advocacy agenda

DS NSW is a leader in DS information, research and best practice expertise

- establish an evidence based Centre of Excellence
- capture organisational, individual and lived experience of DS, families and carers in NSW
- disseminate information, research best practice to members
- disseminate information, research best practice to government, allied health and health care providers, community, partners and others
- proactively engage in research groups, universities and other entities to promote research and data on Down syndrome
- position DS NSW as a thought leader
- develop an annual strategic research and best practice agenda (focus on pre-natal, early intervention, ageing etc)

DS NSW is an employer of choice

- mobilise a high performing workforce with the right skills, capabilities and capacity aligned with organisational purpose, mission and culture
- implement systems and processes to support internal information sharing and development of a staff knowledge bank
- translate our values into practice
- invest in outcomes focused professional development, matched with organisational need
- implement robust, transparent and ethical people practices
- attract the best in the field

DS NSW is known and connected, leveraging partnerships to further our mission

- review current partnerships
- proactive partnerships and stakeholder engagement strategy
- marketing of DS NSW externally to promote our vision
- attracting relevant expertise that's in line with the mission and purpose of the organisation
- actively contribute to partnerships at the national level in collaboration with DSA

DS NSW is financially viable, sustainable and growing

- increase revenue, with a focus on short to medium term sustainability and organisational security
- decrease costs and enhance efficiencies, balanced with maintaining and enhancing quality and impact
- robust financial management
- a culture of continuous improvement
- proactive and responsive business development strategy (grants, submissions, partnerships, corporate, fundraising etc)



Connect



www.downsyndromensw.org.au



www.instagram.com/downsyndromensw/



www.facebook.com/DownSyndromeNSW



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Donate





Down Syndrome
New South Wales

