



ACT
Down Syndrome
Association

Annual Report

2022-2023





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2020-2025

Vision:

ACT Down Syndrome Association leads the way in building an inclusive community for people with Down syndrome and intellectual disabilities.

Mission

ACTDSA works with individuals and families through lifelong engagement to enable them to reach their full potential as active and contributing members of the wider community.

ACTDSA collaborates and builds relationships with business, government and community organisations to create better outcomes for all of society.

Our Core Values:

Inclusion

**Honesty
& Integrity**

Ethics

Our People

Committee Members

Name	Position	Dates acted
Patricia Murray	President	2022 - 2023
Marie Katselas	Vice President	2022 - 2023
Tracey Crump	Treasurer	2022 - 2023
Alicia Flack-Kone	General Member	2022 - 2023
Nicola Cohen	Parent Support Coordinator	2022 - 2023
Lauren Murray	General Member (Down Syndrome Advisory Network Rep)	2022 - 2023
Annie Lee	General Member (Confident Speakers Rep)	2022 - 2023 2022 - 2023
Kathryn Lee	General Member	2022 - 2023

Our People

Employees/ Sub- Contractors

Name	Position
Shannon Kolak	Chief Executive Officer
Gemma Clark	Community Resource Coordinator
Charlotte Bailey	Aministration Support ACT Employment Ammbassador
Kim Adams	ACT Health Ambassador
Dr Vanessa de Kauwe	Adult Educator
Sarah Johnson	Education Consultant

Volunteers

Name	Position
David Williams	Confident Speakers Facilitator
Liz Milbourne	ACT Voice Magazine Editor
Sam Chapman	ACTDSA Photographer
Angela Braidon	Confident Speakers Facilitator
Karen Garrity	Workshop Presenter
Sharon Moore	Workshop Presenter
Kelli Gowland	Workshop Presenter

President's Report By Patricia Murray

I cannot believe that another twelve months have passed since I wrote my first report as President of ACTDSA. Highlights of the year for me personally include another successful Balloon Festival with many familiar faces volunteering at the Lions Club breakfast tent in March, and a brilliant day at StepUp! in October this year. Another highlight was attending the ceremony where staff member Charlotte Bailey won the Commendation for the Young Canberran Citizen of the Year 2022. Charlotte was subsequently nominated for ACT Young Australian of the Year 2023. Charlotte was nominated for her work as an employment and disability advocate

We held a new and successful fundraising event in August this year at Eastlakes with the theme of Resilience. Thank you to Charlotte and Ehren for doing such a great job of hosting the event. The guest speakers were inspiring, the first being Gina Chick of Alone Australia and the second, local young man Elijah Arranz who kept us entertained with his comedic timing and positive take on life. A big thank you to the Xtreme Stars who impressed the audience with their dance moves at the end. Thank you also to Lynda Bailey, Gail Murray and Emma Reilly for volunteering to organise the event, to all our sponsors for their support and of course the hardworking team of Shannon and Gemma in the office for making it such a success.

This year was a big year for the Australian disability community with the release of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability in September 2023 as well as the NDIS Review Panel's 'What We Have Heard' Report in June 2023. The Royal Commission final report is twelve volumes containing 222 recommendations on how to improve laws, policies, structures and practices to ensure a more inclusive and just society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation.

Whilst Down Syndrome Australia continues to represent the voice of people with Down syndrome at a national level, including working with Government on the outcomes and recommendations in the Royal Commission report and the NDIS Review, ACTDSA continues the advocacy at a local level through active consultation with the ACT Government on local issues, including as active members of the Disability Education Reference Group and the ACT Disability Health Strategy Steering Committee.

We support a team of young adults with Down syndrome who continue to impress in their public speaking roles, representing their views on issues such as health and employment at this year's World Down Syndrome Day event at Parliament House as well as one on ones with ACT parliamentarians during the year. Thank you to Kim Adams for her role as the Health Ambassador, Charlotte Bailey for her role as Employment Ambassador and Lauren Murray for continuing as our voice on the national Down Syndrome Advisory Network.

In line with our Vision, the work we do at a local level impacts not only people with Down syndrome but other people with intellectual disabilities. To better reflect this we are seeking your agreement to change our name and constitution to include both people with Down syndrome and people with intellectual disability in the name. This change will signal at a local level that what we do as an association impacts both people with Down syndrome and people with other intellectual disabilities.

I would like to take the time to acknowledge the hard work and dedication of our Chief Executive Officer Shannon Kolak. Over the past few years Shannon has demonstrated strong leadership while supporting the Down syndrome community, organising fundraising events and member social activities. All whilst also raising the local profile of ACTDSA so that we are included in important conversations such as education and health reforms. The team of Shannon and our knowledgeable Community Resource Coordinator Gemma Clark have ensured that the office is an approachable and welcoming space for all members. Thank you to Shannon and Gemma.

Looking forward, I would also 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 is an exciting opportunity for people with Down syndrome, families, advocates, professionals and researchers to meet, and share knowledge, insight and experience with others from different countries around the world. It would be great to see the ACT represented at this international event.

Finally I would like to thank all our volunteers, including my fellow Committee members, for their time and efforts to support our organisation in achieving our Vision of an inclusive community for people with Down syndrome and intellectual disabilities.



Patricia Murray

President - ACT Down Syndrome Association Inc.

Treasurer's Report

By Tracey Crump

The 2022-2023 financial year has been slightly more robust than the previous year. We made a small profit of \$4,819.00 due to end of financial year donations from our members and the Independent Foundation.

We raised a significant amount of money through the Hands Across Canberra - Canberra Day Giving Appeal and the Inclusion and Resilience in the Workplace charity event. Almost \$50,000 was raised in total and this has made a significant impact on the financial position of the organisation. The Southern Cross Club Community Rewards program donated over \$15,000 and Canberra Labor Club donated \$5,000 through their marble run event. I would like to thank everyone who donated and participated in these events and programs. I'd like to say a special thanks to our new corporate donors who's logos can be found at the end of this annual report.

We continue to receive ILC grant funding through Down Syndrome Australia and the Department of Social Services but this amount of funding could be coming to an end soon and we need to find alternative funding streams in order for us to continue to operate at this level into the future. As our members are aware, we are seeking permission to change our name to match our already increased scope of activities and advocacy as a way of attracting additional funding streams. By showing the ACT Government that we are committed to supporting people with Down syndrome and other intellectual disabilities, we hope to attract additional funding and support.

Our organisation has continued to rent our meeting room to other community organisations around Canberra to generate additional income and we will seek to leverage this potential income stream further, as well as continuing to look for additional grant and funding opportunities.



Tracey Crump
Treasurer - ACT Down Syndrome Association



Chief Executive Officer Report

By Shannon Kolak

What a year! We have celebrated many fantastic achievements, built strong sector relationships, advocated for inclusion in all areas of life in the ACT and delivered services and supports to our fantastic community.

We have spent countless enjoyable hours working alongside other community based disability organisations to provide our expertise to the ACT Government and have played a pivotal role in the creation of various disability inclusion strategies.

We are eagerly awaiting the findings of the NDIS Review which will be released in early December and look forward to the launch of the ACT Disability Strategy, ACT Disability Health Strategy and the ACT Inclusive Education Strategy.

The Disability Royal Commission (DRC) handed down their recommendations in September. We will continue to work alongside other ACT advocacy groups over the coming months and years to ensure the implementation of the DRC's findings.

I would like to say a special thanks to everyone who has supported our fundraising events this year. Hands Across Canberra, Canberra Day Giving Appeal and our Inclusion and Resilience in the Workplace event raised almost \$50,000 combined! Thank you to everyone who contributed to these great events or donated money, their time and expertise! I would like to say thank you to Lynda Bailey, Gail Murray and Emma Reilly for your fundraising support. Without your hard work and commitment, we would not have had such a successful event!

I would also like to say a very special thank you to Gary Butcher and the Independent Foundation. Gary and his team have supported ACT Down Syndrome for the past 10 years. Their financial support has been pivotal to the success of ACTDSA and we all consider Gary to be a true friend to our organisation.

I am so incredibly proud of all the amazing work and achievements our staff and members have completed over the past 12 months. Charlotte Bailey has received two amazing awards and was nominated for ACT Young Australian of the Year 2023, Kim Adams presented at the Speak Out Conference in Tasmania, Lauren Murray has successfully facilitated countless workshops and Sam Chapman has received international awards for his part in a local Canberra film!

Finally, thank you to our terrific Committee, Members and of course Staff. Without the commitment, enthusiasm and hard work of everyone involved in our organisation, none of this would be possible.



Shannon Kolak
Chief Executive Officer



Community Report

By Gemma Clark

The 2022/2023 was an exciting year for our community!

After the move to the new office space in early 2022, a series of renovations began to ensure our members have a safe and comfortable environment to come to. We would like to thank all of our amazing donors and volunteers for all of your hard work to make this happen!

In the new workshop space, we continued our Numeracy for Everyday Living group, our Tuesday Science Alliance group and were also able to add a Wednesday group!

Confident speakers continued to meet every month and were some of the first to enjoy the new workshop space! Big thank you to David Williams and Angela for all the hours you have put in to keep the group running smoothly.

StepUP! For Down syndrome was held on October 16th and the Kambah Adventure Playground and it was wonderful to see so many members come out to celebrate!

In December we celebrated Inclusion with the wider disability community at the ACT Chief Ministers Inclusion Awards. On the night Dr Vanessa de Kauwe received the Commendation for 2023 ACT Young Canberra Citizen of the Year and Charlotte Bailey won the ACT Chief Ministers Emerging Young Leader Award! Congratulations to both Dr V and Charlotte on your wins!



World Down Syndrome Day Celebrations went off with a bang! Members were invited to Parliament House where Minister Bill Shorten and Prime Minister Anthony Albanese made a surprise appearance! Members were also invited to the Governor Generals House for a cocktail event in the evening where Mrs Hurly debuted a song she wrote just for the occasion! If that wasn't enough, members then came together at the end of March with a Disco held at the Hellenic Club to end March with fun, laughter and a whole lot of dancing!

We ended the 2022/2023 year supporting our members in Employment, advocating to ACT Government on Education, Health, Housing (and much more!), welcoming new families to the ACT and planning for big changes in 2023/2024! Thank you to all of our wonderful volunteers, members, and friends who have supported us over the past 12 months, we cant wait to see what happens for 2023!



Gemma Clark
Community Resource Coordinator



ACT Employment Ambassador & Admin Officer Report

By Charlotte Bailey

Hello my name is Charlotte Bailey and I am the ACT Employment Ambassador and ACTDSA Office Assistant.

In 2022 I won the ACT Chief Ministers Inclusion Award and won the Commendation for Young Canberra Citizen of the Year. I was so shocked and excited that I was nominated, I had no idea I would win an award!

I went to a dinner with the Prime Minister and Minister Bill Shorten at Parliament House. It was cool to see everything at night time. The next day Gemma and I went to Parliament House again to talk about employment for people with disability.

In January I went to another Conference. The Conference was for children and young people with disability.

In August I hosted an event called Inclusion and Resilience in the Workplace and we raised almost \$40,000!

I was also nominated for ACT Young Australian of the Year and I also found out that I have been awarded a Sue Salthouse Leadership grant to help me present at World Down Syndrome Congress in Brisbane next year.

I am looking forward to next year and all the exciting things that I am going to do.



Charlotte Bailey

ACT Employment Ambassador & ACTDSA Admin Officer



Health Ambassador Report

By Kim Adams

It has been another busy month and interesting year for the health ambassadors.

We have continued to have fortnightly online meetings with Natalie and the other health ambassadors and also during the month. There have been many online meetings involving participation with various health professionals on a range of health issues.

Each month I took part in Disability Health Strategy Committee meetings with ACT health on 21st march I attended a morning tea at Parliament House and met with Ministers Shorten and Rishworth.

Then I attended an afternoon reception at government house hosted by the Governor General and Mrs. Hurley to celebrate World Down Syndrome Day. On may 10 I took part in an online presentation to psychology students at Deakin University Melbourne.

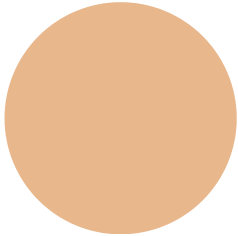
On may 23rd I attended a meeting at parliament house with minister for aged care and health Mark Buttler.

On may 24 we did testing of a new DSA digital literacy program.

On June 7 I participated in UNSW development of a model of preventive cap for people with an intellectual disability.

I took a copy of this to my GP and she thought it was an excellent idea. June 14 online workshop for Community Law, September 27 online Staying Healthy Workshop, October 10 to 12 I travelled to Devonport Tasmania with support from my support worker Hannah Clifford.

I arrived on time but my luggage did not, I spoke at the annual speak out advocacy conference so I arrived on time to meet Gemma meeting her at the back door.



November 13 I did filming of a video about my involvement in the ACT health Disability Strategy Steering Committee for the Inclusion Awards.

On November 23rd I attended a thankyou lunch with Gemma with the ACT health Steering Committee.

Currently the health ambassadors are working together to create an information sheet about coeliac disease in people with down syndrome and intellectual disability.

This will give you an idea of the varied tasks we have taken on this year, thankyou for listening DSA health ambassadors will then go on with everything online. Gemma and I will be looking forward to see you all again very soon but only after the new year and best wishes, have a great Christmas.

Thank you,



Kim Adams
ACT Health Ambassador



Down Syndrome Advisory Network DSAN Report

By Lauren Murray

Hi my name is Lauren and I am the ACT Down Syndrome Australia Network Representative.

Over the past 12 months I have been doing lots of workshops and have gone to lots of meetings.

The workshops I have run have been about Self Advocacy, Using the NDIS, being independent and Rights. It has been really great to run these workshops with Gemma from the office.

I have met with the other DSAN representatives every month. We have spoken about NDIS, how we can help others and World Down Syndrome Congress in 2024.

Next year my goal is to do more public speaking, and to stand up for people's rights in the media. I hope to do a good job representing people with Down syndrome in everything I do next year.



Lauren Murray

ACT Down Syndrome Advisory Network Representative



Confident Speakers Report

By Annie Lee

Good evening, everyone. I am going to talk about confidant speakers.

We have been doing something very different this time. We are working on a play. The play is about a restaurant in Barbie world named The Rainbow Café. The restaurant is run by a group of friends who all have Down Syndrome.

In the first week we discussed and planned the outline of the play. We talked about our characters and what will happen in the play.

Max is the café manger, Alister is the head chef, I am a waitress, Angela is the café owner, Kim is Beach Barbie, Peter is Ken and Neave is Disco Barbie. Last month we got a script and practiced it. We had lots of fun.

We are going to do a performance and we might invite family and friends. Thank you for listening.



Annie Lee
Confident Speakers Representative



Our Supporters

The ACT Down Syndrome Association Committee and Staff would like to thank all of our supporters for the 2022/2023 financial year.

Without your support we would not be able to continue to serve our community.



Make a donation

To make a donation, scan the QR code and follow the prompts, **or** email the office admin@actdsa.org.au for a donation form.



To support an event or fundraising activity or become a corporate sponsor.

Please contact our office on **02 6290 0656** or executive@actdsa.org.au

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