



Down Syndrome
New South Wales

Our Newsletter

The Latest from Down Syndrome NSW

In our November Issue

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CEO Update



Over the last month, you would not be mistaken to think we are still in winter, with the rain and unseasonal cold days. I was talking with some friends in rural NSW, and they were reflecting on comments they made only a couple of years ago when they were praying for rain. Now they are saying enough rain, let us get these crops out of the ground.

This month we have been busy preparing for our NDIS Provider registration, midterm audit. The audit will be held over two days in early December. The audit will measure how we deliver safe and quality services, resolve problems and identify areas for improvement. In addition, five members who access NDIS services through us will be interviewed and asked questions about the supports and services they receive. I will update you in December Newsletter on how we went.

We are in the middle of packing up the Parramatta Office, including the Julie Cromer library and looking for another office location and home for the library that is accessible to everyone. We are aiming to be resettled in the first quarter of 2022. In the meantime, we are just a phone call or email away. Our phone number and postal box will not change.

Our team have been busy this month submitting funding applications, meeting the NSW Minister for Disability, planning for our return to face-to-face programs and support, partnering with NSW Health, sharing lots of information, connecting with employers, creating job opportunities and planning for a big 2022 year!

A big thank you to everyone who supported Down Syndrome Awareness Month by sending in stories, photos and participating/donating to #21YourWay. Next year we hope to hold several StepUP events in different locations to connect as many of our members as possible.

The following month is going to be busy for you and us as we head into Christmas. I hope you all can spend time with your family and friends after a long year of shutdowns. Take care.

Sherie Avalos
CEO

AGM and Board Update

Down Syndrome Association of NSW held the AGM on 31st October 2021, via Zoom. Di Cook a founding Member of Down Syndrome Association of New South Wales as a guest speaker and talked about the vision of the founding members had and the work it took in setting up the Association. Associate Professor Mary-Ann O'Donovan Executive Director Centre for Disability Studies (CDS), also joined the meeting and talked about her background and CDS strategy direction. There will be a number of opportunities for Down Syndrome NSW to connect and partner with CDS in 2022.

Three current members of the Down Syndrome Association of NSW nominated and accepted by members for the Board of the Association.

President	Lorraine Clark
Board Member	Charlie Burfitt
Board Member	Rene Pennock
Board Member	Charlie Burfitt

The following current members of the Board of the Down Syndrome Association of NSW will continue their two-year term of appointment in 2021-2022.

Treasurer	Nick	Gotsis
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Board Member	Chris	Herbert
Board Member	Debra	Jefferis
Board Member	Lyn	Legge
Board Member	Gemma	Namey

There are currently 6 positions vacant on the Board and in accordance with Down Syndrome Association of NSW constitution clause 20(e) the Board may fill up the remaining vacancy or vacancies by appointing a new member at a meeting of the Board. Board vacancies are on the agenda of the November Board meeting.

Down Syndrome Awareness Month: October 2021

The most wonderful month of the year has exceeded our expectations, thanks to the incredible fundraising efforts of our families, the sharing of incredible member stories as well as our awareness raising campaign.

Step UP!

Sadly, due to extended lockdowns in NSW we were unable to host our annual Step UP! Event this year. Look out 2022, we are planning some wonderful celebration events!

#21YourWay

Our biggest year ever! We have been blown away by the 26 fundraisers who collectively raised over \$24,000 for Down Syndrome NSW through their creative challenges. A heartfelt thank you to all.

We have smashed our target of \$15,000 and 100% of these vital funds will be going directly to supporting our key strategic priorities of prenatal support, new parent and baby connections, youth and teens programs and ageing.

Time to get thinking of what your challenge will be next year!

Advocacy, Policy and Strategy Update

Working with our members to create an inclusive, diverse and vibrant NSW for all people with Down syndrome, their families and carers

Policy Updates

We have engaged in the following policy arenas, advocating on behalf of our members:

- PWC consultations on quality indicators in residential aged care;
- Department of Health star ratings consultations;
- DSA constitution.

We are working on the following submissions:

- Parliamentary Joint Standing Committee on NDIS Forecasting and Implementation
- NSW Pre-Budget Submission
- Issues Paper: Royal Commission and NDIS Legislative Review

Funding Update

We are thrilled to have been successful in the following new funding:

- Multicultural NSW: \$28,500 to provide Covid safe equipment, extend online programs to reduce community transmission and share information to keep our members safe.

We have submitted applications for the following:

- NSW Disability Advocacy Futures Program
- NSW Social Sector Support Fund
- Australian Government Strong and Resilient Communities Grant

Strategy Update

We met with the NSW Minister for Disability on 17 November to discuss Down Syndrome NSW, our contribution over the past 40 years, our strategic directions and our key priorities. Minister Henskens acknowledged our important work and

critical role we play in NSW. He has asked us to prepare a follow up brief on key issues for further discussion.

We are busy planning our morning tea at NSW Parliament house to celebrate World Down Syndrome Day in March next year. We have also asked to hold a photography and art exhibition in the foyer, showcasing the stories, skills and talents of our members. As soon as we confirm the date with Parliament House, we will let our members know so you can attend!

We are also working on a report card back to our members on how we are progressing against our strategic plan.

[You can view our strategic plan here.](#)

COVID Update

Keeping our members safe, protected and active across the lifespan.

Covid Boosters for Immunocompromised Populations

ATAGI recommendations on the use of a third primary dose of COVID-19 vaccine in individuals who are severely immunocompromised can be viewed here: [ATAGI recommendations on the use of a third primary dose of COVID-19 vaccine in individuals who are severely immunocompromised | Australian Government Department of Health](#)

You can look up disability specific vaccination hubs here: [Disability vaccination clinics | Australian Government Department of Health](#)

Information for people with disability about vaccinations from the Australian Government Department of Health can be found here: [Information for people with disability about COVID-19 vaccines | Australian Government Department of Health](#)

A great resource featuring a dedicated section on mental health and Covid is available here: [Welcome to Head to Health | Head to Health](#)

Latest Research on Covid and Down Syndrome

A social story for people with intellectual disability has been developed by the Robert Wood Johnson Medical School, to assist in understanding the journey better: [Getting a COVID-19 Vaccine: Social Story \[2\] \(rutgers.edu\)](#)

UP! Club Update

UP!Club

Program for adults with Down syndrome aged 18+ years

December Program

Face to face sessions are back! We are so excited to see you all. Never fear, due to popular demand we will also be running our online sessions also!

[View the full December program online.](#)

Staying Connected in November

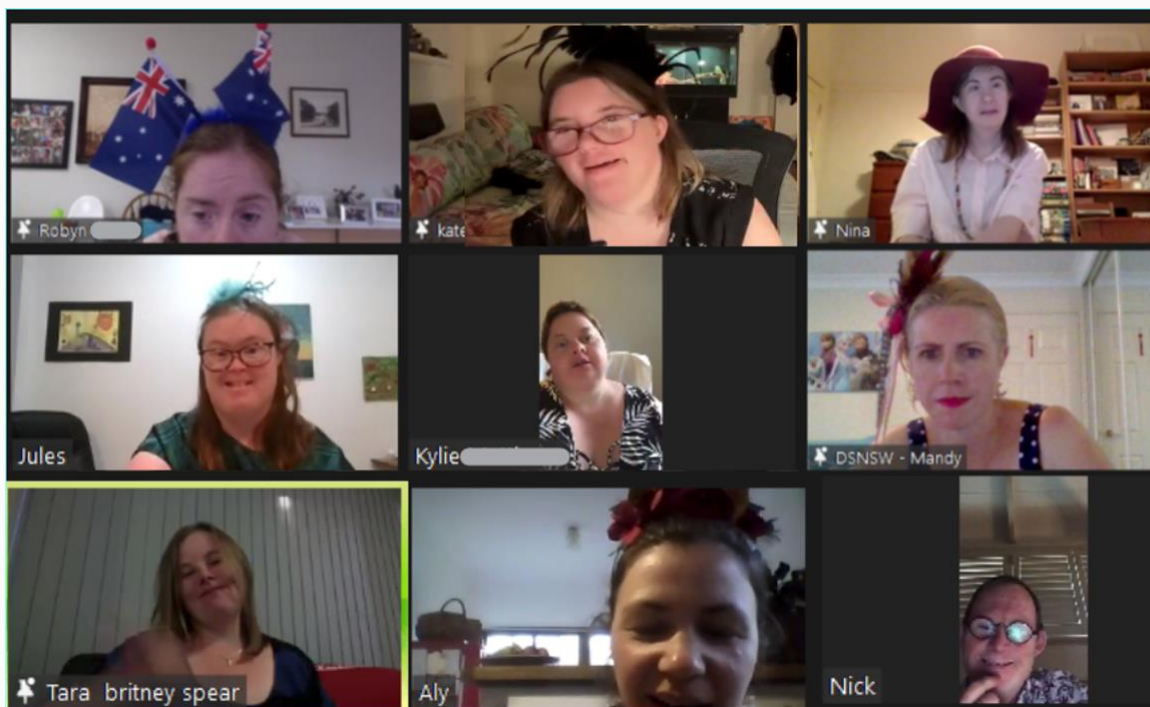
November brought us the Race that Stops the Nation – the Melbourne Cup – which we celebrated in a couple of ways. At our 'Crafternoon Goes to The Races' session, we made Race Day fascinator head pieces or decorated hats, which some people wore to the Racing Theme Dance Party where there was a fashion parade of our fancy outfits:



Fruit Skewers and Spinach Dip
– Healthy Snacks Cooking
Crafternoon session



Caption: Host Mandy, Sam, Belinda, Ellen and Ruth at the Crafternoon Race Day session 3rd November



Caption: Robyn, Kate, Nina, Jules, Kylie, host Mandy, Tara, host Aly and Nick enjoying the Fashion Parade of Fascinator Head pieces at the Dance Party on Saturday 6 November.

At the Tri-State Trivia session, we looked at important festivals for each state. Victoria, of course asked Melbourne Cup questions, Queensland gave us Ekka trivia and we as the New South Wales hosted the event, making sure that our honoured Royal Easter Show had its time in the Trivia hot seat!



Caption: a mix of participants from Queensland's DSQ program, Victoria's Club 21 Program and 6 of our own UP!Clubbers for the Tri State festival themed trivia session last week, with some funny poses!

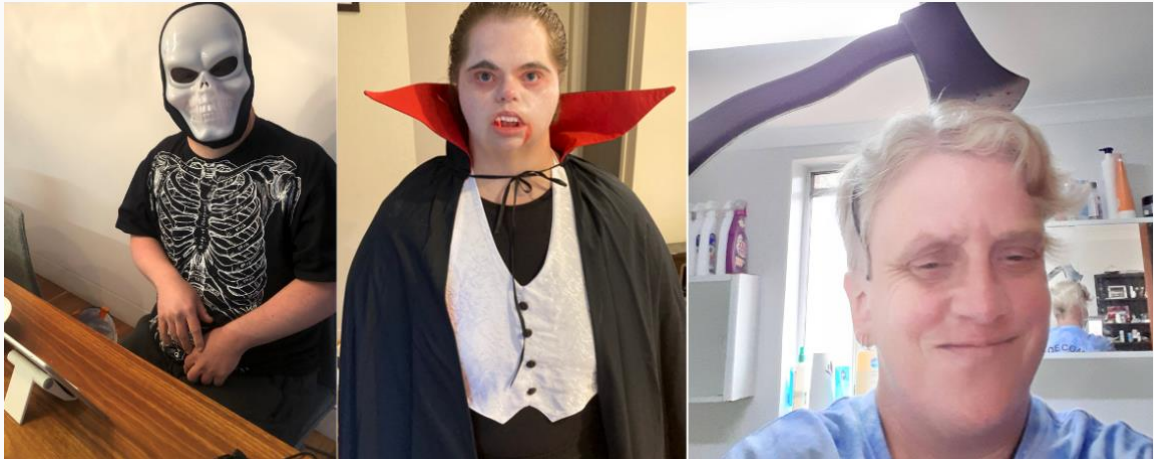


Caption: an example of the Trivia Questions – the answer is B) Fascinator.

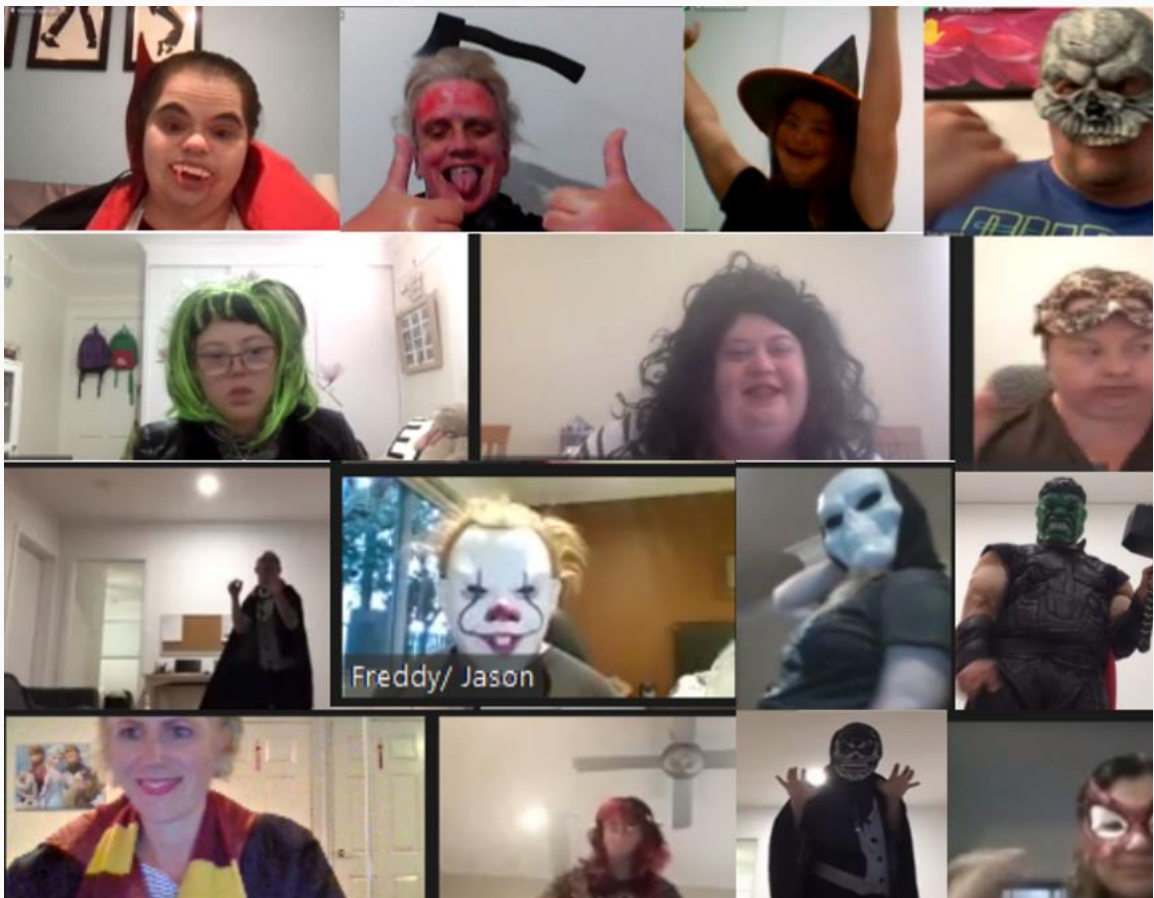
Please note these Tri State Events are open to all, we welcome those outside of UP!Club to also join in the fun with these sessions which have a reduced NDIS service cost – see program for details.

- 2nd Friday of the month – Tri State Trivia afternoon – 2pm – 3pm
- 3rd Wednesday of the month – Tri State Lunch time – 1pm – 2pm

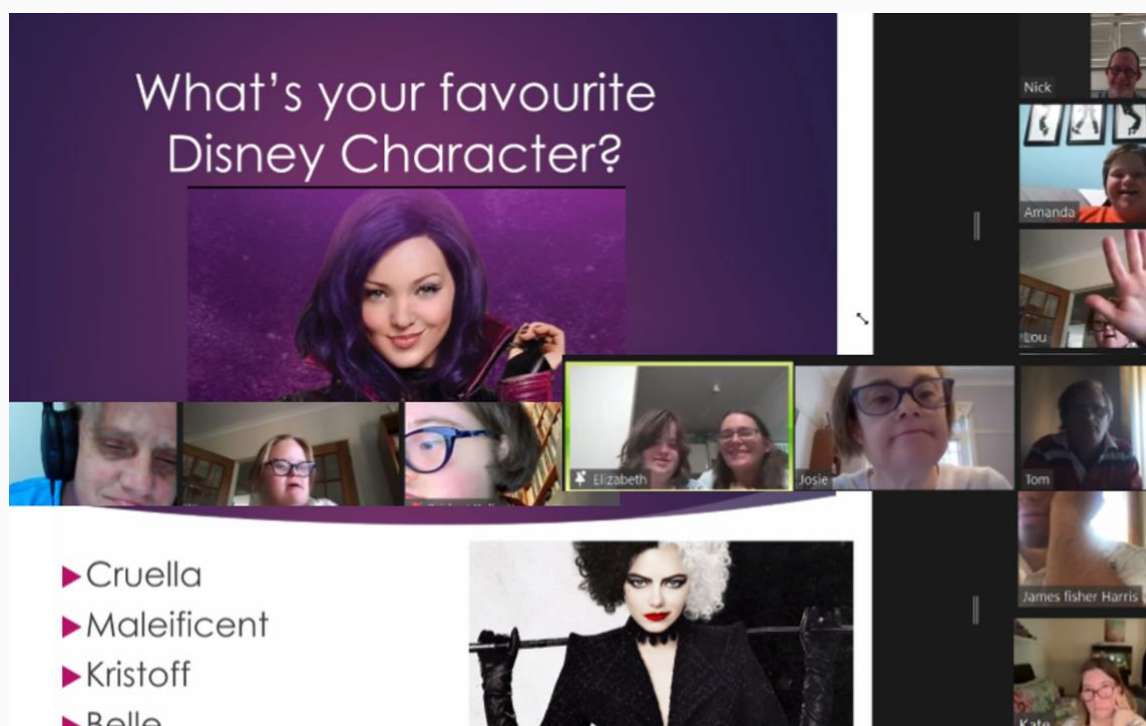
Some Photo Highlights From October



Caption: Some of our UP!Clubbers sent in some photos of them getting into the spirit of Halloween!



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Caption: Disney movie trivia quiz and chat at the UP!Club Yourself session led by UP!Club member Elizabeth on 31 October

Staying Connected - Coming up in December



UP!Club Yourself
– Thursdays –
3:30pm – 5:00pm



Coffee & Music – Fridays –
3:30pm – 5:00pm



Dance Party – Saturday night
6:30pm – 8:00pm



CELEBRATE THE SEASON

We have lots of Christmas events planned with Christmas cooking with Jimmy, for a traditional trifle as well as a dish with some Spanish flair! We will continue with our Christmas card workshops, roll our eyes at our favourite Christmas cracker jokes with our partner States, test our Christmas movie trivia and look online to see how other major cities across the world are preparing for Christmas with EarthCam live streaming. We will even make our own festive baubles for the tree!

Face to Face event: non cost event, we hope you can all make it!



We asked you to 'save the date' for us next month as we are planning a safe return to face to face sessions with a nice Christmas lunch at a venue to be confirmed, but it will likely be a city venue, with a 12 noon meet at Central train Station. All staff, volunteers and

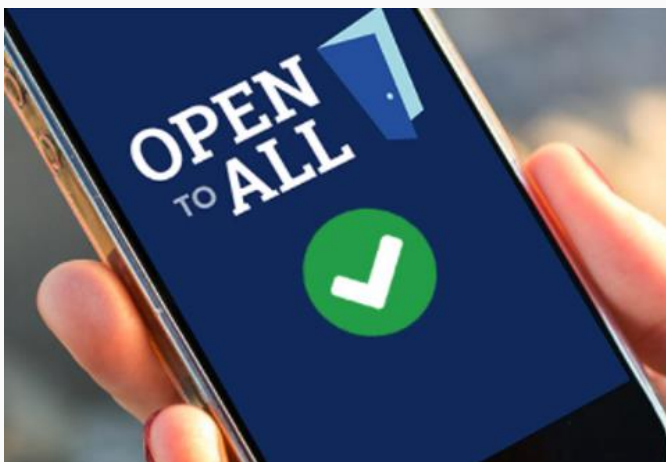
participants will need to be doubly vaccinated with a COVID-19 full vaccination certificate as the venue will be a fully vaccinated one.

Saturday 18 December

- 12 noon meet up at Central station
- 1pm lunch – you can get a lift and meet us at the venue at 1pm
- 4pm return to Central train station
- [Or book in here using the weekend December event link](#)

New for December – Open Events!

We want to ensure that our events and activities meet the needs of our members with Down syndrome as well as be inclusive and open. With this in mind, we have created some events with community engagement in mind and you will notice that some events in your December program are listed as “open” events.



Look out for the “Open events” which are shown with the “Open to all” image.

Some of our events are going to be open to our Up, Up & Away younger

participants, family, friends and those outside of UP!Club, with or without Down syndrome.

As with all things UP!Club, talk to Nikki if you need any more information on our events or individual help on booking in: Nicola.Hayhurst@dsansw.org.au

Up, Up & Away Update

Up, Up & Away

Program for children with Down syndrome aged 4-17 years

Up Up and Away – Dance Party November 2021

We are thrilled to be relaunching our better than ever Up, Up and Away program next year, full of social activities, capacity building, peer support and community participation opportunities. Keep an eye on our December newsletter for more details and dates.

To kick things off, we are busy planning a fun online dance party for our awesome youth and teens in December.

Prenatal and New Parents Update

Passion, expertise and advocacy to give all children and parents the very best start.

DS NSW and NSW Health Partnership

We continue to pursue our strategic priority of prenatal, new babies and early years with NSW Health as a key partner in this space. Our project methodology is in its final stages, following which we will be convening an Expert Advisory Group comprised of Down Syndrome NSW, NSW Health, NSW Department of Communities and Justice, RACGP NSW, parents of children with Down syndrome and other key stakeholders.

As a reminder, through this project we are seeking to:

- Upskill GP's, obstetricians, maternal clinics, nurses, social workers, counsellors and health workers with up to date, evidence based information on Down syndrome;
- Provide fair, balanced and evidence based information to all expectant parents in NSW at the earliest time possible to enable informed decision making;
- Connect with new babies with Down syndrome and their parents in a more robust way, with a focus on early contact, individualised support and partnering with parents at the same stage of this wonderful journey;
- Partner with other organisations and individuals who already provide incredible services and supports in this space to strengthen their impact;
- Create a register of new births in NSW and personalised contact from the beginning, including parent support networks, 'buddy' networks, the reintroduction of Mother's Weekend and Families Weekends, as well as our Life Matters Series which will provide events and workshops at every life stage;
- Reinvigorate parent to parent networks across NSW, as well as mentoring and support.

Another key element of this project is to secure legislative reform, to ensure that the provision of fair, correct and balanced information, as well as connection to the local Down syndrome association is enshrined and mandatory.

Information and Support Update

We are available to you, for all your information and support needs.

Reminder of our Change to Office Hours

With Covid, we have changed the hours for incoming calls to our office. We will now be accepting incoming calls Monday to Friday between 10am and 2pm. Never fear, outside these hours you can still call and leave us a message and you will hear back from us very soon afterwards. We are here with you, every step of the way. We are also looking into an online appointment booking system which will enable our members to pre-book dedicated information and support sessions with our wonderful expert team.

Employment Connections Program Update

Our new program supporting adults with Down syndrome to be work ready with individualised support.

Our Employment Connections Project will address the barriers to employment experienced by people with Down syndrome and will be delivered nationally in collaboration with the Down Syndrome Australia and State and Territory Associations. The project is being funded by the Department of Social Services (DSS).

As we proudly announced in last month's newsletter, our first Employment Connection Ambassador is UP!Club regular participant, Ellen Maher! Ellen will be taking on some leadership training so she can do a great job as our ambassador to share her experiences of working in a paid job in open employment.

Employment Opportunities: Access Easy English

Access Easy English interpret documents into simple, everyday language, supported with images so that people can read, understand and use the written information.

The goal is for important messaging to be presented in the simplest and most effective way. Sometimes they ask us to help them out which is called consumer testing.

Member Spotlight - Tom Hancock

Tom Hancock's paid work opportunity involved a diabetes document which really tapped into Tom's knowledge and lived experience of having diabetes. Tom was able to help with the graphics and told us that he appreciated being called upon as an expert in this area, and being paid for his time made him feel that his contribution was valued.

Rachel at Access Easy English agreed that this had been a very successful meeting with many changes being made based on Tom's input. Rachel told us, "In particular, the length of sentences have been reduced and more everyday words have been substituted. Tom also made suggestions about some of the images".

Thanks to Tom, Access Easy English will now know how best to alter the document to make the message clearer for everyone.

Tom enjoyed the experience and has agreed he can be called upon for his diabetes knowledge again in the future. Great work, Tom!

Your Stories

Our new newsletter section, dedicated to sharing your wonderful stories with our DS NSW community.

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We are delighted to share with you so many wonderful stories and photos sent in over the past month.

Our newsletter would be a novel if we included them all here, so instead we've created a new section on our website! Just click on the links below to read about our amazing members:

- [Meet Sam](#)
- [Meet Tara](#)
- [Meet Jimmy](#)
- [Meet the Legge's](#)
- [Meet the Meyers](#)



Share Your Story

If you'd like to share your story with our community, we'd love to hear from you! Please email Emily Caska with your story and any photos you'd like to share.

We love hearing from you!

From Our Archives





As we approach International Day of People with a Disability, this flashback is from 2007 featuring our very own Ruth Cromer! Ruth was the face of the campaign featuring on the magazine cover, postcards as well as on the M5!

Do you have an archive or flashback to share? [Kindly send to Emily Caska.](#)

Community News

In this section, we share with you community events our members might be interested in attending! With lockdown affecting all of us, we aim to share lots of accessible, relevant and free events to support you all.

If you have any community events you'd like to share with our members, [feel free to email us.](#)

Position Available: Council for Intellectual Disability

CID is recruiting for a project worker with intellectual disability.

The job is part time 4 hours a week until June 2023.

The project worker will help make resources for people with disability, families and service providers.

This could be things like easy read books and videos.

The resources will teach people how to use supported decision making in behaviour support plans.

You can learn more and apply

here: <https://www.ethicaljobs.com.au/members/NSWCID/project-worker-1>

MCA to Celebrate International Day of People with a Disability

In celebration of International Day of People with Disability, the Museum of Contemporary Art will be screening ArtScreen 2021 from 2 – 4 December.

ArtScreen 2021 is a visual art project enabling professional artists with disability to develop new works of video art. This empowering program will be showcased in lunchtime screenings at the Museum of Contemporary Art Australia in Sydney on Thursday 2 and Saturday 4 December 2021.

Artists Sue Jo Wright, Robert Duffield and Sarah Houbolt were selected for this prestigious program. They have been mentored by experienced video artists Dr Zanny Begg, Amala Groom and Berlin based Australian duo Soda_Jerk. The screening will also include the ArtScreen 2020 artwork by Debra Keenahan.

“In celebration of International Day of People with Disability and in acknowledgment of the work by artists with disability, the Museum of Contemporary Art Australia is delighted to present ArtScreen 2021, our partnership initiative with Accessible Arts.

We look forward to screening and premiering the works of so many talented artists here at the Museum,” says Elizabeth Ann Macgregor OBE, MCA Director.

“ArtScreen aims to broaden engagement with, and appreciation of, the distinctive insights and skills of artists with disability,” says Accessible Arts Interim CEO, Liz Martin. “These unique and compelling works make an important contribution to the diversity of cultural expression in Sydney.

The MCA ArtScreen 2021 presentation will include a Q&A panel with the artists on Saturday 4 December. All artworks can be viewed with closed captioning, audio description or Auslan interpreting.

This program has been made possible through support from Create NSW, City of Sydney and People with Disability Australia.

All artworks can be viewed with closed captioning, audio description or Auslan interpreting.

More information is also available [here](#).

Supported Courses at TAFE Ultimo

Ultimo TAFE are offering two courses providing supported access in 2022:

- Certificate I in Access to Work and Training
- Certificate II in Workplace Skills

Both courses are free and run from February to November.

If interested, please contact Tina Binopal

Teacher/Consultant Intellectual Disability

T +61 2 92173970

E tina.binopal@tafensw.edu.au

Fairfield City Open Library Adults Program: November 2021 – February 2022

Fairfield City Open Libraries Adult Programs activities during November 2021-February 2022 include crochet and knitting group; tech help and workshops; book groups; guitar school; English conversation group; and more.

Find out more information here:

[Fairfield City Open Libraries Adult Programs November 2021-February 2022 \(communityconnective.com.au\)](https://communityconnective.com.au)

Mood Active Affordable Online Fitness

Battling with your mental health? Mood Active are a charity organisation that can help you get back on your feet using exercise. Research shows that exercise is a powerful way to manage stress, depression and anxiety. Mood Active

understand it's not always easy to get and stay motivated to exercise, which is why they provide tailored programs with more support.

- Casual exercise classes online
- Morning and evening options
- Yoga, HIIT, Circuit
- Low cost options
- Supportive small groups
- Trainers who care

Learn more here: [Discover the power of exercise to lift your mood – Mood Active](#)

Accessible Film Studies Program

Bus Stop Films is heading to the Blue Mountains to deliver its award-winning Accessible Film Studies Program for people living with disability in partnership with the Blue Mountains City Council.

The classes are aimed at older teens and young adults living with a mild to moderate intellectual disability. The Program offers a film school experience as well as literacy, social and work ready skills, and is a fantastic post school option. Additional screen industry excursions, masterclasses and professional workplace opportunities are offered through the Program.

Mentored by passionate professional filmmakers, students create amazing films of the highest artistic quality, many which have won multiple awards and screened in festivals all over the world.

The program fees can be funded through a participant's NDIS funding.

To get you in the mood the team is hosting Free Taster Workshops at the Blue Mountains Cultural Centre.

Registrations to the workshops are essential.

FREE Taster workshop 1: Monday 10th January 2022 10.00am - 12noon

FREE Taster workshop 2: Monday 17th January 2022 10.00am - 12noon

FREE Taster workshop 3: Thursday 20th January 2022 10.00am - 12noon

For more information and to register:

<https://www.busstopfilms.com.au/programs/>

Head High Virtual Workshops

Head High are offering progressive and interactive virtual programs for adults with a disability. Run by specialist disability consultant and adult educator Julia Ross-Edwards, these sessions are tailored and focus on individual goal setting as well as improving employability skills and daily living skills. This program can be claimed under NDIS.

You can contact Julia for more information at headhighskills@gmail.com or phone 0420 553 695

Australian Centre for Disability Law: Training Sessions

The Australian Centre for Disability Law will be facilitating online training for students with disability, their families and advocates covering:

- Rights
- How to build a good relationship with education providers
- Communication tips
- How to deal with issues if they arise.

For more information, including upcoming training dates throughout November and December please [visit the ACDL website](#). You will also be able to access the Learning Together Resource which provides students and families with detailed information on rights and advocating more effectively for reasonable adjustments

Free Legal Advice for People with Disabilities

Covid has resulted in changes no one could have anticipated. In the disability sector, the pandemic is forcing us to deal with issues and challenges we had not previously considered, while at the same time exacerbating long standing issues.

To help address these issues, the Australian Centre for Disability Law Covid 19 Assistance Project provides free legal assistance to people with disability and their associates who have experienced legal problems due to Covid restrictions.

To learn more and access support, go to:

<https://disabilitylaw.org.au/.../covid19-assistance-project/>

Feel Good Finish



Sibling love: Emily and Matilda with their gorgeous baby brother, Charlie who has undergone surgery recently. A brave boy and beautiful family.