



Down Syndrome
New South Wales

Our Newsletter

The Latest from Down Syndrome NSW

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CSO Report



As the midway point of the year fast approaches (can you believe it?), it is timely to reflect upon all we have achieved together.

Our membership continues to grow, as do our offerings across our engagement and education spheres as we awaken from the pandemic and better align what we offer to what our members need. We aren't fully there yet, though well on our way.

Our approach is to keep listening to our members to guide us.

We are currently undertaking strategic reviews of all our programs, informed by our members through the recent surveys we have released. Thank you to the many who have contributed. Your views are valid and valued. Down Syndrome NSW has such a rich history that informs so much of what we do and why we do it, coupled with environmental scans and a need to look to the future. We hear you and we know that key issues of housing, education, system navigation, ageing, health, early years and connection are more important than ever before – particularly as we are experiencing the first generation of people with disabilities who will outlive their parents. A milestone to be celebrated though a daunting challenge from a system perspective. We are here with you on this path, at every stage.

All of our incredible staff – both new and existing – come with such diverse experience and innovation that we are so thrilled to have in our repertoire as we seek to amplify our strengths, identify our areas to improve and dare to try new approaches to better meet member need. Central to this is our commitment to delivering programs, education, training, resources and support across the full lifespan that are relevant, evidence based and accessible to all members – ensuring equity across metro, regional and rural. Again, a work in progress but one we are wholeheartedly committed to.

[Our Strategic Plan 2020-23](#) continues to be our guiding light in all that we do. Informed by our bi-annual member survey, staff and board consultations, our

focus in this past year has been on improving our member engagement, building a solid foundation for optimal impact and ensuring financial diversification and viability. It is so pleasing to see much headway made, a credit to our talented team for joining me on this journey of change. We are preparing an annual progress report against our Strategic Plan to be released next month, following our staff strategy day.

I am thrilled to soon further our partnership with the Sydney Swans, as well as announce upcoming partnerships with amazing organisations such as Kindred and Relationships Australia. We also have a very exciting and well renowned international speaker coming our way not once but twice a year – details to come very soon!

Our Down syndrome community is strong, unique and connected.

I'd like to take this opportunity to thank our staff for their passion. It is truly inspirational to work with such a committed and connected team, the majority of whom are parents of children with Down syndrome which really speaks to our vision and mission.

To our members, I look forward to continuing to connect with so many of you online and in person. From our play.gro.UP! sessions, to Up, Up and Away activities, Swans games, World Down Syndrome Day and UP! Club events, it is always great to be together.

Emily Caska

Chief Strategy Officer

Board Update

I recently attended our play.gro.UP! session in Parramatta and what a delight! So many members and so many gorgeous children. Nothing beats our face to face events, it is so nice to see them return.

We held a staff meeting at which myself as DSNSW Secretary, Margot Elliffe

joined the team to discuss our rich history and plan for our bright future. It is so encouraging to work with a team of energised and passionate experts.

DSNSW Vice President, Rene Pennock and I recently attended Melbourne to participate in a planning day with representatives across the Federation, facilitated by Apricot Consulting. This two day event was a wonderful opportunity to connect with our counterparts, explore how collectively we can better engage people with Down syndrome, plan together, collaborate and ensure a bright future. It was humbling to hear of the work of the other states and territories as well as share our NSW strategic directions which were very well received.

A passion of mine is our Down Syndrome Input Council, which we continue to develop as a priority of the Board. This group of adults will form a critical part of our governance and provide advice directly to the Board. We are committed to providing exceptional training and support to all members of the Input Council with come with on this in coming months.

Lorraine Clark AM
President
Down Syndrome NSW

Staff Update

More wonderful staff announcements to make as we continue to grow our already incredible team. This month we warmly welcome Lee-Ann Fortuin in our Information and Support Team. Lee-Ann joins us with a wealth of professional experience in the medical and health arena as well as lived experience. Lee-Ann brings a depth of compassion, empathy and practical know-how.

We also welcome Claire Wootton to the role of Events Manager. As we excitedly plan and deliver a range of events across education, training and members events, Claire brings with her an extensive skill set across event management, sponsorship and communications, not to mention a warmth and energy that fits so well with our team and ethos. Claire is with us on Thursdays.

In our next newsletter, we will share our organisational chart as well as profiles of each of our valued team members.

Policy Advocacy and Strategy Update

Drawing on our 40 years of expertise and lived experience to inform policy makers, government and build community capacity and inclusion - By Emily Caska

Advocacy

Thank you to our members for your contributions to our recent survey, NDIS Experiences of People with Down Syndrome, We are currently compiling and analysing the results and will release an issues paper soon. We had an astounding return rate to this survey which is so pleasing. Thank you for taking the time to contribute your valuable experiences.

NDIS Update

We share the media releases from the NDIS to support and inform our members - By Emily Caska

NDIS Media Releases

[Home and living demonstration projects progress to final project design and implementation phase | NDIS](#)

[Supporting more participants with longer plans and fewer reviews | NDIS](#)

[NDIA statement | NDIS](#)

[NDIS legislation amendments 2022 | NDIS](#)

[Updates on NDIA pricing reviews | NDIS](#)

NDIS Monthly Summary

[A great infographic on the key metrics: April 2022 is the latest version available](#)

Education and Training Update

High quality education and training opportunities across the lifespan in a variety of formats to optimise engagement, learning and sharing – By Stephanie Rodden



What a wonderful start to May! [Play.gro.UP's](#) commenced this week and it has been an absolute treat to be able to engage with our members and their little people both online and face to face. Thank you to Margot Elliffe for your wonderful support and expertise during these sessions. Stay tuned for more gorgeous photos when we visit Parramatta and Toukley in the next 2 weeks.



Lots of great things happening in the near future with **Relationships Australia**, **Kindred** and **Smiling Minds** amongst many more as we work to expand our education and training offerings for our valued members, as well as professionals. Emily and I have had a number of meetings with these amazing

organisations and look forward to bringing you several seminars and workshops in partnership with them. Keep an eye open for event details in the following weeks.

We are also soon to announce an online seminar with **Dr Brian Skotko**, who will hold two seminars in partnership with Down Syndrome NSW this year and ongoing. This is very exciting as we know many of our members follow his work and speak volumes of his presentations. Watch this space!

Events Coming Up!

Kindred will be partnering with us to deliver a hosting a 3-part, 2 hour workshop series over 6 weeks, entitled 'Healthy Mothers, Healthy Families'. We have recently surveyed members to ascertain best times and days and will open registrations soon.

Relationships Australia will be partnering with Down Syndrome NSW to deliver a number of online seminars for our members with Down syndrome and their carers including:

- 'Feeling great about ME!' for teens and young adults with Down syndrome;
- 'Healthy relationships for people with disabilities' for adults with Down syndrome;
- 'Fill your cup' and '24/7 Love' for carers of people with Down syndrome;
- 'My pet and me' for people with Down syndrome and their beloved pets.

We will also provide an information seminar to go over all the courses they offer and what they do, to inform and empower our members. This seminar will also have a mindfulness session included with great practical tips on how to remain centred and calm.

If you can't wait for our collaboration and want to join the general sessions with Relationships Australia, some are launching soon which members can register for directly:

Fill Your Cup

A six-part online FREE seminar for people who work in the Disability

Sector. From Wednesdays the 25 May 11am-1pm each week

Learn and develop your:

- Self-care, self-compassion, and easy mindfulness practices for busy workers
- Boundary setting in both professional and personal lives
- Understanding and preventing compassion fatigue and burn out

'Feeling great about ME!'

From June every Friday from the 3 June -24 June 11am -1pm. A FREE four-week online group for people living with disabilities, Feeling Great About Me, get the tools to have great relationships, manage emotions and improve self-care.**Error! Hyperlink reference not valid.**



Dr Brian Skotko will join us (online) twice this year and present on the following topics which are so relevant to our members. There will be the opportunity for Q&A during both sessions, too. We will be releasing dates for these sessions in coming weeks.

We also encourage all members to check out [Down Syndrome](#)

Clinic 2 You.

July 2022:

'Ways in which we might be able to boost cognition and prevent Alzheimer's disease in people with Down syndrome.'

November 2022:

'Keeping children and adolescents with Down syndrome healthy: All the medical updates parents need to know.'

Gift Packs for New Parents



We're delighted to announce a new partnership with Celebrate T21, ensuring families receiving a diagnosis of Down syndrome will receive a very special Celebrate T21 gift pack with from Down Syndrome NSW including information brochures, welcome letter and donated gifts. It's about giving a warm welcome to all families and helping

them access the support and information they need, in a collaborative way.

June will be a fantastic month, there will be many things to reveal on the training and education front. Looking forward to meeting many of you over the course of these events, too.

I would like to take this opportunity to thank you all for your warm welcome, very honoured to be part of such an amazing community.

Story Factory x Down Syndrome NSW School Holiday Workshops



On Tuesday, 12th April a group of our teenage members participated in a creative writing workshop facilitated by Story Factory in Redfern. This project is a partnership between Down Syndrome Australia and Story Factory and is a first for Down Syndrome NSW. The session for high school students centred around the theme of 'Inspiration'. Based on visuals and the 5 senses, the teens shared their ideas around defining inspiration, explored who and what inspires

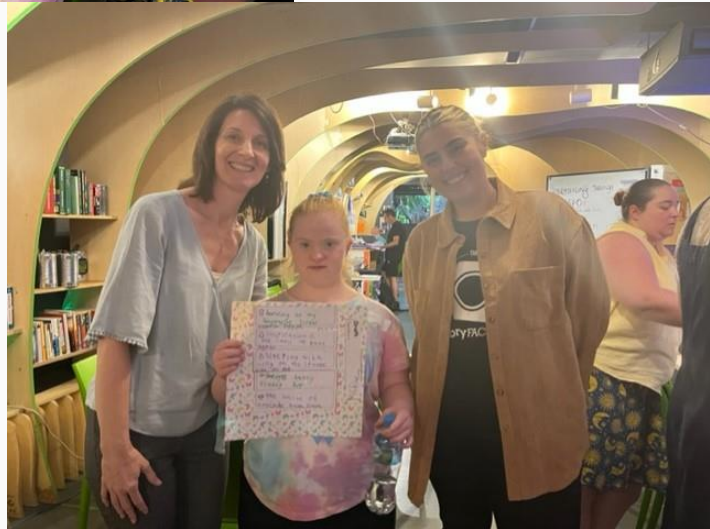
them and shared with the group their amazing suggestions.

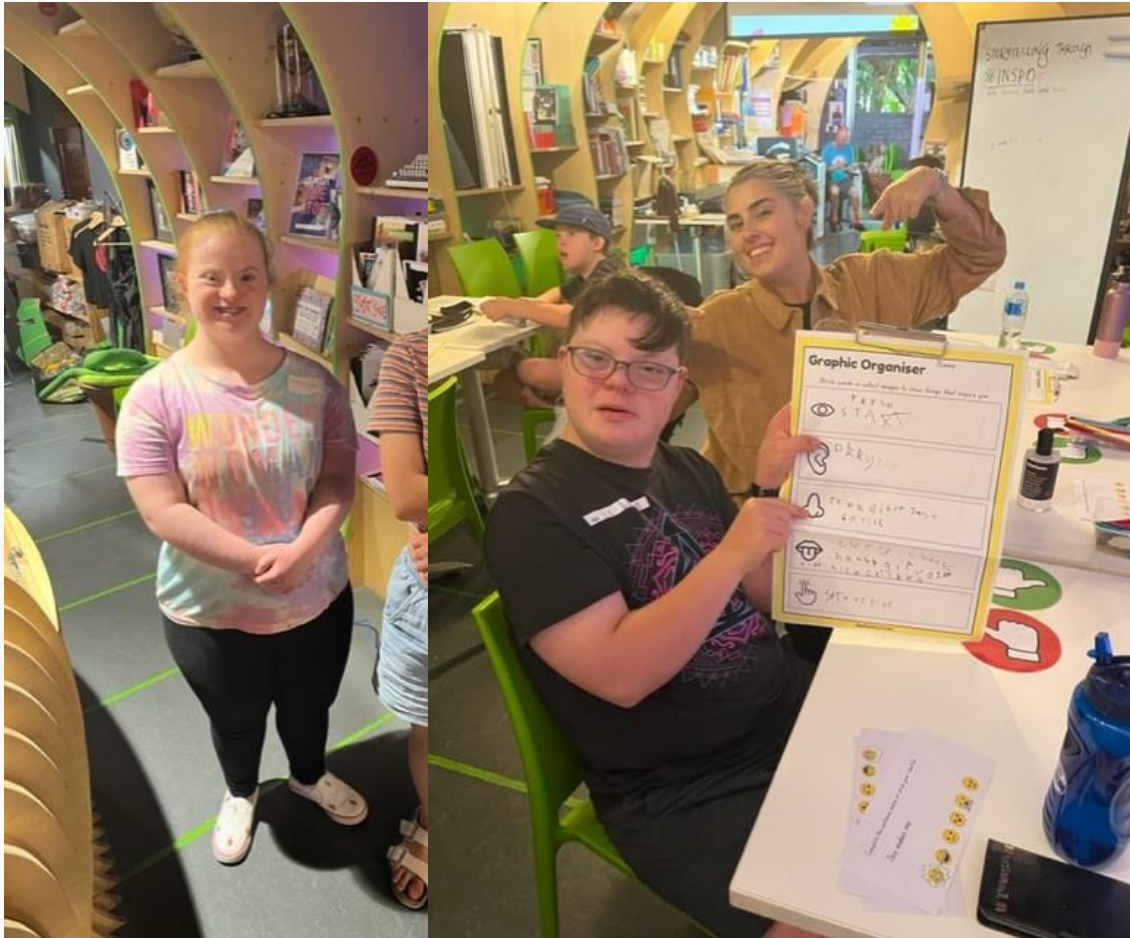
Everyone wrote their own individual poem on a colourful creative poster based on what is important to them. Storytellers from Story Factory assisted and guided our group in different ways to share their ideas and put them down in writing in this fun workshop.

Story Factory has been running free creative writing workshops for young people for 10 years in schools, various community groups and in their own centres.

Down Syndrome NSW looks forward to building on this successful partnership

and inviting primary and high school aged children to participate in more of these workshops as part of our UP UP and AWAY program. Stay tuned!





UP!Club

Our adult engagement and participation program for adults with Down syndrome over 18 years old - By Mark Allder



June Program Released

It's here! Join us for Strike Bowling and an awesome fun day out in Wollongong in June where we'll all head down on the train and our regional members can also join us in Wollongong, along with your old favourites of Fit n Fun Club, UP! Club Yourself, Music and Coffee, Crafternoon and the ever popular Dance Parties!

We'd love to see as many of you as possible at our face to face outings, it's so great to be together again!

[Check out the June Program here.](#)

We still have great activities lined up for the rest of May too -Dance Parties, Mindful Living, Yoga and a great day out to the super fun Powerhouse Museum.

[Check out the May Program here.](#)

Fun Activities in April and May

We spent a Friday evening practising our formal speaking with our guest Toastmasters, Brian Jones and Dianne Sammut who gave us useful feedback about how to engage an audience with interesting stories, descriptive language and good gestures, speaking from the heart about what really interests us. We learnt from Nidhi, one of the expert Toastmasters about what happens at a regular club where you get a coach to help you create your own speeches.

We heard about Toastmaster clubs that are offering online, face to face and even hybrid (a mix of face to face and online attendance). You will surely find a club that suits you to practise your speaking talents: www.toastmasters.org



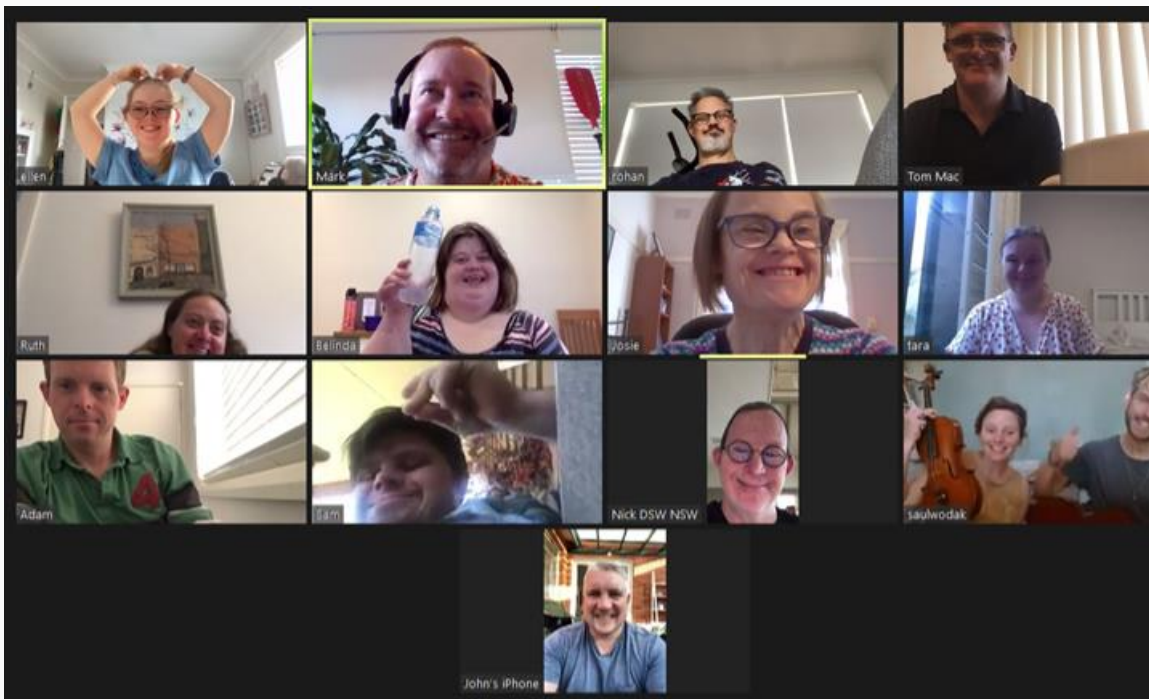
Dianne to Everyone

Parramatta Midday meet a
12 noon until 1.30pm on the
first and third Thursday
each month. The venue is
Level 2, Room A, 1-3
Fitzwilliam St, Parramatta.

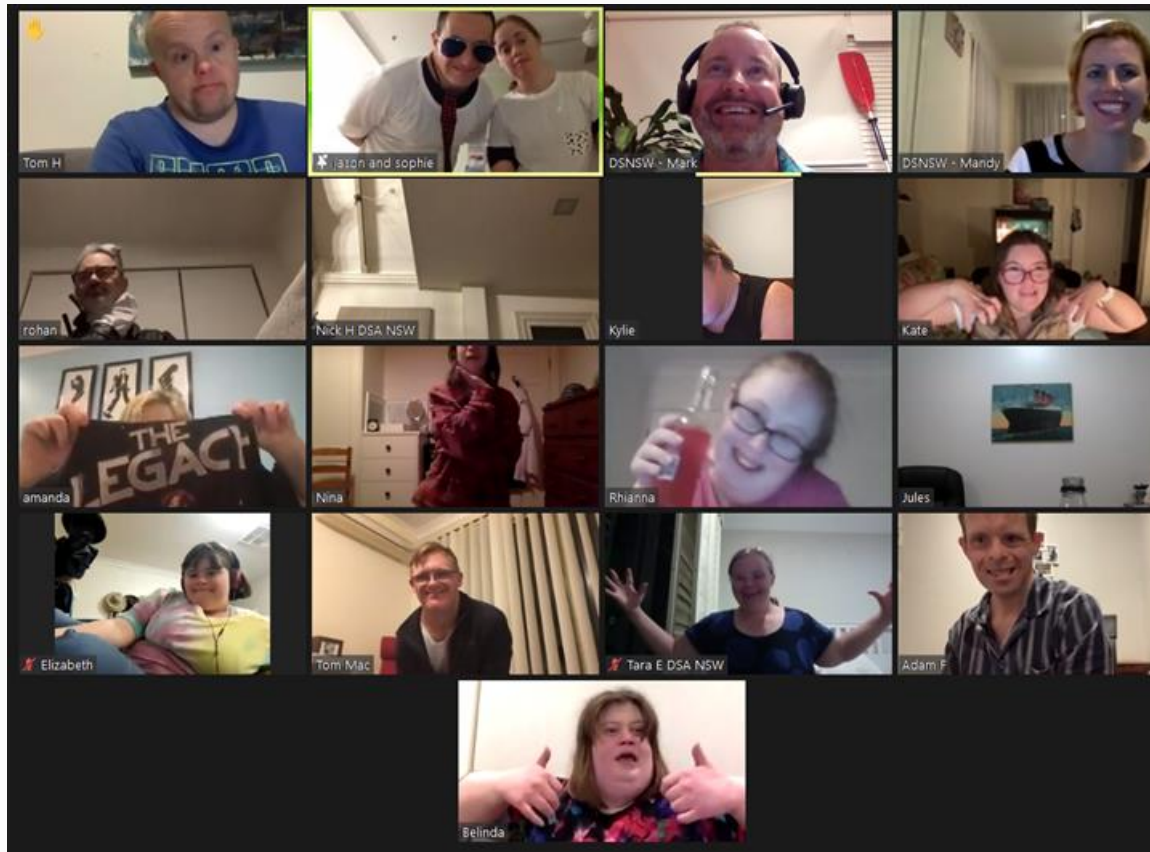
Caption: DSA Nikki with UP!Clubbers Ellen, Belle, Tom M, Gerard, Adam and Rohan.

With thanks to our special Toastmaster guests, Brian, Dianne and Nidhi.
If Toastmasters interests you, let us know and can help you find your nearest
Toastmasters club for where you live, or if we get enough people, we can
organise an UP!Club outing a Toastmaster club!

Our Fridays with live music continue to be popular. We've been singing some
solos and a bit of choir (group singing)! Our volunteer musicians play requests
and also some of their original songs which they have written.



Our Saturday Dance parties are very popular and fun. We had a Michael Jackson theme on 23 April with some of our members dressing up! Dancing to Thriller was a hoot!



On Saturday mornings, we have continued practicing our Yoga poses, we are wearing our warmer clothes in the sessions now as it is getting colder in the morning, especially when the instructor finishes with a beautiful mindful relaxation walking along the winding path of the secret garden!



We also talked again about the Yoga Retreat morning that got postponed because of the Covid restrictions, watch this space for a Winter Retreat coming soon!

In our Face-to-Face outing, on 30th April, we tried a new Bowling Alley this month. Strike bowling at Darling Harbour which was a hit – you could say we were ‘bowled over’ by it! They were also kind enough to lend us one of their karaoke rooms so we could have lunch together.



Next Month at a Glance

JUNE 2022

SUN	MON	TUE	WED	THU	FRI	SAT
29	30	31	1	2 	3 	4 
5	6 	7	8 	9 	10 	11 
12	13 	14	15 	16	17 	18 
19	20	21	22	23 	24 	25 
26 	27	28	29	30	1	2

Up, Up and Away

Our community access and capacity building program for youth and teens aged 4 to 17 years old with Down syndrome - By Melissa Cotterill



On Saturday, 28th May our Up Up and Away program is running a lively session of Music Therapy for 4-12 year olds. Music Therapy engages the individual/group and assists with physical, emotional, cognitive, and social needs. This session is facilitated by a music therapist and includes a variety of activities, such as singing, playing instruments, and having fun on the all-abilities equipment at this fantastic venue in Campbelltown. Limited spaces so be quick.

[View flyer and register for this afternoon event.](#)

UP!Club +

Opportunities for older adults Down syndrome aged over 35 to connect, learn and grow - By Nicola Hayhurst

We are planning another UP!Club + event later in the year so watch this space.

Employment Connections Update

Connecting adults with Down syndrome to employment readiness and opportunities - By Julia McCarthy

We have been busy making connections with employers who are interested in offering employment for a person with Down syndrome who is ready, willing and able to take on a part-time paid role.

Last week, we met with Fullerton Hotel. This week, we met with the Operations Manager and Head Chef at Parliament House to discuss a hospitality role to assist with the setting up of functions!



For those living in the Central Coast area, our Right to Work website picked up some interest from a gardening team who want to provide an opportunity for a person with Down syndrome: Grounds maintenance assistant within an established team, part time hours potentially 7:30am - 3:30pm across 2 or 3 days working within a team of 6, reporting to the Team Supervisor. Would suit a person in good physical health who enjoys doing active outdoors garden work.

Specific tasks to include:

- weeding, raking, detailing of equipment, mowing, grass trimming
- Potential for training on ride on mowers for a capable employee

The workplace is on the existing grounds of the large property (approximately 30 hectares) within the Killcare Heights area as well as potential for moving as part of the maintenance team to other nearby properties.

Email Julia.McCarthy@dsansw.org.au if this interests you.

We are also proud to announce our first Business Connector job is set to start in just a few weeks with one of our graduates from the Work Readiness Program that we ran in March. Andrew will be working part time for a financial institution in an office facilities role. We wish him the best of luck in his new role and once he settles in, we will interview him to find how he is settling in!

Pathways to Independence

*Capacity building opportunities for adults with Down syndrome and their families -
By Nicola Hayhurst*

Watch this space for more workshops coming soon, in June and July this year that will be co-facilitated by either people with Down syndrome or parents of people with Down syndrome on key topics.

Community Events

Wellness Workshop for Mums - Campbelltown

A free wellness workshop at the Shed for Mums (carers and support workers if they wish) will be held on Tuesday 31st May at 10.30am until 1.00pm. Morning Tea will be provided. Register for your free ticket [here](https://www.eventbrite.com.au/e/337116949487)

Happy Mind, Happy Mum

WELLNESS WORKSHOP

Tuesday 31st May 2022
10:30am-1.00pm
Shine Shed Campbelltown
5 Mount Erin Road, Campbelltown

Morning Tea will be provided
Workshop is Free
Must register on link below (limited spots)
Ticket Link: <https://www.eventbrite.com.au/e/337116949487>

Presented by Joline G in conjunction with Shine Shed
10:30-11:00am Meet & Mingle
11:00am- 12:30pm Wellness Presentation
12:30pm - 1:00pm Question & Answers



Your Stories

Thank you to our members who have shared their photos and stories with us!
Here is our selection for April.

Thai chilli jam chicken with basil, cooked by the best in the biz 🙌 Looks
delicious, Cammie ❤️



Daily morning cuteness, brought to you by Miss Arlee Grace



Digby and Camille enjoying that sunshine!



Nothing better than freshly baked Anzac biscuits fresh out of the oven!



Our wonderful member Tiana Legge, front right, marching with Coffs Harbour Girl Guides in today's ANZAC Day March!



Gorgeous Henry enjoying is first time at the beach this Easter



We want to hear from you!

Do you have photos to share, milestones to celebrate, a story to tell?
Our community love connecting, so please send any and all updates to us at
media@dsansw.org.au

We've been absolutely loving the photos and stories coming our way this past month, our most ever! Our community is loving it too on Facebook, where we share daily. Keep them coming!

Connect with Us

In 2022, our monthly newsletter will be with you on the second Wednesday of every month.

Watch that inbox as we share with you our latest news and announcements, as

well as our activity programs and events for the next month to allow you to plan ahead.

In addition to our monthly newsletter, we are very active on social media. We share news articles, government reforms, consultations, member photos, good news stories, events, latest research and more.

Connect with us:

- [Facebook](#)
- [Instagram](#)

Resources

Sharing best practice, information and innovation to build capacity - By Emily Caska

Some interesting articles we've been referring to as a team of late that might be of interest to our members. Our members have been calling Information and Support on some of these important topics:

[Regression in People with Down Syndrome: Current Consensus Update for Families | Adult Down Syndrome Center \(advocatehealth.com\)](#)

[Stereotypes: Repetitive Movements or Sounds | Adult Down Syndrome Center \(advocatehealth.com\)](#)

[Loss of Skills and Alzheimer's Disease | Adult Down Syndrome Center \(advocatehealth.com\)](#)

[Global Medical Care Guidelines for Adults with Down Syndrome | Adult Down Syndrome Center \(advocatehealth.com\)](#)

[Aging and Life Expectancy | Adult Down Syndrome Center \(advocatehealth.com\)](#)

[Self-Talk in People with Down Syndrome Webinar Recording \(11/10/2021\) |](#)

[Adult Down Syndrome Center \(advocatehealth.com\)](#)

[Weight Management in Adults with Down Syndrome | Adult Down Syndrome Center \(advocatehealth.com\)](#)

[Selective Mutism and Other Causes of Loss of Speech in People with Down Syndrome | Adult Down Syndrome Center \(advocatehealth.com\)](#)

Feel Good Finish

Emily, Matilda + Charlie. So much love



Would you like to contribute to our work?

Volunteer

[Donate](#)