



Down Syndrome  
New South Wales

# Our Newsletter

**The Latest from Down Syndrome NSW**

## **In This Issue - July 2021**

(To navigate using the links below, you need to open the email in your email program or view the newsletter in your browser through the link at the top of this newsletter)

**[Board Update](#)**

**[CEO Update](#)**

**[COVID-19 Vaccine Updates](#)**

**[Opportunities](#)**

**[Our Events](#)**

**[Up, Up & Away](#)**

**[UP!Club](#)**

**[Hotel Etico Launch Event](#)**

**[Community Events](#)**

**[Connecting with Members](#)**

**[Member Tip](#)**

---

## Board update

The Board is pleased to announce the appointment of Sherie Avalos as its new Chief Executive Officer. Sherie joins us with over 20 years of leadership experience in disability services with organisations including Disability Services Australia, Share Care and Achieve. Most recently, Sherie has been employed in a senior capacity at the NDIS Quality and Safeguards Commission. Sherie has a deep understanding of the disability landscape, ranging from broad industry and organisational issues around policy, project and program management, strategy, and compliance, to the everyday life and routines of people and their families living with disability. Sherie is passionate about and committed to our members and their families. Sherie will be commencing in early August 2021. In the role of CEO, Sherie will manage the day to day business of DS NSW with an expert lens and focus on member engagement, active rural and regional presence, strategy implementation, high quality service delivery, innovation, business excellence and culture.

Sherie replaces CEO Jennifer Evans who informed the Board of her resignation to be able to provide additional support to her family. Jennifer joined the Association at what was a particularly uncertain and challenging time as we all adjusted to the “new normal” of Covid-19. Jennifer adapted quickly to the changing situation, building on our online service offering whilst making sure that we continued to achieve our mission despite these challenges. Thank you, Jennifer, for your leadership and support over the past 14 months.

The Board also welcomes Emily Caska as its Chief Strategy Officer. Emily joined the Board in October 2020 and was instrumental in the development of the 2021-23 Strategic Plan. Prior to this, Emily served on the DS NSW Board in 2009 and as our UP! Club Co-Ordinator for 3 years prior to this, remaining friends with many of our members since. Since then, Emily has held senior strategy and policy positions at National Disability Services, Lifestyle Solutions, the Australian Chamber of Commerce to Hong Kong, Macau and China as well as NSW Government. Emily has established a number of successful social enterprises employing people with disabilities and mental health needs, and has a sister with intellectual disability. Emily is passionate about authentic engagement with our members, providing value and connection. The purpose of this role is to support the Board and CEO in the implementation of our strategic plan,

financial management, recalibration of our association to be increasingly member-focused, establishing sustainable and diversified revenue streams, communications, enhancing our government relations and policy submissions.

The Board is looking forward to beginning this new phase of the Association's work under Sherie and Emily's leadership. Both roles are part time with Sherie working 4 days a week, and Emily 2 days a week.

We also acknowledge our incredible team of expert staff at DS NSW for their ongoing work ethic, commitment and strong sense of purpose. Our recent strategic planning session with staff, Hayley and Emily highlighted exciting opportunities for our future.

To our members, we thank you for your ongoing support and are excited for our bright future.

Hayley Warren  
President

---

## **CEO update**

### **Farewell and Thank you to Members**

Over the past fourteen months, I have been privileged to work with and on behalf of our membership in pursuit of our vision that all people with Down syndrome in NSW live meaningful lives as valuable and contributing members of their communities.

During this time, with your support, we have developed our 21-23 Strategic Plan, steering a course for our future. Regrettably, I have chosen not to continue this journey with you as CEO due to my family responsibilities and will be finishing up later this month. It is exciting to see the announcement of the new CEO and Chief Strategy Officer by the Board in this newsletter.

I thank you for your support and wish each of you the best for the future.

### **Having Your Voice Heard - Talk to Your Member of Parliament**

At the World Down Syndrome Day event held at Parliament House in March, we heard from MPs across the State that they wanted to hear from you about what was helping you and your family member with Down syndrome and what the challenges were that you were experiencing.

**We are calling on all members to actively engage with their local member of parliament!**



Many of you will have already had experience raising issues with your local MP, but this could be a new experience for many others. To help you plan how you may approach this, we have put together an information sheet. You can access it on our website in [PDF](#) or [Word](#).

### **Winterfest Camp - Milson Island**

I shared a delightful weekend at Milson Island on the Hawkesbury River with 32 of our adult members who have Down syndrome, with 17 men, 15 women, from 18-20 June. It was wonderful to have the opportunity to participate and to see their excitement and enthusiasm for all activities.



We were truly fortunate to hold our camp, our first since COVID 19 and just prior to our current lock down. The cold weather did not dampen the spirits of our campers. The leadership of our dedicated staff Emma Screaton and Nicola Hayhurst and the support of 16 dedicated volunteers ensured a successful experience for all. We managed to have some outdoor activities despite the winds and occasional rain. As usual, Archery was the favourite, followed closely by the bushwalk with campfire damper. Arts and Crafts were also popular throughout the weekend. The Saturday night disco was a huge success, with many dressing up in their Winter Wonderland outfits. Showing off many dance moves, the Boys vs Girls dance battle proved to be a crowd favourite. A big thank you to the volunteers many of whom have attended previous camps and to the campers who wholeheartedly joined in all that was on offer.



**Caption:** Whole camp photo taken on the last day of camp; 32 campers and 15 volunteers who we wholeheartedly thank, we couldn't have provided such a successful camp without them.



**Caption:** Our admin officer Ellen hands the first of our Volunteer bags to our volunteer Mandy; Emma with volunteers Ryan and Atlanta, getting the Sports Hall ready for the Winter Wonderland Disco



**Caption:** Mike was the first to mask up on the coach, some ardent fishing in the rain







**Caption:** Dress up and dancing at the evening disco, awards for Best of at Camp; breakkie on the balcony and Damper Cook with one of our Sport & Rec hosts DJ – we thank you for the great food and support!

## COVID-19 Updates

### Increased Online Programs

With the introduction of the increased restrictions and stay at home orders that came in force from 26 June for the Greater Sydney Area and surrounds, we heard from many families requesting additional online programming. We have responded with an **extended Staying Connected program** and additional Up, Up and Away sessions.

### People with Down Syndrome living alone during COVID-19

One of our members is interested in connecting with other families to share experiences and ideas. Do you have a family member with Down Syndrome who is living on their own outside of the family home? Are their living arrangements outside SDA arrangements (Supported Disability Accommodation) and outside related SIL support (Supported Independent Living)?

If so, you may be grappling with how to access ILO (Independent Living Options) that NDIS is introducing. **Please contact us** if you would like us to connect you with other families in the same situation.

### New mass vaccination hubs to open

Two new vaccination hubs have been announced in southwest Sydney at an old Coles building in Macquarie Fields and another at a former David Jones building on Crown Street in Wollongong.

They will be added to the 100 vaccination clinics and outreach locations across the state. **[The Macquarie Fields site is due to open at the end of this month.](#)**

**[Please continue to check the NSW Health COVID-19 Information page](#)** for further details about opening dates and eligibility.

### **Tara's Vaccination Video**

We were pleased to receive feedback from members as to how helpful the video of Tara Elliffe's receiving her vaccination was to family members in explaining what the experience entailed. You can watch the video below.



Tara Elliffie gets her vaccination at the Sydney Olympic Park Vaccination Hub

---

## **Opportunities**



## **Lots of Socks 2022 Design Competition**

This year Down Syndrome Federation of Australia are holding a design competition for the sock design to be used in the Lots of Socks campaign in March 2022-23.

We are giving individuals with Down syndrome a chance to design the coming year's socks! Two designs will be selected (1 per sock) and will be used to promote WDS in Australia and the Lots of Socks campaign in 2022. As per previous years, the sock sales will directly raise funds for your local Down Syndrome Association.

**Find out more information and submit your design online.** Competition closes 31 July.

## **Achieve Australia are Looking for Quality Champions – Closes 11 July**

Achieve Australia are recruiting for the paid Quality Champion positions and encourage anyone who is interested to apply. A Quality Champion has a lived experience of a disability, is passionate about supporting people to have a voice and wants to share feedback on how to improve disability services. If anyone is interested, they can find out more information by **visiting the website** or applying directly for the position **through this link**.

**An Easy Read version of the job application is also available.**

## **Paid User Testing Opportunity**

Centre for Inclusive Design (CfID) is working with the NSW Department of Education to make the **Post-School Destinations and Experiences Survey** more inclusive. The goal is for more students from diverse backgrounds to respond so that the department can understand how to provide better support to students.

They are wanting people with Cognitive / Intellectual disability to help test their survey.

It would take part online and be a 90-minute observation and conversation where you complete the survey and chat with a facilitator. Participants will receive a \$150 Visa pre-paid gift card. Sessions are online via Zoom between 21st June and 16th July. We can provide accommodations if needed.

If you are interested you can fill out [\*\*this Expression of Interest Registration Form\*\*](#). For more information, please contact Michelle ([\*\*michelle.ou@cfid.org.au\*\*](mailto:michelle.ou@cfid.org.au)) or Gabriela ([\*\*gabriela.martin@cfid.org.au\*\*](mailto:gabriela.martin@cfid.org.au)).

## **Have Your Say - NDIA Consultations**

Have Your Say – NDIA Consultations

The NDIA has two new consultations that will inform the development of a new Home and Living policy and a new Support for Decision Making policy.

To get the consultation started, the NDIA have published two consultation papers and surveys to the [\*\*Have your say\*\*](#) section on their website:

- [\*\*An Ordinary Life at Home consultation paper Consultation paper – An ordinary life at home \(DOCX 1.3MB\)\*\*](#)
- [\*\*Supporting you to make your own decisions consultation paper. Consultation paper – Supporting you to make your own decisions \(DOCX 2MB\)\*\*](#)

The NDIA want to hear from as many people as possible – people with disability, nominees, families and carers, as well as providers and other stakeholders.

Further information about the two consultations is available on the [\*\*Have your say\*\*](#) page on the NDIA website.

Final submissions via our online survey are due by 5pm Friday 27 August 2021.

---

## **Our Events**

# Up, Up & Away

Program for children with Down syndrome aged 4-17 years

If you haven't attended before and would like to know more, please call Christine on 02 9841 4444.

The next Zoom event will be a Free Online Cooking Event for Teens

Saturday 10 July (1pm – 2pm) Let's Cook online with Mia from Kids Love to Cook – follow the recipe supplied when you register to make Apple and Cinnamon Muffins.

**[Click here to book in for this online event](#)**

Due to the extended lockdown in Sydney, our Free Basketball Event for all of our Up, Up and Away Teens on 31st July has had to go online as well, but we are turning it into Christmas in July Rock Party!

You can dress up to celebrate Christmas in July and we will play some great tunes.

If you want you can collect a rock from your garden or during your daily exercise, then with some paints at home (or order online), you can do some Christmas Rock Painting as the music plays.

**[Click here to book in for this event](#)**

Check Facebook and the website for more updates or contact Up Up & Away co-ordinator Nikki for questions, feedback and all things Up Up & Away; **[Nicola.Hayhurst@dsansw.org.au](mailto:Nicola.Hayhurst@dsansw.org.au)**

## Up Up and Away - Survey

It's up to you: What kind of activities would you like us to create for this program?

**Please help us to shape future events by clicking on the survey link and having your say.**

---

# UP!Club

**Program for adults with Down syndrome aged 18+ years**

## **Important Update**

I wanted to advise you on some changes to the processes in managing the UP!Club activities:

As you will no doubt be aware, we have extended our on line Zoom activities from 1 hr to 1.5 hours to better support the program of activities.

To help assist with the management of the sessions given our part time staff, from 1 August bookings for session will close:

- On Tuesday 12 noon for Wednesday, Thursday Friday sessions
- On Friday at 12 noon for Saturday, Sunday, Monday, Tuesday sessions.

We will not be able to process registrations beyond those times. We do appreciate that our Event Booking System can provide some challenges and please contact me if I can be of assistance.

We have updated the terms and conditions of our NDIS Services as outlined below. A copy of the **[new service agreement can be found on our website.](#)**

The update includes:

- that we continue to use the Temporary Transformation Payment item for the core supports
- the current item numbers and rates as of 1 July



- advice that the short notice cancellation fee will be implemented where cancellations of bookings require 48 hours' notice

Please [contact me directly](#) should you require any further information.

### Next Week's UP!Club sessions

Also, a reminder that in addition to our advertised July programming, we have added another bonus session on Thursday afternoons (3:30pm – 5pm) during this extended lockdown time: UP!Club Yourself which can be booked now on the link below.

You can book in for this session and others [using this link for the July UP!Club Program](#).

### Staying Connected online sessions

In response to the increased stay at home orders as the current Sydney Lockdown continues, we have added:

- Lockdown Exercise session last Monday, with more Personal Trainer sessions to come
- Crafternoon Wednesday afternoons for the whole of July
- UP!Club Yourself led by UP!Clubbers on Thursday afternoons
- A Special online event: the AFL goal umpire Michael Craig will join our afternoon coffee club on Tuesday 20th July, so bring your AFL questions and comments to the expert!

### Face to Face Events Moving Online

Face to face events are subject to the latest Public Health Orders and guidance from NSW Health regarding COVID-19 guidance and restrictions. Due to the extended lockdown orders with this very contagious Delta variant, **we have decided to move our proposed face to face events over the rest of the month to an online basis:**

**Saturday 17 July – Cinema outing to move to 90-minute online event 90 mins session**

- 10:00am – 11:30am

**Saturday 24 July – Yoga Retreat outing to move to online 90 mins session at usual time**

- 9:30am – 11:00am

**Christmas in July outing– Saturday 31 July – to move to online 90 mins session**

- 6:30pm – 8:00pm

Prepare your special meal, eat drink and chat, dress up in your Christmas outfit!

Now that these events have moved online, you might now want to book.

[View all July UP!Club! Events](#)

## UP!Club Member Spotlight

A shout out to all of our UP!Clubbers who have kept safe but busy during this COVID-19 resurgence, still smiling and fully participating online, learning new skills, practising known skills and keeping their spirits up with lively chats and encouraging words to their fellow UP!Clubbers.



**Caption:** Left to right: WeFlex Gym Talk Session with Personal Trainer Jaden, Host Nikki, Tara, Belinda, Sam and Ellen.

**UP!Club Members 35+**

We invite our UP!Clubbers aged 35+ to help us to develop a new program, the 35UP Club! We want to hear from our senior members about what you want DSNSW to do for you. **[Fill in our survey if you're interested.](#)**

**[Contact Nikki for questions, feedback and all things UP!Club and Up UP Away.](#)**

---

## **Hotel Etico Launch Event**

Down Syndrome NSW were proud to attend the Official Opening of Hotel Etico Australia last month.

Hotel Etico is a quaint 19th century accommodation situated in Mount Victoria. It is also Australia's first social enterprise hotel aiming to deliver a fantastic holiday experience to guests as well as providing both employment and independent living opportunities to people with intellectual disabilities.



**Caption:** The Hotel Etico Team: Georgia, Harry, Jacob, Josh, Katrina, Quinn and the Hotel Etico Board of Directors.

Andrea Comastri the founder and director says of the project, "Together we can change the world, making a real difference for people with intellectual disability with a true spirit of inclusion!"

Here are some photos that we took on the day.





For more information, please click on the following links provided by Hotel Etico:

[\*\*The Journey so far\*\*](#)

[\*\*Photos\*\*](#)

---

## Community Events

### Art Exhibition in Sydney

The amazingly talented Bridget Kelly will be showing her work at the Chrissie Cotter Gallery later in the month. Follow her on [\*\*Instagram\*\*](#) and more

information on the [Galleries' website](#).

Please check COVID-19 information as this may be impacted.

**BRIDGET KELLY**

**BRIDGET'S  
COLOURS**

 [@itsbridgetkelly](#)

**Chrissie Cotter Gallery**  
31A Pidcock St  
Camperdown NSW

Monday to Friday 11am to 2pm  
Saturday and Sunday 11am to 4pm

From Tuesday 20 July 2021 to Monday 2 August 2021

**Opening Night Saturday**  
24 July 2pm-4pm

**RSVP – Kate McNamara on 0423 328 982**

supported by  
**INNER WEST**  
innerwest.nsw.gov.au/ccd

---

## Connecting with NSW Down Syndrome Members

### Did you know we have a Family Facebook Group?

The group is part of the Down Syndrome NSW Facebook Page where we regularly post information, resources and events. The Family Facebook Group

is for members to request information and share ideas. [You can join here](#). If you would like any further information please email [Bernadette](#).

[Join our Family Facebook Group](#)

---

## Member Tip

### Your Right to Request an Explanation of an NDIS Plan Outcome Decision

Did you know that you can ask for an explanation of your NDIS plan outcome?

Following a request, NDIS Planners must provide an 'explanation of a decision' letter with the reasons for the decision written in plain English, as well as communicate in the participant's preferred format to improve the participant's understanding of how and why the NDIA has made the decision. There is no form for this, you will need to request this letter through your Local Area Coordinator / Early childhood Early Intervention Coordinator within 28 days after your plan is approved.

### Changes- reporting of income for those receiving Disability Support Pension (DSP)

We recently received some information from the Government about the reporting of income process for those receiving Disability Support Pension (DSP).

For anyone receiving the DSP you are required to report any income received every two weeks. The Government will then use that information to calculate the amount of DSP you will receive. The Government has told us that even where you receive the same amount each fortnight, the DSP amount may change for example due to changes in hours worked, leave without pay, overtime and wage increases.

If your employer uses Single Touch Payroll - then your payment information may be automatically showing when you go into the Services Australia portal to report your income.

You can get more information on this below:

**[Disability Support Pension - When to report - Services Australia](#)**

-

**[Disability Support Pension - How to report - Services Australia](#)**

-

**[Disability Support Pension - How to get reminders to report - Services Australia](#)**

**Would you like to contribute to our work?**

**[Volunteer](#)**

**[Donate](#)**

**[Submit a Member Helpful Tip](#)**