



## **Communique from the Special General Meeting held on 11 December 2018 about UP!Club**

A Special General Meeting was held at the request of members of Down Syndrome NSW to discuss concerns about the changes to UP!Club and how it is running and being funded.

Forty-three members of the Association attended the meeting on 11 December 2018. The meeting was chaired by Jason Lloyd, President and a presentation was made by Ryan Blunden, Events and Fundraising Manager. The presentation was followed by questions from members and discussion.

We wish to let all our members know what was discussed in the meeting and the questions raised. The Board of Down Syndrome NSW has discussed the meeting and agreed on some next steps to address the concerns raised - see below. The Special Meeting was an important opportunity to hear first-hand people's concerns, and we fully acknowledge that we could have done much better in communicating about both the changes and the overall strategic directions related to UP!Club.

### ***What was discussed at the Special General Meeting?***

Each year, around 80 people participate in UP!Club and in 2018, there were 60 events held with a participation increase of around 40% on the previous year. UP!Club is a successful way for people with Down Syndrome to come together socially to support each other and build their practical life skills.

Ryan covered the following in his presentation and a copy of his PowerPoint slides can be made available to anyone interested:

- Down Syndrome NSW needs to ensure its financial sustainability and this has meant changes. A few years ago Down Syndrome NSW used to receive government block funding that supported the delivery of our information and support services. We've also been fortunate to receive a lot of funding from the Sherry Hogan Foundation over the years. We now need to look to alternative ways to keep UP!Club going.
- The advent of the National Disability Insurance Scheme (NDIS) has led to changes in UP!Club. The Board of Directors agreed in early 2018 that the best way to ensure the long term sustainability of UP!Club was to register as a NDIS Service Provider and ask participants to contribute to the cost of operating UP!Club. We have endeavoured to minimise the impact of these changes by ensuring our service fees are set 30% lower than the NDIS Price Guide.
- UP!Club has been audited by NDIS, and will continue to be audited. This external auditing process should provide reassurance to our members that we are being scrutinised to ensure we follow the best procedures.
- Staff and volunteer ratios – Feedback was given that a support ratio of 1:3 was not necessary for some participants. Ryan explained that until July 2018, under the NDIS guidelines, this was the only option available to Down Syndrome NSW. Ryan also explained that this has since changed and that there are procedures under review that will allow Group Coordinators to suggest a variable support ratio, based on a risk assessment of any given event. For example, an activity that involves swimming at the beach may be assessed as requiring a support ratio of 1:3 whilst another activity that involves a meal and a movie may be deemed as requiring a support ratio of 1:5. This flexibility aims to ensure the integrity of UP!Club.

### ***What are the future plans for UP!Club?***

The Board of Down Syndrome NSW continues to be supportive of UP!Club as an important peer support program. We want to expand the locations where UP!Club is available. We really want to ensure that those people living outside the Sydney metro area receive the same opportunities to connect with their

peers. This was something the membership asked for in last year's survey, especially our people with Down syndrome.

We want to continue the model of NDIS funding. We need to do this in order for the groups to remain viable.

Some immediate changes:

- The target audience for UP!Club is all adults, not just young adults. This has been changed on our website.
- We will ensure a variety of different activities by diversifying among the newly created activity streams: Speak Up, Healthy Me, Participate, Give Back, Create, and Independent Living. Planning meetings for each UP!Club were held in February to decide on the program of activities for the next 6 months.
- We will provide clearer information about the program activities and who to contact for activities.

We are grateful for the feedback we've received. Many who attended the meeting were very positive and expressed their appreciation that we had taken the time to better communicate what's happening with UP!Club. We know some people still have concerns. We will keep listening although a model based on NDIS funding will continue. We have no other means of funding the program at the present time. At this stage, the Board has voted not to continue the Special General Meeting, although people are very welcome to call me to discuss further.

If you need assistance with preparing for your planning meeting, please contact us for an NDIS quote or for more information. We can provide advice about how to request the relevant funding for UP!Club service provision. Further information on NDIS and planning is available on our websites:

<http://downsyndromensw.org.au/services/ndis-services> and <http://downsyndromensw.org.au/upclub/ndis>

We have prepared a commonly asked questions document for those who want more info – attached. Since December, new people have expressed interest in being part of UP!Club. We look forward to welcoming new members to the next UP!Club Camp in Berry on 15-17 March, as well as welcoming back others who have attended previous UP!Club events.

***Best wishes***

***Dr Kathy Chapman***

***Interim CEO***

## **Commonly Asked Questions and Answers about UP!Club**

### ***Why did UP!Club become a service funded through the NDIS?***

The change to an NDIS funded service model is not to make a profit out of our members but to ensure the long term financial sustainability of UP!Club and Down Syndrome NSW. While in the past Down Syndrome NSW received government block funding and philanthropic support, the Board's decision to move to a NDIS funded model is to ensure we are adapting to the changes brought in by NDIS funding.

Early in 2018, Down Syndrome NSW applied to become an NDIS service provider. We were notified in June 2018 by the NDIS Quality and Safeguards Commission that we were a registered provider under the following classes:

- Specialist positive behaviour support
- Group and centre-based activities
- Participation in community, social and civic activities
- Specialised support coordination

### ***Has Down Syndrome NSW gone through certification to be an NDIS funded service provider?***

Down Syndrome NSW underwent Third Party Verification (TPV) in 2018. The standards that we were tested on included: Rights, Participation and Inclusion, Individual Outcomes, Feedback and Complaints, Service Access, and Service Management. TPV also ensures that our Volunteer Recruitment Process is legitimate; employed staff are adequately qualified, reporting methods are sufficient and risk management is sound. We will have to go through this process again this year as part of the ongoing NDIA certification process. We hope this reassures our members that we are being checked by the NDIA to follow best practice procedures.

### ***What do NDIS funds pay for at UP!Club? Is it a Service Cost or a Support Cost?***

The cost to attend UP!Club is a *service cost*. We would highlight that Down Syndrome NSW currently asks for a third less than the NDIS price guide.

The *service cost* covers a broad range of direct service delivery costs that includes staffing and administrative expenses. It is true that the UP!Club/NDIS model helps to provide funding to Down Syndrome NSW, however the cost to the participant to attend is highly competitive in the market.

Down Syndrome NSW requires all participants to pay a *service cost* to attend UP!Club which provides for the sustainability of the entire operation and is shared equally amongst participants. The focus is not so much on who needs more or less support, rather the service cost covers delivery of the service as a whole.

***Do other community-based disability programs charge a nominated service fee per month, or fee per activity?***

Some organisations may charge a flat monthly fee however most charge per activity - as is the Down Syndrome NSW model. Under our model, if a participant chooses to attend UP!Club once per year, they only pay for the activity they attend. We believe this is more equitable than a monthly subscription fee.

***Are volunteers used to run UP!Club events?***

UP!Club relies on a mix of paid staff and volunteers to deliver the program. Volunteers are engaged to “assist” with events, not “run” events. All volunteers are recruited, inducted and trained under a process checked via TPV. Our volunteers have a similar level of checks as paid employees (and also similar to other organisations such as Hire Up), which contributes to running costs. UP!Club is not unique among community-based programs who utilise volunteers, while also charging participants a service cost.

***What are the staff ratios for UP!Club?***

Until July 2018, under the NDIS guidelines, the only option available to Down Syndrome NSW was a 1:3 staff ratio. This has since changed. There are procedures under review that will allow Group Coordinators to suggest a variable support ratio, based on a risk assessment of any given event. For example, an activity that involves swimming at the beach may be assessed as requiring a support ratio of 1:3 whilst another activity that involves a meal and a movie may be deemed as requiring a support ratio of 1:5.

***What happens if the person with Down syndrome goes straight to the venue?***

Participants may choose to meet directly at the venue. They will be invoiced according to the advertised period of engagement with the specified activity (not travel time) i.e. 4 hours for dinner and movies.

***Can the UP!Club program have more diversity in the activities?***

UP!Club planning days occur twice/year, the most recent were in February 2019. Participants put forward their own ideas for activities. We are focussed on putting together a diverse range of activities in line with the participants’ expectations, preferences and goals. At each planning meeting, ideas are sought for different activities under the newly created activity streams:

- Speak Up
- Healthy Me
- Participate
- Give Back
- Create
- Independent Living.

The program of activities needs to be signed off by the CEO, providing an opportunity to address concerns about too many pub outings and unhealthy food options. We are committed to ensuring healthy supportive environments as much as practical, while balancing the need not to be perceived as the “fun police”.



***Does funding from Sherry Hogan Foundation go toward UP!Club?***

We've been fortunate to receive funding from the Sherry Hogan Foundation for UP!Club over many years. Their most recent funding has helped support the program transition to an NDIS model and exploring how we expand to regional areas.

***What happens when UP!Clubbers for health reasons need 1:1 support with their own support/carer?***

Generally we ask that outside support workers/carers do not attend UP!Club events **except in exceptional circumstances**. This is to protect the integrity of UP!Club's ethos of encouraging independence. However, when there are special circumstances, we take an individual approach and we are committed to ensuring UP!Club is as accessible as possible to all. We encourage anyone with concerns to talk directly to staff on this matter. We are more than happy to be as accommodating and flexible as possible, when we are made aware there may be an issue.

There has been some concern aired about the necessity of participants paying their support/carer fee as well as UP!Club service fee, if they require 1:1 support. Our service fee needs to stand for our service provision. As previously explained, we can accommodate special circumstances for 1:1 support/care however it is the participant's decision if that support is required and how that support will be paid for.

We aren't able to waive fees for participants who attend with their own supports. It would be unfair towards others who have paid fees.

***Could more details be included on the UP!Club notices?***

We are constantly reviewing our communication practices upon feedback from participants. More detailed information will be included on the next program and website content is always being updated. We do however take a balanced approach. Too much information can also cause confusion!

***How do people notify us if they can't make an UP!Club event***

Our upcoming programs will have the name and contact details of the coordinator below each activity. This person will be your contact person for that day. The program will be readily available on the UP!Club website for open access to this information. If someone requires a hard copy of the program, we can post this out to them.

We have RSVP dates for all of our activities. We close registrations once the RSVP date has passed and prepare the attendance list. If a listed participant has not turned up for that event, and not been able to notify us, we would typically try and contact that participant from our attendance list.

***How are incidents at UP!Club monitored and reported?***

We have a procedure where any incidents are reported to the CEO. The subsequent approach for dealing with the incident varies as appropriate. We are mindful of upholding the Rights of people with a disability – Privacy, Dignity, Confidentiality.



The process of incident reporting is currently being streamlined. The Board will be informed of any incidents on a monthly basis to give assurance that Down Syndrome NSW has not only recorded the incident, but also taken the necessary steps to mitigate future occurrence.