

Down Syndrome Advisory Network

DSA welcomes the Down Syndrome Advisory Network who will bring the lived experience of Down syndrome to inform the work we do.

Andrew Domahidy

Andrew is a busy man with a wonderful sense of humour and an interest in meeting new people.

'I do swimming three times a week and I am starting Tae Kwon Do...self-defence. I like to socialise with my family and friends by going to the movies and things like that. I go up to the bowling club for a few drinks, drinking till all hours of the morning!'

'I live in my own flat and I have a double bed. I do my washing on the weekend and I like playing play station too. I like being on the computer too and I use social media. I'm on Instagram, Facebook, Twitter...all the majors. I use it to meet people and try to meet girlfriends and have a relationship. I'm looking for a girlfriend at the moment because I would like to have a family one day but I haven't really got around to thinking about it much though!'

Andrew says that being a part of DSAN is a lifetime goal for him. He has done lots of public speaking before and is a member of a lot of clubs. He likes being on committees and enjoys doing paperwork and computer work. He wants people to learn more about Down syndrome by hearing the things he has to say about himself.

Andrew believes that people can learn more about Down syndrome through journals like *Voice* and social media by getting more people here and overseas to read about Down syndrome. *'We could send it overseas and get half a million people to read it. Then people could learn more by me talking about my life'*, he says.



Claire Mitchell

I live at home with my family. I have my own flat under the family home in the south of Queensland.

One of my favourite things is public speaking. I love it. I love being able to help other people especially those who are under 30. I work in the Children's Hospital at Lady Cilento. I am an office administrator.

Why did you want to be a part of DSAN?

Mainly because I am interested in employment and people having jobs and I think that everyone needs to have a voice and to be heard. It was wonderful being in Melbourne and meeting everyone who was the chair of their states. I like meeting new people. I like people more than I like animals.

How will DSAN help the organisation?

I would like to think it can help every single aspect including aged care. It's really important to think of everyone. I think that when you are trying to make a decision you really don't want those decisions made for you. You want to be making them yourself.

I want a happy and healthy life that everyone is able to achieve. I want to be like everyone else. Everyone needs to be working and you need a job that suits you.

What do you want people to know about Down syndrome?

It's not something to be frightened of. People shouldn't be frightened to come and talk to us. It's important for people with Down syndrome to be heard in their own words. For people who struggle with communication, there are other things out there to use. Disability Standards are done by pictures or if you know sign, you can use that.



Kylie Scott

I am involved in Uni2Beyond. It's a program for people who have intellectual disability at Sydney University. I live independently in a private rented apartment. I am on the Sydney Local Health District NDIS Governance Committee and the Centre for Disability Studies Joint Research Committee.

I also have my business (kyliedownsbarriers.com.au) which is public speaking and arts. I talk about examples in my life to help people understand and learn from people with Down syndrome and intellectual disability.

Why did you want to be a part of DSAN?

It means a lot to me to be part of DSAN. It's exciting. People with Down syndrome need to find a way and be free to have a voice. I will advocate in the meetings and use the skills I have learnt. When I was little, mum and dad showed me how to do things. I'm really close to my mum and dad.

What was it like meeting the other members of the network?

It was a challenge for me. We all have different voices, different names and different faces. It was great.

What do you want people to know about Down syndrome?

We have the same skills and experience. I want families more involved. Communicate with people with Down syndrome more, get them in the centre more...person-centred. I want people to ask me what I want. I want World Peace.

What can society do to make things better for people with Down syndrome?

Be welcoming in the community if they are out in the community activities. Their NDIS plan helps them get into the community.

The planner comes to you and you can ask for things, they help you out. If you don't ask you don't get.

Take one step at a time.



Matthew O'Neil

Matthew is 22 years old and from Melbourne. He has a very busy life working a number of jobs—both paid and volunteer—in retail, hospitality and as an assistant basketball coach.

'I'm alive and healthy. I get on well with my family. I have a voice and an opinion and enough money. People with disabilities are important to other people.'

I have a good attitude and stay calm and strong through tough times. I like to share the love with family and friends and like to feel loved. I like cracking jokes and being a bit silly. I like to stay positive. I would rate my life 10/10.'

He said being part of DSAN was to be a role model and to inspire other people with Down syndrome.

When meeting the team and network he was nervous but hoped that he made a good impression. He is still learning about the process and enjoyed meeting a politician from Canada. He was keen to tell others about the difficulties he experienced in a mainstream school and hoped that it did not happen to others.

He says, *'Other people should know that people with Down syndrome have some similarities and some differences. They are more vulnerable and may need additional help. People need to know that people with Down syndrome need to have jobs, somewhere to live, money and be able to spend time with family and friends.'*

Matthew is red hot to go as part of the network. He will go to all of the meetings, go to fundraisers and spoke as a representative of DSAN to a workshop run by VALID recently.



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Nick McMahon

Nick is 27 years old and lives in Adelaide. He is an active member of Down Syndrome SA and is a part of many of their programs including Life Ed classes, Club Slick and Club Strike activities. He loves rock'n'roll dancing and has performed at World Down Syndrome conferences with his dance group.

Why is it important to be a part of DSAN?

So I can be myself independently sometimes, and to help other people with Down syndrome.

What was it like meeting the network and the team?

It was good with everything—to meet the team and good to stay in Melbourne and go to the meeting.

What do you want people to know about Down syndrome?

We have fun and hangout together with friendships and dancing

How will you help DSA with their work?

I will do apparently any kind of work to help, and how to help them learn dance, but not be overprotective with friends.



Ebony Beveridge

Ebony (21) is currently focusing on moving towards independent living, enjoying a very active lifestyle and is a keen voice for people with Down syndrome. Ebony has presented to a number of audiences including service clubs, TAFE Individual Support students and Down Syndrome Tasmania's professional workshops for teachers and teacher's assistants. Ebony is doing work placements with Family Day Care and the School of Special Education and is a member of the BrightStars Dance Troupe, does hip-hop dance classes and regularly attends the gym. Ebony is experiencing great support and benefits from her NDIS plan and team.



Michael Sullivan

Michael Sullivan is an experienced and seasoned advocate for people with an intellectual disability. He was Chair of NSW Council for Intellectual Disability from 2015–2017. He has previously been on the National Disability Advisory Council in Canberra and currently is on the National Disability Insurance Agency Intellectual Disability Reference Group. Michael is also the Australian representative for Down Syndrome International (self-advocacy group) and the Healthy Ageing Ambassador for the UNSW Department of Developmental Disability Neuropsychiatry. Therefore, Down Syndrome Australia is thrilled that Michael can bring his experience to the network.

When asked about his role in DSAN, Michael says:

'It's important to be part of the DSAN, to get to meet all the other representatives of the states, and to get to know them.'

It's always important to meet the people you are going to work with and for in person. Meeting the team and the network for the first time is really great.

Having Down syndrome, we are no different from anybody else: all we want is to be treated with dignity and respect.

Being the international rep, on Down Syndrome Australia, I will work on anything special that needs to be addressed.'

