

DSAN update

By Michael Sullivan

Firstly, I wanted to thank DSA for asking me to be part of the DSAN – what a great opportunity.

The DSAN this year has been really great, and we've done lots of work that is now being used in various ways. The meetings are really good but I am happy that we have also been asked if we like the way the meetings are run, so we can make them even better. One of the things we decided is that we'd like to meet more often, just so we stay more connected and have that chance to learn more from each other.

The DSAN is very important to the members as we have a chance to have our opinions heard and to have our say. Some of us experienced advocates get a chance to pass on some of our knowledge and some of the younger advocates get to learn more about being leaders.

But the DSAN shouldn't only be important to its members, it should also be important to the actual DSA organisation because they get to have our input and hear our opinions and experiences.

Our opinions are really vital, and our experience.

People need to actually learn to listen to people with Down syndrome, and actually take in what we've said about what's important to us.

One of the things I get to do as the Chair of the DSAN is to report to the DSA board about our work so far. When I am reporting to the board it's actually me giving the opinions and ideas from the whole advisory network, that's really important because that's how we know that the organisation is representing people with Down syndrome, and not just their families.

I think being on the DSAN is good too because I feel like the channels of communication are open between all the DS groups, DSi and the states.

I think learning to listen to and value the opinions of people with Down syndrome is really important. A lot of parents of people with Down syndrome do advocacy



● Michael Sullivan and Nicole Lee at the DSA board meeting 2018

and I think they can fall into the habit of thinking they know best. And often they have great ideas and opinions, but we also need to hear from those of us who have the actual lived experience of Down syndrome.

It's a habit to think sometimes that you know best: you've been making decisions for your child all their life and it can be hard for people to say, 'Ok I'm going to listen to what these people with Down syndrome have to say.'

And a lot of people with Down syndrome or other intellectual disability can get into the habit of having decisions made for them and that can be hard to know then what your opinion is.

So, the process of getting opinions from a person with Down syndrome might be a longer process than just saying 'I'll just decide what to do on my own, it will be much quicker', but it isn't the right thing to do.

That longer process hasn't been in place for many people but it's really important to give it a go. I like that the DSAN is part of that process of encouraging people to listen to people with lived experience.

Michael Sullivan is the chair of the Down Syndrome Advisory Network for DSA.

