

## Down Syndrome Advisory Network

### Terms of Reference



This information is written in an easy to read way. We use pictures to explain some ideas.

Some words are written in **bold**. We explain what these words mean.

This is an Easy Read version of another document. You can ask us for a copy of the other document.

You can ask for help to read this information.

A family member, friend or support person may be able to help you. Let us know if you need us to help you.



This information is the **Terms of Reference** for the **Down Syndrome Advisory Network**. Terms of Reference explain a group's goals, how it works and its rules. We sometimes call the advisory network the **DSAN**.

The DSAN is a group of 5 – 8 people with Down syndrome who advise Down Syndrome about issues that are important to people with Down syndrome.





### **DSAN Guiding Principles**

Guiding Principles are good ideas that Down Syndrome Australia has agreed are goals that will help make the DSAN the best group it can be.



***Having a voice*** – the DSAN is a way for people with Down syndrome to have their say on important issues.



***Access and Equity*** – It doesn't matter where you live in Australia or how much support you need – you have a fair and equal chance to be on the DSAN



***Diversity*** – It doesn't matter what your background is – the DSAN welcomes everyone to apply to be a DSAN member.



**Using resources wisely** – The DSAN has online meetings as much as possible. This leaves more money for supporting DSAN members to take part.



**Capacity Building** – DSAN members learn to be good at speaking up for themselves and other people with Down syndrome. The DSAN helps Down Syndrome Australia to make better decisions.



### **The role of the DSAN**

The role is the work the DSAN does.

The DSAN helps Down Syndrome Australia understand what is important to people with Down syndrome.

This helps Down Syndrome Australia make good decisions and plans.

The DSAN helps Down Syndrome Australia speak out for and with people with Down syndrome.

The DSAN helps people with Down syndrome to become leaders.



## DSAN Members

People can apply to be members when Down Syndrome Australia advertises for new DSAN members.

Down Syndrome Australia and the state and territory Down syndrome organisations choose between 5 and 8 members to be on the DSAN at a time. Members are usually on the DSAN for around 2 years.

DSAN members are people with Down syndrome aged 18 and over who:

- Are interested in having a say on important issues
- Want to help other people with Down syndrome
- Have the right knowledge, qualities and skills
- Come from different backgrounds
- Want to develop their leadership skills
- Take part in DSAN meetings and sometimes other meetings, events and training.

If a member misses more than three meetings without a good reason, they might be asked to leave the DSAN.



## Support

DSAN members get support to do their DSAN work

This includes:

- Training to do the DSAN work.
- A local support person for each member to help with DSAN work
- Staff to help run the DSAN, including organising meetings.
- Help with costs of being a member and taking part in meetings.
- DSAN information in the **format** they need. The format is Easy Read or other kinds of information depending on what they need.

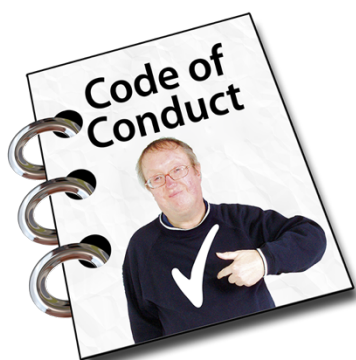






## How the DSAN does its work

The DSAN follows these Terms of Reference and any other rules made by Down Syndrome Australia.



## Code of Conduct

The Code of Conduct says DSAN members must do the right thing in their DSAN work.

They must:

- Follow the DSAN rules
- Respect other people
- Keep information **confidential**. This means keeping information private from people who are not DSAN members or DSA staff
- Say when they may have a **conflict of interest**. This is when they might put their own benefit first instead of putting DSAN first.
- Take part in monthly meetings





## Meetings

- The DSAN has online monthly meetings.
- Sometimes members may go to face to face meetings. They might need to travel a long way to get to the meetings.
- There is a DSAN member who is the leader for meetings. This person is called the Chair.
- The Chair also goes to Down Syndrome Australia Board meetings. The Chair gets any support they need to go to and take part in these meetings.
- The Chair runs the meetings using an **agenda**. This is a list of things members will talk about at the meeting.
- Down Syndrome Australia and the DSAN members tell the DSAN staff what to put on the agenda.
- The DSAN staff write the agenda and send it to members at least 10 days before the meeting. This gives members and their support people time to prepare for the meeting.



- DSAN staff write the **Minutes**. These are notes about what happens in the meetings.



- All DSAN members can have a say on the issues being discussed and how the DSAN is run.
- Sometimes, the DSAN will need to make decisions on topics and let the DSA Board know their decision. The DSAN might need to vote to decide on a decision if they don't all agree. DSAN staff can support the group to do this.



- Sorting out **conflicts** – conflicts are when people don't agree and can't work it out themselves.

If there is a conflict between DSAN members, they should first try to sort the issue out with the help of the DSAN Chair. If this doesn't work, then members should ask the DSAN coordinator to help them sort it out.





- The DSAN has a meeting every year to make plans for the work they are going to do. This might be an online meeting.



### **Reporting**

The DSAN sends its Minutes of meetings to the DSA Board. They also send other reports including an **annual** report. This is a report done once a year about the DSAN's work.



### **Telling people about the DSAN and its work**

Down Syndrome Australia lets people know about the DSAN and its work in stories on the DSA website, newsletters, social media, such as Facebook, and in other ways.



DSAN members might help with this and might have their names and photos used in the stories about the DSAN.



## Review

The DSAN and its work is **reviewed** every 12 months. This means looking at the work they have done, how they have worked together and thinking of changes to make the DSAN better.

DSAN members, the DSA Board, state and territory organisations, the Australian Down syndrome community and other interested people can have their say in the review.

## Review of Terms of Reference

These terms of reference and any other rules relating to the DSAN will be reviewed at least every two years, to see if they work well or can be made better.

## Accessible Information

People can ask for these terms of reference in Easy Read or other formats they may need.

## For more information on the DSAN:

[www.downsyndrome.org.au](http://www.downsyndrome.org.au)

Or contact the DSAN Coordinator:

Deb Green at  
[dsan@downsyndrome.org.au](mailto:dsan@downsyndrome.org.au)