

Self-Advocacy Group Guide

Produced by
Down Syndrome International



Introduction.

About Down Syndrome International (DSi).

We are the global network of people with Down syndrome and their families.

Our network includes people with Down syndrome and other disabilities, friends and family members, professionals and organisations from around the world.

Our network includes over 150 organisations that represent and support the Down syndrome community in their country.

The people in our network tell us about life for people with Down syndrome in different parts of the world.

Together we speak up for the human rights of all people with Down syndrome around the world.

Find out more on the [Down Syndrome International website](https://www.dsinternational.org/).



Aim of this guide.

This guide helps people learn how to run self-advocacy groups for people with Down syndrome.

By the end, you will know:

- Why these groups are important.
- You will learn different ways to lead a group well.
- You will know how to use tools to help everyone join in.
- You will learn fun and creative ideas to make the group better.
- You will make sure everyone is safe and follows the rules.
- You will learn about the laws that keep people safe.
- This training helps you support people with Down syndrome to speak up.

Self-advocacy groups.

What is self-advocacy?

Speaking up for yourself and other people	Being proud of who you are	Speaking up for your rights
Making decisions about your life	Sharing what you think and feel	Knowing your rights and responsibilities

Self-advocacy means people with Down syndrome speak up for themselves. They also speak up for others with disabilities. This helps them have a say in their lives.

People with Down syndrome often don't get to make important choices. Self-advocacy helps them be heard. It makes their voices louder.

Self-advocacy can be about small or big decisions. It can be about personal choices or changes in their community. It can also be about changes in the whole country.

When people with Down syndrome speak up, they can help make things better. They can tell others what they need and want. This helps everyone understand them better.

Self-advocacy is important. It helps people with Down syndrome live better lives. It gives them power to make their own choices.



What is a self-advocacy group?

A self-advocacy group helps people with Down syndrome learn about their rights. They also learn how to speak up for themselves.

Later, the group becomes a place where they can meet and work together. They do advocacy work.

Activities in the group can include talking about their needs and rights. They might also plan events or speak to others about their experiences.

Sharing experiences and feelings	Advocating together for human rights	Supporting each other
Making a difference to the local community	Working on projects	Speaking up for others with Down syndrome

Who is a self-advocacy group for?

A self-advocacy group is for anyone with Down syndrome. It does not matter what skills or experience they have.

The group helps people to share their thoughts and feelings. They can practice speaking up for themselves.

Over time, they will get better at these skills. They will become stronger self-advocates.

Example self-advocacy group - Turkey

In January 2018, Down Syndrome International helped Down Turkey start a self-advocacy group, for people with Down syndrome in Istanbul.

The group met every 2 weeks. They talked about human rights and practised speaking in public.

Group leaders made sure everyone understood the topics. They helped members join in and plan their activities.

In 10 months, the group did many advocacy activities. They met politicians and spoke at the Turkish Parliament.

They also spoke at the United Nations in New York. They held press conferences for journalists from all over Turkey.

The group made a video and a petition. They presented these to the parliament.

Watch here: www.youtube.com/watch?v=iNWdoNUnjSc



The facilitator role.

What is a facilitator?

A facilitator is someone who helps people work together. They do this by giving help and support.

Facilitators help people learn new things. They teach the group new skills or help them understand a topic.

Facilitators also support each person in the group. They make sure everyone can join in and feel included.

Sometimes, people in the group might not agree. Facilitators help solve these problems so everyone can work well together.

Facilitators also help the group meet new people. They connect the group with other people or organisations.

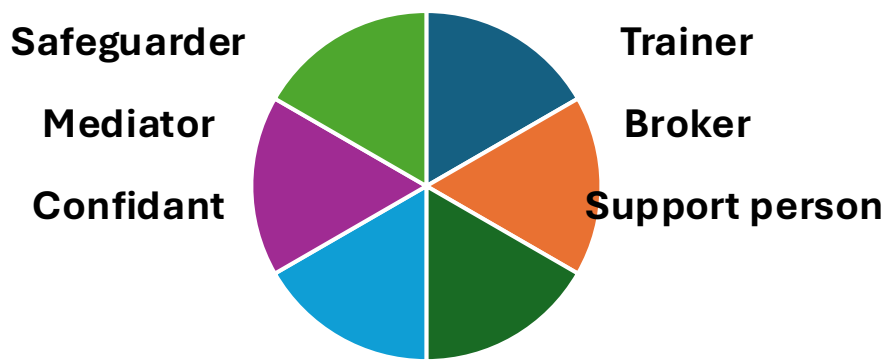
Safety is very important. Facilitators make sure everyone is safe during group activities.

Facilitators wear many hats. They teach, support, solve problems, listen, connect, and keep everyone safe.

Each role is important for the group to work well. Facilitators help the group in many ways.

With a good facilitator, the group can learn, grow, and work together happily and safely.

Facilitator roles



Developing skills of self-advocates.

Facilitators help people learn to speak up for themselves. This is called being a self-advocate.

Here are some of the skills:

Assertiveness	Self-confidence	Communication
Expressing opinions	Teamwork	Listening to other people
Making complaints	Decision making	Standing up for yourself

One skill they teach is **assertiveness**. This means saying what you need in a strong but kind and respectful way.

Another skill is **self-confidence**. This helps you believe in yourself and your abilities.

Communication is also important. This means talking and listening to others clearly.

Sharing what you think and feel about things. This is called **sharing opinions**.

Teamwork is working well with others. It helps you achieve goals together.

Listening to what other people say is important too.

Making complaints is a skill. It means telling someone when something is wrong.

Decision making is choosing what to do. It helps you take control of your life.

Standing up for yourself is very important. It means protecting your rights and needs.

Skills can be learned in many ways.

One way is **teaching**. This means showing someone how to do something.

Another way is giving chances to **practice**. This helps people get better at what they learn.

Real life experience is also important. This means doing things in real life.

For example, let's help someone speak in public.

First:

We can teach them how to give a good speech. We can give them tips and advice.

Next:

We can let them practice speaking. They can practice in a safe group. This helps them feel more confident.

Finally:

We can arrange a real speech. They can speak in front of others in the community. This gives them real experience.

It helps them learn, grow and succeed. They will feel proud of their achievement.

For example, to support a self-advocate to develop the skill at public speaking, you might:

Teaching	Practice	Experience
Give them some tips for doing a good speech.	Provide opportunities for them to practice public speaking within the group.	Arrange for them to deliver a speech in the community.

Teaching self-advocates.

Facilitators need to help self-advocates learn new skills. They also need to help them understand things better.

People with Down syndrome all have their own strengths and challenges.

With the right support, people with Down syndrome can learn and grow. They can do many things well.

Supporting self-advocates to make decisions.

Facilitators should help the group make their own choices. They should not decide everything for the group.

The group needs to make real choices about things that matter to them.

These choices should not be just for show.



Facilitators can use different ways to help people make choices.

Create lists of pros and cons for each option.

Give extra time for the group to discuss the decision.

Provide visuals to show the options.

Use role play to show the options.

Explain how each choice might affect everyone in the group.

Planning group sessions.

Facilitators will need to be able to plan sessions for the self-advocacy group.

Plans should include:

The aim of the session:

- What needs to be achieved for the session to be a success?

The session structure:

- Introduction, activities, summary.

Activities:

- Icebreakers, games, role plays, group discussions, presentations, videos, songs, group work, worksheets, etc.

Roles:

- Who will do what within the session? Which parts will be led by facilitators and when will self-advocates take responsibility?

When planning sessions, it is important to also think about practical things like:

Session timings	Materials and equipment needed	Layout of the room
Venue/travel	Refreshments	Number of facilitators

Getting feedback from self-advocates.

To know if the group is doing well, we need to ask the people in it. It is important to know how they feel about the group.

The people who help run the group should ask for feedback. Feedback means asking people what they think and feel.

This helps make the group better for everyone.

To know if people like something, we can watch how they act. We look at their faces and bodies. But sometimes we can get it wrong. So, we need other ways to find out.

We can ask people questions. This helps us know what they think. We can use forms or surveys. People can write down their thoughts. This gives us clear answers.

We can also talk to people in groups. This is called a focus group. People share their ideas together. We listen to what everyone says. This helps us learn more.

Sometimes, we can watch people over time. This is called observation. We see how they act in different situations. This helps us understand them better.

Using these ways, we can get good feedback. This helps us know if people like something. We can then make things better for everyone.

There are some more ideas in the listen include respect guidelines www.listenincluderespect.com/consultations



Key topics.

Human rights.

It is important for people to know their rights so they can speak up for themselves. Human rights mean being treated with respect, equality and being part of the community. These ideas help people feel strong and included.

The UN Convention on the Rights of Persons with Disabilities (CRPD) is important. It helps us understand the rights of people with Down syndrome and other disabilities. You can read it in Easy Read format here: <https://assets.publishing.service.gov.uk/media/5a7d9f62ed915d497af70837/easy-read-un-convention.pdf>

People should get help to learn about Article 3 of the CRPD. This part talks about important ideas like respect and fairness for everyone. It is good for self-advocates to know these ideas.

The ideas include:

Being able to make your own choices.

- Making your own choices and speaking for yourself is one of the most important things in self-advocacy.

Not being discriminated against.

Being fully included in society.

Being respected for who you are.

- Self-advocacy is about being proud of who you are.

Having equal opportunities.

Accessibility.

- To the physical environment, transport, information and communication.

Men and women being treated equally.

Communication.

People communicate in different ways. Facilitators must make sure everyone can join in the group. They need to know how each person communicates, how to communicate with them, and how to help them communicate with others.

It is important to understand each person's way of communicating. This helps everyone feel included and able to share their ideas. Facilitators should support each person so they can be part of the group.

Communication tools and systems.

There are lots of communication tools and systems that you can use to support Communication, including:



Makaton:

- Uses speech, sign, facial expressions and symbols to convey meaning.



Talking mats:

- Low-tech system for offering people choices using symbols laid on a mat.



Symbol systems:

- Different symbol systems provide a set of symbols to support communication. Examples include Makaton, Picture Communication Symbols (PCS), Widget Symbols.



Objects of reference:

- Uses physical objects to symbolise people, places or activities.



Easy read:

- Tool for making written material more accessible, using pictures and plain language.

You can read more about communication and information in the listen include respect guidelines www.listenincluderespect.com/communication

Safeguarding.

Facilitators help people speak up for themselves.

They must keep everyone safe and happy. This is very important for people with Down syndrome. They might be more at risk of being hurt or treated badly.

Self-advocacy groups are places where people talk about their lives. Sometimes, they might share if someone has abused them. Facilitators need to listen carefully and help if this happens.

Abuse can happen in different ways. It might be physical, like hitting. It can also be emotional, like saying mean things. Facilitators should know about all these types of abuse:

Sexual abuse	Physical abuse
Psychological abuse	Neglect
Financial abuse	Discriminatory abuse
Organisational abuse	Self-neglect
Domestic abuse	Modern slavery

Facilitators need to watch for signs that someone might be being abused. This could be changes in how they act or look. They should be ready to help if they think something is wrong.

If someone says they are being abused, facilitators must know what to do. They should follow the rules of their organisation. This helps keep everyone safe.

Facilitators should also know the laws about keeping people safe. This is called safeguarding. It is important to follow these laws to protect everyone.

Training is important for facilitators. They need to learn how to spot abuse and what to do if they see it. This helps them do their job well.

Keeping people safe is a big job. Facilitators must always be careful and ready to help. This makes sure everyone can speak up and feel safe.