

Information for Organisations

How to Support Survivors of Institutions

Join the Survivor Network

Who is this information for?

This guide is for organisations and supporters who are helping people with intellectual disabilities who are survivors of institutions to join and take part in the Survivor Network of Inclusion International.

This guide will help organisations and supporters understand the goal of the network and provide ideas to help people with intellectual disabilities to take part.

What is an institution?

An institution is any place where people with disabilities live separated from the community.

It is any place in which people do not have control over their lives and their day-to-day decisions like who cares for them and what they do with their time. When people live in institutions their rights are not respected.

An institution can be large when many people live together in the same place. Or small with only a few people.

Institutions can have many different names; a few examples of names might be:

- Long stay hospital
- Special boarding schools
- Nursing home
- Protected living centre.
- Group home

Even when a place is not described as an institution by the people who work there, it can still be an institution.

What is the Survivor Network?

The Survivor Network is for people with intellectual disabilities who have lived or currently live in an institution or any other place where people are institutionalised.

The goal of the network is to:

- Give survivors a place to talk about their experiences.
- Help survivors learn how to speak up for their right to live in the community.
- Share ideas about how to work on deinstitutionalisation.

The Survivor Network has been planned by a steering group of self-advocate survivors from around the world.

How organisations can support survivors:

Support survivors to understand the network

- It is important that survivors understand the goal of the network and the topics that will be discussed.
- The group may be most suitable for experienced self-advocates who understand their rights and deinstitutionalisation.
- Organisations can support self-advocates to prepare by talking through:
 - the importance of deinstitutionalisation
 - the right to be included in the community.
 - what Governments should be doing.
- Inclusion International has some easy videos that may help explain. Here is the playlist [in English](#) and [Spanish](#). All the same information is written here in [English](#) and Spanish.

Help with Language

- The survivor network meetings will have interpretation into English, French, Romanian and Japanese.
- If survivors from your organisation do not speak these languages your organisation may be able to support them with interpretation.

Help with Travel

- The survivor meetings will be online. If survivors need in-person support to join online you may need to support survivors to meet supporters.
- This might mean arranging a taxi or support to use public transport.
- Make sure the meeting place is easy to get to.

Support at Meetings

- Organisations and supporters should meet and ask each survivor what help they need to be part of the meetings. It might be useful to plan to support each person and keep checking if the support is working and change it if needed.
- Supporters should be chosen by the survivor who is joining the meeting. The supporter and self-advocate should know each other well.
- The supporter should understand about the right to live in the community and deinstitutionalisation.
- Try to have the same person support the self-advocate at every meeting.
- Supporters should know how to support survivors in speaking up.
- Supporters should listen carefully and not speak for the survivor.
- Supporters should encourage survivors to share their ideas.
- Supporters should encourage survivors to make their own choices.
- Supporters should never pressure survivors to take part in the meetings or share personal information if they are not ready.
- More information about good support for [self-advocates is here](#).

Organisational support

- It is important that the knowledge and information the survivor gains from the network are shared at your organisation. Lived experiences and knowledge shared from others will make your work better.

- Your organisation should support or create leadership opportunities for the self-advocates involved with the network. For example, include the survivor in project work on deinstitutionalisation, invite the survivor to be part of advocacy work on deinstitutionalisation etc.
- Your organisation should encourage the survivor to share with other self-advocates in your network, for example training events or in group meetings.

Looking After Mental Health

- Institutionalisation is a difficult topic for many people to talk about.
- Survivors may have had experiences whilst institutionalised that they want to share and talk about with peers.
- There may be topics or discussions that are difficult and upsetting.
- Organisations, supporters, and self-advocates should prepare and plan for how to support if the topics make the survivor feel upset.
- Survivors should be supported to leave the meeting if they need a break.
- Supporters should always check in and ask survivors how they are feeling after meetings. Supporters should offer to talk more if survivors want to.
- Supporters and organisations should know who to call if someone needs extra help. For example, your organisation should investigate mental health services that can support the person.

What will Inclusion International do?

Inclusion International helps to coordinate and plan the network meetings.

Inclusion International will plan the meetings in line with the [Listen Include Respect guideline principles.](#)

This means Inclusion International commit to:

- Make information about the meetings is easy to understand,
- That the meetings are accessible and inclusive so that everyone feels safe and welcome.
- Have clear rules for the meetings so everyone is treated respectfully.
- Make sure everyone gets a chance to speak if they want to.
- Give opportunities for people to share their ideas in different ways for example by talking or writing or drawing their ideas.
- Thank people for sharing their ideas.

We want to make sure organisations and supporters feel comfortable supporting survivors to take part.

Inclusion International will consult with experts who work on mental health support. We will share this information with organisations to help them prepare to support survivors.

Inclusion International will hold regular meetings for supporters and organisations to speak about the network, ask questions,

and share ideas. The first of these will be held before the network launches.

Meeting information:

The first Survivor Network meeting will be 12th November 2024 at 7am UK time. [You can check the time for you here.](#)

The first organisation and supporters meeting will be 30th October 2024 at 7am UK time. [You can check the time for you here.](#)

If you would like to join the meetings you can email Ailis or Olivia from Inclusion International.

- Ailis.Hardy@inclusion-international.org
- Olivia@inclusion-international.org

You can also contact Ailis and Olivia if you have more questions.