Information for supporters

The survey

Down Syndrome International and Inclusion International are developing guidelines for organisations on inclusive participation for people with intellectual disabilities.

Inclusive participation is when a person with an intellectual disability:

- gets information in a way that they understand,
- can share their ideas, experiences and knowledge alongside everyone else,
- is given the time and adjustments they need to take part.

Answers from the survey will inform these guidelines by providing a better understanding of the barriers that stop people with intellectual disabilities from being included and what helps them take part in the work of organisations.

To make sure the guidelines are useful and relevant internationally, we are collecting answers from people with intellectual disabilities and the people who support and work with them from around the world.

The survey is split into 7 sections. Each section covers a different topic area and will be introduced by a short video. An Easy Read word version can be downloaded. The survey is available in several different languages.

Below are some suggestions for support persons on how you might explain the survey and work through the survey with the person with an intellectual disability that you support.

Support before answering the survey

- Explain that this work is about creating guidelines for organisations. Organisations need help and advice to make sure they know how to include people with intellectual disabilities in their work. You can explain that being included and having the support and accommodations to take part is a right that is protected by the Convention on the Rights of Persons with Disabilities.
- Have a conversation about what inclusion means and examples of times when the person you support has felt included. Talk about what helped the person to feel included. Also, talk about when the person has felt excluded and what the barriers were that meant that they could not take part.
- If relevant talk about the organisations the person you are supporting may have worked with. Having one or two examples in mind will be helpful when answering the survey.
We are collecting good examples in Section 7 of the survey. We ask for links to websites and the names of organisations who do good work including people. Work with the person you support to talk about good examples and collect the information about these experiences to prepare to answer this section.

Support whilst answering the survey

- The most important thing is to give the person you are supporting as much time as they need to understand the topic area and the question and to think about how they are going to respond.
- Throughout the process, it is important to emphasise to the person you are supporting that:
  - there are no right or wrong answers
  - they should answer the questions from their point of view
  - they should be open and honest in their answers
- There are multiple-choice answers for most of the questions, but we want to make sure people can share their own experiences or ideas. Encourage the person you support to use the ‘Other (please give details)’ box to submit their answers that are not part of the multiple-choice list
- There is the option to provide names and email addresses at the end of the survey, but there is no obligation to do so.

Support after the survey

- Have a conversation with the person you support to make sure they understand what their work and answers have contributed towards. These international guidelines will be useful for everyone.
- If the person is keen to follow up on this work, please encourage them to email us or contact us on social media.
- We are also collecting input from support persons, carers, family members and colleagues of people with intellectual disabilities. So please make sure to submit your answers to the survey as well.

Thank you so much for your support.

We hope the guidelines will enable people with intellectual disabilities to be more fully included in the work of organisations in the future.

If you have any questions please email ListenIncludeRespect@inclusion-international.org