**Focus Group Guide:**

**Talking to Families and Self-Advocates about Care and Support**

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| This focus group guide is a tool for Inclusion International members who want to ensure that the voices of people with intellectual disabilities and their families in their country are represented in the global care and support agenda.  Members interested in hosting a focus group with self-advocates and/or family members in their countries can use the questions in this guide to host a local focus group and collect quotes and experiences on care and support.  Feedback from focus groups can be submitted on a rolling basis until October 15, 2025.  Completed focus group reports can be submitted by email to Olivia Schalkwyk at [olivia@inclusion-international.org](mailto:olivia@inclusion-international.org), copying:   * Manel Mhiri - [manel@inclusion-international.org](mailto:manel@inclusion-international.org) * Kimber Bialik - [kimber@inclusion-international.org](mailto:kimber@inclusion-international.org) * Anna MacQuarrie - [anna.macquarrie@gmail.com](mailto:anna.macquarrie@gmail.com)   For additional questions about how to engage in the global care and support agenda, contact Manel Mhiri at [manel@inclusion-international.org](mailto:manel@inclusion-international.org). |

**Introduction - What is the care and support agenda?**

Around the world, there is an ongoing discussion about building strong care and support systems that are based on human rights and that represent the issues faced by women, persons with disabilities, and older persons.

This international push for governments to make reforms to their care and social protection systems to make them more inclusive and rooted in human rights is called the "care and support agenda."

The Care and Support Agenda is very big and includes lots of ideas, but for Inclusion International’s purposes, we will focus on what care and support means for people with intellectual disabilities and their families.

In every country around the world, it is families who are responsible for providing the bulk of support to persons with disabilities, often with little or no financial compensation, and while managing the discrimination that both themselves and their child with a disability faces.

Our network’s approach to the care and support agenda is based on two key ideas:

* Families need support to address the unique challenges they experience.
* Individuals with intellectual disabilities need support to live meaningful inclusive lives in their communities.

Strong family-based public policies and a valued recognition of the role of families will enable people with intellectual disabilities to get the support they need at all stages of their life, and for families of persons with intellectual disabilities to have ‘typical’ lives like other families. To learn more about the Care and Support Agenda, review our [Primer on the Care and Support Agenda.](https://docs.google.com/document/d/1DjdbbcVXsVTctsf-4ak5m8zDafE0tcRgxFVtPEusXzE/edit?usp=sharing)

**Inclusion International’s Project on Care and Support**

Inclusion International has a new project, funded by the SAGE Fund, focused on ensuring the global Care and Support Agenda is inclusive.

The purpose of the project is to:

* Help make the voices of families and self-advocates part of the global Care and Support Agenda discussions.
* Ensure the Care and Support Agenda includes the issues and experiences of families and self-advocates.
* Document the support and solutions needed in order to get and give fully inclusive care and support that respects dignity and choice.

The activities that Inclusion International will do as part of this project include:

* Hosting focus groups with self-advocates and families
* Partnering with members to develop case studies of good practice models of care and support.
* Creating a report about care and support to help our network’s advocacy work.

This resource supports members to engage in the first activity - hosting focus groups with self-advocates and families.

Inclusion International will be hosting focus groups at the World Congress and online that bring together self-advocates and families from different countries to share their care and support experiences.

But we know that experiences in different countries can be very different, and **we want to hear from self-advocates and families in your country about what inclusive care and support looks like to them.**

**Hosting a Focus Group**

For members who are already hosting a gathering of families or self advocates through your other activities, Inclusion International is asking members to consider including a small focus group on care and support as part of the event. This discussion could be hosted in-person, or online.

By documenting how self-advocates and families answer questions about their experiences of care and support (positive or negative) and their hopes for what an inclusive care and support system can look like, our members can input into resources being developed on care and support and into our network’s global advocacy on the care and support agenda.

Inclusion International has developed [questions for families](#_po1k8u5uprey) and [questions for self-advocates](#_gdlyzfuz347i) for you to use in a focus group - you can find these on the next page of this package. You do not have to ask all of the questions - if there is only one or only a few that are relevant to the activity you are doing with families or self-advocates, please feel free to only ask and share the answers for one question.

Please share the information collected during the focus group with us by filling out the [Focus Group Report template](#_xspi1famw3l) at the end of this package. If you would prefer to use your own template or reporting format, that is fine too, as long as it still includes some direct quotes and basic information about the number and type of participants.

If possible, we would also love to see photos of your focus group meeting and talking about care and support - if you share photos, please have participants sign the [photo release form](#_87r04cvju1my) on the final page of this package.

Completed templates or other reporting formats and photos can be sent to Olivia Schalkwyk at [olivia@inclusion-international.org](mailto:olivia@inclusion-international.org).   
 **Focus Group Questions - For Families**  
  
*Note that you can ask all of these questions if you wish, or a smaller set of questions if that is better suited to the activity you are doing with families.*

*Feel free to translate these questions into your language, or simplify the questions if needed.*

Questions about the support families need

1. What kind of support do you need (from peers, from organisations, from governments, etc.) to help you in your role as a care and support provider?
2. What kind of support do you need (from peers, from organisations, from governments, etc.) to make inclusion of your family member with an intellectual disability meaningful?
3. What care and support measures offered by your government have you used? What exists will be different in every country, but examples could include:  
   1. Financial supports like pensions, allowances, tax breaks, cash transfers to cover costs like personal support, respite, or to offset the additional costs of disability; or
   2. Employment protections for care-givers like flexible times, or
   3. Informal supports in community such as peer support or circles of support.
4. How does your organisation support you with what you need? What should the role of family groups/organisations be in care and support?

Questions about the support families give

1. What kind of support and care do you give your family member with an intellectual disability in their life? For example:  
   1. What kind of support do you provide to make sure your family member is making their own decisions?  
      1. Do they make decisions about the care and support they get from you? Should they? What would need to change for this to happen?
   2. What kind of support do you provide to make sure your family member can live independently in their community?
2. Are families the right people to be delivering all of these forms of care and support?  
   1. Who else should be helping to provide care and support for people with intellectual disabilities?
   2. Where should the role of families start and end?
3. Should families be compensated for providing support to their relatives with an intellectual disability?

*Focus group questions for self-advocates follow on the next page.* **Focus Group Questions - For Self-Advocates**

*Note that you can ask all of these questions if you wish, or a smaller set of questions if that is better suited to the activity you are doing with self-advocates.*

*Feel free to translate these questions in your language, or simplify the questions if needed.*

Questions about the support people with intellectual disabilities need

1. What kind of support do you need (from peers, from organisations, from governments, etc.) to live independently and be included in the community?
2. Why is support important to you?
3. What does good support mean to you?
4. How does your family support you with what you need? What should their role be in providing support and care?
5. How does your organisation support you with what you need? What should the role of organisations be in providing care and support?
6. Do you get to make your own choices about the support you get? What do you want your supporters to do differently to make sure you are making your own decisions about your support?

Questions about the support people with intellectual disabilities give

1. What support do you provide to your family members?
2. What care and support roles do self-advocates fill in their families, homes and communities?
3. What can families and organisations do to make sure that the way people with intellectual disabilities contribute to care and support is recognised?

## **Focus Group Reporting Template**

If you did both a focus group with families and a focus group with self-advocates, please fill out a separate reporting form for each focus group.

Your Contact Information:

|  |  |
| --- | --- |
| **Name of Organisation** |  |
| **Country** |  |
| **Contact Person** |  |
| **Contact’s Email Address** |  |

Participants:

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Number of Participants** |  | | | |
| **Who took part?**  Write an “X” in the box next to who took part - families or self-advocates. |  | Self-advocates |  | Families |
| **Extra information about the group**  What city do they come from? What age range was represented? |  | | | |

Focus Group Responses

*Please add as many boxes to the table as you need based on how many questions you asked.*

|  |  |
| --- | --- |
| **Question** | **Feedback** |
| *Please copy and paste the question into this box.* | *Please write the feedback you heard from the group in response to that question in this box beside the question. Please make sure you include a few quotes!* |
|  |  |
|  |  |
|  |  |
|  |  |

Extra Context (Optional):

*This extra information is optional, but will help us put the experiences of families and self-advocates in your country into context.*

|  |  |
| --- | --- |
| **What care and support measures are available in your country?**  Some examples could include financial supports (like pensions, allowances, cash transfers to cover things like personal support, etc.), employment protections for caregivers like flexible working, or informal supports in community such as peer support or circles of support. |  |
| **What information, supports or services are available to families to help ensure mainstream systems like education and health care or programs delivered for the general population are inclusive and accessible?** |  |

## **Photo Release Form**

**Consent Form and Photo Release**

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This is a **consent form**.

“Consent” means saying you agree that it is okay to do something.

This consent form is about sharing your experiences about care and support, and also about having photos taken of you.

It is something you need to read before you take part in the focus group.

There is information about why we are asking for your consent below.

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**What am I being asked to do?**You are being asked to take part in a focus group.   
  
A “focus group” is when a group of people discuss their experiences about something, and a notetaker writes down what they say.

The focus group is about care and support.

**Why do you want to hear my experiences about care and support?**Inclusion International is collecting information about care and support as part of a project.

What you share about care and support will be used to make reports, resources, and other information that will help organisations make care and support more inclusive.

Information you share can be used in different ways.

For example, Inclusion International might use the things you say are bad and care and support to tell other organisations what to change. Or they might use a story you tell them to explain why something needs to change.  
  
None of the information about your experience that you share will be able to be connected back to you. It will not have your name on it. This is called being “anonymous.”

**Remember, you do not have to take part if you don’t want to.**

**If you say no, nothing bad will happen. You can still take part in other things we do in the future.**

You get to choose how we use your information. You can tell us what the rules are for using your stories by filling out the form below.

**Please check the yes or no box based on what you want.**

|  |  |  |
| --- | --- | --- |
| **To take part, you need to agree to the following 5 things:** | | |
|  | Yes | No |
| I agree to take part in the focus group. |  |  |
| I agree that Inclusion International and the SAGE Fund can use what I say in the project work. For example, to help make reports and tools. |  |  |
| I agree that Inclusion International and the SAGE Fund can use what I say on social media, their websites, or other places. |  |  |

|  |  |  |
| --- | --- | --- |
| **The next section is “optional”. This means that you do not need to say yes, and you can still take part in the focus group if you say no.** | | |
|  | Yes | No |
| I agree that pictures or videos can be taken of me. |  |  |
| I agree that pictures or videos of me can be shared by Inclusion International and the SAGE Project, without my name. |  |  |

**After you have checked the yes and no boxes, sign this page.**

Name of the person taking part:   
  
\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Today’s date:   
  
\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Where you signed this form (city and country):   
  
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Your signature:   
  
\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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**If the person taking part is under 18, a parent or guardian must sign here.**

Name of the parent or guardian:   
  
\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Relationship to the person taking parent (for example, parent):   
  
\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Parent or Guardian’s signature:   
  
\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_