



THE RIGHT TO DECIDE

**Inclusion International's Global Campaign on
Decision-Making**

**Discussion Group Facilitator's Guide
Inclusion International
April 2013**

INTRODUCTION

Inclusion International's global campaign, *The Right to Decide*, is designed to get individuals, families and communities talking about making decisions and supported decision making. This discussion is about our daily lives – the big decisions and the little decisions – that give us voice and control in our lives. It's a discussion about how we make those decisions.

People with intellectual disabilities have told us that realizing their right to make decisions is essential for being seen and treated equally in community. Having voice and control is a priority for people with intellectual disabilities. Yet many individuals, families and communities struggle with this. A great deal of attention is invested in law reform – which is important – but we want to talk about how to make the right to decide real – in people's daily lives. The following discussion guide¹ is designed to help you start a discussion in your community about **the challenges and opportunities for people with intellectual disabilities to make decisions – about daily things in their lives like what to wear, what to eat, how to spend their time etc; and, the big things like where to live, how to manage their money, medical treatments etc.** Inclusion International has developed a toolkit with materials (including powerpoint presentations and background documents) you may find useful. These can be found on our website: www.inclusion-international.org.

Who to talk to?

Discussion groups will be held with families and people with intellectual disabilities.

What to talk about?

The Issues:

- We want to identify the issues people with intellectual disabilities and their families are facing in making their own decisions and having their right to make decisions recognized.

How People are Supported:

- We want to know how families, service providers or other professionals can support people with intellectual disabilities to make their own decisions.
- We want to hear what exists in your family, or your community, to support people with intellectual disabilities to make their own decisions and what you think should exist.

Good Examples of Support:

- We want to identify good examples of laws, policies, community, and family practices that support people with intellectual disabilities to make and act on their own decisions, and to have others respect their decisions.

What does Inclusion International want?

Inclusion International (II) would be grateful for notes from your discussion groups, summary reports, stories, and/or quotes from participants. We need this information to write our global report. Please send us a discussion group report (Appendix A) so we can follow-up with you if/as needed.

Timeframe

In order for your work to be recognized in Inclusion International's Global Report, we require feedback from your discussion groups by **March 01, 2014**.

¹ This discussion guide draws from materials originally developed by the Canadian Association for Community Living. We are grateful to CACL for their permission to use their materials.

Message to Facilitators

Thank you for hosting and facilitating a group discussion on decision making! As a facilitator, please read all the material provided in the Right to Decide Toolkit. If you have questions please contact our campaign team: righttodecide@inclusion-international.org

The role of the facilitator is to provide a brief introduction to the process using the material we are providing. We are aware of the diversity of people with intellectual disability and their families all over the world. Perspectives are shaped on where we live, our culture, our lived experience of disability. We have tried to develop tools that are globally relevant **BUT** we know there may have to be some accommodation of the tools to suit your particular needs. We invite you to use the material provided in a way that is appropriate for your country, your city, your group. We would appreciate feedback from you about the tools and any modifications/changes that you felt were necessary. Please include this information in the discussion group reporting sheet so that we can learn from your experiences.

The reports from discussion groups will be critical in shaping our global report on the Right to Decide which will be launched in June 2014 at Inclusion International's World Congress in Nairboi, Kenya.

Discussion Group Planning

- Discussion groups should be set up with 1 facilitator, 1 note-taker and between 10 – 20 participants, and should run for approximately two to three hours.
- Discussion groups should take place in the community where families and people with intellectual disabilities live. They should be representative of diverse communities (either rural, urban, semi-urban or all)
- Consider attaching a discussion group to an event that is already planned. If there is a group already meeting ask for the possibility to use one of their meetings to host a discussion group.
- Make sure the place is accessible; people might need support for transportation and if possible provide a snack during the meeting. When inviting let them know what will be discussed, if needed use the information we have provided.

Have people sign at the entrance to allow pictures of the group to be used by II, if someone does not want their picture to be used by II let them know is ok and please do not have that person in the pictures you send us.

Who to invite

- If you are doing a discussion group with families, invite 10 - 15 people who have a relative with an intellectual disability
- If you are doing a discussion group with individuals, invite 10-15 people with an intellectual disability (and their support people as needed).

Group Discussion

1. Introduction of participants: The day of the group discussion acknowledge the reality of each participant. Start by reviewing the purpose of the discussion group. Introduce yourself and let each participant introduce themselves. This is an opportunity for participants to share who they are, where they live, and why they are participating in this focus group.
2. Introduction of the Right to Decide: Using the material provided in the Right to Decide Toolkit and the Powerpoint presentations, introduce participants to the right to make decisions.
3. Use the questions provided in this Discussion Guide (pg. 5 for individuals; pg. 7 for families) to guide the discussion.

4. Create a group message on decision making
 - a. To end the discussion group ask the participants for a message that they would want to share with the world about the importance of being able to make decisions.
 - b. Create a group message and take a group picture to go along with the message.

Discussion Group hints and tips:

- Be short
- Use plain language
- Acknowledge everyone understands why are they here
- Make sure everyone's opinion is acknowledge
- Reinforce there are no right and wrong answers
- If the discussion starts going in a different way as the question bring people back to the question discussed
- Encourage broad discussion about all the types of decisions people make (not just day-to-day but big life decisions too)
- Assure them that no names will be collected in your report or used in the material of the Campaign unless someone directly shares it with II and allows us to use it

Collecting Information

- Using the discussion guide questions, create a board chart and record all of the participants' responses.
- Notes should be taken by a person different from the facilitator. The note-taker should:
 - Record the information provided by the participants during the focus group.
 - Include all comments by participants during the discussion. ***We encourage as many quotes as possible since they will be very useful in the global report.***
- Additional information to be collected:
 - A description of the community (urban or rural, size)
 - Profiles of the participants
 - Stories of their experiences related to making decisions
 - Questions participants asked

Questions for Discussion with Individuals

1. What kinds of decisions do you have to make or want to make in your own life?

Prompts, Notes & Sub-Questions:

- As indicated in the toolkit materials, there are three typical decision areas we are talking about: Personal care and personal life; financial and health care. Encourage participants to consider all of these areas – from day-to-day decisions (i.e. do you decide what you want to eat? What you want to wear?) to bigger decisions (i.e. do you decide what kinds of medical treatment you want? Do you live somewhere of your choosing?)
- For reporting purposes and for showing the group the types of decisions you are talking about, it will be easiest to cluster examples within these three areas.

2. How do you make these decisions now?

Prompts, Notes & Sub-Questions:

- Try to encourage discussion in all three areas of personal care and personal life, financial, and health care decisions. Give examples of each, i.e. do you get woken up or do you have an alarm clock? Do you decide when you shower every week?
- Do you make these decisions on your own? E.g. Does someone go with you to the bank? Do you have a worker that helps you with forms? etc... Are there people you talk to that help you make these decisions? Like a worker? Your parents? Your neighbours? A circle of friends?
- Balance the discussion around daily decisions, give examples like above and other type of decisions, i.e. filling out disability support forms, banking, grocery shopping. Note decisions that may have been a major life decision, i.e. moving to a new city, marriage, divorce, etc...
- Note any differences depending on the kind of decision that are being made, i.e. in personal care and life, health, financial.

3. Has anyone ever told you that you can't make these decisions yourself, or stopped you from making your own decisions?

Prompts/Sub-Questions:

- Did they prevent you from making these decisions? How?
- Did they make these decisions for you? Tell us about that experience.
- What happened after the decision was made?
- How did this make you feel?
- Did a doctor or police or even a judge ever decide you could not make a decision?
- Note how formal the process was, i.e. the community support worker just ended up making the decisions. Note whom the power was given to or who took the power to make the decisions.
- If this hasn't happened to the participant, you can ask if they know anyone who was told they couldn't make their own decisions, or was prevented from making their own decisions.

4. What kinds of things help you make your own decisions?

Prompts/Sub-Questions:

- Does it help if a support person comes with you to the bank and explains to you what the banker is saying, and shows you how to do things in the bank and understand the information being provided? Other examples could include meetings with landlords, service providers, employers etc.
- If a person can't speak or has many disabilities, how do you think people can help them make decisions? Who can help them?

- If needed, use examples to get discussion moving – i.e. the support person explained what the doctor was saying, but didn't talk to the doctor about me. The support person let me talk to the doctor once they explained to me what he/she was saying.
- Note examples where support was available, what types of supports were identified, where it has worked well, and where you still had the power to make these decisions.

5. After listening to everyone, what do you think are the main problems people have when they are trying to make decisions for themselves?

6. What kinds of information would help people make their own decisions?

7. What would you like to say to others – like families, support workers, professionals – about making your own decisions?

8. Do you want to say anything else?

Questions for Discussion with Families

1. What kinds of decisions are most important for your family member with a disability to make for themselves?

Prompts/Sub-Questions:

- As indicated in the toolkit materials, there are three typical decision areas we are talking about: Personal care and personal life; financial and health care. For reporting purposes and for showing the group the types of decisions you are talking about, it will be easiest to cluster examples within these three areas.
- Start by asking participants to think about what kinds of decisions they make for themselves and how they make these decisions – do they talk with others? Do they make decisions based on how the outcome will impact others? etc.
- Ask participants if the decisions they see as important to make themselves are different for their family member with a disability. If so, why?

2. Typically, how do these kinds of decisions get made now?

Prompts/Sub-Questions:

- Does your family member make them on his/her own?
- Are you involved?
- Do you tend to make the decisions for your family member with an intellectual disability? If so, has this always been the case, or was there a point at which you began making them?
- What is the process that your family member and yourselves go through to make them?
- Does the process differ, depending on the kind of decision being made – personal care and life, health, financial? If so, how?

3. Has anyone ever told you or your family member that he/she is unable to make personal decisions, financial decisions or health care decisions?

4. If this hasn't happened to you personally, do you know anyone this has happened to?

Prompts/Sub-Questions:

If so,

- Was this a process you initiated yourself, or did some authority initiate it – the public guardian or trustee, a physician, bank/financial institution, service provider?
- What were the specific reasons or events that led to 'triggering' this requirement for substitute decision making?
- Was it less formal than that – where someone other than the individual, like yourself, or community support workers just ended up making the decisions?
- What do you think are the consequences of substitute decision making for you, your family member, or the people you know?

5. What kinds of help do you think should be available to assist people with intellectual disabilities in making decisions?

Prompts, Notes & Sub-Questions

- As a facilitator you should understand the information on legal capacity and supported decision making provided in the Right to Decide toolkit.
- Can you point to examples where these kinds of help were available, either through personal networks, assistive technology or in others ways; examples where it has worked well, with the person still having the power to make his/her own decisions? If so, what was it about this

support that was helpful – the role of the people providing support, how they provided support...?

- What roles do you think a personal network of family, friends and trusted others can play in assisting other parties (e.g. a landlord, financial institution, physician) to respect the legal capacity and enter into agreements with an individual who may have very significant challenges that make it very difficult for others to understand and communicate with that person?
- What about when a person has significant disabilities that make it almost for others to understand and communicate with the person. What roles do you think a personal network of family and friends and advocates can play in this kind of situation, so that person can still have their decisions respected?
- In your experience, and that of your family member, what do you think should count, from a legal perspective, as the minimum capacity to make and communicate these types of decisions? A simple expression of a person's will to do, or not to do something? More than that? Less than that?
- Would your answers to these questions differ depending on the type of decision being made? If so, why?

6. Given our discussion, what kinds of information do you think are needed to help people with an intellectual disability make their own decisions, and to help families to support them to do so?

Prompts, Notes & Sub-Questions:

- Have others respect these decisions?
- What is needed to assist individuals to get the support they need to make these decisions?
- For families to assist individuals, and third parties (service providers, health and financial institutions) to respect an individual's legal capacity (background information available in Right to Decide toolkit as needed) to make decisions, and provide needed assistance for this purpose?

7. Is there anything else you would like to add?

8. What would you like others to know about the importance of decision making?

Discussion Group Reporting Form

Name of Discussion Group Facilitator:

Contact Information for Group Facilitator:

Date of Discussion Group:

Location of Discussion Group:

Type of Discussion Group (families or individuals?)

Number of Participants:

Discussion Group Notes: