

# Changing THE WAY WE *care*



Photo by Schimbator Studio for CRS

## Toolkit for Disability Inclusion in Care Reform

Facilitator's Manual:  
Learning Workshop  
on Participation and  
Advocacy



# Acknowledgement

This **Toolkit for Disability Inclusion in Care Reform** was produced by *Changing the Way We Care*<sup>SM</sup> (CTWWC), an initiative designed to promote safe, nurturing family care for children. It represents a collection of work developed from the experience of many practitioners. The Facilitator Manual for the **Participation & Advocacy Learning Workshop** and the accompanying slides were designed by disability and care reform practitioners and consultants for CTWWC with an aim is to build the capacity and confidence of those working in family strengthening and children's care for work with children with disabilities and their families. We thank the following people and organizations: Elayn Sammon, Gwen Burchell, Leia Isanhart, Kupenda for the Child, Catholic Relief Services, and the CTWWC teams in Kenya and Guatemala for their input, feedback and pilot testing.

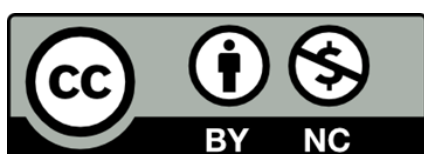
As *Changing the Way We Care* and partners learn from and promote family care we commit to full and meaningful inclusion of children with disabilities and their families throughout the process of care reform and all of our work. Children with disabilities disproportionately live in residential care and are, too often, the last to be deinstitutionalized. We commit to putting them first.



Need to know more? Contact *Changing the Way We Care* at [info@ctwwc.org](mailto:info@ctwwc.org) or visit [changingthewaywecare.org](http://changingthewaywecare.org)

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# Glossary

<b>Advocacy</b>	Advocacy is when people get support to speak up. It is a process of supporting and enabling people to express their views and concerns, access information and services, defend and promote their rights and responsibilities and explore choices and options.
<b>Advocate</b>	(1) The person who supports another through the advocacy process. (2) The act of advocacy
<b>Alternative care</b>	A formal or informal arrangement whereby a child is looked after at least overnight outside the parental home, either by decision of a judicial or administrative authority or duly accredited body, or at the initiative of the child, his/her parent(s) or primary caregivers, or spontaneously by a care provider in the absence of parents. Alternative care includes kinship care, foster care, adoption, <i>kafala</i> , supervised independent living, and residential care.
<b>Child</b>	A child is a person under 18 years of age, unless otherwise defined by national definition
<b>Child protection system</b>	A comprehensive system of laws, policies, procedures and practices designed to ensure the protection of children and to facilitate an effective response to allegations of child abuse, neglect, exploitation and violence.
<b>Community-based Inclusive Development</b>	An approach that brings change in the lives of people with disabilities at community level, working with and through local groups and institutions. CBID addresses challenges experienced by people with disabilities, their families and communities in practical ways.  These enhance and strengthen community-based rehabilitation (CBR) as it has evolved over the last decades.
<b>Developmental delay</b>	Refers to a child's developmental skills developing later than expected, compared to others of the same age. Delays may occur in the areas of motor function, speech and language, cognitive, play, and social skills. Delays can indicate a disability, but not always – many children with delays catch up.
<b>Disability</b>	Disability is a long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder a person's full and effective participation in society on an equal basis with others (UNCRPD).
<b>Discrimination</b>	Discrimination happens when individuals or institutions unjustly deprive others of their rights and life opportunities due to stigma.

<b>Family</b>	Refers to those within the caring circle of a child; those providing daily emotional, physical and psychological care. This caring circle varies according to culture and circumstance; thus, the use of the term family recognizes that in many societies the care environment of a child is broader than the parents of birth or immediate family and includes the extended family, sometimes called <i>kinship network</i> . Families have primary caregivers who can be birth, extended relative, foster or adoptive parents, in some instances, child-, grandparent-, or single parent-headed. CTWWC further expands the term to include families who are providers of family-based alternative care, such as <i>foster family</i> .
<b>Habilitation</b>	This is a process aimed at helping disabled people attain, keep or improve skills and functioning for daily living; its services include physical, occupational, and speech-language therapy; various treatments related to pain management; and audiology and other services that are offered in both hospital and outpatient locations. <sup>1</sup>
<b>Inclusion</b>	Inclusion involves a full reform, which means that children with disabilities can participate fully in the life of the family and community. This means making changes to the environment, the way we all communicate, our attitudes/belief systems and the way we provide services.
<b>Independent living</b>	Here a young person or adult with disabilities is supported in her/his own home, a group home, hostel, or other form of accommodation, to become independent. Support/social workers are available as needed and at planned intervals to offer assistance and support but not to provide supervision. Assistance may include timekeeping, budgeting, cooking, job seeking, counselling, vocational training and parenting.  Independent living/living independently means that individuals with disabilities are provided with all necessary means enabling them to exercise choice and control over their lives and make all decisions concerning their lives (see UNCRPD General comment on Article 19: Living independently and being included in the community). For children with disabilities, this involves ensuring that, in line with their evolving capacities, they have the same freedoms as typically developing children to make choices in life, and that they receive support for the choices they make.
<b>Occupational therapy</b>	This focuses on helping people with a physical, sensory or cognitive disability to be as independent as possible in all areas of their lives. It can help children and adults with a disability improve their cognitive, physical, sensory and motor skills and enhance their self-esteem and sense of accomplishment.
<b>Participation</b>	Participation is exercising the right to be listened to and to involvement in decisions and actions that affect the one participating (such as child participation) and to have those views taken into account.

<sup>1</sup> See RI Global <http://www.riglobal.org/projects/habilitation-rehabilitation/>.

<b>Physiotherapy</b>	Physiotherapy is science-based profession that helps restore movement and function when someone is affected by injury, illness or a disability. It can also prevent deterioration and further loss of function through a maintenance program of rehabilitation based on individual treatment plans.
<b>Rehabilitation</b>	Rehabilitation refers to regaining skills, abilities or knowledge that may have been lost or compromised as a result of acquiring a disability or due to a change in one's disability or circumstances. <sup>2</sup>
<b>Reunification</b>	The physical reuniting of a separated child and his or her family or previous caregiver.
<b>Reintegration</b>	The process of a separated child making what is anticipated to be a permanent transition back to his or her immediate or extended family and the community (usually of origin), in order to receive protection and care and to find a sense of belonging and purpose in all spheres of life. Re/integration can also refer to the process of a person with disability, who has been institutionalized, making a transition back to living in the community.
<b>Residential institution</b>	A large institution is characterized by having 25 or more children living together in one building. A small institution or children's home refers to a building, housing 11 to 24 children. Can also refer to a facility housing adults with disabilities.
<b>Self-advocate</b>	This is a child or individual who has the skills knowledge and support to advocate on their own behalf.
<b>Speech and language therapy</b>	These support children and young people who have a speech disorder (a problem with the actual production of sounds) or a language disorder (a problem understanding or putting words together to communicate ideas). They work on augmentative and alternative communication, which are the methods used to supplement or replace speech or writing for those with impairments in the production or comprehension of spoken or written language.
<b>Stigma</b>	Stigma refers to attitudes and beliefs that lead people to reject, avoid or fear those they perceive as being different.
<b>Typically developing child</b>	This describes a child who meets the usual developmental milestones within the usual timescales.
<b>UNCRC</b>	The United Nations Convention on the Rights of the Child is a legally binding international agreement and human rights instrument setting out the civil, political, economic, social and cultural rights of every child, regardless of their race, religion or abilities.
<b>UNCRPD</b>	The United Nations Convention on the Rights of Persons with Disabilities is a legally binding international agreement and human rights instrument that reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms.

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<sup>2</sup> Ibid.



This facilitator’s guide accompanies the workshop slides by the same title, **Participation and Advocacy: Half-Day Learning Workshop**. It is designed to be used by the person providing the workshop, often called “the facilitator” or “the trainer”.

**It is suggested that participants complete the half-day workshop on disability inclusion included in Toolkit for Disability Inclusion in Care Reform as a foundation for this workshop.**

Each session section of this guide provides the facilitator with a script; however it should not be read verbatim but rather adjusted to the facilitator’s own style. *Scripts will appear in italic font.*

The section description includes content for lecture with accompanying slides, suggested handouts, and exercises.

The facilitator’s guide uses the following symbols to guide the facilitator:



Discussion



Community example



PowerPoint Slide



Written exercise



Question & Answer



Hand out

This training is developed by *Changing the Way We Care<sup>SM</sup>*, primarily for use by staff and partners who are working to promote reintegration into safe, nurturing family care for children from residential care or children at risk of child-family separation. It may also be useful for other professionals who work with children and families, or for civil society organizations. This training is purposefully generic and adopts a global lens so that it is applicable in any context – think about your environment and how the training may need to be adapted. Users are welcome to contextualize the package to their operating environment.

# Introducing the workshop

The workshop should begin with participant introductions, followed by any announcements such as the duration of the sessions, timing of the breaks, location of facilities and issues of confidentiality. The latter is important to ensuring participants feel they can speak up and express ideas and opinions freely. All participants should understand that personal information and stories/experiences shared in the workshop remain in the workshop, even while they are welcome to share learning content with others. If required, confidentiality agreements should be signed as participants enter the workshop and their attendance is noted.

**For an on-line / virtual workshop** the introductory session should include instructions on using the virtual platform, muting/unmuting, hand raising, how and when to ask a question, and use of any other functions, online tools to be used. All features for accommodation such as closed captioning, sign or other language interpretation, should be arranged and tested ahead and the introductory session should include review of how to use these features and

## Interactive online workshop tools

- Mentimeter helps you build interactive presentations and polls – smart device friendly [www.mentimeter.com](http://www.mentimeter.com)
- Google’s Jamboard is a digital interactive whiteboard – [www.google.com/jamboard/](http://www.google.com/jamboard/)
- Platforms like Zoom, Microsoft Teams, Google Meet and others have ability for break out rooms and white boards
- Use Kahoot to make trivia games or fun training quizzes – [www.kahoot.com](http://www.kahoot.com)

how and who to communicate accommodation requests to. Handouts should be emailed or otherwise made electronically available before each session start, and participants should know who to connect with technology or attendance issues.

**In person workshop** introductory sessions should include instructions on: how and when to ask a question, (e.g. hand raising, written questions answered at the end of each session, etc.), agreed ground rules such as

## Tips for virtual introductions and ice breakers

- Ask participants to use video whenever bandwidth allows – this helps to keep attention. Alternatively, ask speakers to use video while others turn video off
- Use a neutral “get-to-know” question: where are you joining from?
- Ask people to “pass the mic” to someone else, i.e. call on the next person in turn
- Turn off all videos, using a list of questions, “turn your video on and wave if you answer yes” Example, if you are a social worker, if you have more than two online calls per day, or more fun, if you had eggs for breakfast, if you were born in March, etc.
- Organize a scavenger hunt – give a list of things participants go away and find – first person to come back with all items wins (e.g. “something living” “something to eat” “something summer” “something red”)
- Depending on time, have participants in small breakout rooms to get to know each other. Provide a list of question or guidance. Example, what their biggest recent work success?



listening with no interruption, mobile phone and laptop usage; switching off mobile phones, closing laptops and accessing break rooms and facilities, etc. Sign language or other interpretation should be arranged in advance and how and who to communicate accommodation requests to must be made clear, including mobility accommodations.

## Slide 1. Title

*Welcome to the workshop on participation of children with disabilities and advocacy. My name is ... I come from ... (locality, country). I have ... (type/years of experience in) ...*

*Please introduce yourselves and tell us your name, where you come from and why you are attending this training.*

Consider using one of the icebreaker exercises you know or suggested in the boxes above.

*This is a learning workshop for people like yourselves who are working or who will be working with children and families to promote safe, nurturing family care for children. Some of you might be working with children in residential care (sometimes called orphanages, children's homes, or insert your country's term) and others with children at risk of child-family separation. The workshop was developed by the Changing the Way We Care initiative out of a desire to make sure that disability is included in their work and yours.*

Here you might also introduce the organization you work for, if different. The workshop may also be useful for others who work with children and families, both government and non-government. Adjust this introduction to meet the characteristics of the participants. This training is generic so that it is applicable in any context; however, it asks that those involved think about the environment in which they work when making decisions about how to proceed at each step.

*As we go through the material together, you might have some questions. If you think these questions can wait until the end of the session, please write them down as a reminder. If you think you need an answer to the question straight away, because it will help you to understand the topic, please raise your hand (if face to face) or use the "raise-your-hand function" on the platform (if virtual). Remember, if you have a question its likely someone else will too.*

*As you will learn throughout the course, the term **disability** includes a wide range of people living in different circumstances. Each person will have different attributes, strengths, needs and lives. We have tried hard to include a broad range of voices and examples, but we recognize that there will be gaps. We encourage you to reflect on the context in your setting as you learn throughout the course.*

## Slide 2. Child with a disability or disabled child?

As we begin, and we are thinking about reflecting on context, it is worth our while taking time to think a bit about the words we use. In the human rights and development context professionals take their cue from the UN Conventions and choose to use 'person-first' language, for example they always say child with a disability or children with disabilities.

However, in some countries some activists prefer to acknowledge the social model and the barriers which society places on them which inhibit their full participation, for example the poor infrastructure or limited services which exclude them from participating fully in the life of the community, and thus they prefer to say disabled child or disabled children because

- a) they do not want to be defined by their impairment (with a disability); and
- b) they want people to acknowledge that their disability is not inherent but to a large extent as result of external forces.

*Just because you are a paid professional or para-professional social service worker, don't think you know best. Always ASK and use the terminology preferred by disabled persons organizations in your country. This is at the heart of what we will be discussing in more detail in this learning workshop on participation and advocacy.*



### Slide 3. Learning Objectives

By the end of this ½ day introductory learning workshop you will:

- understand the benefits of children's participation and family involvement
- have increased knowledge and awareness of self-advocacy approaches
- have generated ideas for introducing this learning in their program planning



Any questions?



Take a few minutes to write down three reasons why you think participation is important for children with disabilities.

Ask each person in the group to read out what they have written and put it up on the board/flipchart/screen.

As you discuss and talk about slides Slide 4, 5 and 6 compare the groups responses to the reasons described.

## What is participation?



### Slide 4. What children say about participation

Participation is the right to be listened to and taken seriously.

Children and young people with disabilities who were involved in the [Listening Together Project](#) initiated by Lumos in Bulgaria, Serbia and the Czech Republic were very clear on their participation rights and requirements.

*"We had a chance to tell the adults our opinion, they heard our voices."*

*"I sang in front of everyone, which I had never done before."*

*"Give us a chance to share our dreams, hopes and problems."*

*"Meetings with new and old friends."*

*"I had a chance to talk about my dreams, getting a job, friendship, doctors and what is good or bad for me."*

*"I rode a bicycle with my friend and after that we discussed children's rights!"*

*"We learnt not to argue in a bad way, and how to work together."*

*"It helped me to become useful for myself and also for others. I got brave, more confident, and I started to feel that people are listening to what I have to say. I became a thoughtful and more independent person who is able to analyse things. The project opened a door to for us to achieve more in our lives."*



## Slide 5. What is participation?

One of the things the UNCRC makes clear is that human rights apply to children and young people, just as they do to adults.

For example, **Article 12** of the UNCRC says that children and young people have the human right to have opinions and for these opinions to matter. It says that the opinions of children and young people should be considered when people make decisions about things that involve them, and they shouldn't be dismissed out of hand on the grounds of age. It also says children and young people should be given the information they need to make good decisions.

Article 12 applies everywhere and to everyone.

The opinion of a child and young person should be considered everywhere, including in their home, in their workplace and at school. This is true no matter how young a child or young person is, although the weight their opinion is given should change as they grow up and become more mature.

Article 12 applies to everyone, and care should be taken to make sure it can be exercised by everyone in reality. For example:

- special materials should be produced for children and young people with disabilities if they need these to participate
- special consideration should be given to children and young people in vulnerable situations, such as those in care or refugees;
- care should be taken to make sure girls' opinions are respected just as much as boys are

### Being able to speak up

Article 12 is also concerned with making sure children and young people feel able to express their opinions. It says that they shouldn't feel their opinions will be dismissed or regarded as invalid because of their age. It also says that children and young people need to know about this right so that they can exercise it, and that adults need to know about this right, so they don't dismiss it out of hand.

Additionally, children and young people should be able to complain about any aspect of their life as easily as adults can. They should have ways to complain about those in a position of power over them – such as parents, guardians or teachers – without an adult knowing, and complaints procedures should be easy for them to access.

### Being able to refuse

Article 12 doesn't mean children and young people have to express an opinion if they don't want to. They can refuse to give their opinion for any reason, and Article 12 shouldn't be used to pressure them into giving it.



### Slide 6. The UNCRPD

The UNCRPD also mentions participation of persons with disabilities. This international agreement on the rights of disabled people is clear that countries must make sure that disabled people have the right to find out and give information and to say what they want, the same as everyone else.

This includes:

- providing information in different ways, EasyRead for example, or using sign languages, Braille and MP3 - ask people how they would like to get information
- telling other services to make their accessible information
- getting the media, including the Internet to provide accessible information
- supporting the use of sign language

The UNCRPD also talks about the right of disabled people to vote and to participate in politics, and in sport and leisure, as well as to be included in all aspects of community life.

**Case Study 1:** supporting communication with peers. Sasha had limited language skills. He communicated through the Picture Exchange Communication System [PECS](#). While this form of communication worked very well in his interaction with an adult practitioner, he could not easily interact with his peers, which was affecting his confidence in himself. During an icebreaker session a Local Coordinator created a guessing game with PECS which raised the interest of other children in this form of communication. Sasha was made an expert, smiling and nodding when other children were right in this new guessing game. Sasha became popular and his self-esteem was restored. Other children learnt about the needs and strengths of Sasha, and most importantly how to be more inclusive.

**Case Study 2:** Providing choices to build self-esteem. Tanya has Down's syndrome and had been lacking in interest to engage in group activities. She was only happy to join in singing children's songs. As a result, she was not accessing the range of other activities available. The more she refused to try

new activities the more her confidence was being affected. The Local Coordinator decided to encourage her to play an active part in the planning of sessions, so she was given a role to choose which song to sing during fun break exercises. Tanya gradually started taking part in choosing other activities too, including a friend to perform an activity with.<sup>3</sup>



Discussion: *Can you think of a child or adult with a disability who you know who finds it difficult to participate and be involved? Why do you think this is? What could you do about it?*



Any questions?



For more information please refer to **Handout 1**. This includes more information about children's participation and links to resources which can be useful in your day-to-day work.

## What is advocacy?



### Slide 7. What is advocacy?

Advocacy is when a person gets the support they need to speak up.

Advocacy in all its forms seeks to ensure that people, particularly those who are most vulnerable in society, are able to:

- Have their opinions heard on issues that are important to them
- Defend and safeguard their rights
- Have their views and wishes genuinely considered when decisions are being made about their lives

In other words, advocacy is a process of supporting and enabling people to:

- Express their views and concerns
- Access information and services
- Defend and promote their rights and responsibilities
- Explore choices and options



### Slide 8. An advocate will...

An advocate is someone who provides advocacy support to a person when they need it. An advocate might help them to access information they need or go with the person to meetings

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<sup>3</sup> Lumos. 2014. *Listening Together*. Accessed at: <https://childhub.org/en/series-of-child-protection-materials/lumos-protecting-children-providing-solutions>

or interviews, in a supportive role. A child with a disability may want an advocate to write letters on their behalf, or to speak for them in situations where they don't feel able to speak for themselves.

An advocate will talk to a child with a disability to find out what they want and how they feel. An advocate will listen, will find the information to help the child to make choices, can talk to other people or groups on behalf of the child (with their permission) and can help the child say what they think about their reintegration process, or any other issue that is important to them.

A child or person with a disability who is supported to speak for themselves is a self-advocate.



Take a few minutes to write down three things you can do to act as an advocate for the children with disabilities with whom you work.

Ask each person in the group to read out what they have written and put it up on the board/flipchart/screen.



#### Slide 9. Recap

*We have learned three important terms today - which can seem to be saying the same thing, but which have slightly nuanced difference in the context we are using them. To be clear:*

- Participation is a human right;
- Advocacy is the support provided to children and families to realize that right; and
- Self-advocacy is when the child has the knowledge, skills and support to advocate on their own behalf.

## Why is involving children and families important?



#### Slide 10. Why involving children and their families is important

The importance of participation is reflected in both the UN Convention on the Rights of the Child and more recently in the UN Convention on the Rights of Persons with Disabilities.

Despite this, children with disabilities and young people have fewer opportunities to participate in decision-making than their non-disabled peers.

Research tells us that many children and young people with disabilities are still being excluded from participation and decision-making opportunities. In many cases decisions are taken without even the involvement of their families. Basic access needs to support participation of



young people with disabilities are not being met, and children and young people with higher support needs and communication impairments face significant additional barriers to participation.

As the services used by children and young people with disabilities change, it's important that we ensure they have opportunities to shape and influence them. Involving children and young people and their families, hearing what they have to say, is key to successful projects and ensures that your work meets their needs. Projects or services for children, young people and their families that incorporate participation will be improved, better informed, better targeted, and more effective.

By asking, listening and responding to the views of children and young people and their families right from the start, your projects will be on the right track from the beginning.



*Discussion: Can you think of one example when the children and families you work with have been excluded from the decision-making process? How would you do things differently in the future, and how do you think this would improve things?*



Any questions?

## Examples of participation and self-advocacy



### Slide 11. Daniela, Henry and Irina

#### **Read these examples to the participants:**

This is the story of Daniela, Henry and Irina, they live in different countries. They are young people who cannot see very well but who all want to read the latest best-selling book such as (insert name of a book read in your country), so they can chat about it with her friends.

Daniela's family were advised by their doctor to take Daniela to a special clinic to see if the doctors can do anything to fix her eyesight, but there is no improvement and Daniela still cannot read the book.

Henry has a similar problem with his eyesight, but he lives in a country where the audio recording of the book was made available by the publishers at the same time as the written text. Henry loves listening to the book but is sorry he can't meet his friends to talk about it.

Irina also has poor eyesight, she lives in a country where not only did she get the audio book, but she gets support to go to an inclusive school. Because this school is inclusive the girls and boys in her class have had special training on how to understand and help a person with very poor eyesight. A girl that Irina goes to school with who lives nearby, learns how to help and guide Irina so that she is as independent as possible and safe; she calls for Irina on her way to meet up with their friends, so that they can go together.



Discuss: Which of the three children is fully participating?



### Slide 12. Self-advocates

#### Read these examples to the participants:

All of the children have an impairment - very poor eyesight, which can limit their participation because they do not have access to the same information as all other children (reading books). When the accessibility barrier is lifted (by recording the text) Henry and Irina can participate a little bit more than Daniela, and when Irina gets help from her friends who understand how to assist appropriately, the participation restriction is lifted completely.

Later on, the doctor who checks Daniela's eyesight introduces her to some other girls and boys of her age who have attended his clinic. His receptionist volunteers to organize a regular meeting for these children. The receptionist becomes their advocate and talks to them about the issues they have in common, she listens to them when they complain that they cannot read the latest best-selling book, she talks to the booksellers and publishers on their behalf, and then helps them to make a video which is sent to the publishers in which they explain their frustrations and what it is they want. Soon the audio book is released in their country.

Henry is fed up because none of the children in his special school have listened to the book and he has no one to talk about it with. His teacher becomes his advocate and talks to him about his frustrations and what it is that Henry wants. The teacher hears that Henry wants to make friends with children his age who are interested in reading and talking about books. The teacher finds out where the nearest youth club to the school is and goes to talk to them about how they can adapt to help Henry to become a member. When Henry joins the club, he realizes that some of the activities on offer could be interesting for more of his friends from school. He asks his youth club friends to help organize a campaign to self-advocate with the adults at the youth club and the teachers at school to make the club more participative.



### Slide 13. Participation can be hard

Some children with disabilities have more difficulty participating than others because:

- In the country where they live it is not culturally appropriate for children to speak up
- They are discriminated against, for example in some countries, girls are discouraged from speaking up
- Adults believe they cannot speak up because they have a disability
- They have profound or multiple disabilities which significantly affect their capacity to communicate



**Handout 1.** There are lots of resources available which can get you started advocating for the children you work with to participate. Although some are linked to technology, many are manual and easily adaptable. For example, there are many apps for tablets and phones, but there are also easy ways to make manual communication boards.



Discuss: *Think of some of the ways you help children to express themselves. These can be your own children, or your nieces and nephews, or children of your friends. For example, for very young children they express themselves through play and interaction, for older children it can be telling you about their day when you are helping with homework...how can you create these opportunities for children with disabilities? Where do you think you could start?*



### Slide 14. Example charters

One of the starting points can be for your organization or project to work on developing an advocacy charter. An advocacy charter can say what action your organization or project is going to take to support disabled children or people with disabilities to say what they want, to secure their rights, to pursue their interests and to get the services they need.

Advocates work in partnership with the people they support and take their side, promoting social inclusion, equality and social justice.

This NDTi Advocacy Charter on the slide is designed for adults, but can be easily adapted. On the left is the written version, on the right is the EasyRead version.<sup>4</sup>



The links to the NDTi Advocacy Charter shown in the slide are included in **Handout 1**



Take a few minutes to write one thing you would do to start the process of designing an advocacy charter for your organization and one thing you would include in the charter.

Ask each person in the group to read out what they have written and put it up on the board/flipchart/screen under column 1 design and column 2 key point in the charter



Discuss: Why did you choose these things? Did any person choose to begin by asking children with a disability or their families what they wanted in the charter?



Any questions?

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<sup>4</sup> National Development Team for Inclusion. *New Advocacy Charter*. Accessed at: <https://www.ndti.org.uk/resources/new-advocacy-charter>

# What you can do



## Slide 15. Turning Impossible, possible

*Now it is over to you. Talking about participation and self-advocacy can sometimes seem like an impossible dream. To make sure that you can take this learning forward you can think about practical ideas which you can easily implement to begin to practice. Read the materials and look at the resources in the handout, talk with your colleagues and make a plan.*



## Slide 16. Recap

To get started...



Take a few minutes to write down one thing (for each of the items below) that you will do to: Encourage participation, and Act as an advocate for the children with disabilities with whom you work when you are: planning the service and setting up individual case plans

Ask each person in the group to read out what they have written and put it up on the board/flipchart/screen.



*The **handouts** you have in your pack of documents will direct you to additional resources where you can find more information.*



Any questions?

# Handouts

## Handout 1. Participation and advocacy resources

The [Golden Rules Symbols](#) resource is a communication tool for children and young people who:

- are non-verbal,
- have speech and language difficulties, and/or
- have additional support needs.

It can also be used to help communicate ideas and information about participation to very young children.

The resource comes in three separate downloadable parts, Golden Rules Pack, Golden Rules symbol cards, Golden Rules conversation cards.

These can be translated for use in your country.

[Involve Me](#) is a resource about how to creatively involve people with profound and multiple disabilities in decision making. It includes practical guidance for working with people who often get left out because we can find it difficult to understand their communication, or are worried about getting it wrong.

[Listening Together](#) provides examples of child participation in action in Bulgaria, the Czech Republic and Serbia; some of the currently available resources listed in the annex to the Listening Together publication are copied here for ease of reference.

[WHO, Better health, better lives](#). Empower children and young people with intellectual disabilities, 2010. The paper provides background information and proposes pragmatic steps for giving effect to Priority no. 7 of European Better Health Better Lives Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families:

[Books Beyond Words](#): Books Beyond Words tell stories in pictures to help people with learning and communication difficulties explore and understand their own experiences.

Hart, R., [Children's Participation](#) – from Tokenism to Citizenship, UNICEF, 1992. Roger Hart's work is widely seen as a key to defining and understanding children's participation, available at: Inter-Parliamentary Union & UNICEF, [A Handbook of Child Participation in Parliament](#), 2011. This handbook addresses some of the ways in which parliamentarians can guarantee that children's voices, concerns and interests find expression in and enjoy meaningful attention from parliaments.

Mount, B. & Zwernik, K., [Making Futures Happen](#) - A Manual for Facilitators of Personal Futures Planning.

[Blissymbolics](#). Bliss is a symbol system first introduced as an alternative means of communication for children with physical impairments more than 20 years ago. Bliss was designed to be an international language.

The [Picture Exchange Communication System \(PECS\)](#) and other [visual supports](#) are aids for children who have difficulty with verbal communication.

The [Advocacy Charter and the EasyRead version](#) are available for download.



[Lumos](#) has a number of articles and videos highlighting the work of self-advocates, including an article/videos about children engaging with MEPs (Members of the European Parliament) at the recent May elections. Young people shared their messages and questions and the MEPs responded.

[Dumitrita is a self-advocate](#) from Moldova and she has spoken at national and international conferences. She lived in an institution for 5 years and is now at home. Read the story of her journey.

Self-advocates in Bulgaria and Moldova were consulted when this training module was being developed. This is what they told us, which we have tried as far as possible to take into consideration.

### **Bulgaria**

- Spend time thinking about in practice to how build an **inclusive environment** for all children to participate; It is really crucial to create the proper space for All and it is not easy and takes time
- Avoid jargon when communicating with children (advice for adults)
- Trainer should include many quotes, stories from children;
- If possible, some children or young people should attend or join for some time during the training

### **Moldova**

- So that people better understand what participation is, give them examples and describe participation activities
- Do more practical exercises, games and to avoid too much theory. It is better to create a space where people will understand, through practice, what participation/advocacy means.
- Organise role-playing games where participants will have the role of persons with disabilities and experts/specialists/adults. This will make them feel differently and to think more and be careful on this aspect.
- Give case studies examples: how participation/advocacy had an influence on the person with disability and what consequences did this had.
- Invite young people to run a part of the training and to give them the possibility to be in the first part of the training. This could be in person or via Skype. Or could be done a short video on this.

## Handout 2. Example of local laws & rights



### Sample Summary of the National Act and Local Laws Regarding Disabilities

#### INTRODUCTION

Persons with disabilities have the same rights as every other Kenyan Citizen.

But persons with disabilities are often denied their rights.

The Government has passed some laws to protect persons with disabilities including Kenya's *Persons Disability Act of 2003* and...

This document summarizes these laws.

#### BASIC RIGHTS

Persons with disabilities have the right to live. It is against the law to kill a person with a disability.

No one is allowed to discriminate (treat differently) persons with disabilities because of their disability.



Persons with disabilities have the right to be called using names that are respectful.

#### CHILDREN WITH DISABILITIES

Children with disabilities have the right to be given nice names (that do not focus on their disability).

They have the right to be registered directly after birth.

They have the right to be fed.

They have the right to stay in the home with the family.

They have the right to enter into places of worship (churches, mosques).

They have the right to play with their friends.

They have the right to take part in the decisions about their lives.



#### Rights in Court

Children with disabilities have the right to justice.

When necessary, children with disabilities have the right to a free lawyer.

People who are deaf or hearing impaired have the right to a translator.

Children with disabilities must not be questioned by the police without their parents or caregivers present.

Children with disabilities should not be detained by the police. When a child needs to be detained, it should be for the shortest time possible and he or she should be separated from adults.



#### Political Rights

Persons with disabilities have a right to vote in all elections.

Persons with disabilities have a right to become members of political parties.

Persons with disabilities also have a right to become politicians.



#### Financial Assistance

Persons with disabilities who are registered with the National Council for Persons with Disabilities can receive assistance from the National Development Fund.

The National Development Fund can provide basic care funds to persons with disabilities and their families.

The National Development Fund can sponsor education for persons with disabilities.

The National Development Fund can assist persons with disabilities to establish a small business.

NGOs can also assist persons with disabilities.



## Handout 3. Participation in case management

### Tips on engaging children, including those with disabilities, in case management

An integral part of the case management process is intentionally engaging both caregivers and children in the different steps of the case management process. This helps to foster a sense of ownership, ability and builds the capacity of both. Engaging children takes a special skill and social service workforce<sup>1</sup> should pay attention to the following suggestions when engaging children.

- Always **introduce yourself** and explain your role. For example, “I am Samuel and I work with XXX. I am here to work with you to ensure that you are happy and healthy. I really want to hear from you and see how we can work together. Is that OK?”
- When speaking to a child or listening to a child **pay attention** with your ears and use your body language to express interest.
- **Pay attention to the child’s non-verbal communication**, and also pay attention to verbal inconsistencies and what the child might not be saying.
- **Sit at the same level** as children. Make sure you get down to the child’s level. Don’t be afraid to lean in or even get down on the floor so you can meet the child’s eye and be an “equal” with them.
- **Use simple language**: Think about the words you use. Long sentences will confuse children.
- **Use a child’s experience to explain things**. Use examples from other children but don’t use names. For example, I have a friend, Elizabeth, and she is also XXX years old. She loves to play outside with her friends. What do you like to do?
- Be **friendly and approachable**. Do not look bored, angry, or worried while a child is talking because this will stop him/her from talking. Maintain eye contact and have a warm and welcoming look on your face. Even if the child tells you something concerning don’t let your face show it. You want to exude comfort, trust and compassion.
- **Actively listen and respond** to the child. Try to answer his/her questions as honestly as possible.
- Provide **adequate time and space** and talk to the child in an appropriate and conducive environment. **Do not rush things** or be in a hurry.
- Make sure that the child knows you will **observe confidentiality**. Reassure them that you will not share with anyone unless it is an emergency, or they need help. If it is an issue that needs to be shared, like suspected abuse, depending on the child’s age you will want to explain that you will need to tell someone whose job it is to keep them safe.
- **Be empathetic** – show that you can understand what the child has been feeling (without saying that you are feeling it yourself).
- **Do not be afraid of silence** when the child needs time and space to gather thoughts. Children sometimes need time to get comfortable and will talk a lot before getting to the point.
- **Encourage the child** by nodding or smiling, but not too often to distract.
- **Ask open-ended questions**. For example, instead of saying, “do you like to play outside?” you can say, “tell me what you like to do when you are not at school.”
- **Summarize and clarify regularly** what the child has said, making sure that you have understood what the child is trying to say and clarifying what the child knows about the situation.
- Use **other means of getting children to express things**. Young children may find it easier to talk

Depending upon the child’s age, they can play a very important role in their own care, decisions and in the development of services to address their needs and those of their family. **Meaningful participation** goes beyond simply **letting children give their opinions to children participating as full partners in the process**. Children must be a part of building their profile, the assessment, family tracking and can be part of case planning, family group decision making, case review and case closure. They can also be part of existing decision-making committees.



through playing games, such as making sad or happy faces, or through pointing at happy or sad pictures. This may also help when communicating with a child who has a learning or speech impairment. Be sure to carry paper and a pencil or crayons so they can draw.

- **Be aware of age specific behavior and dynamics.** For example, older children can at times not wish to share thoughts or feelings, or even say what happens, for fear of negative consequences for themselves or others. A child may feel that they were responsible for an incidence in the past e.g. abuse. In such cases, it is important to make it clear that you are not being judgmental and that you are there to support them.

Very young children may not be able to express themselves in words, but if you put out a series of games and toys for them to play with, they will be able to show you which ones they prefer. Junior-primary school children may be able to express themselves more easily about what they like and don't like rather than answer questions directly. They may find it easier to draw a picture or take some photographs and then describe what their picture is about. With older children, generally above 10, a variety of techniques may be applied, including role-plays and drama, drawing, and small group discussions.

#### **Additional specific issues and approaches to know when engaging children with disabilities:**

Inclusion of children with special needs (i.e., physical, emotional or intellectual disabilities) in programs and activities; regardless of their abilities, to participate actively in daily activities within their home, school, neighborhood, places of worship and community is a right. The child's active participation should be guided by **developmentally and individually appropriate** strategies that **promote meaningful involvement aimed at the best interests of the child.**

**When working with children and youth with disabilities, remember to:**

**Introduce yourself.** Persons with disabilities mention the 'golden rule' – treat others as you would like to be treated. Refer to them by their names.

When talking to a child with a disability remember that you are **interacting with a child and keep the same tone and language as you would with any child of a similar age.** Speak directly to the person and not through a third party

**Don't assume that the child who cannot speak or see, also cannot think or understand.** Speak from a position that is comfortable for everyone example sit down or squat when speaking to someone on a wheelchair.

**Do not speak about the child as if they are not in the room.** Many people make the mistake of talking in front of a child with a disability about them, as if they cannot understand or do not have the same feelings as any other child.

Be **empathetic, warm and genuine and appreciate** that they have a valuable perspective, too. This is important when speaking to any child but is especially important for speaking to a child who has difficulties in seeing. This lets him/her know you are there and helps them to locate your position in the room. If appropriate, you can touch their hand or shoulder to let them know of your presence.

**Use active listening skills, this will help deal with the child's emotion and build trust.**

Consider the following when communicating with children, and discussing the assessment and case planning process:

- Ensure that the child **understands what the project and/or the process** is about, what it is for, who is involved and their role within it.
- Involve the child from the **earliest possible stage.** Considering use of age appropriate approaches e.g., using play materials, role plays, dance; telling the child's narrative in a simple but clear story; drawing with the child; and using toys and other figures to gauge the child's understanding and

explain the situation may be helpful with some children.

- Treat the child with **respect regardless** of their age, situation, ethnicity, abilities or other factors.
- Establish **ground rules with the child at the beginning**.
- Provide the **child enough time and space to ask questions** in their own words so that they are the ones forming the framework for understanding what is happening in their lives.
- Assist the child **express their thoughts and feelings without fear** or worry.
- Let the child know that his/her **participation is voluntary and can withdraw at any time**. Should give informed consent before being involved.
- Try to **manage the child's expectations carefully**. To avoid the child making assumptions based on their limited understanding of the entire situation.

#### **General methods/approaches for use during the assessment and case planning process:**

- Engage in a conversation from which you can provide information. Keep the conversation friendly and relaxed.
- Start with a story about yourself as a child about at the same age as they are. Make the story something the child can relate to. Where possible, show photos of your children, or family. It is also good to share a small treat together and engage in small talk, while drawing, or playing hand games. Laughter expedites trust.
- When the child is feeling safe and engaged (5-10 minutes from beginning), start with open-ended questions. Open-ended questions facilitate the child's offering information rather than choosing a Yes/No answer that interrupts the flow of conversation.
  - "Tell me how you participate in the daily activities in....?" Instead of "Do you participate in activities in....?"
  - "What do you think assessment and planning is?" instead of "Do you know what assessment or planning is?"
  - "Why do you think it is important for you to participate in this assessment or case planning?" Instead of "Do you want to participate in this assessment?"
  - "Tell me about yourself" and ask to follow up questions (e.g. "Do you like....?")
- Briefly summarize your discussion and explain what will happen next. Thank the child for participating in the sessions and sharing with you their story. Let them know you have enjoyed your time with them and leave them happy and feeling appreciated.



## Handout 4. Evaluating participation

Why Child Participation	Evaluating Participation: Simple Questions to Ask Children after their participation
<ul style="list-style-type: none"> <li>▪ Hearing what children and youth have to say gives adults new understanding about their wishes and needs.</li> <li>▪ Involving children and youth builds their own self-esteem and helps them find ways to support themselves and others.</li> <li>▪ Giving children opportunity to share their thoughts and feelings can result in a better and more sustainable support-plan.</li> <li>▪ When children and youth feel they are taken seriously and respected by others, they gain more control over their lives and develop hope for the future</li> <li>▪ Children and youth can influence the behavior of their peers and others in the community. Respecting children by including them in decision-making can help ensure that this influence is positive, rather than negative.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Do you feel that you were listened to?</li> <li>▪ Are there some processes or activities you would have liked to participate in but were not given the chance?</li> <li>▪ Are you in agreement with the outcomes of actions and decisions? Why or why not?</li> <li>▪ Have your suggestions or requests been followed, did the adults explain the reasons to you, and do you understand those reasons?</li> <li>▪ was the process respectful and supportive?</li> <li>▪ Did you feel safe and protected at all times during your participation?</li> <li>▪ How has your life changed since the participation: Are you participating more in making decisions about your life? Do you feel more self-confident as a result of your participation?</li> <li>▪ What recommendations do you have for future child-participation programs/ activities? How can the process be improved?</li> </ul>

Depending upon the child’s age, development and evolving capacity they can play a very important role in their own care decisions and in the development of services to address their needs and those of their family. Meaningful participation goes beyond simply letting children give their opinions to children participating as full partners in the process. Children must be a part of building their profile, the assessment, family tracking and can be part of case planning, family group decision making and case review boards. Principles of child participation include<sup>1</sup>:

- Children (and their families) must understand what the project or the process is about, what it is for, who is involved and their role within it.
- Children should be involved from the earliest possible stage of any initiative or process.
- All children should be treated with equal respect regardless of their age, situation, ethnicity, abilities or other factors.
- Ground rules should be established with all the children at the beginning.
- Children’s ‘evolving capacities’ to participate in decision-making typically refers to their ability to understand multi-dimensional and abstract concepts. Therefore, taking into account the child’s information processing ability and using appropriate methods are essential. Telling the child’s narrative in a simple but clear story, drawing with the child, and using toys and other figures to gauge the child’s understanding and explain the situation may be helpful with some children.
- Further, children should have the opportunity to ask questions in their own words so that they are the ones forming the conceptual framework for understanding what is happening in their lives.
- Children should be assisted in expressing their thoughts and feelings without fear or worry, but they should also understand that a group of caring adults will listen carefully and make a decision that will take into account their feelings but will also serve their best interests.
- Participation should be voluntary, and children should be allowed to withdraw at any time. They should give informed consent before being involved.
- Children’s expectations must be managed carefully, as they may make assumptions based on their limited understanding of the entire situation.



# Notes

Changing  
THE WAY WE  
*care*

