

Changing THE WAY WE *care*



Toolkit for Disability Inclusion in Care Reform

Understanding
Disability Inclusion
Training

Facilitator's Manual

Acknowledgement

This **Toolkit for Disability Inclusion in Care Reform** was produced by *Changing the Way We Care*SM (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 **Understanding Disability**, a training in disability inclusion, 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, 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.



Changing The Way We CareSM (CTWWC) is a global initiative funded by USAID, the MacArthur Foundation and the GHR Foundation, and implemented by Catholic Relief Services and Maestral International, along with other global, national and local partners working together to change the way we care for children around the world. Our principal global partners are Better Care Network, Lumos Foundation, and Faith to Action. CTWWC's vision is to be a bold global initiative designed to promote safe, nurturing family care for children, including reforming national systems of care for children, strengthening families, family reunification and preventing child-family separation, which can have harmful, long-term consequences, development of alternative family-based care, and influencing others to build momentum towards a tipping point of change for children.

Need to know more? Contact *Changing the Way We Care* at info@ctwwc.org or visit changingthewaywecare.org

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Glossary

Advocacy	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.
Advocate	(1) The person who supports another through the advocacy process. (2) The act of advocacy
Alternative care	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.
Child	A child is a person under 18 years of age, unless otherwise defined by national definition
Child protection system	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.
Community-based Inclusive Development	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.
Developmental delay	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.
Disability	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).
Discrimination	Discrimination happens when individuals or institutions unjustly deprive others of their rights and life opportunities due to stigma.

Family	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> .
Habilitation	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. ¹
Inclusion	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.
Independent living	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.
Occupational therapy	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.
Participation	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.

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

Physiotherapy	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.
Rehabilitation	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. ²
Reunification	The physical reuniting of a separated child and his or her family or previous caregiver.
Reintegration	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.
Residential institution	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.
Self-advocate	This is a child or individual who has the skills knowledge and support to advocate on their own behalf.
Speech and language therapy	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.
Stigma	Stigma refers to attitudes and beliefs that lead people to reject, avoid or fear those they perceive as being different.
Typically developing child	This describes a child who meets the usual developmental milestones within the usual timescales.
UNCRC	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.
UNCRPD	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.

² Ibid.

This facilitator’s guide accompanies the workshop slides by the same title, **Understanding Disability**. It is designed to be used by the person providing the workshop, often called “the facilitator” or “the trainer”.

It is suggested that participants familiarize themselves with other resources in the 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



Local example



PowerPoint Slide



Exercise



Question & Answer



Hand out

This training is developed by *Changing the Way We CareSM*, 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.

This training can be delivered in one or two days by shortening or extending time for reflection, discussion and participatory activities.

Workshop Outline

Time Needed	Theme	Slide Number
5 minutes	Introductions	1
10 minutes	Overview of Agenda, Norms, and Objectives	2
10 minutes	What does disability mean to you?	3
10 minutes	Defining Disability	4 & 5
5 minutes	Global and local data	6
10 minutes	The cycle of poverty	7 & 8
5 minutes	Why should we care?	9
10 minutes	Principles of Inclusion	10, 11, & 12
10 minutes	Terminology and Etiquette	13 & 14
20 minutes	Extended Q&A	15
10 minutes	Rights of children with disabilities	16 & 17
20 minutes	Disability in children	18 & 19
20 minutes	Impact of disability and importance of inclusion	20, 21, 22, 23
10 minutes	Overcoming stigma and discrimination	24
20 minutes	Importance of community engagement	25 & 26
10 minutes	Data	27 & 28
15 minutes	Closing	29 & 30

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,

Interactive online workshop tools

- Mentimeter helps you build interactive presentations and polls – smart device friendly www.mentimeter.com
- Google’s Jamboard is a digital interactive whiteboard – 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

and use of any other functions, online tools to be used. When invitations are sent for the workshop, organizers should indicate to whom participants can make accommodation requests. All features for accommodation such as closed captioning, sign or other

language interpretation, should be arranged and tested ahead of the workshop. The introductory session should include a review of how to use these features and how and who to communicate accommodation requests to if any arise during the workshop. Handouts should be emailed or otherwise made electronically available before each session starts, 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 listening with no interruption, mobile phone and laptop usage; switching off mobile phones, closing laptops and accessing break rooms and facilities, etc. When the workshop invitations are sent, organizers should indicate how participants can make accommodation requests. Sign language or other interpretation should be arranged in advance, along with any other requests such as mobility accommodations. It is recommended to hold workshops in rooms on the ground floor with wheelchair accessibility, when possible.

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?

****Facilitator note** – as you plan the training, seek out persons with disabilities who can help plan, co-facilitate, and actively participate in the training. This promotes meaningful participation, models the principles of inclusion which will be introduced in the training, and also helps ensure session content is relevant. If this isn’t possible in advance of the training, acknowledge during the introductions the importance of participation and that the views of participants with disabilities or family members of persons with disabilities are very much welcome and valued throughout the two-day training.



Slide 1. Title

Welcome to the workshop on understanding disability and disability inclusion. 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.*

Note: Some organizations implement pre-training assessments and post-training evaluations. This is the time to have participants complete any pre-training assessment.



Slide 2. Learning Objectives

Take 5 minutes to go over the agenda, norms and objectives for the meeting. For online facilitation, be sure to explain the use of hand-raising function, chat box, and mute buttons. Over the two sessions, staff will have an opportunity to confront their own attitudes about disability. Emphasize that this is a safe space to ask hard questions and to learn together about a topic that sometimes makes us uncomfortable.

****Note:** If a learning assessment is to be administered to participants before the training, incorporate the key feedback into the introduction of the training objectives.

By the end of this learning workshop, you will be able to:

- define disability
- describe the relationship between poverty and disability
- identify steps to take toward inclusion
- understand the basics of disability etiquette
- understand how disability impacts family strengthening programming
- identify roles in mitigating barriers faced by children with disabilities and their families

Defining Disability



Slide 3. Reflection



Write down the answers to each of the following questions. Then take 5 minutes to discuss in groups of 2 or 3. After 5 minutes, ask for anyone willing to share their responses.

What does the word Disability mean to you?

What is your reaction when you see a person with a disability?

What personal experience do you have with disability, either with your own lived experience, within your family, or in your community?



Slide 4. Defining disability

Introduce the UNCRPD definition of disability:

We use the UN Convention on the Rights of People with Disabilities (UNCRPD) definition, which reads, “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”

Explore the definition piece by piece, using the graphic on the slide to guide discussion.

- Impairment is a problem in body function or alterations in body structure.
- Disability is the loss or limitation of opportunities to take part in society on an equal level with others due to social and environmental barriers.
- Disability is therefore the result of negative interaction between a person with an impairment and his or her social environment.
- Impairment + limited action + restricted participation and access = disability



Slide 5. Disability models

Introduce the disability models shown on the slide. Talk about how this graphic depicts the change in time in how disability has been framed.

There are 4 major models.

- The Charity and Medical Models are outdated because they don't affirm the UNCRPD. We should work to leave these behind.
 - Charity- we feel sorry for you. Let's give you something.
 - Medical – there is something wrong with you. Let's treat you.
- Two more widely accepted models by the disability community at present, in alignment with the UNCRPD.
 - Social- there is something wrong with society. Let's change society to be more inclusive.
 - Rights- this is a human rights issue. We must find ways to address it.



How we frame and talk about disability in our work and in the community matters because it influences how we interact with and engage people with disabilities, how we design our programs.

Global and local data



Slide 6. Global Data

Introduce the idea that disability inclusion touches on an enormous percentage of people we work with.



The data tells us that 1 in 7 people have a disability, but how do we know if we are reaching them in our programs? Are we tracking this?

It is estimated that 20% of people who live on less than \$1.25 a day have a disability, and these people have heightened vulnerability to many of the issues we're trying to address through our services.

Key takeaway: There's a strong link between disability and poverty, with disability being both a cause and consequence of poverty. Poor people have a higher risk of becoming disabled and people with disabilities are amongst the poorest of the poor. It is important to consult people with disabilities to understand their situation and better respond to their needs.

It may also be relevant to mention that SGBV rates are higher among women with disabilities. A [2018 ODI global study on adolescents with disability](#) showed that those with disability are 2-3x more likely to experience violence than their peers. If they have an intellectual disability it is even higher. This is an important protection consideration.

Note: You can add a slide with your country-specific data on disability here and share any locally available data on disability prevalence, distribution by regions, disaggregation by gender or age, and statistics on lack of access to services. Qualify this data with an understanding that data is scarce, often out of date, and can be collected with many different metrics that may have bias.

Cycles of Poverty and Disability



Slide 7. Video on Disability and Poverty

Introduce the Cycle of Poverty video. *This video will help us begin to explore and understand the relevance of disability inclusion to the work we do in our programs.*

Watch “cycle of poverty video” at <https://youtu.be/ca64-46rDm0>



Slide 8. Cycles of Poverty and Disability

Display graphic demonstration cycle of disability and poverty



As we saw in the video, people with disabilities are more likely to experience poverty.

And when poor, there’s extra vulnerability to poor health, which then increases vulnerability to disability. What are your reactions to these ideas?

Why should we care?



Slide 9. Why should we care?

Explain that the quote was said at the ground-breaking 2018 Global Disability Summit in London by the then head of DFID. Have someone in the group read the quote aloud:

This is not just the right thing to do for common humanity – but it is the smart thing to do in ending extreme poverty. If we get things right for people with disabilities, we get things right for all people. Penny Mourdant, Secretary of State for International Development, UK. Global Disability Summit, July 2018

Why should we care:

Disability inclusion is a key part of most organization’s missions, but often people with disabilities are left behind, especially in our work with children and families. Ensuring disability

inclusion means that if we get things right for people with disabilities, we serve everyone's needs.

Universal Access – if you can design for the needs of disability in mind, then you're going to serve everyone's needs.



How does this apply to children's care, care reform and family strengthening? What are some ways that designing an activity with the needs of children with disabilities and their families in mind can benefit everyone?

Key Principles of Inclusion



Slide 10. Inclusion involves...

Now that we understand what disability is and have begun exploring why disability inclusion is important to consider/address disability in our work, let's shift to what it would mean to include people with disabilities in our work.

While there are many principles of inclusion, there are 4 we will cover in this discussion today as guiding principles for our work with people with disabilities.

- Non-discrimination
- Universal design
- Reasonable accommodation
- Elimination of stigma

Ask a volunteer to read each of these four definitions.



Slide 11. Inclusion in Action

There are ways we can practice inclusion in our work. Employing the principles of inclusion that we just covered can improve program quality and help us meet our goals. Practical ways to get started include:

- Inviting persons with disabilities to be part of the solution —working hand in hand with organizations of persons with disabilities, seeking their feedback through routine monitoring and beneficiary feedback mechanisms
- Including the voices and interests of people with disabilities at every stage of the project cycle
- Collecting and using disaggregated data
- Identifying and addressing barriers to participation
- Inviting them to be part of the solution
- Using accessible information and communication

- Setting aside a disability inclusion budget of 3-5% of overall project budget
- Hiring staff with disabilities

Not all people with disabilities are the same. We can't assume that by making something wheelchair accessible we are not missing other disabilities. Creating a ramp or installing rails doesn't address the needs of someone who can't hear. This is an important point to keep in mind, but don't feel overwhelmed by this because you can collaborate with organizations of persons with disabilities (OPDs) for greater understanding and to identify solutions.



If time allows, discuss other resources that can be leveraged to identify participation barriers, such as:

- Consult gov't offices in charge of disability
- Consult OPDs and national federation
- Consult disability specialized NGOs
- Consult those who serve people with disabilities already- rehabilitation centers, wheelchair providers, etc. Map this data to use later for referrals. Tap into existing referral networks.



Slide 12: Inclusive Communities

Our goal is to contribute to inclusive communities where children and adults with disabilities can thrive.



What do you notice in this picture? How does this compare to your community?

Terminology and Etiquette



Slide 13. Disability Terminology

Explain that many of us are uncomfortable about what language to use. We don't want to offend. Spend 5 minutes going over the chart of terms to use and not use. *See also the glossary at the beginning of this manual.* Explain that it is always best to ask local OPDs what the preferred local terms are, as terminology shifts from one culture and language to the next.

Show the video on disability etiquette: <https://www.youtube.com/watch?v=Gv1aDEFIXq8>.



Slide 14. Etiquette



Review the key takeaways from the video. *Were there any other take-aways that you noted?*

Using the chat or a white board list the following additional resources share these links:

- <https://disabilityin.org/resource/disability-etiquette/>
- <https://www.vantagemobility.com/blog/disability-etiquette-dos-and-donts>
- <https://www.forbes.com/sites/andrewpulrang/2020/09/30/here-are-some-dos-and-donts-of-disability-language/?sh=2ea703cad170>

Re-cap



Slide 15 provides the space for a pause. This time can be used for question and answer or additional discussion. Note: If the training is being delivered over two days, this is the natural ending to day 1 – use this time to reflect on what was learning. Ask what each participant is taking away.



RECAP: The recap can be done during the middle of a one day training or as the opening for the second day of a two day training.

Ask participants to share what they learned from the previous day

Ask participants to share any key reflections they had overnight (or during the break)

Introduce today's agenda and objectives

The focus will now shift toward what disability inclusion means more specifically in family strengthening and care reform programs. We will review a variety of topics and then follow each with a period of reflection/group discussion. Our reflections will focus on how the topic relates to your context as well as the role you can play in mitigating barriers of children with disabilities and their families.

Rights Perspective



Slide 16. Rights Perspective

Explain that we will start today's conversation by framing around a context of rights.



Ask someone to define what it means to have a right. Then ask who helps uphold those rights.

Just as children have rights that are protected under a UN Convention, people with disabilities also have rights that are protected through the 2006 UN Convention which is called UNCRPD, for short. As of July 2020, there are 163 countries that have signed the convention. The UNCRPD is very important and marks a fundamental shift in how we view people with disabilities as capable of claiming their human rights and making decisions for themselves. The UNCRPD also affirms all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. It qualifies how all categories of rights apply to persons with disabilities and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and areas where their rights have been violated, and where protection of rights must be reinforced.

****Facilitator note:** Before the workshop, research national laws pertaining to disability in your country.



Slide 17. Reflection

Lead a reflection on disability rights in the local community. Read the three questions and facilitate small group discussions or plenary discussion, depending on the size of the group.

Disability in Children

Recap the earlier discussion on defining disability as: the impairment + the limited action + the restricted participation and access. *Let's explore specifically now what that looks like in children.*



Slide 18. Disability in Children

Explain the following key points:

- Disability can happen at birth, either in utero due to genetics, nutrition, environmental factors, etc. or during delivery. It can be acquired, meaning through an accident or illness.
- Disability can impact function in a variety of ways.
- It impacts both internal and external senses.
- There are both disabilities we can and cannot see.

Other information that may be helpful to answer questions during conversation:

Sometimes a disability is not obvious. A hidden disability may not be immediately noticeable except under unusual circumstances or because the person or someone close to the person tells you about it. Some examples of hidden disability include arthritis, mental health difficulties such as depression, and HIV. Can you think of other examples?

Children who have an autism spectrum disorder may look like all other children around them, but they may become disturbed by an outside influence which causes their behavior to become unruly or antisocial. To many people watching, this can seem like a temper tantrum and blame bad parenting.

This can mean that the child, or their parents, don't want them to go out in public and they can become isolated and cut off from learning, social and human development experiences.



Slide 19. Reflection Using the slide, facilitate a discussion around the questions listed on the slide. Depending on group size and time, divide up questions among the participants and then have each group quickly share their reflection. If you anticipate a large group of participants, select 2 or 3 question in advance of this reflection – try doing this reflection in small groups, if time allows. Below are responses to guide discussion on the first two questions.

Not all disabilities are visible. What does this mean for our work? There is a need to administer a standardized disability identification tool to all project participants for disability. This will help facilitate appropriate linkages, referrals, and direct service delivery (where it is possible).

*Facilitator Note: if there are participants who want to learn more about disability identification, refer to the Changing the Way We Care Toolkit, half-day workshop on disability identification in children.

Research shows that family separation and institutionalization negatively impact the physical, cognitive, emotional, and psychosocial development of children. The effects are compounded for children with disabilities.

Conclude discussion of this slide by emphasizing that in many contexts, communities feel that children with disabilities are better cared for by institutions where caregivers have “the right skills” to care for them. This embodies the medical model thinking. Yet, no matter the disability, whether it is visible or not, all children need love, nurturing and attachment that is provided in a family environment, as described in the social model.

Impact of Disability



Slide 20. Impact of Disability

The effects of disability on different individuals and structures may mean different impacts for our work. Explain some of the following, asking participants to describe some of the impacts.

Child disability often keeps the child out of school. No one wants to play with the child. They're left alone for long periods, and they often don't receive health services. This impacts their future relationships, mental and physical wellbeing, education, and employment.

Siblings are often left behind to care for their sibling with disability, meaning they miss out on school, work, and social relationships.

Parents often have to leave work to care for their child with disability. Divorce and spousal abuse happen as relationships suffer from stress and stigma. They're shunned by community and experience incredible stress from isolation and worries. Parents who themselves have disabilities may face challenges caring for their children without support.

Families often separate due to disability. They also are more likely to experience poverty.

If **services** such as school, birth registration, and health facilities are not accessible, children with disabilities can't act on their right to use these services.

Communities often shun individuals with disabilities and their families. Yet, it's society who also loses out because they're leaving behind a substantial percentage of their community, not benefiting from those relationships, talents, and contributions.



Use **Slide 21 Why Inclusion** to review the example from Kenya. This slide discusses the impact of disability within the context of care reform. Review the data provided with training participants. Discuss: is your context similar or different? How does childhood disability impact children's care and protection?



Slide 22. Inclusion Strategies shares examples of strategies and activities taken up by the Changing the Way We Care program in Kenya to address inclusion.



Use **Slide 23** to facilitate a discussion on the two questions about mitigating the impact of disability. The responses below can help participants' reflection:

- **Response in our programs:**
 - Address accessibility to education, health, social services
 - Provide parenting education and other activities to address gaps in skills, knowledge, and attitudes
 - Provide psychosocial support for parents, caregivers, and children
 - Provide economic strengthening opportunities to families
 - Provide respite care
 - Ensure case management processes are inclusive
 - Deliver anti stigma/discrimination and awareness raising campaigns in the community
 - Lead by example
- **What's holding us back?**
 - Stigma
 - Our own fears of doing or saying the wrong thing
 - Our own skills and information gap
 - Not knowing where to start
 - Not knowing how to work with organizations of persons with disabilities
 - Attitude that it's someone else's work
 - Financial reasons
 - Fear of offending

- It's too big of a problem to take on

Overcoming Stigma and Discrimination



Slide 24. Overcoming Stigma and Discrimination

As a transition, remind everyone that we have raised the challenge of stigma and discrimination many times over the course of our discussions together during this training. Ask a participant to read the definitions for stigma and discrimination on Slide 24.

A person with a disability can experience multiple levels of stigma and discrimination: toward themselves, from family, from community, and societal structures/systems.

Eliminating the belief that people with disabilities are unhealthy or less capable of doing things is key to inclusion. That's why stigma matters. We can't fully include people with disabilities until we address stigma and discrimination wherever it appears.



Slide 25. Community Engagement

Community engagement is an important aspect to addressing and overcoming stigma and discrimination.

We have explored many actions we can take individually and collectively to promote inclusion.



Ask participants to describe the roles each of the community groups can play in supporting children with disabilities: faith communities, schools, health centers, parent networks, CBR facilities, OPDs

It is important to remember that no one organization can do it all nor has to act alone; to the contrary, it takes the effort and contributions of all to ensure that children with disabilities and their families have the comprehensive support they need to thrive.

Faith communities can:

- Fight stigma
- Provide respite care
- Provide psychosocial support
- Help refer to other services
- Advocate
- Connect families. Provide support networks
- Conduct home visits

In many places, though, faith communities unknowingly perpetuate stigma/discrimination, so it is important to give them the right skills to be a force for positive change and empowerment.

Schools support social-emotional, physical, and academic development of the child, facilitate play and recreational opportunities, build social relationships and promote independence.

Health Centers can promote overall wellness of the child, provide growth monitoring and access to universal child health services, and encourage parents around family care is best.

Parent networks are incredibly helpful for connecting parents to each other to share lessons learned, talk about where they're finding resources, problem solve together, provide moral support.

Community based rehabilitation (CBR) facilitates access to these services which promotes independence. Communities need to organize access to these services in an accessible way. The matrix on the right of slide 25 shows the different types of services offered to people with disabilities through CBR. Again, no single organization can or should provide all these services.

Organizations of People with Disabilities (OPDs) provide advice and moral support to people with disabilities and their families. They can teach about rights, help individuals and families advocate, and help identify resources. They also provide a sense of community. OPDs can also be important sources of information to service providers, providing feedback to make service delivery more relevant and useful.



Use **Slide 26. Reflection** to facilitate a discussion around community resources that can support family-based care for children with disabilities. If participants struggle, mark this as an action item for the participants to address following the training.

Data



Slide 27. Data

Explain that the last topic of the workshop is disability data. *Data is so important to inclusion that should not be forgotten.* Go over the points on Slide 27. Explain that although there are global and local gaps in disability data, the data we do have can help us see gaps in our programming. *It is important to be thoughtful in what we collect, how we collect it and how it is used.*



Conclude with a brief reflection on the importance of data using **Slide 28. Reflection**

Closing



Slide 29. Key Take Away

To close the workshop, begin by thanking everyone for their active participation and contributions during the workshop. Showing the slide, ask participants first to share their key takeaways.

Close by asking participants to list next steps they want to pursue following this training. Note these either on a flip chart in person or using another slide or chat box for virtual facilitation. These can be shared by email with participants after the workshop.

Handouts

Handout 1. Children's rights and why they matter for children with a disability

All children have the same rights. All of the provisions of the United Nations Convention on the Rights of the Child (UNCRC) apply to them. The UNCRC also makes a specific provision for children with disabilities because they may also need special care and attention.

Article 23 of the UNCRC is about children with a disability.

All children have the right to be safe and happy. When a child has a disability, people should make sure it does not get in the way of this. They should do this no matter what that disability is.

Children and young people should be cared for in a way that takes any disabilities they have into account, and should be taught at school in a way that understands their disability.

People shouldn't treat a child badly because of their disability. They shouldn't stop them from doing things they want to do, and shouldn't try to take away their rights.

Children and young people with disabilities should:

- be able to join in with activities, and their disability shouldn't stop them from taking part
- be able to join in and feel included at school
- get special care if they need it.
- be able to choose what they do, and have a say in choices about their lives.

Article 23 says that children with disabilities have the right to live full and decent lives with dignity and, as far as possible, independence and to play an active part in the community, and that the State must do all it can to support disabled children and their families.

The United Nations Convention on the Rights of Persons with a Disability (UNCRPD) also supports the rights of children and is designed to expand on and support Article 23 of the UNCRC.

You can read a summary of the United Nations Convention on the Rights of the Child (UNCRC) [here](#) and the full text is available [here](#)

There is also a more detailed United Nations [General Comment on the Rights of Children with Disabilities](#) which interprets Article 23 and presents some ideas on what governments should do to implement it.

You can read the full text of the United Nations Convention on the Rights of Persons with a Disability ([UNCRPD](#)) here in different languages and in accessible formats including sign language and easy read versions. The summary of the UNCRPD is [here](#).

If you would like to know more, you can take a short course designed by UNICEF on children's rights [here](#). It's free!

Handout 2. Defining Disability

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) says:

“Persons with a disability include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”

Disability is the complex relationship between the mind, the body and the environment in which a child lives.

- impairment – a problem in body function or structure
- an activity limitation – a difficulty encountered by an individual in executing a task or action
- participation restriction – a problem experienced by an individual in involvement in life situations

A child may experience one or any combination of these three designations and that these may change throughout the life-course; people can be born with a disability, or they can acquire it

The UNCRPD is available in 22 spoken languages, in eight sign languages, and in easy to read versions. For more information on the UNCRPD, to find out if your country has ratified it, and to locate training guides on the Convention, go to the website [here](#). By ratifying the UNCRPD a State commits itself and is obliged to implement the provisions of this international legislation.

[Early Childhood Development and Disability: A Discussion Paper](#) published jointly by WHO and UNICEF is aimed at improving the developmental outcomes, participation and protection of young children with disabilities. It has information on what a disability is and the rights of children with disabilities. It also describes the different factors which can have an effect on a child’s development including poverty; stigma and discrimination; child-parent/caregiver interaction; institutionalization; violence, abuse, exploitation, and neglect; humanitarian situations; and limited access to programs and services.

The [World Health Organization](#) has also posted good resources and explanations about disability and health, including video clips.

Handout 3. Types and impact of disability³

The term developmental disability covers a broad range of conditions, across a broad range of domains, including motor, sensory, cognitive and behavioral functioning. These conditions can be caused by both biological and environmental factors, including genes, toxins in the environment and malnutrition.

Below, we will consider areas of a child's functioning that may be affected by a developmental disability and give examples of common conditions associated with each category.

Domain 1. Motor



Motor skills are an essential component of child development, as they promote independent, goal-oriented actions. Typically, children develop gross motor skills (e.g. crawling, walking) and fine motor skills (e.g. pinching, using a pencil). Impairments in gross and fine motor skills may result in clumsiness, slowness and inaccuracy of motor performance, causing difficulties with many daily activities, such as playing, sports and school work. These impairments can also impede a child's ability to feed or practice self-care, such as washing and toileting, and this

can impact their long-term health and independence.

Common conditions that can cause delays in the development of motor skills include:

- **Cerebral palsy:** a group of disorders of the development of movement, coordination and posture, attributed to non-progressive disturbances that occurred in the developing fetal or infant brain.
- **Spina bifida:** incomplete development of the backbone spinal cord, causing damage to the nervous system.
- **Muscular dystrophies:** a group of conditions in which muscle fibers weaken gradually over time, creating difficulties in movement, balance and sometimes breathing.
- **Developmental Coordination Disorder:** difficulty coordinating movements means that a child has difficulty in performing everyday tasks, such as tying shoelaces.



Domain 2. Sensory

Impairments to one or more of the senses (sight, hearing, smell, touch, taste) can affect how a child gathers information from the world around them. Sensory impairments can have a number of practical considerations, such as the need for alternative modes of communication with a child with hearing impairment, for instance. Sensory impairments can have a negative

³ © The London School of Hygiene & Tropical Medicine

impact on cognitive development, as a child may find it more difficult to learn from their environment and form social bonds.

Common conditions that can cause delays in the development of sensory skills include:

- **Congenital cataracts:** clouding in the lens of the eye that can cause blurred vision or blindness.
- **Retinopathy of prematurity:** abnormal development of blood vessels in children born prematurely.
- **Chronic otitis media:** long-term problems with the middle ear, e.g. hole in the eardrum that does not heal, repeated ear infections or the presence of middle ear fluid (“glue ear”)
- **Sensory processing disorder:** impaired ability to adequately receive and respond to information from the senses (e.g. related to Autism Spectrum Disorder).

Domain 3. Behavioral



All children will display challenging behaviors when they are tired, hungry or upset, but some children may present with challenging behaviors that are inconsistent with their age and expected development. Challenging behaviors may include extreme and unpredictable tantrums, aggression and impulsivity. These behaviors may impact a child’s social development, relationships and ability to interact with their environments.

Common conditions that can cause delays in the development of behavioral skills include:

- **Autism Spectrum Disorder:** covers a wide range of abilities and impairments, but it is generally characterized by impairments in social interaction, behavior and communication.
- **Attention deficit hyperactivity disorder (ADHD):** high levels of hyperactivity, impulsivity and inattentiveness.

Domain 4. Intellectual



Intellectual impairment is characterized by limitations in intellectual functioning (reasoning, learning, problem solving) and adaptive behavior (conceptual, social and practical skills). Intellectual impairments will limit a child’s ability to learn, understand and apply complex information and skills. These impairments range from mild to severe, and can negatively impact a child across other domains, including behavioral problems and communication difficulties. An intellectual impairment will therefore affect a child’s ability to learn in school and find work, and impairments may make it difficult

for them to live independently as an adult.

Common conditions that can cause delays in the development of intellectual functioning include:

- **Down syndrome:** caused by an additional copy of chromosome 21, it will commonly result in mild to moderate intellectual impairment. As well as likely intellectual impairments, children with Down syndrome may face delays in motor and communication development.
- **Fragile X syndrome:** as a result of mutations in the FMR1 gene – most males with the condition have mild to moderate intellectual impairments, about one-third of females have intellectual impairments.

Domain 5. Communication



Some children will exhibit difficulties in understanding or producing language and speech, making it difficult for them to express their thoughts and feelings, or to understand others. Impairments may include limited receptive language skills, limited expressive language skills or non-speech. As a result, children with communication impairments will likely find it difficult to communicate, learn and engage in social interactions.

Common conditions that can cause delays in the development of communication skills include:

- **Speech disorder:** difficulties acquiring and producing speech, resulting in pronunciation errors.
- **Speech fluency disorder:** persistent and frequent disruption of the rhythmic flow of speech (stuttering).
- **Language disorder:** difficulties in understanding and using language (spoken and written).

Conditions across these domains can occur in isolation or in tandem with other conditions. For example, many children with cerebral palsy will demonstrate intellectual impairment, as well as motor impairment, children with autism, and related behavioral difficulties, may also present with intellectual impairment, and children with Down syndrome may find it difficult to develop communication skills.

A disability can affect a child's ability to use words to communicate; to speak clearly and be understood; to understand simple directions; to sit, crawl or walk; to hold or manipulate objects; to use the toilet, dress or feed themselves appropriately.

Following the social model of disability, and because individual children develop at different rates disability is assessed and described in terms of what a child can do, how a child 'functions' rather than a description of a condition. For example, each child with Down Syndrome will have capacities and difficulties in different areas.

A child's disability can be present at birth, sometimes described as a congenital disability. These can be as a result of a genetic inheritance or mutation, for example Down Syndrome. They can also be the result of environmental factors in the time before conception and

during pregnancy or during birth, for example anemia, fetal exposure to alcohol, or being deprived of oxygen during the birth (cerebral palsy).

Children can also acquire a disability later in life, for example because of an injury or an illness, or because they are exposed to violence, abuse, or neglect.

Children living in a residential institution can acquire a disability because of the severe neglect they often experience. This can include physical under-development and motor skills delays as well as psychological harm.

Children with a disability can also experience a mental health disorder. For example, they can be bullied, can have difficulty engaging with their peers, and particularly in adolescence can find it hard to be involved in social activities all of which can lead to depression and anxiety or other mental health disorders.

You can find more information and resources about congenital and acquired disability [here](#).

The World Health Organization has also produced a [factsheet](#) containing links to further information about congenital disability.

The WHO Community-based Rehabilitation Guidelines include a supplementary booklet which provides detailed guidance on [CBR and mental health](#).

This Australian resource on [disability and children's mental health](#) includes key principles for supporting children.

[The International Disability Alliance](#) is comprised of members of global disability organizations which can provide specific support and advice; here are the links for the [IDA member](#) organizations.

The Risk of Harm to Young Children in Institutional Care is described [here](#).

Handout 4. What is inclusion and why is it important?

Including people with disabilities in everyday activities and encouraging them to have roles similar to their peers who do not have a disability is *disability inclusion*. This involves more than simply encouraging people; it requires making sure that adequate policies and practices are in effect in a community or organization.

Inclusion should lead to increased participation in socially expected life roles and activities—such as being a student, worker, friend, community member, patient, spouse, partner, or parent.

Socially expected activities may also include engaging in social activities, using public resources such as transportation and libraries, moving about within communities, receiving adequate health care, having relationships, and enjoying other day-to-day activities.

Mencap is a UK-based organisation which supports people with a learning disability (sometimes called intellectual disability). They have lots of [resources for communication](#) which challenge our ideas of what communication is, so that we can understand and make ourselves understood when communicating with children and adults who have a learning disability. Good communication opens up the world and helps to support the inclusion of children.

Humanity & Inclusion is an international organization. They have lots of [resources about social inclusion](#) on their website.

CBM also has some good resources like [Inclusion Made Easy](#) and [Disability Inclusive Development Toolkit](#). CBM provides step-by-step practical guidance on inclusive humanitarian fieldwork through the [Humanitarian Hands-On Tool](#) an app which has helpful tips for making meetings, project communication, and infrastructure more accessible.

If you would like to read more in-depth information about disability and inclusion GSDRC, a partnership of research institutes, have published a very informative guide which can be found [here](#). This paper summarizes some of the most rigorous available evidence on the key debates and challenges of disability inclusion in development and humanitarian response.

You can find more information on the [benefits to society of an inclusive societies approach](#).

Handout 5. Partnering with organizations of people with disabilities

Organizations of People with Disabilities (OPDs) are organizations established by and for persons with a disability, to assist them in exercising their right to participate in life on an equal basis with others. They are sometimes referred to as disabled people's organizations (DPOs), although OPD is recommended term. They are led and controlled by people with disabilities themselves. Disability-inclusive development is unattainable without effective collaboration and partnership with OPDs.

The Convention on the Rights of Persons with Disabilities (CRPD) recognized the role and importance of OPDs in developing and implementing legislation and policies to enforce the CRPD, in their participation in political and public life, and their roles in their respective national implementation and monitoring of the CRPD's implementation. Their roles include: self-representation, identifying grassroots needs through organizing local chapters, open forums, democratic representations in various national and international disability conferences and summits; and representations to government service providers, and U.N. bodies.

OPDs possess in-depth knowledge and expertise on the core challenges facing their members. OPDs provide leadership on mainstreaming disabilities inclusion issues in decisions and program designs that impact them and can identify important disabilities issues and challenges within the community. By partnering with OPDs, development NGOs can learn what kind of services need to be integrated into their programming to achieve disability-inclusive development. This collaboration can strengthen project outcomes and provide valuable guidance. However, partnerships between mainstream INGOs and OPDs, both local and international, are limited and inconsistent. INGOs can benefit from the expertise of both local OPDs and global groups such as Disabled Peoples International, International Disability Alliance, CBM, and Humanity and Inclusion (HI).

When trying to identify OPDs, start by enquiring with other local partners in country. It may also be helpful to browse the [International Disability Alliance website](#) for a list of member organizations by country and region. This will help you identify national umbrella groups of OPDs. By contacting them first, you can get a sense for the dynamics between and among OPDs in country as well as identify sub-national chapters of each OPD.

When establishing partnerships with OPDs, consider the following tips:

- Ensure accessibility to facilitate full participation in meetings
 - Provide sign language interpreters for participants who are deaf or have a hearing impairment
 - Use plain language handouts
 - Provide easy reading materials
 - Use braille documents for blind persons
 - Select venues which are accessible for persons with mobility impairments, including accessible toilets, ramps, and handrails.
- Agree on a common vision and goals
- Formalize the collaboration and joint decision-making
- Avoid development jargon and acronyms in early meetings. Remember that many OPDs have minimal contact with the mainstream NGO community and may be

unfamiliar with common development technical language.

- Listen and ask questions. Show interest in and value their perspectives.
- Remember that people with disabilities are not a heterogeneous group. Their varied strengths, needs, and perspectives are all valuable to building more inclusive communities.

Resources and Links

International Disability Alliance. <http://www.internationaldisabilityalliance.org/all-countries>

United Nations. Toolkit on Disability for Africa: Module 5- Building multistakeholder partnerships for disability inclusion.

<https://www.un.org/esa/socdev/documents/disability/Toolkit/Building-multi-stakeholders.pdf>

Accessibility Go! Toolkit <https://worldblindunion.org/wp-content/uploads/2020/10/Accessibility-GO-A-Guide-to-Action-WBU-CBM-Global.pdf>

Handout 6. Project budgeting for disability inclusion

Inclusive budgets make provisions for accessibility, reasonable accommodations, inclusive practices, and assistive technologies. Budgeting for inclusion within the project design stage does not need to be a costly addition. It is estimated that only 3-5 percent of a project's budget needs to be allocated for disability-related expenses in order to ensure full inclusion.

During the assessment phase of project design, ask the following questions:

- Is there a budget line item for accessibility, such as alternative formats and sign language?
- If planning to hire or utilize individuals who have physical disabilities as staff or consultants, is there a budget line for a personal care attendant to travel and provide support, if needed? Or, a budget line for a sign language interpreter to travel with staff or consultants who are deaf?
- Does the budget address any additional technical assistance from OPDs or technical experts to serve as consultants to support the project?
- Is there a need to exclusively hire someone to support the disability-related components of the project?
- Are there funds to utilize accessible venues or hire accessible transport to ensure full participation of individuals with disabilities? ([World Vision, 2012](#))

Best Practices during project design:

- Establish a link between the program's goals and disability.
- Add a line-item in the budget for disability-related accommodations to project, administrative, and organization budgets. This will improve equal access of persons with disabilities, through the provision of transportation, sign language interpretation, assistive devices, etc.
- Prioritize funding and capacity building support to enable OPDs to engage more actively in advocacy on budgeting
- Estimate 3-5% of the total program costs for twin-track programs.
- Allocate 2-3% of the total administrative costs to:
 - Support organizational investment in accessibility such as low-cost physical adaptations where needed like wooden/metal ramps; wooden seats over squat-style toilets; making project materials available in alternate formats such as audio, Braille or large print.
 - Provide reasonable accommodations and coverage of travel and participation expenses along with attendance time for people with a disability and OPDs to be actively involved in consultations.

Resources and Links

CBM. (2012). Inclusion Made Easy: A quick program guide to disability in development. https://www.cbm.org/fileadmin/user_upload/Publications/cbm_inclusion_made_easy_a_quick_guide_to_disability_in_development.pdf

CBM HelpAge HI. (2018). Humanitarian inclusion standards for older people and people with disabilities. <https://reliefweb.int/report/world/humanitarian-inclusion-standards-older-people-and-people-disabilities>

Mobility International USA (MIUSA). (2020). <https://www.miusa.org/resource/tipsheet/budgeting>

Disability Budgets Discussion Paper. (2017). <https://docs.google.com/document/d/1TNtME9Na244ltmHMUVmm2yAv2WDCMa3Be8-IBXVzz10/edit#heading=h.k6e0p2legmdp>

Notes

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