



NATIONAL CHILD DEVELOPMENT AGENCY

**Training Package for  
The Tubarerere Mu Muryango programme**  
*(‘Let’s raise children in families’)*

**SUPPORTING CHILDREN WITH DISABILITIES  
& THEIR FAMILIES**

TRAINING MODULE  
FOR *INSHUTI Z’UMURYANGO* (FRIENDS OF THE FAMILY)

Facilitators Manual

4<sup>th</sup> June 2021



unicef   
for every child



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*June 04<sup>th</sup> 2021*

# CONTENTS

Acknowledgements.....	3
Glossary.....	4
A note on terminology.....	6
<b>1. INTRODUCTION.....</b>	<b>7</b>
1.1 Purpose.....	7
1.2 Overview of the TMM Programme.....	7
1.3 Content.....	8
1.4 Advice for Facilitators.....	8
2. One-day learning workshop.....	10
2.1 Introducing participants to the one-day learning workshop.....	10
2.2 Why is it important to include children with a disability?.....	13
2.3 What is disability?.....	16
2.5 What is inclusion and why is it important?.....	23
2.6 Concluding session of the one-day learning workshop.....	28
2.7 Why the words we use to talk about disability are important.....	30
3. How to use the Parent's Guide.....	31



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- the Minimum Standards for Alternative Care and Considerations for Strengthening the Tubarerere Mu Muryango (TMM) Programme for the Inclusion of Children and Adults with Disability Prepared for Government of the Republic of Rwanda Ministry of Local Government by International Centre for Disability and Rehabilitation (ICDR) University of Toronto, Canada
- the Coordinating Comprehensive Care for Children Programme (4Children), initiated in 2015 this five-year USAID-funded consortium of organizations led by Catholic Relief Services (CRS) with partners IntraHealth, Maestral, Pact, Plan International and Westat, helped countries identify practical and appropriate policies, programs and services that promote child wellbeing
- the Partnership for EveryChild Regional Alliance incorporating Partnership for Every Child in Ukraine, Russia and Moldova along with Partnership for Children in Georgia and For Our Children Foundation in Bulgaria, who focus on preventing loss of parental care for vulnerable children and ensuring safe, secure family care for children without parental care
- The National Society for the Prevention of Cruelty to Children (NSPCC) UK, and their learning hub on Safeguarding Children and Child Protection.
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# GLOSSARY

Word or term	Definition as applied in this text
<b>Alternative care</b>	Formal or informal provision for the protection and well-being of children who are deprived of parental care or care in their immediate family of origin. This can include extended family care, adoption and foster care.
<b>Case management</b>	The process of helping individual children and families through direct social-work type support, and information management; <sup>1</sup> A process practiced by social service workers that supports or guides the delivery of social service support to vulnerable children and families and other populations in need. <sup>2</sup>
<b>Case worker</b>	A person employed by the NCD as a Child Protection and Welfare Officer, usually a graduate social worker or psychologist.
<b>Child</b>	A person under 18 years of age.
<b>Child Protection and Welfare Officer</b>	A graduate social worker or a graduate psychologist working for the NCD who uses his/her knowledge and skills to provide social services to ensure the healthy development, protection and well-being of children and their families.
<b>Child protection system</b>	Formal and informal structures, functions, capacities, and other elements organized to achieve safety for children.
<b>Community-based Inclusive Development</b>	Enhances and strengthens earlier work described as Community-based Rehabilitation (CBR).
<b>Community-based Rehabilitation</b>	A community development strategy that aims at enhancing the lives of persons with disabilities within their community. It is a multi-sectoral approach working to improve the equalization of opportunities and social inclusion of persons with disabilities through provision of rehabilitation services, while combating the perpetual cycle of poverty and disability. It emphasizes utilization of locally available resources including beneficiaries, the families of persons with a disability and the community.
<b>Disability</b>	“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.” (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>	In this Operational Guidance, ‘family’ describes the immediate relatives of the child. This can include parents and siblings or another long-term caregiver who has adopted a parental role. Extended family includes grandparents, uncles and aunts, cousins etc. The definition of family acknowledges that primary caregiver/s for the child may be extended family members.
<b>Family care</b>	Care of the child by their family which can include parents. Siblings or immediate relatives
<b>Family-based care</b>	Family-based is where the child is placed into a family that already exists and the caregivers are the parents or main caregivers of the children in that household – this describes foster care. Adoption is technically not family-based care as it is simply family care. Adoptive parents are the same as birth parents in terms of their functions, legal position and care arrangements.
<b>Family-type care</b>	Family-type is residential care (where the caregivers come into the facility to provide the care in shifts) that is organised in smaller groups (like a family), in homes that are in the community and are like ordinary family homes (apartments, houses etc.) and where there may be children of different ages, with different abilities and disabilities, and mixed gender (like a family). Family-type describes care in small-group homes for children
<b>Habilitation</b>	A process aimed at helping persons with disabilities 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 clinical and community settings. <sup>3</sup>

1 Inter-agency Child Protection Working Group, 2014, Inter-agency Guidelines for Child Protection and Case Management. [http://www.cpcnetwork.org/wp-content/uploads/2014/08/CM\\_guidelines\\_ENG\\_.pdf](http://www.cpcnetwork.org/wp-content/uploads/2014/08/CM_guidelines_ENG_.pdf)

2 Global Social Service Workforce Alliance, 2018, Case Management Concept and Principles, GSSWA: Washington DC <http://www.socialserviceworkforce.org/sites/default/files/uploads/Case-Management-Concepts-and-Principles.pdf>

3 Adapted from RI Global <http://www.riglobal.org/projects/habilitation-rehabilitation/>

<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, to the way we all communicate, to our attitudes and belief systems, and to the way we provide services.
<b>Independent living</b>	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. (UNCRC 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>Inshuti z'Umuryango (Friends of the Family)</b>	Cadre of community volunteers composed of one man and one woman with responsibility for promoting child rights, and supporting reintegration.
<b>Malayika Murinzi (Guardian Angels)</b>	A cadre of honest parents (in most case the mothers) known for their good reputation in various Rwandan community, for their goodwill effort to care, protect, and educate vulnerable children particularly orphans.
<b>Occupational therapy</b>	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 to improve their cognitive, physical, sensory, and motor skills and enhance their self-esteem and sense of accomplishment.
<b>Physiotherapy</b>	A science-based profession that helps to 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 programme of rehabilitation based on individual treatment plans.
<b>Placement</b>	The physical act of placing the child in family-based alternative care; it is one step in the reintegration process.
<b>Rehabilitation</b>	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>4</sup>
<b>Reintegration</b>	Reintegration is the process of a separated child making what is anticipated to be a permanent transition back to their family of origin and community or to live in family-based alternative care, where they can have their rights fulfilled and receive the support and love needed to reach their future potential.
<b>Reunification</b>	Reunification is the physical act of returning the child to their family; it is one step in the reintegration process.
<b>Residential institution</b>	A residential institution is defined as any group living arrangement for children without parents or without surrogate parents, in which care is provided by smaller number of paid adult carers. <sup>5</sup>
<b>Speech and language therapy</b>	Supports 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>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>UNCPRD</b>	The United Nations Convention on the Rights of Persons with Disabilities is a legally binding international agreement and human rights instrument which reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms.

<sup>4</sup> Adapted from RI Global <http://www.riglobal.org/projects/habilitation-rehabilitation/>

<sup>5</sup> See "UN Disability and Child Rights Groups on Behalf of Children without Parental Care Key Recommendations June 20, 2019, Core Principles: Right to Family Recognized Under International Law [https://validity.ngo/wp-content/uploads/2019/07/UNGA-Right-to-Family-2019\\_06\\_20.pdf](https://validity.ngo/wp-content/uploads/2019/07/UNGA-Right-to-Family-2019_06_20.pdf)

## A NOTE ON TERMINOLOGY

“Persons with disabilities” or “children with disabilities” are the terms most often used in global development reporting and are preferred by the Rwandan National Council for Persons with a Disability (NCPD). This is because they use ‘people-first’ language. That is, they put the person’s humanity first, so that they are not defined by their impairment. The term “persons with disabilities” is used in the UNCRPD. However, many disability rights campaigners believe that this connects disability solely to the medical model. The use of the word ‘persons’ is also considered by some to be legalistic and formal, whilst ‘people’ is considered more acceptable for general usage. Under the social model of disability many disabled people see themselves as those who experience barriers within society. Thus, many prefer the term “disabled people” or “disabled children”.<sup>6</sup> In general, it is important to listen to how people talk about their disability themselves and take your cue from them. Therefore, the terms persons with disabilities and children with disabilities are used in this document to take account of the position taken by the National Policy on Persons with Disabilities 2019.

The NCPD has developed a recommended terminology to replace culturally based usage that is considered as contributing factor to negative attitudes towards persons with disability in Rwanda. The table indicates discriminative terminologies (left column) and appropriate terminologies (right column)

### Terminology associated with disability in Rwanda

Source: NCPD

N°	Ntibavuga (inyito zipfobya)	Bavuga (inyito iboneye)
1.	Ikimuga, uwamugaye, ubana n’ubumuga, ugendana n’ubumuga	Umuntu ufite ubumuga
2.	Ikirema, Ikimuga, Karema, Kajorite, Igicumba, Gicumba, Utera isekuru, Kaguru, Jekaguru, Ikirema, Karema, Muguruwakenya, Terigeri, Kagurumoya, Kaboko, Mukonomoya, Rukuruzi	Umuntu ufite ubumuga bw’ingingo
3.	Impumyi, Ruhuma, Maso, Gashaza, Miryezi, ...	Umuntu ufite ubumuga bwo kutabona
4.	Igipfamatwi, Ikiragi, Nyamuragi, Ibbubu, Ikiduma, Igihuri, Bihurhuri	Umuntu ufite ubumuga bwo kutumva no kutavuga cyangwa bumwe muri bwo.
5.	Igicucu, igihoni, ikijibwe, ikirimarima, ikiburaburyo, ikiburabwenge, indindagire, ikigoryi, igihwene, ikimara, zezenge, icyontazi, inka, inkaputu.	Umuntu ufite ubumuga bwo mu mutwe
6.	Kanyonjo, gatosho, gatuza	Umuntu ufite ubumuga bw’Inyonjo
7.	Nyamweru, umwera, ibishwamweru, nyamwema, umuzungu wapfubye	Umuntu ufite ubumuga bw’uruhu rwera
8.	igikuri, gikuri, gasongo, nzovu, zakayo, gasyukuri, kilograma	Umuntu ufite ubugufi budasanze

<sup>6</sup> For example, see Damon Rose, 4 October 2004, Don’t Call Me Handicapped! [http://news.bbc.co.uk/2/hi/uk\\_news/magazine/3708576.stm](http://news.bbc.co.uk/2/hi/uk_news/magazine/3708576.stm); The Conversation, 11 April 2019, Should I say disabled person or person with a disability? <https://theconversation.com/should-i-say-disabled-person-or-person-with-a-disability-113618>; Disabled World, 1 September 2011, Disability or Disabled? Which Term is Right? <https://www.disabled-world.com/definitions/disability-disabled.php>; Penny Pepper, 22 November 2016, We’ve had all the insults. Now we’re reclaiming the language of disability. <https://www.theguardian.com/commentisfree/2016/nov/22/language-of-disability-stereotypes-disabled-people>

# 1. INTRODUCTION

## 1.1 Purpose

This is a Training Module for the *Inshuti z'Umuryango volunteer community-based cadre* to support the implementation of the Tubarerere Mu Muryango (TMM) Programme ('Let's raise children in families') led by the National Child Development Agency (NCD).<sup>7</sup>

The purpose of this Training Module is to build awareness amongst the Inshuti z'Umuryango (IZU) community cadre on the rights and needs of children with disabilities, so that they can be allies in helping children with disabilities and families to live in their communities free from stigma and discrimination.

The Facilitators Manual is primarily for use by people who work directly with children and families on inclusive reintegration from residential institutions to family care, and on prevention of family separation. This can include:

- Government of Rwanda, National Child Development Agency (NCD) Child Protection and Welfare Officers, and
- The National Council of Persons with Disability (NCPD), District Disability Mainstreaming Officers, and
- People working in other local government roles e.g. Gender & Family Promotion Officers,
- People working in non-governmental organizations (NGOs) or community-based systems.

These professionals are ideally placed to deliver this training to IZUs because they have the appropriate knowledge, experience, and skills in working with children with disabilities and their families.

## 1.2 Overview of the TMM Programme

In March 2012, the Government of Rwanda endorsed the Strategy for National Child Care Reform.<sup>8</sup> The implementation mechanism for this strategy is the Tubarerere Mu Muryango (TMM) Programme ('Let's raise children in families') led by the National Child Development Agency (NCD).<sup>9</sup> The TMM Programme aims to ensure that children living in institutional care in Rwanda are reunited with their families or placed in suitable forms of family-based alternative care and that children in families are prevented from separating. The Programme uses the childcare reform as a springboard for wider strengthening of the child protection system. The TMM first phase did not have a specific focus on residential institutions for children with disabilities but did include reintegration of a small number of children with disabilities who were residing in the target institutions.<sup>10</sup> The 2018 evaluation of the TMM first phase reported that placement of children with disabilities into families utilizing the existing model was challenging.<sup>11</sup> Therefore a second phase of TMM was initiated by NCD in partnership with the NCPD during 2019. This included the adjustment of the Training Package for the TMM programme to make it more inclusive through the addition of a third module on inclusive case management for reintegration. Inclusive design is considered more appropriate than development of a stand-alone and parallel system which can contribute to further stigmatization and discrimination. The Operational Guidance on Inclusive Children's Reintegration served as the guiding framework for

<sup>7</sup> The NCD established by Presidential Order No. 083/01 of 28/08/2020 absorbs the functions of the National Commission for Children, formerly responsible for TMM, and the National Early Childhood Development Programme (NECDP) with a mission "to foster the development of a child, the promotion and the protection of his or her rights."

<sup>8</sup> Cabinet Brief: Strategy for National Child Care Reform (n.d.).

<sup>9</sup> The NCD established by Presidential Order No. 083/01 of 28/08/2020 absorbs the functions of the National Commission for Children, formerly responsible for TMM, and the National Early Childhood Development Programme (NECDP) with a mission "to foster the development of a child, the promotion and the protection of his or her rights."

<sup>10</sup> Through the implementation of the TMM Programme, 3,216 children and young adults have been placed in family-based environment or supported in independent living by December 2018.

<sup>11</sup> Primson Management Services, 15 January 2018, Summative Evaluation of the Tubarerere Mu Muryango/Let's Raise Children in Families (TMM) Phase I Programme in Rwanda. NCD and UNICEF: Kigali

the development of Module Three of the Training Package. Given that all children, including children with disabilities may require different services across multiple sectors at different times in their lives, the Operational Guidance is underpinned by the functioning case management system and existing mechanisms for coordination and collaboration. Module Three helps the social service workforce to better understand the reintegration process for all children, including children with disabilities who may require more support than children without disabilities. Module Four, is designed to equip a National Trainers Team to deliver training, and ongoing coaching and mentoring support to the workforce (Training of Trainers – ToT).

The complete TMM Programme Training Package is therefore organised in four parts:

- **Module One.** Pre-Service Training Module for the Social Service Professionals, 2017
- **Module Two.** In-service Training Module for the Social Service Professionals, 2017
- **Module Three.** Inclusive Case Management for Reintegration, Training Module for the Social Service Professionals, 2019
- **Module Four.** Training and Mentoring the Social Workforce on Case Management for Reintegrating Children with disabilities, 2021

At the same time several training programmes have been developed for the Inshuti z’Umuryango – IZU (Friends of the Family). These IZUs are community-based child and family protection volunteers, with two (one woman and one man) situated in every village across the country. This cadre is ideally placed to support the inclusive reintegration process and therefore this Training Module – ***Training for the Inshuti z’Umuryango on supporting children with disabilities & their families, 2021*** – has been developed as an extension of the IZU training package, and in support of the overall TMM Programme.

## 1.3 Content

The content has been developed in consultation with IZUs at local level, with NCD, NCPD and UNICEF.

In view of the many responsibilities IZU undertake in their voluntary capacity the training is designed to be concise and succinct and consists of:

- 1 x day training
  - Why it is important to include children with a disability
  - The definition of disability
  - The types and effects of disability
  - Stigma and discrimination; and
  - Why the words we use to talk about disability are important.
- 3 x 2-hour sessional activities to be delivered as convenient
  - How the IZU can use the Parents’ Sheets to work directly with families of children with disabilities in their community

## 1.4 Advice for Facilitators

Each session should begin with introductions, followed by any housekeeping issues including the duration of the session and the timing of the breaks, and issues of confidentiality so that participants feel they can speak up and express ideas and opinions freely.









For a face to face session this can include instructions on how and when to ask a question, by raising a hand at any time, or if the facilitator prefers, asking participants to write down questions to be answered at the end of each session (if the participants have basic literacy and have been provided with pen and paper); to respect individuals ideas and not talk over or through them; to switch off mobile phones, to take handwritten notes with provided pen and paper (if applicable); access to break rooms and toilet facilities.

The text in this Facilitators Manual is intended to guide you in delivering the content interactively. When you are preparing to facilitate a learning workshop or learning session you should make sure to use the words that will be best understood by the IZUs you are working with and that are most suited to the context they are working in. You can encourage discussion and support participants to ask questions.

During the preparation Facilitators should also consider if the participants have basic literacy and have been provided with a pen and paper and can effectively be involved in the written exercises. Otherwise, these should be discussions with their neighbour with verbal feedback to the group, whilst the Facilitator makes a note of the key points in the most appropriate format.

In cases where it is not possible to use a PowerPoint presentation, either using a projector and screen, or on a laptop or tablet, please print off the presentation in enough copies to give to each participant; and enough handouts to give to each participant.

The symbols used in the facilitators text include:

	Discussion		Handout
	PowerPoint slide		Timing
	Any questions?		Written exercise

## 2.1 Introducing participants to the one-day learning workshop



30 minutes



Slide 1



Welcome to this learning workshop on disability inclusion.

My name is ... and I work for ... I have ... type/years of experience in... *[Tell the participants something about yourself so they feel at ease].*

Please introduce yourselves and tell us your name, where you come from and why you are attending this training. *[You can also ask participants to share one thing about themselves that they are good at...etc.].*

This is a general learning workshop (“the workshop”) for Inshuti z’Umuryango who work with children and families. The workshop is developed by NCD, NCPD & UNICEF.

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. *[This means thinking about where the IZU live – is it urban or rural, what facilities do they have access to, are there special features...etc.].*

Some of you will know children with a disability who live in your neighbourhood. Some of you will



have worked with children who have a disability and with their families, and some of you may not have very much experience at all.

When you meet a child with a disability and their family, you might be worried about how to act, or what to say; you may try and avoid the child and family because you do not know what to do.

This workshop will provide you with enough information to be more confident when you meet children with a disability and their families, and when you are talking to other people about the work that you are doing.

The workshop will provide you with information. It will also include time for you to think and reflect on your own attitudes, beliefs, and behaviours.

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. *[Remember to think if the participants have basic literacy and have been provided with a pen and paper and can effectively be involved in the written exercises. Otherwise, these should be discussions with their neighbour with verbal feedback to the group, whilst the Facilitator makes a note of the key points in the most appropriate format].*

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. Remember, if you have a question its likely someone else will too.

As you will hear throughout the workshop, the term *disability* includes a wide range of people living in different circumstances across the country. Each person will have different attributes, needs and lives; they will have different strengths and different abilities – just like we all do. We have tried hard to include a broad range of voices and examples, but we recognise that there will be gaps. We encourage you to reflect on the context in your setting, the experiences from your work and your life, as you learn throughout the workshop.

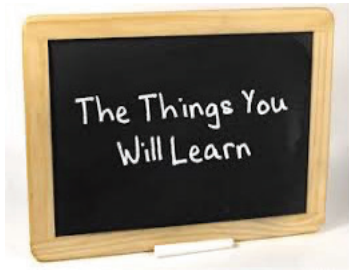
Children with disabilities are often left out when services are being planned. This can be because we simply forget about them, or because we think they don't need the same services as other children or because we think it is too complicated to include them.

But it is **urgent** that we think about how to include them because every day that we don't, they get a little older and lose out on opportunities. It is also urgent because it is their right, just like all other children, to be included. And yes, it can be **complex**, planning what to do and how to do it, but it is **the right thing to do**, and this learning workshop will talk in more detail about why this is so.



## By the end of this learning workshop...

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- Why it is important to include children with a disability
- What is a disability?
- The types and effects of disability
- What inclusion means, and
- Why the words we use to talk about disability are important

At the end of the learning workshop, you will be able to describe:

- Why it is important to include children with a disability
- The definition of disability
- The types and effects of disability
- What inclusion means
- Why the words we use to talk about disability are important.



Any questions?

## 2.2 Why is it important to include children with a disability?



45 minutes

Slide 3

### Why is it important to include children with a disability

- Because it is their right to be included!
- Article 23 of the UNCRC 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
- The UNCRPD also supports the rights of children with disabilities



Children with disabilities should be included because it is their human right.

Children with disabilities are children first, with their own needs, strengths, wants and rights. As for all children, children with disabilities have the right to thrive, not simply survive. This means that they have the right to participate fully in their families and communities, including going to school, and to access the services needed to help them achieve their full potential. These rights are protected and advocated for by the United Nations Convention on the Rights of the Child and the United Nations Convention on the Rights of Persons with Disabilities.

The Government of Rwanda has agreed that all children have these rights because they have signed the UN Conventions and introduced the same provisions into the Constitution and national laws and regulations.

These Conventions mandate that governments make sure that children have:

- the right to life and development
- their best interests respected
- the right to a life free of stigma and discrimination
- the right to participate in society

**All** of the provisions of the United Nations Convention on the Rights of the Child (UNCRC) apply to **children** with disabilities.

Article 23 of the UNCRC also makes specific provision and says that children with disabilities have the right to live full and decent lives with dignity and, as far as possible, to live independently and to play an active part in the community, and that the State must do all it can to support children with disabilities and their families to make this happen.

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. For example, Article 23 says that all children with disabilities “should enjoy a life in dignity in conditions which ensure self-reliance and facilitate active participation in the community”, and the UNCRPD Article 12 expands on this to add that this means children with disabilities should not live in residential institutions but should be supported to live in their family, extended family or in foster care; and in Article 16 (c) that “large or small group homes are especially dangerous for children, for whom there is no substitute for the need to grow up with a family. “Family-like” institutions are still institutions and are no substitute for care by a family.”

It doesn't matter if the child is separated from his or her family at the moment, or whether they are living in residential care or in foster care, or if they are older and living independently, they still have these same rights – each and every one

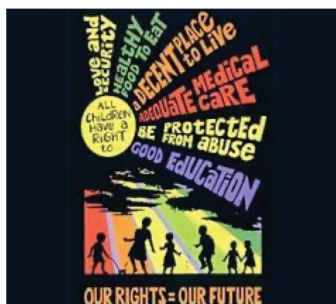


Take three minutes to write down/ discuss three reasons why rights are important for children. Ask each person in the group to read out what they have written and put it up on the board/flipchart. When going through the items below (Slide 4), compare the groups responses to the reasons described.



Slide 4

## Reasons why rights are important...



- Children are individuals
- Children rely on adults for nurturance and guidance
- Policy making which fails children can have an effect on all of society
- Poor health threatens children's future and the future of the community they live in
- If we don't invest in children now their contribution or cost to society in the future can be affected

Rights are important for everyone, but they are especially important for children, because:

- They are individuals - children are not the possessions of parents nor of the State; they have equal status as members of the human family; each one has their own capacities, talents, strengths and values;
- Children start life as totally dependent beings - children must rely on adults for the nurturance and guidance they need to grow towards independence. Sometimes the decisions taken by adults are based on their own personal beliefs and values which can be harmful for children, for example in many countries it's okay to hit children, this routine smacking or other hitting or violence can hurt children very badly; in some countries people think it's okay for girls to get married when they are very young, this too is an adult decision which can have long-lasting damaging consequence for a child. Rights help to protect all children from beliefs, values and practices that are harmful.
- The actions, or inactions, of government impact children more strongly than any other group in society - practically every area of government policy, from education to public health, affects children to some degree. Short-sighted policymaking that fails to take children into account has a negative impact on the future of all members of society. Policies are related to protecting rights – and must protect the rights of all children.
- The healthy development of children is crucial to the future well-being of any society - because they are still developing, children are especially vulnerable, more so than adults, to poor living conditions such as poverty, inadequate health care, nutrition, safe water, housing and environmental pollution. The effects of disease, malnutrition and poverty threaten the future of children and therefore the future of the societies in which they live. All children have rights to life, health, education, and safe, healthy environments.
- The costs to society of failing its children are huge - Social research findings show that children's earliest experiences significantly influence their future development.<sup>12</sup> The course of their development determines their contribution, or cost, to society over the course of their lives. Failing to realise children's rights means costs to society in the immediate and long-term.

Sometimes you will hear people say,

“But there isn't any one with a disability here. And if there are, they're few.”

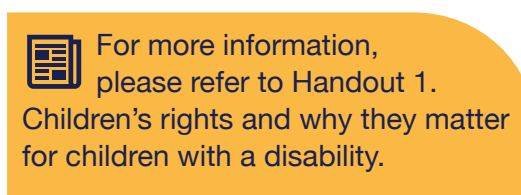
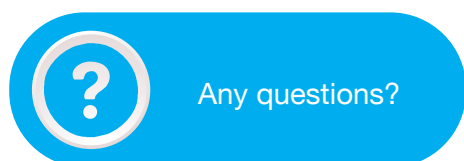
“It's expensive to help people with disabilities, so we can't include them.”

“That's not our work – let the disability specialized organizations work with them.”

“What could I possibly do to include a person with disabilities in our work? It's not like I can provide them with a wheelchair or give them a hearing aid. That's too expensive! So, I'm just not going to work with them.”

These points do not recognise the rights of children with disabilities.

In conclusion, if decisions about children are based on making sure their rights are respected, they are more likely to grow up healthy, safe, and happy. Our commitment to the rights of children with disabilities, acknowledges their specific importance and value to our communities.



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12 See handout 1 for more information about the research

## 2.3 What is disability?



60 minutes

This session is about understanding the globally accepted definition of disability and the different types of disability.



Slide 5

What does the word DISABILITY mean to you?

- Think about a child or a person with a disability – someone you know, or someone you have heard about
- Take three minutes to write down (or talk to your neighbour) three things you think about when you picture a child with a disability
- Afterwards everyone will be asked to read out what they have written, and we will write it on the screen




Take three minutes to write down/discuss with your neighbour three things you think about when you picture a child with a disability.

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



## Defining disability



- impairment – a problem in body function or structure,
- an activity limitation – a difficulty encountered by an individual in executing a task or action, and
- 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

Disability is complex. It can be understood differently and described differently depending on the cultural context. However, there is a general agreement that the definitions provided in global conventions are a good place to start.

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

*“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”.*



How does this compare with what is written on the flipchart? Is this definition the same or different? Why do you think this is?

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

However, people think in different ways about disability. Sometimes they think about it as a medical issue, this is called the *medical model* or medical approach. Sometimes people think that disability is an illness, that it is something which can be treated or cured, or in the negative, something that can be spread to others, like an illness that can be caught. You cannot “catch” a disability like a flu or other disease by being next to a person with a disability.

Thinking about disability as an illness only considers what people assume is wrong with a child; something to be fixed. When people think like this, they do everything they can to get help from doctors and other medical professionals. Sometimes this can help, for example if a child has epilepsy and they experience seizures, they will need to take medicine to control it; or some physical disabilities can be helped through a surgery.



But only dealing with the medical or health related challenge and forgetting about the other ways that disability impacts life can mean that a child with a disability does not get all the support they need. For example, a child who has Down Syndrome may have surgery to correct a heart defect they are born with, but if they do not get the extra support they need for learning and development they may not be able to go to school because they have not learned to dress them self or to socialize with other children; or another child with cerebral palsy may receive injections to relieve muscle spasms but if the infrastructure (for example roads, buildings, public transport) is not suitable for their wheelchair they may not be able to move around easily.

So, an alternative view to the medical model or approach is that children are “disabled” by barriers in society, not by their lack of ability, impairment, or difference. This is called the *social model* or social approach. Barriers can be physical, like buildings not having accessible entrances or toilets. Or they can be caused by people’s negative attitudes to difference, like assuming disabled people can’t do certain things or that a disability can be a punishment from God. These types of negative attitudes prevent children with disabilities from being welcomed as full members of the community, and we need to challenge them.

For example, if a child cannot see very well but wants to read the latest best-selling book, so they can chat about it with their friends, if we only think about the disability as an illness, we will take them to a clinic to see if the doctors can do anything to improve their eyesight. If nothing medical can be done to improve the child’s eyesight and no other support is provided, the child will continue to be excluded. However, if we think about how to help the child overcome the non-medical barriers to reading the book we can find out if there is a full-text recording (MP3) available when the book is published.

This child has an impairment (poor eyesight) which can limit their activity (reading books) until the participation restriction is lifted (by recording the text).



Can you think of other examples?

Sometimes choosing to **only** deal with a medical model or approach or **only** thinking about a social model or approach can mean we don’t seek out all the solutions which can assist the child to realise their rights.

Instead, there is a third model which says that we should try and balance the social and medical model by looking at the whole person, the whole child. This means we think about their physiological (health or body) needs and their social needs, including their interpersonal needs, that is the way we relate to them and support them to relate to the world and the people around them. This is sometimes called the *biopsychosocial* model of disability.

It means we should relate to the child on a number of different levels when assessing their needs, and where necessary adjusting our own behaviours to meet those needs.

For example, the child with poor eyesight who has had healthcare to improve his eyesight as far as possible, and who has access to audiobooks, may still be isolated from his peers because he needs help to move around or because other children of his age are afraid of him because he is different. This boy may need support to go to places where other children of his age meet, to learn to get around by himself (become independent); and the other children and adults around him may need support to learn the facts about disability and to understand the person behind the disability. In this way all of the boy’s needs can be met so that his rights to participate equally are realized.





How does this relate to the answers you gave when you were asked to write down “what you think about when you think of a disability?”. How many of these ideas and descriptions are about something you can see or immediately experience? For example, a child who cannot walk, or has some other restricted movement; a child who cannot see, hear, or talk; a child who displays unusual behaviour such as hand-flapping, or rocking back and forth rhythmically?

Sometimes a disability is not obvious. A *hidden disability* may not be immediately noticeable except under unusual circumstances or because the person or other someone close to the person tells you about it. A hidden disability may have no physical signs. For example, not everyone with a hearing disability uses hearing aids, and you may not notice that they do not hear well. Abel is a four-year-old boy who is always smiling when the IZU comes to visit his parents, but he never speaks, and he is never involved in games with other children. His parents have taken him to see doctors because they believed something was wrong with his tongue or inside his mouth which prevented him from speaking. The IZU did some tests, clapping her hands when Abel’s back was turned, calling his name from behind the door. She suggested his parents took Abel to the clinic to have his hearing checked and it turns out he is deaf. Knowing this they can help him to be more involved in family life by making sure they are facing him always when talking, by using gestures to indicate different actions.



Can you think of any other hidden disabilities?

Children who have an autistic spectrum disorder may look like all other children around them, but they may become disturbed by an outside influence which causes their behaviour to become unruly or antisocial. To many people watching this can seem like a temper tantrum and blame bad parenting. This can mean that they, or their parents don’t want them to go out in public and so they can become isolated and cut off from learning, social and human development experiences.

In conclusion, understanding disability can be complex, a child may experience impairment, an activity limitation, or a participation restriction, or all three, and these may change at different time in the child’s life. For example, the behaviour associated with autism described above can be perceived differently in a 6-year-old and a 17-year-old; people will react differently to a young child having a behavioural tantrum and an older adolescent displaying the same behaviour. It is also important to know that children can be born with a disability, or they can acquire it, for example, as a result of a road accident, or by being severely beaten.



Any questions?



For more information,  
please refer to Handout 2.  
Defining disability

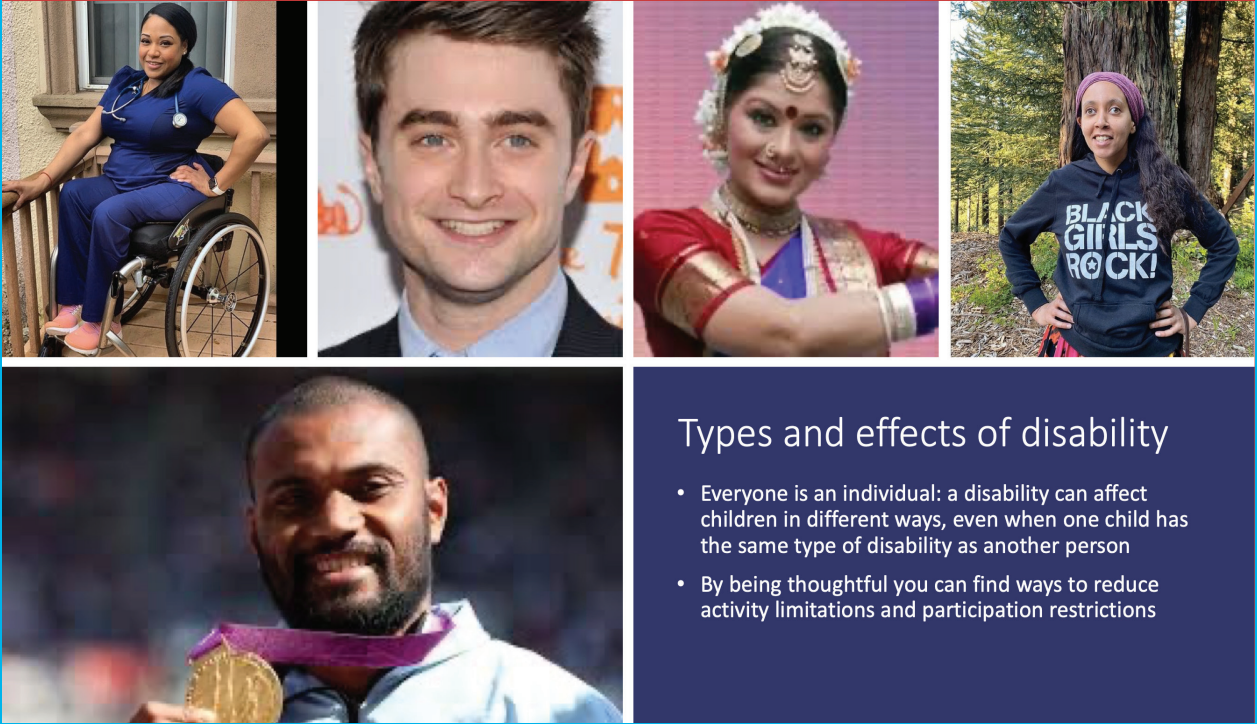
## 2.4 The types and effects of disability



60 minutes



Slide 7



Types and effects of disability

- Everyone is an individual: a disability can affect children in different ways, even when one child has the same type of disability as another person
- By being thoughtful you can find ways to reduce activity limitations and participation restrictions

- Andrea Dalzell is a nurse in New York City, where she has taken care of coronavirus patients during the pandemic. She's a full-time wheelchair user due to a neurological disorder affecting her spine, but that doesn't stop her from giving her patients top-quality care.
- Daniel Radcliffe is a British actor who portrayed Harry Potter, he has dyspraxia, a movement disorder
- Sudha Chandran is an Indian Dancer and Actress, Sudha lost her leg at the age of 16 after a road accident. After a gap of two years, she went back to dancing using a prosthetic leg. She has appeared in TV and films.
- Haben Girma is an American disability rights advocate and the first deafblind graduate of Harvard Law School.
- Iliesa Delana is a Fijian Paralympic gold medal winning athlete and Assistant Government Minister, he is an amputee

A disability can affect children in different ways, even when one child has the same type of disability as another person. Some children have more than one type of disability. There are many types of disabilities, such as those that affect a child's:

- Motor skills
- Sensory ability
- Behavioural skills

- Intellectual functioning
- Communication skills

These difficulties can affect a child's ability to:

- Sit, crawl or walk
- Hold or manipulate objects
- Use the toilet, dress or feed themselves appropriately
- Learn from their environment
- Manage their emotions and demonstrate age-appropriate behaviour
- Learn, understand and apply complex information
- Use words to communicate, express their thoughts and feelings, or to understand others
- Speak clearly and be understood
- Understand simple directions
- Be with, play and relate to their peers or adults

However, if we think about the definition of disability,

*“Disability is usually described as the complex relationship between the mind, the body, and the environment in which a child lives,”*

we can see that the effect of an impairment can be lessened by lifting the activity limitation or participation restriction so that, for example, not being able to see well becomes less disabling for the child.

For example, if a child with poor vision can play football using a ball with a ringing bell inside (lifting the activity limitation), they can participate in 'ringing bell' football with other children if a few safety rules are devised and agreed to (lifting the participation restriction).

A child may also be extremely sensitive (hypersensitive) or not responsive (hyposensitive) to the environment. This means they may have an acute reaction to a minor environmental stimulus such as being distracted by common sounds like the humming of a refrigerator; or they can be unresponsive to the world around them and need additional sensory stimulation to feel content, such as touching things excessively, always turning the volume very loud, or constantly putting objects in their mouth.



How do you think activity limitations and participation restrictions could be lifted in this case?

They may also show unusual or uncontrollable behaviour. Sometimes this behaviour can be caused because the child is sick or in pain and cannot communicate this. It can also be related to emotional issues if the child is sad or unhappy. There can be many causes and it is important to ask a doctor or other specialist in case the behaviour is linked to an illness or injury or other physical cause.

Because each child is unique, disability can affect individual children in different ways, even among children with the same type of disability. Children can also be affected by more than one type of disability, for example their movement and sight, thinking and understanding can all be affected.

Following the biopsychosocial 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. Their disability is not defined by the condition itself but rather by how their functioning is impacted, by the opportunities they have to learn and develop skills and to have the same experiences as their peers.

In this slide you can see some famous people who have a disability but who are mostly well known for other reasons.



Can you think of people you know from Rwanda or who live in your community who are similarly well-known for their career success or how they contribute to their community, and not only for their disability?



Any questions?



For more information, please refer to Handout 4. The types and effects of disability

## 2.5 What is inclusion and why is it important?



60 minutes

Inclusion of children with disabilities and their families in all aspects of daily life is important because it supports their rights.

Children with disabilities do not require different activities or experiences for learning to occur. However, they may need specific, individualized supports to benefit from the positive experiences that all **typically developing children** have access to. For example, adaptations to the built environment/infrastructure (wheelchair ramps), access to assistive devices (a computer with special software for communication), a personal assistant (to help them in the classroom, or to use the toilet at school), habilitation and rehabilitation therapies to support delayed development (physiotherapy, speech therapy, occupational therapy), change in attitude and behaviour of the people around them so that they can be involved in day-to-day life, etc.



Slide 8

Inclusion involves...

Getting

Getting fair treatment from others (nondiscrimination);

Making

Making products, communications, and the physical environment more usable by as many people as possible (universal design);

Modifying

Modifying items, procedures, or systems to enable a person with a disability to use them to the maximum extent possible (reasonable accommodations); and

Eliminating

Eliminating the belief that people with disabilities are unhealthy or less capable of doing things (stigma, stereotypes).

**Inclusion** of children with disabilities into everyday activities involves practices and policies designed to identify and remove barriers such as physical, communication, and attitudinal, that hamper children's ability to have full participation in society, the same as typically developing children. Inclusion involves:

- Getting fair treatment from others (non-discrimination);
- Making products, communications, and the physical environment more usable by as many people as possible (universal design);

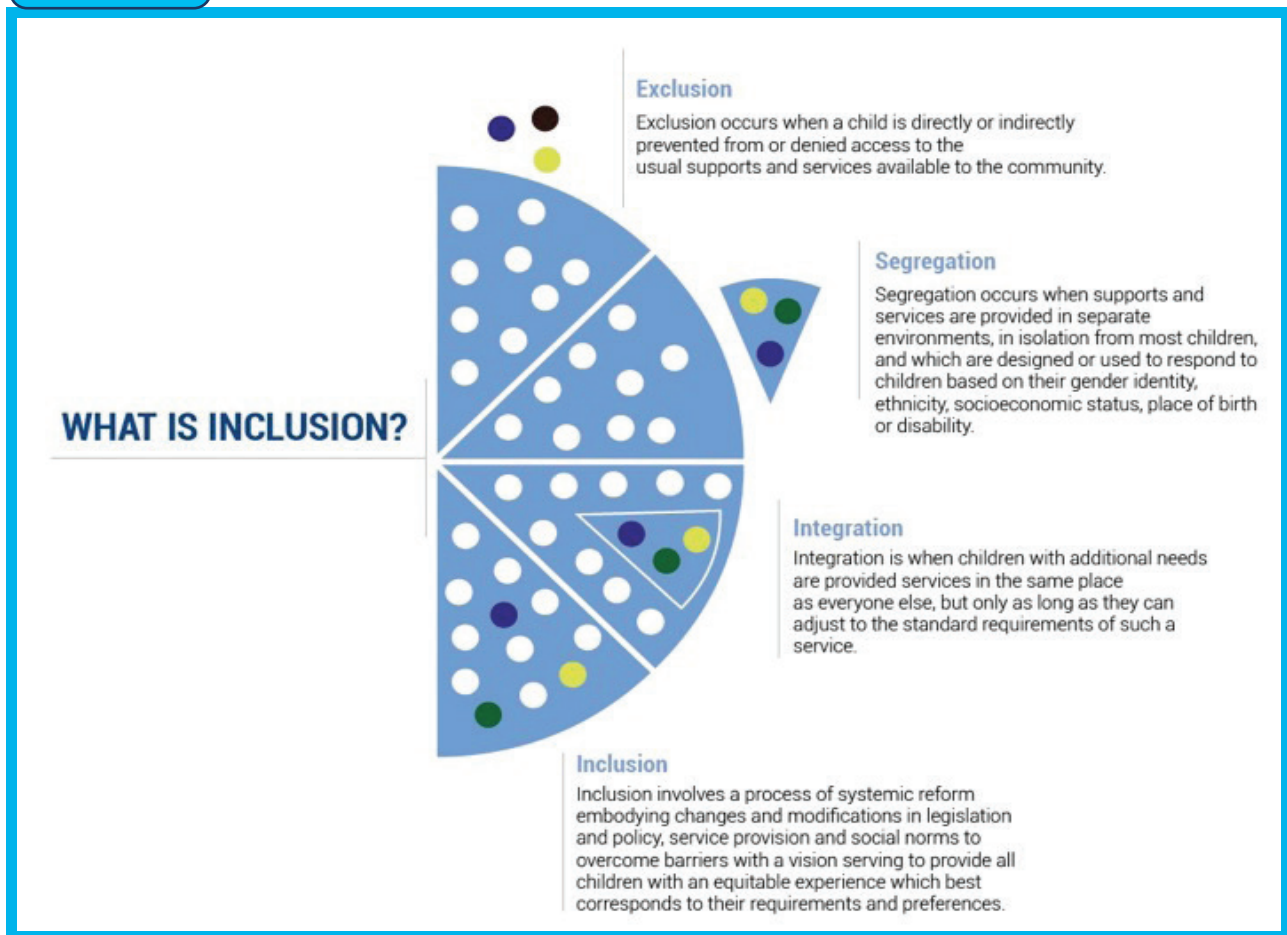
- Modifying items, procedures, or systems to enable a person with a disability to use them to the maximum extent possible (reasonable accommodations); and
- Eliminating the belief that people with disabilities are unhealthy or less capable of doing things (stigma, stereotypes).



Can you think of any examples of inclusion you have noticed in your environment?



Slide 9



**Exclusion** occurs when children are directly or indirectly excluded from the life of the family, school or any part of community-life.

**Segregation** occurs when services for children with disabilities are provided in separate environments designed or used to respond to a specific impairment or set of impairments, in isolation from typically developing children.

**Integration** is when children with disabilities are provided services in the same place as everyone else, as long as they can adjust to the standard requirements of such a service.



**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, to the way we all communicate, to our attitudes and belief systems, and to the way we provide services, so the service adapts and not the child.

Although the research is still limited there is emerging evidence that there are strong economic benefits for the whole community to adopting a disability-inclusive approach. Economic benefits are clearest and have been most commonly highlighted in programmes that supported disabled people's livelihoods and employment or access to credit or finance. Some inclusive education programmes also make explicit links to economic benefits. The theory is plausible, that if we include people with disabilities, we increase the pool of productive citizens who can contribute to reducing poverty.

For example: Let's think about Keza and Kariza who live with their families in the same village.

Keza and Kariza both have disabilities. Because their parents are afraid what other people will think about this (they might be scared, or superstitious, or want to hurt the children) they keep Keza and Kariza at home, in the house or compound where no-one can see them. They don't see visitors, they don't go shopping with their parents or siblings, they aren't enrolled in school. They are invisible to almost everyone. This is exclusion.

One day Keza and Kariza's parents learn there is a residential institution for children like them in a remote place 50 kilometres away situated in a different province. The doctor says it's a good place where the children will be cared for. The village leader also tells the children's parents it's a good place for them. A car comes and takes Keza and Kariza to the institution, where they start their new life. This is segregation.

After some time, the government decides that these isolated institutions are not good for children and so they decide to close them. They slowly move the children to live with other disabled children in a smaller "family-type-group home" in the village they came from. They go to the local school and sit in the classroom with other children, they don't have any extra help in the classroom, and they don't make much progress. This is integration.

# Overcoming stigma and discrimination

- Stigma refers to attitudes and beliefs that lead people to reject, avoid, or fear those they perceive as being different.
- Discrimination happens when individuals or institutions unjustly deprive others of their rights and life opportunities due to stigma.
- What are some of the attitudes and beliefs about disability in your country?
  - Angel
  - Perpetual child
  - Stupid
  - Punishment
  - Evil spirits



It is important that the language used to describe disability is respectful to people with disabilities and in line with the way they describe themselves.

Each country and even individual communities within each country, can have a different context and history that may also affect how people think about disability. The way we talk about disability, and the words we use can reflect this context but sometimes they can be disrespectful and reinforce the label applied to the child as of having little or less value than other children. This is not a rights-based approach and because of this the child and their family can experience stigma, discrimination, exclusion, and isolation.

**Stigma** refers to attitudes and beliefs that lead people to reject, avoid, or fear those they perceive as being different.

**Discrimination** happens when individuals or institutions unjustly deprive others of their rights and life opportunities due to stigma. This lack of understanding can have serious consequences for people with a disability and their families.

For example, some people with a disability do not like it when someone says they are ‘vulnerable’ and need ‘care’. They prefer to think of themselves, and to be thought of by others, as capable, and want the focus to be on the barriers to their inclusion and independence that have been created by society.

Sometimes the words used to describe people with a disability can also be used as terms of abuse. For example, in the past, in the UK the word “idiot” and “moron” were used as an official classification for a person with an intellectual disability. These words are now used as disapproving words of abuse. In the USA “mental retardation” is an official classification of limitations in intellectual functioning, and many young people use the word “retard” when they want to say something nasty about a peer.





At the beginning of this session, we asked you to write down some words used in your country to describe disability. Are these words positive or negative? Would you like someone to use these words when talking about you or a member of your family? What can you do in the future to use more positive language?

In many countries organisations and individuals like to use what is called person-first language. Person first language emphasizes the person first not the disability. For example, when referring to a child with a disability, refer to the child first by using phrases such as: “a child who ...”, “a child with ...” or, “child who has...”. This helps us to remember that they are all children, first and foremost. However, in other countries some people describe themselves as a disabled person in preference to a person who has a disability, because they believe the disability is a part of their identity.



It is a good idea to refer to the appropriate terminologies communicated by the NCPD.



Using Handout 6, go through the NCPD appropriate terminologies

If you use respectful language when you talk about children with disabilities, and if you challenge others when they use negative words, you can begin to make change happen in your community, so that the false and harmful beliefs which create stigma and discrimination will also begin to change.



Any questions?

## 2.6 Concluding session of the one-day learning workshop



30 minutes

In today's learning workshop we have talked about:

- Why it is important to include children with a disability
- What is a disability?
- The types and effects of disability
- What inclusion means, and
- Why the words we use to talk about disability are important

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

We hope that this information is helpful in developing your confidence to work with children with disabilities and their families in the future.

There are three more sessions to follow this workshop; these will be shorter, no longer than 2 hours for each session. During these sessions you will have a chance to share your experience of trying to put what you have learned today into practice. You will also learn more about:

- How you can use the Parents' Guide to work directly with families of children with disability in your community



If there is time, go around the group of participants and ask:

*“What is one thing that you learned today that will be useful in your work?”*

*“What is one positive action you will take to be more inclusive of children with disabilities in your community?”*



Let's have a look at the picture in Slide 10. Step-by-step changes start to happen in the village - when new buildings are constructed the architects and builders have to think how children and other people with disabilities can access them; when professionals in health or education are trained, there is a special module on how to include children with disabilities so they can get the proper services at the ordinary health and education facilities; the village leader talks about the importance of including people with disabilities in the life of the community and dispels the myths. Kariza and Keza and their families are supported so that they can live together again. Because Kariza and Keza are able to grow up in an inclusive society they can continue to contribute as adults, get jobs and contribute to the productive society. This is inclusion.

In your day to day work it is important to remember that involving children and their families in service planning and design from the start creates better services. "Involving" means both listening to and acting on what you hear. This is because the services which are designed to meet the needs of the people who will use them will be more accessible and useful. It also allows service planners to communicate openly and transparently about what is possible and feasible, given financial realities, and to plan for evolving design as resources become available.



What do you think needs to happen to make this a reality in your community? What should the first steps be?



For more information, including the benefits to society of an inclusive approach, please refer to Handout 5. What is inclusion and why is it important?



Any questions?

## 2.7 Why the words we use to talk about disability are important



60 minutes



Take three minutes to write down/discuss some of the words people in your community use when referring to children with a disability. Put a ✓ (tick) against the words which seem to you positive and respectful. Put a X (cross) against those words which seem to you negative and disrespectful. Ask each person in the group to read out what they have written and put it up on the board/flipchart/screen.

Sometimes people use negative words because of some false and harmful beliefs people hold about disability.



Can you think of any false and harmful beliefs people in your community have about disability?



[For example, in some countries, common beliefs about the causes of childhood disability include sin or promiscuity of the mother, an ancestral curse; or demonic possession; a curse from God; breaking laws and family sins; witches and wizards; and adultery, among others]



Can you think of ways to overcome these harmful and false beliefs?

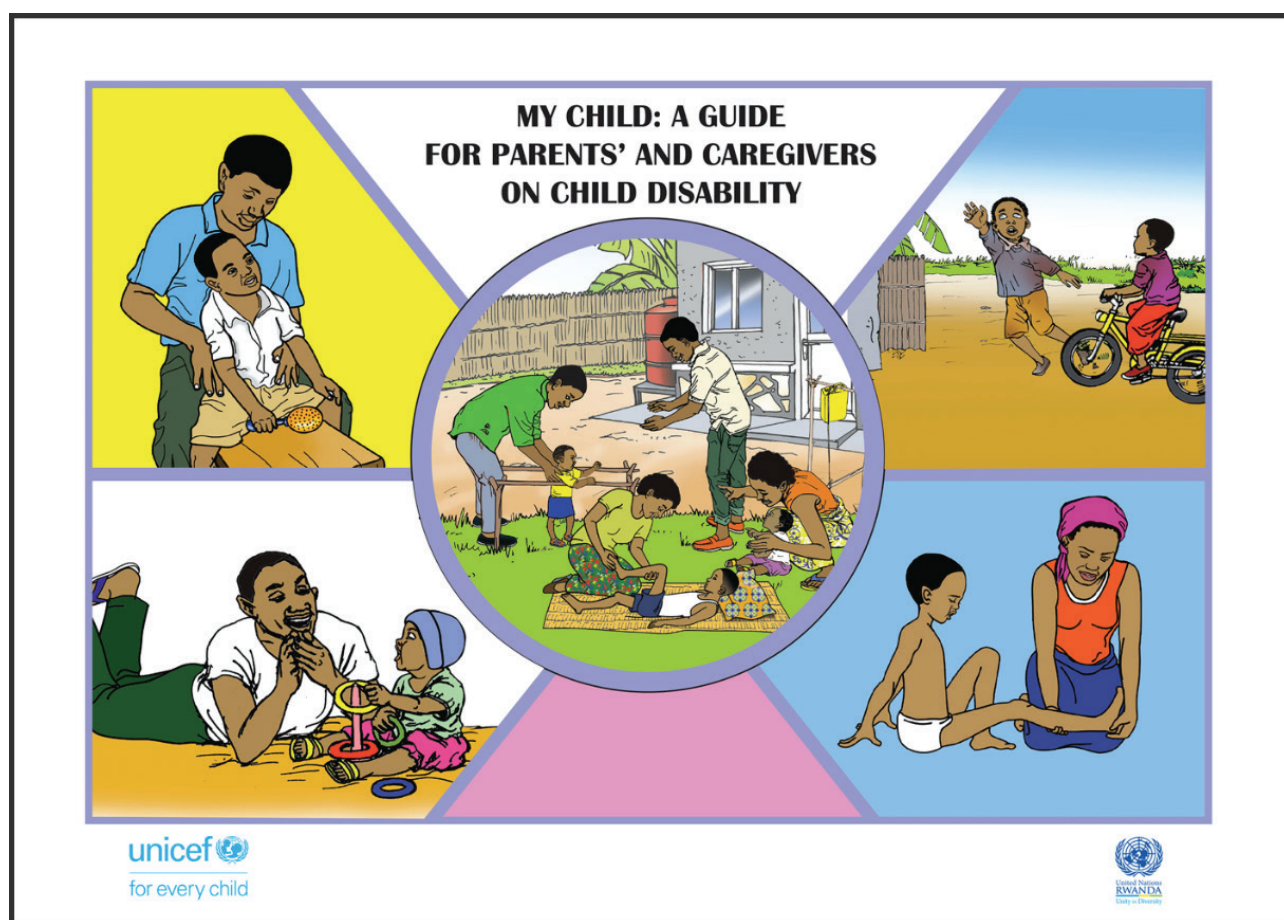
### 3. HOW TO USE THE PARENTS' SHEETS



Total three two-hours/120-minute sessions (the Facilitator should decide in advance how to structure the timing in view of the local context and availability of IZUs, inserting breaks as necessary) Please note, this is a practical session which follows the Parent's Guide. It is conducted sitting on a mat, no equipment is needed except for the flipboard Guide itself.



Following the introductions ask each person in the group to describe one positive interaction or experience and one challenging experience they have had in connection with their work children with disabilities and their families. [This is an opportunity to share experience, to discuss and to find solutions from within the group].



Today we are going to go through Chapters 1-3 or Chapters 4-6 or Chapters 7-10 of the Parents' Guide, so that you can use this tool to work with families of children with disability in your community.

This Guide is mostly for parents and caregivers on child disability. It might also be useful for you to use when you are speaking to other members of the community to explain how they can help and support children with disabilities and their families.

The sharing of the information contained in the Guide should be facilitated by a person with some knowledge of disability. Because you have been involved in the one-day learning workshop, you are ideally qualified to use this Guide.

You can gather a group of parents and caregivers at regular times and go through the Chapters at the most suitable place and convenient times for them. Or you can use the Guide with individual families during regular household visits.

The Guide is designed as a standing flipboard with pictures on one side facing outwards towards the parent and caregiver participants, and with the instructions facing in towards you the IZU facilitator.

With the pictures facing towards the parents, you should point to each picture in turn and describe what is happening, prompted by the text on the side facing you.

**There are ten (10) chapters to work through.**

- Chapter One is a short introduction on what disability is
- Chapter Two talks about the rights of children with disabilities
- Chapter Three describes the types and effects of disability
- Chapter Four describes child developmental milestones and what to do if you suspect a child's development is delayed (sometimes called early identification)
- Chapter Five is about how to detect early if your child has a developmental delay or a disability and how to become involved in learning activities with your child to stimulate their development (sometimes called early detection)
- Chapter Six is about how you can support your child when you notice they might have a delay or disability (sometimes called early intervention)
- Chapter Seven gives some ideas for communicating with a child who has a disability
- Chapter Eight is about how parents and caregivers of children with disabilities can support each other
- Chapter Nine helps parents and caregivers think about how they can involve their child with a disability in the usual community activities
- Chapter Ten helps parents and caregivers to think about the different types of services they can access in their own area if they need help for their child



