



NATIONAL CHILD DEVELOPMENT AGENCY

**Tubarerere mu Muryango programme
(‘Let’s raise children in families’)**

Inclusive Case Management for Children’s Reintegration

Participants Handbook

**Training module for the Social
Service Professionals**

January 2021

Inclusive Case Management for Children's Reintegration

Participants Handbook

Training module for the Social Service Professionals

In partnership with



This training module has been developed through a partnership between the National Child Development Agency, Rwanda and UNICEF Rwanda.

The authors are:

Elayn M. Sammon elaynsammon@gmail.com and Joseph Munyandamutsa josephmunyandamutsa@gmail.com

Suggested citation:

Suggested citation: National Child Development Agency 2021, Training Module 3 for Social Service Professionals on Inclusive Case Management for Reintegration. National Child Development Agency, Rwanda and UNICEF, Rwanda: Kigali.

© 2021 National Child Development Agency, Rwanda

Table of Contents

Abbreviations.....	ii
Acknowledgements.....	1
Glossary.....	2
A note on terminology.....	4
Terminology associated with disability in Rwanda.....	4
Introduction.....	5
Proposed Schedule for the Module Three 3 x day training programme.....	6
Children's rights and child protection.....	6
The importance of family-based care for all children.....	8
The importance of permanency planning.....	10
Defining reintegration.....	11
Children with disabilities.....	12
Engaging with children, families and communities.....	16
Compendium of Resources.....	19

Abbreviations

CHW	Community Health Worker
DMO	District Mainstreaming Officer
ECD	Early Childhood Development
ICF	International Classification of Functioning Disability and Health
IZU	Inshuti z'Umuryango (Friends of the Family)
MIGEPROF	Ministry of Gender and Family Promotion
NCDA	National Child Development Agency
NCPD	National Council for Persons with Disabilities
NST	National Strategy for Transformation
SDG	Sustainable Development Goal
TMM	Tubarerere Mu Muryango programme ("Let's raise children in families")
UNCRC	United Nations Convention on the Rights of the Child
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organization

Acknowledgements

Sincere thanks are due to the officers of the National Child Development Agency in Rwanda (NCDA) and of United Nations Children's Fund (UNICEF) Rwanda for their guidance and contributions during the development of this operational guidance. In addition to the information referenced in the text, the authors would also like to acknowledge the input of all organizations who have contributed to children's health and well-being through their global work on case management for reintegration. This international community of practice generously shares their experience and evidence-based methods for learning and application in dynamic and evolving development contexts. This operational guidance has been informed by the work of many different organizations in many different countries and we offer our sincere thanks to all of them. In particular we acknowledge:

- 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 the Government of the Republic of Rwanda Ministry of Local Government by International Centre for Disability and Rehabilitation 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 with other partners including IntraHealth, Maestral, Pact, Plan International and Westat helped countries identify practical and appropriate policies, programmes and services that promote child well-being.
- The Partnership for Every Child 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 in the United Kingdom (UK), and their learning hub on Safeguarding Children and Child Protection.
- Displaced Children and Orphans Fund of USAID, June 2018, Family Care for Children with Disabilities: Practical Guidance for Frontline Workers in Low- and Middle-Income Countries
- Faith to Action Initiative and their work on transitioning to family care for children
- Lumos who work to make sure children live safely in family-care or family-based alternative care; and who have collated useful research on the risks of harm to children growing up in residential institutions.

Glossary

Word or term	Definition as applied in this text
Alternative care	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.
Case management	The process of helping individual children and families through direct social-work type support, and information management; ¹ 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. ²
Case worker	A person employed by the National Child Development Agency (NCDA) as a Child Protection and Welfare Officer, usually a graduate social worker or psychologist.
Child	A person under 18 years of age.
Child Protection and Welfare Officer	A graduate social worker or a graduate psychologist working for NCDA 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.
Child protection system	Formal and informal structures, functions, capacities, and other elements organized to achieve safety for children.
Community-based Inclusive Development	Enhances and strengthens earlier work described as community-based rehabilitation
Community-based Rehabilitation	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.
Disability	"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." (United Nations Convention on the Rights of Persons with Disabilities – UNCRPD).
Discrimination	Discrimination happens when individuals or institutions unjustly deprive others of their rights and life opportunities due to stigma.
Family	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 the primary caregiver/s for the child may be extended family members.
Habilitation	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. ³
Inclusion	Inclusion involves 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.

¹ Inter-agency Child Protection Working Group, Inter-agency Guidelines for Child Protection and Case Management, 2014. http://www.cpnetwork.org/wp-content/uploads/2014/08/CM_guidelines_ENG_.pdf
² Global Social Service Workforce Alliance, Case Management Concept and Principles, GSSWA: Washington DC, 2018. <http://www.socialserviceworkforce.org/sites/default/files/uploads/Case-Management-Concepts-and-Principles.pdf>

Independent living	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. (UNCRCPD 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.
Inshuti z'Umuryango (Friends of the Family)	A cadre of community volunteers composed of one man and one woman with responsibility for promoting child rights and supporting reintegration.
Malayika Murinzi (Guardian Angels)	A cadre of honest parents known for their good reputation in various Rwandan communities, for their goodwill effort to care, protect, and educate vulnerable children particularly orphans.
Occupational therapy	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.
Physiotherapy	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.
Placement	The physical act of placing the child in family-based alternative care; it is one step in the reintegration process.
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. ⁴
Reintegration	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.
Reunification	Reunification is the physical act of returning the child to their family; it is one step in the reintegration process.
Residential institution	A residential institution is defined as any group living arrangement for children without parents or without surrogate parents, in which care is provided by a smaller number of paid adult carers. ⁵
Speech and language therapy	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.
Stigma	Stigma refers to attitudes and beliefs that lead people to reject, avoid, or fear those they perceive as being different.
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.
UNCRCPD	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.

⁴ Ibid.

⁵ See 'United Nations Disability and Child Rights Groups On Behalf of Children without Parental Care Key Recommendations' 20 June 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

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 United Nations Convention on the Rights of Persons with Disabilities (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, while '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 'child with disabilityren'.⁶ 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.

NCPD has developed recommended terminology to replace culturally-based usage that is considered as a 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

N°	Ntibavuga (inyito zipfobya)	Bavuga (inyito iboneye)
1.	Ikimuga, uwamugaye, ubana n'ubumuga, ugendana n'ubumuga	Umntu ufite ubumuga
2.	Ikirema, Ikimuga, Karema, Kajorite, Igicumba, Gicumba, Utera isekuru, Kaguru, Jekaguru, Ikirema, Karema, Muguruwakenya, Terigeri, Kagurumoya, Kaboko, Mukonomoya, Rukuruzi	Umntu ufite ubumuga bw'ingingo
3.	Impumyi, Ruhuma, Maso, Gashaza, Miryezi, ...	Umntu ufite ubumuga bwo kutabona
4.	Igipfamatwi, Ikiragi, Nyamuragi, Ibubu, Ikiduma, Igihuri, Bihurihuri	Umntu 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.	Umntu ufite ubumuga bwo mu mutwe
6.	Kanyonjo, gatosho, gatuza	Umntu ufite ubumuga bw'inyonjo
7.	Nyamweru, umwera, ibishwamweru, nyamwema, umuzungu wapfubye	Umntu ufite ubumuga bw'uruhu rwera
8.	Igikuri, gikuri, gasongo, nzovu, zakayo, gasyukuri, kilogarama	Umntu ufite ubugufi budasanze

Source: NCPD

⁶ 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; 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>

Introduction

This participant's handbook relates to Module 3 of the Government of Rwanda's Tubarerere Mu Muryango (TMM) training programme.

It is for Child Protection and Welfare Officers⁷ who work directly with children and families on reintegration of children, including children with disabilities from residential institutions. It can also provide useful information to people working in other local government roles, for example District Disability Mainstreaming Officers and Gender and Family Promotion Officers, as well as people working in non-governmental organizations (NGOs) or community-based systems (for example, Inshuti z'Umuryango – Friends of the Family) who support children and families, and particularly those who have contact with children during the reintegration process. It can be helpful for all workers who have limited or no training specifically on inclusive practices.

In March 2012, the Government of Rwanda endorsed the Strategy for National Child Care Reform.⁸ 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 (NCDA). 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 first phase of TMM did not have a specific focus on residential institutions for children with disabilities but included reintegration of a small number of children with disabilities who were residing in the target institutions.⁹ The 2018 evaluation of the first phase of TMM reported that placement of children with disabilities into families utilizing the existing model was challenging.¹⁰ The second phase of TMM has been initiated by NCDA in partnership with the National Council for Persons with Disabilities (NCPD).

This training package is embedded in the TMM programme which has been adjusted in 2019 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 constitutes the guiding framework for the development of Module 3 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 3 will help 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.

This training package is organized in three parts:

- **Module 1:** Pre-service Training Module for Social Service Professionals, 2017
- **Module 2:** In-service Training Module for Social Service Professionals, 2017
- **Module 3:** Inclusive Case Management for Reintegration, Training Module for Social Service Professionals, 2019 (this participant's handbook)

⁷ Previously referred to as a social worker or psychologist depending on their graduate-level qualification and now called Child Protection Welfare Officers, these are also referred to hereinafter as 'case workers'.

⁸ Cabinet Brief: Strategy for National Child Care Reform (n.d.).

⁹ Through the implementation of the Tubarerere Mu Muryango Programme, 3,216 children and young adults have been placed in family-based environments or supported in independent living by December 2018.

¹⁰ Primson Management Services, Summative Evaluation of the Tubarerere Mu Muryango/Let's Raise Children in Families (TMM) Phase I Programme in Rwanda, NCDA and UNICEF Kigali, 15 January 2018.

Proposed Schedule for the Module 3 Three-day training programme

Time	Day One	Day Two	Day Three
09.00-10.00	Welcome, introductions and ground rules	Children with disabilities	Inclusive Case Management for Reintegration - step by step use of the Guidance using real-life case studies
10.00-10.30	Coffee break	Coffee break	Coffee break
10.30-11.30	Refresher - child rights and child protection	Children with disabilities	Inclusive Case Management for Reintegration - step by step use of the Guidance using real-life case studies
11.30-12.30	The importance of family-based care for children		
12.30-13.30	Lunch	Lunch	Lunch
13.30-15.00	The importance of permanency planning	Support for reintegration of children with disabilities to family-based care	Inclusive Case Management for Reintegration - step by step use of the Guidance using real-life case studies
15.00-15.30	Coffee break	Coffee break	Coffee break
15.30-17.00	Defining reintegration	Support for reintegration of children with disabilities to family-based care	Clarifications and discussions; planning for implementation; and closure

Children's rights and child protection

The 1989 **Convention on the Rights of the Child (CRC)** sets out the human rights which apply to all children, from birth to the age of 18. CRC guarantees the rights of all children, without discrimination in any form. It obliges States parties to ensure that each child, girl or boy, within their jurisdiction has all the rights recognized by the Convention.

The Convention is special because it is the most widely supported and comprehensive international human rights treaty. Every country in the world but one has ratified it, and it contains the full range of civil, cultural, economic, political and social rights. It is a fantastic tool, not only for advocacy and programming, but also for guiding our everyday behaviour with children.

All human rights, including **child rights**, are **indivisible and interdependent**: you cannot consider them in isolation. Fulfilling one right helps to fulfil others. **Rights are also inalienable**: you cannot take them away. Having rights does not depend on fulfilling responsibilities. Rights cannot be used as a reward or a punishment.

Those with an obligation to respect, promote and realize children's rights are called **duty bearers**. The State is the main duty bearer, including everyone who works for the State, like police officers, lawyers, teachers and social workers. The State maintains ultimate responsibility, but it may delegate some responsibilities to others (such as private companies or civil society groups). The international community also has obligations to support the State in fulfilling its child rights responsibilities. Parents and other caregivers may be described as secondary duty bearers.

Individuals and groups who benefit from human rights treaties are called **rights holders**. For child rights, the main rights holders are children (under the age of 18). However, parents are also rights holders under the Convention. They are entitled to assistance from the State in raising their children, and they are entitled to provide their children with advice and guidance. All rights holders, including children, are strongly encouraged to respect the rights of others, but rights are not contingent on rights holders fulfilling duties or responsibilities towards others.

The **Committee on the Rights of the Child** monitors the Convention and its three Optional Protocols (on armed conflict, the sale of children, and individual complaints by children to the Committee): these are additional legal mechanisms that complement the Convention and need to be ratified separately. States must report to the Committee every five years. The United Nations Children's Fund (UNICEF), civil society organizations, and children themselves can provide extra information to help the Committee assess how well States are implementing the Convention.

Child rights have grown out of the need for special care and protection and fulfilling children's rights leads to their improved well-being.

Well-being is another way to frame the fulfilment of children's material and psychosocial needs. However, **rights are stronger than needs or well-being**. A charity approach responding to children's needs reinforces power imbalances, relies on sympathy, and is not sustainable. In contrast, an approach based on child rights is grounded in obligations and accountability; working with children, not just for them, respecting their human dignity and agency. It is more universal, holistic, respectful and sustainable.

Other human rights treaties can provide more detailed guidance on specific issues, such as the **Convention on the Rights of Persons with Disabilities (CRPD)**, which is especially relevant to child protection work.

Article 7 of UNCRPD relates specifically to children with disabilities, including that "States Parties shall take all necessary measures to ensure **the full enjoyment by children with disabilities of all human rights** and fundamental freedoms on an equal basis with other children".

The **Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)** calls for positive change in the lives of all girls and women. According to CEDAW, governments should take all necessary or special actions that may be required to make sure girls and women actually experience equality in their lives.

Remember – child rights are indivisible and interdependent: you cannot consider them in isolation. Fulfilling one right helps to fulfil others. **Rights are also inalienable:** you cannot take them away. CRC, CRPD and CEDAW are connected. Women who have had a good education are much better at supporting the education of their children, especially their daughters. When women's rights are protected, fathers are more likely to be involved in parenting and in protecting the rights of girls. This also helps make sure their rights will be protected when they grow up and become women. Making sure that all rights are applied equally to all children everywhere means that they also apply to girls and boys no matter their socio-economic status, ethnicity, country or origin or disability. Using CRC, CRPD and CEDAW together works better for the rights of girls, boys and women at all stages of their lives.

The **Government of Rwanda's national commitments for children** and for children with disabilities include:

- Constitution of the Republic of Rwanda;
 - Law No. 71/2018 relating to the Protection of the Child;
 - Law No. 01/2007 Relating to Protection of People with Disabilities in General;
 - Law No 32/2016 of 28/08/2016 governing persons and families;
 - Integrated Child Rights Policy;
 - Special Needs and Inclusive Education Policy;
 - National Policy on Persons with Disabilities;
 - The 7 Years Government Programme /National Strategy for Transformation;
 - Disability Mainstreaming Guidelines;
 - National Guidelines for Community Based Rehabilitation;
 - Cabinet Brief – Strategy for Child Care Reform, 2012;
 - Inshuti z'Umuryango

The **Rwandan Social Worker's Code of Conduct** provides a unique set of principles and professional standards that guides professional decision making and conduct when ethical issues arise within the workplace. It does not offer a set of rules that recommend how the social service workforce should operate in all situations.

The code of conduct underlines the importance of the professional standards required in social service delivery. Implementation of the code ensures that the members of the workforce are familiar with and practice the professional standards of conduct that the public and stakeholders expect of them.

Six professional standards should be implemented at all times:

1. Protect the rights of and promote the interests of children and caregivers;
2. Strive to establish and maintain the trust and confidence of children and caregivers;
3. Promote the resilience and eventual independence of children while providing protection from danger or harm;
4. Respect the rights of children whilst seeking to ensure that their behaviour does not harm themselves or other people;
5. Uphold public trust and confidence in social services by delivering ethical and good practice; and
6. Be accountable for the quality of your work and take responsibility for maintaining and improving your knowledge and skills to best serve your community.

INSERT:

Full text of the Rwanda Social Service Professional Code of Conduct.

The importance of family-based care for all children

International law establishes that all children – including children with disabilities – have the right to live and grow up in a family.

The UNCRC is clear that:

“The child, for the full and harmonious development of his or her personality, should grow up in a family environment, in an atmosphere of happiness, love and understanding; the family being the fundamental group of society and the natural environment for the growth and well-being of all its members.”

This is because families are of critical importance to children's healthy growth and development. Research shows that children cared for in families do better than those living in residential care facilities across all areas of development and supports the view that family-like institutions are still institutions and are no substitute for care by a family no matter the ability of the child.

Article 19 of UNCRPD protects the right of all people with disabilities to live in the community. In General Comment No. 5 the UNCRPD Committee unequivocally states that “for children, the core of the right to be included in the community entails a right to grow up in a family,” and 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.

[With thanks to Lumos for collating the research.¹¹]

Residential institutions for children have many names around the world, including orphanage, children's home and baby home. Regardless of name, size or location, institutional care is defined by certain characteristics:

- Unrelated children live in the care of paid adults.
- Children are separated from their family and often their community. In many cases, they do not have the opportunity to bond with a caregiver.
- Institutions run according to workplace routines, instead of responding to individual children's needs

Although some institutions are well-resourced with dedicated staff, they cannot replace a family. Eighty years of research has shown the negative impact of institutionalization on children's health, development and life chances, as well as a high risk of abuse.

The Risk to Health

Some children in institutions suffer from poor health due to detrimental physical conditions, a restricted environment or a lack of interaction.

A few examples are given below:

- Malnutrition is a common risk for children who need extra time and support to eat. Young children and those with disabilities often become malnourished when support is not given, even though there is plenty of food available;
- ‘Toxic stress’ can occur when a young child's anxiety is not relieved by the caregiver, and the brain remains on alert. This reduces neural connections and heightens the risk of poor health in adulthood;
- The immune system cannot develop properly if a child is confined to a limited space, seldom leaving the building, or sometimes even their bed. Sickness also spreads easily where there are many beds in one room;
- Physical and learning disabilities may be caused and/or exacerbated by the restricted environment and lack of stimulation children receive in some institutions;
- Hearing and visual problems sometimes result from poor nutrition or under-stimulation of the senses. These are often left undiagnosed and untreated.

¹¹ https://lumos.contentfiles.net/media/documents/document/2017/03/Factsheet_Lumos_Risks.pdf

Toxic Stress Centre on the Developing Child Harvard University

Learning how to cope with adversity is an important part of healthy child development. When we are threatened, our bodies prepare us to respond by increasing our heart rate, blood pressure, and stress hormones, such as cortisol. When a young child's stress response systems are activated within an environment of supportive relationships with adults, these physiological effects are buffered and brought back down to baseline. The result is the development of healthy stress response systems. However, if the stress response is extreme and long-lasting, and buffering relationships are unavailable to the child, the result can be damaged, weakened systems and brain architecture, with lifelong repercussions.

It is important to distinguish among three kinds of responses to stress: positive, tolerable, and toxic. As described below, these three terms refer to the stress response systems' effects on the body, not to the stressful event or experience itself:

- **Positive stress response** is a normal and essential part of healthy development, characterized by brief increases in heart rate and mild elevations in hormone levels. Some situations that might trigger a positive stress response are the first day with a new caregiver or receiving an injected immunization.
- **Tolerable stress response** activates the body's alert systems to a greater degree as a result of more severe, longer-lasting difficulties, such as the loss of a loved one, a natural disaster, or a frightening injury. If the activation is time-limited and buffered by relationships with adults who help the child adapt, the brain and other organs recover from what might otherwise be damaging effects.
- **Toxic stress response** can occur when a child experiences strong, frequent, and/or prolonged adversity – such as physical or emotional abuse, chronic neglect, caregiver substance abuse or mental illness, exposure to violence, and/or the accumulated burdens of family economic hardship – without adequate adult support. This kind of prolonged activation of the stress response systems can disrupt the development of brain architecture and other organ systems and increase the risk for stress-related disease and cognitive impairment, well into the adult years.

The risk to development

Engagement with adult caregivers generates signals and connections in the growing brain, allowing a child to develop intellectual, physical and emotional skills. The more engagement, the stronger the connections.

Many children who were placed in institutions at an early age show delays in these areas of development. In some poor-quality institutions, children may fail to sit, stand, walk and talk by 4 years of age.

Research comparing children who were institutionalized at an early age with their peers raised in birth or foster families showed:

- **Physical stunting.** The Bucharest Early Intervention Project found that Romanian children lost one month of normal growth for every 2.6 months spent in an institution. Other studies in China and Russia found similar results: a one-month delay for every 3 or 3.4 months.
- **Poor social and psychological development.** Studies in several European countries found infants showed insecure attachment to adult caregivers. This was linked to behavioural difficulties and 'internalizing disorders' such as depression or anxiety later in life.
- **Lower intelligence quotients (IQs) and levels of brain activity.** Analysed data on the IQ of 4,000 children in 19 countries: The average IQ of children raised in birth or foster families was 104. The average IQ of children raised in institutions was 84.

Risk of neglect, abuse and exploitation

The United Nations World Report on Violence against Children showed corporal punishment and abusive 'treatments' including physical restraint and electric shock used on children in institutions.

One report of a psychiatric facility in Mexico found children with self-harming behaviour (such as banging their head against a wall) were ignored for long periods or permanently held in physical restraints.

Studies in Europe have shown similarly abusive conditions, especially for children with disabilities.

Children in residential care are six times more likely to be exposed to sexual abuse than children of the same age in the general population.¹²

Risk to long-term life chances

Children living in institutional care often do not develop social networks or skills that are essential in adulthood. It is harder for them to find employment and they are more likely to have behavioural, physical and mental health problems, including high risk behaviours, sexually transmitted infections, alcohol or drug misuse and violence. They are also more likely to be dependent on the state.

¹² Timmerman, G. and Schreuder, P., 'Sexual abuse of children and youth in residential care: An international review', *Aggression and Violent Behavior* 19(6), November 2014.

Children with disabilities often remain in institutions for their entire lives, with no opportunity to appeal the decision.

Survey data in Russia showed outcomes for children who grew up in institutions:

- 1 in 3 became homeless
- 1 in 5 had a criminal record
- 1 in 7 became involved in sex work
- 1 in 10 committed suicide

This session has been about the importance of family-based care for all children. This means that all children should have the opportunity to grow and develop in their families, or in a substitute family. This includes children with disabilities. The risks to a child's health, development and long-term outcomes are too serious to ignore. This is why the government has initiated this programme of care reform.

The importance of permanency planning

Children and young people deserve stability – somewhere safe that they can come home to every day, relationships that are nurtured and developed over time, and a sense of security and belonging. We know that this stability is one of the things that helps children to achieve good outcomes, and for those who come into the care of local councils, it is why working towards permanency from the very start is so important.

For some, permanency will mean returning home to their birth family after a period of time. For other children, adoption may be the best option, or perhaps living with a relative or someone else known to them under a special guardianship order. Similarly, long-term fostering arrangements can offer a stable home without cutting links to the birth family. A very small number of young people might not want to live with another family, or may not be suited to it, and so will stay in residential care until adulthood.

Support for children and their families – both their birth families and carers – should not stop when a placement is made. Some children will have been through very difficult, potentially traumatic experiences before coming into care, and will need extra help to come to terms with that and go on to fulfil their potential.

Types of permanency

Return to birth parents

For many children, a return to their birth family is possible after those issues that led to a period in care have been dealt with.

Kinship (family and friends) care

Kinship care is where a child lives with a relative, friend or other 'connected' person. Many children in kinship care are in informal arrangements, which do not involve the local authority (for example, where a parent asks the child's grandparents to take on full-time caring responsibilities).

Adoption

For some children permanency is achieved through adoption, in which full parental responsibility is legally transferred to the adoptive parents. This is most likely to happen for younger children; adoption can be an excellent route to permanency for children of all ages and should not be discounted purely on the basis of age. Where adoption is considered the best option for a child, avoiding delay is key. Research has shown that a child's chances of being adopted reduce by half for every year of delay, while the age at which the child comes into their adoptive family has a significant impact on adoption outcomes.

Special guardianship

In some countries special guardianship provides an alternative form of legal permanency to adoption and can be used, for example, in cases where children, social workers or the courts feel it would be beneficial to retain links with their birth families. It should:

- Give the carer parental responsibility for all aspects of caring for the child and for taking the decisions to do with their upbringing. The child will no longer be looked after by a local authority.
- Provide a firm foundation on which to build a lifelong permanent relationship between the child and their carer.
- Be legally secure.
- Preserve the basic link between the child and their birth family.
- Be accompanied by access to a full range of support services, including, where appropriate, financial support.

Long-term foster care

Children living in stable, long-term foster care can have similar outcomes to adopted children, and this is a positive permanency option for those children who still identify with, and wish to maintain links to, their birth families. It can also be a positive option for children with complex care needs [who have a disability] or who are harder to place for adoption, such as sibling groups or older children, providing them with long-term stability and ongoing care and support.

Residential placement

Living within a family setting will be the preferred permanency option for most children, including those for whom residential care is a positive short-term option. However, for a small number of children and young people a long-term residential placement could equally be the best option. In particular, this can be useful for older children who are unable or unwilling to participate in family life due to previous experiences or the emotional demands of family living.

Fostering for adoption

Where the preferred form of permanency for a child is adoption, they may be placed with approved adopters who are also approved foster carers while social workers continue to investigate all options for the child. Where the court decides that the child can be placed for adoption, the foster family will then be granted an adoption order, provided social workers and the court are satisfied the child's needs will be met in that placement. Fostering for adoption can limit the number of placement moves for a child, and allows them to begin building a relationship with potential adoptive parents from an early stage.

Finding alternative families for children with disabilities

You can build support for alternative family care by making people aware of the needs and the rights of all children to grow up in a family.

You can talk to the professionals working in existing programmes for foster care and adoption to build disability awareness.

Recruitment, preparation, training and support for foster carers and adoptive parents needs to focus on the specific support needs of children with disabilities. It can require intensive input in the immediate and longer term to make sure that the child is safe and cared for and that the family is supported financially and emotionally. This can include specialized training programmes at the outset and during the child's placement, to make sure that families have the correct information and skills to support the child in different stages in their life.

The CRC seeks to protect children who are unable to live with their parents or remain in a stable family setting (notably, though not only, in Article 20). However, the CRC does not describe in any depth what measures should be taken.

Therefore, the United Nations Guidelines on Alternative Care were developed. The core message in the guidelines is that children must never be placed in alternative care unnecessarily, and where out-of-home care must be provided it should be appropriate to each child's specific needs, circumstances and best interests.

Defining reintegration

There is not yet a globally accepted definition of reintegration, however, it is generally agreed that this is a process rather than an individual action. Sometimes reintegration and reunification are used interchangeably but these are separate and different terms:

- Reintegration is a process consisting of several steps or phases;
- Reunification is a single action or step taken during the reintegration process.

In Rwanda reintegration through TMM includes transition of a child from a residential institution to live with their family of origin or to live in family-based alternative care.

“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.”

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.

Reunification is the physical act of returning the child to their family; it is one step in the reintegration process.

The reintegration process consists of several phases, one of which is reunification, the physical act of returning the child to their family of origin. In cases where the child cannot be reunified a placement in family-based alternative care should be considered.

Children with disabilities need particular assistance during all phases of the reintegration process. During the preparatory phase, it is important to properly assess children with disabilities using a qualified expert and to work to rehabilitate children as appropriate (for example providing physiotherapy or teaching children how to use aids for mobility, bathing, feeding, dressing etc. and for performing daily task as independently as possible).

It is also crucial to identify ongoing support needs and to determine how these will be met, mapping existing services and support and connecting with local organizations working to support children with disabilities in their home communities.

Social workers may need to:

- Access physical aids and assistive devices (such as wheelchairs or hearing aids);
- Train family members in children's care and support or teach them how to effectively communicate with children;
- Ensure that schools and homes are accessible/adapt home environments; and
- Work to tackle discrimination and promote integration into local schools.

In general, the focus should be on making the environment accessible and inclusive, not on trying to 'fix' children with disabilities to make them fit into society. Social workers should link with any community-based expertise and resources, in particular disabled people's organizations, which are run by and for persons with disabilities. When raising the possibility of reintegration, staff are advised to discuss openly any concerns with children and families, and to stress the commitment of NCDA to continue to support access to rehabilitation services, medical treatment (if needed) or other required services once home. Here it is important to stay positive and to focus on children's ability to live independently rather than on loss or deficit. It may be possible to link parents of children with disabilities together and peer-to-peer support can also be valuable for children with disabilities. It may also be important to offer respite care to provide caregivers and children a break.

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 UNCRC and UNCRPD. Equity and inclusion are also fundamental principles of the Constitution of the Republic of Rwanda 2003, revised in 2015.

Child Protection and Welfare Officers have the responsibility to ensure that all children have a fair chance, including those who experience deprivation and discrimination because of their gender, ethnicity, socio-economic status, place of birth or disability status

Equity is the fair treatment, access, opportunity, and advancement for all people, while at the same time striving

to identify and eliminate barriers that have prevented the full participation of some groups.

Inclusion is the act of creating environments in which any individual or group can be and feel welcomed, respected, supported, and valued to fully participate.

Limited knowledge about disability and related negative attitudes can result in the exclusion of children with disabilities within their families, schools and communities. In cultures where guilt, shame and fear are associated with the birth of a child with disability they are frequently hidden from view, ill-treated and excluded from activities that are crucial for their development. As a result of this discrimination, children with disabilities may have poor health and education outcomes; they may have low self-esteem and limited interaction with others; and they may be at higher risk for violence, abuse, neglect and exploitation.

Children with disabilities can be excluded because their families have been advised by medical professionals to place them in residential care facilities, or because they have not had the right support to take care of the child at home. They can also be excluded from care reform processes for example, because they are forgotten, because it is thought to be too difficult, because the prevailing social norms do not consider that children with disabilities have equal rights with all children.

However full and effective participation and inclusion in society is a fundamental principle of both UNCRC which says that children with disabilities have the same rights as all children, and of UNCRPD which says that all persons with disabilities should have full and effective participation and inclusion in society (**Figure 2**).

Inclusion of children with disabilities and their families in all aspects of daily life is important because it supports their rights. However, reintegration of children with disabilities from residential institutions does not guarantee the transition from segregation to inclusion. This requires accompanying services and systems such as rehabilitation, inclusive education and others to be in place and for changes in infrastructure, changes in attitudes to adjust social norms among others.

Children with disabilities do not require different activities or experiences for learning to occur. However, they may need specific, individualized support to benefit from the positive experiences that children without disabilities 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 therapy 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.

Defining disability

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.

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"*.

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

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. This is called the medical model of disability. It 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. 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 themselves or to socialize with other children; or another child with cerebral palsy may receive injections to relieve muscle spasms but if the infrastructure is not suitable for their wheelchair they may not be able to move around easily.

An alternative view is that children are 'disabled' by barriers in society, not by their lack of ability, impairment or difference. This is called the social model of disability. 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 cannot do certain things or that a disability can be 'caught' like a disease.

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, the medical model takes them to a clinic to see if the doctors can do anything to improve their eyesight. The social model solution makes a full-text recording (audio) 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).

Sometimes choosing the medical model over the social model, or the social model over the medical model can mean we do not seek out all the solutions which can assist the child to realize 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; it 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 health care to improve his eyesight as far as possible, and who has access to audio books, may still be isolated from his peers because he needs help to move around or because other children his age are afraid of him because he is different. This boy may need support to go to places where other children his age meet, to learn to get around by himself (become independent); and the other children 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.

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. Some examples of hidden disability include arthritis, mental health difficulties such as depression, and HIV. Not being able to read and write can also be a hidden disability because although there is no physiological impairment, a person who cannot read and write experiences activity limitation and participation restriction. They may not be able to find a job, they may be considered a bad parent because they do not help their children with homework, they may miss out on benefits because they cannot fill in the forms.

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 do not 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. 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.

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

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, we can see that an impairment can be moderated by lifting the activity limitation or participation restriction so that 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.

Children with disabilities 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, or to being hypersensitive or hyposensitive to their environment. 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.

Inclusion involves...

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 support 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 therapy 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.

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

- Getting fair treatment from others (nondiscrimination);
- Making products more user-friendly, communications more understandable and the physical environment physically accessible to as many people as possible;
- 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).

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 with services in the same place as everyone else, as long as they can adjust to the standard requirements of such a service.

Inclusion involves 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 Ana and Henry who live with their families in the same village.

Ana and Henry both have disabilities. Because their parents are afraid of what other people will think about this (they might be scared, or superstitious, or want to hurt the children) they keep Ana and Henry 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 Ana and Henry's parents learn that there is a residential institution for children like them in a remote place 50 kilometres away. The doctor says it is a good place where the children will be cared for. The village leader/head of the local council also tells the children's parents it is a good place for them. A car comes and takes Ana and Henry 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 child with disabilityren 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 do not have any extra help in the classroom, and they do not make much progress. This is integration.

Step-by-step changes start to happen in the village – when new buildings are constructed the architects and builders have to think about 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/head of the council talks about the importance of including people with disabilities in the life of the community and dispels the myths. Henry and Ana and their families are supported so that they can live together again. Because Henry and Ana are able to grow up in an inclusive society, as adults they can get jobs and contribute to 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.

Overcoming stigma and discrimination

It is really important that the language used to describe disability is respectful to people with disabilities and in line with the way they describe themselves. The words we use to talk about children with disabilities can reinforce stereotypes, stigma, segregation, exclusion and discrimination.

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 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 United Kingdom 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 United States of America '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.

In some countries the laws reflect the medical model of disability using words such as, 'with limited health opportunities' to describe disability.

In many countries organizations 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 talk to people with a disability, perhaps members of a disabled persons' organization in your country, to find out what words they would prefer you to use.

Engaging with children, families and communities

Participation is the right to be listened to and taken seriously. Article 12 of UNCRC says that children and young people have the human right to have opinions and for these opinions to matter; Article 12 applies everywhere and to **everyone**;

It is about being able to speak up – even if you have a different opinion from other people or want to complain; It is also a child's right to refuse to give an opinion.

The right to participation applies to all children everywhere.

One of the things UNCRC makes clear is that human rights apply to children and young people, just as they do to adults. This is as true in Kenya, Guatemala or Moldova as it is anywhere else in the world.

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

Article 12 applies everywhere and to everyone.

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

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

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

Being able to speak up

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

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

Being able to refuse

Article 12 does not mean children and young people have to express an opinion if they do not want to. They can refuse to give their opinion for any reason, and Article 12 should not be used to pressure them into giving it.

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

This includes:

- Providing information in different ways, EasyRead for example, or using sign language, Braille and audio – firstly, people should ask disabled people how they would like to get information;
- Telling other services to make their information accessible;
- Getting the media, including the Internet to provide accessible information; and
- Supporting the use of sign language.

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

What is advocacy?

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

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

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

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

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

An advocate is someone who provides advocacy support to a person when they need it. An advocate might help them to access information they need or go with the person to meetings or interviews in a supportive role. A child with a disability may want an advocate to write letters on their behalf, or to speak for them in situations where they do not feel able to speak for themselves.

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

During the reintegration process an advocate will talk to the local authorities, meet teachers and go to the local health centre to make sure they are prepared for the child and can offer appropriate services and support.

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

We have learned three important terms today – which may seem to be saying the same thing, but which have nuances in the context we are using them. To be clear:

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

Why is involving children and their families important?

The importance of participation is reflected in both UNCRC and more recently in the UNCRPD.

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

Research tells us that many children with disabilities and young people are still being excluded from participation and decision-making opportunities. In many cases decisions are taken without even the involvement of their families. Basic access needs to support disabled young people's participation are not being met, and children and young people with higher support needs and communication impairments face significant additional barriers to participation.

As the services children with disabilities and young people use change, it is important that we ensure they have opportunities to shape and influence them. Involving children and young people and their families; hearing what they have to say is key to successful projects and ensures that your work meets their needs. Projects or services for children, young people and their families that incorporate participation will be:

- Improved;
- Better informed;
- Better targeted; and
- More effective.

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

Henry, Irina and Daniela and participation

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

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

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

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

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

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

Henry is fed up because none of the children in his special school have listened to the book and he has no one to talk about it with. His teacher becomes his advocate and

talks to him about his frustrations and what it is that Henry wants. The teacher hears that Henry wants to make friends with children his age who are interested in reading and talking about books. The teacher finds out where the nearest youth club to the school is and goes to talk to them about how they can adapt to help Henry to become a member. When Henry joins the club, he realizes that some of the activities on offer could be interesting for more of his friends from school. He asks his youth club friends to help organize a campaign to self-advocate with the adults at the youth club and the teachers at school to make the club more participative.

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

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

Compendium of Resources

Thematic area	Date	Title	Author	Description	Type	Other
Assistive Technology	2019	Communication for All	CanChild	<p>Short video resource which demonstrates the value of electronic communication assistive devices for children with cerebral palsy.</p> <p>The video also shows the instrument we are working on here at CanChild: the C-BiLLT. This is an accessible test to assess someone's language comprehension skills.</p>	Video	"Musa, Hunter, Marshall, and their families show how technology enables them to play, communicate, learn, work, and have fun.
Assistive Technology	2017	Accessible Information Communication Technology and Assistive Technologies and Persons with Disabilities	International Disability Alliance (IDA) and International Disability and Development Consortium (IDDC)	Technology and accessibility can promote inclusion and help realize the full and equal participation of persons with disabilities in society and shape the future of sustainable development for all. This paper explores the impact and benefits of policy and programmatic measures to improve the well-being and inclusion of persons with disabilities in society and development.	Position Paper	
Autism	2019	Sesame Street and Autism - see amazing in all children	Sesame Workshop	Website with series of videos and information materials related to autism.	Guidance	
Communication and Participation	2010	Involve me	Mencap	The different ways of working with people who have profound and multiple disabilities, who often get left out because we can find it difficult to understand their communication, or are worried about getting it wrong.	Guidance on communication	
Community Based Inclusive Development	2018	National Community-Based Rehabilitation Guidelines	NCPD	Available in Kinyarwanda and English and disseminated to all districts	Guidance	

Early Childhood Development	2019	Are you worried about your child? A Guide to Support Families of Children With Complex Needs And the Professionals Who Care for Them	Interconnections	Guide for parents	Guidance	
Early Childhood Development	2019	Build my Brain	Rollins Center for Language and Literacy	Early experiences affect the architecture of the brain and determine long-term outcomes in health, learning, and behaviour. This course connects the science of early childhood development to work in early childhood education, public health, and social services. No matter your role, you can be a change agent for children's healthy brain development and lifelong well-being.	Free on-line course	
Early Childhood Development	2019	Getting it Right Vol.2 Inclusive Early childhood development and Education Rights	Open Society Initiative for Southern Africa	Disability-inclusive responses, lessons and policy considerations from Southern Africa.	Practice-based evidence	'Learning Stories' based on the experience of 10 organizations in Southern Africa.
Early Childhood Development	2019	Feeding and Positioning Manual: Guidelines for Working with Babies and Children	Holt International	This manual is intended to support the caregivers of infants and children by providing information regarding safe feeding practices.	Manual	
Early Childhood Development	2018	Nurturing Care for Early Childhood Development; a framework for helping children survive and thrive to transform health and human potential (Nurturing Care Framework)	WHO, UNICEF, World Bank	The Nurturing Care Framework provides a road map for action. It builds on state-of-the-art evidence on how early childhood development unfolds and how it can be improved by policies and interventions.	Guidance	
Early Childhood Development	2019	Road map to Accelerate Progress for Every Newborn in Humanitarian Settings 2020 –2025	Save the Children, UNICEF, WHO UNHCR	Addresses newborn health in diverse contexts crossing the boundary between humanitarian and development contexts.	Guidance	
Early Childhood Development	24 May 2019	Family Strengthening Intervention for Early Childhood Development	Boston College School of Social Work	Family-strengthening intervention for early childhood development in Rwanda.	Video	For more details, see www.bc.edu/rpca .

Early Childhood Development	2019	Global Survey of Inclusive Early Childhood Development and Early Childhood Intervention Programs	RISE Institute, UNICEF Early Childhood Development Taskforce	Mapping of Inclusive Early Childhood Development and Early Childhood Intervention Programmes and Support Services.	Research	
Early Identification	May 2019	Identifying Atypical Development: A Role of Day-Care Workers?	Journal of Autism and Developmental Disorders	Research results indicate that most day-care workers can distinguish typical and atypical development in general and might therefore have an important role in early identification.	Peer reviewed journal article	
Education	2019	All Children Reading	ACR GCD	Launched in 2011, All Children Reading: A Grand Challenge for Development (ACR GCD) is a partnership of the United States Agency for International Development (USAID), World Vision and the Australian government that sources and supports the adoption of primarily technology-based innovations to improve reading outcomes for marginalized children in low-resource contexts.	Website with resources inclusive of children with disabilities	Information on innovations for children with disabilities Sign for Literacy prize finalist eKitabu has expanded their sign language video platform into Rwanda. Currently in Kenya, the Studio KSL (Kenyan Sign Language) platform is being prototyped in Rwanda as Studio RSL (Rwandan Sign Language) to create video and EPUB storybooks in local sign languages.
Family Care	2018	Family Care for Children with Disabilities: Practical Guidance for Frontline Workers in Low- and Middle-Income Countries	World Learning, Partnerships for EveryChild, USAID	To help frontline personnel (social service workers and others) in low- and middle-income countries to work effectively with children with disabilities and their families. It was written particularly for those who have little or no experience working with children with disabilities, and it provides easy to read information and advice for those who may have little or no experience working with children with disabilities.	Guidance	Includes extensive compendium of 153 resource links grouped by thematic area.
Family Care	19 March 2019	ABLE Inclusive family-based care for children with disabilities	Programme of the Cambodian NGO, Children in Families	This video highlights the work of ABLE, a programme of the Cambodian NGO Children in Families that provides inclusive family-based care for children with disabilities.	Video	

Habilitation and rehabilitation	1999	Disabled Village Children	Hesperian	A guide for community health workers, rehabilitation workers, and families.	Guidance	
Health Care	2019	Integrated Health Care for Children with Developmental Disabilities	Centre for Evidence in Disability at the London School of Hygiene & Tropical Medicine	Course explores how to deliver appropriate, high-quality health care for children with development disabilities.	Online course	
Health Care	2019	Integrated Health care for Children with Developmental Disabilities	International Centre for Evidence in Disability at the London School of Hygiene & Tropical Medicine	A three-week online course, which explores how to deliver appropriate, high-quality health care for children with development disabilities.	Online training	
Inclusion	2015	Disability Inclusion	Governance and Social Development Resource Centre	Summarizes some of the most rigorous available evidence on the key debates and challenges of disability inclusion in development and humanitarian response.	Research	
Intellectual disability	2019	Special Olympics Health Bulletin	Special Olympics	Three experts inside and outside Special Olympics share their thoughts on how we can build a universal health care system that is inclusive for all.	News	
Monitoring & Evaluation	2019	Evaluating the Implementation of Evidence-based Practices –Tip Sheet Series	The Centre for Early Childhood Data Systems	Concise guidance for collecting and analyzing high-quality data on the implementation of evidence-based practices.	Guidance	
Monitoring & Evaluation		Inclusive Early Childhood Education Self- Reflection Tool	European Agency for Special Needs and Inclusive Education	A tool that all professionals and staff could use to reflect on the inclusiveness of their setting, focusing on the social, learning and physical environment.	Monitoring tool	Available in multiple languages including French
Networks		Africa Disability Alliance		An African knowledge-based organization that works in partnership with the African Union, the United Nations, African governments, civil society organizations, academia and disabled people's organizations to promote inclusive development and human rights for persons with disabilities.		

Networks		IDA		The International Disability Alliance was established in 1999 as a network of global and, since 2007, regional organizations of persons with disabilities and their families.		
Networks		Action on Disability and Development (ADD International)		ADD International is an ally to the global disability movement. They partner with disability activists in Africa and Asia to help them access the tools, resources and support they need to build powerful movements for change.		
Networks		IDDC		The International Disability and Development Consortium and its members aim to support inclusive development. A global consortium of disability and development NGOs, mainstream development NGOs and disabled people's organizations supporting disability and development work in more than 100 countries around the world.		
Networks		Disabled Peoples' International (DPI)		Membership organization of disabled people		
Networks		CBM the overseas disability charity		CBM is an international Christian disability and development organization transforming the lives of disabled people in the world's poorest communities.		In action in Rwanda
Networks		Light for the World		Light for the World is a global disability and development organization breaking down barriers to enrich society and unlock the potential in all of us. Eye health, independent living, inclusive education, disability rights		In action in Rwanda
Networks		Rehabilitation International (RI) Global		A worldwide organization comprised of people with disabilities, service providers, government agencies, academics, researchers and advocates working to improve the quality of life of people with disabilities.		

Networks		Humanity and Inclusion UK Humanity and Inclusion USA		An independent and impartial organization working in situations of poverty and exclusion, conflict and disaster, alongside disabled and vulnerable people to help meet their basic needs, improve their living conditions and promote respect for their dignity and fundamental rights.		In action in Rwanda and here
Parenting	2019	Sesame Street and Autism – see amazing in all children	Sesame Street	Website with resources (including video) for parents and kids all about autism	Website with resources for parents and kids	Peer reviewed journal article about the positive impact of the Sesame Street Autism Initiative
Parenting	10 June 2019	To help deaf children go to school, help their parents	Joanna Clark, Deaf Children Worldwide, Global Partnership for Education	There are still too many children with disabilities who do not go to school. One way to effectively remove a barrier to their schooling is through the transformative power of parents' groups.	Opinion piece	For more information visit Deaf Children Worldwide
Parents & Families	2019	Inclusion FAQs: A Parent and Educator Guide	Inclusion From Square One	Common questions and answers about inclusion.	Sheet on frequently asked questions	
Planning	n.d.	Toolkit on Disability for Africa	United Nations Division for Social Policy Development (DSPD) Department of Economic and Social Affairs (DESA)	Guidance for the development and implementation of national action plans that either focus directly on disability or include a significant disability dimension.	Guidance	
Service Standards	2017	Supporting people with profound and multiple learning disabilities, Core and Essential Service Standards	Mencap	The Core and Essential Service Standards are designed to improve the lives and life experiences of people with profound and multiple learning disabilities.	Guidance	
Supervision	2019	Case Management Supervision and Coaching Package	The Case Management Task Force (CMTF) of the Alliance for Child Protection in Humanitarian Action	To increase case management supervisors' confidence, capacity and support to caseworkers to provide safe, ethical and competent case management services to vulnerable children and their families.	Training Package	
The words we use	14 June 2019	It's perfectly OK to Call a Disabled Person 'Disabled', and Here's Why	Huffington Post	News article from the USA about the words used to talk about disability	News	

(Endnotes)

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
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/>
4. See RI Global, above
5. 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
6. Cabinet Brief: Strategy for National Child Care Reform (n.d.).
7. 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. NCDA and UNICEF: Kigali

