

Changing THE WAY WE care



©Lumos / Toni Perec

Toolkit for Disability Inclusion in Care Reform

Disability
Terminology and
Resources



USAID
FROM THE AMERICAN PEOPLE



MacArthur
Foundation

Acknowledgement

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

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



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

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

©2021 Maestral International LLC. All Rights Reserved. This material may not be reproduced, displayed, modified or distributed without the express prior written permission of copyright holder. For permission, write to info@ctwwc.org. The photographs in this publication are used for illustrative purposes only; they do not imply any particular health, orphanhood, or residential care status on the part of any person who appears in the photographs.

Introduction

The terminology and tips that follow may help as you use this toolkit and apply its principles to your program activities. It is recommended that you become familiar with these terms before reading the rest of the content and revisit as needed. Please keep in mind that disability is an evolving concept. Language that is preferred in one context may be different in another. Ask local organizations of persons with disabilities (OPDs) for the preferred terms in your language and country text.

- **Always use person-first terminology.** For example, use *“person with a disability”* rather than “disabled person,” and *“child who is blind”* or *“child with a vision impairment”* rather than “blind child.”
- **Avoid terms that have negative connotations,** such as “suffer,” “suffering,” “victim” or “handicapped.” Speak of a *“wheelchair user”* rather than a person who is “wheelchair-bound” or “confined to a wheelchair.”
- **Use “persons without disabilities” or “persons without impairments”** rather than “normal or regular persons.”
- **Do not use acronyms** to refer to children with disabilities; use *“persons with disabilities”* instead of “CWD” or “PWD.”

Terms and Definitions

Advocacy	Advocacy is when people get the support they need to vocalize issues. It is a process of supporting and enabling people to express their views/concerns, access information/services, defend and promote their rights/responsibilities and explore choices/options.
Advocate	<ol style="list-style-type: none">1. The person who supports another through the advocacy process.2. The act of advocacy.
Alternative care	A formal or informal arrangement whereby a child is looked after at least overnight outside the parental home, either by decision of a judicial or administrative authority or duly accredited body, or at the initiative of the child, his/her parent(s) or primary caregivers, or spontaneously by a care provider in the absence of parents. Alternative care includes kinship care, foster care, adoption, <i>kafala</i> , supervised independent living, and residential care.
Barriers	These are factors in a person’s environment that hamper participation and create disability. For persons with disabilities, they limit access to and inclusion in society. Barriers may be attitudinal, environmental, institutional, financial or informational.

Carer/ caregiver	This could be either a family member or paid helper who regularly looks after a child, sick person, older person or person with a disability. When speaking of adults with disabilities, it is recommended to use the term “support” rather than “care,” such as personal assistant, peer support or support person.
Child	This is a person under 18 years of age, unless otherwise defined in the national legislation of a country.
Child protection system	A comprehensive system of laws, policies, procedures and practices designed to ensure the protection of children and to facilitate an effective response to allegations of child abuse, neglect, exploitation and violence.
Community-based inclusive development	An approach that brings change in the lives of people with disabilities at community level, working with and through local groups and institutions. CBID addresses challenges experienced by people with disabilities, their families and communities in practical ways. These enhance and strengthen community-based rehabilitation (CBR) as it has evolved over the last decades.
Community-based rehabilitation	Community-based rehabilitation (CBR) is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services.
Deinstitutionalization	The process of closing residential care institutions and providing alternative family-based care, community re/integration and prevention services within 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” (UNCRPD).
Discrimination	Discrimination happens when individuals or institutions unjustly deprive others of their rights and life opportunities due to stigma.
Family	Refers to those within the caring circle of a child; those providing daily emotional, physical and psychological care. This caring circle varies according to culture and circumstance; thus, the use of the term family recognizes that in many societies the care environment of a child is broader than the parents of birth or immediate family and includes the extended family, sometimes called <i>kinship network</i> . Families have primary caregivers who can be birth, extended

	relative, foster or adoptive parents, in some instances, child-, grandparent-, or single parent-headed. CTWWC further expands the term to include families who are providers of family-based alternative care, such as <i>foster family</i> .
Habilitation	This is a process aimed at helping people 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 hospital and outpatient locations.
Inclusion	Inclusion is the process of taking necessary steps to ensure that every young person is given an equal opportunity to develop socially, to learn and to enjoy community life. It is often associated with particular groups of young people: those with disabilities, from ethnic minority communities, people living with HIV, etc. It is also associated with certain regions, cities and neighborhoods.
Independent living	<p>Here a young person or adult with disabilities is supported in her/his own home, a group home, hostel, or other form of accommodation, to become independent. Support/social workers are available as needed and at planned intervals to offer assistance and support but not to provide supervision. Assistance may include timekeeping, budgeting, cooking, job seeking, counselling, vocational training and parenting.</p> <p>Independent living/living independently means that individuals with disabilities are provided with all necessary means, enabling them to exercise choice and control over their lives and make all decisions concerning their lives (see United Nations Convention on the Rights of Persons with Disabilities [UNCRPD] General Comment on Article 19: Living independently and being included in the community). For children with disabilities, this involves ensuring that (appropriate 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.</p>
Mainstreaming	This is a consistent and systematic approach to disability inclusion in all areas of operations and programming. It is a way to promote inclusion and to address the barriers that exclude persons with disabilities from the equal enjoyment of their human rights and involves supporting basic services to ensure that persons with disabilities are included and enjoy equal access.
Organizations of persons with disabilities	These are organizations comprised of a majority of persons with disabilities—at least half of their membership—and governed, led and directed by persons with disabilities. These are also sometimes referred to as Disabled People’s Organizations (DPOs).

Occupational therapy	This focuses on helping people with a physical, sensory or cognitive disability to be as independent as possible in all areas of their lives. It can help children and adults with a disability improve their cognitive, physical, sensory and motor skills and enhance their self-esteem and sense of accomplishment.
Participation	Participation is exercising the right to be listened to and to involvement in decisions and actions that affect the one participating (such as child participation) and to have those views taken into account.
Persons with disabilities	Persons with disabilities are 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.
Physiotherapy	Physiotherapy is a science-based profession that helps restore movement and function when someone is affected by injury, illness or a disability. It can also prevent deterioration and further loss of function through a maintenance program of rehabilitation based on individual treatment plans.
Reasonable accommodation	Reasonable accommodation provides necessary/appropriate modification and adjustments (not imposing a disproportionate or undue burden) to ensure that persons with disabilities have access to fundamental freedoms, enjoyment or exercise on an equal basis with all other humans.
Rehabilitation	Rehabilitation refers to regaining skills, abilities or knowledge that may have been lost or compromised as a result of acquiring a disability or due to a change in one's disability or circumstances.
Reunification	The physical reuniting of a separated child and his or her family or previous caregiver.
Reintegration	The process of a separated child making what is anticipated to be a permanent transition back to his or her immediate or extended family and the community (usually of origin), in order to receive protection and care and to find a sense of belonging and purpose in all spheres of life. Re/integration can also refer to the process of a person with disability, who has been institutionalized, making a transition back to living in the community.
Residential care	Any living arrangement/facility where salaried staff or volunteers ensure care for children living there. This includes large institutions and all other short- and long-term residential institutions including group homes, places of safety, transit centers, and orphanages.
Residential institution	A large institution is characterized by having 25 or more children living together in one building. A small institution or children's home refers to a

	building, housing 11 to 24 children. Can also refer to a facility housing adults with disabilities.
Safeguarding	The responsibility that organizations have to ensure their staff, operations, and programs do no harm to children or vulnerable adults, that is that they do not expose children or vulnerable adults to the risk of harm and abuse, and that any concerns the organization has about children’s or adult’s safety within the communities in which they work, are reported to the appropriate authorities.
Self-advocate	This is a child or individual who has the skills knowledge and support to advocate on their own behalf.
Specific requirements	Persons with disabilities require specific actions to meet the basic and universal needs common to all humans (e.g., foods, employment, health, education, communication, accessibility, assistive technology). The rights-based term recommended for use to describe the needs of persons with disabilities is “ <i>specific requirements</i> ” rather than the term “specific needs.”
Speech and language therapy	These types of therapy support children and young people who have a speech disorder (a problem with the actual production of sounds) or a language disorder (a problem understanding or putting words together to communicate ideas). They work on augmentative and alternative communication, which are the methods used to supplement or replace speech or writing for those with impairments in the production or comprehension of spoken or written language.
Stigma	Stigma refers to attitudes and beliefs that lead people to reject, avoid or fear those they perceive as being different.
Twin-track	This is an approach that combines inclusive mainstream programs with targeted interventions for persons with disabilities. It recognizes the need for providing disability-specific initiatives to support the empowerment of persons with disabilities and integrating disability-sensitive measures into the design, implementation, monitoring and evaluation of all policies and programs.
Typically developing child	This term describes a child who meets the usual developmental milestones within the usual timescales.
UNCRC	The United Nations Convention on the Rights of the Child (UNCRC) is a legally-binding international agreement and human rights instrument setting out the civil, political, economic, social and cultural rights of every child, regardless of their race, religion or abilities.
UNCRPD	The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) 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.
Universal design	This is the design of products, environments, programs and services to be usable by all people—to the greatest extent possible—without the need for adaptation or specialized design.

Additional Resources

- Christian Blind Mission (CBM): <https://www.cbm.org>
 - [Inclusion Made Easy](#)
 - [Disability Inclusive Development Toolkit](#)
 - [Humanitarian Hands-On Tool](#)
- Disability Rights International: www.driadvocacy.org
- Disability Stigma in Developing Countries by Brigitte Rohwerder, Institute of Development Studies:
<https://opendocs.ids.ac.uk/opendocs/handle/20.500.12413/13795>
- Enabling Reform: Why supporting children with disabilities must be at the heart of successful child care reform: <https://bettercarenetwork.org/library/particular-threats-to-childrens-care-and-protection/children-with-disabilities/enabling-reform-why-supporting-children-with-disabilities-must-be-at-the-heart-of-successful-child>
- Family Care for Children with Disabilities: Practical Guidance for Frontline Workers: <https://bettercarenetwork.org/library/particular-threats-to-childrens-care-and-protection/children-with-disabilities/family-care-for-children-with-disabilities-practical-guidance-for-frontline-workers-in-low-and>
- Humanity and Inclusion: www.hi-us.org
- International Disability Alliance: <http://www.internationaldisabilityalliance.org/all-countries>
- Lancet Commission Series on Institutionalization and Deinstitutionalization of Children: <https://bettercarenetwork.org/library/principles-of-good-care-practices/transforming-institutional-care/lancet-group-commission-on-the-institutionalisation-and-deinstitutionalisation-of-children>
- Light of the World. 2017. Resource Book on Disability Inclusion: https://www.light-for-the-world.org/sites/lfdw_org/files/download_files/resource_book_disability_inclusion.pdf

- Mencap, a UK-based organisation which supports people with a learning disability: www.mencap.org.uk/learning-disability-explained/communicating-people-learning-disability
- National Youth Leadership Network on Respectful Disability Language: http://www.aucd.org/docs/add/sa_summits/Language
- Opening Doors Campaign: www.openingdoors.eu
- United Nations. 2008. Convention on the Rights of Persons with Disabilities: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
- United Nations. 2020. UN Disability Inclusion Strategy: <https://www.un.org/disabilitystrategy>, https://www.un.org/en/content/disabilitystrategy/assets/documentation/UN_Disability_Inclusion_Strategy_english.pdf.
- United States Agency for International Development on disability language: https://pdf.usaid.gov/pdf_docs/Pnadh699.pdf
- World Blind Union inclusion resources and toolkits: www.worldblindunion.org/programs/accessibility/
- World Health Organization. 2010. Community-based Inclusive Development: <https://www.who.int/publications/i/item/9789241548052>
- World Health Organization on disability: www.who.int/health-topics/disability