



JUNE 2018

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Family Care for Children with Disabilities:

Practical Guidance for Frontline Workers in Low- and Middle-Income Countries



Acknowledgments

This **Family Care for Children with Disabilities: Practical Guidance for Frontline Workers in Low- and Middle-Income Countries** (hereinafter “the Guidance”) represents a collaborative effort made possible by the contributions of experts in the field of childhood disability around the world. Special thanks are extended to the children and families and to the social service workers who participated in the field testing and review process.

The development of this Guidance would not have been possible without the collaboration and commitment of Vasylyna Dybaylo and Larysa Pietushkova at Partnerships for Every Child (P4EC) Ukraine and Mona Aika at UNICEF Rwanda, who fully supported the process through their diligent facilitation of the field testing and review. We also sincerely thank Esperance Uwicyeza at the Government of Rwanda’s National Commission for Children, for her in-depth assessment and thoughtful comments on the draft Guidance.

Sincere thanks to Joanna Rogers, P4EC Consultancy Group, who provided insightful comment and suggestions as preliminary peer reviewer at each stage of development.

The wide range of views and opinions contributed by interested stakeholders was central to the process of development. Sincere appreciation is extended to Penny Parnes, Cathy Cameron, Donald Njelesani and Janet Njelesani at the International Centre for Disability and Rehabilitation at University of Toronto, *Canada*; Beth Bradford and Kelley Bunkers, Maestral, *Global*; Eileen Ihrig, CRS 4Children, *Uganda*; Jess Whitney, Safe Haven Khmer, *Cambodia*; Robert Common, Save the Children, *Cambodia*; Betsy Sherwood, *Haiti*; Chris Stubbs, MEN-CAFEP, *Sri Lanka*; Blerta Cani, Albanian Disability Rights Foundation, *Albania*; Dr. Vaska Stancheva-Popkostadinova, South-West University “Neofit-Rilski,” *Bulgaria*; Susan Sygall, Mobility International, *USA*; Damon Martin, Marie Jenny and Mia Dambach at International Social Service (ISS), *Geneva and Australia*; and Dr. Maya Thomas, Editor-in-chief, Disability, CBR & Inclusive Development, *India*. Thank you all for your consistent and reliable support.

The authors are indebted to the representatives of USAID’s Displaced Children and Orphans Fund (DCOF), to World Learning and to the members of the Review Committee for their encouragement and guidance:

Jim Crowe, European Association of Service Providers for Persons with Disabilities (EASPD)

Franz Wolfmayr, EASPD

Julie Espinoza, Center for Independent Living

Anna Darling, Lumos

Joshua Josa, USAID/E3/Education

Leah Maxson, USAID/E3/Education

John Williamson, USAID/DCOF

Thanks to Luisa Angelsmith of World Learning and Daniela Mamaliga of Partnerships for Every Child and for their oversight and management of the process for producing this guidance. Thanks also to Amy Bess, of the Global Social Services Workforce Alliance, and Florence Martin of the Better Care Network for their help in planning the workshop to launch this guidance document.

The development of this Guidance was made possible by the generous support and contribution of the American people through the United States Agency for International Development (USAID). The contents of this document are the sole responsibility of World Learning, Partnerships for Every Child, and the authors do not necessarily reflect the views of USAID or the United States Government.

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Preface

UNICEF reports that there are at least 90 million children with disabilities in the world, and that numbers may be much higher! These children are amongst those most likely to experience violation of their rights. Although most organizations involved with children express their commitment to the inclusion of children with disabilities, they often leave their specific interests out when programs for social development are being discussed and prepared.

A case management approach has been shown to improve outcomes for children and families and is widely advocated as an appropriate mechanism for effective social support. Yet, children with disabilities are often excluded from these systems and practices; the additional knowledge and skills that social service workers should have to include this group of children are inadvertently overlooked.

This Guidance is a first step to address this. It is a companion document for social service workers who use case management approaches and practices. It includes basic information about work with children with disabilities and their families and provides links to more resources which workers can access as their confidence grows.

The Guidance was developed collaboratively. The process included consultations with people who work directly and indirectly with children, including children with disabilities, all over the world. It included in-depth review during a workshop with government and non-government social service workers, as well as consultations with children with disabilities and their families in Ukraine. The National Commission for Children in Rwanda also undertook an extensive review and provided input. The final draft was reviewed by children with disabilities and their families, and social service workers in more than eight countries including Albania, Bulgaria, Cambodia, Haiti, Sri Lanka and Uganda. The Guidance is intended for use in different countries and cultures; the approaches and concepts described and the words used in the text are as up-to-date and generally accepted as is possible.

With the right information, social service workers can be more effective in improving outcomes for all children, making sure that children with disabilities have the same opportunities to grow and develop alongside their peers. This Guidance is intended to help make this happen.

Family Care for Children with Disabilities: Practical Guidance for Frontline Workers in Low- and Middle-Income Countries should be considered a work in progress that will need to be revised in the future based on experience with its use, new resources, and new developments in case management practice. To help ensure that the next version will be even stronger and more useful, please share your experience and recommendations for additions or changes at this [site](#). In general, we hope to keep any future version to a similar length, improving or updating the wording to make it more useful and including hyperlinks² to relevant resources.

List of Abbreviations

ART	Antiretroviral Treatment
CBR	Community-based Rehabilitation
CBID	Community Based Inclusive Development
CDC	Centers for Disease Control
ICF	International Classification of Functioning and Health
NGO	Non-governmental organization
SDG	Sustainable Development Goals
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

Note on Case Stories

The case stories described in this Guidance are true examples of children's experience; to preserve the children's privacy, the names have been changed and in some cases their location has been disguised.

Glossary

Alternative care	Formal or informal provision for the protection and well-being of children who are deprived of parental care.
Child	A person under 18 years of age.
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 (CBR).
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;” (UNCRC). For a more detailed commentary see Section 2.2 of this Guidance.
Family	In this Guidance, 'family' describes the immediate relatives of the child. This can include parents and siblings, as well as grandparents, uncles and aunts. The definition of family acknowledges that primary caregiver/s for the child may be extended family members.
Reintegration	The process of a separated child making what is anticipated to be a permanent transition back to his or her family and community, in order to receive protection and care and a sense of belonging and purpose in all spheres of life. ³
Residential institution	A residential institution for children is defined as a group living arrangement for more than 10 children, without parents or surrogate parents, in which care is provided by a much smaller number of paid adult carers. ⁴
Social service worker	Paid and unpaid, governmental and non-governmental professionals and paraprofessionals working to ensure the healthy development and well-being of children and families. ⁵
Social worker	Graduate of a school of social work who uses his/her knowledge and skills to provide social services for clients. ⁶
Typically developing child	Describes a child who meets the usual developmental milestones within the usual timescales.
UNCRC	The United Nations Convention on the Rights of the Child is a legally-binding international agreement and human rights instrument setting out the civil, political, economic, social and cultural rights of every child, regardless of their race, religion or abilities.
UNCRC	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. ⁷

Reference Guide for Signposts, Helpful Tips and Tables

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I Introduction

I.1 Purpose

This Guidance is a resource for people who work with children and families using a case management approach in middle-income and low-income countries.

It contains information about **how to work with children with disabilities and their families**.

Basic case management approaches should be the same for all children but there are additional and specific issues and approaches that you should know about when you work with children with disabilities. This Guidance can help you make your current case management procedures, tools and approaches inclusive of children with disabilities.

Each section includes links to further reading and additional resources.

I.2 Who is this Guidance for?

This Guidance is for people in all regions who work directly with children and families in a government, non-governmental organization (NGO) or community-based system and who have limited or no training specifically on disability. This can include such social service workers as:

- Professional social workers,
- Paraprofessional social workers,
- Primary health care workers,
- Teachers (particularly kindergarten and primary school teachers),
- Staff of residential institutions,
- Community leaders and
- Volunteer community workers.

Families caring for children with disabilities may also find the resources in this guidance useful, although it is not written explicitly for them.

You can also locate hints and tips to help service planners and managers.

Although you may work directly with children and families every day, you may have had no training, or have little experience with disability issues. When you meet a child with a disability and their^a family, you might be worried about how to support the family. You may try and avoid the child and family because you do not know what to do. This Guidance will help to fill this gap in your training and will help you to understand that children with disabilities are in most respects the same as any other children and have the same rights as all other children, but they may require more support than typically developing children. Their families may be overwhelmed, depressed and scared about the future, and you could be the first person who talks to them openly without pity or fear about their child's disability. This Guidance will help you to be that person.

When you work with a child with a disability, your job is to support them, as far as possible, to overcome difficulties in their day-to-day living which prevent them from realizing their rights. To do this, you must develop a positive way of thinking, about opportunities and not problems; you must think about strengths and not weaknesses; and you must see hope and not despair. This Guidance includes information and tools you can use to help children with disabilities and their families to avoid isolation, exclusion and the possibility of the child being placed in formal or informal alternative care. It can also help you work with children who may already be living in residential institutions and to support their reintegration back to their families and communities.

Any child who comes to the attention of social service workers, whether government, NGO or community-based, can have a disability. For example, a child living and working on the street may have been kept from going to school because they have a disability; a child may be at risk of being placed in formal or informal alternative care because they have a disability and that is causing tensions between a husband and wife. In some cases, a child with a disability can be hidden, until the family comes to the attention of the child protection system for some other reason. In these cases, it is not enough to have only case management training. It is essential to understand the additional support requirements of a child with disabilities, and to understand if and how it is possible for you to address these directly, or by arranging support from another organization.

This means thinking about how to make existing systems inclusive.

In many countries, case management is a basic part of the government approach to delivering social services. In others, it is not yet fully adopted by the government but there is some basic system of social service worker or NGO network that is functioning at the community level.

Whichever part of the system you are working in, at whatever level, you can make a difference for children with disabilities and their families by working to prevent isolation and institutionalization, and to support their inclusion in their community. If a child has already been placed into a residential institution, this can include working to reintegrate them into family care.

I.3 How to Use the Guidance

You can use this Guidance to learn more about children with disabilities and how you can support them to live in the care of their family. This can be their immediate or extended family, or a foster or adoptive family. Even if you already have some information, it is good to get to know about the full contents of this guidance so that when you need information about a particular topic you will know where to find it.

You can also use this Guidance to:

- Review and revise your existing case management regulations, guidance and standard operating procedures,
- Build the capacity of the people you work with, and
- Advocate from an informed standpoint for the rights of children with disabilities in your community.

The information is concise. If you would like to explore an issue in more depth, follow the Signposts and links in each section. The resources include links to organizations which are active in the disability sector; to documents and manuals and to short video-clips. Wherever possible the resources are available for download free. In some cases, there may be a cost.

2 Understanding Disability

2.1 The Rights of Children with Disabilities

Children with disabilities are children first. All of the provisions of the United Nations Convention on the Rights of the Child (UNCRC) apply to them. The UNCRC also makes a specific provision for children with disabilities. Article 23 says that children with disabilities have the right to live full and decent lives with dignity and, as far as possible, independence and to play an active part in the community, and that the State must do all it can to support children with disabilities and their families.

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

You can find more information about the UNCRC and the UNCRPD by following the Signposted links in the box below.

SIGNPOST

Children's Rights

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

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

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

2.2 What is a Disability?

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

The 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.

SIGNPOST

What is Disability?

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

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

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

2.3 Types of Disability

There are many types of disabilities, such as those that can limit a child's participation in an unaccommodating environment. A child may have difficulties with:

- Seeing;
- Hearing;
- Comprehension (understanding);
- Movement (mobility);
- Communicating;
- Managing their emotions;
- Social relationships; or
- Mental health.

These difficulties can affect a child's ability to:

- Use words to communicate;
- Speak clearly and be understood;
- Understand simple directions;
- Sit, crawl or walk;
- Hold or manipulate objects; or
- Use the toilet, dress or feed themselves appropriately.

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.

They may also show unusual or uncontrollable behavior. Sometimes this behavior 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 behavior is linked to an illness, injury or other physical cause.

SIGNPOST

Types of Disability

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

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

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

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

[The International Disability Alliance](#) is comprised of members of global disability organizations which can provide specific support and advice; here are the links for the [IDA member](#) organizations which include: the African Disability Forum; the Arab Organization of Persons with Disabilities; Down Syndrome International; Inclusion International; International Federation for Spina Bifida and Hydrocephalus; RIADIS – the Latin American Network of Non-governmental Organizations of Persons with Disabilities and their Families; World Federation of the Deaf; World Network of Users and Survivors of Psychiatry; ASEAN Disability Forum; European Disability Forum; International Federation of Hard of Hearing People; Pacific Disability Forum; World Blind Union; and World Federation of the Deafblind.

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

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 can both be affected.

Following the social model of disability, and because individual children develop at different rates, disability is assessed and described in terms of what a child can do

and how a child 'functions,' rather than a description of a condition. For example, each child with Down Syndrome will have capacities and difficulties in different areas.

A child's disability can be present at birth, sometimes described as a congenital disability. These can be as a result of a genetic inheritance or mutation, such as Down Syndrome. They can also be the result of environmental factors in the time before conception and during pregnancy or during birth, such as anaemia, fetal exposure to alcohol, or being deprived of oxygen during the birth (cerebral palsy).

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

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

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

Some disabilities may not be visible. This means that the disability is not immediately obvious. For example, you may not immediately know that a child is deaf if you cannot see a hearing aid. A child's learning disability may not become obvious until they begin school. As a worker who comes into contact with children and families regularly, it is very important that you consider if a child has a hidden disability which is a barrier to their full participation.

2.4 Effects of Disability

Disability affects the child, and can affect family, friends and the local community as well. It can have physical, emotional and psychological impacts. If you are working directly with children and families, you can support them to adjust to these profound changes.

Having a disability can cause a child to be thought of as different. This perception can also spread to the rest of the family. Being different can create suspicion. If someone looks different and acts differently, it can take an extra effort for you and for other people to feel comfortable with them. Thinking about the child first, and believing in what they CAN DO, is the first step in making sure that everyone believes being different is OK.

Disability can also result in abuse of the child. The child may be physically punished because of their disability; they may be shunned or neglected. As the child becomes older, they can sometimes be locked in the house or be physically restrained. This is sometimes justified by families who will say that they are trying to keep their child safe. You can help to discuss with families more appropriate ways to maintain safety. There is more information on child protection in Section 3.2.5.

Being different can result in stigma and discrimination. Sometimes cultural or religious beliefs can encourage families and communities to believe that the birth of a child with a disability is a punishment or brings 'bad luck.' This can be related to a belief that one or both parents have acted badly in the past, or that the child has been born with a disability because of an act committed in a previous incarnation. In these cases, you can discuss the rights of the child and work with the child's family and caregivers to make sure they have the same opportunities as other children in the community.

Such factors can stop children with disabilities from participating fully in the life of their community and prevent them from fulfilling their true potential. It can mean that children with

CAMILLA'S STORY

The visiting community worker liked to see the village children playing together. One day she realized that Camilla, a happy, smiling five-year-old girl, always played by herself. She asked Camilla's parents why the little girl didn't play with the other children. They told her that Camilla didn't speak, because there was something wrong with her tongue, but that none of the doctors or nurses at the local clinic could find out what was wrong. The community worker spent some time with Camilla and did some simple tests. She realized that Camilla did not speak because she could not hear. After this, Camilla had a proper hearing test and the community worker was able to show her family some different ways to communicate. The community worker also began to investigate the sign language used in her country.

disabilities are bullied by other children in their community and by adults. Their families, including their siblings, may also experience the same stigma and discrimination. This can mean that the whole family becomes isolated. You can find more information about stigma and discrimination in Section 2.4. It is important to talk about this with the child and the whole family, and then to work together to find solutions to help them to maintain their community presence and social status. This can include families of children with disabilities helping each other, individually and in family peer support groups.

With the permission of families, you can begin by helping to put caregivers in touch with each other to share their experiences, including how they have coped with the challenges.

The UNICEF easy-to-read explanation of the UNCRPD, "It's About Ability", says:

"Have you ever felt left out? Children and adults who find it difficult to see, learn, walk or hear often feel excluded. There are many barriers that can prevent them from participating in the same way as others, and most of these barriers are imposed by society. A child in a wheelchair, for example, wants to go to school, too. But he or she may not be able to do so because the school has no ramp and the principal or teachers are not supportive. For everyone to be included, we need to change existing rules, attitudes and even buildings."

The learning guidance that accompanies the explanation, also says:

"Society is composed by individuals and groups with diverse ways of functioning. Disability is part of everyone's life cycle and it can appear in different moments of life."

Keep this in mind as you read through the rest of this Guidance.

SIGNPOST

Resources on Effects of Disabilities

You can read the "It's About Ability" explanation and guides using these links:

[UNICEF \(2008\) 'It's About Ability'. An Explanation of the Convention on the Rights of Persons with Disabilities.](#)

[UNICEF 2009 "It's About Ability." Learning Guide on the Convention on the Rights of Persons with Disabilities.](#)

You will also find some more detailed information about what a disability is in section 2.1.1 of the Guidance.

You can find more information about the experience of setting up a support group for families in Central Asia in this [Experiential Paper](#).

2.5 What is the 'Social Model' of Disability?

In the past, disability was treated as a medical issue. The child was believed to be sick and, although sometimes treated with medicine or other passive methods of therapy, was often considered incurable. The child was a patient and, in many communities today, may still be seen like that. This medical model looks at what it considers is 'wrong' with the child and focuses on curing or managing the disability.

During the 1980s, the Community-based Rehabilitation (CBR) movement started to question the medical focus and suggested that it was society that was putting the barriers in place for children with disabilities, and that it was these barriers which prevented them from being involved in their

SETTING UP A SUPPORT GROUP IN CENTRAL ASIA

One NGO described their experience of helping to establish a family support group. When they first suggested that families meet to talk about their experience, the families were afraid that the authorities would punish them for speaking out. The NGO worked with the families over several years to support them, to give them information, and to provide training in how to care for their children. The families became more confident and now they are regularly seen on television, organizing cultural events for all children together and voicing their concerns in Parliament. They have become a powerful lobby group for children with disabilities. See the link in the Signpost, above, about organizing a support group for families.

communities like other children. This social model looks at how society is organized and focuses on making changes which increase opportunities and choices for children with disabilities. For example, not everyone can grasp a door with a round handle, but, if a lever-type handle is attached, it is much easier for everyone to open the door. This is an example of inclusive thinking to remove a barrier which stops everyone from being involved.

Like all children, a child with a disability may also require medical treatment for specific medical conditions and should have equal access to medical care.

There is a current movement to replace the term CBR with Community Based Inclusive Development (CBID) because it describes the approach more positively. You can find out more about CBR/CBID by accessing the links in the Signpost on page 13.

Equally, consider a child with a disability who has difficulties with walking, who uses a wheelchair and is being educated at home. In the medical model, the child learns at home because he has a disability and cannot walk. In the social model, the child learns at home because the school is not accessible for children with mobility difficulties or who use a wheelchair. The social model changes the focus from the difficulty the child has with walking to the barriers which stop his inclusion.

The social model is linked to the rights-based model which focuses on the humanity of children with disabilities and their rights. Rights are indivisible and universal and therefore children with disabilities should be included in mainstream systems of development to prevent discrimination and exclusion. The table below shows several scenarios and how they are handled under the different models.⁹

Table 1: Scenarios for Including Children with Disabilities in Mainstream Systems of Development

Situation	Medical model	Social model	Rights-based model
Adolescent girl using a wheelchair	This girl should go to a doctor and discuss with him if there is a therapy which could help her to walk like everyone else.	The community is building ramps in front of public buildings so that children like her can participate in social and community life.	When she gets a job, this girl's employer will have to make sure the office is accessible. This is her right!
Boy with an intellectual disability	He should live in a residential institution where he can have the treatment he needs from specialist doctors.	It's great he can live with his brother who helps him go to school with all the other children in the block.	Where does he want to live? Let's ask him!
Parents whose daughter is hearing impaired	I'm sure in a few years there'll be a hearing aid available which will help your daughter hear better.	We should all learn sign language, so that we can communicate with your daughter and all other hearing-impaired people.	When your daughter grows up, she'll study at university, if she wants to.

SIGNPOST

Models and Approaches

You can find out more about the medical model and social model of disability in [The World Report on Disability](#) page 3, published in 2011 by the World Health Organization.

The World Health Organization has published guidelines and tools for [Community-based Rehabilitation](#). They are available in different languages – English, French, Chinese, Spanish, Russian, Arabic, Thai, Korean, Tajik, Vietnamese and Uzbek.

The UK organization [Scope](#) has prepared this informational video.

Other short video clips explaining the difference between the social model and the medical model of disability can be found [here](#) and [here](#).

The [International Disability Alliance](#) is a good place to start if you would like to locate disabled people's organizations in your country.

The [HI Federation](#) implements programs in the field in around 60 countries through its eight national associations known as known as "Handicap International" or "Humanity & Inclusion," depending on the country.

2.6 Overcoming Stigma and Discrimination

As well as the medical and social model, 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. Sometimes the child and their family can experience stigma and discrimination.

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

Discrimination happens when individuals or institutions unjustly deprive others of their rights and life opportunities due to stigma.

This lack of understanding can have serious consequences for people with a disability and their families.

Attitudes and beliefs can be shaped by context, culture and religion. For example, in some countries and communities sometimes people can think that the family of a child with a disability is being punished for some earlier 'bad behavior,' or that having a disability is a person's bad karma. Sometimes the caregivers feel that the good karma they earn from caring for a child with disability has great value for their own future.

In other countries there can be a belief that people with a disability live permanently in a state of childhood, and so they are not given the opportunities to learn and grow up like their peers and be considered as adults. They are not thought of as people who can live independent lives.

Such attitudes and beliefs can interfere with the rights of children with disabilities.

You can think about the beliefs in your country and community, and whether they support the rights of children with disabilities. Talk about this with your friends and family and with the people you work with. They may have a personal experience which you can discuss.

The words we use are also important. They can reinforce stereotypes, stigma and discrimination. 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 that have been created by society.

Sometimes the words used to describe people with a disability can also be used as terms of abuse.

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

You can spend some time thinking about and discussing this with your friends and family. What words do you use in your country to describe disability? Are these words positive or negative? It is also 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.

2.7 Community Engagement

Lack of care for children with disabilities can be related to ignorance about the child's potential, or a lack of services available, or both. By engaging with the whole community, you can help to break down these barriers which contribute to children's exclusion.

The active involvement of all citizens is important so that children's right to be included is realized. Inclusive local communities with strong social networks bring rewards for the whole community. For example, a fully inclusive school offers improved opportunities for all students because of improved infrastructure. Making sure that everyone understands the rights and needs of children with disabilities, including community leaders, religious authorities, as well as voluntary groups, non-governmental organizations and local government authorities, makes change for the better more likely to happen and more likely to be sustained.

HELPFUL TIPS FOR POLICYMAKERS AND PLANNERS

Building Awareness

You can begin a conversation about disability in your workplace and community. You can start a campaign together with people with a disability in your community to make sure that the rights of children with a disability are understood.

Here are some examples of campaigns and public service announcements:

This clip from Azerbaijan shows how the [infrastructure](#) can affect the rights of people with disabilities.

In Jordan, people with disabilities developed their own [public service announcements](#).

This website has stories and video clips about learning disability (sometimes called intellectual disability). The campaign is called [Here I Am](#).

In Mozambique, this short-clip is about "[making the world better for kids with disabilities](#)."

SIGNPOST

Tools for Influencing Communities

[ADD International](#) partners with organizations of disability activists in Africa and Asia. They have lots of resources on their website, including these on [stigma and discrimination](#).

If you are looking for information about working with children and families in faith-based communities, the [Faith to Action Initiative](#) has many resources, including this [family care toolkit](#) which includes specific [resources for working with children with disabilities](#).

This toolkit was developed for the New Zealand context but it has some helpful and practical exercises for [overcoming stigma and discrimination](#) which everyone can use.

This book, commissioned by Mencap in the UK, is about [changing attitudes toward learning disability](#) – sometimes called intellectual disability.

You can find out more about culture, beliefs and disability and how it affects people in this United Nations [toolkit](#).

The [Open University Activity – Changing Labels](#) includes resources and materials to help you to consider how the words we use affect our perceptions of disability.

The Oxford English Dictionary also has an informative section on [the language of disability](#).

USAID has published [Disability Communication Tips](#).

For even more information, the National Center on Disability and Journalism has a style guide [here](#).

2.8 Why is Data Important?

You may be wondering why you need special Guidance, since there seem to be so few children with disabilities in the area where you work. Often this is because children with disabilities are hidden — they stay at home and no one outside the family sees them. This can be because it is difficult to move around, because the family is ashamed or because they want to protect the child from people who may stare and say unkind things. When asked about their child's disability, families may answer that their child does not have a disability, even if they do. Some families are too poor to travel to the department which is responsible for registering a child's disability. In some cases, local government officials tell the family that there is no need to register the birth — which later means that the child may not be able to access certain services, benefits or rights. This can result in children with disabilities being invisible and therefore governments have no data (evidence) to develop policies. **When they are not included in data collection and reporting, children and adults with disabilities are often left out of government planning.** The first step to being counted is when a child receives a birth certificate.

We do know that the average number is about the same in every country — there are approximately the same number of people (as a percentage of the population) with a disability in Germany and in Ghana, in Japan and Jamaica, and in Tanzania and Thailand. The 2011 [World Health Organization World Report on Disability](#) tells us that approximately “15 percent of the world's population lives with some form of disability” and that approximately 5 percent of children have a disability. This means that in your country, more than one in every 10 people probably has a disability.

In some countries figures are not available because disability is not included in usual administrative data collected by government, or because only children with a visible difficulty are counted, or because children with disabilities are hidden. Where there are high levels of poverty, the rate of disability may be far higher than the average. This can mean that children with disabilities are forgotten or left out when services are being planned and implemented. However, now that you are aware that children with disabilities live in every community, you can encourage families to talk about their child with you and you can be the person who begins to make sure that all children are included in community life.

HELPFUL TIPS FOR POLICYMAKERS AND PLANNERS

Data Collection

You can find out more about collecting data on children with disabilities in your country by asking the appropriate local government department that deals with information and planning.

The [Washington Group/UNICEF Module on Child Functioning](#) has been developed to produce data on disability that can be compared across countries by measuring child functioning.

BOREY'S STORY

Kosai is a nurse who visits children and their families in a village in Cambodia. He had been visiting Borey's family for two years before he heard that a three-year-old boy was a member of the family. Borey's family had kept him hidden because he had a disability. Kosai was surprised and pleased to meet Borey. He learned that his parents had not registered his birth. They said he did not need a birth certificate because they did not think he would be able to go to school. When Kosai heard about this, he encouraged Borey's family to get a birth certificate because it is his right, because it is important that he is counted and because the birth certificate will be useful in his future life.

3 Case Management

“Case management is 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.”

Source: Global Social Service Workforce Alliance (2018)
[Core Concepts and Principles of Effective Case Management: Approaches for The Social Service Workforce.](#)

All case management processes follow similar basic stages:

- Identification of the child and family;
- Assessment of the child’s situation;
- Development and implementation of an individual plan, such as referral to rehabilitation services, advocacy with the education department for the child to be included in school, plan to initiate family reunification if the child is in a residential institution, referral to the government department for cash and in-kind benefits, etc.;
- Monitoring child and family well-being, checking the progress of the plan and making changes if necessary; and
- Closing the case, if the goals of the plan have been achieved.

For many countries with limited resources and few experienced workers, it will be important to improvise to make sure that the basic case management approach includes children with disabilities and pays attention to the additional support they might require. You may think that it is not your responsibility to work with these children and families, and that it is the responsibility of other services. However, you are the link between a child or family and the services they require. You may be the only person who tells a family that their child has potential, after years of listening to doctors or other professionals telling them the opposite.

You will need to think about:

- What skills are needed to assess the support requirements of children with disabilities;
- What services are available for children with disabilities, including agencies or centers which support independent living;

- How society views children with disabilities and the impact attitudes, beliefs, stereotypes have on these children's lives; and
- If there is a collaborative approach in your community to make sure education, health, social and other services work together.

This Guidance is designed to follow the typical case management process and help you to provide the support children with disabilities and their families need to realize their rights.

SIGNPOST

Case Management Resources

Your government or organization may have specific regulations and standard operating procedures for its case management work. If you are interested in examples of tools and forms, training materials and other resources on case management, the Global Social Service Workforce Alliance has put together a compendium of resources from around the world which you can access [here](#).

International Social Service (ISS) has developed a case management manual for professionals for promoting family life for children with disabilities in residential care, [A Better Future is Possible](#). The manual is available in English, French and Spanish.

3.1 Identification

In some countries, children with disabilities are part of their communities and are very visible. In these cases, it is possible for you to have a conversation with the child’s family or primary caregiver about how to support the child to achieve their potential and realize their rights. **In some countries and communities, it is more difficult to know where children with disabilities live because they are not a visible part of their community.** To begin to locate these children, you should be sensitive the stigma and discrimination which may exist in your local context.

3.1.1 FINDING CHILDREN WITH DISABILITIES IN YOUR COMMUNITY

You can begin to talk about disability with your community leaders, friends, family and colleagues. Involving existing community structures which are close to families — for example, community health workers, home visiting nursing service and community child protection case management workers can be effective in locating children with disabilities who may benefit from your support. You can also talk about these issues with the families you meet in your day-to-day work. If you know a family whose child has a disability, ask them if they know any other families who might need support. In this way you can let people know that you understand the issues and that you have the skills to help.

If the child's disability is known immediately after birth, this is a critical time for intervention and support. Starting intervention as early as possible is the best way to support the development of children with a disability. This can include referring the child and family for services where they can receive therapies, for example physiotherapy (to help with motor skills like balance, sitting, crawling and walking), speech therapy (to help with help with speech, language, eating and drinking skills), occupational therapy (to help with learning daily living skills), and counselling (to help restore emotional well-being).

You can also:

- Contact maternity departments to discuss how they advise mothers of babies after difficult births or if a child has been born with an obvious disability;
- Contact your local health department to inquire about lists of children who have been identified with a disability;

- Contact social welfare departments to inquire about lists of children who are receiving disability benefits;
- Contact community leaders who will know what is happening in their locality;
- Find out if there are NGOs and faith-based organizations who can assist; and
- Find out if there are local disabled persons' organizations in your area that can provide support.

You should think carefully when speaking to families about their child — sometimes families who are asked 'does your child have a disability?' or 'do you have a child with a disability?' will say "no" to these questions. They may be keeping their children hidden because of the stigma, or they may not have noticed or accepted that their child has some developmental delays. You can work with the family to build up a relationship, by discussing the needs of other children before you address the issues of their child with a disability.

You may know a person with a disability in your community who can go with you when you are visiting a family. This person will often know more about the available resources and may be a good role model.

Once you know who the children are, you can begin contacting their families and caregivers. In some countries, many children on the lists of those receiving disability benefits may not exist or may not even have a disability, so home visiting is important. At the end of a home visit, inquire if the family knows any other children in the area who have a disability. This often results in more families of children with disabilities starting to come forward through word-of-mouth, because someone is giving attention to them.

JERRY'S STORY

Jerry, an 11-year-old boy living with his grandmother in Zimbabwe, could not walk because his legs were paralyzed. He was too big for his grandmother to carry and so stayed home every day. He was very lonely and had no education. Margaret, the village community case management worker, heard about Jerry when his grandmother came to ask if there was any financial help for children orphaned by HIV. Margaret began to visit the house when she could. She arranged for some of the local children to come and play with Jerry, so he wasn't alone so often. Eventually she was able to find a wheelchair for him, so the local children could take turns in helping him to get to school. When other families heard about this, they came to speak to Margaret to find out if she could also help with their children who had a disability. Through word-of-mouth, children who had been hidden, slowly became part of the community.

3.1.2 HOW TO TALK TO FAMILIES AND CAREGIVERS ABOUT THEIR CHILD WITH A DISABILITY

Becoming the parent or primary caregiver of a child with a disability is a unique experience. Parents and family members will each have different and individual feelings. They may not fully understand the situation, they may be angry or scared, or they may feel overwhelmed. What they need is the right support.

It may take many meetings before the families listen to you, understand you and come to believe you. Keep emphasizing the positive aspects of their children and their connection as a family.

It's useful to remember that life changes come to everyone, and they:

- Can be welcome and anticipated, or unwelcome and unexpected;
- May throw people off balance, perhaps momentarily or for longer periods;
- Can create upset, uncertainty or confusion;
- May make people struggle to adapt and cope;
- Are not the same so people will react and feel differently about the same situation; and
- May make people emerge stronger — or feeling hopeless.

Each person in the family will cope with the change differently. It is important for each family member to accept his or her own range of feelings. It may take many years for families to adapt to the loss of the child they had anticipated.

Finding out that their child has a **disability may involve many additional practical demands on the family resources, and often there will be little time to allow for grieving.**

Often people find it difficult to grieve when there are so many practical tasks to be undertaken. Let families know that it is normal to grieve, that they need to go through this stage.

The stages of grief they may experience include:

- Shock and denial;
- Pain and guilt;
- Anger and bargaining; and
- Depression, reflection and loneliness.

Without support, families can get stuck at these negative stages, and revisit the guilt and anger over and over again. This will affect their care of their children, so you must try to

understand their feelings and help them to move toward the final stage of acceptance and hope.

Avoid saying to a family that you know how they feel – unless you are a family member of a child with disabilities yourself. It is all right to tell families that you may not know how they feel, but that you are there to help in any way you can. Encourage them to contact you once they have had time to take in the information about their child's disability.

Sometimes you may not need to say anything. It can be enough to just be with the person and offer a physical sign of caring or understanding. For example, if you feel comfortable, and it is culturally appropriate, you can hold a mother's hand, or put your arm around her shoulders.

When you are talking to families, you need to use active listening skills. **Active listening skills are among the most important skills that you need** to deal with other people's emotions. It will help to build trust, reduce any misunderstandings and help family members and caregivers to open up. More information about active listening is included in the Signpost on the following page.

Families and caregivers should be encouraged to talk. Here are some examples to help you get started:

- "Tell me about the changes this is having on your family life";
- "Let's talk about the other children in the family and their reactions, both good and bad – how is Mia doing, is she playing with the baby yet?";
- "How are you coping on a day-to-day basis?", "What are the most difficult parts of the day for you?";
- "The future may not be as you imagined, but it will bring joys you may not have expected. Let's talk about what the future may hold"; and
- "How else is this changing your lifestyle? Let's think about how you can manage these changes."

To be a good listener, you need to focus on and practice being empathetic, non-judgmental, and genuine.

Empathy and empathetic understanding is:

- The ability to enter into another person's world and to see things as they see them and feel things as they feel them; and
- Not the same as sympathy, which is feeling sorry for someone.

Empathy can help families to feel valued and understood.

A non-judgmental approach is essential if you are to be effective. You may not like the attitudes or behavior of the family members or caregivers you are working with, but that does not mean they do not deserve your support. Focus on the situation and the stress that it is creating. Families often blame themselves for the disability, and feel that they have done something wrong to cause it. If you are judgmental, you may reinforce those feelings and then it will be very hard to build any relationship with the family. It may also mean that the families have difficulty in forming a loving bond with their child.

People generally feel more defensive if they think they are going to be criticized. Through being non-judgmental we will reduce defensive behavior and encourage trust. Showing warmth and respect will overcome defensiveness.

Genuineness refers to the ability to be open and sincere. It implies openness in the acknowledgment and expression of other's feelings and attitudes. You can show this characteristic by being straightforward and acknowledging your own strengths and weaknesses.

You should be aware of your body movement. This will provide you with clues about your own feelings and how you are responding to what the family member is saying. A natural tendency to slouch may convey boredom and disinterest to the family. A forward movement may be encouraging, and a firm nod can be affirming. Body language can also have different meanings in different cultural contexts; you can discuss this with your colleagues to explore this topic as it relates to the culture in which you are working.

Your **body posture, tone of voice, facial expression, and eye contact** are the non-verbal forms of communication that support your listening skills. The willingness to be fully present for the family can be expressed by an open body posture, rather than crossing your arms across your body, for example. Be relaxed, smile, have eye contact and touch someone's arm if you think it will be acceptable.

Try practicing with a family member, friend or colleague. You can make a short video so that you can be more aware of how others see you.

Silence is the most important non-verbal skill of all. Silence can speak volumes at the right moment. It is important to allow others the space and time to experience their deeper feelings. If a family member is speaking, let them finish and pause before you speak. Let them breathe and reflect on what they have said, especially if it is very emotional.

Ask yourself:

- Is the family member pausing as they work through an idea?
- Are they experiencing a feeling, and do they need space for this?
- Are they coming to a difficult or embarrassing part in the story, and do they need time to find the words or the courage to share it?
- Has the family member simply finished what they want to say, and is waiting for a response?

Allowing a longer silence than is usual in everyday conversation may feel uncomfortable at first. However, it is surprising that by giving the family member just a few more seconds before you speak, they may be able to share something else with you. So, when in doubt, hold back and stay silent!

SIGNPOST

Active Listening

This [video resource](#) describes six tips for active listening.

3.1.3 HOW TO TALK TO A CHILD WITH A DISABILITY

Many people with a disability mention the 'golden rule' – treat others as you would like to be treated. When talking to a child with a disability, remember that you are interacting with a child, and keep the same tone and language as you would with any child of a similar age.

Try particularly not to speak about the child as if they are not in the room. Many people make the mistake of talking in front of a child with a disability about them, as if they cannot understand or do not have the same feelings as any other child. They do! Be empathetic, warm and genuine and appreciate that they have a valuable perspective too.

If the child cannot hear, it is important that you don't walk around or move your head while talking with the child. Make sure you are looking at them when you speak, and make sure they are looking at you and can see your face and mouth. Use gestures where appropriate; for example, you can mime holding a glass and drinking when asking the child if they would like a drink. You can ask if there is anyone in the family who can help to interpret for you or find out if there is a person in the local community who uses sign language and who can

assist. You should be thoughtful in using whatever communication aids you have. You can draw a picture to describe something, or for a child who can read, write things down.

If you are speaking to a child with an intellectual disability, you can first talk to their family for advice on the best methods of communicating, and the child's family may also be able to help with interpreting the child's movements or sounds if they cannot speak. You should use all of the guidance above and make sure that you do not speak to the child in a way which makes you appear superior.

Always speak clearly, using short sentences. Use the child's name so they know you are talking to them. It is very important to respond to the child's attempts to communicate, so they understand the effectiveness and importance of communication. If a child points to an object of interest, you can point to it and clearly name it to indicate that you have understood and are listening.

Remember to introduce yourself. This is important when speaking to any child, but is especially important when speaking to a child who has difficulties in seeing. This lets them know you are there and helps them to locate your position in the room.

You can also talk to adults with a disability in your community and ask them for their advice. This can involve finding out if there are any disabled people's organizations so that you can get to know them and ask for their support when you need it.

SIGNPOST

Children's Voices

This Plan International [video resource](#) from Sierra Leone included children with disabilities talking about their experience and rights.

In this [video resource](#), adolescents from the United States are speaking out to say they need education, jobs and opportunities, just like anybody else.

3.1.4 HOW TO TALK TO SIBLINGS (SISTERS AND BROTHERS) OF A CHILD WITH A DISABILITY

Siblings are often overlooked and sidelined, when the child with a disability requires so much of the families' attention and effort. They may also be asked to help as the child's carer, which can lead to resentment if they become overburdened. Take time to listen to the child's brothers and sisters,

be honest with them about the situation and the future and understand that they may be angry and upset too, as they come to terms with their sibling's disability. They may well be working through the same stages of grief. Help them to move forward to acceptance and hope. You may also need to be an intermediary between the siblings of a child with a disability and their family. You can encourage everyone in the family to think about what is reasonable for each individual to do to support the child with a disability. This may mean that siblings sometimes invite their brother or sister with a disability to join them and their friends for play, but also have time to play separately. Negotiating these new roles is something that you can help families with.

3.1.5 CHILDREN IN RESIDENTIAL INSTITUTIONS

3.1.5.1 Effects on the child

Around the world, most children live at home with family members who love them and give them lots of attention. This family support helps children to learn, grow and develop. Decades of research and practical experience have shown that children need the opportunity to grow up in a family environment in order to develop fully their emotional, social and psychological capacities. However, families sometimes seek other ways for their child with a disability to be looked after. This can be because they are poor and cannot afford additional costs associated with looking after their child, because they are advised that the child will be a 'burden' to the family or can be better looked after in a residential institution, or due to practical and emotional challenges of meeting the support requirements of a child with a disability. For example, getting around with a child who has a physical disability or managing unusual behavior may be difficult for families and caregivers. Sometimes this can mean asking for help from members of the extended family. Other family members may be able to help with costs or with taking care of the child if their families cannot.

In some countries, families are advised that their children can be best looked after in residential institutions. Sometimes these are called orphanages, even though the children typically have at least one living parent. These **residential institutions can be harmful because they isolate children from their families and communities and because the care and attention which children need to develop is often lacking.** All children need to develop all their senses – sight, touch, smell, taste and hearing. Each sense gives us information about our environment. Children living in residential institutional care sometimes do not have the same sensory opportunities as other children to learn about the world around them.

There have also been reports that children living in residential institutions can be more at risk of violence, abuse and neglect.

All children must have love and attention to develop and grow. Because the natural development of a child with a disability can be slower than a typically developing child, they may require more individual attention. Children who are placed in a residential institution because they have a disability do not have the same opportunities to learn, grow and develop because they do not get this individual attention consistently. They also miss the opportunities to learn social and practical skills that children gain through living in a family and community environment. For example, children growing up in a family are often shy with strangers, but children in a residential institution typically run to visitors, wanting physical contact and attention. This is due to their lack of opportunity to form an ongoing attachment to a specific adult and is not typical behavior for a child. It can put their safety at risk.

Research shows that a typically developing child who grows up in residential institutional care can also acquire a disability, or a child with a disability can become even more disabled by the limited opportunities to form an attachment and regularly interact with a specific adult caregiver and because they are isolated and lack stimulation.¹⁰ In some institutions, children are physically restrained, which is harmful and an abuse of their rights.

In some countries, families can be given inaccurate information about their child and what is best for them. Doctors, nurses or others can tell families that a child with a disability can be

better looked after in a residential institution. In this case, you can talk to them about the UNCRC, the most widely ratified human rights treaty in the world, which says that children should grow up in a family environment.

If there are children living in a residential institution in your community, as a first step, you can think about how to support those children to have improved opportunities for learning, development and contact with their families, and to be included in their local communities. Then you can make plans for individual children who may be able to go home to their families or to other family-type care, as discussed in the following section.

SIGNPOST

Institutionalization Effects and Children's Rights

Lumos has gathered [children's stories](#) about their experience of living in residential institutions and the difference for them when they moved to family-type care.

You can check on the ratification status of your country to the [UNCRC](#) and [UNCPRD](#).

TURAL'S STORY

Four-year-old Tural has difficulty with mobility and speech and cannot feed or dress himself or use the toilet independently. His parents were finding it increasingly difficult to cope with caring for him. Tural's dad was also unemployed, so there was not much money in the household. All of this made Tural's parents argue and fight. They decided it would be better if he was placed in a residential institution.

By chance, a social service worker happened to meet the parents when they brought their son to the institution; she explained the effects that institutionalization would have on Tural, and offered to visit the family at home, to teach them how to care for their son and develop his skills at home. However, the parents were determined to leave Tural in the institution.

After a few days, the parents returned and saw that Tural was very unhappy. They took him home immediately and called the social service worker who then started to visit the family every month, helping them to teach Tural to feed and dress himself, and how to go to the toilet independently.

Tural's mother spread the word about this help, and more families asked for help. There is now a team of five social service workers working with more than 100 children every month.

With ongoing support, Tural started going to kindergarten with his brother. With lower levels of stress at home, his father was able to find and keep a job, and the family is now a strong unit again.

3.1.5.2 Support for reintegration to family care

As a social service worker, you can support families to look after their child with a disability at home. You may already be involved in helping children in residential institutions to return to family care. All too often, children with disabilities are left out of family reunification and reintegration programming, and you can help to ensure that they are included. You can work with the child and family to support their moving home, and the guidance in this document is intended to help you do that. In some countries, workers have found that families are very happy to have their child with a disability come home when the correct supports for the child and the family are in place.

Supporting any child's reunification and the process of reintegration into their own family requires careful planning. Reintegration is achieved by a child and their family together. You can support this process by working with the child, the child's family and community, and the staff of the residential institution to develop a case plan so that the child can move home. There can be particular challenges in supporting the reintegration of a child with disabilities who has lived in a residential institution:

Staff resistance – the staff in the residential institution may be reluctant to work with you to return children home because it means their lives will change too, and that scares them. They may also be concerned that the child will not receive proper care if they leave the residential institution. You should be sensitive to their fears and talk them through the process; you can talk about what a child gains by living in a family, and how the staff have skills and experience that can be redirected to support children and families in their communities. Avoid talking to them as if they are wrong; it will just create more resistance. Be understanding and listen to them, but be firm about the rights and needs of the children. Some staff will truly believe that the institution is better for a child with disabilities, that they can look after the child better than the family. They may have accepted this belief without ever having really thought about it or discussed it. There is plenty of information in this Guidance to help you have a meaningful discussion with the staff to begin the process of changing attitudes. A key point for such a discussion is that every child needs and learns from the experience of being part of a family, and this is every bit as true for children with disabilities as for other children. As noted above, "Children with disabilities are children first."

Hostile environment – in some countries, institutions are large-scale employers and policymakers may be reluctant to adopt a policy of reintegration because they fear public outcry over job losses. This may be an excuse to avoid change, but it can create great challenges for implementing social welfare reforms. Experience in countries which have made a policy decision to move from a system of residential institutions to community-based family care and alternative family care shows that the short-term disruption can have longer-lasting positive effects for everyone involved.

Family concerns – families may have placed their child in an institution because of the lack of support in their family or community, or because they believed that the child would have all their needs met by the institution. It may take some time to help them overcome these fears or misguided beliefs and rebuild the connection between the child and family.

You can begin by developing warm but professional relationships with the child and all of the people who are involved in their life. The case plan will include efforts to re-build the relationship between the child and their family who may have been separated for some time. You may also have to work hard with the staff of the residential institution to persuade them that reintegration is in the child's best interests.

"Reintegration is not a single event, but a longer process involving extensive preparation and follow-up support. Adequate time should be devoted to each stage in the process to allow reintegration to happen at a pace that suits the needs of each child and their family."

Source: Guidelines on Children's Reintegration, Inter-agency group on children's reintegration.

This means that through the case management process you can make sure there is enough support for the child and family in their local community.

You may need to think about the services and support the child will need to enable them to move home. This can include assistive aids and devices (for example, a wheelchair). It might include negotiating with the local school to make sure there is a place for the child and support for them to attend. You may want to discuss with the family how they can adapt their home to meet the needs of the child. This planning can be done jointly with the child, their family and the staff of the residential institution. After the child has moved home, you should plan to be in regular contact with the family. This can be an

emotional time, and they may need to ask questions or share their worries. Make frequent follow-up visits for the first few months so that they feel supported and help them find groups or services in their area, such as other families of children with disabilities or local NGOs. Be aware that the parents might

feel a lot of guilt for having 'abandoned' their child, and the child may have anger toward their parents as well as happiness to be back at home. This may be one of the most challenging types of cases to work on, so plan well. There are very useful resources in the Signpost below to help you.

SIGNPOST

Tools to Support Children's Reintegration

The Better Care Network has an extensive library of resources about [the effects of residential institutions on children](#).

The [Guidelines on Children's Reintegration](#) were written by a core group of 14 global agencies involved in children's care. These guidelines take a child right's approach. These guidelines set out guiding principles, along with assessments and plan development models. With these guidelines, care professionals can develop successful **plans for reintegration with families, communities and schools**.

International Social Service (ISS) has published a manual [A Better Future is Possible: Promoting Family Life for Children with Disabilities in Residential Care – Manual for Professionals](#) that provides **guidance to professionals who work with children with disabilities in residential institutions**. It includes methods for interventions for professionals in direct contact with children with disabilities

in residential care. It provides guidance for developing individual and short-term care plans, as well as for child assessment. The manual also provides guidance on preparation of the child and family for a return to family life, recommendations for governments on reintegration, and advice on adoption and foster care for children with disabilities.

Standard operating procedures for **reintegration of children living on the street** are available from [Retrak](#); these include specific guidance for a child who has an illness or a disability.

In the Committee on the Rights of Persons with Disabilities' [General Comment No. 5 \(2017\) on living independently and being included in the community](#), paragraphs 11, 12, 16 (c), 37, 67, 70, and 87 clarify the responsibilities that States have undertaken by ratifying the UNCRPD.

NURLANA'S STORY

Nurlana is a 6-year-old girl in Azerbaijan who was born without sight. When her family found that she could not see, they thought it was a punishment and were scared that their neighbors would condemn them. But Nurlana's grandmother, who had slowly lost her sight five years before, encouraged the family to take care of their daughter.

The health worker came and suggested they give the baby a lot of stimulation in hearing, feeling and smelling things, to make up for what she could not see.

The family took her advice. They put all kinds of things in Nurlana's hands and told her what they were. They gave her bells and squeakers, and cans and bottles to bang on. They played games and sang to her. As Nurlana grew older, the health worker talked with the neighbors, and their children. A few children came to make friends and play with Nurlana.

When she was six, Nurlana started school. The children from the neighborhood came for her every day. When the people saw them, all walking down the road together, it was hard to guess which one could not see.

Another little girl from the same village was placed in residential institutional care the year before Nurlana was born. Leyla could not see either, but her parents kept her hidden and the health worker could not advise them. The staff in the residential institution thought that because she could not see, she could not learn. She spent most of her time alone. Leyla is now seven years old, she does not speak, or go to school, and has no friends.

3.1.5.3 Support for family-based alternative care

For children who cannot return to their own family or be assisted to live with members of their extended family, family-based alternative care can be an option (instead of residential institutions). This includes adoption in the country where the child was born, international adoption, foster care or 'Kafala' of Islamic law. You can refer to your national policy and legislation for guidance on alternative care.

Finding alternative families for children with disabilities can be challenging. 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 programs 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 programs at the out-set 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.

SIGNPOST

Alternative Care Guidance and Resources

The UN [Guidelines for the Alternative Care of Children](#) are intended to enhance implementation of the UNCRC for children deprived of parental care or at risk of being so.

There is also a [Manual](#) for implementing the guidelines.

The [Better Care Network](#) has a lot of resources related to alternative care, as well as on [adoption and Kafala law](#).

3.2 Assessment

Once you have identified a child with a disability or suspected disability, you will do an assessment of their strengths and needs, in the same way you would for any child and family who comes to your attention. This means collecting information, then analyzing and discussing with the child and their family to find out what support could help and can be provided. There are many different types and levels of assessment for children and families and there are also targeted assessments for children with disabilities.

During this process you may use:

- The standard assessment tools for children and families which are part of your current case management system. This will include the assessment of the families' living conditions and child-family relationships; or
- Checklists specifically developed to quickly assess developmental delay in children. These resources are Signposted on the following pages.

During this assessment process, you should make sure that you have addressed all of the child's support requirements by making sure that you have involved everyone. This can mean talking with health care providers, schools or any other relevant people who are involved or whom you think should be involved in the child's life.

Involving everyone includes the child with a disability. Make sure that you ask them about their feelings, interests and opinions. Spend time with the child, talking and observing to find out about their strengths as well as any difficulties they experience.

3.2.1 INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF)

In 2001, the World Health Organization (WHO) published the International Classification of Functioning, Disability and Health (ICF), which includes the following description:

*“Information about **functioning and disability** is essential for statistical use, health and social policy, advocacy and clinical use. Increasingly, countries are adding data about human functioning to health statistics. Outside of health; in employment, education and community life generally, it is becoming more obvious that sound policy depends on information about disability and human functioning. However **good statistics depend on standards**, and in today’s interlinking information systems, there is a clear need for data harmonization for comparability and ease of access. The ICF is the internationally agreed standard.”*

Source: The World Health Organization ICF e-Learning Course

This is a common framework for the assessment of disability in clinical and research contexts. It considers the factors that affect a person with a disability. In 2007, the ICF was further developed for children and youth. The people who use ICF to assess disability are trained medical and social sector professionals, such as paediatricians, speech therapists, physiotherapists, psychologists and social workers, who work together to complete the complex assessment. In some countries, governments use ICF to assess if a child or adult is eligible for disability-related benefits. The ICF considers a range of factors associated with disability:

- Activity
- Participation
- Body Structures
- Body Functions
- Personal Factors
- Health Conditions
- Activity Limitations
- Functional Limitations
- Environmental Factors
- Participation Restrictions

As a social service worker, it is useful that you know about the ICF because it is the international standard promoted by WHO. If your government has adopted ICF, they will provide training for the multi-disciplinary teams who will use it. You should not try to use ICF without training because there is a risk you can cause harm to the person being assessed. The ICF can also be useful for planners when developing national standard operating procedures for disability assessment and for designing national data collection systems.

HELPFUL TIPS FOR POLICYMAKERS AND PLANNERS

ICF Tools

If you have limited experience, the [ICF eLearning Tool](#) can help you understand the ICF model and classification terms. Furthermore, this course will help you learn how to apply and use the ICF in practice.

The [ICF Practical Manual](#) is another good place to learn more. It provides information on:

- Getting started with the ICF;
- How the ICF is used to describe functioning;
- How it can be used in clinical practice and for the education of health professionals;
- How it can be used to plan for community support services and income support;
- For population-based, census or survey data;
- For developing or adapting education systems;
- For policy and program purposes; and
- For advocacy and empowerment purposes.

SIGNPOST

Tools to Assess Functioning

Learn more about the [ICF](#) at the World Health Organization website; and about the ICF for Children and Youth [here](#).

World Health Organization. How to use the ICF: [A practical manual for using the International Classification of Functioning, Disability and Health \(ICF\)](#). Exposure draft for comment. October 2013. Geneva: WHO

UNICEF has worked with The Washington Group on Disability Statistics to develop [specific sets of questions on child functioning](#). These take the ICF into consideration. There are two questionnaires, for children aged under 5 and for children aged 5 to 17, which can be used for identifying children with disabilities.

3.2.2 EARLY IDENTIFICATION AND EARLY INTERVENTION

The following information and links will help you to understand more about a child's development and will help you to guide the child's family.

Early identification and early intervention refer to the process in which the child protection system identifies a congenital disability or a developmental delay and immediately intervenes to help the child and their family. This intervention considers any medical treatment a child might need but also the developmental needs for daily living skills that most children grow up learning naturally in a family and community environment.

If a child is born with an obvious disability, intervention can begin immediately. From birth to age three is a critical period of brain development, and is crucial to encourage and stimulate all children as much as possible during this time. The neural pathways develop with every touch, movement and new sensation; the more experiences a child has during this important period, the better their brain development.

In other cases, it might become obvious over time to a family that the child is not doing the same things as other children would at the same age, such as sitting up, babbling or taking first steps. When a child goes for a regular health check the nurse or doctor might find that the child is not meeting the developmental milestones of a typically developing child.

If you work in a country where there are no regular health checks for infants and young children, families or community workers might be the first to notice that a child has a developmental delay. Knowing about a child's typical development milestones, listed below, is very important for assessment.

It is extremely important to identify a developmental delay as soon as possible in order to provide the necessary support. The cause of delay may not be serious, or it may be a symptom of cerebral palsy, other neurological problem or physical disability. In any case, the child needs attention, stimulation and play in order to be supported and to have an opportunity to develop in a positive way. If the delay is a result of disability, the child needs access to early intervention as soon as possible to ensure that no time is lost. If you suspect a child has a developmental delay or disability, you should speak to other professionals in the health and social protection sectors to make sure the child and their family receive all of the necessary supports.

Early intervention services can include:

- Training for medical staff in general disability issues;
- Immediate referral to rehabilitation services;
- Advice pamphlet for families;
- Referral to family support groups; and
- Specialist home-visiting services for children with disabilities.

If there is a home-visiting service, such as midwives who visit mothers and babies at home after delivery, that is another key opportunity to detect delays in the child's development not identified at birth, and to give the family advice and information in stimulating and observing the development of their child.

If the child's development is delayed, one of the most effective early intervention measures is learning through play. Play is essential in the development of all children and is how children learn. This can be as simple as a child putting a safe toy in their mouth to understand how it feels, to throwing something to see what happens.

BIRTH TO AGE 8 MONTHS: TYPICAL DEVELOPMENT TIMELINE

1–4 weeks old — loves looking at faces and begins to recognize family members/primary caregiver; may be startled if they hear loud and sudden noises

4–6 weeks old — starts to smile and respond to the sounds around them

4–12 weeks old — lifts their head while lying on their front

3–5 months old — reaches out for objects as their muscles develop

4–6 months old — starts making noises, enjoys making new and different sounds

5 months old — lifts objects and tries to suck on them

6 months old — hand-to-hand coordination, will learn to pass things from one hand to another

6–8 months old — sits without support

[Adapted from NHS Choices Birth to five development timeline](#)

Playtime is also an opportunity for families and caregivers to develop a loving bond with their child, which is very important for brain development. [International research](#) shows that the interaction in these early months and years is linked to the child's potential and happiness as an adult.

Most children will instinctively try to play with anything in reach from their birth onwards. If the child has a disability or developmental delay, then the families and other caregivers can use play as a way to promote learning. Too often, adults think that if the child can't play, then they are not interested. In reality, they may just need help to learn.

SIGNPOST

Play Resources

These are just a few of the many resources about learning through play. Many of the toolkits are designed for work with a child who is developing typically, and the same principles are relevant for children with disabilities:

Scope UK has produced this [video resource](#) about encouraging inclusive play.

The open source book, [Play Development in Children with Disabilities](#) has information about developmental play with children who are visually and hearing impaired, who have intellectual disabilities and/or multiple disabilities, communication difficulties, etc.

[Play and Children with Disabilities. Interdisciplinary Perspectives](#) is a journal published by the Centre of Research in Child-Parent Interaction. This edition is intended to raise awareness among professionals to ensure that the right to play for all children is assured.

Additional resources include:

[Learning Through Play in the Early Years](#)

[Early Years Matter](#)

[Learning and developing through play](#)

[Royal National Institute for the Blind \(RNIB\) Learning through play in the early years](#) (has a lot of good ideas for easy and cheap-to-make toys)

[I want to play too – inclusive play and leisure for children and young people](#)

[Sensory play ideas for children](#)

[Sense Play Toolkits](#)

[Toys to make from everyday items](#)

[Everyday items make the best toddler toys](#)

SIX STAGES OF PLAY DEVELOPMENT

- Unoccupied Play (Birth–3 Months):** At this stage, a baby is just making a lot of movements with their arms, legs, hands, feet, etc. They are learning about and discovering how their body moves.
- Solitary Play (Birth–2 Years):** This is the stage when a child plays alone. They are not interested in playing with others quite yet.
- Spectator/Onlooker Behavior (2 Years):** During this stage, a child begins to watch other children playing but does not play with them.
- Parallel Play (2+ Years):** When a child plays alongside or near others but does not play with them, this stage is referred to as parallel play.
- Associate Play (3–4 Years):** When a child starts to interact with others during play, but there is not a large amount of interaction. A child might be doing an activity related to the children around them, but might not actually be interacting with them. For example, children might all be playing on the same piece of playground equipment but all doing different things, like climbing, swinging, etc.
- Cooperative Play (4+ years):** When a child plays together with others and has interest in both the activity and other children involved in playing they are participating in cooperative play.

Source: [Pathways.org](#)

HELPFUL TIPS FOR POLICYMAKERS AND PLANNERS

Professional Assessment Tools

For more experienced practitioners, there are a range of resources for assessing childhood disability. However, in many cases these require an organization to pay to hold a license to use the product, which can be expensive. This is because the developer of the assessment tools wants to make sure that they are being properly used by fully qualified workers. In some cases, because the resource has been developed for use in a particular country context, the tool also needs to be validated to make sure that it is appropriate in a different context.

Learn more about assessment tools which can be used by more experienced practitioners. These resources usually have an associated cost and can be expensive. They are usually introduced through national or regional programs.

Ages and Stages Questionnaire [ASQ](#)

Bayley Scales Infant Development [BSID](#)

Childhood Autism Rating Scales [CARS](#)

Transdisciplinary Play-based System [TPBA 2 and TPBI 2](#)

As an example, you may come to meet a 3-year-old who is still putting every object into his mouth, in the sensory development stage. This means that the child is developmentally at the stage of a 0–6-month baby. To help this child develop, you and the child's family and caregivers can encourage play activities aimed at this age range, to help the child develop the learning they need in order to develop to the next stage. If you try and jump ahead to play activities for a 3-year-old, all the learning stages beforehand have been missed, and the child will not learn and may become frustrated. If the child is crying a lot, it could be because they do not understand what is expected of them since they have not developed enough to understand.

When playing with the child, there are some general rules to follow:

- Provide a safe environment;
- Encourage the child to choose activities;
- Choose toys appropriate to the child's developmental level;
- Approach the child gently and quietly;

SIGNPOST

Early Identification Tools

UNICEF East Caribbean developed this [video resource](#) to demonstrate developmental milestones in children.

This UNICEF Uganda [video resource](#) on early childhood development discusses the importance of caring for children in the early years.

There are many different checklists available to find out if a child is meeting typical developmental milestones. These can also be used by families who can then discuss any concerns with you or with a specialist during the child's regular health check-up. These include:

Pathways.org [checklists for children from birth to 6 years](#).

Centers for Disease Control (CDC) checklists have descriptions of the usual milestones and what you/family members/caregivers can do to help children learn and grow — CDC [checklists](#).

The development [checklist](#) is especially for family members.

You can also check out [Disabled Village Children](#) as well as the accompanying manuals for helping [children who are deaf](#) and [children who are blind](#). These contain detailed checklists and visual aids, including pictures of developmental milestones, which are especially useful for people who may have difficulties with literacy. This resource has a small cost.

The [National Portage Association](#) also provides resources for early identification and early intervention.

[UNICEF's Early Child Development Toolkit](#) is designed to help program planners and managers understand how to give children the best start in life.

The Global Health e-Learning Center, a USAID initiative, offers six different on-line certificated training courses in [Early Childhood Development](#).

- Talk to the child and always explain what is going on (this will help them to develop their understanding and connection between words and objects);
- Be on the same level with the child (for example, get down on the floor with the child or sit together with the child at a table);

- Do not force a child, but give them time to process your actions and words; and
- Provide variety in play.

For older children, it is important to try and find ways for children with disabilities and typically developing children to play together. This can be done by establishing inclusive sports teams or organizing sessions at the local playground.

3.2.3 ACCESS TO EDUCATION

The child's right to education without discrimination and on the basis of equal opportunities is included in the UNCRC, Article 28 and the UNCRPD, Article 24. However, children with disabilities can face significant challenges in accessing education. In 2016 the United Nations issued a General Comment on the right to inclusive education, which says that inclusive education is a fundamental right of all learners, at pre-school, primary, secondary and tertiary level.

Equitable access to education is also included in the Sustainable Development Goals (SDGs). "Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all", SDG 4. The Goal includes specific targets for pre-school and basic education and for children with disabilities and girls.

In some limited-resource contexts, where there are costs associated with sending children to school, the family may prioritize the education of the other children in the family over a child with disabilities. It is important to discuss with them the rights of all children to receive an education and the importance of going to school for their child's individual development.

Inclusive education means more than placing a child with a disability in a mainstream classroom. Inclusive education for children with disabilities means that they have the right to access quality education on an equal basis with all children. In practical terms, this means they are given the opportunity to attend school and, when required, are provided with extra support to do so. Additional support may mean that they are provided with assistive technology to access education materials (i.e., a magnifying glass to enlarge text on a page for reading, a pencil gripper to enable better control for writing) or provided with individualized instruction or tutoring on certain subjects. They may also need specially trained teachers, such as professionals who can teach deaf children using sign language.

Children with disabilities are not all the same. Individual learning needs and preferences should be identified early on and recommendations should be made to honor these needs and preferences to the extent possible. In some countries, children with disabilities have an individual education plan which is a legally binding document, and addresses each child's unique learning issues, and includes specific educational goals. This learning plan can be developed jointly by the people involved in the child's life, including the child's family, teachers, school psychologist or other therapists and service providers who work with the child.

In some countries, children with disabilities go to special schools, such as those children who are blind or visually impaired, or who have complex disabilities. Although this type of education is separate, it is important that it stays in place and is of a good quality, until the correct provisions for inclusive education are available.

Table 2: Education Scenarios for Children with Disabilities

Special education	Integrated education	Inclusive education
Two parallel education systems – one for typically developing children and a separate one for children with disabilities.	Placing the child with disabilities in the classroom without or with limited additional support.	All children are different; we change the system to accommodate everyone and provide all the additional support that individual children require.

ALAN'S STORY

An Argentinian man with an intellectual disability was denied his high school certificate when he graduated from his mainstream school. Alan took the Ministry of Education to court. After listening to many arguments, the judge decided that Alan had been discriminated against. The Ministry took the case to the Court of Appeal, which also agreed that the young man should be given his highschool certificate. You can read Alan's story in full [here](#).

In the Signpost below you can find more practical information on how an education system can be more inclusive.

During the case management process, the worker should assess the child's inclusion in the education system and plan to overcome barriers which are preventing them going to school. For example, this might mean finding the right people to help the child to get to school, and to make sure the conditions in the school help the child with a disability to **learn on an equal basis with the other children whilst they are there.**

This might mean that initially you will have to work closely with the education authorities to advocate for the child's right to education, and to make sure that they provide all the right help. You might also talk to community leaders about children's rights and disabilities and ask for their help to change attitudes. Family groups can also be effective advocates to build the understanding and political will needed to find extra resources for inclusive education.

SIGNPOST

Tools for Inclusive Education

Examples of inclusive education programming and practical tools/resources are available on the [USAID website](#).

You can find out more about inclusive education by reading [General Comment No. 4](#).

The aim of the [CBR Guidelines Education Component](#) is to work with the education sector to help make education inclusive at all levels, and to facilitate access to education and lifelong learning for people with disabilities.

The Sustainable Development Knowledge Platform includes a reference section with more info about [SDG 4](#).

UNESCO has produced a toolkit for creating inclusive learning friendly

environments called [Embracing Diversity](#). This toolkit can help teachers and school administrators to improve access to schools and learning for children who usually do not go to school. It can help you to have a discussion with the education services about what is needed to make sure that individual children with disabilities can be included.

These [inclusive practices resources](#) help you to plan and prepare for a more inclusive educational environment. This toolkit includes surveys and action planning templates which can be adapted for use in your locality.

This [Toolkit on Disability for Africa Inclusive Education](#) includes technical

content and resources to make inclusive education a reality for all children with disabilities.

Information and resources from UNICEF on inclusive education for children with disabilities can be found [here](#).

Credit Suisse and Leonard Cheshire Zambia have partnered to develop this [video resource](#) on inclusive education.

UNICEF Europe and Central Asia produced this short [video resource](#) which describes why inclusive education is important.

Mobility International USA has a program for young people with disabilities to [study or intern](#) in the USA.

ADRIAN'S STORY

Adrian is a 7-year-old Albanian boy who cannot hear. The government has included his right to education in national legislation and has included provision for support teachers to help him integrate in a mainstream school. The local multi-sectoral commission decided that Adrian needed a support teacher for two hours a day to attend school. They identified a support teacher who has not had any special training, does not know sign language and has difficulty communicating with Adrian. Although his support teacher tries very hard to communicate with Adrian by speaking slowly and looking at him, and also writing things down, Adrian is frustrated because he cannot understand what is happening in the classroom.

For Adrian, lack of access to sign language prevents him from succeeding in school. Imagine how his experience would be different if he were in a classroom with a teacher who was fluent in Albanian sign language, or if he was provided with a sign language interpreter in the classroom.

Families can resist sending their child with a disability to school. This can be because the child has been isolated at home, or because the family is afraid that their child will be uncomfortable, discriminated against while at school, or at risk of being bullied or exposed to violence and abuse. You may need to work with the child's family over time to help them to acknowledge the importance of their child going to school, to make sure the right supports are in place in the school and to help the child get to school.

3.2.4 ACCESS TO HEALTH

Article 25 of the UNCRPD says that it is the right of all people (including children) with disabilities to have the highest standard of health care, without discrimination.

While some conditions associated with disability result in poor health and extensive health care needs, others do not. However, all children with disabilities have the same general health care needs as everyone else, and therefore need access to mainstream health care services. For example, children with disabilities should be included in post-natal home-visiting services and clinic visits, and should receive their regular vaccinations and immunizations, along with all children. Furthermore, in adolescence, they should access services for sexual and reproductive health.

Children with disabilities should also have access to specialist health care services such as physiotherapy, occupational therapy and speech therapy.

Children with disabilities can often face barriers in accessing basic and specialist health care. This can be because families cannot understand the complex health needs of their children, do not have the information about available services and resources, or do not acknowledge that their child has a disability requiring health care, because there are financial barriers in seeking health care.

Community-based Rehabilitation (CBR) is one model for supporting access to health care. CBR is a strategy for community-based development involving people with disabilities. It encourages the empowerment of people with disabilities and their families to improve their quality of life. You can find out more about the health component of CBR by accessing the Signposted links on page 33.

You can also talk to healthcare providers in your community to make sure that they are doing everything they can to make sure they have eliminated the barriers to access. This can include making the local clinic physically accessible (putting in ramps and handrails) as well as training health care workers to include children with disabilities.

3.2.4.1 Children with disabilities and HIV

Children with disabilities are often at higher risk of exposure to HIV. They can be left out of education and awareness programs, are less likely to access testing and antiretroviral treatment (ART) and can experience greater levels of sexual violence. In places where resources are limited they may be considered a low-priority for testing and treatment. The barriers they face in accessing services on a day-to-day basis extend to HIV prevention and response services. In your role as a social service worker, you can make sure that children with disabilities are included in all HIV programming activities in your area. You can talk to the HIV service providers to find out how children with disabilities can get the right information in a format they understand, and how they can be included in HIV prevention, care and support programs including sexual and reproductive health services.

A child may also acquire a disability because of HIV-related conditions or side effects of treatment. These effects may be related to the physical effects of the virus itself or indirectly to the effects of HIV on the caregiving environment. Children infected with and affected by HIV may be less likely to have their basic needs met and more likely to be sick, malnourished, suffer psychological trauma, or exposed to abuse. You can play a key role in supporting them to access health-related care and treatment.

SIGNPOST

HIV and Disability

The [CBR Guidelines Health Component](#) facilitates inclusive health by working with the health sector to ensure access for all people with disabilities, advocating for health services to accommodate the rights of people with disabilities and be responsive, community-based and participatory.

For more information about disability and HIV you can read the World Health Organization Policy Brief [here](#).

UNICEF has posted more information and links to resources about disability and HIV [here](#).

This packet of [resources](#) on disability and HIV is available in the Spanish language.

The Global Health e-Learning Center online certificated course on [Early Childhood Development](#) integrates learning on the impact of HIV on children's development.

3.2.5 CHILD PROTECTION

Children with disabilities experience more violence, abuse, neglect and exploitation than typically developing children. Research shows that children with disabilities are three-to-four times more likely to experience violence than their non-disabled peers.¹¹ Girls with disabilities are more likely to experience physical and sexual violence than boys with disabilities.

In most cases of violence and abuse against children, the perpetrator is a family member or close family friend. In the case of children with disabilities, they can be increasingly at risk because they are isolated, kept at home or unable to tell someone about the abuse because they do not have the communication skills. Sometimes the signs of abuse are non-verbal; for example, a sign could be a change in behavior such as the child appearing more withdrawn, appears reluctant to be in the company of specific people, etc.

In some countries, when a child is born with a disability, doctors advise the family to not feed the child. This is a severe form of abuse. In residential institutions, where children do not have a voice or any close adult to care for them, they may be used for sex by the staff and others. This is abuse. Sometimes, families have another child specifically to look after the child with disabilities once the older members of the family have died. That child is given no choice and is being exploited.

Where you have protection concerns regarding a child with a disability, you should follow your own country's legislation, policy and guidance on reporting incidences of violence, abuse, exploitation and neglect, and providing follow-up. If you are working for a non-governmental organization, these provisions should be included in the organization's child protection policy.

Children with disabilities can also experience harmful bullying from their peers. In this situation, you can think about how to ensure the whole community understands disability issues.

"The prevalence of violence against children with disabilities can be expected to be higher in lower and middle-income countries where there are greater stigmas associated with having a child with a disability, less resources for families who have children with disabilities, and wider acceptance of the use of corporal punishment to discipline children".¹²

SIGNPOST

Child Protection Resources

In case you are thinking about **developing or reviewing your organization's child protection policy**, the [Keeping Children Safe Child Safeguarding Standards](#) are a good place to start. These were developed by a coalition of more than 14 organizations, and have recently been updated.

Information and resources from UNICEF about the protection of children with disabilities can be found [here](#).

The Women's Refugee Commission has published gender-based violence against children and youth with disabilities [toolkit](#) along with [guidance for psychosocial support facilitators on disability inclusion](#), in English and Arabic, and guidance tools for [disability inclusion in Child Protection and GBV programs](#).

USAID requirements on child safeguarding are specified in [Standard Provisions for U.S. Nongovernmental Organizations: A Mandatory Reference for ADS Chapter 303](#).

3.3 Develop, Implement and Review the Case Plan

3.3.1 DEVELOPING THE CASE PLAN

The case plan is developed to respond to the strengths and needs identified during the assessment.

A case plan describes the specific actions which need to be taken to meet the needs of a child with a disability. These may change over time, so the plan should be regularly reviewed and updated. (For more information, refer to the resources on case management at the beginning of Section 3).

Developing a case plan for a child with a disability is the same as for a child developing typically. It is developed with the child and their family or caregivers, and outlines specific actions required to build on the strengths, and to meet the needs and goals they identify. It should also say who is responsible for making these things happen, and when action needs to be taken to make sure the appropriate help and support is provided. Goals can be immediate — for example, teaching a child to hold and drink from a cup, or longer-term, such as supporting the family to apply for available social security benefits.

The case plan may include goals about going to school or getting special equipment to help with reading, but it may also include a plan for developing functional skills. This can be about supporting a child with self-help skills such as dressing, feeding, going to the toilet, self-care and so on. These early skills are the basis for future independent living and should be addressed as early as possible.

The case plan can also include the support which a child with a disability and their family should have to stay together, or for a child living in a residential institution to return to family care (with their own family or in alternative care).

You should follow your own organization's case management guidance and standard operating procedures. You may also find the resources mentioned in Section 3 useful.

The case plan for a child with a disability may include specific actions related to the individual child's development. This development plan is designed to make it easy to record what you and the family members and caregivers can do and to evaluate what progress the child is making. It does not replace the support of a fully-trained professional rehabilitation therapist, but it will be very useful if you and the family do not have access to specialist support.

In some areas of skill, the child's development may have progressed well and be in the typical (or advanced) range, but in other areas they may be slower. Skills are all linked and depend on each other. Therefore, it is important to understand what level the child has reached in each of the main skill areas, so that you and the family can find appropriate activities to help the child learn new skills. You can use the assessment tools and development checklists discussed on pages 25–56 when you are reviewing the child's progress.

The case plan should include details of how you will guide a family to stimulate their child's development from the very earliest days.

If the child is an adolescent or approaching adulthood, you can talk to them and their family about including a plan to get ready for independent living. Discuss their expectations, both the adolescent's and their family's, and plan how these can be reasonably met.

In some cases, you may wish to have your meeting with the family first, and a meeting with the child separately. For example, there may be things which an adolescent does not want to discuss in front of their parents. Eventually, the case plan needs to be agreed upon by everyone involved.

You will also be liaising on behalf of the child and family with other people in the community including people who provide services, such as at the local health center and school.

3.3.1.1 Identifying services and resources in the community

In the same way that you will have involved many people in the child's assessment, you should also include relevant people from different sectors in developing the child's case plan. It is important to find out about services in the community for all children and families and any extra services for children with a disability. You can find out if there are any disabled person's organizations working in your area and contact them for information, referrals and advice. This process helps you to find out who should be involved in the case planning process for each child. For example, you may want to include the pre-school teacher to ask for advice on preparing the child for school.

You can also think about how existing non-specialist services for a child with a disability can be inclusive. You will need to encourage people to adapt existing services to enable the child's access. For example, you may need to talk to the leader of a youth group to find ways to include a child with a disability in the activities. This can include children volunteering to assist with helping the child with a disability, or you might like to talk to them to introduce the child with a disability. Another activity that can be helpful in an environment with limited resources is an equipment library managed by a group of families. These voluntary groups gather equipment and toys that are shared, returned and then shared again with other children and families.

HELPFUL TIPS FOR POLICYMAKERS AND PLANNERS

CBR Resources

For program planners in countries with few services and minimal resources, CBR can help you build services and systems for children and adolescents with disabilities. The following is a list of the most useful resources to use:

You can download the [CBR Matrix](#) which gives an overall visual representation of CBR. The matrix illustrates the different sectors, which can make up a CBR strategy.

The [World Health Organization](#) site includes a wide range of CBR resources which you can download.

[Disability, CBR and Inclusive Development](#) is an academic journal which publishes evidence-based information for policymakers.

You can watch a documentary about CBR in Nepal [here](#) and about CBR in Ethiopia [here](#).

3.3.1.2 Making adaptations to meet the needs of a child with a disability

If rehabilitation services are available in your area, their staff can advise on what supports are available. This can include assessment for assistive equipment such as wheelchairs or hearing aids, Braille readers for children who are blind, or sign language training for children who are deaf or hard of hearing and their family members. They can provide advice on making adaptations at home to assist a child with movement, eating and other activities of daily living. You can also local disabled people's organizations find out what resources are available.

HELPFUL TIPS FOR POLICYMAKERS AND PLANNERS

Universal Design for Adaptation

[Universal Design](#) is the design and composition of an environment so that it can be accessed, understood and used to the greatest extent possible by all people regardless of their age, size, ability or disability. This is not a special requirement for the benefit of only a minority of the population. It is a fundamental condition of good design. The principles of Universal Design can be applied when planning new environments.

EXAMPLES OF INCLUSIVE AND COMMUNITY-BASED SERVICES

Early identification and [early intervention](#) — try to recognize difficulties quickly, **identify** and make a prompt **intervention** to support children and their families so that issues are tackled before they become ingrained problems. Thinking in this way, **early identification** and **intervention** are important rights through a child's life.

Inclusive education — Where education is inclusive, all children attend and are welcomed by their neighborhood schools (pre-school, primary, secondary and tertiary) in age-appropriate, regular classes and are supported to learn, contribute and participate in all aspects of the life of the school. See Section 3.2.3 for more resources on inclusive education.

[Community-based Rehabilitation](#) — CBR is a model that aims to reach every child, youth and adult with disabilities in a community. CBR uses trainings to share basic rehabilitation skills so that health, education and social services can develop; it works to empower people with disabilities and their families to achieve their rights; and it raises awareness in communities in order to achieve full inclusion. CBR can be a state-run, NGO-run or parent-led program. "Initially a strategy to increase access to rehabilitation services in resource-constrained settings, CBR is now a multisectoral approach working to improve the equalization of opportunities and social inclusion of people with disabilities while combating the perpetual cycle of poverty and disability. CBR is implemented through the combined efforts of people with disabilities, their families and communities, and relevant government and non-government health, education, vocational, social and other services," ([World Health Organization 2018](#)).

[Habilitation and rehabilitation services](#) — These Services are aimed at helping children with disabilities attain, keep or improve skills and functioning for daily living or regain skills, abilities or knowledge that may have been lost or compromised as a result of acquiring a disability. Specialists include occupational therapists, physiotherapists, communication therapists, psychologists and play therapists. Please note that massage serves the role of warming muscles up or calming a child before therapy starts. It is not a therapy by itself. However, good physical contact between parent and child is the basis for emotional and social development of the child.

Social protection and social welfare services — Examples can include assistance provided to families which can be in-kind (e.g., food tokens, clothing, educational material) or cash (e.g., a child grant) as well as social work family support, and other types of service such as family planning, child care, counseling, etc.

Access to information — Knowing where to get information and advice is an important component of disability services to enable people to fulfill their rights. This can include hotlines, pamphlets, and TV and radio spots.

Mental health — Long-term mental health issues can have an effect on a child's ability to undertake day-to-day activities, and thus can be considered a disability. Equally, many children with disabilities may also have an overlying mental health condition such as depression. Thus, mental health services are a core resource. For more information, see the Signposted resources on disability and mental health in Section 2.3.

SIGNPOST

Assistive Technology Resources

The [Disabled Village Children Manual](#) provides instruction on working with children with disabilities in less-resourced settings. It contains detailed descriptions on managing a specific disability, undertaking basic physical therapy and preventing injury, as well as how to make adaptations to the home.

Hesperian Health Resources include downloadable materials for [Helping Children Who Are Blind](#) and [Helping Children Who Are Deaf](#).

UNICEF promotes [assistive technology for children with disabilities](#) whilst acknowledging the barriers in less-resourced environments; in these cases they promote the [Community-based Rehabilitation Guidelines](#), which are available in 12 languages and in MP3 audio files.

WHO has developed a [Priority Assistive Products List](#) to promote access to assistive technology.

WHO has also produced guidelines for the production of manual wheelchairs in less resourced settings. The manual and associated training packages are available for download [here](#).

This website has some good hints and tips for [making adaptations to accommodate children with disabilities](#), and includes links to specific information on adapting the child care environment for children with certain types of disabilities including hearing, learning, visual, physical and social and emotional disabilities.

The ideas in this handout are provided as examples of some of the potential [adaptations](#) that can be made to common materials and activities to ensure that young children with disabilities can be included.

Storybook apps for smartphones can also be a useful tool for children who have difficulties with their vision and/or hearing. Some apps (in English and American Sign Language) can be found [here](#).

Information about refreshable Braille displays which provide access to information on a computer screen can be found [here](#).

This website provides simple and easy to understand guidance on how to work with children who are [visually impaired](#).

Adaptations may also be needed in existing services to make sure they are inclusive, such as making sure there are handrails, ramps, and accessible toilet facilities in government buildings.

If there are gaps in the services available, you can also refer to the 'Assistive Technology Resources', to the left, and in the section on play, to find out more about how to make adaptations to meet the needs of a child with a disability.

3.3.1.3 Life-course approach

Childhood is when the foundation is laid for all future development. It is when the neural pathways develop and make the connections that the brain needs to function. The early years are especially important. The more opportunity you give to the child to develop their neural pathways, the more the brain and the child's abilities will develop. The period of adolescence is important because this is also one of the most rapid phases of brain development. The changes in adolescence also have consequences for a child with a disability. These developmental needs across the life-course of a child with a disability should be considered during the development of the case plan.

A child with a disability will need different supports at different stages in their life and development. For example, developmental play will differ in activity, style and location for a three-year-old child and a 15-year-old adolescent.

Adolescents and their families may need additional support when they are approaching puberty. There may be information available for families of children developing typically, which you can think about adapting. There are also Signposts to resources on the following page.

As children grow older, they are also preparing for independence. It is important that you think about how a child with a disability who is preparing for adulthood and independence can become self-supporting, including relevant education or skill training and what financial support they may be able to access through the government. More information and resources are provided in the Signpost on Adolescence and Disability below.

SIGNPOST

Adolescence and Disability

The [Better Parenting Training Manual and Job Aid](#) were developed for use in Ethiopia, but they contain information that is easily adaptable for any environment. These resources also include information about stages of development, changing needs as children grow older and children with disabilities.

The Parent Center Hub has lots of resources for families to discuss [sexuality education](#) with adolescents with disabilities.

This manual on [Sexuality Education For Children And Adolescents With Developmental Disabilities](#) includes hints and tips for families to talk to children with disabilities at different life-course stages and includes advice on child protection.

Respectability.org has a list of resources and links on [sexual education](#) for children with disabilities, including how to be safe and protected.

3.3.1.4 Especially for girls

“Women and girls with disabilities face significantly more difficulties – in both public and private spheres – in attaining access to adequate housing, health, education, vocational training and employment, and are more likely to be institutionalized.”

Source: United Nations Division for Social Policy and Development, [Women and Girls with Disability](#).

It is especially important to consider the needs of girls with disabilities. The UN Division for Social Policy and Development has gathered many resources on their webpage (link above), which can help you find the information you need to think about how to support girls.

The [2011 World Report on Disability](#) says that girls and boys with a disability can be more exposed to violence, abuse, exploitation and neglect than their peers — and that girls are more at risk than boys. Girls with disabilities can be exposed to sexual abuse at home or in residential institutions.

When you are developing a case plan for a girl with a disability, think about her vulnerability and the discrimination she might face, and how you can plan to help her overcome these risks.

An individual girl's case plan should consider what protective measures might need to be put in place, while at the same time balancing this against children's rights. For example, a family member who wants to protect their daughter from exploitation may try and keep her at home and prevent her from enjoying her right to leisure, play and culture.

Girls with disabilities can also require support to manage menstruation. Adolescent girls with disabilities should have clear information and support to manage their periods. They might need teaching to learn to manage their menstrual hygiene by themselves, or they may need support to help them change their hygiene pads and underwear. They may also need support to help manage the emotional and behavioral changes which can be associated with menstruation, especially if they have difficulties with comprehension or communication.

3.3.1.5 Independent living

Article 19 of the UNCRPD is about living independently and being part of the community. This is an important consideration for adolescents with a disability. This does not mean that children with disabilities are necessarily expected to be self-sufficient when they become adults. Independence is created by having assistance when and how a person requires it. Independent living (IL) means all people with disabilities having the same choice, control and freedom as any other citizen, at home, at work and as members of the community. This does not necessarily mean people with disabilities 'doing everything for themselves,' but it does mean that any practical assistance people need should be based on their own choices and aspirations.

During the case management process, you can talk with the child and their family about their aspirations for the future. You can make sure the care plan includes actions to help the child move toward independence and get the right support. This might include working with the child to help them dress themselves, learn how to cook or apply for a job. It may also include working with potential employers in the community to help them understand more about disability and employing young people with disabilities.

SIGNPOST

Independent Living Tools and Resources

[Mobility International USA](#) has produced a video about their leadership training for women with disabilities which demonstrates how women and girls can be included. They also produced a music video demonstrating how women and girls with disabilities all over the world can be [Loud Proud and Passionate](#).

Women Enabled International has produced [a map of where Women and Disability Rights Organizations are active all over the world](#). If one is near you, it may be able to help with advice on working with girls with disabilities in your country.

The UN has developed guidance in [General comment No. 5](#) (2017) on living independently and being included in the community.

The [Independent Living Myth Buster](#) has lots of information about what IL is and is not.

The [European Network on Independent Living](#) contains links to a lot of resources including the [Independent Living Manual](#) which contains 'tools for change through information.'

The [Independent Living Institute](#) provides information and training materials, and develops solutions for services for persons with extensive disabilities in Sweden and internationally.

[Leonard Cheshire Disability](#) is an international organization that supports independent living in 13 African and Asian countries, as well as the UK. Their experience may give you ideas for use in your community.

The Asia-Pacific Network for Independent Living Centers can be contacted [here](#).

The USA-based National Council on Independent Living provides resources and information on the IL movement [here](#).

This [Independent Living Manual](#) was developed by the [European Network on Independent Living](#) with the Center for Independent Living in Sofia, Bulgaria and the Initiative for Human Rights in Mental Health.

The UK has developed a range of resources about [preparing for adulthood](#), which provide useful information and can be adapted to your context.

3.4 Implementing the Case Plan

3.4.1 SUPPORT VISITS AND LIAISON

During the implementation of the case plan, you will continue to build your relationship with the child and their family. You will have agreed in the plan as to how often you will make support visits. These regular visits are important so that the child and family know you are undertaking your agreed-upon responsibilities. This also helps you to encourage them to undertake their agreed-upon responsibilities.

It is important to plan and conduct contact visits with a clear purpose and an understanding of the planned outcome of each visit. Visits should be:

- Optimistic and hopeful;
- Meaningful, purposeful and goal-directed;
- Child-focused and take into account the child's needs, views, well-being and safety; and
- Inform the assessment of the child's and family's strengths and needs and progress toward the case plan goal and outcomes.

As recommended above in the section on developing the case plan, you may wish to have your meeting with the family first, and a meeting with the child separately. This will be agreed to by everyone in the case plan.

You will also continue to speak on behalf of the child and family with other people in the community including people who provide services, such as at the local health center and school.

Encouraging families to find support groups or establish one themselves will help the child and family become more accepting and independent.

Working with families to build a CBR program may become an important part of your work if you are in a country with a limited support system or resources.

Prevention of institutionalization may be a key goal at this stage, and each visit you make could be another step to achieve this.

As the child grows and develops, the family becomes more confident in supporting the child and the community offers more resources, the number and frequency of support visits can change.

3.4.2 MONITORING AND REVIEW

As part of implementing the case plan, you are responsible for monitoring progress through regular contacts with the child, family members and service providers. During these contacts, you will be assessing the progress, safety and well-being of the child with a disability. You will need to make a record of these contacts and their outcomes so that you can recognize and celebrate successes and move forward.

It is important to maintain open communication with the child and their family and caregivers, which you established while you were making the assessment and developing the care plan. Everyone needs to know what is happening at each step of the process.

When you review the plan together with the child and their family, you may agree to make changes to meet the changing needs of the child.

Any changes to the case plan should be recorded. If your case management process involves multi-sectoral reviews, you can support the child and the family to have their voices heard by working with them to prepare what they want to say in advance.

This monitoring and review stage is also an opportunity to review the number and frequency of support visits. These can be reduced as the child and family become more confident in accessing the support they need independently.

It may be that you will come back to the child and family at different points during the child's life, depending on the disability and the child's needs at different ages. For example, the first year after a child is born may be an intensive time for you and the family. Then the situation may settle down, until it is time for the child to go to school, and you may become more involved again. You may be the resource the family turns to at many stages in the child's life as he or she grows up.

3.4.3 CASE CLOSURE

The case plan should include a statement of what needs to be accomplished so that the case can eventually be closed. A case is closed when all the goals jointly identified in the case plan have been met, they are no longer relevant or feasible, or new goals are not required. In some situations, a case might be closed because the child moves from the area, or because another service provider takes over. A closed case can be re-opened in the future if the child and/or family needs additional help and support.

Annex:

Compendium of Resource Links

Documents and other resources referenced above in this document are listed below by subject area and language. They were sourced through three primary means:

- Identified by USAID and World Learning;
- Referenced and shared by key informants; and
- Located through on-line research.

These were further reviewed and selected for inclusion based on their:

- Relevance to the Guidance;
- Usefulness (as identified by key informants);
- Current practice and thinking; and
- Availability online (open-source and at cost).

Those selected for inclusion in the Guidance are considered to meet all of the above criteria.

Some of the resources identified were not included because, for example, they use out-dated terminology or because a link could not be located. A total of 153 resources are presented. These include reports, training manuals, guides, video and other web-based resources as well as links to Disabled

Person's Organizations. This does not represent an exhaustive catalogue of disability related materials. However, it presents the best available resources for the intended audience at the current time. The resources are grouped by thematic area:

- Alternative Care
- Assessment
- Case Management
- Child Protection
- Community-based Rehabilitation
- Culture and Language
- Data
- Early Childhood Development
- Emergency
- Human and Child's Rights
- Inclusive and Community-based Services
- Inclusive Education
- Information
- Participation

Thematic Area	Date	Title	Author and Publisher	Language	Comment
Alternative Care (& Case Management)	2016	A Better Future is Possible	International Social Service	English French Spanish	Promoting family life for children with disabilities in residential care, manual for professionals
Alternative Care	2010	Guidelines for the Alternative Care of Children	UN General Assembly	English	Resolution adopted by the General Assembly
Alternative Care		Website	Better Care Network	English	Better Care Network (BCN) is an international network of organizations committed to supporting children without adequate family care around the world
Alternative Care	Undated	Adoption and Kafala law	Better Care Network	English	Webpage with resources
Alternative Care	2012	Moving Forward: Implementing the 'Guidelines for the Alternative Care of Children'	Centre for Excellence for Looked After Children in Scotland	English	Aims to support implementation of the guidelines by making strong connections between national policy, direct practice and the guidelines themselves
Alternative Care	2013	Study on Deinstitutionalisation of Children with Disabilities in Europe and Eurasia	USAID	English	Considers progress by governments in developing community-based alternatives to institutional care of children and adults with disabilities in the E&E region
Alternative Care	2009	The Risk of Harm to Young People in Institutional Care	Better Care Network and Save the Children UK	English	This paper provides an international summary of the extent and scale of young children living without parents in residential care 'children's homes', and of the reasons they are there. This is followed by an overview of the risk of harm to young children's care and development after being placed in institutional care
Alternative Care	Undated	Guidelines on Children's Reintegration	Inter-agency group on children's reintegration	English	These guidelines provide a framework for anyone seeking to ensure family care for children
Alternative Care		Effects of institutional care	Better Care Network		Web-based resource library on the effects of institutional care on children
Alternative Care	2015	Standard Operating Procedures Family Reintegration	Retrak	English	Standard operating procedures for \reintegration of children living on the street; includes specific guidance for a child who has a long-term illness or disability
Assessment	2016	Child Functioning Question Sets; ages 5 to 17; age under-5	Washington Group on Disability Statistics and UNICEF	English	Child functioning question sets
Assessment	2001	International Classification of Functioning, Disability and Health (ICF)	WHO	English	Web-based resource library about ICF
Assessment	2007	ICF Children and Youth Version	WHO	English	The ICF-CY offers a conceptual framework and a common language and terminology for recording problems manifested in infancy, childhood and adolescence involving functions and structures of the body, activity limitations and participation restrictions, and environmental factors important for children and youth

Thematic Area	Date	Title	Author and Publisher	Language	Comment
Assessment	2013	How to use the ICF. A Practical Manual for using the International classification of Functioning, Disability and Health	WHO	English	People interested in functioning and disability and seeking ways to apply the ICF should find the contents of this Practical Manual helpful
Assessment	2012	Monitoring Child development (0–6 Years) in the IMCI Context	Pan American Health Organization	English Spanish	Intended for professionals in the basic health network rather than specialists in child development. It contains basic information on development during the first 6 years of life that every primary care health professional should know
Assessment	2007	The Guide for Monitoring Child Development	American Academy of Pediatrics	English	An innovative method for monitoring child development that is designed specifically for use by health care providers in low- and middle-income countries. Studies in Turkey provide preliminary evidence for its reliability and validity
Assessment	2016	Birth to five development timeline	UK National Health Service	English	Web-based resource guide to the milestones in children's development from birth to five years old. Use it to see when children may gain certain skills and learn new things. The ages given are averages and many children will gain one skill earlier than another
Assessment	2011	Developmental Milestones in Children	UNICEF East Caribbean	English	Video resource
Assessment	2018	All Development Milestones	Pathways.org	English	Web-based resource library including checklists on child development based on American Academy of Pediatrics findings
Assessment	Undated	Child Development Checklists	Center for Disease Control and Prevention (CDC)	English	Child development checklists
Assessment	2018	Ages and Stages Questionnaire	Paul H Brookes Publishing company Inc.		Screening tool for young child development for use by early years educators and health care professionals
Assessment	2005	Bayley Scales of Infant and Toddler Development (Bayley III) Motor Scale	Pearson	English	Instructions and help can be provided by the publisher; please revert to publisher for information on availability in other languages
Assessment	2005	Bayley Scales of Infant and Toddler Development (Bayley III) Screening	Pearson	English	Instructions and help can be provided by the publisher; please revert to publisher for information on availability on other languages
Assessment	2010	Childhood Autism Rating Scale	Schopler E, Van Bourgondien ME, Wellman, GJ, Love SR (2010). Childhood Autism Rating Scale – 2nd Edition. Los Angeles: Western Psychological Services	English	A clinician rating scale to be completed after a direct observation of the child by a professional familiar with autism who had also obtained some brief training on how to rate the CARS items; please revert to publisher for information on availability on other languages
Assessment	Undated	Developmental milestones checklist for parents	New South Wales Government Australia	English	Developmental milestones checklist for parents

Thematic Area	Date	Title	Author and Publisher	Language	Comment
Case Management	2014	Interagency Guidelines for Case Management and Child Protection	Child Protection Working Group	English	Provides detailed information on case management for child protection; also includes template for child protection policy
Case Management	2018	Core Concepts and Principles of Effective Case Management: Approaches for the Social Service Workforce	Global Social Service Workforce Alliance	English	To support the social service workers responsible for implementing a case management process, by articulating the main principles and concepts of case management. It includes foundational definitions and descriptions of the basic components
Case Management	2018	Compendium on Case Management Tools and Resources	Global Social Service Workforce Alliance	English	Global case management resources including standard operation procedures, tools and forms, and training manuals
Case Management	2014	Case Management Toolkit: A User's Guide For Strengthening Case Management Services In Child Welfare	USAID	English	To assist USAID Mission staff working in the Europe & Eurasia region in identifying and propagating good practices in case management services
Case Management	2017	Core Concepts and Principles of Effective Case Management: Approaches for The Social Service Workforce	Global Social Service Workforce Alliance	English	Core concepts and principles of effective case management
Case Management	2017	Case Management Compendium	Global Social Service Workforce Alliance	English	First edition compendium of open-source materials on case management including tools and forms, standard operating procedures and training materials
Case Management	2017	Case Management Guidelines for Reintegration of Children in Residential Care to Family Care	USAID	English	Developed in Uganda and pending finalization and publication; includes Standard Operating Procedures and a training manual; references the specific needs of children with disabilities in the process of reintegration
Child Protection	2014	Keeping Children Safe Child Safeguarding Standards	Keeping Children Safe	English	Making sure your organization is doing all it can to prevent harm to children
Child Protection	Undated	Child Protection – Children and adolescents with disabilities	UNICEF	English	Web-based child protection resources
Child Protection	2017	Disability Inclusion in Child Protection and GBV Programs	Women's Refugee Council	English	Web-based child protection resource
Child Protection	2017	Gender-based violence against children and youth with disabilities toolkit	Women's Refugee Council	English, French, Arabic and English accessible	Web-based toolkit
Child Protection	2017	Disability Inclusion in psychosocial support programs	Women's Refugee Council	English and Arabic	Web-based resource

Thematic Area	Date	Title	Author and Publisher	Language	Comment
Community-based Rehabilitation	2004	CBR A Strategy for Equalization of Opportunities, Poverty Reduction and Social Inclusion of People with Disabilities	ILO, UNESCO, WHO	Arabic Chinese Portuguese English French Spanish	Joint position paper
Community-based Rehabilitation	Undated	CBR Matrix	WHO	English	CBR Matrix
Community-based Rehabilitation	2003	Manual for CBR Planners	Maya Thomas, MJ Thomas	English	Guidance Manual on Community-based Rehabilitation for Program Planners. Includes guidance for rural and urban settings. Authors permission received for citation here.
Community-based Rehabilitation	2010	CBR Guidelines and other technical resources	WHO	English French Chinese Spanish Russian Arabic Thai Korean Tajik Vietnamese Uzbek	Provides guidance on how to develop and strengthen CBR programs; Promote CBR as a strategy for community-based development involving people with disabilities.
Community-based Rehabilitation	2010	CBR Guidelines Supplementary Booklet	WHO		Addresses specific issues including mental health, HIV and AIDS, leprosy and CBR in humanitarian crises
Community-based Rehabilitation	2012–2013	Disability and children's mental health	Commonwealth of Australia	English	Factsheet including key principles for supporting children
Overcoming Stigma and Discrimination	2012	Making Social Work Work: Improving social work for vulnerable families and children without parental care around the world	Every Child	English	This literature review calls for families and children in developing countries to be supported in ways that are appropriate to the conditions, culture and resources available
Overcoming Stigma and Discrimination	Undated	Toolkit on Disability for Africa Culture, Beliefs, and Disability	UN Division for Social Policy Development and Department for Social and Economic Affairs	English	Training manual
Overcoming Stigma and Discrimination	2018	Open University Activity — Changing Labels	Open University	English	Website training resource; Students learn how the words we use to describe people with learning disabilities become terms of abuse
Overcoming Stigma and Discrimination	2018	The language of mental of physical disability	Oxford University Press	English	Web-based resource on appropriate language for use in connection with people with disabilities
Overcoming Stigma and Discrimination	Undated	Language and disability	USAID	English	

Thematic Area	Date	Title	Author and Publisher	Language	Comment
Overcoming Stigma and Discrimination	Undated	Disability Language Style Guide	National Center on Disability and Journalism	English	The style guide is intended for journalists, communication professionals and members of the general public who are seeking the appropriate and accurate language to use when writing or talking about people living with disabilities
Overcoming Stigma and Discrimination	2018	Faith to Action Initiative	Faith to Action Initiative	English	Web-based resources for working with children and families in faith communities
Overcoming Stigma and Discrimination	2018	Family Care Toolkit	Faith to Action Initiative	English	Web-based resources for working with children and families in faith communities
Overcoming Stigma and Discrimination	2018	Caring for Children with Special Needs or Circumstances	Faith to Action Initiative	English	Web-based resources for working with children and families in faith communities
Overcoming Stigma and Discrimination	2018	Equal Rights	United Aid for Azerbaijan (UAFA)	Silent video	Video resource showing how infrastructure can affect disabled people rights
Data	2014	Collecting Data on Child Disability	UNICEF	English	To understand why data on children with disabilities are currently inadequate, the difficulties that surround the gathering of high-quality data on children with disabilities, and why there is a real need to improve the collection, analysis, dissemination and use of disability data
Data	2016	Washington Group UNICEF Module on Child Functioning	UNICEF	English	Web-based resources for measuring child functioning
Early Childhood Development	2018	Early Childhood Development	Global Health e-Learning Center	English	Tailored on-line certificated courses on early childhood development; included a focus on impact of HIV on children's development
Early Childhood Development	2016	The importance of early bonding on the long-term mental health and resilience of children	London Journal of Primary Care	English	Research article on the importance of developing loving relationships with children from infancy
Early Childhood Development	2012	Early Childhood Development and Disability: A Discussion Paper	WHO and UNICEF	English	Aimed at improving the developmental outcomes, participation and protection of young children with disabilities. It has information on what a disability is and the rights of children with disabilities
Early Childhood Development	2018	National Portage Association	National Portage Association	English	Portage is a home-visiting educational service for pre-school children with additional support needs and their families. The web-based resource includes assessment tools and support for families and professionals
Early Childhood Development	2017	What is Early Childhood Development?	UNICEF Uganda	English	Video resource; Television commercial highlighting the definition of Early Childhood Development – ECD

Thematic Area	Date	Title	Author and Publisher	Language	Comment
Early Childhood Development	Undated	ECD Resource Pack	UNICEF	English	Designed to help program planners and managers understand the basic elements of the best start in life for children and how to most effectively work together to achieve those goals. It combines advocacy arguments with experiences, exercises and information that can be used to develop skills and understand programming for young children in development and emergency situations
Early Childhood Development	2016	The importance of early bonding on the long-term mental health and resilience of children	London Journal of Primary Care	English	Academic research paper
Early Childhood Development	Undated	Learning Through Play in the Early Years	Early Years Interboard Panel	English	Resource for teachers and parents
Early Childhood Development	2018	Early Years Matter – Play and Learning	Early Years Matter	English	Web-based resource for parents and professionals
Early Childhood Development	2009	‘Aistear’ – The Early Childhood Curriculum Framework – learning and developing through play	National Council for Curriculum and Assessment of Ireland	English	A component of the curriculum for early years learning for children aged 0 to 6 years
Early Childhood Development	2017	Play Development in Children with Disabilities	Serenella Besio, Daniela Bulgarelli and Vaska Stancheva-Popkostadinova (Eds.)	English	Open source book with resources about play with children with a range of disabilities
Early Childhood Development	2017	Teaching and Learning Guidance – Learning through play in the early years	Royal National Institute for the Blind	English	Web-based resources for children with vision impairments
Early Childhood Development	2004	‘I Want to Play Too’ – developing inclusive play and leisure for children and young people	Barnardo’s	English	Aims to give some practical ideas about how the inclusive play opportunities for children with disabilities can be developed and problems overcome
Early Childhood Development	2016	Sensory Play Ideas for Special Needs Children	Pentagon for Learning and Play	English	Suggestions for developing outdoor sensory play areas
Early Childhood Development	2015	Games For All Kids – Free Online Guide for Parents of Disabled Children	Scope UK	English	Video resource about inclusive play
Early Childhood Development	2017	Making Play Inclusive	Sense UK	English	Web-based resource including play toolkits for parents and for play-settings
Early Childhood Development	2018	Play and Children with Disabilities. Interdisciplinary Perspectives	Today’s Children Tomorrow’s Parents	English	Interdisciplinary Academic Journal

Thematic Area	Date	Title	Author and Publisher	Language	Comment
Early Childhood Development	2018	Toys to make from everyday items	Kidspot	English	Web-based resource with play ideas
Early Childhood Development	Undated	Everyday items make the best toddler toys	Care for the Family	English	One-page resource with suggestions for making toys from household items
Early Intervention	Undated	Early Intervention Foundation	EIF	English	Web-based resources including planning tools for managers, guidebook and standards
Emergency	2013	Guidance Note on Disability and Emergency Risk Management for Health	World Health Organization	English	Guidance note is intended primarily for health actors working in emergency and disaster risk management (hereafter 'emergency risk management') at the local, national or international level, and in governmental or non-governmental agencies.
Emergency	2009	Education in Emergencies: Including Everyone	Inter-agency Network for Education in Emergencies	English	Handbook for field staff
Emergency	Undated	Landmine Awareness	Action for the Rights of Children (ARC)	English	Training manual
Emergency	2017	Vulnerability- and resilience-based approaches in response to the Syrian crisis: Implications for women, children and youth with disabilities	Women's Refugee Commission	English	Recommendations and actions that can be taken to ensure that diversity and resilience of refugees with disabilities are recognized and fostered in humanitarian programming
Human and Child's Rights	1990	United Nations Convention on the Rights of the Child	UN	English	Summary of the Convention here
Human and Child's Rights	2006	UNCRC General Comment # 9. The rights of children with disabilities	UN	English	
Human and Child's Rights	2008	It's About Ability. An Explanation of the Convention on the Rights of Persons with a Disability	UNICEF	English	Explanation/summary of UNCRPD
Human and Child's Rights	2009	It's About Ability. Learning Guide on the Convention on the Rights of Persons with a Disability	UNICEF	English	Learning Guide on UNCRPD
Human and Child's Rights	2009	United Nations Convention on the Rights of Persons with Disabilities	UN	English	Full text of the UNCRPD
Human and Child's Rights	Undated	UNCRPD training guides	UN Division for Social Policy and Development	English and other	Web-based resource with easy-read versions, training guides and States ratification status in a range of languages

Thematic Area	Date	Title	Author and Publisher	Language	Comment
Human and Child's Rights	2016	General Comment #4 – Right to Inclusive Education	UN Committee on the Rights of Persons with Disabilities	English	Provides detailed information on how to implement the UNCRPD Article 24
Human and Child's Rights	2017	General Comment #5 – Living independently and being included in the community	UN Committee on the Rights of Persons with Disabilities	English	Provides detailed information on how to implement the UNCRPD Article 19
Human and Child's Rights	Undated	Women and girls with disabilities – using both gender and disability lens	UN Division for Social Policy and Development	English	Web-based resource library which provides gender perspectives on disability and the disability perspective on the situation of women and girls with disabilities
Inclusive and Community-based Services	2014	Changing Attitudes To Learning Disability	Mencap	English	Overview of attempts to change attitudes to individuals with learning disabilities (intellectual disabilities)
Inclusive and Community-based Services	Undated	Definitions of Stigma and Discrimination	Disability Rights California	English	Factsheet
Inclusive and Community-based Services	2009	Challenging stigma and discrimination	The National Centre of Mental Health Research, Information and Workforce Development New Zealand	English	Learning module
Inclusive and Community-based Services	Undated	ADD International	ADD International	English	ADD International is an ally to the global disability movement. We 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.
Overcoming Stigma and Discrimination		Disability stigma. A deadly enemy.	ADD International	English	Information about stigma and disability
Inclusive and Community-based Services	2009 (2nd Ed.)	Disabled Village Children	Hesperian	English	A guide for community health workers, rehabilitation workers, and families
Inclusive and Community-based Services	2016	Living Well With a Disability, A Self-Management Program	US Department of Health and Human Services and Centers for Disease Control and Prevention	English	Overview of the USA Living Well with a Disability program
Inclusive and Community-based Services	2016	Empowering People with Intellectual Disabilities Living in Communities in Massachusetts	Harvard FXB Center for Health and Human Rights	English	Explores good practices as exemplified by emerging strategies that provide housing and other services to those with intellectual disabilities
Inclusive and Community-based Services	1989	Training in the Community for People with Disabilities	WHO	English French	This manual is for people in the community who are planning, implementing or evaluating a community-based rehabilitation program.
Inclusive and Community-based Services	Undated	RI Global Work – Habilitation and Rehabilitation	Rehabilitation International (RI Global)	English	Factsheet on Health, habilitation and rehabilitation; this website also contains other resources useful for rehabilitation and habilitation practitioners

Thematic Area	Date	Title	Author and Publisher	Language	Comment
Inclusive and Community-based Services	2015	Assistive Technology for Children with Disabilities: Creating Opportunities for Education, Inclusion and Participation: A discussion paper	UNICEF and WHO	English	To improve access to assistive technology for children with disabilities
Inclusive and Community-based Services	2016	Priority Assistive Products List	WHO	Arabic Chinese English French Portuguese Russian Spanish	The Priority Assistive Products List aspires to follow in the footsteps of the WHO Model List of Essential Medicines, which creates awareness among the public, mobilizes resources and stimulates competition
Inclusive and Community-based Services	2008	Guidelines on the provision of manual wheelchairs in less-resourced settings	WHO, ISPO, USAID	Albanian Chinese English French Portuguese Romanian Russian Spanish	The guidelines, developed for use in less resourced settings, address the design, production, supply and service delivery of manual wheelchairs, in particular for long-term wheelchair users
Inclusive and Community-based Services	2018	Adapting the Child Care Environment for Children with Special Needs	Extension.org	English	Suggestions for modifications and links to useful resources for children with specific needs
Inclusive and Community-based Services	2012	Bilingual Apps for Deaf Readers	Gallaudet University	Dutch Saudi Russian Japanese Norwegian ASL English	A selection of bilingual apps which can be downloaded for iPad and Android
Inclusive and Community-based Services	2018	Refreshable Braille Displays	American Foundation for the Blind	English	Product information
Inclusive and Community-based Services	2014	Better Parenting Job Aid and Training Manual	FHI 360 and PACT Ethiopia	English	Developed in Ethiopia and endorsed by REPSI; how to strengthen the parenting capacity of parents and caregivers in their community
Inclusive and Community-based Services	2014	Myth-buster – Independent Living	European Network on Independent Living	English	Deals with some of the most common misconceptions about people with disabilities, independent living and personal assistance
Inclusive and Community-based Services	2015	Independent Living Manual	European Network on Independent Living	English	This manual is written to provide tools for change through information. It has a focus on Turkey but is internationally relevant
Inclusive and Community-based Services	Undated	The Independent Living Institute	ILI	English	Resource-rich site providing information, training materials and solutions for services for persons with extensive disabilities in Sweden and internationally

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Inclusive and Community-based Services	Undated	Asia-Pacific Network of Independent Living Centres	Asia Pacific Network of IL Centres	English	
Inclusive and Community-based Services	Undated	National Council on Independent Living	National Council on Independent Living	English	US-based service with information and resources
Inclusive and Community-based Services		Disability, CBR, and Inclusive Development Journal	Vrije Universiteit Amsterdam	English	Publishes evidence-based information to address needs of practitioners (particularly those from developing countries), policymakers, organizations of persons with disabilities and the scientific community
Inclusive and Community-based Services	Undated	Psychosocial Support for Children with a Disability and their Carers	REPSSI	English	A discussion paper
Inclusive and Community-based Services		Look at me, not my disability!	UNESCO Jordan	Silent video	Video resource; public service announcement produced by people with disabilities
Inclusive and Community-based Services		Here I Am	Mencap UK	English	Stories and video clips about learning disability
Inclusive and Community-based Services	2015	FairnSquare: Making the world better for kids with disabilities	Handicap International and UNICEF Mozambique	English	Video animation; learn how to make the world more inclusive for children with disabilities
Inclusive and Community-based Services	2015	CBR for Inclusive Development in Nepal	Thomas Koopman	Nepalese (English subtitles)	Video documentary
Inclusive and Community-based Services	2014	Community Based Rehabilitation in Ethiopia	CBM Worldwide	English	Video resource
Inclusive Education	Undated	Guidance Note Inclusive Education	USAID	English	This document serves as a guide on including persons with disabilities into USAID's education planning and implementation
Inclusive Education	2016	Inclusive Education: What, Why, and How?	Save the Children	English	Handbook for field staff at any stage of program implementation
Inclusive Education	2008	Making Schools Inclusive – how change can happen	Save the Children UK	English	This book is about how non-governmental organizations (NGOs) can help school systems in developing countries become more inclusive. It shares experience of developing tools and approaches that have improved education for the most excluded children in society
Inclusive Education	2014	Parents, Family and Community Participation in Inclusive Education	UNICEF	English	Companion technical booklet to assist UNICEF staff and our partners to understand the importance of engaging with parents, families and communities in the process of implementing inclusive education, with an emphasis on children with disabilities

Thematic Area	Date	Title	Author and Publisher	Language	Comment
Inclusive Education	2013	Inclusive Education Practices Toolkit	Wellbeing at School	English	Web-based resource developed by the New Zealand Government to undertake an inclusivity survey and develop actions plans for improvement
Inclusive Education	2012	Education	UNICEF	English	Web-based resources on inclusive education including advocacy tools and guidance
Inclusive Education	2015	Inclusive Education in Zambia	Credit Suisse and Leonard Cheshire International	English	Video resource
Inclusive Education	2015	Inclusive Education – Education Equity Now	UNICEF Europe and Central Asia	English	Video resource
Inclusive Education	2015	Embracing Diversity Toolkit for Creating Inclusive Learning-Friendly Environment	UNESCO	English	Offers a holistic, practical perspective on how schools and classrooms can become more inclusive and learning-friendly
Information		Sustainable Development Goals Knowledge Platform	UN	English	Sustainable Development goals
Information	2013	State of the World's Children – Children with Disabilities	UNICEF	English French Spanish Turkish Russian	The report examines the barriers that deprive children with disabilities of their rights and which keep them from participating fully in society. It also lays out some of the key elements of inclusive societies that respect and protect children with disabilities
Information	2011	The World Report on Disability	WHO	English	
Information		International Disability Alliance		English	Website with links to international disabled persons organizations and resources
Information	2017	Congenital Disabilities	Oxford University Press	English	Web-based general overview
Information	2017	The social model of disability	Scope	English	Informational video
Information	2016	Medical and social models of disability	Ann Chambers	English	Informational video
Information	2016	Congenital Anomalies	WHO	English	Web-based general overview
Information	2009	Disability and HIV Policy Brief	WHO	English	Policy Brief
Information	Undated	Disability, HIV and AIDS	UNICEF	English	Website with access to resources about disability and HIV
Information		Disability and HIV	World Bank	Spanish	Resource developed for use in Central America but with potential for global application
Information	2015	Six tips for active listening	SpunOut.ie	English	Animated video resource
Information	2016	Sexuality Education for Students with Disabilities	Parent Center Hub	English	Parent information and resources

Thematic Area	Date	Title	Author and Publisher	Language	Comment
Information	2005	Sexuality Education for Children and Adolescents with Developmental Disabilities	Florida Developmental Disabilities Council, Inc.	English	An instructional manual for Parents or caregivers of and individuals with Developmental disabilities
Information		Sexual Education Resources	Respectability.org		A list of resources and links on all aspects of sexuality and safety
Participation	2016	Guidelines for consulting with children and Young People with Disabilities	Plan International	English	Provides practical suggestions for consulting with children and young people with disabilities in a variety of situations.
Participation	2011	The Importance of Fingerspelling for Reading	NSF Science of Learning Center	English, Mandarin and Spanish	Research brief #1 To understand the role of fingerspelling in language acquisition and later literacy, it is important to understand how fingerspelling is naturally acquired by deaf and hard of hearing children
Participation	2011	Advantages of Early Visual Language	NSF Science of Learning Center	English, Mandarin and Spanish	Research brief #2 early language acquisition in young deaf and hard of hearing children
Participation	2011	Visual Attention and Deafness	NSF Science of Learning Center	English, Mandarin and Spanish	Research Brief #3 Maintaining improved visual attention for improved learning outcomes in young deaf hard of hearing children and adults
Participation	2011	Reading Research and Deaf Children	NSF Science of Learning Center	English, Mandarin and Spanish	Research brief #4 Summary of the research related to deaf readers and to identify key findings that impact the development of fluent reading skills in deaf children
Participation	2011	Eye Gaze and Joint Attention	NSF Science of Learning Center	English, Mandarin and Spanish	Research brief #5 Fundamental skills for successful interactions in home and school environments
Participation	2011	Children with Cochlear Implants	NSF Science of Learning Center	English, Mandarin and Spanish	Research brief #6 The Implications of Bimodal Bilingual Approaches for Children with Cochlear Implants
Participation	2011	The Benefits of Bilingualism	NSF Science of Learning Center	English, Mandarin and Spanish	Research brief #7 Research into use of American Sign Language and English
Participation	2011	American Sign Language/English: Bilingual Education	NSF Science of Learning Center	English, Mandarin and Spanish	Research brief #8 Models, methodologies, and strategies of ASL/English Bilingual Education
Participation	2011	Family Involvement in ASL Acquisition	NSF Science of Learning Center	English, Mandarin and Spanish	Research brief #9 Discusses how parental involvement is a critical factor in deaf children's language acquisition
Participation	2011	Different Ways of Thinking	NSF Science of Learning Center	English, Mandarin and Spanish	Research brief #10 Discusses the critical role that gesture plays in language acquisition for young deaf and hard of hearing children
Participation	2017	Not special needs	Notspecialneeds.com	English	Video resource. Adolescents with Down Syndrome changing language changing attitudes

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Participation	2013	Listen up! Children with disabilities speak out	Plan International Sierra Leone	French (English subtitles)	Video resource
Participation	2011	Raising the Whole Child	NSF Science of Learning Center	English, Mandarin and Spanish	Research brief #11 Reviews the research on social-emotional development in children from birth to 12th grade, particularly focusing on deaf and hard of hearing children
Participation	Undated	Children's voices	Lumos	English	Children's stories about their experience of living in residential institutions and the difference for them when they moved to family-type care.

Endnotes

- ¹ <https://www.unicef.org/disabilities/>
- ² The hyperlinks in this document were live as of June 1, 2018.
- ³ Taken from Guidelines on Children's Reintegration, Inter-agency group on children's reintegration (2016) https://www.familyforeverychild.org/wp-content/uploads/2016/08/RG_Digital_DC.pdf
- ⁴ Adapted from Browne, K. (2009) The Risk of Harm to Young Children in Institutional Care. Save the Children: London https://www.bettercarenetwork.org/sites/default/files/The%20Risk%20of%20Harm%20to%20Young%20Children%20in%20Institutional%20Care_0.pdf
- ⁵ Adapted from <http://www.socialserviceworkforce.org/social-service-workforce>
- ⁶ Barker, 2003, cited in <http://www.socialserviceworkforce.org/sites/default/files/uploads/Case-Management-Concepts-and-Principles.pdf>
- ⁷ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
- ⁸ Note that "they", "their", and "them" are used as singular, gender-neutral pronouns throughout this document.
- ⁹ Adapted from Handicap International and CBM <http://www.making-prsp-inclusive.org/en/6-disability/61-what-is-disability/611-the-four-models.html> and the International Disability and Human Rights Network <http://www.daa.org.uk/uploads/pdf/Disability,%20Development%20&%20HR.pdf>
- ¹⁰ Browne, K. (2009) The Risk of Harm to Young People in Institutional Care. Save the Children: London available at <https://bettercarenetwork.org/library/particular-threats-to-childrens-care-and-protection/effects-of-institutional-care/the-risk-of-harm-to-young-people-in-institutional-care>
- ¹¹ Jones L et al. Prevalence and risk of violence against adults with disabilities: a systematic review and meta-analysis of observational studies. *Lancet*, 2012; July 12 (doi:10.1016/S0140-6736(12)60692-8). Cited in WHO and UNICEF (2012) Early Childhood Development and Disability: A discussion paper
- ¹² Nejelesani, J., Hashemi, G., Cameron, C., Cameron, D., Richard, D. and Parnes, P. (2018) From the day they are born: a qualitative study exploring violence against children with disabilities in West Africa. *BMC Public Health* 18:153 <https://bmcpublihealth.biomedcentral.com/articles/10.1186/s12889-018-5057-x>

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