Toolkit for Disability Inclusion in Care Reform

Service and Resource Mapping Guidance to Support Inclusion of Children with Disabilities
This Toolkit for Disability Inclusion in Care Reform was produced by Changing the Way We CareSM (CTWWC), an initiative designed to promote safe, nurturing family care for children. It represents a collection of work developed from the experience of many practitioners. We thank the following people and organizations for their significant contributions: Elayn Sammon, Gwen Burchell, Leia Isanhart and Kupenda for the Child. Appreciation also to the CRS and CTWWC teams in Kenya, Guatemala, Zambia and beyond for their input, feedback and pilot testing.

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

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

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# Glossary

| **Advocacy** | Advocacy is when people get support to speak up. It is a process of supporting and enabling people to express their views and concerns, access information and services, defend and promote their rights and responsibilities and explore choices and options. |
| **Advocate** | (1) The person who supports another through the advocacy process.  
(2) The act of advocacy |
| **Alternative care** | A formal or informal arrangement whereby a child is looked after at least overnight outside the parental home, either by decision of a judicial or administrative authority or duly accredited body, or at the initiative of the child, his/her parent(s) or primary caregivers, or spontaneously by a care provider in the absence of parents. Alternative care includes kinship care, foster care, adoption, *kafala*, supervised independent living, and residential care. |
| **Child** | A child is a person under 18 years of age, unless otherwise defined by national definition |
| **Child protection system** | A comprehensive system of laws, policies, procedures and practices designed to ensure the protection of children and to facilitate an effective response to allegations of child abuse, neglect, exploitation and violence. |
| **Community-based Inclusive Development** | An approach that brings change in the lives of people with disabilities at community level, working with and through local groups and institutions. CBID addresses challenges experienced by people with disabilities, their families and communities in practical ways.  
These enhance and strengthen community-based rehabilitation (CBR) as it has evolved over the last decades. |
| **Developmental delay** | Refers to a child’s developmental skills developing later than expected, compared to others of the same age. Delays may occur in the areas of motor function, speech and language, cognitive, play, and social skills. Delays can indicate a disability, but not always – many children with delays catch up. |
| **Disability** | Disability is a long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder a person’s full and effective participation in society on an equal basis with others (UNCRPD). |
| **Discrimination** | Discrimination happens when individuals or institutions unjustly deprive others of their rights and life opportunities due to stigma. |
| **Family** | Refers to those within the caring circle of a child; those providing daily emotional, physical and psychological care. This caring circle varies according to culture and circumstance; thus, the use of the term family recognizes that in many societies the care environment of a child is broader than the parents of birth or immediate family and includes the extended family, sometimes called *kinship network*. Families have primary caregivers who can be birth, extended relative, foster or adoptive parents, in some instances, child-, grandparent-, or single parent-headed. CTWWC further expands the term to include families who are providers of family-based alternative care, such as *foster family*. |
| **Habilitation** | This is a process aimed at helping disabled people attain, keep or improve skills and functioning for daily living; its services include physical, occupational, and speech-language therapy; various treatments related to pain management; and audiology and other services that are offered in both hospital and outpatient locations.¹ |
| **Inclusion** | Inclusion involves a full reform, which means that children with disabilities can participate fully in the life of the family and community. This means making changes to the environment, the way we all communicate, our attitudes/belief systems and the way we provide services. |

### Independent living

Here a young person or adult with disabilities is supported in her/his own home, a group home, hostel, or other form of accommodation, to become independent. Support/social workers are available as needed and at planned intervals to offer assistance and support but not to provide supervision. Assistance may include timekeeping, budgeting, cooking, job seeking, counselling, vocational training and parenting.

Independent living/living independently means that individuals with disabilities are provided with all necessary means enabling them to exercise choice and control over their lives and make all decisions concerning their lives (see UNCRPD General comment on Article 19: Living independently and being included in the community). For children with disabilities, this involves ensuring that, in line with their evolving capacities, they have the same freedoms as typically developing children to make choices in life, and that they receive support for the choices they make.

### Occupational therapy

This focuses on helping people with a physical, sensory or cognitive disability to be as independent as possible in all areas of their lives. It can help children and adults with a disability improve their cognitive, physical, sensory and motor skills and enhance their self-esteem and sense of accomplishment.

### Participation

Participation is exercising the right to be listened to and to involvement in decisions and actions that affect the one participating (such as child participation) and to have those views taken into account.

### Physiotherapy

Physiotherapy is science-based profession that helps restore movement and function when someone is affected by injury, illness or a disability. It can also prevent deterioration and further loss of function through a maintenance program of rehabilitation based on individual treatment plans.

### Rehabilitation

Rehabilitation refers to regaining skills, abilities or knowledge that may have been lost or compromised as a result of acquiring a disability or due to a change in one’s disability or circumstances.²

### Reunification

The physical reuniting of a separated child and his or her family or previous caregiver.

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² Ibid.
| **Reintegration** | The process of a separated child making what is anticipated to be a permanent transition back to his or her immediate or extended family and the community (usually of origin), in order to receive protection and care and to find a sense of belonging and purpose in all spheres of life. Re/integration can also refer to the process of a person with disability, who has been institutionalized, making a transition back to living in the community. |
| **Residential institution** | A large institution is characterized by having 25 or more children living together in one building. A small institution or children's home refers to a building, housing 11 to 24 children. Can also refer to a facility housing adults with disabilities. |
| **Self-advocate** | This is a child or individual who has the skills knowledge and support to advocate on their own behalf. |
| **Speech and language therapy** | These support children and young people who have a speech disorder (a problem with the actual production of sounds) or a language disorder (a problem understanding or putting words together to communicate ideas). They work on augmentative and alternative communication, which are the methods used to supplement or replace speech or writing for those with impairments in the production or comprehension of spoken or written language. |
| **Stigma** | Stigma refers to attitudes and beliefs that lead people to reject, avoid or fear those they perceive as being different. |
| **Typically developing child** | This describes a child who meets the usual developmental milestones within the usual timescales. |
| **UNCRC** | The United Nations Convention on the Rights of the Child is a legally binding international agreement and human rights instrument setting out the civil, political, economic, social and cultural rights of every child, regardless of their race, religion or abilities. |
| **UNCRPD** | The United Nations Convention on the Rights of Persons with Disabilities is a legally binding international agreement and human rights instrument that reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. |
Section 1: What is Service Mapping

This guidance specifically refers to mapping of services as the process of locating and sharing information to a wide range of people about available services to support children with disabilities and their families.

The mapping of services and resources to support inclusion of children with disabilities involves finding out what services and resources are available, their quality and their accessibility. By creating this type of listing, social workers, other professionals working with children/families and families themselves know where they can go to get the help they need.

The map can be geographic showing the area covered and pinpointing the services (Figures 1 and 2).

*Figure 1. Map of local tourist services in Antigua, Guatemala*
Figure 2. Map of local veterinary services, Nairobi, Kenya

The mapping can also be presented as a directory or a listing of the services with addresses and other contact details. These directories can be sub-divided by theme (Figure 3).

They may also be available both as a paper-based and/or electronic and interactive resource (Figure 4).

Figure 3. Example of a paper-based service directory

Some examples of electronic service and resource directories can be found by following the links below.

- Information sharing about HIV and AIDS; and on-line global directory
- Birmingham Women’s and Children’s NHS Foundation Trust Searchable Service Directory
- Kenya National Directory for Children’s Service Providers
Figure 4. Example of an electronic service directory
Section 2: Why is service mapping important

There are many reasons why service mapping is important. Creating and maintaining an up-to-date list of services and resources in the community, county and even nationally enables the social service, health, education and social protection workers to know what, where and how to connect children, youth, family members and other caregivers to the services that allow them to lead full, productive lives. The mapping process itself can help a community understand the strengths and needs of those with disabilities better and identify gaps in services that all community members could benefit from. Service mapping can:

- Identify new resources, services, partners to develop, enhance, and sustain goals around improving children’s care;
- Highlight the unique assets and challenges of a community
- Determine the efficiency and effectiveness of existing resources and services;
- Improve alignment and coordination of resources and services;
- Enhance coordination, collaboration and referral mechanisms amongst stakeholders; and
- Inform local policies better meet goals around children’s care and disability inclusion.

Mapping that is done with community members, youth, children and families can help to build a more cohesive community and address stigma and other barriers to service access. The mapping process requires strong partnerships, good communication between stakeholders, commitment to data collection and analysis, and on-going effort for continuous improvement. Done collaboratively, mapping can help a community recognize itself as a whole and unite around children and families, and can build bridges across differences and ensure voices of the most marginalized are heard.
Section 3: How to Start the Process of Mapping

The service manager should identify a responsible person within the organization who supports the objectives of the mapping, the timeline and the available resources (level of effort and budget).

When developing and agreeing on the objectives of the mapping, the service manager and responsible person should consider:

- What is the geographic focus?
- What is already known about the service needs of families in the area?
- What services and resources should be included?
- What kind of information should you have about the services and resources (e.g., contact details, opening times, cost, referral mechanisms)?
- How will the presentation and dissemination of the mapping be made available to the people who need it?
- How will you gather and verify the information?
- How will the information be updated?
Section 4: Determining Geographic Focus

The services and resources included in the mapping will depend on the geographic focus. If you live and work in a capital city, such as Nairobi or Guatemala City, it is likely that there will be many more services and resources available. However, if the metropolitan area is very large you may decide that there are too many services, or that these are inaccessible to most people because of distance or cost. In this case, you may decide to use the zone, constituency or ward in which you work as the starting point. If you live and work in a more remote town or rural area where there are fewer services, you may consider including the services in your immediate area and in the nearest largest district or provincial capital. Some mappings will lay out services and resources at the national and sub-national levels. For example, if there is an assessment and rehabilitation center for children with disabilities in the capital city but not in other towns, this could be included; or, if there are district clinics with a physiotherapist, these would be included at the sub-national level.

It is good to start with your local area first, and then define your geographic focus by radiating outwards (Figure 5.).

Figure 5. Defining geographic focus
Section 5: Determining Services and Resources

A service is a valuable action planned in an organized way and performed to satisfy a need or to fulfill a demand. It is an act, or a variety of work done for others, often on a regular basis. Vaccinations are an example of a health service and foster care is an example of a social care and support service.

A resource is a source of help or information, or an asset than can be used by a person or an organization to obtain or deliver a service. Examples include a training manual, information pamphlets, websites, etc.

This guide is about mapping services and resources to support inclusion of children with disabilities in family care. You should look for and include general services and resources which are available to support children and families (for example, clinics, schools, social services offices and legal advice centers) and specialist services for children with disabilities and their families (for example, inclusive pre-schools, assessment centers, rehabilitation centers and civil society organizations for people with disabilities—see Table 1). These services may be provided by government, civil-society/faith-based organizations or private sector suppliers. For all services—whether general or specialized—consider accessibility of the service in terms of geographic location, physical infrastructure (including furniture within the building), cost, attitude of providers, availability of information about the service and communication used by service provider. Organizations for persons with disabilities are great resources to help evaluate accessibility.

Begin by having a brainstorming session in your workplace. This will help you think about what services there are in your area. Then ask other people what services they know about, which should then be included. This could mean putting this on the agenda for discussion at the next multi-sectoral coordination meeting or talking to people who work in health or education services about what they offer. Families are also a useful source of information; parents and caregivers can tell you a lot about what is already available, and they can also tell you about informal groups. Parents and caregivers might suggest what information would be useful for them to have about particular services and resources.

It is also a good idea to discuss with your local government partners to find out if any service directories already exist, and to hear from them what is most important to include.

In some countries, where there are strong systems in place for regulation, there may be a requirement to license services provided by civil society, faith-based organizations and private sector suppliers. If this is the case, ask the service to provide a copy of their license so that you can verify and include this information in the directory.

The terminology around social care and support can be complex and confusing and is usually determined in national policy; this guidance uses social care and support to describe a service which benefits an individual child and their family, or an older person or a person with a disability, either through offering a direct service or referral to a specialized service; social care and support is described by UNICEF as services that are resource-intensive which help identify and reduce vulnerability and exclusion, particularly at the child and household level by strengthening individuals’ and households’ resilience; improving their capacity to overcome shocks and strains; and linking households to existing programs and services.

Section 6: Information to Include

The information in your mapping or service directory should be useful for the people who are going to use it. Begin by thinking about what information you might need in order to make referrals. Next, ask other professionals working in your area and families of the children you are working with, what kinds of information they need.

At a minimum you should include:

- Name of the service
- Type or variety of service offered
- Target client group (e.g., children ages 0–6, children with disabilities, adolescents)
- Physical address/location
- Transportation links
- Contact telephone number/s
- Contact email
- Website address
- Opening hours

You may choose to include the name of a contact person for the service; however, if the person changes jobs this information can become quickly outdated.

Other helpful information to include:

- Eligibility criteria for inclusion as a service client
- Referral process
- Accessibility (e.g., is the location easy to access for people with activity limitations; is there a sign language interpreter available?)
- Service fees (e.g., is the service free or do clients pay for the service?)
- Quality (e.g., is the provider registered; are services up to date?)

In some locations, services may be provided by government and non-governmental organizations (NGOs) on a project basis—they are financed by a donor in the short-term with the expectation that long-term costs will be funded locally. Sometimes this does not happen, and the service ceases to exist when the project ends. Consider including the information that this is a project-based service in the listing, and where possible, include the project closure date.
Section 7: Making Service Mapping Available to People Who Need It

The information should be presented in a way that is easy to navigate to find the necessary information. Think about the structure as you collect the information (Table 1). This can include sub-divisions for service availability at the national and sub-national levels:

- government, civil society and/or private sector service provider
- general and specialist services

Table 1. Examples of local Service Mapping structure by sections and type of services

<table>
<thead>
<tr>
<th></th>
<th>Government</th>
<th>Civil Society Organizations</th>
<th>Private Sector</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinics and hospitals</td>
<td>Habilitation and rehabilitation, involving physiotherapy, speech therapy, occupational therapy</td>
<td>Parenting classes</td>
<td>Counseling</td>
</tr>
<tr>
<td>Pre-schools, primary and secondary schools</td>
<td>Inclusive school with support teachers in place</td>
<td>Maternal and child health volunteer group</td>
<td>Early intervention home-visiting</td>
</tr>
<tr>
<td>Foster care</td>
<td>Specialist, foster care</td>
<td>Adolescent job clubs</td>
<td>Independent living service</td>
</tr>
<tr>
<td>Social care and support services (social worker and case management)</td>
<td>Disability-specific social work team</td>
<td>In-kind school supplies</td>
<td>Assistive devices for learning (e.g., Braille machines, tablet computers)</td>
</tr>
<tr>
<td>Child-friendly courts</td>
<td>Accessible and inclusive child-friendly courts</td>
<td>Free legal advice</td>
<td>Free disability rights legal advice</td>
</tr>
<tr>
<td>Social protection (cash and in-kind benefits)</td>
<td>Assistive devices for learning (e.g., Braille machines, tablet computers)</td>
<td>Transport</td>
<td>Accessible transport</td>
</tr>
<tr>
<td>Council-run sports center</td>
<td>Fully accessible council-run sports center</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

List resources in a separate section and—where possible—details on where and how to access the resource; this can include embedding a link to the electronic resource or providing advice on where the paper-based resource can be accessed (Figure 6).
Deciding what format to use to store and disseminate the information depends on several factors:

- **Who will be using the service and resource mapping?**
- **What budget is available?**
- **Do the people who will be using it have access to technology?**

For people with limited access to technology, who may live in rural areas and have limited storage facilities, the service and resource mapping may need to be paper based. In this case it should be robust enough to withstand regular handling.

If the service directory is to be made available to families or community groups/leaders, whose literacy skills may be limited, consider how to present the information in an “easy-to-read” format.

If budget and technology are accessible, an electronic format may be preferable. This can be more quickly and easily updated and maintained. It can also be searchable and easier to navigate than a paper based directory.

A sample referral guide is provided in the annex.
Section 8: Gathering, Verifying and Updating

The responsible person will begin to collect information and resources by:

- using their own local knowledge
- asking other professionals in their network
- adding the service mapping as an agenda item at multi-sectoral coordination meetings
- talking to parents and caregivers
- talking to disabled people’s organizations or individuals
- conducting an internet search

Before including the information in a directory, it should be validated by:

- visiting the service and observing it
- telephoning the service and confirming the service type and contact details
- asking to see the service license (if a regulatory system is in place)

The mapping of resources and services is like a photograph—it records the availability of a specific service at a given moment. This means that the information can easily become out-of-date if new services become available and are not included, if existing services cease functioning, or if resources are updated to include new information.

The developers of the service mapping should build in a system for updating the information.

For a paper-based service and resource directory, this may include keeping a local database (for example, using an Excel spreadsheet). The responsible person should add and remove information as it becomes known. This means the information is easily available and can simply be updated when the directory is renewed on a regular, agreed-upon basis.

For an electronic service and resource directory, the responsible person should add and remove information as it becomes known, so that the data is always up to date.

The service and resource directory should be reviewed by the team annually, at minimum. This can mean that the responsible person calls each service in the directory to verify their information. Details will then be updated or the information removed if the service is no longer provided.
Section 9: Additional Resources

- Christian Alliance for Orphans: [www.cafo.org](http://www.cafo.org)
  - Community mapping
  - Free course on community mapping
- Christian Blind Mission (CBM): [https://www.cbm.org](https://www.cbm.org)
  - Inclusion Made Easy
  - Disability Inclusive Development Toolkit
  - Humanitarian Hands-On Tool
- International Disability Alliance: [http://www.internationaldisabilityalliance.org/all-countries](http://www.internationaldisabilityalliance.org/all-countries)
- World Blind Union inclusion resources and toolkits: [www.worldblindunion.org/programs/accessibility/](http://www.worldblindunion.org/programs/accessibility/)
- World Health Organization (2010). Community-based Inclusive Development: [https://www.who.int/publications/i/item/9789241548052](https://www.who.int/publications/i/item/9789241548052)
- World Health Organization on disability: [www.who.int/health-topics/disability](http://www.who.int/health-topics/disability)
### Kilifi County Sample Service Referral Guide for Children with Disabilities

(Note: Shared only as an example, information has not be updated)

<table>
<thead>
<tr>
<th>Child Protection Center</th>
<th>Services</th>
<th>Location</th>
</tr>
</thead>
</table>
| Malindi Child Protection Centre | ▪ Referral to other service providers (e.g. hospitals, schools, police, other NGOs, government offices, etc.)  
▪ Assessment of cases & provision of assistance.  
▪ Child and family counselling.  
▪ Legal advice and aid for parents/caregivers and children.  
▪ Tracing and family reunification for lost or abandoned children.  
▪ Library services and leisure during open days when children come to the center to have fun interact and also learn about their rights. | The Malindi office is opposite Mijikenda  
Monday – Friday: 8am – 5pm  
Tel: 0702 170 165  
cpcmaliindi@yahoo.com  
www.cpckenya.org |
| Comitato Internazionale per lo Sviluppo dei Popoli (CISP) | ▪ CISP has recruited and trained legal officers, social workers, counsellors, and volunteers to provide services to children at the centers.  
▪ Trains service providers, teachers, chiefs, local and religious leaders, village elders, and community groups with the aim of deepening and sharing knowledge about children’s rights.  
▪ CISP supports case management at CPCs and through mobile services, by covering fees, facilitating repatriation and family reintegration of separated children. | #20 Loiyangalani Dr., off Convent Dr., Lavington, Nairobi  
Tel: +254 733 441 441  
Email: nairobi@cisp-ngo.org |
| Traced Kenya | ▪ Rescues, rehabilitates and reintegrates women, youth and child survivors of human trafficking in Kenya  
▪ Works closely with the Kenya National Commission on Human Rights (KNCHR) on issues of counter human trafficking, including referrals cases for follow-up. | The Traced Kenya office is in Mtwap  
+254 702 361 137  
+254 715 645 110  
info@tracedkenya.org  
www.tracedkenya.org |

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