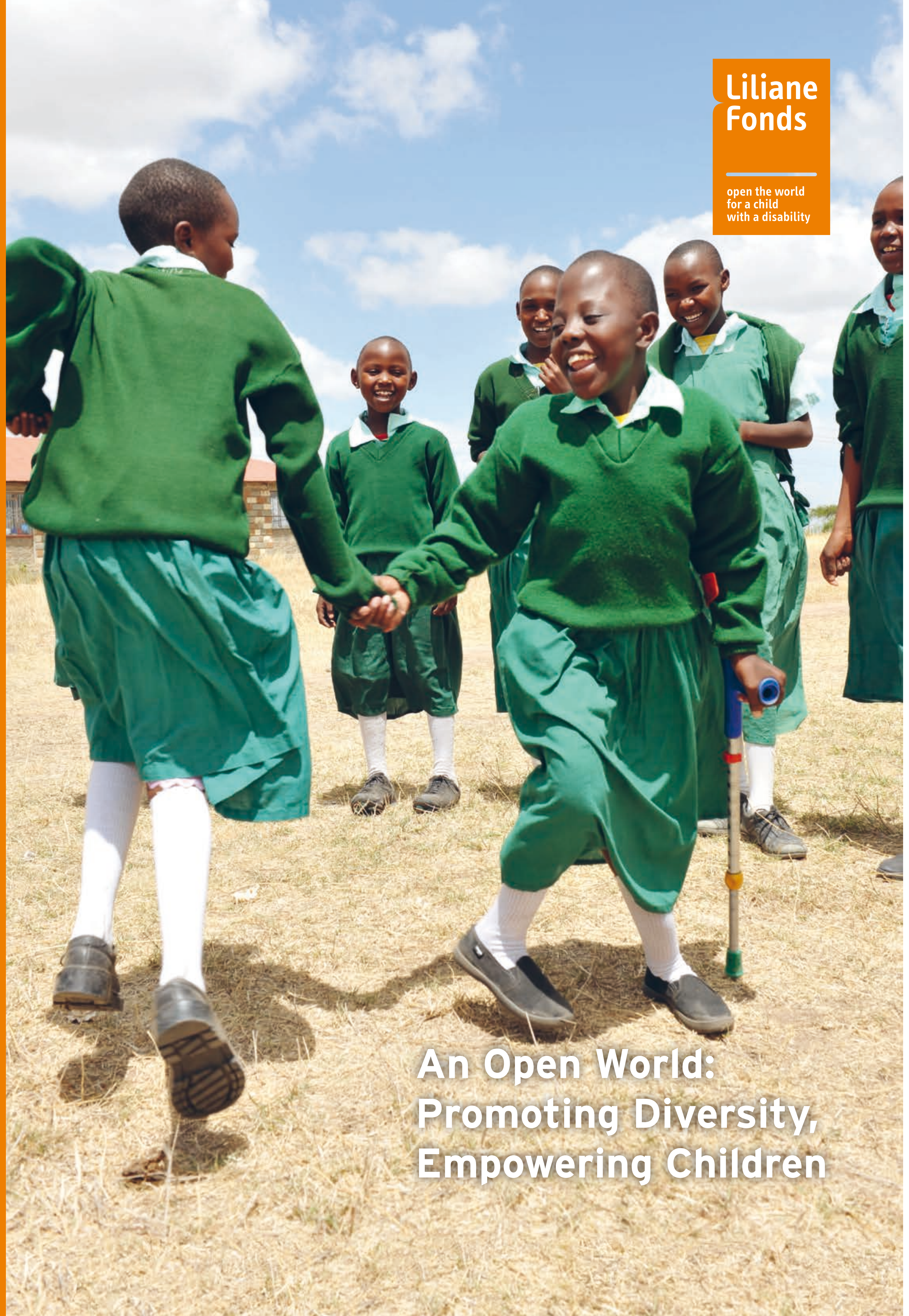
Our Dream is an animation that presents the vision and the core strategy of the LF in a simple yet creative way. The animation was designed by **Kim Ravers**, a visual artist and owner of **Custom Heartwork** and her team of associates, **Hans Jong** and **Tineke Blok**. Thanks to their professionalism and great effort, we have a communication tool that can be used towards variety of stakeholders with which we collaborate.

An Open World: Promoting Diversity, Empowering Children

Liliane
Fonds

open the world
for a child
with a disability



An Open World: Promoting Diversity, Empowering Children

image: Maaike van den Bemt

"People need each other in order to feel complete. When others avoid, exclude or ignore you, as a person, you languish. But also when you are the one rejecting another person, closing your eyes to him, wanting nothing to do with him, you fall short as a person. By being diverse people can enrich, strengthen, feed and complement each other. To become 'whole' you must be willing to share as well as be open."

Liliane Brekelmans - Gronert
Founder, Liliane Foundation
(1929 - 2009)

Maria, a Masai girl from Kenya, suffers from severe deformities to her legs and wrists. She lives in a rehabilitation centre where they have numerous aids and she receives physiotherapy. She also visits an ordinary school not far from the centre. Maria comes from a poor family. Her parents live 90 km (56 miles) away and she only sees them at Christmas. Fortunately, Maria enjoys living at the centre. She has lots of friends and the atmosphere is fine. The Liliane Foundation supports Maria and pays for her stay at the centre, her physiotherapy, her crutches and her schooling.

Abbreviations

ADL	Activity of Daily Living
CBOs	Community Based Organisations
CBR	Community Based Rehabilitation
CE	Child Empowerment
DCA	Direct Child Assistance
DPOs	Disabled People's Organisations
FBOs	Faith Based Organisations
ICF	International Classification of Functioning
ILO	International Labour Organisation
LF	Liliane Foundation
MDGs	Millennium Development Goals
MFIs	Micro Financing Institutions
NCTs	National Coordination Teams
NGOs	Non Governmental Organisations
POs	Partner Organisations
PSHG	Parents Self Help Groups
SHG	Self Help Groups
SPOs	Strategic Partner Organisations
(UN)CRC	United Nations Convention on the Rights of the Child
(UN)CRPD	United Nations Convention on the Rights of the Persons with Disabilities

Image: Maaike van den Bemt

An Open World: Promoting Diversity, Empowering Children

Liliane Fonds

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Image: Dennis Brussaard

Foreword

From its very beginning the Liliane Foundation promoted participation and equality for children with disabilities. The founders were inspired by their strong belief in the intrinsic value of every person. We still are today. Just as we still share their conviction that direct, individual, tailor-made support helps children with disabilities to become more closely involved in their families and their communities.

Over the years, we stayed true to our roots and our principles, but we also kept developing them. Informed by practice at grassroots level, in dialogue with stakeholders. Having an eye for new opportunities and insights, changing world relations and a shifting Zeitgeist. We have broadened our horizons. Step by step, we have become what we are today: an organisation fully committed to championing the fulfillment of disabled children's rights, at small and large scales, in co-operation with allies.

Ambition

Our ambition is not limited to the children we actually support. In the poorest parts of the world, millions more children with disabilities are in the same unacceptable circumstances. We and our allies must therefore do everything in our power to promote a disability inclusive world. After centuries of denial and neglect, now is the time to focus on the rights and interests of people with disabilities. This focus should in the coming years be reflected in policies at national, international and supranational level. We are aiming for the Dutch government to formulate and implement a disability-inclusive international cooperation policy, and we will plead for inclusion as a leading principle in the Post-2015 Development Agenda.

The contents of this paper are evidence of the Liliane Foundation's continuing development, especially in recent years. I am proud and confident that this paper will support us all in contributing to the fulfillment of the rights of children with disabilities.

Kees van den Broek,
Director, Liliane Foundation


image: Henk Braam

Table of contents

Readers' Guide

→
This LF publication will serve as a policy document that will guide the LF staff and partners on how to contextualize the LF Core Strategy in the field.

The Liliane Foundation (LF) has expanded its core strategy, which is now referred to as Child Empowerment. This publication offers a common understanding of Child Empowerment to the wide network of the LF's partner organisations. It focuses solely on Child Empowerment and its two components: Child Development and an Enabling Environment. It takes the reader on a journey, starting at the very beginning of why LF chose to expand its core strategy; then focusing on the implementation of the Child Empowerment strategy and providing practical steps for partners to translate the new strategy into their practice in the field. Due to its focus on the content of the core strategy, this publication does not encompass the facilitative process of capacity building of the partner network that is required for the organisational implementation of the core strategy.

1

Disability in the International Development Arena

In Chapter one, the concept of disability is reviewed as a phenomenon in society, and explored in the light of current developments within the international development sector, and the sector's future directions.

2

Pillars of the Liliane Foundation's Core Strategy

In Chapter two, LF reviews its own position as a disability focused organisation within the sector and the value it adds, and analyses the international initiatives and strategies that gave the LF inspiration to further develop its core strategy based on the following three pillars:

- International Classification of Functioning, Disability and Health (ICF)
- The UN Convention on the Rights of the Child and UN Convention on the Rights of Persons with Disabilities
- Community Based Rehabilitation

3

The Liliane Foundation's Core Strategy Development

In Chapter three, LF reflects on (past and present) objectives and practices of the Direct Child Assistance approach, and gives new policy directions for the core strategy of LF. It explores the different models of disability, and discusses the ICF as a bio-psychosocial model of disability and optimum model for the new LF core strategy.

4

Child Empowerment Strategy

To articulate the new changes in the core strategy, LF simultaneously revised its vision and mission which are elaborated in Chapter four. The expanded core strategy is then further explored in the light of Community Based Rehabilitation components, and related to practical implications of Child Development and an Enabling Environment.

5

Actors in the Child Empowerment Strategy

Chapter five discusses the role of the local partner organisations as the main implementing actors of the Child Empowerment Strategy. It suggests further ways to safeguard the holistic approach and to cultivate networking activities with relevant stakeholders in the community.

6

The Liliane Foundation's Dream of a Disability-Inclusive Society

In Chapter six, a final attempt is made to bring the dream of inclusive societies closer to reality by exploring six steps required for the achievement of sustainable improvements for children and youngsters with disabilities. These six steps should assist partners in integrating the new strategy into their own programmes.

image: Morad Bouchakour

chapter one

Disability in the International Development Arena

The aim of this chapter is to reflect on disability as a phenomenon in society and to review the developments within the international development sector, analysing why the sector missed the opportunity to develop disability - inclusive Millennium Development Goals (MDGs), and what is the future direction of the post 2015 development agenda.

Disability: Facts and Figures

According to the World Bank and the World Health Organisation, an estimated 15% of the world's population lives with a disability, of which 150-200 million are children under the age of 18.[1] While this staggering figure includes a range of physical, mental, intellectual and sensory impairments, it is further estimated that 90 million children aged 0-14 experience a moderate or severe form of disability and 13 million of these children experience difficulties in life situations.[2] Of the total number of persons with disabilities, 80% are living in middle and low-income countries. These people often do not receive adequate technical, medical or social support with the potential to improve their living conditions.[3]

It is furthermore estimated that in the near future, disability might be on the rise as the world population is ageing. This is due to a global increase in chronic health conditions and mental health disorders, but also to road traffic accidents, armed conflicts and other forms of trauma. In addition, as a consequence of the relative success of the MDGs, more newborns remain alive with severe impairments such as cerebral palsy. These issues, coupled with environmental factors that influence participation, such as climate, infrastructure, policies of governmental institutions and attitudes of other members of society, all negatively affect the inclusion of persons with disabilities.

←
90 million children aged 0-14 experience a moderate or severe form of disability and 13 million of these children experience difficulties in life situations.

Disability and Poverty

People with disabilities make up an estimated 20% of the poorest populations.[4] There is growing consensus among disability advocates and experts that the most serious issue faced globally by persons with disabilities is not their specific impairment, but rather their lack of equitable access to resources and services such as education, employment, healthcare and social and legal support systems.[5] As a result, persons with disabilities are socially more vulnerable, at higher risk of social exclusion and therefore more prone to poverty. Persons with disabilities are also considered among the most eligible recipients of social protection measures.

←
Disability contributes to poverty, while poverty increases the likelihood of becoming disabled.

Disability contributes to poverty, while poverty increases the likelihood of becoming disabled. As demonstrated in the previous paragraph, being disabled can be seen as an important vulnerability factor that can lead persons with disabilities and their families to resort to strategies that push them into critical poverty.[6]

While the linkages between disability and poverty are complex, there is a strong consensus that persons with disabilities and households with disabled members are often significantly poorer, with fewer resources and more fragile support networks, than non-disabled individuals, and households with no disabled members.[7]

Households of people with disabilities typically possess lower human capital (encompassing health, education and labour, comprimized by either the impairment(s) or social discrimination) than households of able bodied people.

Households of persons with disabilities typically possess lower human capital (encompassing health, education and labour, compromised by either the impairment(s) or social discrimination) than households of able bodied people. Consequently, the earning capacity of persons with disabilities as well as their caregivers is reduced. Furthermore, disabled persons' households face disability related expenses that most households do not face (e.g. assistive devices, transport, health care costs, increased housing costs), aggravating income poverty. In developing countries, where formal support systems are limited, social interaction and support are considered valuable resources. Persons with disabilities and their households often experience low levels of social interaction and support, however, due to social discrimination. Income poverty may in turn trigger chronic (long term/intergenerational) poverty, as households of persons with disabilities are deprived of opportunities for participating in society and accessing services.[8]

The MDGs are the world's time-bound, quantified targets for addressing extreme poverty. The fact that persons with disabilities are not explicitly included in any of the MDGs represents a lost opportunity to address their needs and may increase their poverty.

Disability in the MDGs Development Agenda

Over the last 15 years, the Millennium Declaration and the MDGs have been the most prominent international development instruments tackling poverty. The MDGs are the world's time-bound, quantified targets for addressing extreme poverty in its many dimensions—income poverty, hunger, disease, lack of adequate shelter and exclusion—while promoting gender equality, education, and environmental sustainability.[9] All these focus areas are equally important to persons with disabilities, as they may be at increased risk of becoming and remaining poor.

The fact that persons with disabilities are not explicitly included in any of the MDGs and related Targets or Indicators represents a lost opportunity to address the pressing social, educational, health and economic concerns of millions of the world's most marginalized citizens. This significant oversight is evident in the lack of systematic inclusion of persons with disabilities in the policy development and programme planning of governments and development organisations implementing activities around the MDGs.[10] Moreover, their exclusion from the MDG efforts may increase their risks of getting unequal opportunities when compared with their fellow citizens who are benefiting from policies and programmes linked to the MDGs.[11] The result of this exclusion can lead to a widening of the gap between persons with disabilities and non-disabled persons.

There are two main reasons why the international community failed to include persons with disabilities on the global development agenda. Firstly, persons with disabilities have been incorrectly seen as people whose lives are defined by their impairment and therefore by their special medical and rehabilitative needs (medical model). Secondly, they were seen as individuals who are simply unable to participate fully in society and therefore considered to be recipients of social charity support (charity model).

The social model of disability argues that constraints faced by persons with disabilities reflect the attitudinal, policy, communication and infrastructural barriers imposed by society.

The growing global Disability Rights Movement established by the strong voices of Disability People's Organisations worldwide, opposed this ignorance and stigmatization of persons with disabilities by promoting the social model of disability. This model has fostered a rethinking of earlier models by arguing that the constraints faced by persons with disabilities reflect attitudinal, policy, communication and infrastructural barriers imposed by society. The social model was broadened in recent years to include the concept of a Human Rights model. A significant milestone in the Disability Rights Movement was the adoption of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) by the UN General Assembly in 2006, which in turn has had significant implications for the implementation and revision of the MDGs. The UNCRPD is discussed further in the second chapter.

Besides defining disability as a human right issue, the Convention also stipulates that disability is a development issue. This implies that all countries that ratified the Convention have to ensure that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities.[12] The implications of this Convention and other human rights frameworks have to be substantially incorporated into future development frameworks that prioritize the promotion and protection of the human rights of the most marginalized and poorest people in the world.

The international community has an excellent opportunity to ensure the inclusion of disability in the emerging global sustainable development agenda by focusing on excluded groups, among which are persons with disabilities.

Disability in the Post MDGs Development Agenda

As discussions regarding the post-2015 agenda gain momentum, the international community has an excellent opportunity to critically reflect on disability and ensure its inclusion in the emerging global sustainable development agenda. The post – 2015 agenda needs to be built on the principle of equality, for the purpose of creating a global development framework that will be universal, inclusive and accessible for all.[13] This shift requires a reduction of poverty and the ending of extreme poverty in all its forms. Moreover, the new or revised goals need to focus on reaching out towards the excluded groups, including persons with disabilities. By providing social protection and strengthening their resilience, the international community will empower them to become active agents of change.[14] By integrating a human rights-based approach to disability in all Targets and Indicators, the new agenda will be an effective tool for "measurable, accountable, and inclusive development for all persons, without discrimination."[15]

key points chapter two

1 Why has the LF widened its core strategy?
LF strives for an open world in which children and youngsters with disabilities should have equal opportunities to fulfil their personal potential. Therefore the LF's decision to widen its strategy was in line with its aim of actively contributing to the movement towards inclusion of children and youngsters with disabilities in society, by supporting children's special needs and removing the barriers that prevent them from participating and fully enjoying their rights.

2 What would the LF like to focus on in implementation of the core strategy? LF would like to measure outcome level changes in functionality and participation of children and youngsters with disabilities in the programmes of local partners. The important instrument used here is International Classification of Functioning (ICF) as a model that reconciles the medical and the social aspects of disability, and provides a conceptual framework for measuring levels of disability and changes in persons' lives. In ICF, disability and functioning are viewed as outcomes of interactions between health conditions (diseases, disorders and injuries) and contextual factors (personal and environmental).

3 How would the LF like its core strategy to be implemented in the field? The LF is supporting partners that use the Community Based Rehabilitation (CBR) strategy and framework in the planning of their interventions. CBR is a "strategy which, within general community development, promotes rehabilitation, equalization of opportunities, poverty reduction and social inclusion for all children and adults with disabilities at a local level." It involves working closely with persons with disabilities, their families, service providers, local government and other relevant stakeholders to remove barriers that result in the exclusion of persons with disabilities from participation in community life.

chapter two

Pillars of the Liliane Foundation's Core Strategy

The aim of this chapter is to review the position of the LF as a disability - focused organisation in the sector and the value it adds, and to analyse the international initiatives and strategies that gave the LF inspiration to further develop its core strategy.

The **Liliane Foundation (LF)** is a Dutch disability - focused organisation established in 1980 as a private initiative of Liliane Brekelmans-Gronert. The organisation was established to urgently address the exclusion and lack of access to services for children with disabilities, who are disproportionately poor in the low income countries. As these children were rarely targeted by mainstream organisations, and support was not often tailored to their needs, the LF core strategy emerged to fill a gap that existed in the development sector. Providing direct, tailor-made and small-scale assistance for children and youngsters with disabilities, who live in poverty, became the principal way the LF added value in the sector.

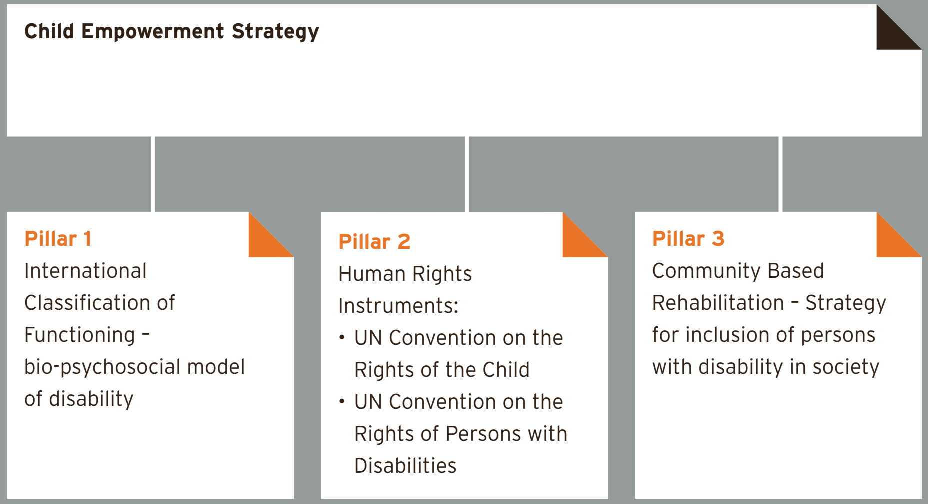
← The LF was established to urgently address the exclusion and lack of access to services for children with disabilities, who are living in poverty in low income countries.

Disability as a concept has evolved significantly since the establishment of LF. The reasons for this evolution are initiatives and strategies undertaken on social inclusion of persons with disabilities by international actors. The LF used these international initiatives as a foundation to expand its own organisational strategy. The reason for this move was to create a strategy that complemented the strategies of other relevant stakeholders in the sector and together to contribute towards a more disability inclusive world. This chapter outlines the most important international initiatives and strategies which represent **pillars in the development of the LF core strategy**:

Pillar 1 International Classification of Functioning, Disability and Health (ICF) – a bio-psycho-social model of disability;

Pillar 2 The UN Convention on the Rights of the Child and UN Convention on the Rights of Persons with Disabilities – the most prominent international human rights instruments;

Pillar 3 Community Based Rehabilitation – the most relevant strategy for inclusion of persons with disability in society.



Child Empowerment Strategy

Pillar 1
International Classification of Functioning – bio-psychosocial model of disability

Pillar 2
Human Rights Instruments:
- UN Convention on the Rights of the Child
- UN Convention on the Rights of Persons with Disabilities

Pillar 3
Community Based Rehabilitation – Strategy for inclusion of persons with disability in society

Figure 1
Three pillars of the LF core strategy

The transition from the individual, medical perspective to a structural, social perspective has been described as a shift from a medical model to a social model, in which people are viewed as being disabled by society rather than by their bodies.

Pillar 1: Understanding Disability with the ICF model

Disability is a complex, dynamic, multidimensional and controversial concept.[16] Over recent decades, the Disabled People's Movement in collaboration with research from the social and health sciences have identified social and environmental barriers that contribute to disability. The transition from the individual, medical perspective to a structural, social perspective has been described as a shift from a medical model to a social model, in which people are viewed as being disabled by society rather than by their bodies.[17]

The tension that existed between the medical and the social models of disability was reconciled when the International Classification of Functioning, Disability and Health (ICF) was adopted by the World Health Organisation in 2001.[18]

The ICF gives appropriate weight to the different aspects of disability, from both a medical and a social perspective. The ICF is promoted as a bio-psycho-social model that addresses disability as an umbrella term for impairments, activity limitations and participation restrictions. In doing so, the model refers to the challenging aspects of the interactions between an individual (with his/her health condition) and his or her contextual factors (personal and environmental). Stakeholders therefore have to include a focus on improving social participation, by addressing the environmental barriers (attitudinal, physical, communicational, policy and institutional) which hinder persons with disabilities in their everyday lives, rather than seeing the disability as an attribute of the person. This means reflecting on the disability as a result of the interaction between the person with the impairment, and the barriers that hinder their full and effective participation in society on an equal basis with others.

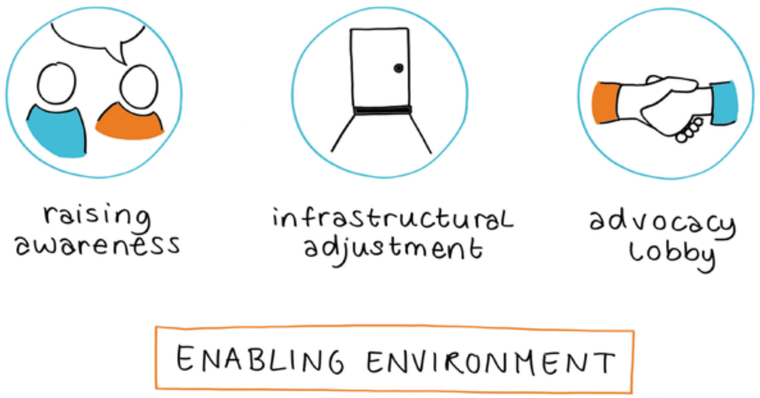
The ICF conceptual framework is taken as the first pillar that has led to the LF revising its core strategy. Based on the previously dominant medical model, children with disabilities were largely provided assistance in residential institutions with specialized services such as rehabilitation centres, specialized schools, etc. LF policy in recent years has also expanded towards community participation and inclusion. Hence, isolated medical solutions are giving way to more integrated approaches, recognizing that children are disabled not only by their impairments but also by a variety of environmental factors. Chapter 3 will further analyze how LF is applying the ICF in its core strategy.

LF policy is expanding towards community participation and inclusion, and isolated medical solutions are giving way to more integrated approaches.

Creating an Enabling Environment

The environment in which children with disabilities live has a great impact on how they experience disability. An inaccessible environment is one in which there are lots of barriers for these children to participating and feeling included. For example, a wheelchair user cannot be mobile and self-sufficient in a building without accessible toilets or a lift.[19] However, the environment includes more than merely the physical space in which a person lives. It also includes the institutional, policy and attitudinal environment in which people live and conduct their lives.[20] These barriers are further described in the next chapter.

The environment in which children with disabilities live has a great impact on how they experience disability.



The importance of promoting an enabling environment as a contributory factor to effective implementation of the rights of children with disabilities is mentioned in the UN Convention on the Rights of Persons with Disabilities (UNCRPD) as follows:

> "Recognizing the importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information and communication, in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms." [21]

In the quest to create a better enabling environment for children and youngsters with disabilities, the LF and its partners need to look beyond individual (medical) interventions. This means that children and youngsters with disabilities should not be seen as recipients of aid but as right-holders who are fully entitled to enjoy their rights on an equal basis with all other children in the world. In the quest to achieve a more inclusive society, international policy makers[22] recognize a number of prerequisites that can contribute to ensuring an enabling environment for inclusion:

- Involvement of local government institutions that promote and ensure children's participation and full implementation of their rights;
- Advocacy opportunities for children with disabilities and their families to influence disability-related policies;

Children and youngsters with disabilities should not be seen as recipients of aid but as right-holders who are fully entitled to enjoy their rights on an equal basis with all other children in the world.

- Awareness-raising campaigns to promote critical thinking and reduce prejudice among the public;
- Technical assistance for governments that lack the necessary skills and capacity to work on the elimination of environmental barriers;
- Allocating appropriate budgets for improving the participation of children in their communities and society at large.

This chapter shines further light on the nature of human rights as universal principles of equality, and the value of the international human rights instruments in affirming and promoting the rights of children with disabilities as preconditions for inclusion.

Human rights have provided the foundation for the movement towards inclusion of children and youngsters with disabilities.

Pillar 2: Rights of Children with Disabilities

Human rights Conventions set out an internationally accepted moral code by which the intrinsic humanity of every individual is recognized and protected. Human rights are the fundamental, universal and indivisible principles by which every human being can claim justice and equality. Human rights have provided the foundation for the movement towards inclusion of children and youngsters with disabilities. This inclusion requires the recognition of all children and youngsters with disabilities as full members of society and the respect of all their rights, regardless of age, gender, ethnicity, social status or impairment.[23] Inclusion also involves the elimination of the barriers that might prevent children from enjoying these rights. Consequently, it requires all stakeholders to facilitate an appropriate, supportive and protective environment in which children with disabilities can grow, develop and become active agents of change in society.

The two most relevant international standards and mechanisms for the LF are: United Nations Convention on the Rights of the Child (UNCRC) and United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

In the last four decades, the United Nations has made a strong commitment to the rights of persons with disabilities. This commitment is reflected in dozens of international human rights instruments and high-level decisions, reinforcing the rights of persons with disabilities.[24]
The human rights approach is the second pillar of importance for the revised core strategy of the LF. The two most relevant international standards and mechanisms for the LF are the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). These conventions will be further addressed in the following sections.

UNCRC represents the first legally binding international instrument to deal comprehensively with the human rights of children, and, more significantly, for the inclusion of children with disabilities.

UN Convention on the Rights of the Child (CRC)

The CRC was adopted by the UN Assembly in 1989 and it represents the first legally binding international instrument to deal comprehensively with the human rights of children, and, more significantly, for the inclusion of children with disabilities. The CRC is based on four main principles: non-discrimination; the best interest of the child; survival, and development and respect for the views of the child. The principle of non-discrimination as stated in article 2 of the CRC specifically prohibits discrimination on the ground of disability.[25] For the LF, article 23 of CRC is especially important due to the recognition that children with mental and physical disabilities are entitled to enjoy a full and decent life in conditions that ensure dignity, promote self-reliance and facilitate the child's active participation in the community.[26] More important for the LF core strategy is that this special article on children with disabilities is considered without undermining the general applicability of the principles and provisions of the CRC to the situation of children with disabilities. Instead, it enforces the other provisions, such as:

- The child's right not to be separated from his or her family (article 9).
- Services and assistance to support parents in their child-rearing responsibilities (article 18).
- Protection from injury, neglect and any form of violence or torture (article 19, 33, 34, 37).
- Protection of children deprived of a family environment (article 20).
- Periodic review of treatment for children with disabilities (article 25).
- The child's right to free and compulsory primary education, to secondary and vocational education, and the prevention of dropping-out of education (article 28).

UN Convention on the Rights of Persons with Disabilities (CRPD)

The signing of the UN Convention on the Rights of the Persons with Disabilities (CRPD) was, the most prominent international milestone supporting the international disability rights movement. It was adopted by the UN Assembly in 2006 and enforced in 2008. The CRPD adds a new dimension to the rights of persons with disabilities by moving away from perceiving persons with disabilities as "objects" of charity, medical treatment and social protection, instead acknowledging them as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free, informed consent as well as being active members of society.[27] The CRPD is the first document to adopt a broad categorization of persons with disabilities as it "reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms"`.[28] The Convention further clarifies and strengthens the position of persons with disabilities in other international human rights instruments.[29]

UNCRPD is moving away from perceiving persons with disabilities as "objects" of charity, by acknowledging them as "subjects" with rights.

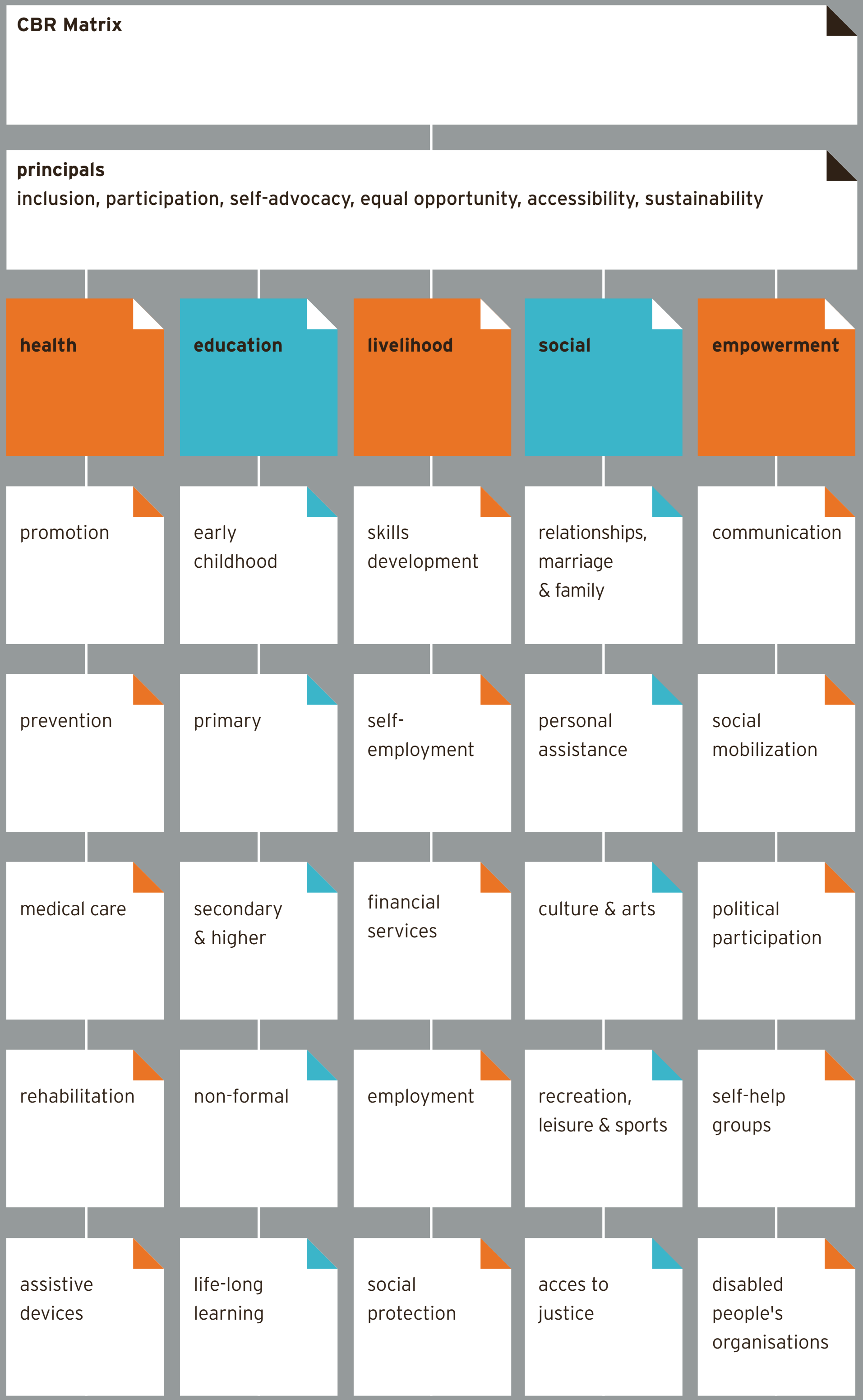
For the LF it is extremely important that the CRPD explicitly mentions children with disabilities, recognizing that they should "have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children".[30] The CRPD further stipulates that, in all actions concerning children with disabilities, the best interest of the child needs to be taken into account and that children with disabilities have the right to express their views freely and participate in taking decisions on all matters that affect them.[31] The LF core strategy, focusing on the aspects of education, health and rehabilitation, work and employment and social protection, is in line with and further reinforced by the clear commitment of the CRPD to protect these rights.

The bipartite character of the UNCRPD in "mainstreaming where possible and being specific where needed" is the principle of the Twin-Track Approach which implies including the perspectives of persons with disabilities in all relevant development projects, while at the same time empowering them through disability specific projects or components.

The CRPD initially promotes the principle of **mainstreaming** by confirming that persons, including children, with disabilities should have a right to the enjoyment of the highest attainable standard of health and fully accessible, free and affordable health services on an equal basis with others. Furthermore, they should have inclusive educational services and a right to work on an equal basis with others. This includes the opportunity to earn a living through a job that is freely chosen; being accepted in a labour market and working in an environment that is open, inclusive and accessible to persons with disabilities.[32]

"Mainstreaming where possible and being specific where needed" is a principle of the Twin-Track Approach which implies including the perspectives of persons with disabilities in all relevant development projects, while at the same time empowering persons with disabilities through disability specific projects.

The CRPD secondly gives significant attention to the **disability-specific needs** of persons with disabilities. In education, children with severe and complex sensory impairments should be entitled to access to specific learning aids such as sign language, Braille and low-vision aids.[33] Other children with disabilities may also need modifications to the curriculum, teaching styles, and the organisation of the classroom. Furthermore, they have the right to specific health- and rehabilitation services because of their disabilities, including early identification and intervention as appropriate and services designed to minimize and prevent further disabilities.[34]



CBR Matrix

principals
inclusion, participation, self-advocacy, equal opportunity, accessibility, sustainability

health	education	livelihood	social	empowerment
promotion	early childhood	skills development	relationships, marriage & family	communication
prevention	primary	self-employment	personal assistance	social mobilization
medical care	secondary & higher	financial services	culture & arts	political participation
rehabilitation	non-formal	employment	recreation, leisure & sports	self-help groups
assistive devices	life-long learning	social protection	acces to justice	disabled people's organisations

Figure 2
CBR matix

Pillar 3: Community Based Rehabilitation (CBR)

Service provision to all children with disabilities should be individually tailored and relevant to the local context in which the children live. Clearly, parents/caregivers and the children themselves should be fully involved in the decision-making process about the nature and intensity of such support, the period for which it is needed and the ways it can be implemented. Moreover, these children are entitled to access to all services necessary for them to live as decent a life as everyone else. CBR is an empowering strategy that strives for exactly that: improving the quality of life of persons with disabilities.

CBR represents the **third pillar** on which the LF core strategy is further built. CBR is referred to as a “strategy which, within general community development, promotes rehabilitation, equalization of opportunities, poverty reduction and social inclusion for all children and adults with disabilities at a local level.”[35] It involves working closely with persons with disabilities, their families, service providers, local government and other relevant stakeholders to remove barriers that result in the exclusion of persons with disabilities from participation in community life.[36] The capacities of all these stakeholders are significantly important and closing the knowledge gap between them is something that the LF has incorporated as a core aspect of its strategic focus for the future. The CBR strategy includes a matrix with diverse domains within which stakeholders can plan and implement their interventions.
The domains of the CBR matrix are: Health, Education, Livelihood, Social and Empowerment.

In the last decade, the CBR approach was perceived through the social and the human rights models of thinking. Caution is needed, however, when the “rights” jargon is being used, while in reality, appropriate implementation of these rights is lacking.[37] From the LF perspective, children with disabilities cannot achieve a better quality of life only from human rights instruments and legislation. Rights without implementation are useless. They need to be implemented in practice in order for these children to “benefit from the conductive environment brought by the legislation”.[38] Therefore, the CBR is not an end in itself, but it can rather serve as a strategy to enforce the implementation of equal rights and to allow the provision of the best possible services to children with disabilities.[39]

←
LF follows CBR as a “strategy which, within general community development, promotes rehabilitation, equalization of opportunities, poverty reduction and social inclusion for all children and adults with disabilities at a local level.

image: Joris van Gennip

image: Jonannes Odé

key points chapter three

The LF understanding of the holistic approach has evolved on the basis of the trends and the relevant disability models in the sector used in the last three decades. At present, the LF uses the holistic approach, looking at the child as an individual in the context of his/her family, community and broadly in society, analyzing all the factors (personal and environmental) that influence his/her development and quality of life, and tackling them with appropriate interventions. Balanced and simultaneous focus from the local partner organisations, to improve the child's functioning and reduce the diverse barriers to participation, can improve the child's position in the community. When this is done in synergy with other stakeholders at local and national level, then multiple positive effects on society as a whole are inevitable. Children feel more empowered to take their destinies into their own hands and contribute to a better, more diverse and inclusive society.

chapter three

The Liliane Foundation's Core Strategy Development

The aim of this chapter is to review past and present objectives and practices of the Direct Child Assistance approach and to give new policy directions for the core strategy of LF. It reflects on the different models of disability. It then explains the ICF as a bio-psychosocial model of disability and an optimum model for the LF core strategy. ICF simultaneously addresses the functioning, activity limitations and participation restrictions, in combination with the environmental and personal factors affecting children and youngsters with disabilities.

Since its inception in 1980, LF has focused primarily on providing access to rehabilitation services for children and youngsters with disabilities living in poverty in low income countries. The assistance was provided by grass-roots organisations and local contact persons who had a direct connection with the children. The assistance was based on the local resources in the community and tailored to the needs of each child. This way of working was recognized as Direct Child Assistance (DCA) and it became a core intervention strategy and "trademark" of the LF.

In more than three decades of development efforts, the LF has always used the holistic approach in addressing the needs of children and youngsters with disabilities. A holistic approach to child development means an approach that simultaneously address the physical, emotional, relational, intellectual, and spiritual aspects of a child's life. The understanding and implementation of this holistic approach within the Direct Child Assistance evolved as the organisation grew and matured. Now that the LF is striving to achieve greater sustainability, it is important to reflect on the understanding and implementation of the holistic approach within the DCA.

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The LF has always used the holistic approach to child development, which means an approach that simultaneously address the physical, emotional, relational, intellectual, and spiritual aspects of a child's life.

Reflections on the Past

Nowadays, the priorities in the development sector are different from those that were set 30 years ago. When it came to the delivery of aid for marginalized groups, women and certain ethnic groups in conflict zones were given a prominent position compared to persons with disabilities. Persons with disabilities and in particular children with disabilities in developing countries were almost always at the bottom of the priority list, invisible to both their own communities and the NGOs in the development sector. This was one of the reasons why the LF was established. The primary aim was to help children with disabilities that live in poverty to gain better prospects for their lives.

In its starting years, LF's main cooperation was with non-profit, non-governmental organisations that showed goodwill and commitment to help children with disabilities in their own communities.

In its starting years, LF's main cooperation was with non-profit, non-governmental organisations that showed goodwill and commitment to help children with disabilities in their own communities. The way in which the holistic approach was implemented in those years was with a primary focus on the children and youngsters with disabilities and the family situation of the child. The children and youngsters within the programme were often considered as recipients of long-term support and special attention.

With the extension of the network of partner organisations over time, expertise in rehabilitation also grew. The LF approach became known as direct, individual, tailor-made assistance for children and youngsters with disabilities which focused on health, education, work and income, and participation within the family and community. It was considered that local partners and their mediators used a holistic approach in their activities, by providing access to services or providing the services themselves in the above mentioned focal areas. Most of the LF partners primarily used the medical model of disability in addressing the disability issues for each individual child.

The **medical model** of disability views disability as a feature of the person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals. This model:[40]

- Defines disability as a problem in the child who needs special medical treatment;
- Focuses on a child's impairment as an obstacle to participation in society;
- Defines the disabled person primarily as a patient with medical and special needs;
- Addresses the special needs of persons with disabilities away from mainstream society;
- Offers only medical help, carried out by specialists in medical institutions developed for persons with disabilities.

LF made the decision to involve the communities of children and youngsters with disabilities in interventions on their behalf because disability is also a socially created problem.

Expanding the Existing Practices

Recent research evaluations[41] have confirmed LF's assumption that, if it wants to have a more sustainable positive impact on the lives of children and youngsters with disabilities, it needs to broaden its focus from investing mainly in the children and families, to investing simultaneously in children's communities. This shift in emphasis by LF recognizes that community members and organisations are important actors influencing a child's development.

In widening the existing approach, LF made the decision to involve the communities of children and youngsters with disabilities in interventions on their behalf. This approach resulted from the rationale that disability is a socially created problem and not only an attribute of an individual.

In the social model disability demands a political response, since the problem is created by an unaccommodating physical environment brought about by attitudes and other characteristics of the social environment.

Overcoming the difficulties faced by children with disabilities requires interventions to remove environmental and social barriers, and empowering children to become active agents in their own development.

The Social Model of Disability **focuses on inclusion[42] through activities which:**

- Focus on society, not persons with disabilities, as the problem;
- Regard persons with disabilities as part of society, rather than separate;
- See people as being disabled by society denying their rights and opportunities;
- See disability as the social consequence of impairment;
- See persons with disabilities as having needs and rights which are the same as non-disabled persons – e.g. rights to education, health, employment, adequate standard of living, participation, etc.;
- Identify and remove attitudinal, environmental and institutional barriers that block inclusion. These barriers are described in more detail through the ICF model.

The above characteristics of the social model make it obvious that overcoming the difficulties faced by children with disabilities requires interventions to remove environmental and social barriers, and empowerment of children to become active agents in their own development.

Future Policy Directions

In finding a good balance when addressing the medical and social aspects of disability, the LF has chosen the ICF model.

Disability as a complex and context-specific phenomenon is always determined from the interaction between characteristics of the person and characteristics of the overall context in which the person lives. However, some aspects of disability are almost entirely internal to the person, while other aspects are almost entirely external.[43] For the LF, both the medical and the social responses became important for children and youngsters with disabilities and both should be equally balanced in the process of designing interventions for them. It is also important to affirm the LF's position that in addressing the medical and the social aspects, the human rights of the children and youngsters with disabilities need to be taken into account as the foundation on which the interventions for these children will be developed.

International Classification of Functioning (ICF) Model

In ICF, disability and functioning are viewed as outcomes of interactions between health conditions (diseases, disorders and injuries) and contextual factors.

In finding a good balance when addressing the medical and social aspects of disability, the LF has chosen the ICF model. The ICF[44] model was developed by the World Health Organisation. It reconciles the differences between the **medical and social models,** and therefore synthesizes the truth of both models, without making the mistake of reducing the whole, complex notion of disability to one of its aspects. This model of disability is called the **bio-psychosocial model.**

Concepts of functioning and disability

As Figure 3 indicates, in ICF, disability and functioning are viewed as outcomes of interactions between health conditions (diseases, disorders and injuries) and contextual factors. Contextual factors influence how disability is experienced by the individual and consist of external environmental factors and individual factors. External environmental factors include: social attitudes, architectural characteristics, legal and social structures, as well as climate, terrain and so forth. Individual factors include: gender, age, coping styles, social background, education, profession, past and current experience, overall behaviour pattern and character.

The ICF identifies three levels of human functioning classified by ICF, namely functioning at the level of body or body part, the whole person, and the whole person in a social context.

The Figure identifies the three levels of human functioning classified by ICF, namely functioning at the level of body or body part, the whole person, and the whole person in a social context. Disability therefore involves dysfunction at one or more of these levels that are referred to as either impairments, activity limitations or participation restrictions. The formal definitions of these components of ICF are as follows:

- **Body functions** are physiological functions of body systems (including psychological functions).
- **Body structures** are anatomical parts of the body such as organs, limbs and their components.
- **Impairments** are problems in body function or structure such as a significant deviation or loss.
- **Activity** is the execution of a task or action by an individual.
- **Participation** is involvement in a life situation.
- **Activity limitations** are difficulties an individual may have in executing activities.
- **Participation restrictions** are problems an individual may experience in involvement in life situations.
- Contextual factors are the factors that together constitute the complete context of an individual's life, and in particular, the backgrounds against which health states are classified in ICF. There are two components of contextual factors:
  - **Environmental factors** make up the physical, social/institutional/policy and attitudinal environment in which people live and conduct their lives.
  - **Personal factors** make up the characteristics of each individual: gender, age, coping skills, level of resilience, lifestyle, etc.

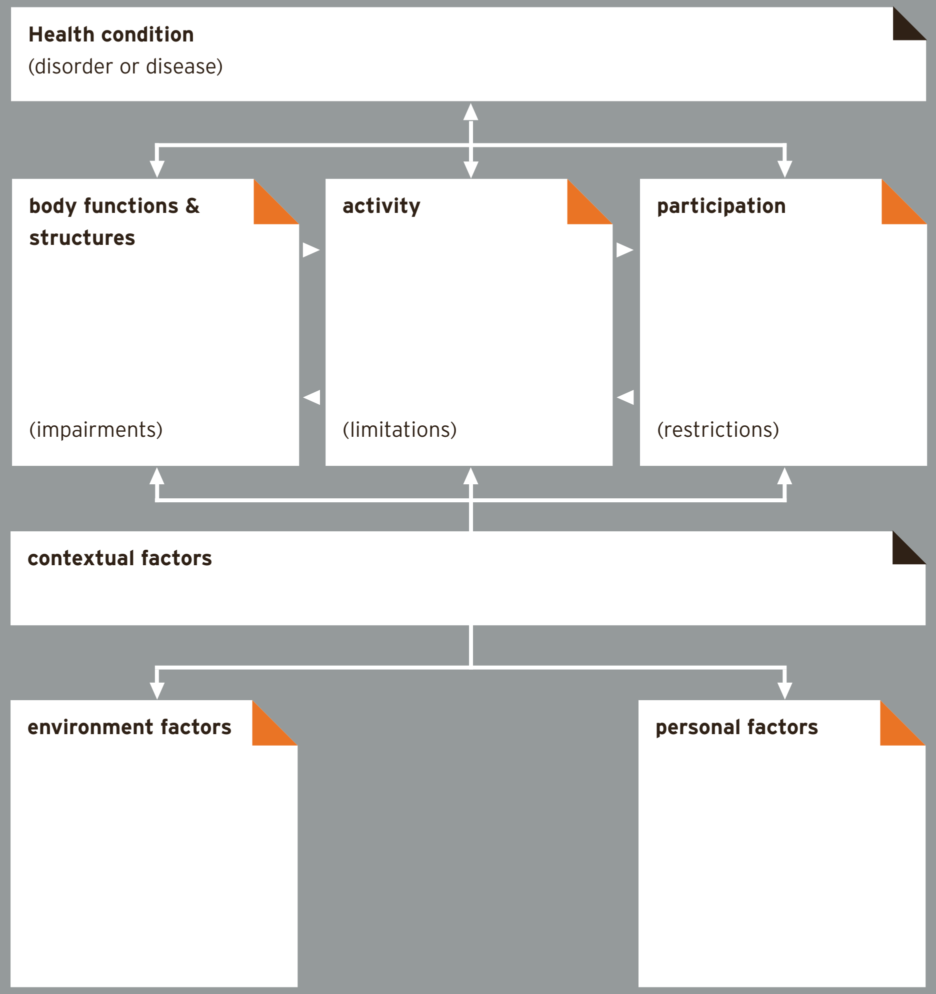

Figure 3
International Classification of Functioning (ICF)

Environmental factors/facilitators
Environmental factors constitute a component of ICF, and refer to all aspects of the external or extrinsic world that form the context of an individual's life and, as such, have an impact on that person's functioning. Environmental factors include the physical world and its features, the human-made physical world, other people in different relationships and roles, attitudes and values, social systems and services, and policies, rules and laws.

Environmental factors constitute a component of ICF, and refer to all aspects of the external or extrinsic world that form the context of an individual's life and, as such, have an impact on that person's functioning.

Facilitators are factors in a person's environment that, through their absence or presence, can improve a child's functioning and reduce their disability. These include aspects such as physically accessible infrastructure such as roads or buildings; availability of assistive technology and devices, and positive nurturing attitudes of people towards disability, as well as services, systems and policies that aim to increase participation of children with disabilities in every area of life. Absence of a factor can also be facilitating, for example, the absence of stigma or negative attitudes. Facilitators can prevent an impairment or activity limitation from becoming a participation restriction.

Environmental barriers
If LF wants to reach more sustainable results and positive changes for children with disabilities, it also has to address the barriers that prevent children from participating in their communities. The environmental barriers and factors can be divided into three general types: attitudinal, infrastructural/communicational and institutional/policy barriers.

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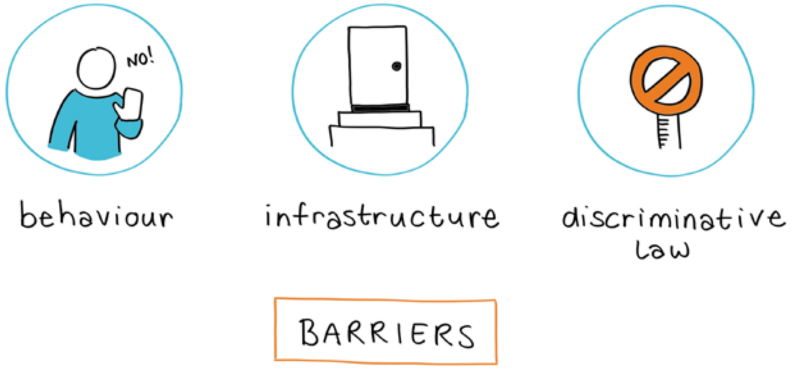


Attitudinal barriers
Prejudice, discrimination and stigma can cause the biggest problems for children and youngsters with disabilities, who are assumed to be one or more of the following: Incapable or worthless, of low intelligence, needing special services or support, or dependent on their parents and care-givers for all their lives.

Attitudinal barriers are: prejudice, discrimination, stigma, overprotection and hero-worshiping.

On the other hand, **overprotection and hero-worshipping** can be other extreme forms of disabling attitudes towards children and youngsters with disabilities. Parents and care-givers tend to overprotect their children because they are afraid that something bad will happen to them. Therefore, they keep them inside their homes and decide on their behalf. Hero-worship is also an unrealistic attitude towards children and youngsters with disabilities. Some of those children tend to use their image and voice as role models in awareness-raising campaigns in society. Indeed, as role models, children

Image: Petra Brands

Image: Jan-Joseph Stok

and youngsters with disabilities can make a difference for many, but apart from this they have the right to lead their life just like anyone else.

Infrastructural and communication barriers
Children and youngsters with disabilities also encounter environmental barriers in the areas of housing, educational facilities, health facilities, public places, public transport, offices, religious and cultural places, media and communication means, and public information systems. When we define the **physical** we do not only address the **infrastructural barriers** – e.g. a rehabilitation centre is inaccessible for wheelchair users if it has stairs and narrow doorways. It is relatively easy to identify these – in consultation with children and youngsters with disabilities – once aware. However, **the means of communication** can also be disabling for those with sensory impairment e.g. for persons with hearing impairment if there's no sign language; for those with visual impairments if there are no books in Braille. These people are unlikely to have access to vital information and are therefore unable to fully participate in life situations unless their access needs are met.

← Infrastructural barriers are: physical inaccessibility of buildings, roads and other public places.

Institutional/policy barriers
These barriers exclude children and youngsters with disabilities from many policies related to the areas of their interest, namely educational policies, the legal system, employment laws, health service provision, social service, belief systems, and religious and humanitarian/development agency policies.

← Institutional barriers are: discriminative or absence of policies and laws that address the rights of persons with disabilities.

Many of the systems that are taken for granted by mainstream society are not inclusive of children and youngsters with disabilities. Exclusion from institutions has a secondary negative effect. For example: special education with poor standards often has lower academic expectations and demands from students, therefore the students' performance is weaker, which in turn does not give them equal chances to compete in the labour market. In many countries, these youngsters are also excluded from the employment systems and micro-financing schemes because they are perceived to be incapable of being entrepreneurs, employees or independent and self-sufficient in their own lives. Furthermore, these youngsters are less likely to be in full-time employment and more likely to be in low-paid jobs with poor career prospects and working conditions.[45] The low expectations and the prejudice that these institutions have regarding youngsters with disabilities makes their future uncertain and even more challenging.

Personal Factors
Personal factors are contextual factors that relate to the individual such as age, gender, social status, life experiences and so on. These are not currently classified in the ICF but may be incorporated by users in their application of the classification.

← Personal factors are: age, gender, social status, life experiences, level of resilience, coping style, etc.

Holistic Child Empowerment Strategy
In 2013, the LF decided to expand and rename its core strategy by taking into account the ICF model, the rights-based approach through the international human rights instruments, and the CBR strategy. The purpose of this decision was achieving more holistic and sustainable results for the children and youngsters with disabilities in the programmes of the LF's partners.

Child Empowerment (CE) is the new name of what used to be called Direct Child Assistance (DCA). Empowerment means increasing the child's personal, social, educational and economic strengths to become **agents of change** in their own communities, and with its proactive role to enrich the diversity in society. The LF would like to further stimulate local partner organisations to ensure that children and youngsters with disabilities are given the opportunity


image: Jan-Joseph Stok

to **decide for themselves** in all cases where this is possible and not obstructed by the severity of their impairment. It also means that children and youngsters with disabilities are recognized as citizens with **equal rights just like** everyone else. The empowerment also means that these youngsters can become **self-advocates,** organizing themselves in groups, lobbying for their rights and making informed decisions about what they need. When the local partner organisations work simultaneously on improving the functioning of the children and youngsters with disabilities and elimination of environmental barriers for their participation in the communities, they eventually contribute towards their empowerment and social inclusion.

In the quest to effectively address the functioning of children and youngsters with disabilities and the barriers that they face in their communities, the LF will also encourage its partners to use the principles of the Community-Based Rehabilitation (CBR) strategy. This strategy promotes collaboration among community leaders, persons with disabilities, their families and other concerned citizens to provide equal opportunities for all persons with disabilities in the community.

The LF will encourage and facilitate partners to address the elimination of the aforementioned environmental barriers, in cooperation and partnership with other relevant stakeholders in their communities. This aims to bring more sustainable results for children and youngsters with disabilities. **Sustainability** requires coordination among governmental and non-governmental organisations for persons with disabilities: service providers, research institutions, civil society, faith-based groups, and the private sector. The goal of this **multi-stakeholder cooperation** at local and national level is to create an **enabling environment** and a more **inclusive society** in which each child and youngster with a disability can develop him/herself and attain the highest possible quality of life.

←
Child Empowerment (CE) is the new name of the LF core strategy. Empowerment means increasing of the child's personal, social, educational and economic strengths to become agents of change in their own communities.

Image: Liliane Foundation

Image: Henk Braam

Core Strategy: Child Empowerment (CE)

Child Development (CD):

We address the child's impairment, improve their functioning and make children resilient and self-aware. We make it easier for them to participate and to stand up for themselves. The situation, the character and needs of each child are always the starting point for support. The parents or guardians play a key role.

Enabling Environment (EE):

We reduce the barriers that hinder the participation of children with disabilities in society, since society is not well equipped to facilitate their participation. The (social) infrastructure, communications, attitude and behaviour of other people and the policies of the (local) government are all taken into consideration.

Supporting strategies

Partners' Capacity Development:

We strengthen local partner organisations so that they are sufficiently knowledgeable and equipped to implement the core strategy.

Lobbying and Advocacy:

We contribute to lobbying for safeguarding the interests of persons with disabilities in the Dutch policy for international cooperation.

image: Liliane Foundation

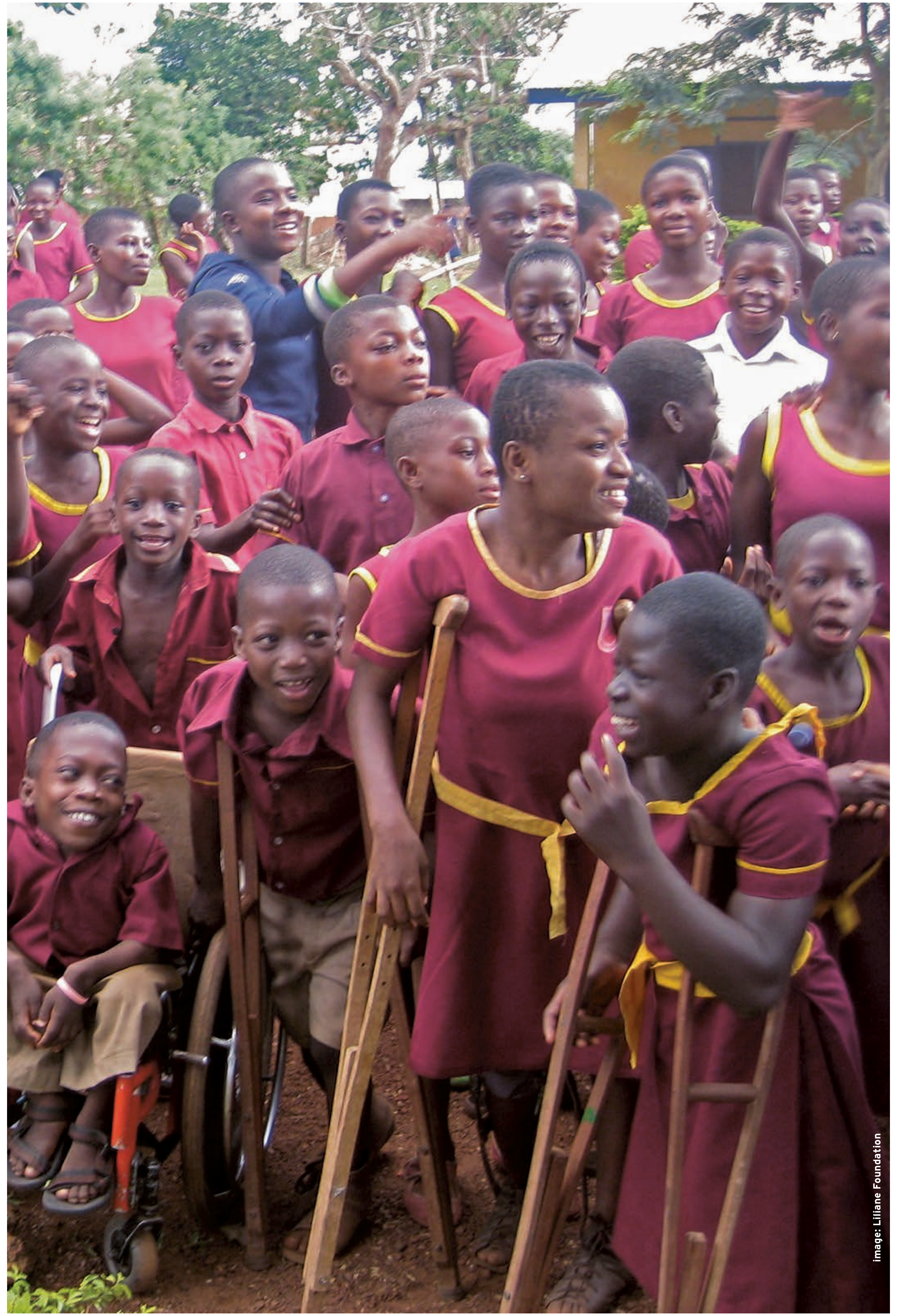


image: Liliane Foundation

Vision

Children and youngsters with disabilities who live in poverty participate equally and as fully as possible in their families and communities, so that their lives have the highest possible quality.

Mission

The Liliane Foundation contributes to a world that is open for everyone, and in which children and youngsters with disabilities who live in poverty can develop and use their talents. Together with local organisations in Africa, Asia and Latin America, we enable children to become stronger and their environment more accessible.

Joel Laguna Condori
Bolivia

Joel Laguna Condori is 14 years of age, lives in Potosí, and comes from a poor family. His father works occasionally in the field and his mother does not have any work, but takes care of Joel and her two daughters.

At 9 years, Joel had an accident while playing and ended with paraplegia. During the medical control they found out that he could still feel his legs. To confirm this they made a MRI of his lumbar spine and diagnosed that with a surgery on his spine, he would be able to walk again.

This diagnosis gave hope to Joel and his mother and they looked for help at different institutions. The Liliane Foundation partner Fraternnidad Cristitana de Personas supported Joel to undergo a surgery which at the end proved to be successful.

Today, he can already stop using assistive devices and make some short steps. It is expected that the rehabilitation of Joel will progress gradually, and in this way, step by step, his dream to walk again will come true.

Gifty Mankattah
Ghana

Gifty Mankattah, a 21 year old Ghanaian girl, spent her days in a wheelchair begging on the street in Bukom, a suburb of Accra. She has a physical disability from the waist downward. Her father left home when she was nine years old and never came back. A staff member of Hope for Life, a partner organisation of the Liliane Foundation, met her on the streets and after a short chat , he followed Gifty home and opened up a case file for her.

Available medical records kept by Gifty's mother showed that she had already undergone a series of medical examinations and treatments. Hope for Life referred Gifty to the Orthopedic Training Centre (OTC) at Nsawam, a town close to Accra, for further physiotherapy assessment. Gifty's mother also took an important part in Gifty's needs assessment. Gifty successfully underwent surgical treatment and was provided with double prostheses at OTC, which has greatly improved her mobility. She continues to receive annual post-surgery reviews at OTC. With improved mobility, Gifty returned to school and joined her classmates in Junior High School 1. She has friends who visit her at home, is a member of the local Youth Club,and is actively involved in Church activities. Gifty's mother went blind in 2012, and now Gifty has to do almost all the household chores as well.

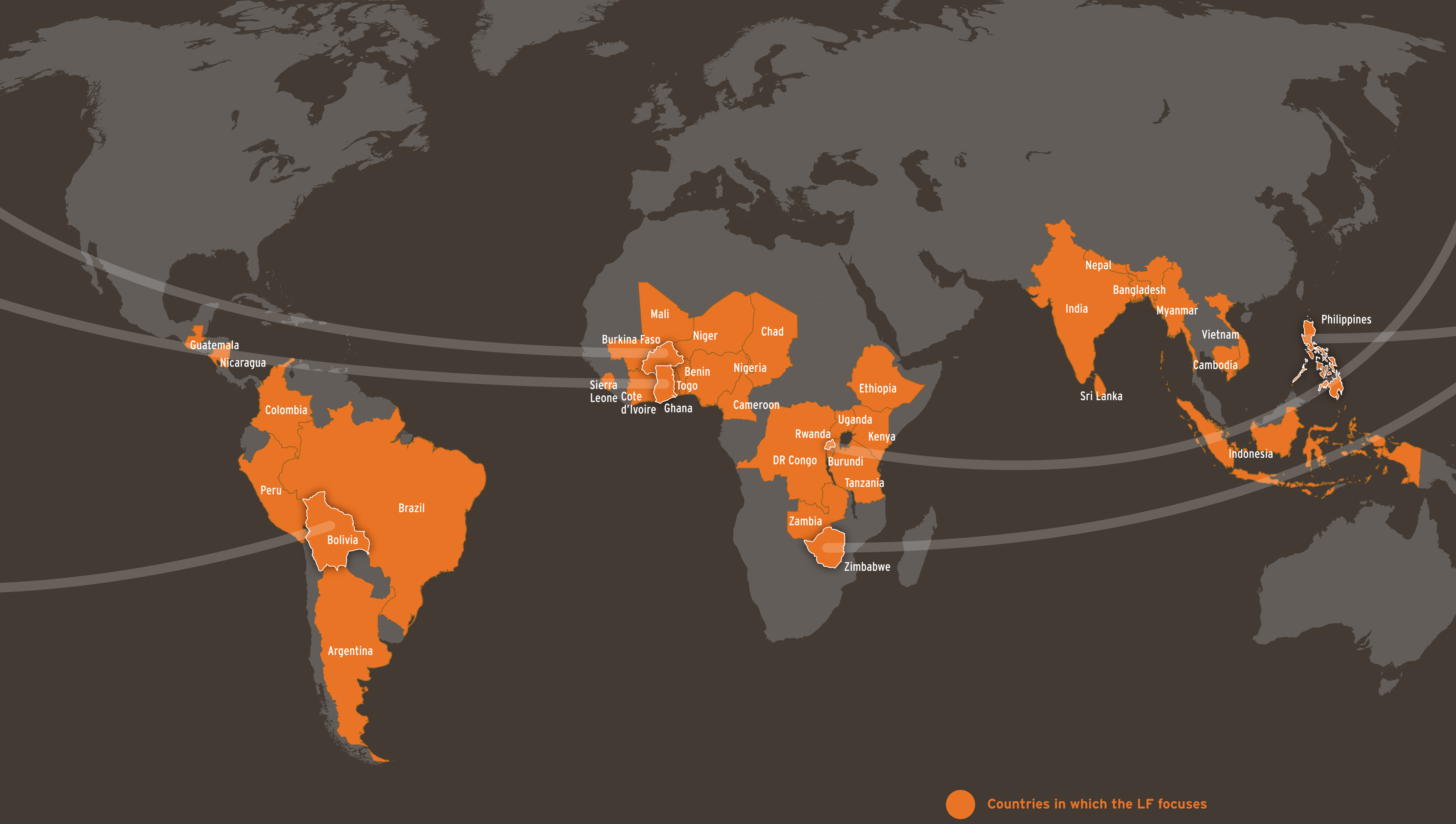
The treatment Gifty received consisted of surgery to correct her deformed feet, post-surgery support, facilitating social interaction, support to continue her education and exploring possibilities of economic rehabilitation for her mother. This holistic approach made the difference for Gifty. She finished high school and is on her way to independence.

Issa Sawadogo
Burkina Faso

Issa Sawadogo is a physically disabled youngster living in Burkina Faso. He is well-educated and has received a certificate that gives access to certain jobs in public service in the country. Issa has registered at a vocational school in the city of Fada , to maximize his chances of getting a much-wanted teaching job. He successfully finished his training and obtained his proficiency certificate. Even with this second diploma, however, Issa spent three years applying for an entrance exam for public service – before he was finally allowed to take the exam. During the formalities for taking up office at the public school where he had been appointed, discrimination issues started and he still could not obtain a job as teacher.

Issa's story reached the organisation Handicap Solidaire Burkina, and spread to other local NGOs. The local organisations mobilized themselves against this issue of refusal, considering it to be a major injustice and discrimination towards disabled people. Submitting a serious number of pleas to solve this problem did not lead to any meaningful results. Approaching the President of Burkina Faso in person did help, and Issa has been rehabilitated and appointed to a job at the Ministry of Social Action and National Solidarity.

Since dealing with Issa's case, the government of Burkina has made a lot of progress with respect to politics and care of disabled persons. This story has given all actors a chance to organize themselves and to cooperate synergistically to continue the fight for the reintegration of disabled persons at all levels, and for a change in attitude towards disability in general and the disabled person in particular.



Liliane Umumararungu
Rwanda

Liliane Umumararungu lives in Karambo, Rwanda. She suffers from dwarfism, a genetic condition that affects many in her family. Her mother is of average height, but her father and the four children are very small. Most of them cannot walk normally and live in a very small house that family members have built to help them. Liliane's parents are very aware of the challenges faced by their children and they are concerned about their future, but they lack the financial resources to deal with the situation.

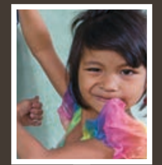
A nurse at the Rwamagana hospital made arrangements to link the family with the Bernardine Sisters, a partner of Liliane Foundation, which could help these children. The partner organisation made sure that Liliane's siblings were accepted in the local regular school. Liliane has also been examined to check whether her limbs can be straightened. After three medical consultations with a neurological surgeon, it was decided to place Liliane in a suitable school until it becomes possible for her to fully and appropriately receive expert intervention. Thanks to the close collaboration of the family, the community and of the Bernardine Sisters' rehabilitation centre in Kamonyi, Liliane now attends school. Her school did everything necessary for her and other children with disabilities to have easy physical access to the school facilities and be accepted by other children and the school staff. Liliane is in the second grade of the elementary school in Kamonyi and is doing very well. She feels accepted by the other children and the teachers, and studies with great enthusiasm, because for her, education is a window to a world of great possibilities.

Shupikai Whiskey
Zimbabwe

Shupikai Whiskey is a 29 year old man with Athetoid Cerebral Palsy. In primary school, he used his foot to write. In secondary school, this became uncomfortable and Shupikai was forced to use his left hand for writing. As a result, he couldn't keep up with his classmates. He had to ask invigilators to allow him to write with his foot in a separate room during the final exams, but by then it was already too late. He only passed two subjects and instead of moving on to higher education, he started selling Kapenta (a kind of fish) with minimal returns. When Shupikai registered for the Livelihoods Resource Centre Programme at the non-profit organisation strategic partner of the LF, Leonard Cheshire Disability Zimbabwe Trust (LCDZT), he had written a novel. It had been three years since he finished writing it, but he did not have the funds to publish it.

Shupikai indicated his desire to have the novel published. Shupikai received Career Guidance Counselling, and training in Soft Skills and Business Proposal writing. With assistance from the LCDZT he managed to type his 142 page Shona novel in six weeks at the Computer Library, using his foot. LCDZT then approached a publishing company that had agreed to edit the novel. If they find it worthy of publishing, they will publish and market it free of charge and Shupikai will receive 10% of royalties.

Shupikai developed a positive attitude as he was initially embarrassed to be seen typing, eating or writing with his foot. He could now do it even in the presence of other clients. His typing skills got better and he also became optimistic about the prospects of his book being published. He has lost his shyness and can now market himself in the media.



Rolliane
Philippines

Rolliane, 9 years old girl, is also known as Yang-Yang to her friends and family was discovered by the local partner organisation in Southside dumpsite area when she was just 6 years old. She has a Cerebral Palsy, Athetoid type with concomitant Speech Deficit. At that time, she was totally unable to move around and she was always carried around by her mother or by her siblings. She was given physiotherapy and occupational therapy services and she was enrolled in The Birthright Center in Southside, San Pedro (Dumpsite). Slowly, she was able to acquire balance and motor coordination skills. After several months, she was able to stand up and walk slowly with the aid of a walker. She is now being trained to walk without the assistive device. She also gained some motor control of her both arms which she uses for her self-help skills training.

She is loved by her family and friends, and her parents try to provide for her needs as best as they can. However, being mere scavengers in the dumpsite, their meagre income is barely enough to provide food for the whole family. Her parents are very supportive when it comes to her welfare. She plays with the other children in her neighbourhood despite her condition. She does not allow her disability to be a hindrance to live a normal life. She goes to school at The Birthright Center and she participates in all school activities. After school hours, she goes home and plays with her playmates.

key points chapter four

Child Empowerment as a demand driven strategy aims:
1 To promote quality rehabilitation services that improve the functionality of children and youngsters with disabilities (Child Development component);
2 To ensure the systematic removal of barriers and biases that children in the programme experience in their communities, and enable their participation and inclusion (Enabling Environment component).

LF supports local partner organisations in planning and implementing interventions on topics related to the CBR domains of: health, education, livelihood and social development. Empowerment as a key theme of the strategy can be included as a cross-cutting theme in the four above mentioned domains.

Local partners can plan activities:
1 At the individual child level within the Child Development Component, for e.g. access and provision of rehabilitation services, assistive devices, school fees, etc.
2 At the small-scale community level for children registered in the programme, within the Enabling Environment component, for e.g training of teachers on improving their coping and teaching skills; adjusting infrastructure of schools, rehabilitation centres or homes of children, etc.

chapter four

Child Empowerment Strategy

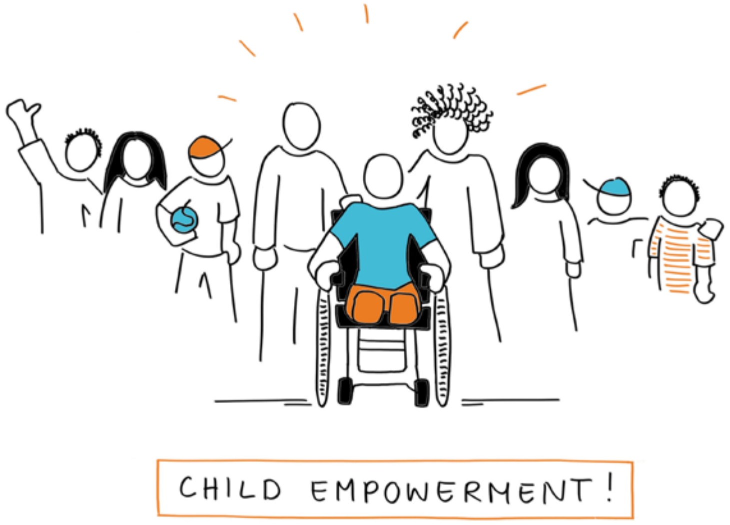
As well as amending its core strategy, the LF also reviewed its vision and mission and consequently revised the two to articulate new organisational developments. This chapter further explores the core strategy through the CBR components, by addressing possible interventions through the components of Child Development and an Enabling Environment.

The LF, together with its partners, envisions an inclusive world which respects the rights and needs of children and youngsters with disabilities. The premise of this new agenda is the notion that disability results from a complex interaction between a person's health condition and broader contextual factors.

←
Child Empowerment is a demand driven strategy with 2 main components: Child Development and Enabling Environment.

To keep abreast of such changes, the LF is gradually focusing on strengthening community-based interventions in the quest to mitigate the causes and consequences of disabilities among children and their immediate environment / extended family. Child Empowerment as a demand driven strategy aims:

1. To promote quality rehabilitation services that increase the functionality of children and youngsters with disabilities (Child Development component);
2. To ensure systematic removal of barriers and biases that children in the programme experience in their communities, and enable their participation and inclusion (Enabling Environment component).



In this chapter the two components of the Child Empowerment strategy are discussed. These components are elaborated upon in the CBR matrix. Each component of the CBR matrix is discussed in terms of the Child Development and Enabling Environment strategies.

→
The Liliane Foundation has integrated the CBR matrix into its Child Empowerment Strategy using the principles of inclusion, participation, self advocacy, accessibility and sustainability.

Child Empowerment Through the CBR strategy

The Liliane Foundation has integrated the CBR matrix into its Child Empowerment Strategy, using the principles of inclusion, participation, self advocacy, accessibility and sustainability. The LF is using the CBR matrix as it was designed by the World Health Organisation, with the aim of achieving better functioning of children with disabilities, and reducing the barriers that hinder their participation in society.

Empowerment: Nucleus of the CBR Strategy

The LF considers the domain of Empowerment as a cross-cutting theme that is considered to be core in the CBR framework.[46] Empowerment entails a change in the attitudes of people and occurs when persons with disabilities start to perceive themselves as actors in their development instead of passive receivers of support.[47] Empowerment is therefore a contributory factor in overcoming the attitudinal, institutional and physical barriers that may be present in the community.[48]

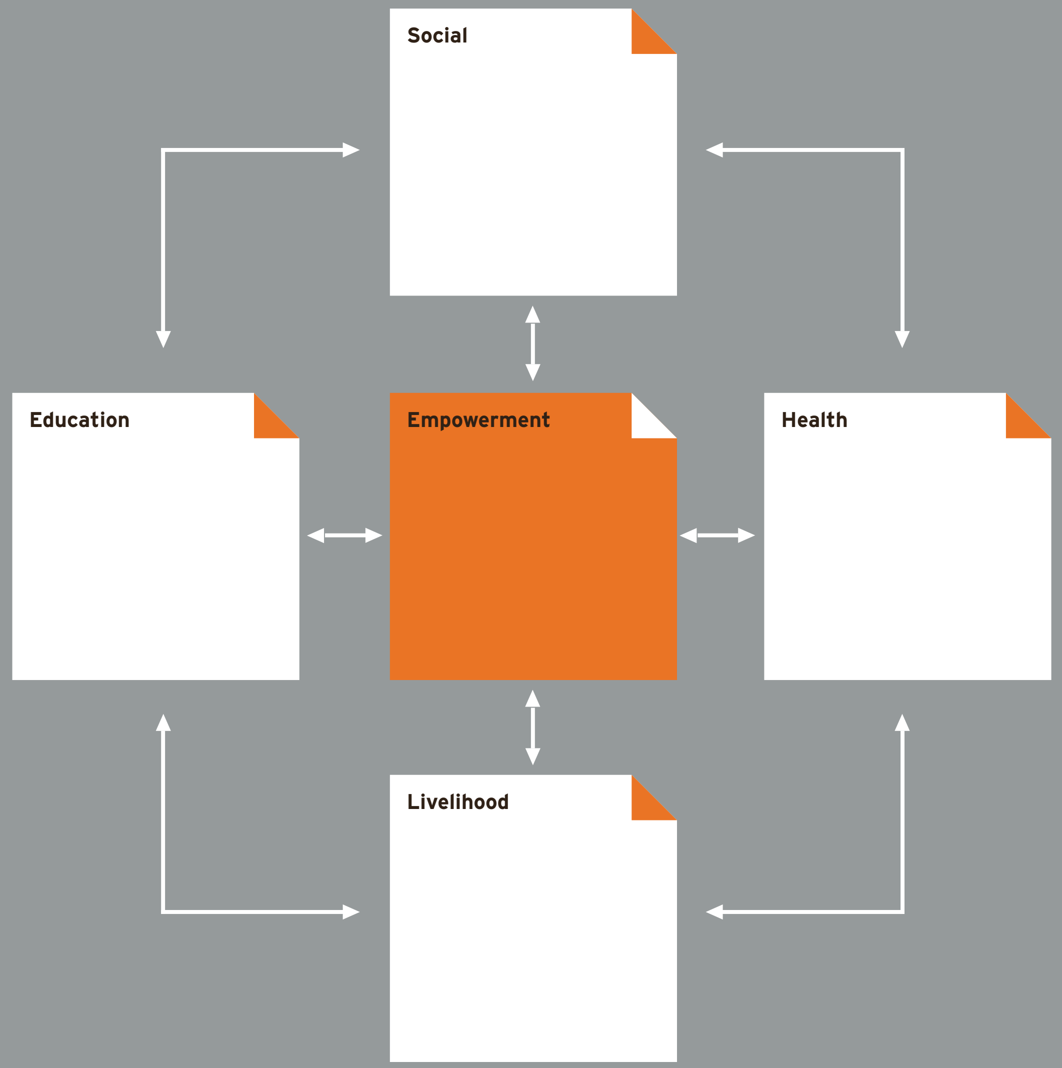


Figure 4
CBR domains and their relationships

Activities that are included in the Empowerment of children with disabilities are, for example:

- Awareness raising of community members about the equal right to education and opportunities that should be enjoyed by children with disabilities.
- Information sharing: ensuring that children with disabilities and their families have the right information about how, where and from whom they can claim their rights.
- Peer support: bringing families of children with disabilities together for the purpose of helping each other and minimizing isolation. This can be encouraged through formation of self-help groups, parents groups or DPOs.

For the LF, there are two important strategies that can be used by partner organisations in the empowerment process, both of which can be used in all other domains from the CBR matrix, as follows:

Advocacy

The LF supports the grass-roots advocacy activities of local partner organisations. An effective means of implementing advocacy at the grass-roots level is by introducing the concept of people-centred-advocacy. This process "involves the coordinated efforts of people to change policies, practices, ideas, and values that perpetuate inequality, intolerance, and exclusion. It strengthens citizens' capacity as decision makers and builds more accountable and equitable institutions of power".[49] In line with this, the LF supports local partners to strengthen and develop the self-esteem and resilience of children in order for them to gain a voice and claim their rights from society. For example, local organisation can empower a youngster to claim his admission to vocational training based on his right to education.
In adopting an approach of people-centred-advocacy, LF will continue its focus on the individual child and simultaneously support local advocacy interventions that empower children and youngsters with disabilities in the communities.[50] This approach enables LF to support the local advocacy efforts of its partners without distancing itself from the individual child or losing the organisational values.

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In adopting an approach of people-centred-advocacy, LF will continue its focus on the individual child, and simultaneously support local advocacy interventions that empower children and youngsters with disabilities in the communities.

Community mobilization

Community mobilization is a process that brings together as many stakeholders as possible to raise people's awareness of, and demand for a particular programme. This leads them to assist in the delivery of services and resources and to strengthen community participation for sustainability and self-reliance. In line with its new core strategy and vision, LF believes that communities should take the leading role in development activities, by deciding on interventions to address their own challenges. CBR programmes are therefore more likely to benefit children and youngsters with disabilities and their families when communities are involved, especially even after the funding of the programme has ended. An example of community mobilization is use of human and material resources in the community to make small infrastructural adjustments to improve the accessibility of the school in the community.

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In line with its new core strategy and vision, LF believes that communities should take the leading role in development activities, by deciding on interventions to address their own challenges.

Education

In many countries of the world, the majority of children with disabilities, especially those with moderate or severe impairment, are out of school because of stigma and discrimination. Lack of adequate education remains the key risk factor for poverty and exclusion for all children, both with and without disabilities. The risk of poverty due to lack of education may be even higher for children with disabilities, than for those without, so that children with disabilities who are excluded from education are at a higher risk of lifelong poverty.

The CBR strategy focuses on early childhood education, primary education, secondary and higher education, non-formal education and lifelong learning.

Education is about all people being able to learn what they need and want throughout their lives, according to their potential. Education is much broader than schooling. Schooling, although vital, needs to be seen within the context of a lifelong learning process.
The CBR strategy focuses on early childhood education, primary education, secondary and higher education, non-formal education and lifelong learning.[51]

Education can be **formal, non-formal or informal** and **inclusive, special** and integrated. In general, formal education refers to education that takes place in organized institutions, e.g. schools, colleges and universities often leading to recognized qualifications and certifications.[52] The non-formal education refers to organized educational activity outside the formal educational system.[53] **Inclusive education** focuses on changing the system to fit the student, rather than changing the student to fit the system.[54] **Informal education** refers to all the learning that happens throughout life as a whole,- from family, friends and communities which is often not organized, unlike both formal and non-formal education.[55] Special education is a broad term which can refer to the provision of extra assistance, adapted programmes, learning environments or specialized equipment, materials or methods to support children in accessing education.[56] An Integrated school is one in which both inclusive and special services are separately developed. For example, in integrated school there are special classrooms for deaf students.

In the intervention component of Child Development the LF is supporting local POs to invest in children and tailor the interventions to their individual needs.

Child Development in the education component
The LF supports local partners to invest in children and tailor the interventions to their individual needs in the intervention component of Child Development. The provision of extra assistance, specialized equipment, audio and other devices, Braille, sign language, and school fees for children are individual interventions that are taken into consideration when the local partner organisation applies for funding. This list is not exhaustive and it depends on the individual needs of the children registered in the programme of the partner organisation. Many of these interventions are related to special education. Although the LF promotes inclusive education, "special schools" are a reality for many children with disabilities who live in low income developing countries, because they may be the only option available for children who are deaf, blind, or who have an intellectual impairment. In such cases, the local partner needs to conduct an analysis and have reasonable argument as to why the special school is a better option for the child, and what the prospects are of the child to be reintegrated into the community after the completion of special education.

In the intervention component of Enabling Environment, the LF supports local partner organisations in investing in small-scale capacity development projects at community level.

Enabling Environment in the education component
In the intervention component of Enabling Environment, the LF supports local partner organisations in investing in small-scale capacity development projects at community level. The purpose of these projects is to reduce barriers for participation of children who are part of the partner's programme funded by the LF, in their communities. These barriers relate to communication, infrastructure and the physical environment, public attitudes, and policy. The LF supports local partner organisations in investing in projects to do with raising awareness and changing the attitudes of families, neighbours and teachers to the potential and talent of children and youngsters with disabilities, as well as appropriate treatments at home and in school. This may encompass, for example, the training of teachers in how to use and teach Braille or other sign language, or the training of parents to support early learning in the home and encouraging them to involve their children in activity-based learning in creative and lively ways. Furthermore, small-scale infrastructural adjustments in schools and other education facilities can improve access to education for these children and further enhance their opportunities for participation. In addition, awareness-raising and advocacy, aimed at local government by local partners, about implementation of the right to education are also encouraged at the local level.

Health
Out of 200 million children living with some form of disability, only a few of those living in developing countries have access to appropriate health and rehabilitation services and support.[57] Mortality of children with disabilities under the age of five can be considerably higher in low and middle income countries and children with disabilities might not survive childhood due to a lack of primary health care facilities.[58] Moreover, the rehabilitation services in these countries are often concentrated in urban areas or in the capital, and can be very expensive. In these cases children are often left for weeks by their parents while they receive care, in order to receive the appropriate treatment, which in many cases can have profound psychological effects on their wellbeing.[59]

The right to health is not merely about access to health services, but also about underlying determinants of health, such as access to safe drinking water, sanitation and housing.

The right to health is not merely about access to health services, but also about underlying determinants of health, such as access to safe drinking water, sanitation and housing. The right to health also implies certain freedoms such as the right to be free from non-consensual medical treatment and the right to be free from abuse or other inhuman and degrading treatment. The right to health also implies certain entitlements such as the right to a system of health protection and prevention, access to essential medicines and the rights of each child to participate in decisions regarding his/her own health.

Health is one of the five components of the CBR strategy. It covers five key areas: health promotion, prevention, medical care, rehabilitation, and assistive devices.

Health as a CBR component covers five key areas: health promotion, prevention, medical care, rehabilitation, and assistive devices.

Child Development in the health component
In this component the LF supports local partners to invest in children and tailor the interventions to their individual needs, such as the provision of different assistive devices. These can be mobility devices, positioning devices, daily living devices, vision devices, hearing devices, communication devices, and cognitive devices.

The LF further supports partners to facilitate different sorts of therapies and surgeries for children and youngsters with disabilities. For example, physiotherapy, occupational therapy, speech therapy, Activities of Daily Living (ADL), corrective surgery, and medicines for epilepsy and leprosy. This list is not exhaustive and the interventions depend on the individual needs of the children registered in the programme of the PO.

LF supports local partners to improve the accessibility of medical and rehabilitation services and the provision of different assistive devices.

In providing access to medical care, and assistive devices and technology, LF expects partners to take into consideration the environmental, cultural, social and economic factors that influence communities and individuals. Many types of technology that are frequently used in Western countries are not suitable for rural/remote areas and low income countries. The assistive devices and technologies need to meet children's needs by using local skills, tools and materials in a simple, effective and affordable manner.[60] Therefore, the technology used in the assistive devices should be carefully designed, produced and selected to ensure they meet these criteria.[61]

Reducing barriers and assuring accessible health-care services and practices is only possible when local partner organisations invest in reducing the different sorts of barriers that are present in the communities of children with disabilities.

Enabling Environment in the health component

Reducing barriers and ensuring accessible healthcare services and practices is only possible when local partner organisations invest in reducing the different sorts of barriers that are present in the communities of children with disabilities. This requires, firstly, a change in the attitudes and coping skills of parents and families towards the health situation of their children, increasing their ability to manage the child's impairment and improve their knowledge and skill for home-based rehabilitation. A second need is for partners who can work on improving the skills and competencies of the staff within the medical institutions (hospitals, rehabilitation centres) and raising awareness that children with disabilities have equal rights to receive health-care and appropriate treatment. Thirdly, the infrastructure of medical institutions should be adjusted and they should be provided with equipment that can be effectively maintained and sustained. This can increase the quality of health services for children and youngsters with disabilities, and enable them to participate better in their communities. Finally, partners should consider changes in policies and laws on health, which should be disability inclusive, and implemented in an equal way towards all citizens. Local partners are thus stimulated to raise the awareness of local government of the need to implement more disability- inclusive policies on health, and to take responsibility for the implementation of children's right to health.

The opportunities to take part in social activities in the family and community can have a great positive impact on the lives of children with disabilities, their identity, self-esteem, quality of life and social status.

Social

The opportunities to take part in social activities in the family and community can have a great positive impact on the lives of children with disabilities, their identity, self-esteem, quality of life and social status. Although the rehabilitation process is an important aspect of improving the functionality and participation of children with disabilities, the relationships that these children and youngsters form with their peers and family, and cultural, sporting and artistic activities that can shape their spirit, sense of self-worth and resilience, are equally important and often crucial for their independent living. These factors also have a positive effect on the ability of these children to become role models for others in their community.

According to the CBR guidelines there are five key elements to the Social Component, namely: personal assistance; relationships, marriage and family; culture and arts; recreation, leisure and sport, and access to justice. These elements are crucial in efforts to address the barriers and other negative issues hindering the social inclusion of children with disabilities.

Raising awareness and challenging the attitudes of family and community members by highlighting the talents and skills of children and youngsters with disabilities can reshape and develop whole communities.

Child Development in the social component

Some of the child-based interventions that contribute to the Social component are closely linked to the interventions in the health and education component. Sometimes, getting an appropriate assistive device can enable a child to move better and participate in a sporting activity. There are other sporting, recreational and artistic activities at the community level that partners can contribute to with the support of the LF, for example: fees for sporting activities, and costs for artistic materials suitable for the child's age, development and needs.

Enabling Environment in the social component

In this component, the LF supports local partner organisations in reducing the barriers to social participation of children and youngsters with disabilities. Raising awareness and challenging the attitudes of family and community members by highlighting the talents and skills of children and youngsters with disabilities can reshape and develop whole communities. Improving the infrastructure and the means of communication available to community centres, sporting and artistic venues can increase the participation of the children considerably. Examples are local sports grounds that are equipped for blind children and local theatres that have spaces at the front for wheelchairs. Furthermore, raising the awareness of the national and local authorities can also stimulate partner organisations to work on disability inclusive laws and their effective implementation.

Livelihood

People living in extreme poverty are significantly more likely to have or incur a disability within their lifetime. On the other hand, impairments independently or in tandem with one another, may increase the likelihood of becoming poor. Youngsters of working age with disabilities should be encouraged to develop skills and acquire decent and meaningful work as the means by which they can escape poverty. Not all work is decent. ILO defines decent work as:

> "work that is productive and delivers a fair income, security in the workplace and social protection for families, better prospects for personal development and social integration, freedom for people to express their concerns, organize and participate in the decisions that affect their lives and equality of opportunity and treatment for all women and men."[62]

Youngsters with disabilities of working age should be encouraged to develop skills and acquire decent and meaningful work as the means by which they can escape poverty.

There are 5 key elements in the Livelihood Component: skills development, self-employment, wage employment, financial assistance, and social protection.

Child Development in the livelihood component

Most of the livelihood interventions that fall under this component are linked with individual support for youngsters in pursuing skills development training as a preparation for acquiring meaningful and decent work, and giving them better opportunities for wage employment. The LF does not provide loans or credit, but supports local partners in facilitating access to microcredit and microfinance services to youngsters with disabilities, and development of saving groups. In this situation, the principle of multi-stakeholder collaboration emerges as a way for the local partners to establish relationships with already existing Micro-Financing Institutions (MFIs), raise their awareness on the abilities and the potential of these youngsters, and further convince MFIs to include them in their schemes.

The LF does not provide loans or credit, but supports local partners in facilitating access to microcredit and microfinance services to youngsters with disabilities, and development of saving groups.

Enabling Environment in the livelihood component

Creating a more enabling environment for livelihood support requires activities that reduce the diverse barriers that can exist in communities. Firstly, local and national governments, and non-governmental enterprises and companies need to become more open, and improve their attitudes towards these youngsters by seeing them as having comparable capabilities to non-disabled people. Secondly, they need to change their policies and practices to include persons with disabilities in the training and assistance they provide. Thirdly, youngsters with disabilities need to be given access to support services – basic business skills training, business development and financial services – to initiate or expand entrepreneurial activities. This is possible when training institutions are aware and skilful in addressing the needs, interests and talents of these youngsters. Positive role models also need to emerge. Youngsters with disabilities, who are already active in the labour market, need to be recognized as successful entrepreneurs and productive, contributing members of the community. They can also act as trainers of other persons with disabilities. These activities can be initiated and facilitated by local partner organisations in the countries where the LF's partners are active. It is important that these local partners collaborate with other relevant stakeholders in the community and make a difference to the livelihoods of the youngsters with disabilities through joint effort.

Local and national governments, and non-governmental enterprises and companies need to become more open, and improve their attitudes towards these youngsters by seeing them as having comparable capabilities to non-disabled people.


education

image: Johannes Odé


health

image: Bente Hamelink


social

image: Joris van Gennip


livelihood

image: Jan-Joseph Stok

key points chapter five

As a demand driven strategy, Child Empowerment strategy remains the driving force through which community based rehabilitation and access to services will be promoted under leadership and facilitation of local partner organisations. First, the local partner organisation needs to understand and be embedded in the local context in which it works. Secondly, it needs to facilitate internal mediation process in which the functionality and participation of children and youngsters with disabilities will be consequently addressed. Thirdly, there is a need to safeguard the child-centred approach through involvement of families and children and youngsters with disabilities in the decision making process about their rehabilitation. Fourthly, the local partner is also encouraged to connect and collaborate with other relevant stakeholders in the community in order to implement interventions that will cover different aspects of the child's well-being and therefore safeguard the holistic approach and ultimately contribute towards inclusion of children and youngsters with disabilities in society.

chapter five

Actors in the Child Empowerment Strategy

This chapter discusses the role of the local partner organisations as the main implementing actors of the LF core strategy, ways to safeguard the holistic approach within these local partners, and networking activities between them and the other relevant stakeholders in their communities.

LF sees local partner organisations as core implementers of the LF core strategy in their communities, safeguarding a child-centred approach within their organisations and focusing on empowerment of children and youngsters with disabilities by improving their functioning and participation. Local partner organisations work holistically and in synergy with other stakeholders in the region and / or country. This network of organisations is referred to as a **local cooperative system** among which the local partner organisation is the focal contact point of the strategic partner in the country. A more effective local cooperative system means that the holistic approach for child empowerment is better implemented in the field.

← LF sees local partner organisations as core implementers of the LF core strategy in their communities, safeguarding a child-centred approach within their organisations and focusing on empowerment of children and youngsters with disabilities by improving their functioning and participation.

The sorts of local partners that the LF supports in the national programmes of the Strategic Partner Organisations (SPOs) and the minimum expectations it has for the networks of local partners in the countries are discussed in this chapter.

Local Partner Organisations

In the past, the LF collaborated mainly at a grass-roots level with diverse local partner organisations such as non-governmental organisations (NGOs); faith-based organisations (FBOs); community-based organisations (CBOs); disabled people organisations (DPOs) and a variety of service providers such as rehabilitation centres, hospitals, and specialized schools. This collaboration was established by the National Coordination Teams (NCTs). These NCTs were units that were employed by the SPOs but in the past were directly managed by the LF office in The Netherlands. At present, the NCTs are becoming a functional part of the SPOs. The SPOs have also been given more authority and responsibilities at the national level for developing, organizing and coordinating national programmes on disability. This policy paper elaborates on the LF core strategy, and the POs as the principal implementing actors; the role of the SPOs is therefore not elaborated here. The role of the SPOs as the main coordinators and managing organisations of the national programmes is elaborated on in the Strategic Partnership Policy of the LF.[63]

In order for the local partner organisation to safeguard the holistic approach in its activities, it is required to focus on the following aspects:

1 Increasing understanding and awareness of its context and field of work;
2 Ensuring effective implementation of a mediation process by a number of its employees;
3 Safeguarding a child-centred approach;
4 Establishing collaboration with other relevant stakeholders in the local context;

All these aspects are respectively elaborated upon further in this chapter.

→
Local partners need to be embedded in their communities, to understand the local context in which they operate and focus on disability by addressing the needs and problems of the children and youngsters with disabilities that live in the community.

Awareness of the Local Context

The most important characteristic of the local partners is that they are organisations embedded in their communities, with understanding of the local context in which they operate and focusing on disability by addressing the needs and problems of the children and youngsters with disabilities that live in the community. Community Based Organisations (CBOs) are non-profit groups that work at a local level to improve the lives of children with disabilities. The focus is to build equality across society in all areas – access to healthcare, quality of education, access to technology, access to spaces and information for the disabled, access to working opportunities, etc. CBOs are typically, and almost necessarily, staffed by local members - community members who experience at first hand the needs within their neighbourhoods. Besides being connected geographically, the only link between staff members and their interests is often the desire and willingness to help. The CBOs are seen as "bottom-up" organisations that are more effective in addressing local needs and providing sustainable solutions at a local level.

Effective Mediation Process

In the past few years, the LF has reviewed the role of the mediator as an important actor in the field, who has always been a direct contact with the children and youngsters with disabilities. In order to establish more significant improvements in the lives of the children and youngsters with disabilities, the LF has decided to widen the focus of its policy and to recognize that all "mediator" work in practice can be realised by a variety of persons / staff working for the PO. The direct and small-scale approach, including child and family visits and making referrals to special centres, needs to be implemented and safeguarded by the local partner organisation. This process does not necessarily have to be attached to one of their employees, the mediator, but the process itself needs to be secured by the greater number of their staff. The LF therefore refers to this process, as a mediation process. In the mediation process, numbers of employees within, and also outside, the local partner organisation with specific expertise (rehabilitation, social work, policy) facilitate the rehabilitation process in the broader sense, for the children and youngsters with disabilities in the programme. The purpose of the mediation process is to address the functioning and participation limitations of the child, overcoming those limitations in collaboration with different stakeholders in the community, and consequently increasing the child's opportunities to be included in society. The activities of the mediation process within the local partner organisation are: identification of the child, assessment of the child and the environmental barriers affecting him or her, planning of relevant child specific and community specific interventions, and monitoring of the progress of the child and reducing of the environmental barriers to participation.

The effectiveness of the mediation process[64] is not solely based on the qualifications or training of the partner's employees but rather on the skills that these employees possess to address the needs of the children and youngsters with disabilities, while at the same time respecting them and treating them as human beings. Hence, the mediation process incorporates the following aspects:

- Skills in facilitation and community mobilization;
- Negotiation skills to involve various stakeholders;
- Having a listening ear and allowing clients to talk about their needs;
- Keeping regular contact with the family and the client;
- Not instilling fear among their clients and family that support will stop, and persuading them that decisions are appropriate.

←
The effectiveness of the mediation process is not solely based on qualification or training of the partner's employees but rather on the skills that these employees possess to address needs of the children and youngsters with disabilities, while at the same time respecting and treating them as human beings.

The mediation process needs to be further be safeguarded within the local partner organisation among a variety of employees and is therefore no longer the responsibility of one employee. It is desirable that, for every child in the programme of the partner organisation, one of the employees who is involved in the mediation process oversees the rehabilitation process and manages the information relating to the child.

Safeguarding a Child-Centred Approach

In addressing the emerging needs of the children and youngsters with disabilities living in the community, the local partners need to identify and assess the needs of each individual child and youngster and how these needs can best be met at a local level, taking account of the CBR components of health, education, social development, livelihood and empowerment. The child-centred approach can be implemented when the local partner focuses on:

- Participatory needs assessment of the child or youngster;
- Transfer of knowledge about disabilities and skills in rehabilitation to children and youngsters with disabilities, their families and communities;
- Involvement of the families and communities in planning, decision making, implementation and evaluation.

→ Families should be involved during all stages of the rehabilitation process, to enable the acceptance of children and youngsters with disabilities by the family.

Caregivers and families

Families should be involved during all stages of the rehabilitation process, to enable the acceptance of children and youngsters with disabilities by the family. The Child Empowerment targets parents, particularly mothers, to ensure that services reach their children. Mothers will be targeted as key care givers to children and youngsters with disabilities, based on their understanding of service options and their ability to provide supportive care to their children.

Furthermore, parents/caregivers can also establish Parents' Self-Help Groups (PSHGs). Parents/caregivers need to be strong to be able to take care of their children. When parents are empowered, their children gain possibilities for better participation. The PSHG is about coming together to share experiences, difficulties, and successes. These parents should be drawn together by a common background of exclusion and isolation from their families and society as a result of having children with disabilities. These groups are usually platforms where parents meet with each other to share their experiences, knowledge, strengths and hopes. Parents support each other as they cope with the stigmatisation of their children and themselves, by sharing experiences and advocating for better implementation of their rights and against this stigmatisation.

Self-help groups (SHGs)

Besides parents/caregivers, other people, such as youngsters with disabilities themselves, can also establish Self-help groups as a way to address their common problems. While self-help might imply a focus on the individual, one important characteristic of self-help groups is the idea of mutual support – people helping each other. Self-help groups can be a catalyst for empowerment of children and youngsters with disabilities, as belonging to a group can be one of the first steps towards participation in their communities. Through the involvement in these groups, children and youngsters with disabilities can strengthen their awareness and their ability to organize, take action and become agents of change.

While many of the partners' programmes are focused on the individual, e.g. on providing direct assistance such as basic therapy, this policy encourages partner organisations to bring children and youngsters with disabilities and their family members together to form self-help groups to address and propose solutions to their own problems. In this way, self-help groups can play a crucial role in the implementation of a child's individual rehabilitation plan. It is also the responsibility of the community, through SHGs, to identify and engage in development activities which benefit the children and youngsters with disabilities. The local partners can become the main facilitators driving the formation of SHGs, and allowing them to take an active role in promoting the rights of children with disabilities, identifying needs, and engaging in social and information networks for the purpose of sustainable inclusion and better quality of life for these children and youngsters.

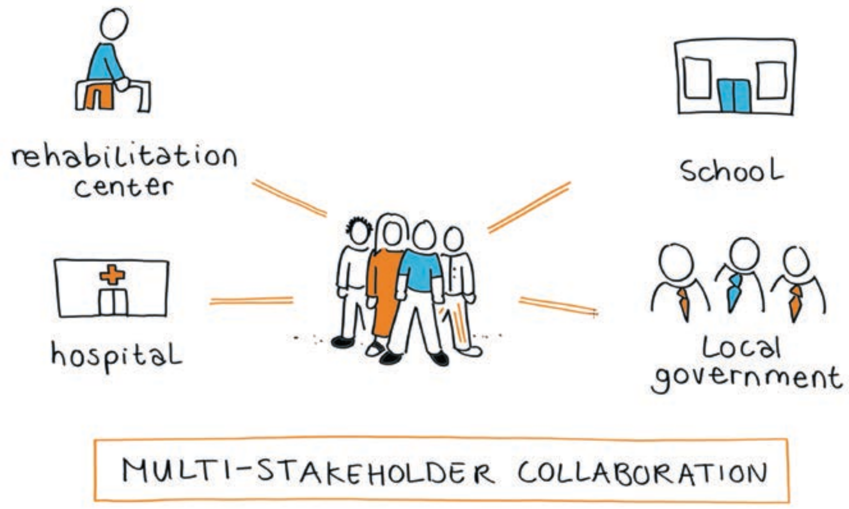
Multi-Stakeholder Collaboration

In order to successfully implement the Child Empowerment Strategy, structural collaboration of the local partner organisations with other stakeholders is crucial. The local partner needs to be a facilitator/broker among different stakeholders at community level, ensuring that there is access to a variety of service providers and that the barriers to participation are reduced. This can be implemented when the PO focuses on:

- Utilisation of available resources in the community;
- Strengthening of referral services that are able to perform skilled assessments, make rehabilitation plans, and participate in training and supervision;
- Utilisation of coordinated, multi-stakeholder collaboration.

← In order to successfully implement the Child Empowerment Strategy, structural collaboration of the local partner organisations with other stakeholders is crucial.

Multi-stakeholder collaboration is both a pre-condition and a result of a good mediation process conducted by local partners. In a multi-stakeholder collaboration, each stakeholder adds unique knowledge and resources to support a joint action. The purpose of this is to foster more effective and sustainable results from the interventions on behalf of the children and youngsters with disabilities.



There are a number of reasons for supporting multi-stakeholder collaboration, both at the community and the national level:

- **Since multiple factors influence each child's functionality and participation, single-sector or stakeholder actions cannot effectively influence all aspects of his/her wellbeing in a holistic way.** To create the necessary positive changes in the lives of children and youngsters with disabilities, all interventions need to address the variety of factors that influence each child. Only multiple stakeholders working together have the ability to implement the actions necessary to tackle these different factors and achieve optimum impact and success.
- **Collaborating together will maximize impact.** Stakeholders often work in isolation, unaware of the ambitions and activities of other relevant stakeholders. Aligning each other's goals and resources in a coordinated manner can multiply the impact of individual stakeholders. Moreover, exploring mutually beneficial linkages across their programmes can contribute to building organisational capacity, particularly in low income countries.
- **Tackling resource limitations.** A multi-stakeholder approach means pooling of resources, allowing collaboration to maximize its financial and technical expertise, which is particularly important in financially constrained environments.


Image: Johannes Odé

- **Foster innovation for achieving outcomes.** By working together, stakeholders can draw on their collective core competencies to create a more comprehensive set of capabilities. For instance, the digital revolution and information technologies offer innovative tools for promoting healthy lives; applying these tools will require participation from partners across different sectors.

Partners are encouraged to find out which stakeholders are active in the community, what their relevance and competencies are in providing services to the children and youngsters with disabilities, or in reducing the barriers for children's participation. For example, the partners can be encouraged to collaborate with (other) rehabilitation services to ensure that medical treatment, rehabilitation and disability aids and equipment are easily accessible. Furthermore, the partners can also establish partnerships with other relevant organisations, such as Disabled People's Organisations (DPOs) and Parent Organisations.

← Partners are encouraged to find out which stakeholders are active in the community, what their relevance and competencies are in providing services to the children and youngsters with disabilities.

The role of these stakeholders is integrated into a so called **local cooperative system.** This system can function as a synergetic mechanism of different stakeholders who together can improve the functioning and participation of children with disabilities, including them in society and increasing their quality of life. Among the stakeholders who can be a part of this system are: Disabled People's Organisations (DPOs), a variety of service providers, private sector and employers, local government, self-help groups, etc. This chapter provides more details about some of them.

Disabled People's Organisations (DPOs)

Throughout the world, disabled people have united in organisations as advocates for their own rights to influence decision-makers in governments and all sectors of society.[65] These organisations are known as Disabled People's Organisations (DPOs). DPOs have arisen in response to societal barriers that have prevented the equal participation of persons with disabilities, and as a reaction against the control of persons with disabilities by others. For a long time, persons with disabilities have been spoken for by health professionals, family and others without regard for their own needs, priorities or choices. Persons with disabilities are their own best spokespersons and representatives, as they know best their needs and aspirations.[66]

← The local cooperative system can function as synergetic mechanism of different stakeholders who together can improve the functioning and participation of children with disabilities, including them in society and increasing their quality of life.

The main purpose of involving and collaborating with DPOs at the local and national level is ensuring equal opportunities and social inclusion of persons with disabilities. In situations where the DPOs are not direct partners, it is important that both DPOs and local partners have mutual respect for each other and work towards developing successful partnerships. They should also meet common goals and ensure the development of national legislation that will protect the rights of persons with disabilities, or simply ensure more effective implementation of the existing legislation.

← Collaborating with DPOs at the local and national level ensures equal opportunities and social inclusion of persons with disabilities.

Service providers

Ensuring awareness of the existence of services among children and youngsters with disabilities and their families in rural and remote communities is essential if access to them is to improve. In principle, primary health care services are the most accessible, affordable and acceptable at community level. Service providers might need to accommodate the specific needs of the children and youngsters with disabilities related to their impairments, and to include them in the primary health care services. Adaptations to achieve this include:

- **Structural modification of facilities:** building ramps, adjusting the layout of examination rooms and other clinic spaces, widening doorways, etc.

- **Using equipment with universal design features:** Providing height-adjustable examination tables, a lower cot or bed for examination, etc.
- **Appropriate communication means:** using Braille, sign language, images, audio messages, etc.
- **Using alternative models of services:** telemedicine, mobile clinics in remote areas, involvement of families in the assessments, consultations and follow up, etc.
- **Using local resources:** Using local resources for developing equipment and assistive devices.

The service providers are crucially important in CBR programming and interventions at the community level. Increasing the capacities of the service providers and educating them on disability is an important priority to meet the specific needs of the children and youngsters with disabilities, and improve their access to services. Providing adequate and affordable services contributes to better participation and inclusion of children and youngsters with disabilities in society and should therefore be included in the local cooperative system.

→ The local partners need to have a practical understanding of how the government works in order to enable them to collaborate and contribute to positive change.

Local government

The local government is also very important stakeholder within the local cooperative system. The local partners need to have a practical understanding of how the government works in order to enable them to collaborate and contribute to positive change. Identifying key legislation and policies related to disability is an important step in reducing the policy and institutional barriers for participation. Finding out about the political structures; how government decisions are filtered down to the local level and to what extent the local government has power to make decisions, can increase the impact of the CBR programmes. Meeting regularly with governmental representatives, raising their awareness and advocating on behalf of children and youngsters with disabilities can be effective tools for maintaining the accountability of the local government. Moreover, the local partners might also provide some technical assistance to the local government, sharing knowledge on how to better implement the laws in practice and how to involve persons with disabilities in the decision making process.

→ The local partner might facilitate access to employment within the public or the private sector to achieve more independent and sustainable livelihoods for youngsters with disabilities.

Private sector

The local partner might facilitate access to employment within the public or the private sector to achieve more independent and sustainable livelihoods for youngsters with disabilities. Collaboration with companies, local businesses, MFIs and public administration is therefore important. In this regard, partners might first raise the awareness among employers that disability is not inability, that many of these youngsters have suitable job skills and competencies to be involved in a labour process and earn their living in a decent way. The employers need to make their policies inclusive and reduce the infrastructural and communication barriers in their own working environment.
Furthermore, the local partners can develop partnerships with employment agencies, educational institutions, vocational and skills training programmes to build a skilled workforce that includes youngsters with disabilities.[67]
In countries and communities where the informal economy is predominant, the local partners can collaborate with MFIs in order to improve access to microfinance by better outreach and customized credit conditions.

image: Gideon van Aartsen

community awareness raising by a local partner

image: Liliane Foundation

parents training

Image: Johannes Odé


Image: Petra Brands

chapter six

The Liliane Foundation's Dream of a Disability-Inclusive Society

The LF believes that children and youngsters with disabilities living in poor families and communities are entitled to be included in society and to enjoy the highest attainable quality of life. But the question remains: How can we make this dream possible, and what steps will achieve a sustainable impact on these children and youngsters? The LF defines six important aspects which, if implemented simultaneously, will contribute towards realizing this dream of an inclusive society in which children and youngsters with disabilities enjoy equal rights and quality of life. The LF encourages partners to take these six steps into consideration when they develop their own programmes and to strive as far as possible towards their implementation, taking into consideration their capacities and the context in which they work.

Raise public awareness about disability

Beliefs and perceptions have a deep impact on the mutual understanding and respect among people in society. Judgements and stigma that exist about children with disabilities can have devastating effects on their lives and their future prospects for participation and inclusion. Policies can often be improved, infrastructure can be adjusted, communication means can be provided, but belief systems are difficult to change. It is therefore vital to improve public understanding of disability, confront negative perceptions, and emphasize that disability represents diversity and not inability. Collecting information on beliefs and attitudes about disability can help identify gaps in public understanding that can be bridged through awareness-raising, education and public information.[68] Involving the media is vital to the success of awareness-raising campaigns, and to ensuring the dissemination of positive stories about disabled people and their families.

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It is vital to improve public understanding of disability, confront negative perceptions, and emphasize that disability represents diversity and not inability.

Involve children and youngsters with disabilities in the programme management cycle

Children and youngsters with disabilities often have unique insights about their disability and their situation. In the process of formulating and implementing programmes, children and youngsters with disabilities should be consulted and actively involved. Partner organisations may need capacity-building and support to empower children and youngsters with disabilities and advocate for their needs. These children and youngsters are entitled to make choices for their lives and therefore need to be consulted on issues that concern them directly – whether in health, education, rehabilitation, or community living. Supported decision-making may be necessary to enable some individuals to communicate their needs and fully enjoy their rights. Consequently, children and youngsters with disabilities need to be involved in all steps of the programme cycle of the organisations from whose programmes they benefit, such as: planning, monitoring and evaluation.

←
In the process of formulating and implementing programmes, children and youngsters with disabilities should be consulted and actively involved.

Strive for access to all mainstream policies, systems and services

Children and youngsters with disabilities have ordinary needs for health, education, social protection, job opportunities and economic independence and participation in their communities. Whenever and wherever possible, these needs should be met in mainstream programmes and services that exist at the local

Image: Johannes Odé

level in the communities where these children live. Mainstreaming enforces the principle of equality and human rights and it is more effective and efficient. Mainstreaming is also an important aspect of the twin track approach. It is a process by which governments and other stakeholders ensure that persons with disabilities participate equally with others in any activity, and gain benefit from services intended for the general public such as education, health, employment and social services.[69] The barriers to participation therefore need to be identified and removed, and this might require changes in the laws, policies, infrastructure, attitudes of people, means of communication, etc.

Mainstreaming enforces the principle of equality and human rights and it is more effective and efficient.

Focus on specific programmes and services for children and youngsters with disabilities

Simultaneously with mainstreaming services, some children and youngsters with disabilities might require specific services and attention, such as rehabilitation, assistive devices, personal assistance, etc. This aspect is linked with the principles of equity and justice; children's specific needs should be met in order to enable them to enjoy and participate in community life as equals. The provision of specific services and programmes is the other aspect of the twin track approach. In low-income developing countries, there is need for higher quality services, which means better, more accessible, flexible and integrated, and well-coordinated multidisciplinary services, that can cover a variety of impairments.[70] These services should be continuously improved in terms of their effectiveness and efficiency, as well to fit the local context and culture.

Children's specific needs should be met in order to enable them to enjoy and participate in community life as equals.

Collaborate with other stakeholders

Collaboration and partnerships with other relevant stakeholders at the local and national level increases the chances of more sustainable results, and it can be particularly effective for sharing best practices, experiences and resources. Global policies and commitments might become concrete activities on the ground thanks to multi-stakeholders' collaboration. This could be achieved through the effective formulation of joint regional and national plans by partners, where implementation is strengthened by the use of measurable targets and indicators for monitoring progress in specific local contexts.[71] The partners of LF need to scout opportunities to participate in regional and national alliances and networks, harnessing their strengths in promoting development initiatives inclusive of disability. Forms of decentralized cooperation partnerships have been gaining ground rapidly, whereby multi-stakeholder engagement between local government authorities, civil society and the private sector has played an increasingly central role in development.[72] This bottom-up approach mobilizes and draws on the capacity, knowledge and expertise of local actors. In the context of disability, such forms of partnership can be particularly helpful in capitalizing on local expertise and knowledge, based on the full and effective participation of persons with disabilities.

Partnerships with other relevant stakeholders at the local and national level increases the chances of more sustainable results, and it can be particularly effective for sharing best practices, experiences and resources.

Promote and strengthen diverse resource opportunities

In order for the local partners to reach all target beneficiaries, sufficient, diverse and sustainable resources are needed. Fostering public-private partnerships and approaching institutional and local donors can contribute to stable and sustainable programmes. During the development of national disability programmes and related action plans, the affordability and sustainability of the proposed measures should be considered and adequately funded. Harmonization among donors here also plays a crucial role in effective and sustainable results. Programme costs and outcomes should be monitored and evaluated, so that more cost-effective solutions are developed and implemented. The increasingly important role of the private sector can not only generate innumerable benefits but also accelerate progress.[73]
The private sector can increase visibility, assist in the transfer of technology and promote innovative approaches to disability inclusive development.

Fostering public-private partnerships and approaching institutional and local donors can contribute to stable and sustainable programmes.

image: Johannes Odé

Endnotes

1 World Health Organisation (WHO), (2012). ***World Report on Disability.***
2 Ibid.
3 International Labour Organisation (ILO), (2011). ***Facts on Disability and Child Labour,*** www.ilo.org
4 Ibid.
5 World Health Organisation (WHO), (2012). ***World Report on Disability.***
6 Schneider, M., Waliuya, W., Munsanje, J. & Swartz, L. (2011). ***Reflections on Including Disability in Social Protection Programmes. IDS Bulletin, 42(6), pp. 38–44.***
7 Narayan, D., P. Petesch (2002). ***Voices of the Poor: From Many Lands.*** Washington, D.C.: The World Bank.
8 Palmer, M. (2013). ***Social Protection and Disability: A Call for Action. Oxford Development Studies, 41(2), pp. 139–154.***
9 Ibid.
10 United Nations (UN), 2010. ***Disability and Milllenium Development Goals, A Review of the MDG Process and Strategies for Inclusion of Disability Issues in Millennium Development Goal Efforts.***
11 Ibid.
12 UNCRPD, Article 32.
13 http://www.post2015hlp.org/wp-content/uploads/2013/05/UN-Report.pdf
14 http://www.post2015hlp.org/wp-content/uploads/2013/05/UN-Report.pdf
15 http://www.worldwewant2015.org/n ode/299198
16 World Health Organisation (2011). ***World Report on Disability*** www.who.org
17 Ibid.
18 Ibid.
19 Ibid.
20 World Health Organisation (2001). ***International Classification of Functioning, Disability and Health (ICF).***
21 UNCRPD (2006), preamble.
22 UNCEF (2008). ***Innocenti Digest No.13: Promoting the Rights of the Children with Disabilities,*** www.unicef-irc.org/publications/pdf/digest13-disability.pdf
23 Ibid.
24 Ibid.
25 UNCRC (1989). Article 2: ***States parties shall respect and ensure the rights set forth in the present Convention to each child …without discrimination of any kind, irrespective of the child's…disability…or other status.***
26 UNCRC (1989). Article 23.
27 www.un.org/disabilities
28 Ibid.
29 Ibid.
30 UNCRPD (2006). preamble, section (r).
31 UNCRPD (2006). Article 7.
32 UNCRPD (2006).
33 UNCRPD (2006). Right to education (article 24).
34 UNCRPD (2006). Right to health (article 25).
35 WHO (2010). ***Community Based-Rehabilitation Guidelines.***
36 Ibid.
37 Cornielje, H., Bogopane-Zulu, H. (2010). ***The implementation of Policies in Community Based Rehabilitation,*** page 25.
38 Cornielje, H., Bogopane-Zulu, H. (2010). ***The implementation of Policies in Community Based Rehabilitation,*** from an e-mail of Magic Nkhwashu 02.03.2007, page 27.
39 Ibid.
40 Coe, S. and Wapling, L. (2010). ***Travelling Together,*** World Vision, United Kingdom.
41 Holle, F. (2012). ***Impact of Liliane Foundation Support on the Lives of Children with Disabilities and their Caretakers,*** a Pilot Study in Uganda. And Magyarszeky, Z. (2012). ***Investigating Communication Flows between the Stakeholders of the Liliane Foundation,*** a Pilot Study in Zimbabwe.
42 Coe, S. and Wapling, L. (2010). ***Travelling Together,*** World Vision, United Kingdom.
43 World Health Organisation (WHO), (2002). ***Towards a Common Language for Functioning, Disability and Health International Classification of Functioning (ICF).***
44 Ibid.
45 International Labour Organisation (2013). ***Disability: A human rights issue,*** www.ilo.org/disability
46 The position of the LF is built on evidence and lessons provided from ***Enablement-*** training, research and development institute that is specialized in Community Based Rehabilitation (CBR) and inclusive development.
47 WHO (2010), ***Community Based Rehabilitation Guidelines, Empowerment Component,*** page 4.
48 Ibid.
49 Veneklasen, L., Miller, V. (2002). ***A New Weave of Power, People & Politics: The Action Guide for Advocacy and Citizen Participation.*** Stylus Publishing: Sterling.
50 Koeman, M. (2012). ***Position Paper: Open the World for a Child with a Disability; Advocacy for Inclusion,*** page 10.
51 World Health Organisation (2010), ***Community- Based Rehabilitation, CBR Guidelines, Education Component,*** page 8.
52 World Health Organisation (2010), ***Community- Based Rehabilitation, CBR Guidelines, Education Component,*** page 4.
53 Ibid.
54 Ibid.
55 Ibid.
56 Ibid.
57 UNCEF (2008). ***Innocenti Digest No.13: Promoting the Rights of the Children with Disabilities,*** www.unicef-irc.org/publications/pdf/digest13-disability.pdf
58 Ibid.
59 Ibid.
60 WHO (2010). ***Community Based Rehabilitation, Health Component,*** page 62.
61 Ibid.
62 International Labour Organisation (ILO) (2010). ***Decent work,*** www.ilo.org
63 Liliane Foundation (2013), ***Steering from the Top, Building from the Bottom,*** Strategic Partnership for Sustainable Results, 12 Steps in the Partnering Process.
64 Singh, M. (2011). ***Analysis of the interventions of lay and professional community based rehabilitation (CBR) workers in promoting social integration of disabled individuals with multiple impairments in Sierra Leone,*** University of Leeds.
65 UN (1982). ***World Programme of Action concerning Disabled Persons.***
66 Enns H. (undated). ***The role of organisations of disabled people: a disabled people's international discussion paper.*** Stockholm, Independent Living Institute.
67 WHO (2010). ***World Report on Disability,*** page 275.
68 WHO (2010). ***World Report on Disability,*** page 291.
69 WHO (2010). World Report on Disability, page 264.
70 Ibid.
71 United Nations, General Assembly (2013). ***The way forward: a disability-inclusive development agenda towards 2015 and beyond.***
72 See ***A renewed global partnership for development,*** available from: www.un.org/en/development/ desa/policy/untaskteam_undf/report2.shtml
73 United Nations, General Assembly (2013), ***The way forward: a disability-inclusive development agenda towards 2015 and beyond.***

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