



Inclusion ***Needs Action***

Taking steps forward with community-based inclusive development

Table of Contents

04	Introduction Change Is Happening
07	Introduction Beyond Institutions
10	Human Rights Approach El Salvador 'Without Human Rights, Everything Is Nothing'
12	Access to Health Cambodia Challenging the Service Gap
18	Access to Health For Everybody Cambodia RehApp: A Digital Everyday Assistant
20	Access to Education Peru Everyone Learns in a Different Way
26	Access to Labour Market Egypt 'Inclusion Is Not Charity. We Demand Real Jobs'
30	Access to Social Life Tajikistan Getting Out of the Shadows
34	Empower for Self-Representation El Salvador Nothing About Us Without Us
40	Improving Education Tajikistan Upgrade Social Workforces
44	Spread Best Practices Iraq & Egypt Global Knowledge Transfer
48	Localisation Lebanon Inclusive Aid Through Local Lead
52	Inclusive Humanitarian Aid Indonesia Inclusive Disaster Risk Reduction

IMPRINT

Caritas Germany | Caritas international
Karlstraße 40 | 79104 Freiburg
phone: +49 (0)761 200-288 | email: contact@caritas.de
www.caritas-international.de | www.caritas-germany.org

Edited by: Dariush Ghobad (resp. for content), Stefanie Santo
Contributors: Andrea Edler, Charlott Friederich, Reiner Fritz, Kilian Linder, Sven Recker,
Anna Lena Timme, Christine Wegner-Schneider
Proofreading: Anke Becker, Joseph Hoyek, Christian Stock, Linda Tenbohlen, Stefan Teplan,
Christine Wegner-Schneider

Twenty-five-year-old Rami Yussef was educated at the Caritas Centre in Baghdad, Iraq.
Children with Down syndrome are still not allowed to attend public schools. Today, he
runs a flower shop together with his sister and niece. © Annette Etges

Editorial Deadline: 20/03/2025
Layout: Carina Ulmann
Illustrations: Lea Berndorfer (leab Berndorfer.com)
Print: schwarz auf weiß GmbH | Freiburg



Dear Reader,

‘Inclusion Needs Action’ – this is the title of this brochure, and it is also our conviction. Working towards equal opportunities for people with and without disabilities is a priority for Caritas Germany and its national and international work. Our experience shows that inclusion is not a process that can be planned on the drawing board. It is a process of trial and error, with stumbling, failing, getting up again and looking for new ways. It requires special actors like our partner organisations. Dedicated people, with and without disabilities, who use their expertise and powers of persuasion to bring about change. They have clear goals but are flexible and creative when faced with obstacles. They tackle problems in the here and now, but not releasing their government from its responsibilities. They constantly remind the state of the commitments it made when it signed and ratified the UN Convention on the Rights of Persons with Disabilities, and fight for inclusion laws worthy of the name.

This booklet is not a policy paper or a methodology manual. Rather, our partners from El Salvador and Peru, Egypt, Iraq and Lebanon, Cambodia, Tajikistan and Indonesia provide a very personal and direct insight into their challenging daily lives and their commitment to more inclusion. How do you bring children with disabilities into mainstream society when they are hidden away at home in shame? How can children with disabilities receive early support when doctors and specialists lack knowledge about diagnosis and therapy? How do young people with cognitive disabilities manage the leap into the mainstream labour market? How can project partners learn from each other? How should social work education and training programmes be adapted so that graduates become experts in community-based rehabilitation/inclusive development (CBR/CBID)

and drivers of inclusion? These are just some of the questions that are of concern to our partners. We are addressing these issues collaboratively, with the support of the Federal Ministry for Economic Cooperation and Development, as part of numerous programmes.

One thing is obvious: inclusion can only succeed if it is locally rooted. It needs local partners at the heart of society. People who have the trust of the community, who speak its language, who share its culture. And who will continue to provide support even in times of crisis and war. So it is these local actors who must be at the centre of distribution of international funding.

Hard-won gains in inclusion can quickly be lost when governments turn into autocracies. This is a painful experience our partner in El Salvador is currently going through. We must remain vigilant. Inclusion is not a given; it is a social and political struggle that must be waged anew every day – and defended by all of us.

I hope you find this booklet inspiring.



Dr Oliver Müller

*Head of International Department of Caritas Germany
Board Member of Caritas Germany*

PS: All the articles in this booklet are also available on our website in audio format and in easy-to-read English. This is a first step towards greater accessibility and more will follow.



This text is available in audio and easy language.





Change *Is Happening*

Right in the middle,
not just on the
sidelines: Burhonjon
from Tajikistan
together with his
friends.

The World Health Organization (WHO) estimates that 1.3 billion people around the world are living with a disability, 80 percent of them in developing countries. In 2025, people with disabilities will still be severely affected by poverty and exclusion, and will largely lack access to education, the labour market and health care. However, a look at the last few decades shows that much has changed.

Disability – a dynamic concept

The changes that have taken place in recent years in the field of working with and for people with disabilities can be characterised as a paradigm shift. Until the late 1960s, disability was seen as an individual impairment, a personal deficit that had to be compensated for by surgery, aids or medication. The treating physician usually had the final say on what should be ‘rehabilitated’. The stated aim was to ‘cure’ disabled men, women and children, to integrate them into so-called ‘normal society’ and to (re)establish their productivity and ability to work. This ‘medical

model’ of disability created a direct link between personal impairment and limited social participation, and completely ignored the many barriers in the environment.

During the social upheavals of the late 1960s, more and more self-representation organisations of people with disabilities were formed and made their voices heard, supported by renowned health and social scientists. They established the ‘social model’ of disability: it does not prioritise cure, but focuses on the removal of physical and social barriers and on the exist-



© Bente Stachowiske

ing capacities of disabled people. ‘Nothing about us without us’ is a slogan of the disability rights movement of the 1990s, reflecting the growing self-confidence of the community and its will to have a voice and participate in decision-making.

Today, a holistic view of disability has emerged, taking into account both personal and contextual factors. It is based on the International Classification of Functioning, Disability and Health (ICF), published by the World Health Organization (WHO) in 2001. According to this ‘bio-psycho-social model’, disability consists of individual impairments, activity limitations and participation restrictions. All three elements interact and are also influenced by environmental and personal factors. This model illustrates that there is no prototype of a disabled person. Even the same functional impairment can have very different effects depending on other parameters.

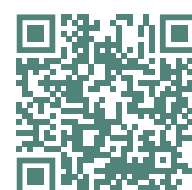
A breakthrough: the UN Convention on the rights of persons with disabilities

The historically almost revolutionary concept of disability as the interaction between long-term physical, mental, intellectual or sensory impairments and various barriers only became widely accepted with the Convention on the Rights of Persons with Disabilities (UNCRPD). As the eighth of nine human rights conventions, it was designed to ‘promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms for all persons with disabilities, and to promote respect for their inherent dignity’. The Convention was developed jointly by people with disabilities and their self-representation organisations and remains a document of hope for people with disabilities around the world. Adopted by the United Nations in 2006, it has been signed and ratified by 185 of the 193 UN member states.

The Convention on the Rights of Persons with Disabilities is not a separate treaty. Its purpose is to make recognised universal human rights accessible to people with disabilities. On the one hand, the UNCRPD identifies areas where adjustments are needed to enable men, women and children with disabilities to exercise their human rights. On the other hand, it also identifies areas where their rights need special protection. For example, Article 24 of the Convention calls for equal ‘access to inclusive, quality and free primary and secondary education’ – a right already enshrined in Article 26 of the Universal Declaration of Human Rights or Articles 28 and 29 of the Convention on the Rights of the Child.

But the UNCRPD goes further, calling for ‘effective individualised support’ (such as school assistants or sign language teachers) to make the right to attend mainstream schools a reality. The articles of the Convention are equally valid and binding for all ratifying states. However, their implementation is subject to a degree of proportionality. For example, Germany’s economic strength and its status as a welfare state mean that it must achieve its inclusion goals more quickly than a country such as El Salvador, where there is no social security system.

This text is available in audio and easy language.





© Philipp Spalek

Poverty and disability amplify each other – even more so for women. Dukini Bumij, 21, from Tiprachora Tea Gardens in Bangladesh, lost her right leg as a young child. Training as a dress-maker gives her the opportunity to earn her own income.

Inclusion as a guiding principle

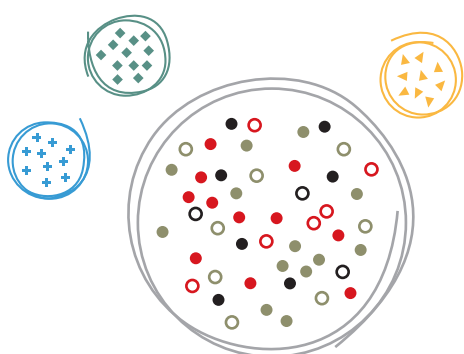
Inclusion is the guiding principle of the Convention on the Rights of Persons with Disabilities. The concept makes diversity the social norm and recognises the different strengths, abilities and needs of people. Inclusion aims to rethink and redesign social structures and spaces, facilities and services so that they are accessible to all. To give an example, it is not the child with a disability who needs to be integrated into the school, but the school, the teaching methods and the teachers need to change so that they are equitable for all children. This means that par-

ticipation is no longer dependent on the good will of individuals, but is structurally embedded and a legally enforceable right. Inclusion is a clear rejection of the long-established concept of integration, which aims to integrate disabled people into so-called ‘mainstream’ society and places the responsibility for successful integration on those affected.

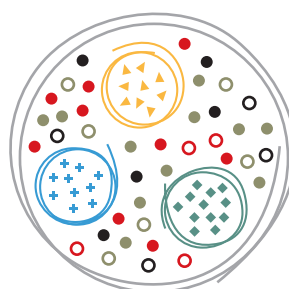
Mandate for development cooperation

In September 2015, UN member states adopted a total of 17 Sustainable Development Goals (SDGs) as part of the 2030 Agenda, ranging from ending poverty and hunger to gender equality and access to education for all. The SDGs are guided by the principle of ‘Leave No One Behind’. Compared to the Millennium Development Goals/MDGs of the 2015 Agenda, the SDGs and their sub-targets place a strong emphasis on the inclusion of vulnerable groups, including persons with disabilities. It has become clear to the international community that sustainability and inclusion go hand in hand, and that many goals can only be achieved if people with disabilities are included.

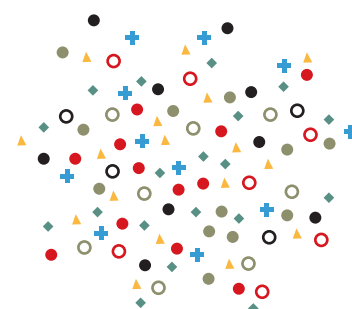
While the UN Convention on the Rights of Persons with Disabilities (UNCRPD) provides the legal framework, community-based rehabilitation/inclusive development (CBR/CBID) is a key development cooperation tool that helps to implement the rights guaranteed.



SEGREGATION



INTEGRATION



INCLUSION

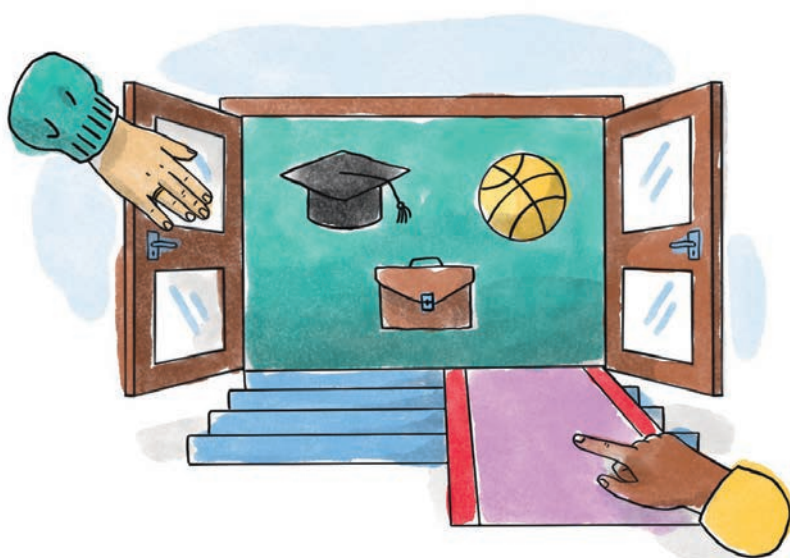
Beyond Institutions

Where there is no support system for people with disabilities, other strategies are needed. For decades, Caritas Germany and its partner organisations have been promoting the inclusion of people with disabilities through community-based rehabilitation (CBR). What is the essence of this approach? How has it evolved over the years? And what is special about the current approach, community-based inclusive development (CBID)?

It was in the mid-1970s that the World Health Organization (WHO) introduced the concept of community-based rehabilitation (CBR). Studies had shown that, particularly in poorer countries, medical services for people with disabilities were either non-existent or woefully inadequate. The few existing facilities were unable to meet the huge demand, and rural areas were particularly underserved. At the same time, it was considered financially unfeasible to establish a comprehensive institutional support system similar to that in countries such as Germany. It was therefore necessary to mobilise previously untapped resources to improve care. Basic knowledge and skills in areas such as physiotherapy and the manufacture of assistive devices were provided directly to people with disabilities, their families, communities and local civil society organisations, making them key players in the rehabilitation process.

Investing in community-based work

As the WHO found the pilot projects to be effective, the limited resources available were to be invested in community-based projects. The benefits of CBR were obvious: people with disabilities and their families were now actively involved in the therapeutic process. Knowledge and techniques were made available where they were needed on a day-to-day basis. Support was provided close to or in the homes of people with disabilities, which proved successful even in rural areas with weak infrastructure. The involvement of volunteers also brought about changes at the community level and, not least, CBR work was seen as a cost-effective alternative to institutional care.



Initially a strong medical focus

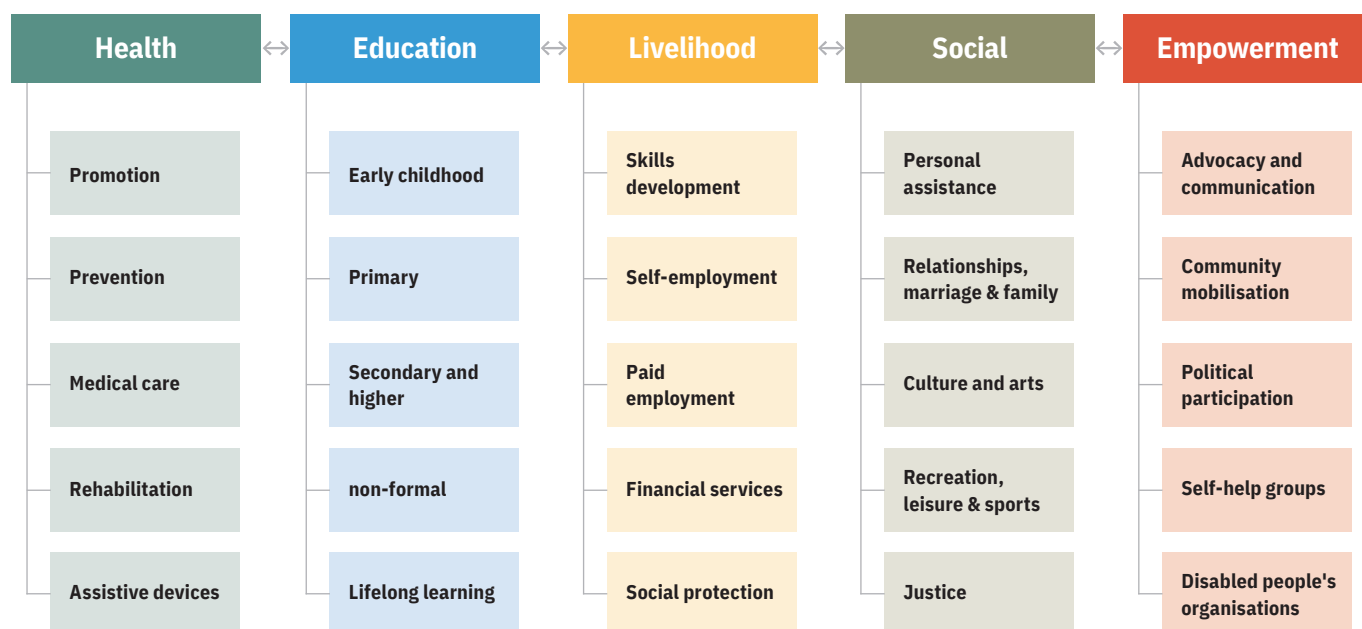
However, critics argued that the early projects were heavily medicalised and focused on individual disabilities. While the focus was on the (re)establishment of physical function and the integration (i.e. adaptation to the so-called social norm) of disabled people, attitudinal, structural or institutional barriers did not yet play a role. Further points of criticism arose from the use of 'locally available resources': Can families who are struggling to survive on a daily basis be expected to take on the additional responsibility of rehabilitating a disabled family member? Can and should CBR work be based on the commitment of volunteers in contexts where few can afford to work for free? How can CBR meet the needs of people with severe and multiple disabilities? These questions have led to further development of the CBR concept, and some of them are still being discussed today.

This text is available in audio and easy language.



COMMUNITY-BASED REHABILITATION

Source: WHO, community-based rehabilitation Matrix



In the 1990s it was recognised that medical and therapeutic services alone were not enough to improve the situation of men, women and children with disabilities. Self-representative organisations pointed out that what was really needed was equal opportunities: access to education, to the labour market and social life. In 1994, WHO, together with UNESCO and the International Labour Organization (ILO), published a position paper stressing the need for a multisectoral strategy. Contextual factors subsequently became a greater focus of CBR work. Major information and awareness campaigns were launched, and many self-help and self-representative groups emerged. Some governments passed laws specifically protecting the rights of people with disabilities, while others adopted CBR as a national strategy. However, addressing contextual factors proved to be much more complex, time-consuming and resource-intensive than medical rehabilitation. And it became clear that statements of intent alone are not enough to achieve inclusion; it requires clear political will on the part of governments.

The multisectoral approach

In 2004, an expanded new edition of the 1994 position paper was published. It defines CBR as 'a strategy within community development for the rehabilitation, equalization of opportunities, poverty reduction and social inclusion of all people with disabilities. It is implemented through the combined efforts of disabled people themselves, their families and communities and the appropriate health, education and vocational and social services'. This led to the development of the CBR matrix, which is still used today as a framework for CBR work. As the diagram shows, CBR has evolved from an exclusively medical approach to a multisectoral one, encompassing the five areas of health, education, livelihoods, social life and empowerment. Each area is in turn divided into five components. The aim is not for individual CBR projects to cover the entire matrix. Rather, it is about selecting the areas and components that best fit local needs and available resources. It is highly desirable to link the areas together – within a project or through cooperation with organisations working in complementary areas. But how does CBR work in practice?

The CBR guidelines

In 2010, the so-called CBR Guidelines were published, handbooks for working in the field. They had been developed by CBR practitioners in an elaborate participatory process and brought together the knowledge of 30 years of experience. For the first time, they created a common understanding of community-based rehabilitation. They show how CBR projects can be implemented, strengthened and developed, and provide practical examples of how the needs of people with disabilities can be effectively addressed and their quality of life improved. They also highlight the particular importance of empowerment.

The twin-track approach

The Guidelines make it clear that CBR not only covers all areas of life, but also follows a twin-track approach: mainstreaming in general and targeting where necessary. The aim of mainstreaming is to ensure that the interests and needs of people with disabilities are taken into account as a matter of course in all processes and decisions at all levels of social development and to break down barriers. Targeting, on the other hand, aims to empower people with disabilities to participate in mainstream society in a self-determined way. This tailored support ranges from simple aids to personal assistance and empowerment in self-help or self-representative organisations. It is necessary to use both tracks to achieve inclusion. This approach has now been expanded in the relevant discussion to include a third track, namely political dialogue, with the aim of shaping the framework conditions for inclusion in a positive and sustainable way.

Community-based inclusive development (CBID)

With the introduction of the international CBR guidelines in 2010, calls grew louder to replace the term ‘community-based rehabilitation’ with ‘community-based inclusive development’, or CBID for short. On the one hand, some experts feared that the term ‘rehabilitation’ would continue to promote a purely medical perspective. On the other hand, they wanted to emphasise the multisectoral and, above all, rights-based

understanding of the approach and its stated goal: inclusion. With the adoption of the 2030 Agenda and the SDGs, which are guided by the motto ‘Leave No One Behind’, the term CBID has become even more relevant. Community-based inclusive development relies on the participation of persons with disabilities and the active role of their self-representative organisations, which contribute their expertise and are increasingly taking the lead. It works with local communities, NGOs and government to remove barriers, promote social justice and create sustainable structures that enable equal participation. While the focus is on people with disabilities, the approach is often applied more broadly to include other marginalised groups and to promote structural change. As CBID is based on the principles of the CBR Guidelines and the two approaches are closely linked, the dual term CBR/CBID is used in this booklet.

Inclusion – a learning process

Time has shown that inclusion is not a process that can be planned on the drawing board. It requires a willingness to approach the subject cautiously, to try things out, to discard and to redesign. And it is a process – this too is becoming clear – that requires the political struggle of people with and without disabilities.





‘Without Human Rights, Everything Is Nothing’

The Salvadoran organisation Los Angelitos is deeply committed to a human rights-based approach. For co-founder Michael Kleutgens, this is not just a guiding principle, but an absolute necessity. In this interview, he explains why this approach is essential and why it needs to be applied more widely.

The interview was conducted by Stefanie Santo, Public Relations, Caritas Germany.

‘Mr Kleutgens, you are critical of some development cooperation projects in the field of disability.’

KLEUTGENS: For us, disability is primarily a social issue and only secondarily a medical one. The main key is to break down social barriers that prevent equal participation. Unfortunately, many projects still focus solely on the immediate everyday needs of people with disabilities. This is important, but without the socio-political struggle, long-term, sustainable change often fails to materialise, and many of these projects eventually fade away at the local level.

Why is that?

KLEUTGENS: The problem we see is that the term ‘community-based’ is still often misunderstood in CBR and CBID projects. It is reduced to the immediate environment of people with disabilities. As a result, the responsibility for inclusion is mainly delegated to people with disabilities themselves, their families and local civil society organisations. These actors are expected to ensure inclusion with few resources and often only with the support of volunteers. This cannot work out and, in our view, is doomed to fail. Without human rights, everything is nothing.

That sounds rather harsh, doesn't it?

KLEUTGENS: We don't want to diminish the successes – on the contrary, we are proud of what we have achieved on the ground. But in reality, many barriers simply cannot be removed at the local level, especially in countries with highly centralised structures like El Salvador. Whether buses are accessible is not decided by the local bus company, but by the Ministry of Transport. And how a child with Down's syndrome is taught, how grades are given and whether the child is promoted to the next grade is not up to the teacher, but up to the Ministry of Education. And without government investment, it is impossible to develop or sustain appropriate therapy services with the limited resources available locally – yet this is what people with disabilities have a right to.

What are the practical consequences?

KLEUTGENS: Let's take a child with cerebral palsy. Above all, he or she needs long-term, reliable and professional support. Only the state can guarantee this. If it doesn't, aid organisations step in. But what happens when project funding runs out? When volunteers can no longer help because they themselves have to find work to make ends meet? Or when the organisation reaches limits beyond its control? Then there is a risk of exclusion and lack of participation for people with disabilities. So if we are serious about inclusion, we need to address both the individual needs of people with disabilities and the social barriers – and to remind the state repeatedly and loudly of its responsibilities.

What would an alternative understanding of the term 'community-based' look like?

KLEUTGENS: 'Community' is not just the local place, but a context of relationships that we

have to actively shape – at local, regional and national levels. The key question is: How do I build a community when exclusion and invisibility are the biggest problems? How do I get people with disabilities and their families on board? And how do I convince local councils, mayors and ministers that inclusion must be an achievable goal?

What do you think is the most important thing to really promote inclusion?

KLEUTGENS: The most important thing for people with disabilities and their families is to organise and represent themselves. They are the ones who are most interested in ending exclusion and who know exactly what is needed for real inclusion. Self-organisation has to start at the local level, but it has to grow beyond that – with continuous representation at all political levels. To do this, existing opportunities for participation must be used, whether they are specifically designed for people with disabilities or are broader in scope. For example, we have been able to ensure that all our therapy rooms are free of charge.

How do you convince politicians to do more for inclusion?

KLEUTGENS: This can only be done with a rights-based approach! By ratifying the UN Convention on the Rights of Persons with Disabilities, El Salvador has committed itself to many things: Article 25 guarantees the right to equal health care, Article 26 obliges the state to train professionals in rehabilitation, and Article 9 calls for the removal of barriers. No mayor or minister can claim, 'This is none of my business'. It is the responsibility of the state to implement the convention. And it is our responsibility to demand it, again and again.

This text is available in audio and easy language.



Michael Kleutgens is a medical doctor who has lived in El Salvador for more than 35 years. He is a co-founder of the parents'

organisation 'Los Angelitos' and was responsible for the organisation's rehabilitation work for many years.



Challenging the Service Gap

Dr Bhoomikumar Jegannathan conducting a screening in the village of Kos Ras Leu, Cambodia. Pregnant and lactating women are also screened for iron and iodine deficiency, which can affect the development of the unborn child.

As the only facility for children with neurological impairments, learning disabilities and mental health problems, the CCAMH (Centre for Child and Adolescent Mental Health) in Cambodia has potentially hundreds of thousands of young clients.

Dr Bhoomikumar Jegannathan, director of the centre, talks about the challenge of helping as many children as possible across the country. By Dr Bhoomikumar Jegannathan, transcribed by Stefanie Santo, Public Relations, Caritas Germany.

There is no medication that can 'cure' autism or Down's syndrome – although there are still parents who come to me with that hope. But what we can work on are the barriers that stand in the way of children with disabilities. As doctors, we are like the conductor of an orchestra. For example, we set the pace with a child's diagnosis

or a doctor's recommendation. But our real job is to bring everyone together: Therapists, families, teachers, authorities, and the community as a whole. Only when everyone works well together can the child experience the best possible growth and development.



© Bente Stachowske

The Centre for Child and Adolescent Mental Health, where I have worked for about 30 years, is a value-based centre that practices a holistic approach. It is the only centre in Cambodia for children with neurological disabilities, learning difficulties and mental health problems. From

the outset, it was clear that it should be more than just a day clinic in the capital. It was to become the hub of a support network reaching out to the most remote regions of the country.

But why should one institution take on such a huge responsibility? To understand, we need to look at Cambodia's history. Some 50 years ago, between 1975 and 1979, Pol Pot's Khmer Rouge imposed one of the most brutal regimes of the 20th century. Their goal was a radical agrarian society in which the cities were depopulated, private property abolished and all intellectual influence wiped out. An estimated two million people – almost a quarter of the population – died from forced labour, starvation, disease or systematic executions. Academics were deliberately persecuted, schools and universities destroyed in an attempt to eradicate knowledge, individual thought and the family as a unit.

A past that lingers

The consequences are still felt today. There is a shortage of doctors, therapists and teachers, especially in Cambodia's rural areas. At the same time, living conditions are poor and the risk of disability is high. Due to the post-conflict situation, both the government health system and international agencies have focused mainly on landmine victims. And Caritas-CCAMH has played an important role in changing this by focusing on other disabilities. We see cases of brain damage in early childhood due to poor obstetric care and lack of oxygen during birth. We see cognitive disabilities caused by infectious diseases such as tuberculosis and measles due to lack of comprehensive immunisation or medication. There is also poor nutrition, especially in vulnerable communities. For expectant mothers, this

This text is available in audio and easy language.



Dr Bhoomikumar Jegannathan
Programme Director at CCAMH since 1996, has a Masters and Doctorate in Paediatrics, Public Health and Child and Adolescent

Psychiatry, and many years of experience in the field of neurological, intellectual and psychosocial disabilities.



Parents of children with disabilities have to do many things at once: Be there for their child, provide therapy, earn a living and fight for inclusion. The CCAMH parent groups support them in this mammoth task.

often leads to a lack of micronutrients such as iron and iodine, which are particularly important for the development of the child's brain.

In this situation of deficiency, we at CCAMH take on a responsibility that goes far beyond that of a regular medical centre dispensing drugs. This involves travelling out several times a week to give consultations in new villages. We check the health of children and adolescents, inform them and their parents about vaccinations and, if necessary, prescribe medicines, nutritional supplements or deworming treatments. If we suspect a child is disabled, we contact the parents, siblings and grandparents to discuss the situation and possible support.

Essential: the parents

When I meet a child in a consultation, it is only a brief moment, a tiny snippet of their life. The parents, on the other hand, have known their child since birth and are with them day and night. As doctors, we need to listen to them; they are the real experts and play an important role in the inclusion process. At the same time, it is the parents who are stretched to the limit. They juggle between working, looking after siblings

and caring for their disabled child. Then there is the social stigma, which is also deeply rooted in the language: the Cambodian word for epilepsy, 'chikot-chiruk', means 'pig madness'.

In addition to a sound diagnosis at our centre and targeted therapeutic recommendations, much more is planned to provide sustainable support for children with disabilities and their families. Parents need a continuous and reliable social support network and professional help to strengthen them and to show: You are not alone. This is where our Parent Support Groups come in. They provide a safe space and social safety net where parents can share ideas, support each other and work together to find solutions to the challenges of everyday life.

Indispensable everyday helpers

They are facilitated by Volunteers for Child Development – usually one woman and/or man per village. They are supported by the government and receive regular training at our centre. Their training focuses on practical issues that can make a difference to the daily lives of families: How do I interact with a child with autism who has communication problems, or feed a child with cerebral palsy who has difficulty in swallowing? How do I guide and encourage them to go to the toilet independently? How do I help children with intellectual disabilities to dress themselves? These volunteers are much more than facilitators. Through regular home visits, they ensure that parents receive rapid, low-threshold support at home. They organise inclusive playgroups to bring disabled and non-disabled children together in the community, and they are our direct contacts in the villages, for example when we run medical camps to check up on all the children under the age of ten in their village. At the same time, they maintain close contact with local primary health centres to ensure medical care.

While the Child Development Volunteers pave the way for families to access professional support structures, the Child Health Messengers take on the role of agents of change and communicators of key health messages within their

own families. They are usually siblings of children with disabilities who learn how to support their brother or sister, for example through simple motor exercises or play sessions. Many Child Health Messengers also become key people in their neighbourhoods. They are often the first to identify other children with developmental problems and encourage families to seek help.

Self-advocacy as a key to inclusion

Another component of our support network is the self-help groups set up by Caritas Siem Reap. The inclusive groups, almost half of which are led by persons with disabilities, follow a rights-based approach: members support each other in applying for social benefits, run their own savings and microcredit programmes, receive training in leadership, facilitation and advocacy skills, and organise meetings with government representatives. Working closely with government agencies, they help to empower people and promote inclusion. But no matter how diverse our 'orchestra' is (to return to the image from the beginning), what happens if there is a shortage of conductors?

The structural challenge of skills shortages

Many hospitals and primary health care units in the country lack doctors and nurses with the basic knowledge and skills to diagnose different types of disability and to manage support. Occupational therapists, speech therapists, physiotherapists and social workers are also in short supply and there are no training programmes in the country. Caritas-CCAMH has evolved over the years in response to this situation. Today, we are not only a place of treatment, but also a centre for human resource development, research and capacity building. We train doctors, nurses and social workers in health centres and hospitals in the medical care of children with cognitive, mental and neurological developmental disorders, in partnership with renowned institutions and universities in India, Germany, Norway, Singapore, Sweden, the UK and the USA.

A national standard for primary health centres

Through intensive advocacy, we have succeeded in integrating child and adolescent mental health

services into the health care system in Kampong Cham province. Based on this experience, Caritas-CCAMH works to extend a minimum package of services to all 1,220 primary health centres in the country. In concrete terms, this means that staff at each centre must not only be able to diagnose cognitive impairment through newborn screening, but also provide psycho-education and referral when needed. The fact that the funding of components of primary health care is a government obligation provides a particularly favourable framework for sustainability. Although this important step still requires more political will, policy change and substantial funding.



The Volunteers for Child Development are regularly trained by CCAMH. They are important advisors on issues such as nutrition and child's independence. And they are close companions to children with disabilities.

Many experts believe that tackling the health problem is the key to success. And yes, if we can significantly reduce the number of seizures in a young patient with epilepsy, that is a success. But that is not the end of our mission. The child must also be able to go to school, make friends, play and reach his or her full potential. Inclusion is so much more than medical care. Our work is successful when children with disabilities grow up to be a natural part of society, making independent decisions about their own lives and contributing to the development of the community like everyone else.

The programme is funded by the



Federal Ministry
for Economic Cooperation
and Development



“One day, CBID workers came to our door and told me about their parent support groups. I wasn't sure at first, but my parents encouraged me to give it a try. I joined a mother-child group and found so much understanding, emotional support and practical advice. My daughter connected with other children, and the specialists helped us to improve communication and navigate daily life. It was incredibly helpful, and over time, I gained so much confidence. Now, we go to the market, we visit the theatre, we do everything. What started with me joining a support group ended up with me becoming a CBR/CBID coordinator, and now I'm head of Dasti Khair, a public organisation. These groups are really important in making sure children with disabilities aren't isolated.”

Mehriniso Nasretdinova | Head of Dasti Khair | Tajikistan

Learn more about Dasti Khair





Bi-Lay has cerebral palsy and is closely supported by her sister and mother.

The CCAMH in Cambodia assists the family, for example by providing guidance on the physiotherapy exercises Bi-Lay needs to perform on a daily basis.

RehApp: A Digital Everyday Assistant

How to recognise cerebral palsy and what causes it? How can you create an accessible home with simple means? Caritas Germany supports the further development of RehApp¹, a digital guide for local CBR/CBID stakeholders.

Written by Christine Wegner-Schneider, focal person for disability inclusion, Caritas Germany.

In many parts of Cambodia, access to basic rehabilitation services is difficult – especially for families with children with neurological disorders such as cerebral palsy or intellectual disabilities. ‘Poverty, long distances and bad roads make it almost impossible for them to get the help they need,’ explains Dr Bhoomikumar Jegannathan, a consultant child psychiatrist and director of the Caritas Cambodia Centre CCAMH². He describes the situation in Chrom Chrey village: The nearest health centre or hospital is several kilometres

away and cannot be reached during the rainy season. ‘In addition, many health centre staff do not know how to properly support children with disabilities. They lack knowledge about different types of disabilities, as well as the practical skills to provide adequate therapy or support to families,’ adds Jegannathan.

At the same time, more and more people in rural areas of low-income countries own a smartphone – an opportunity that the Dutch organisa-

tion Enablement Foundation is taking advantage of. It has developed RehApp. In countries with well-developed healthcare systems, there are specialists for every disability. In rural areas of low-income countries, however, parents, volunteers or health workers – often without specialist knowledge – bear the main responsibility. ‘RehApp serves as a bridge: it helps people to learn more about disabilities, to support families with practical self-help methods, and to better assess when a referral to professional services is needed,’ explains Dearozet Sok, Senior Psychologist and CBR/CBID Programme Manager at CCAMH.

15 chapters in 10 languages

The current 15 chapters (with more in development) are organised by disability type and allow easy navigation to more detailed topics. Each chapter begins with an introduction that provides information on causes and manifestations, while also clarifying common misconceptions, such as the belief that ‘a child with Down’s syndrome will negatively affect his or her siblings’. In many countries, traditional misconceptions about disability are still widespread. RehApp helps to educate communities and reduce stigma.

The chapters are illustrated and easy to understand. For example, users can follow step-by-step instructions on how to care for a stump after an amputation. They get practical tips on how to feed children with cerebral palsy in a stable position to prevent choking, or how simple tools – such as a zip puller extension – can help people maintain their independence.

But RehApp is not just about specific everyday tips and medical knowledge. For each type of disability, the app’s ‘environmental factors’ section offers practical suggestions for promoting participation and inclusive education. To highlight the importance of access to education and employment, the app features real-life stories that show what people can achieve regardless of their disability.

Aiming for better understanding

RehApp is designed to help people with disabilities

lead more independent, empowered and dignified lives. The texts are currently available in ten languages, and a newly integrated content management system will allow further translation into local languages. The app can also be used to create individualised support plans and document progress directly. A mobile phone is all that’s needed – no internet connection required. Once downloaded, the app also works offline. RehApp is currently being used and tested in eleven African countries, eight Asian countries and one European country (Tajikistan). There is strong international interest in further translation and development.

Study confirms the impact of RehApp

CCAMH tested the app in the field during an 11-month study phase. The results showed that the use of RehApp significantly improved the knowledge, attitudes and practices of CBR/CBID field workers. Initially, their understanding ranged from low to medium, but by the end of the study it had increased to almost 80 – 100 per cent. The 23 study participants reported improved ability to differentiate between disabilities, increased confidence in assessing needs, and improved skills in setting rehabilitation goals for home-based intervention plans – making individuals more independent in their daily lives.

Advocacy for inclusive development also increased, with more field workers actively working with community leaders to remove barriers. In addition, participants felt better equipped to coordinate with rehabilitation specialists, leading to more effective referrals. The results suggest that RehApp is helping to fill gaps in rehabilitation services by providing field workers with practical tools for their daily work.

This text is available in audio and easy language.



¹ The RehApp is available to download free of charge from the Google Playstore and the Apple Store. In addition to the digital RehApp, there is also a set of maps that can be used on site. It is currently available in English, French, Portuguese, Nepali, Khmer, Kinyarwanda, Vietnamese, Bahasa/Indonesian, Bangla/Bengali and Tagalog.

² Centre for Child and Adolescent Mental Health, Cambodia.



'Parents are the most important actors in the process of inclusion,' explains Sonia Hanco (left), who works for Caritas Arequipa. Here she is with Yesenia and her mother, Margarita Taco, in front of the family's small shop.

Everyone Learns in a Different Way

Inclusion in schools is a hot topic around the world. But it is already a reality in a pilot project in Peru. Sonja Hanco, project manager at the diocesan Caritas in Arequipa, and Margarita Taco, mother of a daughter with Down's syndrome, explain what it takes to make inclusion work in schools. Written by Charlott Friederich, Online Editor, Caritas Germany.

On paper, everything is clear: the UN Convention on the Rights of Persons with Disabilities stipulates access to 'inclusive, quality and free primary and secondary education' and guarantees 'effective individualised support measures'. But paper is notoriously patient, and reality is often different. According to UNESCO, children with disabilities are less likely to be

enrolled in school than children without disabilities. They spend significantly less time in school and are less likely to go on to secondary school. Children with cognitive disabilities have a particularly difficult time.

Peru is no exception: although the country ratified the UN Convention on the Rights of Persons



with Disabilities in 2007, only around 58 per cent of children with disabilities attend mainstream schools. And as recently as 2019, only around a fifth of schools had at least one pupil with special educational needs. The consequences are dramatic: lack of education limits job opportunities, deepens poverty, reduces social recognition in the family and society, and increases social exclusion.

Ms Hanco, why is progress in school inclusion so slow?

Sonja Hanco is a social worker at Caritas Arequipa and has dedicated the last 12 years of her career to promoting inclusion.

Margarita Taco is a grocery sales woman, inclusion activist and a mother of two children.

There are clear guidelines: the law requires two places per class to be reserved for children with disabilities. But in practice, things are often very different. Parents face many obstacles when trying to enrol their children in school. The biggest problem is the reluctance of schools. Many teachers and school administrators feel insecure, often overwhelmed and inadequately prepared to teach children with disabilities – and then react negatively.

Ms Taco, your daughter has Down's syndrome and attends a mainstream school. How did you manage this?

In our case, it was luck that I found out about the SAANEE programme through Caritas Peru. They helped me to enrol my daughter Yesenia first in a pre-school and then in a regular primary school. Today she is in the fifth grade of secondary school. It's like a dream for me. However, there are challenges. For example, when new teachers take over the class at the beginning of the school year and they don't know my daughter.

In Peru, there are a few state-run special schools that provide education for children with severe and multiple disabilities and also serve as resource and skills centres for mainstream schools. These special schools have teams – known as SAANEE teams – that support inclusion in mainstream schools. Ideally, each team consists of psychologists, speech and language therapists and physiotherapists who specialise in different cognitive, physical and sensory impairments. They are the guides on the road to greater inclusion: they follow the children in need of inclusion, support the mainstream staff in adapting their teaching methods and provide them with advice. This sounds very good, but

This text is available in audio and easy language.





© John Rossi/Caritas del Peru

Children learn in different ways. For this reason, differentiation is key to greater inclusion in mainstream schools.

still falls short of wider implementation in the country. There are only about 230 SAANEE workers throughout Peru, and only a few mainstream schools use their services. It is clear that no Ministry of Education or government agency can bring about such change on its own. In the Arequipa region, Caritas Peru is working to integrate the government's SAANEE programme into individual schools and to establish structural benchmarks for inclusive education.

Ms Hanco, how does Caritas approach these issues?

First, we analyse the situation in each school: how aware are the management, the teachers and the rest of the school community of the issue of inclusion? What are their attitudes and how much do they already know? We use the answers to develop the training content. Often we have to start with the basics. The first thing we cover is the social model of disability and the right to inclusive education as enshrined in the UNCRPD. Then we look together at different types of disability and their characteristics. In fact, we are most often confronted with cognitive disabilities and autism. So we prioritise these. We teach teachers how to differentiate teaching and how to write an individual education plan.

Inclusive education cannot be planned in a cookie-cutter way. It requires a universal design

that can be flexibly broken down to meet the different abilities, needs and interests of students. Teachers need to be able to adapt content, methods, learning assessments and assessment criteria to the individual child. For example, if a child is visually impaired, the subject matter should be taught orally and written work on the board should be read aloud. Working in small groups also makes it easier for visually impaired children to concentrate. If a child with a cognitive disability is still unable to read or write in higher grades, the focus should be on encouraging and emphasising oral participation.

Is learning only a matter of school, Ms Taco?

No, there is also 'alternative education', which takes place outside normal school hours and is tailored to the needs of each individual child. For example, it is about improving concentration, training memory, reading together or strengthening text comprehension. Practical things like going shopping are also taught. For years, my daughter Yesenia has had a volunteer at her side every afternoon to help her. Through many discussions with the specialists, I have developed a deep understanding of my daughter and can now provide her with targeted support.

Parents play a central role in the early development of their children with disabilities, but are often hopelessly overwhelmed: many do not know how best to support, communicate with and encourage their child's development. Parents are torn between the often high level of care required for the disabled child, the needs of their siblings and the need to earn a living. They also often lack access to counselling and support services. This is where Caritas Peru comes in with targeted family support: volunteers and parents' associations help families who have reached their limits due to poverty or high levels of stress. They provide daily support, facilitate access to government early intervention programmes, provide access to health care and assistive devices, and accompany children with disabilities to school. This holistic approach gives children with disabilities better opportunities for inclusive education and enables them and their families to participate in society.

Ms Hanco, to put it bluntly: no inclusion in school without the participation of families?

Absolutely. Parents are the most important actors in the inclusion process. Margarita Taco is a good example: she spends a lot of time and energy supporting her daughter Yesenia. She accompanies her to physiotherapy and speech therapy, has worked with us to provide 'alternative education' in the afternoons, and enables Yesenia to take part in holiday programmes and sports courses. She is also involved in parent work and runs a small shop. Yesenia has learned to read and write. She now attends a regular fifth grade class, learns traditional dances and plays basketball. She does her homework reliably, helps her mother around the house and can go shopping on her own.

That sounds very encouraging, Ms Taco!

I always tell the other parents: get involved! Work with the teachers, share experiences, get involved in parent initiatives. We are in this together – and the more you give, the more progress the children will make. They need to be supported early on so that they can live as independently and self-determinedly as possible.

Caritas Peru bases its work on the community-based inclusive development (CBR/CBID) approach and, in addition to school inclusion, is involved in early childhood intervention, vocational training and labour market inclusion. Over the past decade, the organisation has also invested in the development of parents' organisations. Specialist advisors have supported the establishment of associations and helped to organise regular meetings. They have explained the legal basis of the UNCRPD and its implementation in Peru. The associations are now independent and have become a place where parents can exchange ideas, give each other advice and support. At the same time, the parents' associations are political actors fighting for the rights of their children with disabilities. When the Peruvian government wanted to place inclusion facilitators in every school, in addition to the mobile SAANEE specialists, the programme was on the verge of running out of funding just one year after its launch. But parents'



Yesenia is passionate about basketball. A holistic, inclusive education encompasses music, art, and sports.

organisations and other inclusion stakeholders took to the streets in protest and managed to keep the programme going. At least for now.

In times of tight budgets, there is a great danger that inclusion projects will slip down the list of priorities. Vigilance and constant lobbying are needed if we are to succeed in making education systems inclusive. And it needs civil society organisations, such as Caritas, and self-representative organisations to bring their expertise to bear on teacher training, accessibility of buildings, programmes and learning materials, and reform of curricula and examination regulations.

Ms Taco, what is your wish for children with disabilities?

I would like inclusive education programmes not to be constantly questioned, but to be permanently and reliably funded. I would like to see more opportunities in areas such as sports, music and art. Education is about more than just learning to read and write; it should engage the whole child. But my biggest wish is that all children with disabilities really have the opportunity to go to school.

The programme is funded by the



Federal Ministry
for Economic Cooperation
and Development



“We want everyone to know that disability is neither a disease nor a punishment. Our children are human beings who deserve respect, and their rights must be upheld. Our community has a tremendous empowering effect. At Los Angelitos we learn to be fearless, to stand up and to resist. We are like one big family, we know each other and we support each other. My daughter Tatiana has cerebral palsy and she really benefits from being part of Los Angelitos: she meets new people, takes responsibility, forms her own opinion on various topics and takes part in public awareness activities.”

**María Deyssi Pineda Campos | Activist and Board Member
of Los Angelitos | El Salvador**

Learn more about Los Angelitos







‘Inclusion Is Not Charity, We Demand Real Jobs’

How can people with cognitive impairments successfully enter the Egyptian labour market? An interview with Dr Madlin Sabry Azmy Ghobrial, Head of the SETI (Support for Education, Training for Inclusion) Centre/Caritas Egypt, and Eglal Chenouda, Executive Director. The interview was conducted by Sven Recker, Press Officer, Caritas Germany.

‘Dr Azmy, Ms Chenouda, there is a law in Egypt that requires companies with more than 20 employees to reserve at least five per cent of jobs for people with disabilities. Surely that should work in your favour?’

AZMY: Not exactly. Ten per cent of people in Egypt are disabled. So ten per cent of jobs should be available for them. But much more important than the law is how well it is implemented.

Ms Chenouda, how is it being implemented in practice?

CHENOUDA: More bad than good. We estimate that less than 20 per cent of Egyptian companies

employ people with disabilities. Of these, people with motor or sensory impairments (such as visual or hearing impairments) are more likely to be employed than those with cognitive impairments. This is despite the latter being the largest group within the disabled population. Studies conducted by the American University in Cairo indicate that the number of people with intellectual disabilities in Egypt is three times higher than the number of people with motor and sensory disabilities combined.

Dr Azmy, how do companies manage to avoid their obligations?

AZMY: The implementation of the law is poorly monitored by the state. When a labour inspector visits a company, he is often presented with falsified documents to prove that a sufficient

This young man has found employment in the shipping department of a major shoe manufacturer, with the assistance of SETI.

number of people with disabilities are employed. This is rarely verified.

Does that mean the documents are fake?

CHENOUDA: Not really. People with disabilities are given formal contracts with full pay, albeit the minimum wage. But many companies don't actually require them to come to work. They think they've fulfilled their obligation by hiring them and don't want to bother with on-the-job training. It's a win-win situation for the company: they avoid hefty fines, which increase with each vacancy, and they see it as allowing the person to 'rest' at home. Sadly, even some disabled people see this as a good deal. They get a salary without the hassle of commuting and working. But to us, and to most young people with disabilities, this is blatant discrimination. They don't want token jobs, they want real opportunities to prove themselves and succeed.

So it takes a lot of persuasion to get real employment opportunities?

AZMY: That's the reality. Families, especially those of young women and girls with disabilities, tend to be very cautious. Many fear that their daughters might be abused – either at work or on the way to work – and often rule out public transport. To address these concerns, our vocational programme includes a special module on protection and self-advocacy. We equip young people with disabilities with the knowledge to recognise and respond to potentially harmful situations, such as sexual harassment.

Aren't these fears justified?

AZMY: We take them very seriously and work closely with families to find practical solutions. If the company doesn't provide transport, we look

for work opportunities in the family's neighbourhood. In some cases, we accompany the mother and her child on trial commutes to allay their fears and build confidence.

CHENOUDA: We also provide self-protection training and prepare both the employee with disability and their future colleagues for an inclusive work environment. The probationary period, which is an integral part of our programmes, plays a crucial role in reducing mutual fears and insecurities.

How do you convince companies to come on board?

CHENOUDA: It's often a long process. When we first approach them, we often hear something along the lines of 'yeah, yeah, just send a couple of people over and we'll see what we can do'. It's usually well-intentioned, but it reflects a lack of real commitment or understanding of what inclusion really means.

AZMY: That's when we push back. We don't just send people in – we ask companies what vacancies they have and where they see unmet needs. This often surprises them because many still see inclusion as an act of charity. But we insist: Inclusion is not charity. We demand real jobs where people with disabilities can really contribute, grow and be valued as employees.

Why is it so difficult to get real jobs for people with disabilities?

AZMY: The majority of people we support into employment have cognitive impairments, and unfortunately the stigma against them is far greater than against people with physical disabilities. Many employers simply don't believe

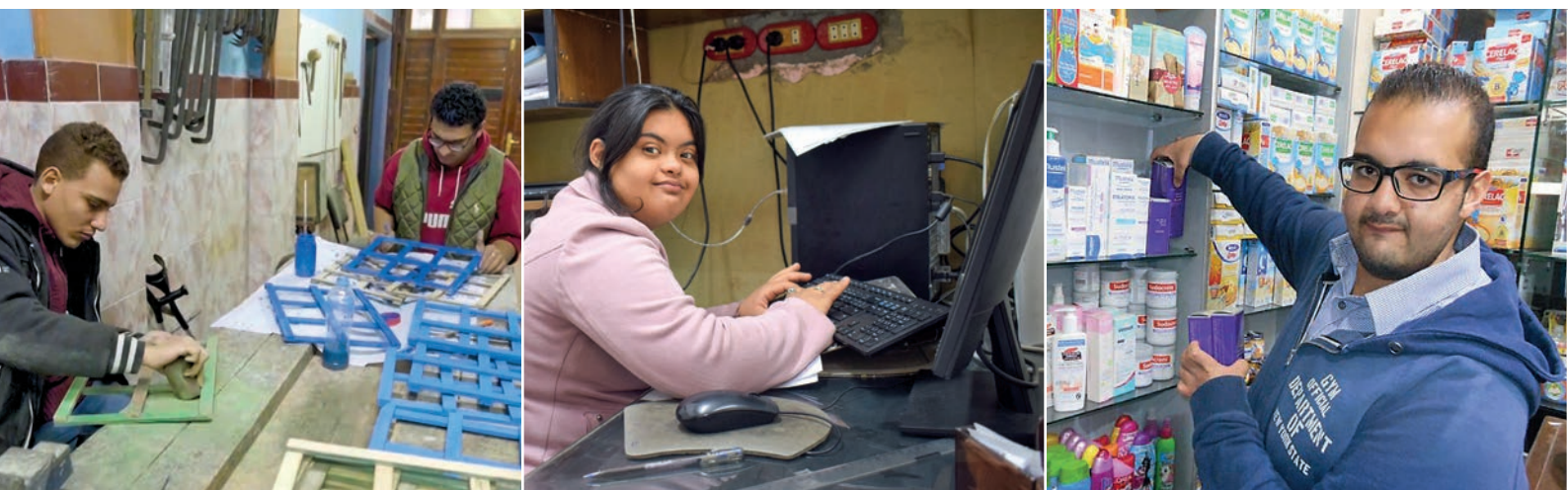
This text is available in audio and easy language.



Dr Madlin Sabry Azmy Ghobrial, Director of SETI Centre/Caritas Egypt, holds a PhD in Paediatrics and Disability and a Master's Degree in Community Disability Studies.

Eglal Chenouda, Executive Director of SETI Centre/Caritas Egypt, holds a Master's Degree in Disability and Inclusion and has led the disability programme for over 30 years.





The most important thing is to find the right job for the right person. Basically, there are no limits.

that people with autism or Down's syndrome can contribute to their company's productivity. A common, almost absurd stereotype we hear is: 'They'll break all our machines!' It just goes to show how much misinformation and fear still exists.

How do you combat these prejudices?

CHENOUDA: It's a process that involves both employers and employees. On the employee side, we start at an early age. Our vocational rehabilitation programme welcomes young people from the age of 15 and prepares them for the realities of working life. We cover the basics: Why is punctuality important? How do I plan my commute? What is appropriate work attire? How do I interact with colleagues and managers? We also focus on aspirations. What kind of job do you see for yourself? Do your skills and strengths match that vision?

AZMY: Parents play a key role in this process. If they support their child's career ambitions, they become important allies. Their trust in the process can make a real difference. Sometimes it even opens doors. Many families have relatives working in different companies and these personal connections can help break down barriers.

Are there specific sectors where job placement tends to work better?

CHENOUDA: Not at all. We approach companies

in all sectors because young people with disabilities are just like any other young people. They have individual skills, interests and strengths. It's not about fitting them into predefined roles or restricting them to certain types of jobs. We've placed people everywhere, from small family-run craft businesses to large supermarket chains, hotels, catering services, fast-food restaurants and even major pharmaceutical companies. The key is always the same: finding the right match between the person and the job.

Let's say a fast food restaurant has a vacancy.

How does SETI assist in the placement process?

AZMY: If we've successfully placed someone in that restaurant before, we can build on that experience. We already have training materials, understand the job requirements and know what skills are needed. This allows us to prepare the candidate in a way that matches both their skills and the role. It's all about making the right match. Who would be good at customer service, who would be better in the kitchen? Does the job require strong communication skills, like interacting with customers, or is it more about concentration, like quality control? By breaking it down in this way, we ensure that placements are much more than just filling a vacancy.

And once these questions have been answered?

CHENOUDA: That brings us to the probationary period. This is crucial for both the employer and



The process is closely monitored by job coaches, who act as mediators between employees and employers.

the future employee, because we agree from the outset that it is a test for both sides, which is also accompanied by our so-called job coaches.

What is the role of these job coaches?

AZMY: Our job coaches play a crucial role, they are the bridge between our rehabilitation centres, our clients and the employers. Once a young person starts working, the job coach checks in regularly, talks to the employee, gathers feedback from colleagues and management, and makes sure that expectations are being met on both sides. I remember one case in particular: we placed a young man with Down's syndrome in a fast-food restaurant because we felt he would be a great fit for the role. Initially, the manager was reluctant and only agreed to take him on if he worked in the kitchen, away from the customers. However, once he started, his warm and engaging personality became apparent. One day, when the restaurant was short of staff, they decided to let him fill in as a waiter. The response was overwhelmingly positive, customers kept asking for him on their return visits. This not only led to his promotion, but also changed the mindset of the company.

And what happens if the placement doesn't work out?

AZMY: Then the young person returns to our rehabilitation centre and we start the selection process again. Sometimes, despite careful

preparation, a job doesn't turn out to be the right fit. For example, if a kitchen job still requires more communication than expected and is challenging for someone with autism, we'll reassess their strengths and look for a more suitable position – perhaps in quality control in an industrial company where structured and detail-oriented work is key.

How many people have you successfully placed in jobs so far?

CHENOUDA: So far, about 2,000. Over time, the process has become smoother for us because we built a database from the beginning. It helps us to match candidates with the right opportunities more efficiently. We know what training is needed, which employers offer what types of jobs, and how to organise transport to ensure accessibility. This structure makes a big difference.

AZMY: The duration depends on the specific vocational rehabilitation programme required. It can range from a few weeks to several months. But it is well worth the effort – both for the young people, who often become the main breadwinners for their families, and for the companies, whose employees often report an improved working atmosphere. Ultimately, companies also benefit from being recognised as socially responsible employers.



Getting Out of the Shadows

Opening a clothes peg and attaching it to the line: Mehriniso Nasretidinova shows a mother how to support her child with small tasks and exercises.

How can inclusion succeed when only a fraction of children with disabilities are diagnosed and registered, and many families hide them for fear of social exclusion? It takes perseverance and people who are committed to inclusion, such as Umeda Munavvarova, CBR/CBID programme manager at the Caritas Germany office in Tajikistan, and Mehriniso Nasretidinova, a CBR/CBID expert. A report by Anna Lena Timme, social inclusion consultant at Caritas Germany.

150,000 people in Tajikistan are officially registered as having a disability, or about 1.5 per cent of the population. This is a strikingly low figure, given that the World Health Organization (WHO) estimates that around 15 per cent of the world's population has a disability. 'There is undoubtedly a significant discrepancy between the official figures and the reality', says Umeda Munavvarova. An outdated diagnosis and registration system means that many disabilities go unrecorded. 'If this system were modernised, many more peo-

ple with disabilities would be entitled to support, that the state is unable to provide.'

The Tajik government has tried to do a lot for the situation of people with disabilities in recent years, but the poor economic situation following the civil war has made it even more difficult. 'There is still limited access to health care and high bureaucratic hurdles that prevent many people from applying for disability status. Disability is also still stigmatised. Many families



© Bente Stachowske

hide their disabled children out of shame and fear of social exclusion', Munavvarova continues. She also reports that irrational fear of infection is still widespread.

The consequences are serious: children with disabilities often live in the shadows. They have little access to early intervention, rarely go to school, are unable to learn a trade and do not

participate in social life. This situation prompted Umeda Munavvarova, who had worked as a surgeon and taught at the Tajik State Medical University for 15 years, to study social work and become involved in setting up CBR/CBID programmes in Tajikistan. Since Caritas Germany opened its office in the capital Dushanbe in 2007 and began working in various pilot regions, it had the goal to improve diagnosis, enable early intervention, to teach parents how to support their children successfully and to empower them becoming motors for inclusion.

Early detection, early support

One starting point was the health system. Many disabilities go undetected due to a lack of specialists and the necessary know-how. To change this, Caritas has started to set up early detection centres in several locations. In specially developed training courses, general practitioners, paediatricians and paediatric nurses learned how to make a sound assessment of the child through targeted observation, simple exercises, small play sessions and discussions with the parents; an approach based on the U-checks for early detection in Germany. Caritas also developed a central database to better coordinate the children's progress and the support offered. This made it possible to track therapy processes and ensure that each child received the support they needed. If developmental delays were identified or a disability was diagnosed, the child was enrolled in the programme. The next step was to provide targeted support: Caritas drew up individual care plans, referred children to specialists, provided assistive devices as needed and organised home visits.

This text is available in audio and easy language.



Umeda Munavvarova holds master's degrees in medicine, social work and early childhood development and education, and has coordinated CBR/CBID projects in Tajikistan for Caritas Germany for 10 years.

Mehriniso Nasretdinova is head of the public organisation 'Dasti Khair' and has worked as a specialist in early childhood and long-term care for the elderly in the CBR/CBID programme for 10 years.





© Bente Stachowske

Laughing, crying, dealing with problems together – mothers' groups offer support and security. Many fathers in Tajikistan leave their families when a child is born with a disability.

Despite these efforts, many parents remained reluctant and suspicious. 'Some feared that the CBR/CBID teams would interfere in their family affairs,' explains Mehriniso Nasretidinova. Others feared they would be misunderstood or ignored. 'Building trust takes time and patience, but it is the key to positive change.'

Locals: Key people for inclusion

Local actors – those deeply rooted in the communities – were crucial in gaining trust. These included staff from partner organisations, whose close links with the community facilitated access to affected families. Local government and health workers who conducted household surveys to get a first-hand picture of the situation. And committed community members who knew exactly where help was needed and were able to provide valuable information. In the beginning CBR/CBID teams have repeatedly hired community halls, created a welcoming atmosphere with coffee and biscuits, and talked about the support services they provide. And small teams went door to door in the villages of the pilot regions, offering their help. This was the case for Mehriniso Nasretidinova, whose daughter has cerebral palsy. 'After my daughter was born, I was very depressed. I rarely left the house, I just wanted my daughter to be accepted for who she is. One day CBR/CBID workers came to our door and told me about their parent support groups. I wasn't sure at first, but my parents encouraged me to give it a try,' she recalls.

Sharing provides confidence

One of the biggest lessons from Caritas' work is that inclusion begins in the family. 'The determination and support of parents is crucial,' says Mehriniso Nasretidinova. And only the empowerment of parents can subsequently lead to community inclusiveness.

Parent support groups provide a safe space, especially for mothers. Many are single parents because fathers often leave the family when a child with a disability is born. 'I finally had a place where people understood what I was going through, where I could learn to cope with challenges and find emotional support,' says Mehriniso Nasretidinova. Specialists educate mothers about different types of disabilities and their causes, teach playful exercises that promote children's development, help make the home environment less restrictive and improve parent-child communication. 'It is truly touching to see the children grow and the mothers blossom. There is no greater feeling than knowing that another child is coming out of the shadows and getting the attention and care it deserves,' says Mehriniso Nasretidinova. 'Word of mouth is helping to spread the word about the parent-child groups. Relatives, friends and neighbours tell each other about their experiences here, and now new members often contact us themselves,' adds Umeda Munavarova.

For Mehriniso Nasretidinova and many other parents, participation in the project also marked the beginning of their professional careers. After a while, she took over the leadership of a mother-child group, trained as a social worker and now heads the organisation 'Dasti Khair', which also promotes inclusion.

Inclusion starts within the family

But it is not only the parents who play a key role, but also the siblings. They are often exposed to the anxiety and despair of their parents, are heavily involved in caring for their brother or sister with disabilities (girls are often even taken out of school) and at the same time have to maintain confidentiality towards outsiders. In addition, support services are often focused exclusively on children with disabilities. This can be a challenge for their siblings. A lot of attention and care is given to the child with special needs, while the siblings often feel neglected and left alone.

It was very important to involve the siblings in all ongoing activities. For example, during the parent-child groups, play activities were also offered for them. During home visits, social workers specifically scheduled time to talk to the siblings, listen to their concerns and needs, or give them space for their own activities. During the holidays, summer camps were organized, allowing the children to meet other affected families in similar situations. This helped them overcome feelings of isolation and loneliness and discover their own strengths in a supportive environment. By playing together under supervision, they learned how to interact with their brother or sister with a disability and share positive experiences. As a result, many siblings developed strong social skills, and some even showed leadership qualities.

To further promote inclusion and understanding, awareness-raising campaigns were organised in the schools attended by the siblings to promote acceptance of people with disabilities. Another important initiative was the sale of handicrafts. This not only developed the children's creative skills, but also boosted their self-confidence and increased their recognition in the community.

'A wonderful example of this is Raykhona, one of our participants, who has a mild form of cerebral palsy,' says Mehriniso Nasretidinova. 'We organised a beading course for her and her sister. While Raykhona learned how to embellish with beads, her sister discovered her passion for sewing. Today, she makes traditional dresses that Raykhona embellishes with intricate beadwork. The result? Beautiful, unique pieces.' All these activities have helped the siblings to see themselves not just as caregivers or supporters, but as individuals with their own interests, strengths and needs.



Can Faruna put her finger to her nose even with her eyes closed? This exercise is a small building block for early detection.

Family activities such as hiking and museum visits can also help to promote inclusion. In cooperation with Special Olympics, the Gayrat wheelchair basketball club and the Paralympic Committee, Caritas has organised several inclusive sports events. There have also been art exhibitions, music concerts and several inclusive theatre plays in which young people have performed together. 'The most important thing is the willingness, the desire to participate, to make time for leisure activities,' says Mehriniso Nasretidinova. 'The CBR/CBID programme has helped our children to be happy, to feel loved and important. What could be better?'

The programme was funded by the



Federal Ministry
for Economic Cooperation
and Development



Nothing About Us Without Us

Photo from better days: Until 2020, it was easier to bring people with disabilities and their supporters onto the streets for protests.

Now, due to the political situation, many fear arbitrary arrests.

Inclusive societies are best built through political self-representation. But how can people with disabilities and their families be inspired to work together for a common cause? How can they organise themselves to achieve political assertiveness? And what leeway remains when the government tilts towards autocracy? María Deyssi Pineda Campos and Michael Kleutgens of Los Angelitos, provide insights into the situation in El Salvador. Transcribed by Stefanie Santo, Public Relations, Caritas Germany.

At Los Angelitos, we are a community of parents and their children with disabilities. When new parents join us, they have often already gone the extra mile – in search of suitable therapy for their child, financial support or aids such as a wheelchair. While we offer support in these areas, our primary focus remains on advocating for the rights of people with disabilities in El Salvador. In a country where many rights may be enshrined in law, but are not yet fully implemented in practice, our role as campaigners is crucial.

We provide parents with a three-month period to familiarise themselves with our organisation and the work we do. Following this, parents have the option of becoming a member, which involves certain obligations. These include naming a contact person within the family who will reliably accompany the child during the rehabilitation process and provide support at home. Members are also expected to actively participate in the organisation's meetings, training courses and public events. Ultimately, without membership, there is no therapy.

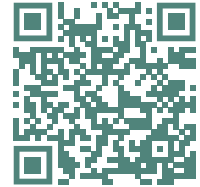


learn to be fearless, to stand up and resist. We are like one big family, we know and support each other.

Of course, we could focus solely on political work. But we see it as our responsibility to enable every child with a disability to access professional rehabilitation close to home – as enshrined in Article 26 of the UN Convention on the Rights of Persons with Disabilities. Therapy is not merely about providing support in everyday life; we use it as a hook for political engagement, because people do not get involved with the hope that their own situation will only improve in ten or fifteen years. The situation has to improve in the here and now.

In our therapeutic work, we rely on our specialist team of physiotherapists, occupational therapists, educationalists and social workers. They are supported by 23 promoters, many of whom have relatives with disabilities themselves and are passionate about inclusion. Their main task is to visit the children at home and to guide and support the families in their therapeutic work. They are trained by the specialist team, receive weekly supervision and are paid for their work.

This text is available in audio and easy language.



The key to increased involvement

Self-representation and advocacy organisations are vital for raising the visibility of people with disabilities and removing barriers to their equal participation. Informed, trained and self-confident representatives who actively engage in political processes are urgently needed. Organisations such as Los Angelitos provide a training ground for this – empowering individuals to raise their voices and work together for real change. Additionally, the community has a tremendously empowering effect. At Los Angelitos, parents

From concerned parents to political activists

But how do concerned parents become determined activists who successfully achieve their goals? This requires knowledge of political processes and strong communication skills. To this end, the specialist team regularly offers further training for grassroots members and trains board members in organisational methods and political advocacy. The authority to set guidelines always lies with the parents and increasingly with the adolescents and young adults with

María Deyssi Pineda is a board member of Los Angelitos, a political activist and the mother of a child with cerebral palsy.

Michael Kleutgens is a medical doctor and co-founder of Los Angelitos. He has been responsible for the organisation's rehabilitation work for many years.



disabilities themselves. They are the experts on their own needs; they experience exclusion and discrimination on a daily basis. In broad-based participatory processes, they develop their demands and back them up with legal foundations.

However, maintaining a balance between the technical knowledge of the specialist team and the decision-making power of parents and young people with disabilities remains a challenge. Clear responsibilities and regular exchange – for example in joint meetings – promote cooperation. Based on the principle that people with disabilities have the same rights as everyone else, Los Angelitos uses existing civic participation spaces, such as youth councils or city committees. If, for example, local transport is discussed there, they bring the topic of accessibility into the debate.

Forging alliances

An important part of our work is to involve the public. We celebrate festivals, organise events and use these opportunities to educate people about disability and raise awareness. We also offer our therapy services to people who are not officially recognised as disabled but who still need support – for example, the seam-

stress with chronic back pain or the pensioner with knee problems. In this way, we show that solidarity is not a one-way street but is based on mutual give and take.

Political achievements

A significant milestone was the adoption of the 'Law for the Inclusion of People with Disabilities', which came into force on 1 January 2021. This legislation was drafted and submitted by us and other campaigners in 2016, and its passage through parliament was protracted. It took numerous discussions with MPs, frequent demonstrations, targeted media campaigns, and a consistent presence in parliamentary committees.

The law represents a significant milestone, formalising the full legal capacity of persons with disabilities, ensuring equal representation on the National Council for Inclusion (CONAIPD), and mandating state agencies to allocate fixed funding for work with persons with disabilities. It also enshrines the fundamental right to state financial support and outlines clear sanctions for violations.

Setbacks and repression

Unfortunately, the situation has regressed considerably since then. First, the arrival of the



pandemic and subsequent lockdowns brought our efforts to a grinding halt. Then, in March 2022, President Nayib Bukele declared a state of emergency to combat gang crime, resulting in a long ban on demonstrations, sit-ins and public gatherings. While these are now theoretically possible again, fear remains prevalent. Since the state of emergency began, more than 81,000 people have been arrested, thousands of them without due cause. Anonymous reports are often sufficient for police targeting, with suspects facing extended prison sentences without the benefit of a court case or proper defence.

Political disruption

President Bukele's political reforms pose significant challenges. In 2023, he reduced the number of parliamentary seats from 82 to 60 and the number of municipalities from 262 to 44 through his electoral and territorial reform. This has resulted in the elimination of over 80 per cent of elected positions, thereby securing a two-thirds majority for his party in parliament. Consequently, we have experienced a significant loss of direct contacts at the municipal level, including mayors, municipal councils and local authorities.

Concurrently, established participatory structures that enabled civil society organisations to engage with their communities' politics have either been dissolved or aligned with the government's agenda. Notably, the National Council for Inclusion, the body entrusted with formulating the country's inclusion policy, has been suspended. The Inclusion Law itself is now subject to review, which could potentially reverse significant progress made in safeguarding the rights of people with disabilities in El Salvador.

Maintaining cohesion

How can an organisation maintain unity and motivate its members during times of adversity? This is the question we address daily. We maintain close communication with our members, some of whom are considering leaving due to frustration with the government's apparent disregard for the Inclusion Law. We are working to encourage them to remain, emphasising the



importance of our joint efforts at this critical juncture. In light of these challenges, we are undertaking a deliberate review and systematisation of our experiences from the past two decades. We have engaged parents since the project's inception to reflect on our origins and achievements. This review is intended to provide orientation and encourage newcomers, demonstrating that our work is not just about resistance, but also about achieving real change.

Remaining active

We are working to maintain visibility and activity. In December 2024, we participated in the International Day of Persons with Disabilities, and we are in regular contact with other disability organisations in the form of a permanent roundtable. We are also focusing more on media work. When our scope for participation is being taken away from us at the local and national level, we look for international avenues, such as engaging in dialogue with diplomatic missions and international aid organisations.

We are working to develop a shadow report that will critically supplement the official information provided by the government and show, from the perspective of those affected, where gaps still exist and where urgent action is needed. Giving up is not an option.



‘As a local NGO, you don't choose when or where to intervene, no matter the nature of the crisis. Whenever people are in need, Mousawat is right next to them. We don't know the full impact of the war yet, or if it's really over. But we do know that violent conflicts always result in people losing their assistive devices and access to medical care. Thousands have been injured so far, many of whom will become disabled, and we will need to work with them. To us, this is more than a job – it's our life, our community, our future. It's quite clear that localisation is the best way forward.’

Kassem Sabbah | Founder & Executive Director Mousawat | Lebanon

Learn more about Mousawat





Upgrade Social Workforces

In many countries, social workers are an invaluable resource for people with disabilities and for the goal of inclusion. In Tajikistan, the profession was not really established until the 2000s and there was a lack of standardised training and study programmes. Umeda Munavvarova, CBR/CBID programme manager at the Caritas Germany office in Tajikistan, talks about the challenge of creating an entire modern social work profession. The interview was conducted by Stefanie Santo, Public Relations, Caritas Germany.

‘Ms Munavvarova, what is the situation of social work in Tajikistan?’

MUNAVVAROVA: Social work is still a young discipline in our country. It didn't exist in this form during the Soviet era – people with disabilities were mostly cared for in closed institutions, and the medical model dominated: disability was seen as a deficit that had to be treated or cured.

When did this change?

MUNAVVAROVA: Actually, it happened slowly after independence from the Soviet Union and the end of the civil war in Tajikistan in 1997. A

first step was taken between 2004 and 2006 through a UNICEF project with the University of Stockholm: 14 teachers completed a master's degree in social work and formed the teaching base. The process of developing curricula and standards for higher education institutions began. The first chair in social work was opened in 2008, and in 2012 social work became a degree programme.

Has social perception evolved so quickly?

MUNAVVAROVA: Unlike doctors or teachers, social workers often receive little social recognition and appreciation, earn significantly less, and often work in the most difficult conditions.

So, many students do not see it as an attractive career option. The cultural context also plays a role. In Tajikistan, family ties are traditionally very strong. Many people turn to family, neighbours or friends for support rather than seeking professional social workers. In recent years, however, the institution of the family has been weakened by high levels of labour migration and an increase in the number of divorces, so the need for the services of social workers has also increased.

What problems arise from the lack of a standardised training system for social workers? What does this mean for people with disabilities in particular?

MUNAVVAROVA: Ultimately, it limits the ability of people with disabilities to participate equally in all aspects of life, whether it is access to health care, education or the labour market. Take schools, for example: There are still no social workers, psychologists or tutors in schools. As a result, there is a lack of teachers who can work competently with students with disabilities. Curricula and materials are often not adapted to their needs, making learning difficult or even impossible. In addition, many students with disabilities experience prejudice and discrimination in everyday school life, which affects their motivation and self-esteem.

What was the situation before you started?

MUNAVVAROVA: There was a lack of a basic understanding of social work. The profession was often seen as a cleaning and kitchen service, especially for older people with age-related disabilities. In the approximately three-week training courses offered by both the Ministry of Labour and the Ministry of Health, dealing with beneficiaries was explained at a basic level.

Some what later, a four-year degree programme was introduced, but this was geared more towards administration than practice. In addition, there were still no clear rules on the responsibilities and powers of social workers, which made their professionalisation even more difficult.

What were the first steps?

MUNAVVAROVA: An initiative supported by Caritas Germany was launched to address these problems. It brought together different ministries to modernise training. The result was a common concept linking social work with the CBR/CBID approach and developing standardised curricula for all levels of training. The aim was to improve the quality of training and include practical content. Caritas was instrumental in defining the role of social workers and creating a career path for the profession, from caregiver to director of social services.

Why did you choose the CBR/CBID approach?

MUNAVVAROVA: There are a few well-equipped rehabilitation centres in Tajikistan, but they are mainly located in large cities and are inaccessible to people from rural areas. The CBR/CBID approach offered an alternative. It changed the approach from treatment to acceptance and adapted the environment to the needs of people with disabilities. It brought therapy and support directly to families and communities – making them agents of rehabilitation and inclusion. And it empowered families to demand services from government and to speak out about what kind of professional services they really wanted.

Where did the CBR/CBID expertise come from?

MUNAVVAROVA: The integration of CBR/CBID modules into social work curricula was initially based on WHO training modules and materials

This text is available in audio and easy language.



Umeda Munavvarova holds master's degrees in medicine, social work and early childhood development and education,

and has coordinated CBR/CBID projects in Tajikistan for Caritas Germany for 10 years.

that we had used for our own staff. As our activities expanded, so did the list of topics and modules. For example, we added early identification and intervention to the curriculum after successfully piloting the child development screening tools and early childhood development programme in our pilot districts. We later added a module on organising community-based inclusive playgroups as a method of promoting early childhood development. Our practical experience served as the basis for standardising these tools and methods at the national level for dissemination throughout the country.



© Bente Stachowske

The success of common learning also depends on the specialist support that mainstream schools can rely on. School social work is an important building block.

How was CBR/CBID integrated into university social work education?

MUNAVVAROVA: The integration took place in several steps. First, curricula were analysed to see where CBR/CBID modules could be included. At the Tajik National University, they were integrated into mandatory courses such as ‘Social Work with People with Disabilities’ and ‘Social Work Techniques’, and were also offered as elective courses. Lecturers received targeted training through seminars and workshops to ensure quality teaching. In addition, an evaluation system was introduced to assess whether the content achieved the desired learning outcomes.

How do you ensure that CBR/CBID training is effective?

MUNAVVAROVA: A practical component is essential for a true understanding of the CBR/CBID concept. Seminars and workshops in which students work on specific case studies promote problem-solving skills and critical thinking. Mandatory internships and job shadowing give students valuable experience in direct client contact and real-life situations, which not only strengthens their skills but also boosts their motivation. It is also important to regularly update training materials and case studies so that they remain practical and reflect current developments in CBR/CBID.

What stakeholders were involved?

MUNAVVAROVA: On the one hand, there were the universities, in particular the faculty management and the lecturers, who were responsible for developing and implementing the curricula. Students also played an important role, not only in absorbing the content of the courses, but also in providing feedback to help develop the programmes. In addition, professional associations such as the National Association of Schools for Social Work provided central support by providing resources and helping to integrate the CBR/CBID modules into the training by making recommendations based on practical experience.

What is the role of people with disabilities in the development of the modules?

MUNAVVAROVA: They definitely need to be involved. Without their perspective, there is a risk of promoting ineffective interventions or even doing harm. They can be teachers or coaches in practical skills training. They can be involved in the selection of module topics, the development of glossaries of non-discriminatory terms and the creation of educational videos. In Kazakhstan, for example, people with visual impairments were involved in the scripting and acting of a training video. Such training also helps to reduce prejudice. Learning first-hand in workshops about the barriers that exist and how they have been overcome creates a new generation of social workers who are more aware, empathetic and understand the value of inclusion and equality. We have many examples of parents and

The programme was funded by the



Federal Ministry
for Economic Cooperation
and Development



young people with disabilities who have been professionalised through our CBR/CBID projects and now hold key positions in inclusion work, either in NGOs or in government agencies. This also brings us closer to the claim 'Nothing About Us Without Us'.

How do international cooperation and networks influence the development of CBR/CBID and social work in Tajikistan and neighbouring countries?

MUNAVVAROVA: International organisations such as WHO, Caritas Germany and UNICEF support Tajikistan in implementing CBR/CBID by providing not only financial resources but also technical and professional expertise. At the same time, they are promoting the development of networks to better link state and local actors. As a result, a national CBR/CBID network has been established to link authorities, organisations and communities, enabling better programme adaptation and more sustainable structures. Regional cooperation is also growing. In the last two project phases, Caritas Germany in cooperation with the German Federal Ministry for Economic Cooperation and Development

established structures between Tajikistan, Kyrgyzstan, Kazakhstan and Uzbekistan. At the end of the project, their university associations joined forces to form the 'Central Asian Alliance of Schools of Social Work'. This platform enables regional exchange on current challenges, good practices and country-specific experiences.

What does it take to be successful?

MUNAVVAROVA: Stable funding is crucial for the long-term successful integration of CBR/CBID into academic education. The state can lay the foundation by creating targeted funding programmes and a legal framework. At the same time, the private sector can also play an important role by investing in programmes that will later provide them with well-trained professionals. Cooperation between universities and the private sector to pool resources and benefit from shared expertise is another possibility. CBR/CBID is the shortest way to build a more inclusive society. The motivation for such an inclusive development of society is that no one should be left behind because of disability, age, gender, ethnicity or any other factor.

Training at home: The CBR/CBID teams bring support and knowledge to where it is needed every day: To the families and communities.



Global Knowledge Transfer

For almost 20 years, Caritas Germany has supported the exchange between its partner organisations SETI/Caritas Egypt and Caritas Iraq on the topic of inclusion. In 2023, the focus was on advocacy for people with disabilities. But how does this exchange work in practice? What are the key success factors? And what progress has been made? We discuss this with Ahlam Danial Yokhanna, technical expert on inclusion and MHPSS (Mental Health and Psychosocial Support) at Caritas Iraq, and Dr Madlin Sabry Azmy Ghobrial, director of SETI Centre/Caritas Egypt.

The interview was conducted by Stefanie Santo, Public Relations, Caritas Germany.

‘Dr Azmy, the SETI Centre has been doing pioneering work with and for people with disabilities for almost 40 years and has received many awards for its efforts. You have also been sharing your knowledge with other organisations for many years. What are the prerequisites for a successful exchange?’

AZMY: The most important thing is that the topics are defined by the teams and organisations themselves: What are the challenges we face in our daily work? Where do we urgently need more expertise? Only if the training is practical and needs-driven can it provide real added value. In addition to a good learning environment and supportive materials, the enthusiasm and commitment of the participants is crucial. And learning doesn't end with the training – for knowledge to have a lasting effect, it needs ongoing support, sharing and the opportunity to build on what has been learnt in practice.

Ms Danial, what issues have you focused on in the past?

DANIAL: We have had regular exchanges since 2005, except for the years when the political tensions between Iraq and Egypt were too high. For example, SETI has helped us to deal more professionally with various disabilities such as ADHD (Attention Deficit Hyperactivity Disorder) and ASD (Autism Spectrum Disorder). We have gained valuable insight into international diagnostic standards and learned about new methods such as sensory-motor training and Montessori education.

What form does the training take?

AZMY: Our training approach is deeply rooted in experiential learning. This means that we start by identifying the real challenges our colleagues face in their daily work and build the learning process around these experiences. Rather than relying solely on theoretical instruction, we emphasise practical, hands-on engagement. At SETI, we act as coaches and mentors, providing guidance and tailored advice to support the professional development. A key element of our methodology is simulation-based learning: we recreate typical scenarios involving children with disabilities and their families. This allows participants to practice their responses, refine their skills and gain confidence in dealing with complex situations. By combining direct experience with structured reflection and expert support, we ensure that the training is both relevant and effective.

In 2023, you've put advocacy on the agenda. What led you to choose this topic?

DANIAL: In Iraqi society, there are different perspectives on people with disabilities and

their families. Prejudice often prevails – many consider them less capable or less reliable. Some see disability as a punishment from God or a shame. In addition, although Iraq signed the UN Convention on the Rights of Persons with Disabilities in 2012 and ratified it in 2013, implementation has been slow. Inclusion and the rights of people with disabilities are simply not a priority, and this puts an enormous strain on families.

Iraqi Law 38/2013 on the Rights of Persons with Disabilities was heavily criticised immediately after its adoption. Why?

DANIAL: The main criticism of Law 38/2013 is that it reflects an outdated, care-based perspective rather than a modern, rights-based approach. Even the title – Law 38/2013 for the Care of Disabled Persons and Persons with Special Needs – reinforces this mindset by distinguishing between different groups of persons with disabilities. It defines disability in negative terms, describing persons with disabilities as incapable compared to 'normal' persons, rather than recognising human diversity as natural. The law also relies on outdated criteria from 1998, requiring an 80 per cent degree of disability to access benefits, which excludes many from essential support. Finally, it focuses on care and protection rather than ensuring equal rights and full inclusion as outlined in the United Nations Convention on the Rights of Persons with Disabilities.

So advocacy is urgently needed.

DANIAL: Yes. And we have many dedicated mothers and fathers in our centre who are willing to fight for their children and initiate real change. This has strengthened our choice of advocacy.

This text is available in audio and easy language.



Ahlam Danial Yokhanna holds a Master's Degree in Psychological Counselling and Educational Guidance. She is an expert in MHPSS and has been working at Caritas Iraq for 20 years.

Dr Madlin Sabry Azmy Ghobrial, Director of SETI Centre/Caritas Egypt, holds a PhD in Paediatrics and Disability and a Master's Degree in Community Disability Studies.



Who better to speak for themselves than the people themselves? People with disabilities and their families know exactly what they need – and they are ready to fight for it as long as it takes.

How does SETI/Caritas Egypt organise its own advocacy work?

AZMY: It is based on several pillars. We provide support and information to families, empowering them to represent themselves and proactively advocate for their children's rights. We facilitate connections between families and community members, as well as policymakers, fostering dialogue regarding the impact of existing laws and enhancing awareness of the concerns of people with disabilities. Furthermore, we organise festivals that provide individuals with cognitive disabilities with a platform to showcase their abilities. We also use digital channels to share success stories with the general public and educate them about the rights of people with disabilities.



What support is my child with disability entitled to? And how do I apply for it? Questions like these are answered by the parent-led advocacy groups at the Caritas Centre in Baghdad.

How comparable are the political conditions for lobbying in Egypt and Iraq?

AZMY: In Egypt, the political environment for the rights of people with disabilities has improved

in recent years, mainly due to the disability law and the alignment with the UN Convention on the Rights of Persons with Disabilities. It is particularly helpful that each ministry is obliged to implement the law. This creates many entry points for advocacy and makes it possible to initiate change at different levels. This is much more difficult in Iraq.

DANIAL: The political conditions for advocacy in Iraq are very different from those in Egypt. Iraq has suffered from instability for many years, so we are still in the early stages of building public awareness and pressure. But we've seen the first signs of progress. A small but important movement has already emerged in this area, and it played a key role in pushing through the first amendment to Law 38 of 2013.

How has the exchange worked in practice?

DANIAL: In 2023, we went to Egypt as a team of nine and worked intensively for a week. We studied the UN Convention on the Rights of Persons with Disabilities and its implementation in Iraq, learned about the different structures of advocacy teams and familiarised ourselves with campaign planning. As well as the theory, there were lots of practical exercises: We did interview training, wrote press releases and prepared meetings with ministry representatives.

SETI trains organisations all over the world. Is it easier when the culture and language are similar?

AZMY: Yes, definitely, it makes communication much easier. There is no need for translation, the social conditions are more familiar and it takes less time to develop a deep understanding of the situation on the ground. This makes it easier to transfer what you have learned to your own context and work, and it also increases the efficiency of the exchange. A good example is our cooperation with Caritas Iraq. Our Iraqi colleagues can experience SETI's work first hand and talk directly to Egyptian parents and their children with disabilities.

What has the exchange taught you?

DANIAL: A big step forward was the formation of our three advocacy teams, each focusing on

a key issue: access to health, education and legal information. It is particularly encouraging to see that parents are no longer just focusing on the situation of their own child, but are also advocating for other children with disabilities. This is creating a growing network of committed parents and supporters – and this is what will bring about more change in the long term.

How do Caritas Iraq's advocacy teams try to influence legislation?

DANIAL: Our advocacy work focuses on several areas. First, we equip our advocacy team with solid legal knowledge and keep them up to date on current procedures. We also raise awareness among our programme beneficiaries by forming small teams and introducing them to the law, its loopholes and recent updates. At the community level, we focus on mothers of children with disabilities, helping them to understand the strengths and weaknesses of the law and empowering them to advocate for important changes.

Has this ever worked before?

DANIAL: Yes, it has! For example, Law 38/2013 was amended and we were able to achieve some significant improvements. Financial support for mothers of children with at least 75 per cent disability has been increased from US\$170 to US\$250 per month once the child turns 14.

What other activities are there?

DANIAL: Our teams have produced easy-to-understand information materials for different purposes. A major focus is on raising awareness in schools. Through targeted campaigns, the teams aim to improve the situation of children with disabilities in mainstream schools. This is where we often encounter discriminatory situations – on the part of the pupils, but unfortunately also on the part of the teaching staff. To further raise awareness of the rights of people with disabilities, they have also designed posters to hang up in schoolyards and classrooms.

And what if implementation stalls?

AZMY: Regular exchange and feedback are a matter of course for us in order to continuously



Eleven-year-old Eliyah has autism. When his mother Lana Mazin Younis does exercises with him, she uses what she learned at the Caritas centre in Baghdad.

improve our cooperation. We meet – online or in person – to refine the focus and objectives together. Feedback during and after the training helps us to be even more responsive to participants' needs. And, of course, we're always available to answer any questions.

What are the next advocacy goals in Iraq?

DANIAL: The teams are planning to organise special meetings with decision-makers to highlight the loopholes in the first amendment No. 11 of 2024 to the original Law No. 38 of 2013 and to address the legal gaps that remain unresolved. In addition, some members of the advocacy team may participate in television or radio interviews to raise public awareness of these issues. The aim is to inform public opinion, build wider support and solidarity, and ultimately expand the pressure group to push for meaningful change.



© Bente Stachowske

Inclusive Aid Through Local Lead

Local organisations know the local people, speak their language and enjoy their trust. They are and will remain on the ground – even in times of war and crisis.

Mousawat (Arabic for equality), a local organisation in Lebanon, works to make society more inclusive. Kassem Sabbah, its founder and executive director, talks about his journey as a person with a disability, the challenges he has faced and why localising aid is the best way forward, especially in times of crisis.

By Kassem Sabbah. Transcribed by Anna Lena Timme, Inclusion Consultant of Caritas Germany.

I was injured by a grenade at the age of 19 and subsequently suffered a spinal cord injury. I have been in a wheelchair for over 40 years. I was a university student at the time of my injury and spent two years trying to figure out what to do next. Finally, I decided to get involved in the disability movement and started working in the field. As a result, I have worked for Norwegian People's Aid for almost 25 years in various positions where I have received a lot of professional and paramedical training.

I have experienced first-hand the challenges faced by people with disabilities in Lebanon,

from lack of accessibility to social stigma. At the same time, I have always tried to use my experience to inspire others in similar situations, whether they are Palestinian or Syrian refugees living throughout Lebanon or people injured in Gaza. I wanted to set an example and show that life in a wheelchair can be full of dignity and productivity. Of course, it always depends on each individual's circumstances. Obviously, I was lucky enough to already be at university, so I tried to follow that path. If I had been injured at a younger age, I might not have even considered going to university. However, it was very challenging as I needed assistance with transportation,



accessing the necessary books, and moving between lectures. Depending on a person's socio-economic status, it can be easier or harder to overcome the challenges of disability.

Becoming a local NGO

The decision to establish Mousawat was taken in 2008. Norwegian People's Aid was beginning to change its mandate from being a service provider to focusing more on advocacy, policy change, democracy and peace. These new priorities were not directly related to our work, so it was jointly decided that Mousawat would become its own organisation as part of a local-

isation strategy. In this way, we could diversify our funding sources and have freedom over our mandate and strategy without being tied to an international NGO that might change its focus. It has been a long and challenging process. While I am the founder and executive director of Mousawat, the board of our organisation is made up of volunteers. We started with 14 staff and one rehabilitation centre. Now we have almost 180 staff and support 13 centres. Twenty per cent of our staff are people with disabilities. We have occupational therapists, speech therapists, physiotherapists, social workers, doctors and psychologists. This has been one of the rare successful localisation experiences in our region, and we are now a recognised and comprehensive service provider in the field of inclusion in Lebanon. Recently, we have changed our strategy. In order to make inclusion the cornerstone of our vision, our original slogan changed from 'Removing Barriers and Creating Opportunities' to 'Towards an Inclusive Society'. Our vision focuses on education, employment and social life. Everything we do promotes inclusion. This is a challenge anywhere, but in this part of the world we have the added challenges of slow policy change and frequent emergencies.

The long road to inclusion

The problem in Lebanon is that we have laws, but they are not protective and they are not implemented. According to these laws, public transport and places should be accessible. But in reality, I cannot move around the city alone. Even with two people accompanying me, it is still difficult. Although children with disabilities have the right to education, when you go to register your child in school, you may be denied access. What can you do as an individual? Nothing. If someone breaks the law, they are not held accountable.

This text is available in audio and easy language.



Kassem Sabbah, Founder of the Palestinian Disability Forum, the Palestinian Union for People

with Disabilities and Director of Mousawat, holds a Master's Degree in Health Management.



© Bente Stachowske

Assessment at the Mousawat Centre; therapist Reem Zein Al-Deen discusses Aya's support needs due to Trisomy 21 (Down's syndrome) with her mother.

That is why it is so important for organisations and individuals to get involved in advocacy, making people with and without disabilities aware of their rights and how to claim them. Even if that means providing legal support through a lawyer. We do research, write papers, present them to ministers and organise discussion groups with people with disabilities. We have trained more than 1,000 government officials on disability rights, because most of them are unaware of their own laws and policies. We also network with other like-minded organisations and coordinate our advocacy efforts through the Disability Hub in Lebanon. Mousawat was part of a selected team working on the draft strategy for the rights of people with disabilities in Lebanon 2024–2026, but any progress remains frozen due to political paralysis.

However, we will not be deterred in our efforts. We have four main programmes. One focuses on rehabilitation. In our centres, we provide physiotherapy, occupational therapy, speech therapy and psycho-social support for people with disabilities, especially Palestinian and Syrian refugees. The second programme promotes community-based rehabilitation. Outside of in-

stitutions, we work with communities and local organisations to make societies more inclusive and encourage people with disabilities to participate, engage and take space. The third pillar is inclusive education. We train staff in kindergartens and preschools to give them the skills they need to adapt their curriculum to be more inclusive. We provide transportation and shadow teachers to support children with disabilities and local teachers in the classroom. The fourth programme focuses on emergency response. In emergencies, we prioritise inclusive aid to ensure that people with disabilities are not left behind. We provide medical supplies, food and non-food items, and mattresses. Our two mobile medical clinics specifically support people with disabilities when they are internally displaced. Since our establishment in 2008, we have responded to crises such as the Syrian conflict and recent events in Gaza and Lebanon.

Promoting localisation in a challenging landscape

Today, everyone claims to support localisation. In our experience, however, most donor agencies and policy- and decision-makers do not. There is still a clear preference for funding international organisations because their systems tend to be more professional, while most local NGOs are still a work in progress. In discussions with the government, representatives of INGOs are taken more seriously because they are backed by international donors. When I used to work for Norwegian People's Aid, it was much easier to get a meeting with the government authorities than if I mention that I work for Mousawat as it is now. However, one of the biggest problems – especially when thinking about the sustainability of local organisations – is that most donors only cover operating costs. They are not willing or able to pay for overheads, which makes it very difficult to plan for the future. Lebanon faces systemic challenges such as sectarian division, a deteriorating economy and a dysfunctional national administration. Local organisations are trying to overcome these challenges and find ways to advance inclusion. Without progress on localisation, their capacity will remain limited.

The power of localisation

Even though the current international system is not supporting local growth, we see the benefits in the communities. With Lebanon's highly diverse population, both culturally and religiously, people in the communities accept us. We're naturally culturally sensitive as we're part of the community, so they know us and trust us. We often feel things without needing to ask because we live among the people and suffer the same way they do. They also know that international NGOs have a limited time to stay and a specific mandate to implement projects, and when they leave, they don't leave much behind. Local organisations, on the other hand, are a continuation of community activities, like youth clubs or religious groups – they're ongoing. This became very evident during the recent war with Israel. While most expatriates were evacuated, we kept working to the best of our ability. Most of our staff were mobilised to support our emergency work, and we covered the needs of people in 13 shelters, made sure they had food and basic hygiene stuff, and were able to keep warm. We even supported the evacuation of people with disabilities and their families, and supported their specific and medical needs through our mobile clinics. Our initiatives were essential, because there were much fewer organisations on the ground compared to when we had the Beirut explosion in 2020. There were hundreds of supporters and loads of funds available back then, but this time it was different. The region's tense political situation meant efforts were much lower. As



Amir, 12, dreams of becoming a computer programmer. Physiotherapist Khaled Ali Abadi helps him improve his gross and fine motor skills.

a local NGO, you don't choose when or where to intervene, no matter the nature of the crisis. Whenever people are in need, Mousawat is right next to them. We don't know the full impact of the war yet, or if it's really over. But we do know that violent conflicts always result in people losing their assistive devices and access to medical care. Thousands have been injured so far, many of whom will become disabled, and we will need to work with them. To us, this is more than a job – it's our life, our community, our future. It's quite clear that localisation is the best way forward.



Lebanon has been following a strategy where people with disabilities are institutionalised. Children enter so-called 'shelters' where they live, receive education and later protected employment. It's a closed environment with little exposure to mainstream society, and most of these institutions are affiliated with specific religious groups and parties. Mousawat criticises this charity approach and is championing inclusion, rather than separation and institutionalisation.

Inclusive Disaster Risk Reduction

Indonesia is one of the world's most affected countries by natural disasters. Caritas Germany is working closely with the Indonesian National Board for Disaster Management (BNPB) to make disaster risk reduction inclusive.

Written by Andrea Edler, Journalist.

Since the devastating tsunami in December 2004, Indonesia has invested heavily in the development of disaster risk reduction (DRR) and disaster risk management (DRM). However, it became apparent that well-developed concepts and detailed plans alone were insufficient to meet the challenges posed by the nation's 17,000 islands and 73,000 village communities. In response, the Indonesian Disaster Management Authority sought to implement prevention measures at the local level in an inclusive manner, recognising the need for additional support to reach these communities. Caritas has been a key partner in model projects in three regions and approximately 32 village communities, both on Java and six other islands across Indonesia.

Edy Supriyanto runs the Office for Persons with Disabilities in Central Java. At a meeting of volunteers in the village of Patihan, he talks about inclusive disaster relief activities.

Inclusion is more than a project

For Caritas staff member Lioni-Beatrik Tobing, inclusion is by no means a new concept. Together with her colleague Dewi Kurniawati, her daily work for years has revolved around the question: How can people with disabilities be included? The true essence of inclusion, they argue, lies not merely in the execution of inclusive projects, but in ensuring that all segments of society are genuinely included. Since Caritas Germany entered into a cooperation with the agency responsible for disaster risk reduction in Indonesia (BNPB) in 2021, they have also been contributing their expertise in inclusion to vari-



ous pilot projects for the practical implementation of national disaster risk reduction. 'For us, inclusion means more than just the participation of people with disabilities,' explains Dewi Kurniawati. 'It also includes older people and children, and it takes into account gender-specific aspects. Inclusion is about addressing all forms of disadvantage and ensuring equal participation'.

Caritas has taken gradual steps toward inclusion for years. Initially, teams implemented community-based rehabilitation (CBR) projects to uphold persons 'with disabilities' rights to access healthcare, education, livelihoods, social life and empowerment. Following this, Caritas placed additional focus on community-based inclusive development (CBID), placing even greater emphasis on empowerment and more meaningful participation across many sectors of development, including the disaster management sector.

Inclusivity ensures that no one is left behind, particularly those who are more vulnerable, and it recognises the importance of equal access, participation, and protection in both disaster response and long-term recovery efforts.

Good data is important

A key requirement for inclusion in the event of a disaster is reliable data. How many older people who are no longer able to walk independently live in a disaster-prone region? How can you communicate with deaf people in an emergency? Are there enough wheelchairs? In the event of an evacuation, it is crucial to know how many people are dependent on which aids and whether, for example, the agreed assembly point is accessible to everyone in the event of flooding. The two

Caritas employees have worked intensively with various assessment tools to answer these questions and developed a suitable questionnaire for data collection. Lioni-Beatrik Tobing and Dewi Kurniawati are aware from years of experience that enabling people with disabilities to participate is easier said than done, and that no policy paper or preparedness concept can provide solutions for every challenge. Therefore, those working locally for inclusion require customised approaches.

Sensitive handling of stigma

The social acceptance that Caritas employees encounter for their projects varies from region to region. Dewi Kurniawati explains that in the eastern part of Indonesia, especially in very grassroots communities, traditional beliefs about disability still persist. She says, 'In some areas, for example, disability is seen as a punishment from God or as bad karma. We can't simply arrive and demand immediate inclusion. First, we must create opportunities for the population to interact positively with people with disabilities.'

The approach they are taking to counteract stigmatisation can already be seen in the collection of data. 'We use this step to raise awareness of what people with disabilities can achieve', reports Dewi Kurniawati. One of Caritas Germany's partners is the Indonesian Association of Women with Disabilities (HWDI), a national organisation with sub-district branches throughout Indonesia. The board and members of this organisation consist mostly of women with various disabilities. The organisation has trained persons with disabilities to carry out the data collection. 'This way, we create an initial positive point of contact. For many villagers, this is the

This text is available in audio and easy language.



Lioni-Beatrik Tobing, DRR/CCA Senior Project Officer at Caritas Germany Indonesia (CGIO) for the past 8 years, holds Master's Degrees in Political Science and Sustainable Economic Development.

Dewi Kurniawati, Inclusion Senior Project Officer at CGIO, with 20 years of professional experience. She holds a Master's Degree in English Literature and has completed various trainings on inclusion.



first time they have seen a person with a disability in an official role,' says Dewi Kurniawati.

Each village establishes a self-representation

Another important step towards greater participation and decision-making is the convening of Resilient Village Groups, which include people with and without disabilities. The primary objective of these local groups as initiated by HWDI in North Lombok and the other partner SEHATI in Sragen, is to revise village development plans and ensure the inclusion of all residents' needs in evacuation plans. To this end, they receive training and support from employees of partner organisations.

These groups address crucial questions such as: Who will ensure that older people are not overlooked in the event of a disaster? Where is a ramp urgently needed so that more people can access a critical distribution point? Or should the assembly point be relocated because its current location is unsuitable? During SEHATI's training sessions, employees demonstrate how individuals with disabilities can assume specific roles in disaster plans, ensuring they are not

merely perceived as individuals in need of assistance. As Dewi Kurniawati explains, 'We refer to these as 'showcases'. In our training sessions, we actively encourage the identification of specific roles for individuals within the community'. For instance, when a person in a wheelchair is designated as a Disability Focal Point within a community disaster preparedness committee or a Village Disability Group, they advise on accessibility issues. This includes ensuring evacuation routes and shelters are wheelchair-friendly, and communicating disaster information in accessible formats, such as braille or audio. Additionally, they may lead workshops to train the community and first responders on how to assist people with disabilities during a disaster. This approach underscores the proactive involvement of individuals with disabilities, as outlined in the guidelines developed by SEHATI for handling individuals with disabilities during emergencies.

Another example she cites is the significant impact of acknowledging the experience-based knowledge of older people in dealing with disasters at village meetings. She emphasises that

Practising for an emergency: the evacuation of wheelchair users is simulated as part of targeted inclusive disaster relief.



© Caritas Germany

older people should not be perceived as a burden due to their inability to get to safety, but rather be recognised as valuable assets. The vision is for these groups to evolve into a representative body through which people with disabilities can advocate for their rights.

The existing national disaster risk reduction concept includes provisions for the establishment of accessible local Disability Units, which serve as service centres for individuals with disabilities and their families. While this initiative is commendable, the Indonesian government has demonstrated a sluggish pace in its implementation. Resilient Village Groups have the potential to stimulate civil society to establish these units by promoting awareness of their significance. They can also help train local leaders and first responders on the specific needs of people with disabilities during emergencies, ensuring that policies and practices reflect those needs.

A mix of advocacy and training

Caritas' strategy for more inclusive disaster relief aims to influence policy-making and shape disaster risk reduction and disaster protection frameworks through active lobbying at the national level. At the same time, the practical implementation of these concepts is being tested in pilot projects, with lessons learned feeding back into disaster risk management strategies.

Key questions to be addressed include: Where have the desired improvements already been achieved, and where is room for improvement? Where do national policies fail to address existing capacity gaps on the ground? What kind of local forums could help bridge these gaps?

To achieve these goals, Caritas is currently working with three project partners. Two of them are established experts in working with people with disabilities and facilitating participation processes, while the third is the aforementioned self-representative organisation for women with disabilities (HWDI). Another milestone is training relevant government agency employees to embed awareness of the needs of persons with disabilities in disaster response planning.



Recognising potential obstacles: In the village of Patiham, volunteers practise evacuation together with elderly people.

Inclusion needs to be prepared

Disaster relief can only be inclusive if disaster risk reduction is designed inclusively from the outset. For this, both comprehensive data collection and locally developed evacuation plans are crucial. The feedback loop between practical experiences in pilot villages and the refinement of national disaster risk reduction plans, as is currently taking place in Indonesia through the close cooperation between Caritas and the Indonesian National Board for Disaster Management (BNPB), is likely unique.

Collaboration with the self-representative group for women with disabilities ensures that those affected play an active role in developing concepts and evaluating pilot projects. For Caritas experts Lioni-Beatrik Tobing and Dewi Kurniawati, this partnership also offers an opportunity to use their limited resources as efficiently as possible. The simulation videos they helped create – demonstrating best practices for assisting people with disabilities during disasters – are now accessible nationwide via the Indonesian disaster management authority's website. 'Caritas alone', notes Lioni-Beatrik Tobing, 'could never achieve this level of reach'.

The programme is funded by the



Federal Ministry
for Economic Cooperation
and Development



Caritas Germany | Caritas international

Karlstraße 40, 79104 Freiburg
phone: +49 (0)761 200-288, fax: -730
email: contact@caritas.de

Caritas international
SozialBank
IBAN: DE88 6602 0500 0202 0202 02
BIC: BFSWDE33XXX

The International Department of Caritas Germany provides disaster relief worldwide and supports social projects for children, the elderly, and for people with disabilities. Caritas Germany helps regardless of religion, origin or nationality and cooperates with more than 160 national Caritas organisations around the world.

www.caritas-international.de | www.caritas-germany.org

