

Karuna*foundation*

Prevention, Rehabilitation, and Inclusion

Leaving no one behind in Nepal

Living with a disability in Nepal

Nepal, like the rest of the world, has become more aware of the well-being of people with disabilities in recent years. Politically, there is a conviction that these people should not depend on charity for their existence but are entitled to social services. This aspiration has been translated into legislation and social services. This is a huge step for one of the poorest countries in the world.

Unfortunately, in practice, it proves difficult to improve the situation of people with disabilities. Stigma and superstition play a major role in this. People with disabilities in Nepal are still among the poorest people in society. The belief that having a disability is a punishment for bad behavior in a previous life is widely held and leads even people with disabilities to believe that they are not entitled to the use of social services. Children with disabilities are kept in by parents out of shame and to protect them from a harsh society. Thus, these children cannot develop, remain dependent on care from others, and are vulnerable to abuse. Another reason why the situation for people with disabilities has not improved yet is that the government does not have a good approach to implementing its legislation. It is difficult for the government to reach people in remote areas.

Community-Based Rehabilitation

The internationally recognized Community Based Rehabilitation (CBR) approach aims to improve the lives of people with disabilities within their communities and enable them to achieve maximum independence and full participation in all aspects of life. The strategy consists of five components: health, education, livelihoods, social affairs, and empowerment. Especially in a country like Nepal where the community determines the acceptance and development of people with disabilities, the CBR strategy offers a good approach to achieving structural improvement.

From "Inspire2Care" to the Disability Prevention and Rehabilitation Program.

From 2005 to 2019, within the "Inspire2Care" program, Karuna Foundation Nepal successfully implemented and further developed the CBR approach in eleven municipalities in Ilam District in Province 1. In doing so, it has added several components to the CBR approach. One of these components concerns preventive care. Some of the disabilities can be prevented by improving prenatal and perinatal care for pregnant women in Nepal. For example, by providing folic acid to women who wish to have children and screening newborn babies for birth defects so they can be treated immediately before the condition leads to complications. Karuna has also added to the CBR approach the screening of school children for disabilities. In this way, we solve problems early on before developmental delays occur, for example by providing glasses or hearing aids. Connecting people with disabilities to government social services is also an important and sustainable component; with a so-called ID card, they can receive benefits or apply for reimbursement for healthcare costs.

Results in the Ilam District of Province 1

Two independent impact studies showed that Inspire2Care in the Ilam district contributed to:

- 62% reduction in birth defects in Inspire2Care communities
- 61% increase in the number of deliveries at a clinic
- 70% of children with disabilities reported a good or significant improvement in their lives
- Access to social services through ID cards increased from 24% to 89%
- Visibility, recognition, and acceptance of and care for people with disabilities increased
- 100% of all villages continue the program at their own expense after Karuna's departure

Het Disability Prevention and Rehabilitation Program (DPRP)

In 2019, the government of Province 1 formally adopted the program into their primary health care system and signed an agreement with Karuna Foundation to implement the CBR approach in all 128 municipalities to improve the lives of people with disabilities in Province 1. In doing so, the name of the program was changed from Inspire2Care to Disability Prevention and Rehabilitation Program (DPRP) with the following objectives:

1. prevent as many as possible physical and mental disabilities in newborns by ensuring proper prenatal and perinatal counseling of pregnant women
2. improve the care and rehabilitation of children and adults with physical or mental disabilities so that they can once again participate in the social life of their local communities.
3. strengthen the local (care) systems aimed at sustainability of successful measures and interventions.

Within the DPRP program, the Karuna Foundation supports a municipality for three years with knowledge, expertise, and financial resources on the condition that the municipality contributes to 1/3 of the implementation costs and commits in advance to an independent continuation of the CBR strategy at the end of the project period. The provincial government also co-finances 1/3 of costs in municipalities and coordinates the implementation.

See Annex 1 for a description of the different activities in the lifeline of persons with a disability. See also the video on the activities in the Ilam region: <https://youtu.be/ArZ5-haErs>

Expected impact of the DPRP in Province 1.

By 2027, Karuna Nepal expects that:

- In all 128 communities of Province 1, the CBR approach has been implemented enabling 55,000 people with disabilities to receive proper care and treatment, attend a school where possible, be active members of cooperatives and generate a source of income and live as full members of the community.
- 100,000 pregnant women are provided with folic acid annually and unborn and newborn babies are screened for conditions, reducing the number of birth defects and early developed disabilities.
- All 128 municipalities continue the program independently.

The impact of the DPRP program in Province 1 is being studied by the Royal Tropical Institute in Amsterdam on behalf of the UBS Optimus Foundation. This includes measuring the relationship between impact and cost. An initial forecast shows that compared to the earlier Inspire2Care program in the Ilam district, the costs per village have been halved.

Towards a modified Disability Prevention and Rehabilitation Program (DPRP 2.0).

The original DPRP had a phasing, implementing the program first in one half of Province 1, followed by replication in the other half. This scenario was updated in 2022. The Covid-19 pandemic also struck Nepal in 2020 and 2021. This led to a delay in the first phase, which will now be completed in 2024. This created time to experiment with adapted approaches and to look closely at the lessons, which could be learned in this first phase. Some components prove less effective, others are also offered by another NGO, or have meanwhile been taken over by the government. This gives the project an even sharper focus.

Meanwhile, questions have been raised about a possible expansion of the DPRP to other provinces of Nepal. Province 1 will be a kind of showcase, on which other municipalities and provinces can graft their improvement of prevention, rehabilitation, and inclusion. Karuna Nepal does not have the ambition nor the possibilities to be involved as intensively as in Province 1. However, Karuna Nepal can share knowledge and successes with national and regional governments to include the CBR approach in national health plans and budgets. To this end, a Training Center is being established, which when rolled out to other provinces can provide technical support in the form of training and access to information through a portal, an app, online training, helpdesk, and videos. Karuna Nepal is also in talks with UNICEF Nepal about a partnership to achieve this goal

The DPRP 2.0

In July 2023, the government will start implementing the DPRP 2.0 program, supported by Karuna Nepal. It is based on the ongoing DPRP but modified based on the above considerations. The outline of the program is as follows:

1. Roll out a modified DPRP in the second half of Province 1 in 59 municipalities with co-financing by municipalities and the province. Support by Karuna Nepal focuses on:

Prevention:

- Contributing to a public campaign and distribution of folic acid.
- providing "best wishes" cards to every married person with advice on how to have a good pregnancy
- provide good "birth defect" screening through targeted checks at each birth and referral for early treatment
- training school nurses and teachers in recognizing disabilities

CBR:

- ensuring the appointment and providing the training of Community Based Rehabilitation Facilitators in each municipality
- supporting these CBRFs in making rehabilitation plans, providing physiotherapy and care, organizing medical appliances, and referrals to centers for treatments
- support CBRFs in organizing home education for children with disabilities and entry into regular education, and existing youth clubs.
- Establishment and training of OPD (local organization of people with disabilities) and self-help groups (cooperatives)

Strengthen local care systems for program sustainability:

- Set up and train local management committees in each village

- Training and support of government staff to manage the program (including budget management)
- Training and mentoring of staff of local health centers
- Set up a steering committee in the province and support staff for coordination, supervision, and monitoring.
- Development of new governmental guidelines for DPRP implementation and cost-sharing.

The activities of DPRP 2.0 in the second half of Province 1 are shown in the attached "Lifecycle".

2. Formation of a "Training and Expertise Center". When rolled out to other provinces, this center will provide technical support to government staff through training and access to information through a portal, an app, online training, a help desk, and videos.

Organization

The Karuna Foundation is a Nepalese organization based in the capital Kathmandu and the city of Itahari in Province 1. Two Nepalese directors lead a motivated team of 80 committed professionals. Both have been involved since the program began in 2007. The organization has its local board and is responsible for the strategy and implementation of the program. To support the activities of the Karuna Foundation, a foundation with ANBI status has been established in the Netherlands under the name KarunaNL. This foundation raises funds for the Nepalese program, supervises the correct and responsible spending thereof, and assists and advises the Nepalese foundation. KarunaNL has a three-member board, a director, and an accountant.

Our funding partners

The current major funding partners of KarunaNL (> €100.000/yr.) in phase 1 are UBS Optimus Foundation, Perspective Foundation, Orphanage of the Baptists Foundation, Ineke Feitz Foundation, Hofstee Foundation, and Provicimis Foundation. The total budget for DPRP phase 1 was €12.7 million, of which €7.5 was funded by KarunaNL while the province and municipalities contributed €5.26.

Costs and Budget.

The expected cost for the implementation of DPRP 2.0 in the period 2023-2027 is for KarunaNL an average of €1.1 million per year for 4 years. In total, the Provincial and all 59 municipalities will contribute €4.2 million.

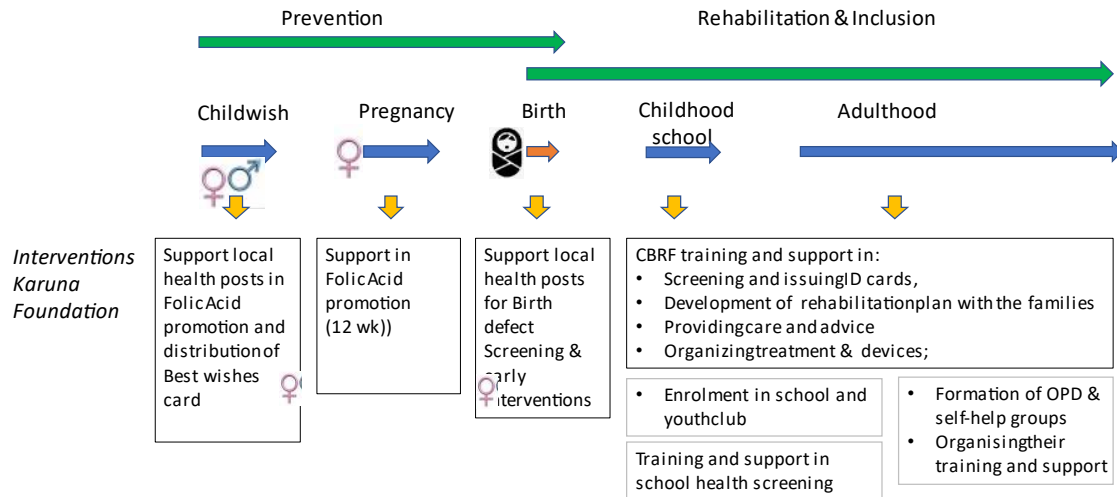
The total cost of the program per municipality for the Karuna Foundation is €152,136. Of this, Karuna is funding: €75,574. The province and municipality are funding €76,562.

Budget DPRP 2.0 DRAFT

	Costs KFNL € total	Costs KFNL € 2023-2024	Costs KFNL € 2024-2025	Costs KFNL € 2025-2026	Costs KFNL € 2026-2027
Prevention	185.406	30.901	61.802	61.802	30.901
CBR	1.513.465	252.244	504.488	504.488	252.244
System strengthening	130.174	21.696	43.391	43.391	21.696
Program support costs	766.590	191.647	191.647	191.647	191.647
Karuna Nepal management	1.476.427	369.107	369.107	369.107	369.107
Karuna NL management	445.086	111.272	111.272	111.272	111.272
Total	4.517.147	976.866	1.281.707	1.281.707	976.866

Annex 1: Interventions DPRP in the lifeline of persons with disabilities

lifeline of disabilities



Right: daughter Sunia received her first disability ID card
 Middle: sign language in an inclusive school in Biratnagar
 Middle: a CBRF develops a rehabilitation plan for the boy Krishna together with the mother and his mother now knows how to care for him
 Left: Ram has CP and was laying in bed. Now the boy can sit as he received physiotherapy
 Meeting by a health worker to share information about the use of folium acid and good postnatal care (best wishes card)