

A system change in rehabilitation and health care in Nepal

Karuna Foundation Nepal

Summary

On June 16th, 2019, the provincial government of Province number 1 in Nepal decided to adopt the Inspire2Care(I2C) programme, a community-based healthcare and rehabilitation programme, as developed by the Karuna Foundation in the past 12 years. The Ministry of Social Development in the province has the responsibility to implement the program in collaboration with the municipalities and the Karuna Foundation. They have allocated budgets, approved new cost-sharing modalities, agreed on implementation guidelines and renamed the program to the Disability Prevention and Rehabilitation Program (DPRP). We see this as a great step towards changing the maternal/child health care system and developing disability inclusive society in Province 1. The program focusses on:

- Strengthening the existing maternal and childcare to prevent birth defects, maternal and neonatal mortality and (childhood) disabilities.
- Developing disability-inclusive societies by improving access to healthcare, education, livelihood opportunities and participation in social life for persons with a disability.

The program aims at reaching 540,000 pregnant women, 800,000 children and 100,000 persons with a disability (plus their families) in Province 1 by 2025. The Karuna Foundation will support the government in the scaling and implementation of the program in the coming 5 years in Province 1 and develop a resource centre to share their knowledge and experience. Karuna expects to inspire the remaining six provinces and the federal government in Nepal to adopt the programme too.

Why this program?

An estimated 100.000 persons with a disability live in Province 1 (out of 5 million inhabitants). They are stigmatised, considered a burden for the family and society and often hidden in the houses. Family members do not know how to care for their children with a disability, nor do they see any potential. While there have been strides of improvement in maternal and child health over the years in Nepal, the figures on neonatal deaths, rates of disability by birth and stunted growth are still high, as quality of health care is lacking behind. The table below lists the characteristics of the current care system:

System characteristics	Persisting factors	Impact
Culture of blame, shame Lack of awareness on potential of persons with disability	No figures, invisibility of the problem No example of how they can rehabilitate/participate in society	100.000 persons left behind
A basic maternal and child health care system exists, but quality of care still lacking behind	Absence of well-trained community health workers. Inconsistent data collection (HMIS). Poor implementation of evidence-based interventions	High prevalence of birth defects and stunted growth (36%) putting pressure on local society to care. Low trust in health care system: Ante Natal Care by 59%_ . Low percentage of institutional delivery (62%)
Legal framework (Disability Act, ratified UNCRPD), but lack of CBR programs	Lack of cost-effective CBR programs and good results. Fragmented programs. Culture of stigmatisation, hiding	Care takers overburdened, losing a social life and source of income.

Decentralized government that can decide on funding, implementation and are accountable for success	Lack of funding and technical capacity Politicians not aware	Eagerness mayors to improve the situation. More power to the people
Gender inequality	Women blamed for disability Poor social/economic position of women. Male domination	Potential of women underutilised.

The Disability Prevention and Rehabilitation Program (DPRP)

In the new system we foresee 117 municipalities in Province 1 capable of organising a disability inclusive society, with their own ongoing CBR program. We also foresee a cost-effective maternal health care system and strengthened female leadership in care. Our key levers to change are:

<p>1. Strengthening of maternal, neonatal and child health care to prevent deaths and disabilities by:</p> <ul style="list-style-type: none"> - distribution of folic acid tablets to just married couples - registration of pregnant women via a mobile-Health program and sending messages for ANC and PNC. - professional support during delivery in the upgraded birthing centres - training of local health workers on birth defects prevention and identification, - organising school health screening camps to screen children below 10 years
<p>2. A proven cost effective CBR program, manageable and fundable by the local government with:</p> <ul style="list-style-type: none"> - door to door visits to persons with disabilities for counselling, physiotherapy and other CBR services by the new local health and rehabilitation workers, employed by local government - assessment by multi-disciplinary team to identify rehabilitation need - participation of family in setting rehabilitation goals, its implementation and evaluation - support to children with a disability to enter school and inclusive child clubs and peer education - establishment of self-help groups (providing seed capital and vocational training - cooperation with other NGO's, hospitals and schools to organise specialised care and devices
<p>3. Adoption by the Government via:</p> <ul style="list-style-type: none"> - new directives and Implementation Guidelines by Provincial Government - a steering committee of stakeholders of different Ministries and Karuna foundation in the province - responsibility of local government for plan, implementation, budget and success (in agreement) - local program management committees-to steer progress and results - introduction of mobile technology and set-up of MIS with health posts - training & Resource Centre to share information/knowledge on disability prevention and rehabilitation - strengthening the role of DPO to raise the voice of the persons with disability in the future - tri-partite co-funding (2 years) and support by Karuna for 3 years in 117 municipalities.
<p>4. Strengthening of gender equality and female leadership</p> <ul style="list-style-type: none"> - introduction of around 500 local health and rehabilitation workers (currently 86% are women) - involvement of women in local advocacy "Milijuli" groups - access to self-help groups (cooperatives) to generate income for women

Key-actors to make this change happen:

- the provincial and local governments (municipalities and wards) of Province 1
- the National Federation of Disabled Nepal (NFDN) and DPO's
- Organisations offering "specialised care"
- Medic Mobile Nepal
- the Karuna Foundation Nepal (strategy and implementation)
- The Karuna Foundation NL (coordinated funding)
- the federal government and other Provincial governments

Expected impact on health care



70% of the 16.000 children with disabilities experienced an improvement in their quality of life (scores measured by WHO Quality of Life Tool).

20% of the 62.000 adults with disabilities experience this improvement in quality of life



80% of the expected 108.000 deliveries/year are professionally guided in a clinic (compared to 62% in 2016).

Maternal mortality is reduced by **40%** and child mortality by **38%**.



From 2016-2015, amongst **786.000 children below 10** years old:

- Decrease in stunting from 33 to **20%**.
- Decrease in wasting from 12 to **5%**.
- Decrease in underweight from 24 to **16%**.



108.000 pregnant women per year receive 4 prenatal and 2 postnatal check-ups. This is increased to **80%**; The current percentage is 59%.

50% of expected pregnant mothers taking folic acid prior to conception.

We expect 80% of all municipalities to continue the programme after Karuna exits.

Track record so far

Studies on the impact of the pilot program in the district of Ilam– by [Karak Enterprise Development Service India in 2017](#) and by [Health Economist Kelsey Vaughan in 2018, assigned by UBS-OF](#), showed the following;

- 62% reduction in birth defects in Inspire2Care communities.
- 61% increase of birth deliveries in a clinic.
- 70% of children with a disability indicated moderate to significant improvement in their quality of live.
- Access to government services via ID cards increased from 24% to 89%.
- Visibility, recognition and acceptance and care for people with disability increased.
- 80% of all villages continue the programme after the exit of Karuna at their own costs.
- Calculated cost per DALY (*Disability Adjusted Life Year*) of €262.

Track record of Karuna Foundation:

2018 the [top 10 'most scalable solutions' of the Zero Project Impact Transfer programme](#), a collaboration between Essl Foundation and Ashoka. It was also selected as [Innovative Practice on Accessibility](#).

2017 [EVPA success story](#). By the European Venture Philanthropy Association

2017 an [Innovative Practice 2017 on Employment, Work and Vocational Education](#) (Zero Project Conference)

2016 a 'good example of a sustainable and innovative method' during the World Congress on CBR in Kuala Lumpur.

2015 [one of the five best practices in integrating people with disabilities in their own communities](#), (the Asian Pacific Centre for Development and Disability in an investigation among 53 Asian countries).

What makes this program innovative?

- **The introduction of the CBR worker in the current health care system.** This person, preferably living in and from the local society, will be recruited and employed by the local government. She provides door-to-door care to persons with a disability
- **A model for affordable care for persons with a disability.** This model strengthens the provides basic care facilities. For specialised care the program started a collaboration with different clinics, care centres, NGO's and hospitals in the province.
- **Linking care for persons with a disability to a prevention program.** The local support for and the impact of the program increased with the introduction of a maternal and childcare program to prevent disabilities.

- **The involvement and commitment of the local community** makes them responsible for the success of the program and helps them to adopt persons with disability in the social life in their village (via school, cooperatives, youth clubs, council etc.). Hence, “disability inclusive societies” are formed.
- **A new form of cost-sharing (PPS)**, The implementation costs of the program in the villages is shared by three parties: Province, Municipality and the Karuna Foundation (each 1/3). The government of Nepal responded positively to this model and aims at replicating it in other programs too.
- **Exit strategy** Karuna foundations will fund the introduction of the program in each municipality for 2,5 years. Afterwards municipality with provincial support will continue the program at their own cost and responsibility.
- **The scaling strategy with the government.** The provincial government adopted the program under the conditions of replication in all municipalities. The next elections in 2023 determined the planning of the scaling in order to keep political momentum. In the coming years we expect to inspire other provinces to adopt the program.
- **The development of an on-line community** for health workers and persons with a disability giving them access to relevant information via a portal. It will provide data for the government on how and where to strengthen the program.
- **The introduction of the Medic Mobile program;** health workers receive a mobile phone and training in a messaging system for pregnant women to make them aware of their 4 Ante Natal Care (ANC) visits and 2 Post Natal Care visits. They are also trained in data collection to support the local Health-MIS
- **A system for distribution of ID-cards to persons with a disability**, allowing them to get access to government services and support.

Budget

The budget of the Replication Plan in Province 1 is € 23.016.563 of which the Provincial and Local Government have committed € 9.242.761. Hence, the budget for KarunaNL will be € 13.773.802

Team

Karuna Foundation Nepal is a local NGO in Nepal, led by Deepak Raj Sapkota and Yogendra Giri since the start in 2008. They lead an enthusiastic and highly committed young team of over seventy professionals. Karuna has built the reputation of a reliable and effective organisation in Nepal, capable of cooperating with the different government bodies and NGOs, building mutual trust and understanding. Karuna Nepal has its [own board](#).