

# ***Cost-effectiveness assessment of the Inspire2Care program in Ilam***

FINAL REPORT  
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## Acronyms

ADL	Activities of Daily Living
ANC	Antenatal care
CBR	Community-Based Rehabilitation
DALY	Disability-Adjusted Life Year
DHO	District Health Office
FCHV	Female community Health Volunteer
GBD	Global Burden of Disease
GDP	Gross Domestic Product
HFOMC	Health Facility Operation & Management Committee
HMIS	Health Management Information System
I2C	Inspire2Care
ICF	International Classification of Functioning
IFA	Iron and Folic Acid
KFN	Karuna Foundation Nepal
M&E	Monitoring & Evaluation
NHSP	Nepal Health Sector Programme
NLR	Netherlands Leprosy Relief
NPR	Nepalese Rupee
P&R	Prevention and Rehabilitation
PNC	Post-Natal Care
Td Vaccine	Tetanus, Diphtheria Vaccine
ToR	Terms of Reference
VDC	Village Development Committee
VDRC	Village Disability Rehabilitation Committee
WHO	World Health Organization

## Executive Summary

Since 2011, Karuna Foundation Nepal has been implementing a disability prevention and rehabilitation program, previously known as Prevention and Rehabilitation (P&R) and now called Inspire2Care (I2C), in Nepal. I2C includes both prevention-related activities (largely in partnership with local government health facilities), community rehabilitation of children and adults with disability and strengthening of local systems. The rehabilitation component of the pilot I2C program, implemented in four villages in Rasuwa district and three villages in Sunsari district, was evaluated previously by this team of evaluators<sup>1,2</sup>.

At the request of the Inspire2Care Investors Consortium and Stichting 't Bosje, a team of consultants were contracted to conduct a cost-effectiveness assessment of the scale-up phase of I2C, as implemented through December 2017 in Ilam. Completed during the period March-September 2018, this assessment included extensive document review, a field visit to Ilam district, a cost-effectiveness analysis looking at cost per DALY averted of Ilam batches 1 and 2 (implementation through December 2017) and predicted cost-effectiveness of Ilam batch 3. The consultants also compared the results with the cost-effectiveness and efficiency results from the I2C pilot implemented in Rasuwa and Sunsari and assessed by Vaughan and Thapa in 2014.<sup>3</sup> Finally, a review of the program's prevention component and evidence on prevention-related interventions was conducted.

The assessment has found that the I2C program cost EUR 740,308 to implement over the period January 2014 to December 2017, of which 73% was funded by Karuna Foundation Nepal, 16% by Karuna Foundation Netherlands and 11% from local resources (note: this excludes prevention-related expenditures of 40% of total I2C expenditures, see explanation elsewhere in report). In total an estimated 1,926 DALYs were averted using the 2004 weights and 878 using the 2016 weights. This gives a cost per DALY averted of EUR 384-843 depending on the weights used. Estimated expenditures for batch 3 and results in line with batch 2 would result in a batch 3 cost per DALY averted of EUR 322-693.

The anticipated cost-effectiveness of the CBR component of I2C in the planned replication prototype municipality, excluding Karuna Foundation Netherlands expenditures and Karuna Foundation Nepal indirect administrative expenses, is EUR 51-107. This is likely an improvement on current performance, and acting on the recommendations from this report should further improve cost-effectiveness. The investors' consortium is, however, cautioned to keep administrative costs to a minimum as more partners become involved, as these expenses can quickly have a negative impact on overall cost-effectiveness.

This cost per Disability-Adjusted Life Years (DALY) averted is well within the reach of the Government of Nepal. The cost-effectiveness of the basic package of health services as implemented through the Nepal Health Sector Programme during the period 2005-2015 was estimated to be EUR 120-123 per DALY averted on average, meaning some interventions were less cost-effective and some were more cost-effective. Using WHO benchmarks, I2C Ilam is still considered highly cost-effective or cost-effective, depending on the batch assessed and disability weights

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<sup>1</sup> Vaughan, Kelsey (2015). Cost-effectiveness and efficiency assessment of the Inspire2Care program, 2011-2013. <http://www.karunafoundation.nl/download/Final%20report%202%20February%202015.pdf>

<sup>2</sup> Vaughan, Kelsey and Thapa, Aradhana (2015). Cost-effectiveness of a community-based rehabilitation programme in Nepal. Disability, CBR and Inclusive Development (DCID). Vol. 26, No.4. <http://dcidj.org/article/view/457/273>

<sup>3</sup> Vaughan, Kelsey (2015). Cost-effectiveness and efficiency assessment of the Inspire2Care program, 2011-2013. <http://www.karunafoundation.nl/download/Final%20report%202%20February%202015.pdf>

used, though it should be noted that the approach of comparing cost-effectiveness against GDP per capita has recently been criticized for not taking into account local resource availability.

It is important to note that some of the major benefits or gains from the program – particularly the community mobilization around disability, skill gained by members of families of persons with disabilities, improvements in attitudes of community members towards persons with disability and social cohesion – are not captured in the cost per DALY averted statistic. This is an important limitation of the DALY and the research itself.

The numerous data challenges continue to make it challenging to measure the impact of the prevention side of the component. That said, a review of the literature has produced important findings about effective interventions for preventing birth defects, which hopefully can be useful for improving I2C. Over 20 evidence-based interventions were identified for delivery during preconception or pregnancy, 12 of which Karuna is currently doing.

The research has produced a number of recommendations which are focused on improving performance management and allowing for stronger research in the future. In terms of the CBR side of the program, cost-effectiveness may be improved through better recruitment and retention efforts of CBR Facilitators and improved performance of certain VDCs. The monitoring and evaluation system can be significantly strengthened by training CBR facilitators in objective initial scoring and ongoing assessment of children and adults with disability who are part of the program. By incorporating the ICF classifications and improvement score criteria in routine assessments of progress, and adopting a standard Excel tracking and scoring sheet similar to the one used in this assessment, it will be possible to keep track of DALYs averted on an ongoing basis without needing to commission researchers.

In terms of the prevention component of the program, the main recommendation is for Karuna Foundation Nepal to generate the high-quality data needed to measure the impact of I2C, whether this is through the revised Medic Mobile system, a batch 1 mid- or end-line study or a randomized control trial. The program components should also be looked at in light of the evidence from the literature review. Recommendations are made in 15 areas to strengthen the program, many of which can be incorporated through counselling. Additionally, interventions which are not evidence-based should be removed.

Longer-term outlooks for incorporation into the government system and sustainability through local systems are good from the perspective of cost-effectiveness and financial sustainability, in that the program is designed to be sustainable and shows evidence in batches 1 and 2 of being so. Additionally, planned changes to the program for the replication strengthen sustainability even further. Changes to both the prevention and CBR components, and their M&E, should ensure strong evidence on cost-effectiveness of I2C is available for future advocacy efforts.



# 1 Background

## 1.1 About Karuna's Inspire2Care (I2C) program

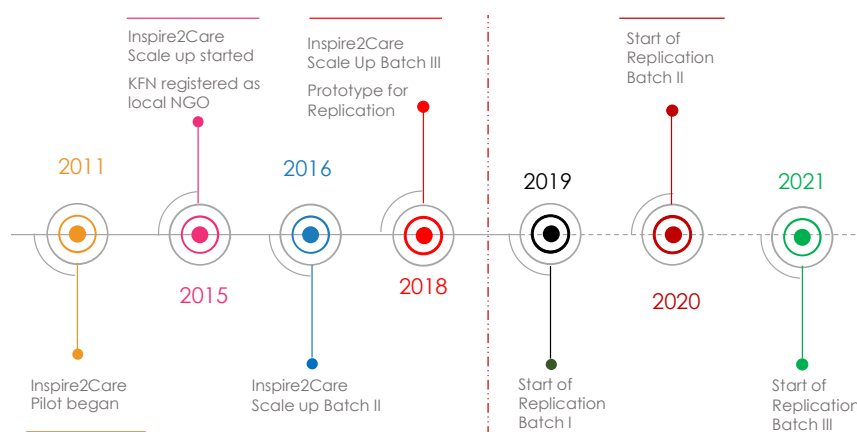
Disability is a significant health and social issue in Nepal. The National Census 2011 found 1.94% of the population in Nepal has a disability, though the figure is suspected to be higher. Globally around 10-15% of persons have a disability<sup>4,5,6</sup>. There are a number of national policies, acts and regulations in Nepal related to disability, which in practice are operationalized in nine areas<sup>7</sup>:

1. Identity cards
2. Free education and educational accommodations
3. Scholarships
4. Limited medical care
5. Civil service workforce quotas
6. Reserved and discounted transportation
7. Public building accessibility
8. Tax benefits
9. Social welfare allowances

However, there are gaps in the Government disability programs, evidence by the large number of organizations working on disability prevention and rehabilitation in Nepal, including Karuna Foundation Nepal. The organization's vision is for "a world in which each individual, with or without disabilities, has equal access to quality health care and education, can lead a dignified life and can participate as much as possible in community

life." This mission is to save children from disability, one by one, and create an inclusive society.<sup>8</sup> This is primarily achieved through a disability prevention and rehabilitation program, originally known as Prevention and Rehabilitation (P&R) and in 2014 renamed Inspire2Care (I2C). I2C was designed and is implemented through government system, with the eventual goal that it is entirely absorbed by government. I2C was implemented as a pilot in Sunsari and

**Figure 1 History of Inspire2Care (I2C) in Nepal**



Rasuwa starting in 2011. It was then scaled-up to Ilam starting in 2015. Plans for replication elsewhere in the

<sup>4</sup> World Bank, 2000

<sup>5</sup> Thapaliya, MP. A Report on Disability in Nepal 2016. Australian Himalayan Foundation.

<sup>6</sup> WHO/World Bank. 2010. World Disability Report.

<sup>7</sup> Thapaliya, MP. A Report on Disability in Nepal 2016. Australian Himalayan Foundation.

<sup>8</sup> Inspire2Care Funding Partners' Consortium Meeting. 3-4 September 2018. Presentation by Karuna Foundation Nepal. Amsterdam, the Netherlands.

country are currently underway. Figure 1 shows the history of Inspire2Care and Figure 2 shows the location of past and current I2C projects in Nepal.

I2C is a synchronized package of interventions aimed at prevention of avoidable disabilities, community-based rehabilitation of persons with disabilities and strengthening local government systems for health, education and community. It focuses on both children and adults with disability.

Disability prevention activities are largely implemented by the health post through the Best Wishes Program<sup>9</sup>, sometimes with Karuna financial support. These include:

- Renovation of health facilities including birthing Centers, Out Reach Clinics (building, equipment, furniture)
- Pregnancy registration and follow-up (mHealth)
- Capacity building of health workers and Health Facility Operation and Management Committee (HFOMC) members
- School health education, screening camps and referral
- Health and nutrition education to Golden 1000 Days<sup>10</sup> mothers
- Data management, use and monitoring at local level

The rehabilitation side of the program uses a community-based rehabilitation (CBR) facilitator, employed by the HFOMC, (now Rural Municipality and Municipality). The CBR facilitator takes the lead in organizing an assessment camp for all individuals in the village and subsequently developing rehabilitation plans for each individual with disability. The CBR facilitator also takes the lead in some general activities not tied to a specific individual's rehabilitation plan. Activities come from all five components of the CBR matrix (health, education, livelihood, empowerment and social) and include:

- Treatment, assistive devices, physiotherapy, nutrition counselling, training for parents
- Enrollment support in formal and non-formal education including securing government scholarships, showcasing disability friendly school
- Vocational training, seed capital, saving and credit activities, linking with social security allowance provision from Government of Nepal and other provisions
- Recreation, peer education and awareness activities
- Group mobilization, capacity building, child clubs, Milijuli Samuha (Self Help Group), disabled persons organizations, advocacy and communication, job placement, reasonable accommodation support

**Figure 2 I2C implementation in Nepal**



<sup>9</sup> Best Wishes program is mainly focused on increasing maternal and child health indicators including antenatal care (ANC) visits, institutional deliveries, post-natal care (PNC) visits, immunization coverage and nutritional status of mothers and children. Karuna Foundation Nepal's support for the program stems from the belief that if these indicators improve, the chances of delivering a baby with a disability or who develops a disability in the first days of life will decrease. The Best Wishes program includes marriage registration and counseling to newly married couples, pregnancy registration (now via mobile messaging), issuance of a Best Wishes card for tracking, awareness events, follow up of pregnant women on use of health services and institutional delivery, nutritional assessment of children, support to birthing centers by providing training, equipment and furniture and school health screening for early identification and treatment of disabilities (secondary prevention). In some cases, Karuna Foundation Nepal has also supported the construction of new buildings. Karuna Foundation Nepal also supports other prevention-related activities that may lead to better outcomes in Best Wishes, such as training health workers and improving growth monitoring.

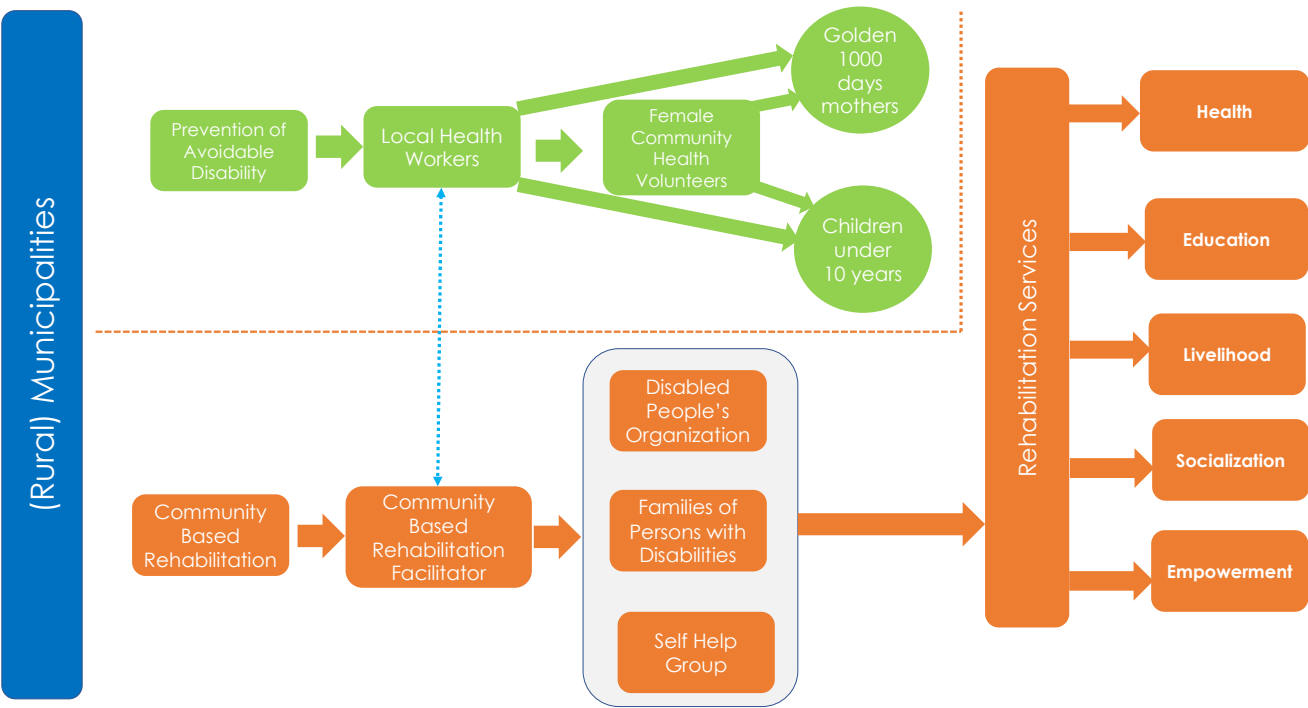
<sup>10</sup> Refers to the period between conception and a child's second birthday.

For all full list of activities, see Annex 3 – Activities implemented as part of I2C

The HFOMC (now Rural Municipality or Municipality) then approves the activities and corresponding budget. Wherever possible, treatment and/or rehabilitation services are provided through existing organizations or programs which the CBR facilitator helps identify and arrange.

I2C is operated in direct partnership with the local government: this ensures local leadership and ownership, helping ensure long-term sustainability. There is also a cost sharing component with the community, also for reasons for ownership and sustainability. The implementation modality is depicted in Figure 3.

**Figure 3 I2C implementation modality**



Source: Inspire2Care Funding Partners' Consortium Meeting. 3-4 September 2018. Presentation by Karuna Foundation Nepal. Amsterdam, the Netherlands.

## 1.2 Assessment

In 2014 Karuna Nepal initiated the scaling up of I2C to 56 villages<sup>11</sup> in three phases. The first phase (known as batch 1) started in January 2015 in 12 villages in Ilam and 3 villages in Jhapa (by NLR). In April 2016 Karuna Nepal started in another 14 villages in Ilam and 1 in Jhapa (batch 2). The third phase (batch 3) started in July 2017 in 16 villages and three municipalities in Ilam. Different donors are direct partners of Karuna Nepal in these scaling up

<sup>11</sup> The number of villages across the three batches does not sum to 56; there was a governmental restructuring midway through I2C implementation, resulting in a change in the number of VDCs. I2C now uses program units instead of VDCs, which are distributed across batches as follows: Batch 1 – eight program units (one Jhapa), Batch 2 – 17 program units (one Jhapa), Batch 3 – 26 program units.

phases: Ineke Feitz Stichting (batch 1, batch III), UBS Optimus Foundation (batch 2), True Blue (batch 2), Stichting 't Bosje (batch 2, batch 3) and Makoto Maki (batches 2 and 3).

At the request of the Inspire2Care Investors Consortium and Stichting 't Bosje, a consultant team of Kelsey Vaughan and Aradhana Thapa were contracted in March 2018 to conduct a cost-effectiveness assessment of I2C implementation in Ilam. Rashmi Paudel later joined the team. The assessment aimed to:

1. Assess the cost-effectiveness of I2C implementation in Ilam only (Jhapa villages are excluded)
  - a. Ilam batch 1 (to-date implementation)
  - b. Ilam batch 2 (to-date implementation)
  - c. Ilam batch 3 (predicted)
2. Compare cost-effectiveness findings from the pilot implementation in Rasuwa and Sunsari, batch 1, batch 2 and batch 3 and provide recommendations

The contract with the consultants also included revision of Karuna Foundation Netherlands's prevention of birth defects and disability calculation tool; that work was amended to include a literature review and comparison with current I2C activities. For the full terms of reference, please see Annex 1 – Proposal and Annex 2 – Prevention tool TORs. Findings from the cost-effectiveness analyses are expected to serve as input to work to be carried out in 2018 by Effective Giving.<sup>12</sup>

The sections that follow outline the methodology used for the assessment, and discuss cost-effectiveness findings and compare results across batches and with the pilot assessment findings.

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<sup>12</sup> In essence, the cost-effectiveness analyses outlined here answer the question, "is I2C cost-effective?", whereas the work by Effective Giving will answer the question, "does I2C represent effective giving?", according to the organization's criteria for effective giving. For a full explanation of Effective Giving, please see <https://www.effectivegiving.nl/>.

## 2 Methodology

This section describes the methodology used for the cost-effectiveness assessment, which followed the methodology previously used in the pilot assessment as close as possible to allow for comparability, and the prevention evidence review. The outcome measure of the cost-effectiveness analysis is cost per DALY averted; though technically this is a cost-utility analysis, the term “cost-effectiveness” is used for ease of understanding, as is widely done elsewhere<sup>13</sup>.

### 2.1 *Cost-effectiveness assessment*

#### 2.1.1 Overview

We reviewed budgets, expenditure reports, various results files, program documents and reports and other related documents. A field visit was also conducted. A list of reviewed documents is provided in Annex 4 – Documents reviewed. The travel itinerary detailing meetings held and persons met is provided in Annex 5 – Field visit itinerary.

#### 2.1.2 Assessment period

The assessment period is from June 2014 to December 2017. Batches 1 and 2 are assessed retrospectively from the preparation phase (beginning June 2014) through December 2017, regardless of the batch end date.

We also include a prospective assessment of the full implementation of batch 3, from July 2017 to December 2021.

Batch	Batch start date	Batch end date	Total batch duration	Number of Ilam VDCs* included in assessment	Number of Jhapa VDCs* not included in assessment
Preparation	June 2014	March 2015	10 months	--	--
Batch 1	January 2015	December 2019	5 years	12	3
Batch 2	January 2016	December 2020	5 years	14	1
Batch 3	July 2017	December 2021	4.5 years	19**	4

\* Due to restructuring by the Government of Nepal in March 2017<sup>14</sup>, some VDCs were converted to municipalities. For the purpose of I2C, VDCs are now called program units. Batch 1 includes 7 program units in Ilam and 1 in Jhapa, batch 2 16 program units in Ilam and 1 in Jhapa and batch 3 26 program units.

\*\* 16 VDCs + 3 municipalities

#### 2.1.3 Measuring cost-effectiveness

Cost-effectiveness in this assessment refers to the generic term for economic evaluations comparing the costs and benefits of two or more interventions or programs and not the specific cost per natural outcome (Drummond et al, 2005). This cost-effectiveness assessment takes a program (implementer) perspective, meaning only costs and benefits incurred by the implementer are included, and uses the cost per DALY averted measurement (also

<sup>13</sup> Svensson M and Hultkrantz L. 2017. A comparison of cost-benefit and cost-effectiveness analysis in practice: divergent policy practices in Sweden. *Nordic Journal of Health Economics*; 5;2. 41-53.

<sup>14</sup> INSECOOnline. 2017. VDC and municipality structure dissolved, 744 local levels to be maintained. <http://inseconline.org/en/news/vdc-and-municipality-structure-dissolved-744-local-levels-to-be-maintained/>

known as cost-utility analysis). Cost per DALY averted is a common measurement of cost-effectiveness, used extensively by the World Health Organization (WHO). We compare the costs and benefits of the I2C program with the cost per DALY averted of other health programs implemented in Nepal and elsewhere. The below sections detail the methodology for assessing the costs and benefits of the I2C program.

#### **2.1.3.1 Measuring total expenditure**

The first step in assessing the cost-effectiveness of I2C Ilam through December 2017 was to identify how much money was spent, in total and from all sources, on the program. Total expenditure (not budgeted amounts) from inception through December 2017 was derived from multiple sources as it needed to include Karuna contributions (from both Karuna Foundation Nepal and Karuna Foundation Netherlands) as well as local resources from VDCs. Both direct and indirect expenditures are included.

##### **2.1.3.1.1 Karuna Foundation Nepal expenditures**

Karuna Foundation Nepal expenses (as supported by different organisations UBS Optimus Foundation, Ineke Feitz Stichting, Karuna Netherlands, Makoto Maki Foundation, Stichting 't Bosje and True Blue) were derived from audited expenditure reports they furnished and Excel spreadsheets from audits, as well as unaudited expenditures for the period July-December 2017. Expenditures include both contributions to HFOMC (as well as other expenses, both in the implementation districts as well as at the Central Office. From the above-mentioned sources, expenses not related to I2C were eliminated. Costs exclusively for I2C were allocated 100% to I2C. Shared human source and administrative expenses (such as office costs, salaries of persons working on both I2C and other programs) were extracted from the above sources and apportioned to I2C Ilam (including Jhapa) by Karuna Foundation Nepal staff, according to the breakdown of work between I2C and other programs.

I2C Ilam expenditures (including Jhapa) were then apportioned to the Ilam VDCs on the basis of share of total VDCs (Ilam plus Jhapa). For preparation expenditures, this was done using the share of Ilam villages to total villages (92%). For expenditures related to specific batches, the share of Ilam to total villages for that batch specifically was used.

##### **2.1.3.1.2 Karuna Foundation Netherlands expenditures**

Karuna Foundation Netherlands expenditures related to I2C Ilam were extracted by Karuna Foundation Netherlands staff from Dutch audit reports and apportioned to I2C Ilam using different percentages, according to the expenditure, based on the number and size of programs supported.

I2C Ilam expenditures (including Jhapa) were then apportioned to the Ilam VDCs based on share of total VDCs (Ilam plus Jhapa).

##### **2.1.3.1.3 Non-Karuna expenditures**

At the village level, I2C is funded on the basis of signed agreements with HFOMC (now Rural Municipality or Municipality). These agreements are signed yearly and specify the financial contribution of each party, as noted in Table 1.

**Table 1 Agreed financial contributions, by batch and year (EUR)**

Batch	No. VDCs	Cost-sharing (Karuna-VDCs)	Amount per VDC (EUR)							Total
			2015	2016	2017	2018	2019	2020	2021	
1	12	Year 1: 80/20	568	2,138	2,618	3,743	3,716	---	---	12,783
2	14	Year 2: 50/50	---	887	2,190	3,306	4,059	4,044	---	14,486
3	19	Year 3: 30/70	---	---	---	18,099	14,705	9,073	8,429	50,306

Note: actual local contributions and expenditures for 2015-2017 were provided by Karuna Foundation Nepal using a template developed by the office's auditors. Only contributions for the Ilam VDCs (not Jhapa) were included. These amounts reflect only a percentage of actual expenses; saving from VDC allocated amounts were placed in a reserve fund in the village for use after Karuna cost-sharing ends.

#### **2.1.3.1.4 Annualizing preparation expenses**

Expenditures incurred by Karuna Foundation Nepal and Karuna Foundation Netherlands in preparation years, prior to implementation of batches 1, 2 and/or 3, were annualized across the program years, effectively allocating them across years and batches. This was done using a 3% discount rate.

#### **2.1.3.1.5 Removing prevention-related expenditures**

Similar to the pilot assessment, 40% of all relevant I2C expenditures incurred by Karuna Nepal, Karuna Netherlands<sup>15</sup> (including some costs of partners) as well as the VDC contributions were removed to account for prevention-related activities, based on an expenditures analysis done by Karuna Foundation Netherlands staff for the 2016 and 2017 annual reports. Note that this is higher than the percentages removed in the pilot assessment (27% in Rasuwa and 25% in Sunsari), which were based on an analysis by Karuna Foundation Nepal staff of prevention expenditures at village level, then extrapolated to higher levels.

#### **2.1.3.1.6 Total expenditure**

Karuna Foundation Nepal, Karuna Foundation Netherlands and non-Karuna contributions at the village level, minus prevention-related expenditures, were summed for a total program expenditure. Amounts noted in the HFOMC audits (Karuna and non-Karuna contributions) have been subtracted from this total to estimate the non-village level expenditure.

#### **2.1.3.1.7 Excluded expenditures**

This assessment only includes expenditures made by Karuna Foundation Nepal, Karuna Foundation Netherlands and the HFOMC. Expenditures made by other organizations, such as a wheelchair provided to an individual in the I2C program at that organization's own cost, are not included. This is partly due to data availability and partly due to the nature of the assessment. Out-of-pocket expenditures by parents (for example, for transportation to treatment or rehabilitation appointments) are also excluded.

#### **2.1.3.2 Measuring effectiveness**

Like the previous assessment, we measure effectiveness in terms of disability-adjusted life years (DALYs) averted. The DALY was developed by Harvard University for the World Bank in the early 1990s as a single indicator for use

<sup>15</sup> Includes some partner costs, notably: field visit of two persons from Liliane Foundation (2014), programmatic workshop including Liliane Foundation Netherlands, Liliane Foundation India, Netherlands Leprosy Relief (NLR) and NLR Nepal (2015), visit by Annet van den Hoek, Ineke Feitz Foundation (2016), visit of the full board of Ineke Feitz Foundation (2017) and various staff time of persons from Ineke Feitz Foundation, NLR and Liliane Foundation (2015-2017).

in developing countries which incorporates both morbidity and mortality: time lived with a disability and time lost due to premature mortality (Murray, 1994). It quantifies levels and trends of health loss due to diseases, injuries, and risk factors on a scale of 0 to 1, with 0 indicating perfect health and 1 being equivalent to death (WHO, no date).

The formula for calculating the DALY is as follows:

$$\text{DALY} = \text{YLL} + \text{YLD}$$

where YLL is the Years of Life Lost and YLD is the Years Lost due to Disability.

The formula for YLL is as follows:

$$\text{YLL} = N \times L$$

where N is the number of deaths and L stands for standard life expectancy at age of death in years.

There are two formulas for calculating YLD. The incidence formula multiplies number of incident cases by the disability weight for each case by the average duration of the case until remission or death (years):

$$\text{YLD} = I \times \text{DW} \times L$$

The prevalence formula is the number of prevalent cases multiplied by the disability weight of each case:

$$\text{YLD} = P \times \text{DW}$$

All formulas come from WHO (no date).

For this assessment we have assumed YLL is zero based on the information available about each individual and his/her condition, although some premature deaths as a result of disability may occur. For YLD, we have used the prevalence formula.

The major benefit of the DALY is that it allows comparison across diseases; for example, it's possible to compare the burden of disease and improvements made in HIV and maternal health where previously this was difficult because HIV was measured in terms of number or percentage of new transmissions and maternal health may be measured in terms of percentage of safe deliveries or ANC 4th visit coverage.

The DALY is not without criticism or limitations, of course. The main criticisms and limitations to note with regards to this research are as follows:

1. The DALY cannot capture hard to measure outcomes such as development of an inclusive society, such as recognition & acceptance of persons with disabilities in families and communities. Parks (2014) notes that "discounting life in general is problematic, but especially so for people with life-long disabilities; disabled activists make a philosophical argument that their lives should be valued equally to those of people with no disabilities."
2. The DALY is an individual measure; it does not capture the health state or change in health state of family members, such as reduced depression, as a result of an intervention directed towards another individual.



3. The ability to avert DALYs may be limited by local, geographic settings. For example, a physically disabled person's mobility could be enhanced by a wheelchair if good roads and physical infrastructures were present. In the absence of this infrastructure, however, a wheelchair is not of much help.
4. Recent research suggests that not all health state preferences are universal<sup>16</sup>; the use of a single set of disability weights is likely not appropriate in all settings. Local weights are not available for Nepal.

In response to this criticism, we note that the DALY measure does not mean to devalue the lives of persons with disabilities, but rather reflect the change in health status this population experiences, though as a primarily health-focused measure it certainly cannot capture all outcomes. For the time being, in the absence of local weights, the use of universal weights must be continued, but development of local weights would certainly be a methodological improvement.

Despite these limitations, the DALY provides a commonly accepted way to measure improvements in health status that can be achieved by programs such as I2C. It also makes it possible to argue for the cost-effectiveness of such programs by making them comparable to other health programs outside the realm of disability. For I2C, this is especially important metric to present to the Government of Nepal during future advocacy efforts.

#### **2.1.3.2.1 Disability weights**

The DALY works by assigning disability weights to health conditions. This effectively reflects the loss in health status an individual experiences as a result of his or her condition.

We calculate DALYs averted using two different sets of disability weights:

1. Global Burden of Disease (GBD) 2004 study<sup>17</sup>: these are the weights used in the previous assessment, allowing for comparability of findings with the Rasuwa and Sunsari assessment.
2. GBD 2016<sup>18</sup>: these are the most up-to-date weights available, and are the same disability weights used in GBD 2013 and GBD 2015. Weights for an expanded number of diseases and health states are available, based on new data collection and reanalysis of new and existing (2010) data. Additionally, lay descriptions of health states have been updated.<sup>19</sup>

#### **2.1.3.2.2 Scoring**

The team scored each individual receiving rehabilitation services from Karuna Foundation Nepal using records they provided about the type of disability identified during the assessment camp (prior to receiving any I2C-related intervention), the services provided through I2C during the assessment period, and the progress/achievement as of December 2017. Each step of the scoring process is described below, and a sample scoring sheet is included in Annex 9 – Sample DALYs averted scoring sheet.

<sup>16</sup> Neethling I, Jelsma J, Ramma L, Schneider H, Bradshaw D. 2016. Disability weights from a household survey in a low socio-economic setting: how does it compare to the global burden of disease 2010 study? *Global Health Action* 9:10.

<sup>17</sup> World Health Organization. Global Burden of Disease 2004 update: Disability weights for diseases and conditions. [www.who.int/healthinfo/global\\_burden\\_disease/GBD2004\\_DisabilityWeights.pdf](http://www.who.int/healthinfo/global_burden_disease/GBD2004_DisabilityWeights.pdf)

<sup>18</sup> Global Burden of Disease Collaborative Network. Global Burden of Disease Study 2016 (GBD 2016) Disability Weights. Seattle, United States: Institute for Health Metrics and Evaluation (IHME), 2017.

<sup>19</sup> Salomon JA, Haagsma JA, Davis A, Maertens de Noordhout C, Polinder S, Havelaar AH, Cassini A, Devleesschauwer B, Kretzschmar M, Speybroeck N, Murray CJL, Vos T. 2015. Disability weights for the Global Burden of Disease 2013 study. *Lancet Glob Health*; 3: e712–23.

### Sample selection

Given the large number of VDCs (30 total in batches 1 and 2) and poor data quality at some VDCs, a sample of 15 VDCs from batches 1 and 2 was chosen. This was later reduced to 10 VDCs (four VDCs from batch 1 and six from batch 2) when findings across the 10 sampled VDCs showed consistency. This represents a sample of 33% of VDCs (10/30).

### Baseline status code

The first step was to assign each individual a baseline status code, developed by the research team to correspond to a specific disability weight. For example, an individual with deformity of the right knee, resulting problems walking, was coded “Motor moderate”, corresponding to the disability weight for “Motor impairment, moderate, defined as “has some difficulty in moving around, and difficulty in lifting and holding objects, dressing and sitting upright, but is able to walk without help” (GBD 2016). Note that the research team attempted to use the same codes for 2004 and 2016 weights, though the weights themselves often differed. In the above example, there was only a single weight for motor impairment in GBD 2004 (0.381), but in GBD 2016 the weight was 0.061.

The research team noted that more detailed information was available in some VDCs as compared to others. Likewise, there was a difference in level of detail available for each individual. In many cases, the research team clarified information about the individuals’ conditions with Karuna field staff before assigning a code.

### Starting disability weight

Based on this information, we assigned up to three pre-intervention disability weights to each individual. In some cases the exact condition was not referenced in GBD 2004 or GBD 2016, so a similar condition was used (see notes). See Annex 6 – 2004 disability weights and Annex 7 – 2016 disability weights for a list of the disability weights used.

### Improvement score

Based on the qualitative description of services received and the progress/achievement noted, we assessed each individual’s improvement on a scale of 0 to 4, as described in general terms in Table 2 below:

**Table 2 Explanation of the assessment improvement scale**

Assessment improvement scale number	Description of improvement
0	No noticeable improvement seen
1	Minimal reduction in function limitations, some improvement in social participation, significant further interventions needed. This classification was used for individuals who are “improving” and perform ADL with supervision.
2	Moderate reduction in function limitations, moderate improvement in social participation, moderate further interventions needed. This classification was used for individuals who have shown “improvement” and can perform ADL independently
3	Significant reduction in function limitations, significant improvement in social participation, minimal further interventions needed. This classification was used for individuals who

	perform ADL independently, have had successful surgeries, attend school and social activities regularly without participation restrictions but continue to receive some support or treatment.
4	Fully rehabilitated: no functional limitations or restriction in social participation, and no further intervention needed apart from follow-up

Source: Based on assessment improvement scale used in the previous assessment, with some additions to clarify scoring of training and livelihood interventions.

More detailed descriptions of each number on the scale are found in Annex 8 – Assessment improvement scale. It is assumed that each individual starts at a 0 on the improvement scale, corresponding to no change in their status, which is what we assume to see without the I2C intervention. From pre-intervention disability status, the disability can be “downgraded” four possible steps, from 1 to 4, with 1 representing small improvements and 4 reflecting that the individual has been deemed by Karuna to be fully rehabilitated. Karuna follows the ICF classification and defines “fully rehabilitated” to mean no function limitations or restriction in social participation, and no further intervention needed apart from follow-up. Definitions of each level of the assessment improvement scale are detailed in Table 2 Explanation of the assessment improvement scale.

If limited information was provided about the individual’s improvement but some improvement is noted, the individual received a “1” on the assessment improvement scale. No additional DALYs were measured in the case that a negative improvement was seen; these cases are recorded as 0 on the assessment improvement scale.

All scoring was reviewed by a second member of the assessment team; any disagreements were discussed and resolved. Additionally, we asked Karuna Foundation Nepal to provide additional information about X individuals or to clarify the information provided, as we were unable to complete the scoring based on the provided information.

### Change in disability weight

If the condition is treated, a person can gain back that loss in health; similarly, a condition can be prevented through a prevention program. In both cases DALYs have been averted. Each assessment improvement scale increase (from 1 to 2, or from 2 to 3) represents a 25% reduction in the DALY weight; for example, an individual whose progress/achievement is rated as “3” reduces their starting disability weight by 75%. If their starting disability weight was 0.170 (for example, low vision due to refractive errors), the weight is reduced by 0.1275, to 0.0425. The change in disability weight was then used to calculate DALYs averted using the prevalence formula ( $YLD = I \times DW \times L$ ). Life expectancy refers to the duration the benefit will be sustained without further investment. This is different for different types of interventions:

- Non-medical interventions such as educational gains, the ID card and social participation will last a life time, so it is assumed the duration of benefits is the individual’s remaining life expectancy
- It is assumed assistive devices have a lifespan of five years (Temple-Bird et al, no date)
- For surgeries, it is assumed that the impact gained will last the individual’s remaining life time
- For other cases including physiotherapy, the benefits gained will last a life time without any additional cost. Some individuals will also continue physiotherapy at home since their family members have been

trained to provide it; this is also without additional program costs. As with the above point, it is assumed the duration of benefits is the individual's remaining life expectancy

- For individuals deemed fully rehabilitated, no further services are needed, therefore the duration of benefit is the individual's remaining lifetime

Remaining life expectancy from time of improvement (December 2017) was calculated assuming the average life expectancy at birth for each individual (ranging from 35.2 for anyone born prior to 1961 to 70.3 years for someone born in 2017, based on World Bank data (World Development Indicators database) minus years of life already lived (their age) as of 2017.

These calculations attribute 100% of the claimed DALYs averted to I2C even though some expenditures (like the donated wheelchairs) which contributed to averting these DALYs have been excluded from the expenditure calculations.

### **2.1.3.3 Extrapolation of findings to non-sampled VDCs**

We extrapolated findings from the sampled VDCs to non-sampled VDCs as follows: average change in disability weight per person x average duration of benefits x estimated persons in non-sampled VDCs, based on average persons per VDC in sampled VDCs. This was done separately for batch 1 (using batch 1 results) and batch 2 (using batch 2 results). Batch 3 was based on batch 2 results.

### **2.1.3.4 Cost per DALY averted**

Cost per DALY averted is calculated as follows:

$$\text{Cost per DALY averted} = \frac{\text{Total intervention cost until December 2017}}{\text{DALYs averted until December 2017}}$$

The cost per DALY averted of the I2C program and other health programs can then be compared. The one with a lower cost per DALY averted is said to be more cost-effective, since that means it costs less to "gain back" health in that scenario than the comparator. In other words, you can "gain" more health with less money.

### **2.1.3.5 Cost-effectiveness of replication**

We estimated the cost-effectiveness of replication by considering 24 months of prototype village expenditures and assuming the average number of DALYs averted per person from batch 2 and 1,300 persons with a disability.

### **2.1.3.6 Limitations of cost-effectiveness analysis**

There are a number of limitations related to the assessment. To start, we have only included Karuna and HFOMC expenditures (see section on excluded expenditures); there are other financial and non-financial costs of the program including donated wheelchairs, donated time of member of HFOMC and former VDC etc. that are not included. Likewise, some treatment support costs were borne by families, and the countless caretaking hours of

family members are also notable. These contributions also are not accounted for. On the other hand, it is reasonable to assume any replication of the program (for example, by the Government of Nepal) would also rely on these donated items and family contributions as well.

We have only captured gains in health status; prevented deterioration in health status from conditions such as cerebral palsy or muscular dystrophy which are treated with physiotherapy is not captured. These cases have been scored “no improvement” since no reduction in functional limitation is seen, though further deterioration is prevented. Where there was indication that livelihood status is accompanied by improved social integration in the form of communication and interaction skills, etc., we scored according to the communication and interaction skills. Please also refer to the section on the DALY for a discussion of its limitations.

Additionally, this assessment attributes 100% of the claimed DALYs averted to I2C even though some expenditures (like the donated wheelchairs) which contributed to averting these DALYs have been excluded from the expenditure calculations because of the program/implementer perspective of the evaluation. The report assumes the wheelchair likely wouldn't have been donated without I2C. Although the direct expenses of the wheel chair have not been included, the coordination cost which has resulted in getting these wheelchairs has been included. The assessment did not compare results in the I2C VDCs with non-I2C VDCs, making it impossible to make claims about attribution. There are likely many confounders which are also contributing to the results noted.

Our assessment of improvement scores and starting disability weights is only as good as the data provided by Karuna field staff. Though we sent all scoring files back to the field for review and confirmation, there may be some variation in quality of reporting between VDCs which we couldn't account for. It is also possible that some VDCs not sampled had very different results; this may be the case for VDCs with a high number of surgeries, for example.

The assessment focuses only on the period through December 2017; predictions about expenditures and DALYs averted cannot be made for the remaining years of the program. The majority of expenses occur in the early years of the program, and we believe that the majority of DALYs averted also occur during this time period. Nonetheless, cost-effectiveness results may vary when considering the entire five or four and a half years of implementation. Another assessment could be done at the conclusion of the program, at which time expenditures and DALYs averted for the full program duration will be known.

Likewise, this assessment cannot anticipate DALYs averted after five years, nor expected expenditures or long-term care needs of individuals beyond the assessed period.

#### **2.1.4 Prevention evidence review**

The terms of reference called for a revision of Karuna Foundation Netherlands's prevention of birth defects and disability calculation tool. Developed for internal use in 2011 by the then Senior Program manager of Karuna Foundation, the original “prevention calculation tool” was an Excel sheet and methodology to estimate the number of prevented birth defects that could be attributed to Karuna's interventions. The assumptions behind the Excel sheet calculations are based on some published data (from the Government Health Management Information System data collected during the Training of Professionals program developed and implemented by Karuna, which was carried out in 150 villages in Kavre district and Sunsari districts) and expert opinion.

It was envisioned that the consultants would look critically at the relevance of the current tool as opposed to newer approaches/ideas that might be useful, and also examine the treatment of confounders as well as the underlying data of the tool to see if new published data is available. If deemed feasible, the updated literature would be used to revise the tool and methodology. The original TORs for the prevention tool can be found in Annex 2.

A consultant was hired by Karuna Foundation Nepal to conduct the literature search according to the ToRs. After reviewing the literature search results, the team concluded that there were inadequate evidences to update the prevention tool and attribute prevention of birth defects to existing I2C interventions. Consequently, it was decided to revise the original goal of the literature search, from updating the prevention tool to finding evidence-based, antenatal and delivery care interventions that prevent birth defects and/or promote maternal and child health. The literature review methodology for the revised study is elaborated below.

#### **2.1.4.1 Literature review methodology**

This section contains the methodology that was used for establishing the relationship between antenatal maternal health interventions and birth outcomes i.e. positive or adverse including low birth weight, preterm babies, small for gestational age, congenital defects, etc. Literature was searched in various steps for various purposes, as noted in Table 3.

**Table 3 Details of search strategies used**

<b>Purpose</b>	<b>Search strategy</b>
1. To establish the relationship between different interventions and birth defects	Medline search from 2 April 2018 to 22 May 2018 using a detailed search strategy (see Annex 10 – Literature review search strategy), established in consultation with Karuna Foundation Netherlands and an external expert
2. To establish the relationship between maternal intervention and DALY averted (for analysis of DALYs averted as a result of Karuna's preventive efforts)	Same Medline search from purpose 1 above as it also looked at the relationship between maternal interventions and DALYs averted
3. To establish the relationship between maternal interventions and birth outcomes	<p>Review of:</p> <ul style="list-style-type: none"> <li>- WHO recommendation on antenatal care for a positive pregnancy experience (2016), a comprehensive compilation of evidence from multiple meta analyses and literature reviews. It includes different pregnancy outcomes based on individual ANC interventions.</li> <li>- Additional WHO proceedings from the 63<sup>rd</sup> World Health Assembly to explore any additional interventions that were related to prevention of birth defects.</li> </ul> <p>Further search was done as other leads came up without adequate information in the document: Iodine, Warfarin, Anti-epileptic drugs, Advanced Maternal Age</p>

Finally, all evidence was reviewed in light of the current package of I2C interventions. The team made recommendations for strengthening Karuna's impact on prevention of birth defects via different maternal health interventions.

#### **2.1.4.2 HMIS**

HMIS data from fiscal years 2070/71 (mid-August 2013/mid-August 2014) up to 2074/75 (mid-August 2017 to mid-August 2018) was analyzed to compare the trend of change in maternal interventions, particularly those that contribute to prevention of birth defects, and promotion of maternal health before and after introduction of Inspire to Care (I2C) program in Ilam district. To attribute the changes observed in the interventions, VDCs without I2C program were established as a comparison group.

Target population for the fiscal year 2074/75 (2017/18) were extrapolated based on the trend observation of the fiscal year 2072/73 and 2073/74. This was done because some of the previous VDCs had been restructured into Rural Municipalities), as a result of restructuring process in Nepal and hence, extrapolation allowed compatibility. The data was received from District Public Health Offices and triangulation was not possible given a lack of data and the quality of data received from the District Public Health Office.

For a summary of the HMIS data analyzed, please see Annex 11 – Sample HMIS data analysis sheet.

#### **2.1.4.3 Prevention of birth defects data**

Information on children with birth defect in Ilam district was collected for comparison of the number of birth defects reported/ observed before and after the implementation of I2C program. A list of such children was collected for 2 years before and after I2C program. From list of children with disabilities provided by Karuna Foundation Nepal, individuals were classified according to whether they were conceived pre-I2C or after I2C had started.

## 3 Results and Discussion

### 3.1 Cost-effectiveness

#### 3.1.1 Total expenditure

The below tables present the annualized I2C expenditure (CBR only), by year and contributor, for batch 1 (Table 4), batch 2 (Table 5) and batches 1 and 2 combined (Table 6). All expenditures are in euros of the year in which they were originally incurred.

The results show that expenditures are lower in batch 2 compared to batch 1, reflecting both an expensive baseline done in batch 1 that was not repeated for batch 2, as well as an effort to streamline expenses during batch 2 by reducing staff and eliminating activities that were not producing results. In addition to eliminating some activities that were not producing results between batches 1 and 2, a child protection component was added in batch 2. Finally, administrative costs incurred after the start of batch 2 were divided between all implementing VDCs (batch 1 and batch 2), meaning a lower cost per VDC in batch 2 as compared with batch 1.

**Table 4 Total I2C expenditures by year and contributor – batch 1**

	January-December 2014	January-December 2015	January-December 2016	January-December 2017	TOTAL January 2014-December 2017
Karuna Nepal	€ 6,131	€ 74,916	€ 113,876	€ 96,570	€ 291,494 (68%)
Karuna Netherlands	€ 6,376	€ 21,164	€ 29,781	€ 35,345	€ 92,666 (22%)
VDCs	€ 0	€ 4,656	€ 20,757	€ 22,403	€ 47,815 (11%)
<b>TOTAL EXPENDITURE Batch 1</b>	<b>€ 12,507</b>	<b>€ 100,736</b>	<b>€ 164,414</b>	<b>€ 154,317</b>	<b>€ 431,975 (100%)</b>

**Table 5 Total I2C expenditures by year and contributor – batch 2**

	January-December 2014	January-December 2015	January-December 2016	January-December 2017	TOTAL January 2014-December 2017
Karuna Nepal	€ 2,625	€ 19,411	€ 98,915	€ 127,871	€ 248,822 (81%)
Karuna Netherlands	€ 2,730	€ 2,730	€ 7,901	€ 12,416	€ 25,777 (8%)
VDCs	€ 0	€ 0	€ 10,513	€ 23,221	€ 33,734 (11%)
<b>TOTAL EXPENDITURE Batch 2</b>	<b>€ 5,355</b>	<b>€ 22,141</b>	<b>€ 117,328</b>	<b>€ 163,508</b>	<b>€ 308,333 (100%)</b>



**Table 6 Total I2C expenditures by year and contributor – batches 1 and 2**

	January- December 2014	January- December 2015	January- December 2016	January- December 2017	<b>TOTAL January 2014- December 2017 (%)</b>
Karuna Nepal	€ 8,757	€ 94,328	€ 212,792	€ 224,441	<b>€ 540,316 (73%)</b>
Karuna Netherlands	€ 9,106	€ 23,894	€ 37,682	€ 47,761	<b>€ 118,443 (16%)</b>
VDCs	€ 0	€ 4,656	€ 31,269	€ 45,624	<b>€ 81,549 (11%)</b>
<b>TOTAL EXPENDITURE Batch 1 &amp; 2</b>	<b>€ 17,863</b>	<b>€ 122,877</b>	<b>€ 281,743</b>	<b>€ 317,825</b>	<b>€ 740,308 (100%)</b>

VDC contributions are strong, with some reserves being stored for when Karuna cost sharing ends and the community is entirely responsible for the program's finances.

### 3.1.2 DALYs averted

The following tables show the DALYs averted findings for batch 1 (Table 7), batch 2 (Table 8) and batches 1 and 2 combined (Table 9). Results are presented separately for children, adults and then as a combined total. In both batches, children start out with a higher average disability weight per person, show more improvement (both in terms of the assessment improvement score and change in disability weight) and have a greater number of DALYs averted. In sum, children improve more than adults. This could be due to the longer possible duration of benefits, since their remaining lifetimes are longer and increased possibilities for treatment and/or rehabilitation given their young age, both from having had less treatment and/or rehabilitation to date and given a possibly increased openness to intervention given their younger age. It may also be driven by the higher average starting disability weight per person, meaning they have more improvement to make.

The higher number of DALYs averted in batch 2 may be attributed to the higher quality CBR facilitators hired for batch 2 and the higher number of outlier villages in batch 1.

Some differences may also be the result of differences in the interventions implemented in batch 1 and batch 2.

**Table 7 DALYs averted – batch 1**

	Number of persons (%)	Average improvement score per person	Average starting disability weight per person (2004 weights)	Average starting disability weight per person (2016 weights)	Average change in disability weight per person (2004 weights)	Average change in disability weight per person (2016 weights)	Average DALYs averted per person (2004 weights)	Average DALYs averted per person (2016 weights)
Children	47 (21%)	1.47	0.33	0.17	0.12	0.05	3.20	0.87
Adults	172 (79%)	1.01	0.31	0.13	0.09	0.04	0.72	0.44
<b>TOTAL</b>	<b>219 (100%)</b>	<b>1.11</b>	<b>0.31</b>	<b>0.14</b>	<b>0.10</b>	<b>0.04</b>	<b>1.25</b>	<b>0.53</b>

Table 8 DALYs averted – batch 2

	Number of persons (%)	Average improvement score per person	Average starting disability weight per person (2004 weights)	Average starting disability weight per person (2016 weights)	Average change in disability weight per person (2004 weights)	Average change in disability weight per person (2016 weights)	Average DALYs averted per person (2004 weights)	Average DALYs averted per person (2016 weights)
Children	76 (19%)	1.80	0.33	0.17	0.13	0.06	3.38	1.47
Adults	319 (81%)	1.27	0.28	0.14	0.09	0.04	0.78	0.41
<b>TOTAL</b>	<b>395 (100%)</b>	<b>1.37</b>	<b>0.29</b>	<b>0.15</b>	<b>0.10</b>	<b>0.04</b>	<b>1.28</b>	<b>0.61</b>

Table 9 DALYs averted – batches 1 and 2

	Number of persons (%)	Average improvement score per person	Average starting disability weight per person (2004 weights)	Average starting disability weight per person (2016 weights)	Average change in disability weight per person (2004 weights)	Average change in disability weight per person (2016 weights)	Average DALYs averted per person (2004 weights)	Average DALYs averted per person (2016 weights)
Children	123 (20%)	1.67	0.33	0.17	0.13	0.05	3.31	1.24
Adults	491 (80%)	1.18	0.29	0.14	0.09	0.04	0.76	0.42
<b>TOTAL</b>	<b>614 (100%)</b>	<b>1.28</b>	<b>0.30</b>	<b>0.14</b>	<b>0.10</b>	<b>0.04</b>	<b>1.27</b>	<b>0.58</b>

### 3.1.3 Cost-effectiveness of I2C implementation to date

Table 10 presents cost-effectiveness findings (in euros) for batches 1 and 2.

Table 10 Cost-effectiveness findings – batches 1 and 2

	Batch 1		Batch 2		TOTAL	
	2004 weights	2016 weights	2004 weights	2016 weights	2004 weights	2016 weights
Total I2C expenditure (all sources) (EUR)	431,975	431,975	308,333	308,333	740,308	740,308
Estimated DALYs averted	748	323	1,178	555	1,926	878
<i>Cost per DALY averted (EUR)</i>	577	1,336	262	556	384	843

### 3.1.4 Cost-effectiveness of I2C batch 3

Table 11 presents anticipated cost-effectiveness findings (in euros) for batch 3, based on actual and planned expenditures and expected results, both for a 24-month period. However, given changes to the program introduced at the start of batch 3 and the possibility for differences in both expenditures as well as DALYs averted, actual results may vary.

**Table 11 Anticipated cost-effectiveness of batch 3**

	2004 weights	2016 weights
Total I2C expenditure (all sources)* (EUR)	464,127	464,127
Estimated DALYs averted**	1,440	670
<i>Cost per DALY averted (EUR)</i>	322	693

\* 24 months of implementation; based on actual expenditures to-date and planned future expenditures

\*\* Based on batch 2 results

### 3.1.5 Cost-effectiveness of I2C scaling in Ilam district

It is hard to predict the cost-effectiveness of I2C as implemented during the current scaling phase in Ilam district. On the one hand there is evidence of falling costs from batch 1 to batch 2 and further cuts to the replication budget, as well as better results in terms of DALYs averted. Normally at higher volumes cost per capita also falls. On the other hand, increased partners in the investors' consortium may cause administrative costs to rise. Additionally, changes have already been made and will still be made to the design of the program itself, which may have an impact on both expenditures as well as results.

Using the prototype village, annualized preparation expenses and 24 months of implementation, we can expect direct expenditures incurred by Karuna Foundation Nepal to be EUR 98,076. Note that this excludes administrative expenditures which are shared across all batches in current implementation. The CBR-related share of these direct program expenditures would be EUR 58,846. Based on batch 2 average DALYs averted per person results and 1,300 individuals identified with a disability, we can expect 1,668 and 799 DALYs averted, based on the 2004 and 2016 weights, respectively. This would result in a direct program cost per DALY averted of EUR 35 and 73, including only Karuna Foundation Nepal direct program expenditures.

Adding in the CBR-share of expected community contributions brings total expenditures to EUR 85,784. This will bring the cost per DALY averted to EUR 51 and 107, based on the 2004 and 2016 weights, respectively. This would likely be a significant improvement in cost-effectiveness as compared to batch 1 and batch 2, even once a share of administrative expenditures and Karuna Foundation Netherlands expenditures are added in.

It is also important to note that the overall I2C cost-effectiveness, looking at both the CBR program and the prevention component, may differ from the cost-effectiveness of CBR component only.

### 3.1.6 Comparison of findings

#### 3.1.6.1 Comparison with pilot

Comparing Ilam batch 1 and 2 findings with the pilot implemented in Sunsari and Rasuwa, we see lower performance in the scale-up as compared to the pilot, and a higher cost per DALY averted (Table 12). There are numerous possible explanations for this. Between the pilot and scale-up, there were numerous changes made to the program both in terms of design (inclusion of adults, for example, who show fewer DALYs averted than children, and changes to interventions offered) and organization (the scale-up was initially implemented by a consortium, presumably incurring higher costs than implementation by a single organization). For these reasons, batch 1 could still be considered a pilot as compared with batch 2, meaning costs and results are not representative. Other reasons for lower performance of batch 1 as compared with batch 2 are also applicable here.

Additionally, while all efforts were made to use the same assessment methodology between the pilot and scale-up, there were some minor differences: persons who died or moved were excluded from the pilot assessment but included in this assessment, and we performed more thorough scoring in this assessment as compared to the pilot. We tested the impact of these differences on scoring by rescoring one pilot VDC using the methodology from Ilam. This resulted in slight changes to the results (pilot scoring versus the revised pilot scoring using this assessment's slightly more rigorous methodology), but it is impossible to know if that alone explains the difference without rescoring all pilot VDCs.

**Table 12 Comparison of findings: pilot vs Ilam**

Areas of comparison	Pilot phase (Rasuwa and Sunsari)	Scale-up phase (Ilam)	Possible explanation
Number of VDCs	7	10	
Number of children with disability assessed	248	123	
Average improvement score per person	1.82	1.67	
Average starting disability weight per person	0.22	0.33	Slightly different use of baseline codes (more use of motor-related baseline conditions in Ilam, use of up to three baseline disability codes per person, etc.)
Average change in disability weight per person	0.10	0.13	Due to higher starting disability weight per person in scale-up, the change in disability weight/person is also higher
Average DALYs averted per person	3.67	3.31	Slight methodology difference for starting disability weight per person and by the low performing/ outlier VDCs in scale-up

### 3.1.6.2 Comparison with other available evidence: Nepal and internationally

The cost per DALY averted is compared with other available evidence, including cost per DALY averted under the pilot program, Nepal Health Sector Programme (NHSP) I and II, and other programs, as seen in Table 13. It is likely the methodology used to assess the cost per DALY averted in the listed programs is not identical to the methodology used in this assessment, e.g. different types of expenditures may be included or excluded, different disability weights used, etc. Costs were assessed in different years and have not been adjusted to 2017 levels; see the comments column for more details where they are available. Therefore, these comparisons are for benchmarking purposes only and should not be seen as direct comparisons.

**Table 13 Comparison of findings**

Category	Program	Cost per DALY averted*
I2C pilot	I2C, all expenditure	197 euros
I2C Ilam (batch 1 & 2)	I2C, all expenditure	262-1,336 euros**
NHSP	NHSP-I (2005-2010)	120 euros
	NHSP-II (2010-2015)	123 euros
	NHSP-III (2015-2020)	Unknown
Chagas disease	Vector control, developing countries (Jamison et al, 2006)	US\$260
	Treatment of children under 5, developing countries (Jamison et al, 2006)	US\$100
HIV and TB	Preventing and treating coinfection (HIV) with tuberculosis, developing countries (Jamison et al, 2006)	US\$120
	BCG vaccination, developing countries (Jamison et al, 2006)	US\$40-170
Leprosy	Leprosy patients in generic setting (Remme, 2006, cited in van Veen et al, February 2009)	US\$7-110
	Leprosy case detection and treatment (Jamison et al, 2006)	US\$38
	Prevention of leprosy disability, generic estimate (Jamison et al, 2006)	US\$1-110
Malaria	Malaria intermittent prevention treatment in infants (IPTi) in Mozambique and Tanzania (Hutton et al, 2009)	US\$4-11
Maternal and child health	Promoting exclusive breastfeeding, measles immunization, ORT, and hygiene, developing countries (Jamison et al, 2006)	Less than US\$5
	Packages to improve the coverage and/or quality of routine maternal care (including nutritional supplementation), Sub-Saharan Africa and South Asia (Jamison et al, 2006)	US\$77-150
Water, sanitation and hygiene	Promoting better sanitation through public policy, developing countries (Jamison et al, 2006)	US\$11
	Investing in and maintaining hand pumps for water, developing countries (Jamison et al, 2006)	US\$94
	House connections for potable water, developing countries (Jamison et al, 2006)	US\$223
	Construction and promotion of basic sanitation facilities, developing countries (Jamison et al, 2006)	More than US\$270

\* Only I2C pilot findings and NHSP have been brought to 2017 euros; the rest of the comparators are presented in original year and currency.

\*\* Range depending on batch and disability weight (2004 and 2016); refer to Table 10.

Additionally, it should be noted many of the cost per DALY estimates are for prevention interventions, which are usually more cost-effective than treatment interventions like the part of the I2C program that was assessed (Partnership for Prevention, no date).

The cost per DALY of I2C is best compared against interventions being implemented by the government in Nepal, as this gives an indication of what the government is able to afford. Cost per DALY averted findings from NHSP-I and II indicate I2C is less cost-effective than interventions implemented under NHSP. However, the NHSP cost per DALY averted is an average of all interventions in the basic package, composed of both very cost-effective prevention interventions which might only be cents per DALY averted, and interventions with a cost per DALY averted much higher than the average. Based on this, the I2C findings likely put the intervention within reach of government.

Previously, WHO suggested comparing cost per DALY averted with a country’s GDP to assess cost-effectiveness. A program or intervention was considered highly cost-effective if the cost per DALY averted fell below the country’s GDP per capita, cost-effective if cost per DALY averted was between one and three times GDP per capita, and not cost-effective if cost per DALY averted was more than three times GDP per capita. Using these metrics, the pilot was found to be highly cost-effective. However, recent consensus is that these types of generic thresholds may not be useful, and results should be considered in the context of each individual situation, as done above (Bertram et al, 2016; Robinson et al, 2017; Leech et al, 2018).

It is not possible to accurately estimate the cost-effectiveness of the entire five-year I2C scaling program in Ilam district as both expenditures and benefits during years to come are not known. In the absence of this information, data from pilot implementation could be used, or I2C Ilam reassessed once actual expenditures and benefits for the full duration of the program are known, for example at the conclusion of batch 1.

### 3.2 Prevention

#### 3.2.1 Literature review

##### 3.2.1.1 Search results

Search results are noted in Table 14, by purpose.

**Table 14 Search results**

Purpose	Search results	Included in study	Details
To establish the relationship between different interventions and birth defects	63	16	Mostly on use of iron and folic acid for the prevention of birth defects, mainly neural tube defects
To establish the relationship between maternal intervention and DALY averted (for analysis of DALYs averted as a result of Karuna’s preventive efforts)			
To establish the relationship between maternal interventions and birth outcomes	WHO meta-analysis <sup>1</sup> , WHO	7 additional articles	

	report <sup>2</sup> and further literature search		
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<sup>1</sup> WHO Recommendation on antenatal care for a positive pregnancy experience (2016)

<sup>2</sup> Birth Defects, World Health Organization - Sixty-third World Health Assembly. Geneva (CH): WHO, 2010

See also Annex 10 – Literature review search strategy for more information on the search results.

### **3.2.1.2 Interventions which prevent birth defects**

Birth defects can be defined as structural or functional abnormalities, including metabolic disorders, which are present from birth<sup>20</sup>. Birth can be caused by single gene defects, chromosomal disorders, multifactorial inheritance, environmental teratogens and micronutrient deficiencies. Maternal illnesses like syphilis, rubella, diabetes mellitus, conditions such as iodine and folic acid deficiency, and exposure to medicines (warfarin, antiepileptic) and certain environmental chemicals, and high doses of radiation are also factors that cause birth defects.

Interventions to prevent birth defects can be targeted at three times:

1. Before conception
2. During pregnancy
3. During child care after birth

Preconception care interventions are targeted at ensuring optimal physical and mental well-being of women and their partners at the onset of and during early pregnancy, to increase the likelihood of a healthy pregnancy and the delivery of a healthy infant. Prevention during pregnancy requires balanced diet and optimal mental health throughout pregnancy and risk identification and management. Newborn infant and child care interventions are aimed at screening and early treatment and rehabilitation interventions for newborns, infant and children. Factors associated with birth defects and prevention interventions at each target point are summarized in Table 15.

<sup>20</sup> Management of birth defects and haemoglobin disorders: report of a joint WHO–March of Dimes meeting, Geneva, Switzerland, 17–19 May 2006. Geneva, World Health Organization, 2006.

**Table 15 Prevention of birth defects in preconception, pregnancy and post-pregnancy**

1. Preconception care	2. Pregnancy care	3. Newborn infant and child care
<p>1a. Family planning:</p> <ul style="list-style-type: none"> <li>Advanced maternal age increases the risk of birth prevalence with autosomal trisomies, particularly Down syndrome</li> <li>Family history with birth defect</li> </ul> <p>1b. Preconception screening and counselling:</p> <ul style="list-style-type: none"> <li>Identify individuals at risk of having affected children</li> <li>Carrier screening for common recessive disorders (e.g. thalassaemia and sickle cell disorders)</li> <li>Women's diet before and throughout pregnancy</li> <li>Use salt fortified with iodine to prevent iodine deficiency disorder – one of the major causes of preventable mental impairment</li> <li>Folic acid before and during pregnancy to prevent neural tube defects and other malformations</li> <li>Preventing and treating teratogen-induced infections before and throughout pregnancy – e.g. syphilis, rubella</li> </ul> <p>1c. Optimize preconception maternal health and treatment for:</p> <ul style="list-style-type: none"> <li>Insulin-dependent diabetics</li> <li>Women on treatment for epilepsy</li> <li>Women on treatment with warfarin</li> </ul>	<p>2a. Nutritional care:</p> <ul style="list-style-type: none"> <li>Balanced adequate diet (e.g. protein, calories, iron, etc.)</li> <li>Iron and folic acid to prevent neural tube defect</li> <li>Iodine to prevent developmental delays and mental impairment</li> <li>Avoid alcohol, tobacco and cocaine</li> </ul> <p>2b. Antenatal screening for:</p> <ul style="list-style-type: none"> <li>Rhesus status, Syphilis, Down syndrome (advanced maternal age; maternal serum screening; early ultrasound scanning)</li> <li>Major malformations (ultrasound fetal anomaly scanning (18+ weeks gestation)</li> <li>Carriers of common recessive disorders (e.g. thalassaemia and sickle cell disorders)</li> </ul> <p>2c. Fetal treatment for:</p> <ul style="list-style-type: none"> <li>Syphilis</li> <li>Fetal anaemia with intrauterine transfusion</li> </ul> <p>2d. Antenatal preventive measures, such as:</p> <ul style="list-style-type: none"> <li>Preventive antihelminthic treatment</li> <li>Antenatal anti-D immunoglobulin administration</li> <li>TT vaccination</li> <li>Rubella vaccination</li> <li>Iodine</li> </ul>	<p>3a. Newborn infant examination by trained examiner to detect birth defects</p> <p>3b. If birth defects found, medical treatment, for example:</p> <ul style="list-style-type: none"> <li>Neonatal jaundice in glucose-phosphate dehydrogenase deficiency and Rhesus incompatibility</li> <li>Treatment and care for children with blood disorders such as sickle-cell disorder, thalassaemia, etc.</li> <li>Treatment of some inborn errors of metabolism</li> <li>Care of children with cystic fibrosis</li> </ul> <p>3c. If birth defects found, corrective surgery, for example:</p> <ul style="list-style-type: none"> <li>Simple congenital heart defects</li> <li>Cleft lip and palate</li> <li>Club foot</li> <li>Congenital cataracts</li> </ul> <p>3d. If birth defects found, rehabilitation and palliative care utilizing WHO CBR Matrix or as appropriate</p>

Source: adapted from Birth Defects, World Health Organization - Sixty-third World Health Assembly. Geneva: WHO, 2010.



**Error! Reference source not found.** outlines the detailed, evidence-based, recommended interventions that fall under preconception and pregnancy and the maternal, fetal and neonatal outcomes they are linked with. We then compare the recommended interventions against Karuna’s existing I2C interventions and make recommendations for changes to I2C offerings based on the comparison between the recommended interventions and the current I2C offerings. Please note that not all listed recommended interventions might be feasible or appropriate for Nepal; feasibility in Nepal is, however, taken into consideration in the recommendations column. We have included both recommendations that require Karuna Foundation Nepal to work with healthcare facilities (for example, to provide interventions to ensure preconception and newborn infant and child care at facility level), while other recommendations can be implemented directly by Karuna Foundation Nepal (such as some of the pregnancy care interventions, where Karuna Foundation Nepal has existing interventions to reach and influence decision making).

The table does not address newborn infant and child care, as it is assumed these interventions are covered by Karuna’s assessment camp.

**Table 16 Prevention interventions and recommendations from the literature review**

	Intervention	Recommended Intervention	Maternal Outcomes	Fetal and Neonatal Outcomes	Karuna's Existing Intervention	Recommendations
<b>1a. PRECONCEPTION CARE – FAMILY PLANNING</b>						
1.	Family planning counseling	Family planning counseling to married women of reproductive age		Reduces the risk of birth prevalence with autosomal trisomie, particularly Down's syndrome	Best Wishes card is provided to newly married couple which also includes information on family planning	Target married women, newly married couple for family planning counseling (balanced counseling preferably). Offer family planning information to allow women to make informed choices
<b>1b. PRECONCEPTION CARE – PRECONCEPTION SCREENING AND COUNSELLING</b>						
1	Daily iron and folic acid supplements <sup>3-5,7,10,11,13,15,17,19,20,27</sup>	Daily oral iron and folic acid supplementation of 30-60 mg elemental iron and 400 µg (0.4 mg) folic acid for pregnant women; should be commenced as early as possible	Reduces risk of maternal anemia at term and postpartum, puerperal sepsis <sup>a</sup>	Prevents neural tube defects, pre-term birth (<34 weeks) and low birth weight	Pregnant women are encouraged to consume daily iron and folic acid tablets from second trimester; pregnant women are linked to public health facilities which provide daily iron and folic acid tablets. In addition, planning underway to distribute folic acid to newly married couple	Target married couple who are planning for children in future for counseling to consume folic acid before conception
<b>1c. PRECONCEPTION CARE – PRECONCEPTION MATERNAL HEALTH AND TREATMENT</b>						
1	Preconception maternal health and treatment for insulin-dependent diabetics, women on treatment for epilepsy and women being treated with warfarin	No specifically recommended interventions	N/A	N/A	N/A	N/A

	Intervention	Recommended Intervention	Maternal Outcomes	Fetal and Neonatal Outcomes	Karuna's Existing Intervention	Recommendations
2a. PREGNANCY CARE – NUTRITIONAL CARE						
1	Daily iron and folic acid supplements <sup>3-5,7,10,11,13,15,17,19,20,27</sup>	Daily oral iron and folic acid supplementation of 30-60 mg elemental iron and 400 µg (0.4 mg) folic acid for pregnant women; should be commenced as early as possible (ideally before conception)	Reduces risk of maternal anemia at term and postpartum, puerperal sepsis <sup>a</sup>	Prevents pre-term birth (<34 weeks) and low birth weight	Pregnant women are encouraged to consume daily iron and folic acid tablets from second trimester; pregnant women are linked to public health facilities which provide daily iron and folic acid tablets	Track consumption and trend of consumption of IFA among pregnant women.
2	Calcium Supplements <sup>27</sup>	In populations with low dietary calcium intake, daily calcium supplementation (1.5–2.0 g oral elemental calcium) should be taken by pregnant women	Reduces risk of pre-eclampsia <sup>d</sup>	Probably reduces preterm birth with high-dose calcium>1000mg	Pregnant women are encouraged to consume calcium tablets starting from second trimester (purchased at own cost as health facilities do not provide them)	Promote traditional diets of jwano and gundruk during lactation <sup>e</sup> . Consider providing pregnant women with calcium tablets
3	Vitamin A supplements <sup>27</sup>	In areas where vitamin A deficiency is a severe public health problem <sup>m</sup> , pregnant women should take Vitamin A supplementation to prevent night blindness	Vitamin A supplementation probably reduces maternal anaemia (in vitamin A deficient population) and maternal infection <sup>i,k</sup>	Neonatal infections and congenital anomalies were not reported in the trials assessed <sup>q</sup>	Post-partum vitamin A supplementation (single dose) provided by health facilities	Vitamin A supplementation <i>during pregnancy</i> is not a part of government's current public health program. Purchasing Vitamin A supplements might be out of reach for many pregnant women and families in Nepal and hence, local foods that are rich in Vitamin A should be a part of counseling for pregnant women
4	Zinc supplements <sup>27</sup>	Zinc supplementation should be taken by pregnant women in the context of rigorous research	May reduce preterm birth <sup>j</sup>	None <sup>r</sup>	None	Need further research before considering this intervention

	Intervention	Recommended Intervention	Maternal Outcomes	Fetal and Neonatal Outcomes	Karuna's Existing Intervention	Recommendations
5	Multiple micronutrient (MMN) supplements <sup>12,26,27</sup>	Multiple micronutrient supplementation is <b>NOT</b> recommended for pregnant women to improve maternal and perinatal outcomes	Reduced risk of maternal anaemia (similar effect to iron and folic acid supplementation)	Reduced risk of having a low birth weight neonate compared with iron and folic acid supplements only <sup>h</sup>	None	Continue to focus on balanced diet uptake <sup>p</sup>
6	Vitamin B6 (pyridoxine) supplements <sup>27</sup>	Vitamin B6 (pyridoxine) supplementation is <b>NOT</b> recommended for pregnant women to improve maternal and perinatal outcomes	No significant effects reported		None	None (supplementation not recommended)
7	Vitamin E and C supplements <sup>27</sup>	Vitamin E and C supplementation is <b>NOT</b> recommended for pregnant women to improve maternal and perinatal outcomes	No significant beneficial effects reported <sup>l</sup>		None	None (supplementation not recommended)
8	Vitamin D supplements <sup>27</sup>	Vitamin D supplementation is <b>NOT</b> recommended for pregnant women to improve maternal and perinatal outcomes due to the additional cost of the supplements and/or its unavailability in some places		May reduce low birth weight neonates and preterm birth (<37 weeks of gestation) <sup>g</sup>	None	Dietary counseling recommended but supplementation not recommended
9	Restricting caffeine intake <sup>27</sup>	For pregnant women with high daily caffeine intake (more than 300 mg per day), lowering daily caffeine intake during pregnancy should be done		Restricting high caffeine intake (more than 300 mg) probably reduces the risk of low birth weight and pregnancy loss i.e. still birth and miscarriage	None	Include in counseling package

	Intervention	Recommended Intervention	Maternal Outcomes	Fetal and Neonatal Outcomes	Karuna's Existing Intervention	Recommendations
10	Counselling on healthy diet and exercise <sup>27</sup>	Counselling about healthy eating and keeping physically active during pregnancy should be done to stay healthy and to prevent excessive weight gain during pregnancy	Mothers are healthy and do not gain excessive weight during their pregnancy	Diet and/or exercise interventions probably prevents neonatal macrosomia particularly in overweight and obese women receiving diet and exercise counselling interventions	One among many messages in Best Wishes card	Include in counseling package
11	Nutrition education on increase in daily energy and protein intake <sup>27</sup>	In undernourished populations <sup>a</sup> , nutrition education on increasing daily energy and protein intake should be done for pregnant women		Reduces the risk of low birth weight babies	None	Include in counseling package
12	Counselling on balanced energy and protein dietary supplementation <sup>27</sup>	In undernourished populations, balanced energy and protein dietary supplementation should be encouraged for pregnant women		Reduces the risk of stillbirths and small-for-gestational age (SGA) neonates	None	Include in counseling package
13	High protein supplementation <sup>27</sup>	In undernourished populations, high-protein supplementation is <b>NOT</b> recommended for pregnant women to improve maternal and perinatal outcomes		High-protein supplementation increases SGA neonates <sup>e</sup>	None	Include in counseling package; supplementation not recommended
<b>2b. PREGNANCY CARE – ANTENATAL SCREENING</b>						
1	Antenatal screening for Rhesus status, syphilis, Down syndrome, major malformations and carriers of common recessive disorders <sup>27</sup>	Antenatal prophylaxis with anti-D immunoglobulin in non-sensitized Rh-negative pregnant women at 28 and 34 weeks of gestation; see also items 1 and 3 under 2c and item 1 under 1a	Reduces incidence of RhD alloimmunization	None	None	Need further research before considering this intervention

Intervention	Recommended Intervention	Maternal Outcomes	Fetal and Neonatal Outcomes	Karuna's Existing Intervention	Recommendations
<b>2c. PREGNANCY CARE – FETAL ASSESSMENT</b>					
1      Ultrasound scan <sup>27</sup>	One ultrasound scan before 24 weeks of gestation (early ultrasound) should be done for pregnant women	Reduces induction of labor for post-term pregnancy and improve pregnancy experience	Early ultrasound scans help establish accurate gestational age and may increase detection of congenital anomalies and multiple pregnancies	Ultrasound scan is encouraged as standard component of ANC, though may not be available at all health posts (should be available at higher centers)	Continue existing intervention
2      Tobacco and substance use <sup>9,18,21,22</sup>	Health-care providers should ask all pregnant women about their tobacco and substance use (past and present) and exposure to second-hand smoke as early as possible in pregnancy and at every antenatal care visit		Cigarette smoking and alcohol use increases the risk of preterm birth; alcohol consumption of 12g/day or greater was positively associated with low birth weight	Best Wishes card incorporates messages on avoidance of alcohol and tobacco during pregnancy; health facilities should take histories and provide appropriate counselling	Continue existing interventions
3      Human immunodeficiency virus (HIV) and syphilis <sup>16,27</sup>	In high-prevalence settings, a provider-initiated testing and counselling (PITC) for HIV should be considered a routine component of the package of care for pregnancy women in all antenatal care settings. In low-prevalence settings, PITC can be considered for pregnant women in antenatal care settings		PITC for pregnant women helps in HIV/syphilis detection and reduces chances of mother to child transmission of HIV, syphilis and birth defects; along with reduced chances of early fetal loss/stillbirth, neonatal death, prematurity or low birth weight	Done by health facilities as part of government protocol	Support public health facilities to continue existing intervention
<b>2d. PREGNANCY CARE – ANTENATAL PREVENTIVE MEASURES</b>					
1      Preventive antihelminthic treatment <sup>27</sup>	In endemic areas, a preventive anthelmintic treatment (single-dose albendazole 400 mg or mebendazole 500 mg) should be taken by pregnant women after the first trimester as part of worm infection reduction programs	Prophylactic anthelmintic treatment in endemic areas may reduce severe maternal anaemia and result in fewer still births and perinatal deaths	Prophylactic anthelmintic treatment in endemic areas may reduce severe maternal anaemia and result in fewer still births and perinatal deaths	Anthelmintic treatment (albendazole) provided by health facilities during first antenatal checkup (4th month)	Continue existing intervention

Intervention	Recommended Intervention	Maternal Outcomes	Fetal and Neonatal Outcomes	Karuna's Existing Intervention	Recommendations
2	Antenatal anti-D immunoglobulin administration <sup>2,27</sup>	Antenatal prophylaxis with anti-D immunoglobulin in non-sensitized Rh-negative pregnant women at 28 and 34 weeks of gestation to prevent RhD alloimmunization is only recommended in the context of rigorous research <sup>f</sup>	No sufficient evidence could be established as alloimmunization and HDN is a rare event	Tertiary hospitals provide anti-D immunoglobulin to Rh negative mothers giving birth to Rh positive babies; in health posts with no such services, women are referred to other health facilities to receive such services	Continue existing intervention
3	Tetanus toxoid vaccination <sup>27</sup>	Tetanus toxoid vaccination is recommended for all pregnant women, depending on previous tetanus vaccination exposure	Fewer neonatal cases were observed among neonates whose mother receive TT vaccination; two of more doses of TT reduces neonatal mortality due to any cause and from tetanus	Best Wishes card encourages Td vaccination; pregnant women linked with health facility where they receive services	Continue existing intervention
4	Rubella vaccination <sup>1,6,8,23,25</sup>	Rubella vaccination is recommended to be included in immunization schedule (which it is in Nepal, for children ages 9 and 15 months); if not, it should be provided to women of reproductive age	Reduces occurrence of Congenital Rubella Syndrome, fetal death, miscarriages caused by mother to child transmission of rubella virus before 12 weeks of gestation	None	Verify that women have received rubella vaccination as children; if not, ensure they receive it as adults (not currently routinely done)
5	Iodine <sup>14,24</sup>	Daily consumption of salt fortified with iodine is a proven effective strategy for prevention of iodine deficiency disorders	Functional and developmental abnormalities such as brain damage and irreversible mental retardation	None <sup>o</sup>	Encourage consumption of salt fortified with iodine and ensure iodine-fortified salt available for purchase if not available in the program areas. Providing it directly to women free of charge or at cost could also be considered <sup>b</sup>

- <sup>a</sup> Found little or no effect on pre-eclampsia, antepartum and postpartum haemorrhage, maternal mortality, congenital anomalies and neonatal death
- <sup>b</sup> Iodine deficiency in pregnancy causes more than 200,000 babies a year to be born mentally impaired in Nepal. In Karuna's catchment areas, intellectual disabilities are one of the most common disabilities seen.
- <sup>c</sup> Moser et al found that locally available foods in Nepal which are traditionally encouraged for lactating women, including jwano and gundruk, were found to have high concentrations of Ca and Mg. Though diet patterns among pregnant women vary in Nepal and by region, exploring the local diet in program areas and promoting the encouraged traditional diets during lactation may be beneficial.
- <sup>d</sup> Found no important effects on maternal anaemia, Caesarean section and little or no effect on maternal mortality, preterm birth (<37 weeks) and LBW
- <sup>e</sup> Little or no effect on preterm birth, still birth and neonatal death
- <sup>f</sup> However, Anti-D immunoglobulin can be administered to Rh negative women giving birth to Rh positive baby within 782 hours to prevent alloimmunization and HDN (Hemolytic disease of the newborn) in subsequent pregnancy (also to avoid administering Anti-D immunoglobulin to all Rh negative women)
- <sup>g</sup> Low certainty evidence
- <sup>h</sup> MMN supplements have a harmful effect on neonatal mortality when compared to 60 mg iron and 400 µg folic acid supplementation
- <sup>i</sup> Miscarriage and teratogenicity have been associated with high vitamin A intake within 60 days of conception
- <sup>j</sup> Little or no effect on congenital anomaly, low birth weight SGA (Small for Gestational Age) babies
- <sup>k</sup> Found little or no effect on maternal mortality, perinatal mortality, neonatal mortality, stillbirths, low birth weight and preterm birth
- <sup>l</sup> Vitamin E and C supplementation is associated with an increased risk of abdominal pain during pregnancy
- <sup>m</sup> Unknown if vitamin A deficiency is a severe public health problem in I2C intervention areas, defined as 5% or more of women in a population having a history of night blindness in their most recent pregnancy in the previous 3–5 years that ended in a live birth, or 20% or more of pregnant women having a serum retinol level below 0.70 µmol/L
- <sup>n</sup> Seventeen percent of women age 15–49 years are thin (BMI<18.5); 11% are short (<145cm) (NDHS 2016). The Ministry of Health's 2015/16 annual report also notes that 18.2 percent of mothers suffering chronic energy deficiency
- <sup>o</sup> 95% of households are reported to use iodized salt as per NDHS 2016
- <sup>p</sup> Overall there was insufficient evidence to warrant a recommendation. More research is needed to determine which micronutrients improve maternal and perinatal outcomes, and how these can be optimally combined into a single supplement and thus, no additional recommendation specific to MMN made to Karuna at this time
- <sup>q</sup> Vitamin A supplementation makes little or no difference to perinatal mortality, neonatal mortality, stillbirths and probably has little or no effect on low birth weight, and preterm birth
- <sup>r</sup> Zinc supplementation probably makes little or no difference to the risk of having SGA (Small for Gestational Age). Zinc supplementation may have little or no effect on congenital anomalies and needs to be explored

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### 3.2.2 HMIS

The HMIS data analysis showed a decreasing trend of achievements for almost all indicators for both intervention and comparison group. Based on discussions between the Karuna team and the District Public Health Office, it is believed this is due to a problem with the target population in the most recent year, which didn't reflect the actual population. Although the District Health Public Office is reviewing the data, it is not expected that corrections will be made.

Hence, it was concluded that the HMIS analysis was not possible at this time. As an alternative, we attempted to use Medic Mobile data, a mHealth patient tracking system implemented in Ilam since mid-2016. Unfortunately, the Medic Mobile data was found not to track health service utilization according to the protocol of the Government of Nepal (ANC visits, etc.). Additionally, there were also data quality issues, as the data showed even less coverage than HMIS. Medic Mobile is currently revising indicators (with input from Karuna Foundation Nepal) which will more closely align them with government service protocols for the future; however, for this assessment the data cannot be used.

### 3.2.3 Birth defects

From the review of the list of persons reporting birth defects, the team identified one person from batch 1 born with a disability after I2C started, but they were likely conceived before I2C started. However, we found many issues with the data, which do not allow us to comfortably draw any conclusions from it. The issues include the possibility of confounders in the before-after design, small sample size (only 76 children were under the age of 8) and unreliable self-reporting, including the issue of whether the disability was in fact a birth defect or disability developed post-birth but identified as a birth defect.

As an alternate we looked into using data from a study by Family Health Division (now Family Welfare Division) on birth defects. However, Family Welfare Division indicated that the data generated by the study was not satisfactory enough.

## 4 Recommendations and conclusions

This consolidated list of recommendations coming from this research is organized by program aspect (CBR followed by prevention). Additionally, some recommendations related to the program replication are also noted in Table 17. The recommendations are aimed at:

- Introducing increased objectivity to assessment and progress tracking of individuals in the I2C program
- Improving ongoing performance management
- Saving front line workers' time, allowing them to focus more on care delivery
- Allowing for methodologically strong future research

Table 17 Recommendations

Component	Area	Recommendations
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CBR cost-effectiveness	Recruitment and retention	<ol style="list-style-type: none"> <li>1. Reconsider I2C recruitment strategies and/or efforts to prevent dropout: <ul style="list-style-type: none"> <li>- Community sensitization to manage expectations</li> <li>- Closer follow-up, family counselling to prevent dropout</li> </ul> </li> </ol>
	M&E	<ol style="list-style-type: none"> <li>2. Strengthen the recording/reporting system <ul style="list-style-type: none"> <li>- Use ICF classification (in line with disability weights) and improvement score criteria to record and report on individuals in I2C</li> <li>- Train CBR facilitators in objective assessment and reporting to bring uniformity in reporting of initial status and progress of individuals in I2C</li> <li>- Use digital tools and real time recording based on above principles, allowing for automatic calculation and analysis. Incorporate validation techniques such as drop-down menu for type of disability and its severity to maintain data quality and comparability</li> <li>- Standardize interval for reporting progress (e.g. every three months, every six months, etc.)</li> <li>- More regularly review VDC performance to identify and correct issues with implementation and progress of children and adults participating in I2C</li> </ul> </li> </ol>
	Performance	<ol style="list-style-type: none"> <li>3. Further investigate causes of poor performance in outlier VDCs and implement corrective actions</li> </ol>
Prevention component	M&E	<ol style="list-style-type: none"> <li>4. Generate high quality data needed to measure prevention impact <ul style="list-style-type: none"> <li>- Continue efforts to strengthen HMIS but the data likely cannot be relied on to measure I2C impact (unless year 74/75 data can be corrected)</li> <li>- Revise Medic Mobile tracking indicators to better align with service protocols and standard reporting (e.g. number of ANC visits, etc.)</li> <li>- Consider batch 1 mid-line or end-line study</li> <li>- Consider gold standard randomized control trials – would also allow for higher confidence on attribution</li> </ul> </li> </ol>
	Interventions	<ol style="list-style-type: none"> <li>5. Review evidence on prevention of birth defects and I2C interventions <ul style="list-style-type: none"> <li>- Consider removing interventions which are not evidence-based and for which there isn't anecdotal suggestion of effectiveness</li> <li>- Incorporate more evidence-driven interventions into I2C, including those targeted to neonates, infants and children</li> </ul> </li> </ol>
Replication	Prevention	<ol style="list-style-type: none"> <li>6. Take the necessary time to revise interventions based on evidence and the local context, and design a results matrix with M&amp;E plan that ensures the impact of the prevention component of the program can be assessed</li> </ol>

Longer-term outlooks for incorporation into the government system and sustainability through local systems are good from the perspective of cost-effectiveness and financial sustainability, in that the program is designed to be sustainable and shows evidence in batches 1 and 2 of being so. Additionally, planned changes to the program for the replication strengthen sustainability even further. Changes to both the prevention and CBR components, and their M&E, should ensure strong evidence on cost-effectiveness of I2C is available for future advocacy efforts.

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# Annexes

## ***Annex 1 – Proposal***

Proposal for updating the prevention tool and conducting cost-effectiveness analyses

Kelsey Vaughan and Aradhana Thapa

27 February 2018

### Background

Since 2011, Karuna Foundation Nepal is implementing a disability prevention and rehabilitation program, previously known as Prevention and Rehabilitation (P&R) and later in 2014 renamed Inspire2Care (I2C), in Nepal. I2C includes both prevention-related activities (largely in collaboration with local health facilities through the Best Wishes Programme<sup>21</sup>, along with other support for preventing disabilities) and community rehabilitation of children and adults with disability using WHO's 5 x 5 matrix to develop and execute individualized rehabilitation plans. The rehabilitation component of the pilot I2C programme, implemented in four villages in Rasuwa district and three villages in Sunsari district, was evaluated previously by this team of evaluators (see evaluation report and publication<sup>22,23</sup>). This evaluation was commissioned by Liliane Foundation and Netherlands Leprosy Relief (NLR).

In 2014 Karuna Nepal initiated the scaling up of I2C to 56 villages in three phases. The first phase (known as batch 1) started in 2015 in 12 villages in Ilam and 3 villages in Jhapa (by NLR). In April 2016 Karuna Nepal started in another 15 villages in Ilam and 1 in Jhapa (batch 2). The third phase (batch 3) is starting in January 2018 in 20 villages in Ilam. Different donors are direct partners of Karuna Nepal in these scaling up phases: Ineke Feitz Stichting (batch 1), UBS Optimus Foundation (batch 2), Stichting 't Bosje (batch 2) and Makoto Maki (batches 2 and 3).

At the request of the Inspire2Care Investors Consortium and Stichting 't Bosje, this document outlines a proposal for two pieces of work related to I2C:

3. Revision of Karuna Foundation Netherlands's prevention of birth defects and disability calculation tool
4. Assessment of cost-effectiveness of I2C implementation in Ilam only (Jhapa villages are excluded)
  - a. Ilam batch 1 (to-date implementation)
  - b. Ilam batch 2 (to-date implementation)
  - c. Ilam batch 3 (predicted)

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<sup>21</sup> Best Wishes program is mainly focused on increasing maternal and child health indicators including antenatal care (ANC) visits, institutional deliveries, post-natal care (PNC) visits, immunization coverage and nutritional status of mothers and children. Karuna Foundation Nepal's support for the programme stems from the belief that if these indicators improve, the chances of delivering a baby with a disability or who develops a disability in the first days of life will decrease. The Best Wishes programme includes marriage registration and counseling to newly married couples, pregnancy registration (now via mobile messaging), issuance of a Best Wishes card for tracking, awareness events, follow up of pregnant women on use of health services and institutional delivery, nutritional assessment of children, support to birthing centers by providing training, equipment and furniture and school health screening for early identification and treatment of disabilities (secondary prevention). In some cases, Karuna Foundation Nepal has also supported the construction of new buildings. Karuna Foundation Nepal also supports other prevention-related activities that may lead to better outcomes in Best Wishes, such as training health workers and improving growth monitoring.

<sup>22</sup> Vaughan, Kelsey (2015). Cost-effectiveness and efficiency assessment of the Inspire2Care program, 2011-2013. <http://www.karunafoundation.nl/download/Final%20report%20%20February%202015.pdf>

<sup>23</sup> Vaughan, Kelsey and Thapa, Aradhana (2015). Cost-effectiveness of a community-based rehabilitation programme in Nepal. Disability, CBR and Inclusive Development (DCID). Vol. 26, No.4. <http://dcidj.org/article/view/457/273>

d. Comparative analysis of pilot, batch 1, batch 2 and batch 3 and recommendations

The cost-effectiveness analyses would serve as input to work to be carried out ASAP by Effective Giving. In essence, the cost-effectiveness analyses outlined here answer the question, “is I2C cost-effective?”, whereas the work by Effective Giving will answer the question, “does I2C represent effective giving?”, according to the organization’s criteria for effective giving.

Details about each piece of work is outlined separately below.

1. Prevention tool

In 2011, Archana Shrestha, the then M&E manager of Karuna Foundation, developed for internal use a “prevention calculation tool”, an Excel sheet and methodology to estimate the number of prevented birth defects that could be attributed to Karuna’s interventions. The assumptions behind the Excel sheet calculations are based on some published data (from the Government Health Management Information System data collected during the Training of Professionals program developed and implemented by Karuna, which was carried out in 150 villages in Kavre district and Sunsari district) and expert opinion.

The consultants will look critically at the relevance of the current tool as opposed to newer approaches/ideas that might be useful, and also examine the treatment of confounders as well as the underlying data of the tool to see if new published data is available. Under the guidance of the consultants, a public health consultant to be hired by Karuna Foundation Nepal will assist the consultants with this review. If deemed feasible, the consultants will then guide Karuna Foundation Nepal in revising the tool and its methodology, in consultation with Karuna Foundation Netherlands and external advisors. Please see the annexed “Prevention tool TORs” for more information.

2. Cost-effectiveness

a. Cost-effectiveness of Ilam batch 1 implementation to-date

The cost-effectiveness of Ilam batch 1 implementation will be estimated for the period April 2015-December 2017. This will include both the prevention and rehabilitation-related components, using actual expenditures and results from the first 33 months. The prevention-related results will be estimated partially based on the updated prevention tool. See annex 1 for details of the proposed methodology.

b. Cost-effectiveness of Ilam batch 2 implementation to-date

The cost-effectiveness of Ilam batch 2 implementation will be estimated for the period April 2016-December 2017. Actual expenditures and results from the first 21 months will be used. The prevention-related results will be estimated partially based on the updated prevention tool.

c. Predicted cost-effectiveness of Ilam batch 3

Ilam batch 3 villages are preparing to introduce I2C in January 2018. A number of changes to the program have been made based on lessons learned from earlier batches, and the budget reduced in an effort to improve cost-effectiveness.

Based on the budget and targets/indicators that have been set for these villages, the consultants will predict the cost-effectiveness of I2C using the methodology previously used for CBR and a new proposed methodology for I2C's prevention component, based partially on the updated prevention tool. See annex 1 for details of the proposed methodology. This desk work will cover the full 4.5 years of batch 3 implementation.

d. Comparative analysis and recommendations

At the conclusion of the cost-effectiveness research, the consultants will produce a short summary report comparing the cost-effectiveness of the pilot implementation in Rasuwa and Sunsari (previously assessed, rehabilitation component only), batch 1, batch 2 (CBR only) and batch 3 (predicted). All expenditures will be brought to present value to allow for comparison. The analysis will also look at the program's comparative cost-effectiveness achieved through the prevention vs. rehabilitation components. The consultants will make concrete recommendations for strengthening I2C in future rollouts in Ilam, elsewhere in Nepal and internationally.

Deliverables

For the first work component (updated prevention tool), the draft and final tool will be submitted. For the cost-effectiveness components, a draft and final report will be submitted, organized by findings by batch. The comparative analysis will be included in this report.

Documents and assistance to be provided by Kaurna Foundation

- For prevention tool:
  - o Appointment of Karuna Foundation Nepal staff person to lead tool update (in consultation with consultants)
  - o Hiring of KFN consultant and email introduction to him/her
  - o Introduction to Hans Lohuis (independent consultant) & Remi Verduin (St t Bosje)
  - o Input on draft revisions
- For cost-effectiveness analyses:
  - o For all batches:
    - Contracting of KFN consultant
    - Fieldwork arrangements
  - o Cost-effectiveness of batches 1 and 2:
    - Audited expenditure reports from both Nepal and the Netherlands 2015, 2016 and 2017 (pre-audited if necessary)
    - Explanation of calculation of preparation costs
    - Baseline data and disability assessment camp data
  - o HMIS/Best Wishes data for Ilam I2C villages for the intervention period Predicted cost-effectiveness of batch 3:
    - Latest batch 3 budget
    - Baseline data from HERD evaluation
    - Data on set targets and indicators

Timeline

A summary of activities and key dates is outlined below.

	<u>Jan</u> <u>2018</u>	<u>Feb</u> <u>2018</u>	<u>Mar</u> <u>2018</u>	<u>Apr</u> <u>2018</u>	<u>May</u> <u>2018</u>	<u>June</u> <u>2018</u>
Methodology refinements and contracting	X	X				
Data gathering		X	X			
1. Prevention tool			X	X	X	
2. Cost-effectiveness						
a. Collection and analysis of desk review data (budgets, expenditures, baseline data, HMIS data, etc.)		X	X			
b. Field work and analysis of field work data			X	X		
c. Report writing				X	X	X
d. Comparative analysis and recommendations					X	X

Specific dates related to each piece of work will be agreed upon by email with Karuna Foundation Nepal.

## Annex 1: Methodology for the cost-effectiveness analyses

This section outlines the detailed methodology for the Ilam cost-effectiveness analyses. Both analyses will use a before-after study design, with batches 1 and 2 being retrospective studies, with the cases being women from Ilam batch 1 or 2 villages who became pregnant, enrolled in Best Wishes and gave birth within the study period, and the batch 3 assessment based on predicted expenditures (budget) and targets/indicators.

We will follow the methodology used in the pilot assessment as close as possible to allow for comparability. However, since we will now assess the prevention component of the programme, which was not done previously, some changes have been made.

The methodology is the same for each component, with any exceptions noted.

In summary, the proposed methodology is as follows:

### 1. Analyze baseline data or targets/indicators

For Ilam batch 1: As part of the I2C rollout, Karuna Foundation Nepal collected extensive baseline data on the I2C batch 1 villages. We will use the information collected from the 12 Ilam VDCs, which includes 693 women who gave birth in the year prior to the survey, to establish a baseline, and compare outcomes achieved during I2C (based on 712 women in the I2C programme in 2015 and 1,294 in 2016) with those documented in the baseline data (pre-I2C).

For Ilam batch 2: There is no household-level baseline data for the programme's prevention-related component, but we can use HMIS and other available data, to be provided by Karuna Foundation Nepal.

For Ilam batch 3: We will use the baseline data collected by HERD, combined with the assessment camp results (to be available in March 2018).

For all batches: A selection will be made from the below available data, to be decided in consultation with Karuna Foundation Netherlands:

- ANC visits (four are recommended as per protocol)
- Live births in last year
- Maternal, infant and child mortality<sup>24</sup>
- Birth defects/disabilities at birth for those who delivered in last year (although we understand these may be underreported)
- Disabilities developed during the first five years of life
- Institutional deliveries
- PNC visits (note: the survey data is unclear if this is just the first visit, though three visits are recommended)

There is additional data on ANC visits (including Td vaccination of mothers), use of IFA and deworming tablets during pregnancy (mothers), use of alcohol and tobacco during pregnancy (mothers), maternal nutrition, birth

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<sup>24</sup> The maternal mortality data gathered in the baseline surveys is for the last five years. From the district health system, Karuna Foundation Nepal will obtain maternal and child mortality data corresponding to the same time period as other baseline data.

weight, breastfeeding, etc. that can be discussed. Karuna Foundation Nepal should advise on which data are most reliable. The consultants will also consider that other possible contributing factors could be consanguineous marriage, family history of any disability, exposure to pesticides, radiation hazards and sexually transmitted infections (STIs) during pregnancy, though these indicators are not collected by Karuna.

## 2. Determine budget and/or expenditures

For Ilam batches 1 and 2: We will determine total prevention- and rehabilitation-related expenditure for the period April 2015-December 2017 for batch 1, and rehabilitation-related expenditure for April 2016-December 2017 for batch 2.

For Ilam batch 3: We will use the latest batch 3 five-year budget, to be provided by Karuna.

For all batches, costs incurred by all parties will be considered. This includes direct support to Best Wishes as well as other prevention activities that may support Best Wishes directly or indirect. Further, it includes all relevant programme costs incurred by any partners, present or past, including but possibly not limited to:

- Liliane Foundation and Netherlands Leprosy Relief (NLR)
- Time of government staff in district offices, health posts and village-level leaders
- Existing health post government budget for maternal child health at village level (vaccinations, supplements, dressings, etc.)
- Medic Mobile (partner in prevention component for tracking and registering pregnant women)

Excluded are rehabilitation-related expenditures incurred by outside parties (donated devices, etc.). Out-of-pocket expenditures by families or other organizations are also excluded, as are anticipated additional programme expenditures in future years of the programme since the focus of the evaluation is on implementation to date.

Additionally, initial preparation costs of 150.000 euro (incurred in 2014) and a partnership meeting held in Nepal will be included. A proportion of these expenditures will be applied to the Ilam batch 1 villages on the basis of:

- Number of total villages supported ( $12/(50 \text{ Ilam} + 12 \text{ Jhapa}) = 19\%$ )
- Annualization of any longer-term expenditures (such as startup expenditures, construction of facilities, training); appropriate lifetimes and discount rates will be discussed and agreed upon

The Karuna expenditures will be determined by Karuna Foundation staff based on a line item review. Shared expenditures (contributing to both the prevention and rehabilitation components, such as human resources and indirects) will be allocated to I2C by Karuna Foundation in consultation with the evaluators on the basis of a line item review and in a step-wise process: first to I2C and non-I2C and then the I2C share further allocated to prevention and rehabilitation.

For local expenditures, the KFN consultant will travel to Ilam District Health Office to quantify their inputs related to "Best Wishes" and rehabilitation activities – for example, any birthing clinics they built as a result of the programme, advertising they did about it, community sensitization sessions, etc. Anything that was done as a

result of the programme, that wouldn't have been done in villages where I2C was not operating, will be quantified and valued.

A similar assessment will be made of any extra prevention- or rehabilitation-related expenditures (beyond those considered standard for the Best Wishes programme) made by the district health office or other partners in the pre-intervention period. This includes both financial and non-financial investments such as human resources' time.

### 3. Estimate incremental health outcomes

For Ilam batches 1 and 2: We will use actual disability improvements documented by Karuna for each individual based on the initial and most recent assessment. We understand there are 177 children and 803 adults with a disability in batch 1 and 252 children and X adults with a disability in batch 2.

<b>Batch and district</b>	<b>Children with disabilities</b>	<b>Adults with disabilities</b>	<b>Total persons with disabilities</b>
Batch 1 Ilam (12 villages)	177	659	836
Batch 2 Ilam (15 Villages)	252	1152	1,404
<b>Total</b>	<b>429</b>	<b>1,811</b>	<b>2,240</b>

For prevention (batches 1 and 2), we propose to compare data from the Best Wishes programme cards (aggregated at health posts) from the intervention villages with the baseline data discussed above in #1. Again, the exact indicators will be agreed upon in consultation with Karuna Foundation.

For Ilam batch 3: We will use either the disability camp assessment and expected disability improvement (predicted by Karuna based on each individual's rehabilitation plan) or on average disability improvement from earlier batches and/or the pilot assessment. Prevention can be assessed using the revised tool or data from earlier batches and/or the pilot assessment.

We will also discuss with district health officials about the existence of any additional programs other than Best Wishes or any external factors that may be responsible for changes in indicators.

### 4. Estimate prevention of birth defects

Based on the incremental health outcomes observed in the I2C Ilam batch 1 villages as compared to the non-I2C villages, we will use the updated prevention tool to estimate the number of birth defects prevented that can be attributed to Karuna's interventions. We will then convert the number of children born without disability to disability-adjusted life years (DALYs)<sup>25</sup> averted using DALY weights and life expectancy, using a standard DALY weight for disability as agreed upon with Karuna Foundation Nepal. Deaths averted will also be incorporated.

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<sup>25</sup> DALYs are the appropriate measure for developing countries like Nepal, and their use ensures consistency with the assessment of the pilot in Sunsari and Rasuwa.

We will attempt to do the same for batch 2, using the available baseline data.

Findings from Ilam batch 1 and/or 2 will be extrapolated to batch 3 on a per birth or per pregnant woman basis, as agreed upon with Karuna Foundation Netherlands.

5. Estimate cost-effectiveness in terms of cost per DALY averted

The cost per DALY averted for (separate for each batch) will be calculated as the total intervention cost (budget for batch 3, expenditures for batches 1 and 2) for the assessed period divided by the total DALYs averted (batches 1 and 2) or estimated DALYs averted (batch 3).



## ***Annex 2 – Prevention tool TORs***

### **Terms of Reference Prevention Tool Update**

#### **Background Information and Rationale**

In 2011, Karuna Foundation Nepal developed a “prevention calculation tool” (Annex 1), an Excel sheet and methodology to estimate the number of prevented birth defects that could be attributed to Karuna’s interventions. The assumptions behind the Excel sheet calculations are based on some published data (from the Government Health Management Information System data collected during the Training of Professionals program developed and implemented by Karuna, which was carried out in 150 villages in Kavre district and Sunsari district). Building off this tool and previous studies conducted by Karuna, consultants will review literature and design methodology to capture disability estimates prevented by Karuna Foundation’s efforts. A Public Health consultant will be arranged and hired by Karuna Foundation Nepal to review literature and under the guidance of the consultants and external advisors, analyse data to estimate disability prevention attributable to Karuna’s Intervention.

#### **Scope of the Review**

This exercise will be focused on two components:

1. Consultants will explore literature, design and finalize methodology to estimate disability prevention estimates attributable to Karuna’s interventions
2. KFN consultant will utilize finalized methodology, under the guidance of consultants, to calculate disability prevented due to Karuna’s interventions in Ilam I2C villages, batches 1-2 and 3 (expected), for the same dates as the cost-effectiveness analysis (see proposal)

#### **Professional Qualification of Intern**

- Master Degree in Public Health (preferable) or relevant academic degree or Undergraduates in Public Health with atleast two years of research experience

#### **Methodology**

We will explore prevalence of childhood disability and extract causal factors and percentage attribution of birth defects and disability factors in Low and Middle Income Countries. The evidences will guide us to understand causal factors before, during and after birth associated with birth defects and childhood disability and subsequently design a prevention calculation framework building off Karuna’s previous reports. In absence of required data, best proxy indicators will be utilized to inform achievements in preventing disability.

#### **Expected Deliverables and Timeline**

- 1) Consultants will define AoRs for KFN consultant by 9<sup>th</sup> March ’18.
- 2) Consultants will propose methodology by and Karuna to provide inputs by 16<sup>th</sup> March ’18.
- 3) Consultants will submit draft report by 5<sup>th</sup> May ’18.

- 4) Consultants will incorporate inputs and submit final report by 25<sup>th</sup> May '18.

## Annex 1: Prevention of Disability Summary Sheet

<b>For inhouse use: Rough calculation of number of children that could have been saved from Disability</b>			
Note: There are many assumptions made based on logical reasoning without scientific evidences, so not appropriate for publishing, needs intensive research !			
Assumptions, based on facts			
Causes of birth defects and childhood disability, according to March of Dimes	Effectiveness		
<i>Before birth</i>	44%		
Genetic	39.6%		
Pre natal care	4.4%	80%	Does not cover all interventions
<i>During birth (Intra natal care)</i>	46%	95%	Human error 5%
<i>After birth</i>	10%	50%	Does not cover all interventions
We will measure effect in following interventions where we make significant changes			
Prenatal care			
Intra and Post natal care			
Early childhood care			
So, major assumption for this calculations are			
The estimates given by March of Dimes are true in this population			
The causal link that is published is true (although, no concrete evidence exist on this aspect)			
However, all the interventions needed were not addressed, there are issue of quality of services as well			
So, the intervention were not 100% effective for all interventions (though it is not possible to quantify)			
The prevalence of childhood disability is 2 % in this population, this is based on experience of studies of KFN in its SC VDCs			
The mortality of children with disability is high, and there is attrition from this group due to age factor, so the new cases is also around 2%			
The rise in health indicators is not solely due to KFN interventions, however KFN intervention contributed in creating synergetic effect on existing system			
Summary			
	<b>Saved in total</b>	<b>Saved due to ToP</b>	<b>Percent</b>
<i>Kavre</i>	871	72	9% of baseline
<i>Sunsari</i>	4100	70	2% of baseline
<i>Rasuwa</i>	90	12	15.3% of baseline
<b>Total</b>	<b>5061</b>	<b>154</b>	

### ***Annex 3 – Activities implemented as part of I2C***

**Table 18 Batch 1 activities implemented as part of I2C**

#### **Palika and Ward Level Program**

#### **Activity    Activities**

#### **Code**

#### **No.**

#### **Outcome 1: Improved health status of mothers and children by increased utilization of MCH services**

#### **Output 1: Strengthened MCH service environment**

##### **1.1            Support to birthing center-**

1.1.1          Renovation of Birthing Centre Building

1.1.2          Support equipment to birthing center

1.1.3          Installation or renovation of Water and Sanitation facility at birthing center

1.1.4          Furniture support to birthing center

1.1.5          Installation of Electricity/Solar at birthing center

##### **1.2            PHC/ORC Strengthening**

1.2.1          Furniture support to ORC

1.2.2          Equipment support to ORC

1.2.3          ORC room construction/renovation support

1.2.4          Stretcher support to ORC

#### **Output 2: Health Service provider behavior, service delivery improved**

2.1            Encourage monthly meeting of Health staff

2.2            Installation of Suggestion Box at Health facility

2.3            Consultation with Gynecologist to handle complicated delivery - Communication Charge

2.4            Support to establish emergency fund to manage obstetric delivery for the needy women

2.5            STI Case Management Training to Health facility staff

2.6            SBA Training to ANM

2.7            Helping Baby Breathing Training to ANM

2.8            Training in identification of birth defects and disability to Health facility staff

#### **Output 3: Increased use of ANC/institutional Delivery and PNC services**

#### **Best Wishes Program**

3.1            Orientation on Best Wishes Program to Health Facility Staff

3.2            Orientation to FCHV on Best Wishes Program

3.3            Ensure marriage registration (information card)

3.4            Orientation sessions to unreached/marginalized community on safe motherhood, vaccination

3.5            Pregnancy tracking by FCHVs (forms filled up by FCHV monthly)

3.6            Pregnancy registration at health institution and update

3.7            Issue Best Wishes card to pregnant women (Delivered by FCHV to PW)

3.8            Follow up by ANM and FCHV to Pregnant Women to use services -Communication Charge

3.9            Communication charge to in charge

3.10          Ensure Birth Registration

3.11          Encourage FCHV monthly meeting

3.12          Review of Best Wishes program at VDC

3.13          MCH day celebration

#### **Best Wishes forms and formats**

3.14          Best Wishes card

3.15          Best Wishes Register

**Health Education/Community Awareness program**

- 3.16 Orientation to mother group on disability prevention(MCH service utilization and BPP)
- 3.17 Orientation to Newly married couple-group: Marriage Registration, disability prevention
- 3.18 School Health Education
- 3.19 Wall painting/Hoarding board/Poster/Pamphlet/Radio
- 3.20 Orientation of vulnerable groups on workplace safety
- 3.21 Orientation of community on road traffic safety

**Output 4: Improved use of child health service and nutrition**

- 4.1 Strengthen Growth monitoring program
- 4.2 Identification of malnourished children
- 4.3 Referral of Malnourished Children to specialized service center
- 4.4 School health screening camp to identify malnourishment
- 4.5 Nutrition education (Recipe development+ Kitchen gardening ) to mothers of golden 1000 days
- 4.6 Plant Seed provision/ distribution to mothers of golden 1000 days
- 4.7 Training to CBRF on screening malnourishment
- 4.8 Development of Nutrition related posters/fliers/IEC materials
- 4.9 ToT on Nutrition education

**Outcome 2: Improved Quality of Life of Person with Disability through Community Based Rehabilitation****Output 1: Updated Information Management of Person with Disabilities**

- 1.1 Identification and Update the Data of Person with Disability
- 1.2 Disability Assessment Camp (by multidisciplinary team; doctors, physiotherapist, orthopedics etc.)
- 1.3 Rehabilitation Plan, Profile development and update

**Output 2: Improved Health Status of Person with Disabilities**

- 2.1 Home Visit
- 2.2 Home Based Primary Rehabilitation Therapy
- 2.3 Medical Treatment Support and follow up
- 2.4 Assistive or protective Device Support
- 2.5 Nutrition Support
- 2.6 Coordination and referral to specialized service Center
- 2.7 Support to establish day care center for children with intellectual disability
- 2.8 Training on Self Care for the needed
- 2.9 Transfer of skills to the parents/care takers

**Output 3: Increased Access in Education**

- 3.1 Support to Schools/ECDs
- 3.2 School Enrollment Support
- 3.3 Peer Education Training to Student (Community/School)
- 3.4 Education material support to children with disability
- 3.5 Strengthen Scholarship provisions
- 3.6 Support for the establishment of one Disability Friendly model School
- 3.7 Training to Teachers in Inclusive Education
- 3.8 Training to ECD facilitator on disability issues and child care
- 3.9 Home Based Education services (Non formal education)

**Output 4: Increased Economic Status/Livelihood of Person with Disabilities**

- 4.1 Identification of BPL (below poverty line) Family among Person with Disability
- 4.2 Entrepreneurship Training to BPL family
- 4.3 Vocational and Skill Development Training
- 4.4 Loan Support for Income Generating Activities
- 4.4 Advocacy for employment opportunities- Meeting expenses

**Output 5: Increased Access on Social Activities**

- 5.1 Orientation on Disability and CBR and common rights, UNCRPD and schemes to community groups
- 5.2 Celebration of International Disability Day
- 5.3 Formation of inclusive Child Club
- 5.4 Meeting of Child Club
- 5.5 Playing Materials support to Child Club
- 5.6 Extra-curricular activities in Child Club
- 5.7 Support to Recreational activities

**Output 6: Empowered Family and Person with Disability**

- 6.1 Formation of Self Help Group of Parents
- 6.2 Meeting of Self Help Groups
- 6.3 Leadership Development Training to SHG
- 6.4 Leadership Training to Child Club
- 6.5 Access to Birth Certificate
- 6.6 Access to Identity Card
- 6.7 Access to disability allowance
- 6.8 Counseling for Persons with Disabilities
- 6.9 Training SHG on Management and Leadership
- 6.10 Training to child club for leadership development and management
- 6.11 Support for Reasonable Accommodation at Home and School

**Outcome 3: Strengthened Community Support System****Output 1: Strengthened local government system**

- 1.1 Orientation of I2C program to VDC secretary and health facility In-charge at district level
- 1.2 Orientation regarding I2C program to community at VDC level
- 1.3 HFOMC meeting
- 1.4 VDRC formation meeting
- 1.5 VDRC Meeting
- 1.6 Annual Planning Workshop
- 1.7 Review meeting at ward level
- 1.8 Program Management and Leadership Development Training to VDRC/HFOMC
- 1.9 Furniture and equipment support to HFOMC
- 1.10 Communication charge to the Chairperson of HFOMC
- 1.11 Monthly reporting
- 1.12 Financial recording and reporting capacity development training to Health facility In charge and CBRF
- 1.13 Administrative cost for HFOMC/VDRC
- 1.14 Baseline survey

**Output 2: Strengthened mothers' group**

- 2.1 Regular meeting of mother groups
- 2.2 Passbooks and Register for saving and credit scheme
- 2.3 Saving and Credit mobilization Training
- 2.4 Women's cooperatives through mother groups

**Output 3: Improved Administration and Management**

- 3.1 Appointment of CBR Facilitator
- 3.2 Training to CBRF (Disability management and CBR)
- 3.3 Forms and Format Printing
- 3.4 Supervision and Monitoring by HFOMC
- 3.5 Salary of CBR Facilitator

- 3.6 Induction to CBRF
- 3.7 Basic Computer Training for CBRF
- 3.8 Incentive for accounting staff AND health coordinator at (Rural) Municipality (2:1)

**Table 19 Batch 2 activities implemented as part of I2C**

**Palika level activities**

**Annual Plan 2018**

**S.No. Activities**

**Outcome 1: Improved health status of mothers and children by increased utilization of MCH services**

**Output 1: Strengthened MCH service environment**

**1.1 Support to birthing center-**

- 1.1.1 Renovation of Birthing Centre Building
- 1.1.2 Support equipment to birthing center
- 1.1.3 Installation or renovation of Water and Sanitation facility at birthing center
- 1.1.4 Furniture support to birthing center
- 1.1.5 Installation of Electricity/Solar at birthing center

**1.2 PHC/ORC Strengthening**

- 1.2.1 Furniture support to ORC
- 1.2.2 Equipment support to ORC
- 1.2.3 ORC room construction/renovation support
- 1.2.4 Stretcher support to ORC

**Output 2: Health Service provider behavior, service delivery improved**

- 2.1 Encourage monthly meeting of Health staff
- 2.2 Support to establish emergency fund to manage obstetric delivery for the needy women
- 2.3 Helping Baby Breathing Training to ANM
- 2.4 Training in identification of birth defects and disability to Health facility staff

**Output 3: Increased use of ANC/institutional Delivery and PNC services**

**Best Wishes Program**

- 3.1 Orientation on Best Wishes Program to Health Facility Staff
- 3.2 Orientation to FCHV on Best Wishes Program
- 3.3 Ensure marriage registration (information card)
- 3.4 Orientation sessions to unreached/marginalized community on safe motherhood, vaccination
- 3.5 Pregnancy tracking by FCHVs (forms filled up by FCHV monthly)
- 3.6 Pregnancy registration at health institution and update
- 3.7 Issue Best Wishes card to pregnant women (Delivered by FCHV to PW)
- 3.8 Follow up by ANM and FCHV to Pregnant Women to use services -Communication Charge
- 3.9 Communication charge to in charge
- 3.10 Ensure Birth Registration
- 3.11 Encourage FCHV monthly meeting
- 3.12 Review of Best Wishes program at VDC
- 3.13 MCH day celebration

**Best Wishes forms and formats**

- 3.14 Best Wishes card
- 3.15 Best Wishes Register

**Health Education/Community Awareness program**

- 3.16 Orientation to mother group on disability prevention (MCH service utilization and BPP)

- 3.17 Orientation to Newly married couple-group: Marriage Registration, disability prevention
- 3.18 School Health Education
- 3.19 Wall painting/Hoarding board/Poster/Pamphlet/Radio
- 3.2 Orientation of vulnerable groups on workplace safety
- 3.21 Orientation of community on road traffic safety

**Output 4: Improved use of child health service and nutrition**

- 4.1 Strengthen Growth monitoring program
- 4.2 Identification of malnourished children
- 4.3 Referral of Malnourished Children to specialized service center
- 4.4 School health screening camp to identify malnourishment
- 4.5 Nutrition education (Recipe development+ Kitchen gardening ) to mothers of golden 1000 days
- 4.6 Training to CBRF on screening malnourishment
- 4.7 Development of Nutrition related posters/fliers/IEC materials
- 4.8 ToT on Nutrition education to FCHV or HFOMC member

**Outcome 2: Improved Quality of Life of Person with Disability through Community Based Rehabilitation**

**Output 1: Updated Information Management of Person with Disabilities**

- 1.1 Identification and Update the Data of Person with Disability
- 1.2 Disability Assessment Camp (by multidisciplinary team; doctors, physiotherapist, orthopedics etc.)
- 1.3 Rehabilitation Plan, Profile development and update

**Output 2: Improved Health Status of Person with Disabilities**

- 2.1 Home Visit
- 2.2 Home Based Primary Rehabilitation Therapy
- 2.3 Medical Treatment Support and follow up
- 2.4 Assistive or protective Device Support
- 2.5 Coordination and referral to specialized service Center
- 2.6 Transfer of skills to the parents/care takers

**Output 3: Increased Access in Education**

- 3.1 Support to Schools/ECDs
- 3.2 School Enrollment Support
- 3.3 Peer Education Training to Student (Community/School)
- 3.4 Education material support to children with disability
- 3.5 Strengthen Scholarship provisions
- 3.6 Support for the establishment of one Disability Friendly model School
- 3.7 Training to Teachers in Inclusive Education
- 3.8 Training to ECD facilitator on disability issues and child care
- 3.9 Home Based Education services (Non formal education)

**Output 4: Increased Economic Status/Livelihood of Person with Disabilities**

- 4.1 Identification of BPL (below poverty line) Family among Person with Disability
- 4.2 Entrepreneurship Training to BPL family
- 4.3 Vocational and Skill Development Training
- 4.4 Loan Support for Income Generating Activities

**Output 5 : Increased Access on Social Activities**

- 5.1 Orientation on Disability and CBR and common rights of person with disability to community groups
- 5.2 Celebration of International Disability Day

**Output 6 : Empowered Family and Person with Disability**

- 6.1 Formation of Milijuli Group of Parents
- 6.2 Meeting of Milijulu Group

- 6.3 Leadership Development Training to SHG
- 6.4 Access to Birth Certificate
- 6.5 Access to Identity Card
- 6.6 Access to disability allowance
- 6.7 Counseling for Persons with Disabilities
- 6.8 Training SHG on Management and Leadership
- 6.9 Support for Reasonable Accommodation at Home and School

### **Outcome 3: Strengthened Community Support System**

#### **Output 1: Strengthened local government system**

- 1.1 Orientation of I2C program to VDC secretary and health facility In-charge at district level
- 1.2 Orientation regarding I2C program to community at VDC level
- 1.3 HFOMC meeting
- 1.4 VDRC formation meeting
- 1.5 Annual Planning Workshop
- 1.6 Review meeting at ward level
- 1.7 Program Management and Leadership Development Training to VDRC/HFOMC
- 1.8 Furniture and equipment support to HFOMC
- 1.9 Communication charge to the Chairperson of HFOMC
- 1.10 Monthly reporting
- 1.11 Financial recording and reporting capacity development training to Health facility In charge and CBRF
- 1.12 Administrative cost
- 1.13 Baseline survey

#### **Output 2 : Strengthened mothers' group**

- 2.1 Regular meeting of mother groups
- 2.2 Passbooks and Register for saving and credit scheme
- 2.3 Saving and Credit mobilization Training
- 2.4 Women's cooperatives through mother groups

#### **Output3: Improved Administration and Management**

- 3.1 Appointment of CBR Facilitator
- 3.2 Training to CBRF (Disability management and CBR)
- 3.3 Forms and Format Printing
- 3.4 Supervision and Monitoring by VDRC/HFOMC
- 3.5 Salary of CBR Facilitator
- 3.6 Induction to CBRF
- 3.7 Basic Computer Training for CBRF

### **Outcome 4: Improved status of child protection environment and decreased violence against children**

#### **Output 1: Strengthened Village Child Protection Committee**

- 1.1 CFLGC formation
- 1.2 CFLGC meeting
- 1.3 Training to CFLGC regarding child right
- 1.4 Develop Village child profile

#### **Output 2: Improved status of knowledge of parents regarding skillful parenting**

- 2.1 Training to parents in Community
- 2.2 Follow up and monitoring

#### **Output 3: Strengthened child club**

- 3.1 Formation of inclusive Child Club
- 3.2 Meeting of Child Club



- 3.4 Extra-curricular activities in Child Club
- 3.5 Support to Recreational activities
- 3.6 Training to child club for child right
- 3.7 Celebration of International Child Right Day

**Output 4: Improved child friendly teaching and learning environment**

- 4.1 Positive discipline training to ECD facilitators
- 4.2 Positive discipline training to school teachers
- 4.3 Support of child friendly teaching and learning material to the schools and ECDs

**Table 20 Batch 3 activities implemented as part of I2C**

**Program unit and Ward level Program**

**Activity Activities**

**Code**

**No.**

**Outcome 1: Improved health status of mothers and children by increased utilization of MCH services**

**Output 1: Strengthened MCH service environment**

- 1.1 Support to Health institution to improve physical facilities
- 1.2 Support to PHC/ORC to improve physical facility

**Output 2: Health Service provider behavior, service delivery improved**

- 2.1 Helping Baby Breathing Training to ANM
- 2.2 SBA Training
- 2.3 Training in identification of birth defects and disability to Health facility staff

**Output 3: Increased use of ANC/institutional Delivery and PNC services**

**Best Wishes Program**

- 3.1 Orientation on Best Wishes Program to Health Facility Staff
- 3.2 Orientation to FCHV on Best Wishes Program
- 3.3 Ensure marriage registration (information card)
- 3.4 Pregnancy tracking and registration by FCHVs
- 3.5 Follow up by ANM and FCHV to Pregnant Women to use services -Communication Charge
- 3.6 Communication charge to Incharge
- 3.7 Encourage FCHV monthly meeting
- 3.8 Review of Best Wishes program at VDC
- 3.9 Best Wishes Card and Register printing

**Awareness Program**

- 3.10 Orientation to Mother's group on disability prevention
- 3.11 Wall painting/Hoarding board/Poster/Pamphlet/Radio
- 3.12 Orientation of community on road traffic safety

**Output 4: Improved use of child health service and nutrition**

- 4.1 Equipment for Growth monitoring program
- 4.2 Referral of Malnourished Children to specialized service centre
- 4.3 School health screening camp to identify malnourishment
- 4.4 ToT on school health screening camp to identify malnourishment and disability
- 4.5 Nutrition education and disability prevention education to mothers including 1000 Golden Days mothers

**Outcome 2: Improved Quality of Life of Person with Disability through Community Based Rehabilitation**

**Output 1: Updated Information Management of Person with Disabilities**

- 1.1 Identification of person with disability

- 1.2 Disability Assessment Camp (by multidisciplinary team; doctors, physiotherapist, orthopedics etc.)
- 1.3 Rehabilitation Plan, Profile development and update

**Output 2: Improved Health Status of Person with Disabilities**

- 2.1 Home Visit
- 2.2 Home Based Primary Rehabilitation Therapy
- 2.3 Medical Treatment Support and follow up
- 2.4 Assistive or protective Device Support
- 2.5 Nutrition Support
- 2.6 Transfer of skills to the parents/care takers

**Output 3: Increased Access to Education**

- 3.1 School Enrollment Support
- 3.2 Education material support to children with disability
- 3.3 Support for the establishment of one Disability Friendly model School
- 3.4 Training to teachers and ECD facilitators on Inclusive Education
- 3.5 Home Based Education services (Non formal education)

**Output 4: Increased Economic Status/Livelihood of Person with Disabilities**

- 4.1 Vocational and Skill Development Training
- 4.2 Seed Capital to Milijuli Samuha

**Output 5: Increased Access to Social Activities**

- 5.1 Orientation on Disability and CBR to community groups
- 5.2 Celebration of International Disability Day
- 5.3 Formation of inclusive Child Club
- 5.4 Meeting of Child Club
- 5.5 Extra-curricular activities in Child Club

**Output 6: Empowered Family and Person with Disability**

- 6.1 Formation of Milijuli Samuha of Parents
- 6.2 Meeting of Milijuli Samuha
- 6.3 Leadership Development and Saving and Credit Mobilization training to Milijuli Samuha
- 6.4 Leadership Training to Child Club
- 6.5 Support for access to identity card
- 6.6 Support Passbook and Register to SHG
- 6.7 Training Milijuli Samuha on Management and Leadership
- 6.8 Training to child club for leadership development and management
- 6.9 Support for Reasonable Accommodation at Home and School

**Outcome 3: Strengthened Community Support System**

**Output 1: Strengthened local government system**

- 1.1 Orientation to Chairperson/Mayor and Vicechairperson/Deputy Mayor about Inspire2Care program at district level including EO
- 1.2 Orientation to elected bodies about Inspire2Care program including health facility staffs at Village level
- 1.3 HFOMC meeting
- 1.4 Annual Planning Workshop
- 1.5 Review meeting at ward level
- 1.6 Program Management and Leadership Development Training to VDRC/HFOMC
- 1.7 Furniture and equipment support to CBRF office
- 1.8 Communication charge to the Chairperson of HFOMC
- 1.9 Financial recording and reporting capacity development training to Health facility Incharge and CBRF

1.10 Administrative cost

1.11 Baseline Survey

**Output 2: Improved Administration and Management**

2.1 Training to CBRF (Disability management, CBR, screening of malnourishment and Computer)

2.2 Forms and Format Printing

2.3 Supervision and Monitoring by VDRC/HFOMC

2.4 Salary of CBR Facilitator

2.5 Induction to CBRF

## ***Annex 4 – Documents reviewed***

Karuna Foundation website

Budget for Batch 3 – Ilam (July 2017 – December 2021)

I2C Expenditure Reports (2014 - 2017)

Ilam audit reports (2014- 2017) and Excel spreadsheets from audit reports

Unaudited expenditure report (July 2-17 – December 2017)

Actual local contributions and expenditures 2015 – 2017 provided by Karuna Foundation Nepal

Expenditure analysis done by Karuna Foundation Netherlands

Karuna Nepal year reports 2014 -2017

I2C activity list, batches 1, 2 and 3

I2C implementation agreements, various HFOMC

I2C program results (2014-2017), various Excel files

Summary lists of children with birth defects, Ilam district (Various VDCs)

Concept note for expansion of the Inspire2Care project in Nepal (July 2014)

I2C expansion plan, Batch 3

Essential Health Care Services Capacity Assessment for Health Systems Strengthening, Dr. Louise Hulton et al, December 2010

Qualitative service delivery and progress record for 2015-2017, Ilam Batch 1 and 2, compiled June 2018

I2C prevention results, I2C villages, various Excel files

I2C expansion budgets, various formats

HMIS, Ilam (June 2014 – June 2018)

Email correspondence with Karuna Foundation staff (Betteke de Gaay Fortman, Merel Schreurs, Deepak Sapkota, Ram Thapa)

Karuna Foundation Nepal audit reports (2014 - 2017)

“Persons with disabilities and their access to health care services in Nepal” report by Eva Schildbach et al, November 2012

Various documents on DALYs, disability, CBR matrix (see reference list)

Vaughan, Kelsey (2015). Cost-effectiveness and efficiency assessment of the Inspire2Care program, 2011-2013.

Vaughan, Kelsey and Thapa, Aradhana (2015). Cost-effectiveness of a community-based rehabilitation programme in Nepal. Disability, CBR and Inclusive Development (DCID). Vol. 26, No.4.

Prevention of birth defects and disability calculation tool provided by Karuna team

### ***Annex 5 – Field visit itinerary***

<b>Day/Date</b>	<b>Time</b>	<b>What</b>	<b>Involvement</b>	<b>Responsible</b>	<b>Logistics</b>	<b>Venue</b>	<b>Remarks</b>
<b>Wed 2nd May 2018</b>	Flight time: 11: 20 am	Buddha Air	Ram, Rashmi			KTM to Bhadrapur	45 mins flight
	12:05 PM	Pick up from Bhadrapur airport	Ram, Rashmi		Vehicle, Room arrangement for 2 person	Greenview hotel	4 hrs journey
	5:00 PM	Drop at Greenview hotel					
<b>Thu 3rd May 2018</b>	8:00 AM	Start for field	Rashmi,Ram, KFN field staff	KFN staff	Vehicle to be hired by KFN staff	Visit to Sumbec	2.5 hour of travel
	10:30 AM	Visit to health facility and meeting with HFOMC	Rashmi,Ram, KFN field staff				1 hr for meeting/ interview
	11:45 AM	Meeting with ward chairperson					1 hr for meeting/ interview
	12:45 AM	Lunch					45 mins
	1:30 AM	Miscellaneous activities with CBRF staff					30 mins
	2:00 PM	Return to Ilam				Ilam to Sumbee	2.5 hrs of travvel
	4:30 PM	Reach Hotel green View					
		Draft report of the interview					
<b>Fri 4th May 2018</b>	8:00 AM	Start for field	Rashmi, Ram, KFN field staff	KFN staff	Vehicle to be hired by KFN staff	Visit to Namsaling (Phase-1VDC)	2 hrs of travel

	10: 00AM	Visit to health facility and meeting with HFOMC	Rashmi, Ram, KFN field staff				1 hr for meeting/ interview
	11:15 AM	Meeting with ward chairperson					1 hr for meeting/ interview
	12:15 PM	Miscellaneous activities with CBRF staff					30 mins
	12:45 PM	Lunch					45 mins
	1:30 PM	Return to Ilam					2 hrs of travel
	3:30 PM	Reach hotel Greenview					
		Draft report of the interview					
<b>Sun 6th May 2018</b>	8:00 AM	Start for field	Rashmi, Ram, KFN field staff	KFN staff	Vehicle to be hired by KFN staff	Visit to Gorkhe (Phase-11 VDC)	2 hrs of travel
	10: 00AM	Visit to health facility and meeting with HFOMC	Rashmi, Ram, KFN field staff				1 hr for meeting/ interview
	11:15 AM	Meeting with ward chairperson					1 hr for meeting/ interview
	12:15 PM	Miscellaneous activities with CBRF staff					30 mins
	12:45 PM	Lunch					45 mins
	1:30 PM	Return to Ilam					2 hrs of travel
	3:30 PM	Reach hotel Greenview					

		Draft report of the interview					
<b>Mon 7th May 2018</b>	7:00 AM	Pick up from Greenview hotel	Ram, Rashmi				4 hours of journey
	11:00 AM	Drop at Bhadrapur airport					
	11:20 AM	Flight to Kathmandu	Ram, Rashmi				45 mins flight
	12:05 PM	Arrival at Kathmandu airport					



## ***Annex 6 – 2004 disability weights***

Baseline status code	Baseline status general description	GBD 2004		
		Condition	Disability weight	Notes (both from GBD 2004 and team's own)
Amputation	Amputee	Amputee	0.213	Average amputee weight of 6 amputee conditions
Ankle	Ankle fracture	Fracture, ankle, short-term, untreated	0.196	Used for club foot
Blind	Blind (refractive)	Refractive errors: blindness	0.43	Half weight used for blindness in one eye (not from GBD)
Blind_2	Blind (macular degeneration)	Macular degeneration: blindness	0.6	
Blindness_One eye	Blindness in one eye	Blindness in one eye	0.215	Half weight used for blindness in one eye (not from GBD)
Burn	Burn	Burn, > 20% and < 60%, long-term, untreated	0.255	
Clavicle	Clavicle fracture	Fractured clavicle, scapula or humerus, short-term untreated (long-term does not exist)	0.153	
Cleft_lip	Cleft Lip	Cleft lip – cases	0.05	
Cleft_palate	Cleft Palate	Cleft palate – cases	0.103	
Cognitive	Mental illness		0.024	Weight for 'Cognitive impairment or developmental disability
Deaf	Deaf	Deafness	0.229	
Depression_mild	Mild depression		0.14	
Depression_moderate	Moderate depression		0.35	
Depression_severe	Severe depression		0.76	
Developmental	Delayed development	Protein-energy malnutrition developmental disability	0.024	
Disfigurement_mild	Disfigurement, level 1		0.011	Weight from 2016 as did not exist in 2004

Disfigurement_moderate	Disfigurement, level 2		0.067	Weight from 2016 as did not exist in 2004
Disfigurement_severe	Disfigurement, level 3		0.405	Weight from 2016 as did not exist in 2004
Dislocation	Dislocation	Dislocation of shoulder, elbow or hip	0.074	Short-term, untreated (long-term not available)
Down	Down syndrome	Down syndrome – cases	0.593	
Epilepsy	Epilepsy	Epilepsy - Cases	0.113	
Eye	Eyes Injury	Injury to eyes – untreated, long-term weight	0.3	
Femur	Femur fracture	Fracture, femur, long-term, untreated	0.272	Used for Genu Valgus
General_pain	General pain or muscle tightness	General pain or muscle tightness	0.1	Not from GBD – evaluator’s own
Hand	Hand bone Fracture	Fracture, hand bone, short-term untreated (long term doesn’t exist)	0.1	
Hearing_mild	Hearing loss- mild	Hearing loss, adult onset: mild	0	Assumed to have no disability for GBD
Hearing_moderate	Hearing loss, adult onset: moderate, treated	Hearing loss, adult onset: moderate, treated	0.04	Assumed similar to mild hearing loss
Hearing_moderate	Hearing loss- moderate	Hearing loss, adult onset: moderate, untreated	0.12	
Hearing_severe	Hearing loss, adult onset: severe or profound, treated	Hearing loss, adult onset: severe or profound, treated	0.12	Assumed similar to moderate hearing loss
Hearing_severe	Hearing loss- severe	Hearing loss, adult onset: severe or profound, untreated	0.333	

Intellectual_borderline	Borderline intellectual disability		0.012	Used half of intellectual_mild
Intellectual_mild	Developmental/ cognitive disability	Cognitive impairment or developmental disability	0.024	
Intellectual_moderate	Moderate intellectual disability		0.164	Used 1/3 of intellectual_mild and intellectual_profound
Intellectual_profound	Profound intellectual disability	Cognitive impairment	0.468	Cognitive impairment
Intellectual_severe	Severe intellectual disability		0.328	Used 2/3 of intellectual_mild and intellectual_profound
Low_vision	Low vision	Low vision	0.17	
Migraine	Migraine	Migraine	0.029	
Motor	Motor	Motor deficit	0.381	Varies with age and treatment
Motor_mild	Motor impairment, mild		0.381	Only single motor in 2004
Motor_moderate	Motor impairment, moderate		0.381	Only single motor in 2004
Motor_severe	Motor impairment, severe		0.381	Only single motor in 2004
Motor1	Motor impairment, moderate		0.381	Only single motor in 2004
Motor2	Motor impairment, severe		0.381	Only single motor in 2004
MR	Mental retardation	Mental retardation	0.459	

Muscular dystrophy	Muscular dystrophy			
Neoplasm	Neoplasm, malignant, other	Neoplasm, malignant, other	0.09	Used half weight for non-malignant (evaluator's own)
Pelvis	Pelvis fracture	Fractured pelvis, short-term (long-term not available)	0.247	
Polio	Polio	Poliomyelitis - cases - lameness	0.369	
Schizophrenia	Schizophrenia	Schizophrenia - cases	0.528	Did not use in original assessment
Severe	Other severe disability		0.8	Not from GBD – evaluator's own
Skull	Skull fracture	Fractured skull, 0-44 years, untreated, long-term	0.41	Used for physical head injury post operative
Speech	Vocal and speech issues (without hearing problem)		0.2	Did not use in original assessment; weight is unspecified as condition does not exist in GBD 2004
Spinal	Spinal cord Injury	Injured spinal cord – untreated, long-term weight	0.725	
Unspecified	Unspecified	Unspecified physical or neurological disability	0.2	Not from GBD – evaluator's own
None	Was assessed in camp and/ or services provided but wasn't considered person with disability		0	

### ***Annex 7 – 2016 disability weights***

Baseline status code	Baseline status general description	GBD 2016				
		Health state name	Disability weight	Health state lay description	Notes (both from GBD 2016 and team's own)	Other comments
Amputation	Amputee		0.061		There is only diabetic neuropathy with amputation, but has a 0 disability weight	Weight is from motor_moderate
Ankle	Ankle fracture				Does not exist	
Blind	Blind (refractive)		0.187		Various blindness weights due to blindness from different causes, but all carry same disability weight	
Blind_2	Blind (macular degeneration)	Distance vision blindness	0.187	Is completely blind, which causes great difficulty in some daily activities, worry and anxiety, and great difficulty going outside the home without assistance.		
Blindness_One eye	Blindness in one eye	Distance vision, monocular	0.017	Is blind in one eye and has difficulty judging distances		
Burn	Burn		0.067		Does not exist	Used disfigurement_moderate
Clavicle	Clavicle fracture				Does not exist	
Cleft_lip	Cleft Lip				Classify as disfigurement level 2 or level 1	

Cleft_palate	Cleft Palate				Classify as disfigurement level 2 or level 1	
Cognitive	Mental illness		0.051		Does not exist	GBD 2016 only has "Motor plus cognitive impairments"; used speech weight
Deaf	Deaf	Hearing loss, complete	0.215	Cannot hear at all in any situation, including even the loudest sounds, and cannot communicate verbally or use a phone. Difficulties with communicating and relating to others often cause worry, depression or loneliness.		
Depression_ mild	Mild depression	Major depressive disorder, mild episode	0.145	Feels persistent sadness and has lost interest in usual activities. The person sometimes sleeps badly, feels tired, or has trouble concentrating but still manages to function in daily life with extra effort.		
Depression_ moderate	Moderate depression	Major depressive disorder, moderate episode	0.396	Has constant sadness and has lost interest in usual activities. The person has some difficulty in daily life, sleeps badly, has trouble concentrating, and sometimes thinks about		

				harming himself (or herself).		
Depression_ severe	Severe depression	Major depressive disorder, severe episode	0.658	Has overwhelming, constant sadness and cannot function in daily life. The person sometimes loses touch with reality and wants to harm or kill himself (or herself).		
Developmental	Delayed development	Intellectual disability / mental retardation, mild	0.043			
Disfigurement_ mild	Disfigurement, level 1		0.011	Has a slight, visible physical deformity that others notice, which causes some worry and discomfort.		
Disfigurement_ moderate	Disfigurement, level 2		0.067	Has a visible physical deformity that causes others to stare and comment. As a result, the person is worried and has trouble sleeping and concentrating.		
Disfigurement_ severe	Disfigurement, level 3		0.405	Has an obvious physical deformity that makes others uncomfortable, which causes the person to avoid social contact, feel worried, sleep poorly, and think about suicide.		

Dislocation	Dislocation		0.011		Does not exist	Used disfigurement_mi ld
Down	Down syndrome				Classify in terms of intellectual disability / mental retardation	
Epilepsy	Epilepsy				Classify in terms of severity: severe = seizures >= 1/month, 0.552, less severe = seizures 1-11/year, 0.263, seizure- free/treated, 0.049	
Eye	Eyes Injury				Classify in terms of how vision is affected	
Femur	Femur fracture		0.061		Does not exist	Weight is from motor_moderate
General_pain	General pain or muscle tightness	Generic uncomplicated disease: worry and daily medication	0.049	Has a chronic disease that requires medication every day and causes some worry but minimal interference with daily activities.		
Hand	Hand bone Fracture		0.011		Does not exist	Weight is from disfigurement_ mild
Hearing_mild	Hearing loss- mild	Hearing loss, mild	0.01	Has great difficulty hearing and understanding another person talking in a noisy place (for example, on an urban street).		
Hearing_moderate	Hearing loss, adult onset:	Hearing loss, moderate	0.027	Is unable to hear and understand another person talking in a noisy place (for		



	moderate, treated			example, on an urban street), and has difficulty hearing another person talking even in a quiet place or on the phone.		
Hearing_ moderate	Hearing loss- moderate		0.027		Does not exist	
Hearing_severe	Hearing loss, adult onset: severe or profound, treated		0.204			
Hearing_severe	Hearing loss- severe	Hearing loss, profound	0.204	Is unable to hear and understand another person talking, even in a quiet place, is unable to take part in a phone conversation, and has great difficulty hearing anything in any other situation. Difficulties with communicating and relating to others often cause worry, depression, and loneliness.		
Intellectual_ borderline	Borderline intellectual disability	Borderline intellectual functioning	0.011	Is slow in learning at school. As an adult, the person has some difficulty doing complex or unfamiliar tasks but otherwise functions independently.		
Intellectual_ mild	Developmental / cognitive disability	Intellectual disability / mental	0.043	Has low intelligence and is slow in learning at school. As an adult, the person can		

		retardation, mild		live independently, but often needs help to raise children and can only work at simple supervised jobs.		
Intellectual_moderate	Moderate intellectual disability	Intellectual disability / mental retardation, moderate	0.1	Has low intelligence, and is slow in learning to speak and to do even simple tasks. As an adult, the person requires a lot of support to live independently and raise children. The person can only work at the simplest supervised jobs.		
Intellectual_profound	Profound intellectual disability	Intellectual disability / mental retardation, profound	0.2	Has very low intelligence, has almost no language, and does not understand even the most basic requests or instructions. The person requires constant supervision and help for all activities.		
Intellectual_severe	Severe intellectual disability	Intellectual disability / mental retardation, severe	0.16	Has very low intelligence and cannot speak more than a few words, needs constant supervision and help with most daily activities, and can do only the simplest tasks.		
Low_vision	Low vision		0.184		Does not exist; used distance vision, severe 0.184	
Migraine	Migraine	Headache, migraine	0.441	Has severe, throbbing head pain and nausea that cause		

				great difficulty in daily activities and sometimes confine the person to bed. Moving around, light, and noise make it worse.		
Motor	Motor	Motor impairment, mild	0.01	Has some difficulty in moving around but is able to walk without help.		Includes any of following: one part paralysis; club foot; one leg shortening; motor impairment mild
Motor_mild	Motor impairment, mild	Motor impairment, mild	0.01	Has some difficulty in moving around but is able to walk without help.		Includes any of following: one part paralysis; club foot; one leg shortening; motor impairment mild
Motor_moderate	Motor impairment, moderate	Motor impairment, moderate	0.061	Has some difficulty in moving around, and difficulty in lifting and holding objects, dressing and sitting upright, but is able to walk without help.		
Motor_severe	Motor impairment, severe	Motor impairment, severe	0.402	Is unable to move around without help, and is not able to lift or hold objects, get dressed or sit upright.		
Motor1	Motor impairment, moderate	Motor impairment, moderate	0.061	Has some difficulty in moving around, and difficulty in lifting and holding objects, dressing		

				and sitting upright, but is able to walk without help.		
Motor2	Motor impairment, severe	Motor impairment, severe	0.402	Is unable to move around without help, and is not able to lift or hold objects, get dressed or sit upright.		
MR	Mental retardation				Classify in terms of severity (see intellectual disability/mental retardation)	
Muscular dystrophy	Muscular dystrophy				Does not exist	
Neoplasm	Neoplasm, malignant, other		0.288		Does not exist	Used cancer, diagnosis and primary therapy
Pelvis	Pelvis fracture		0.061		Does not exist	Weight is from motor_moderate
Polio	Polio				Does not exist	
Schizophrenia	Schizophrenia	Schizophrenia acute/residual state	0.683	Schizophrenia, acute/residual state. Acute: hears and sees things that are not real and is afraid, confused, and sometimes violent. The person has great difficulty with communication and daily activities, and sometimes wants to harm or kill himself (or herself). Residual: hears and sees things that are not real and has trouble communicating. The		Took average of acute and residual states

				person can be forgetful, has difficulty with daily activities, and thinks about hurting himself (or herself).		
Severe	Other severe disability	Multiple sclerosis, severe [combined disability weight]	0.719	Has slurred speech and difficulty swallowing. The person has weak arms and hands, very limited and stiff leg movement, has loss of vision in both eyes and cannot control urinating.	Used for a single case of multiple conditions; summing them produced a disability weight >1	
Skull	Skull fracture				Does not exist	
Speech	Vocal and speech issues (without hearing problem)	Speech problems	0.051	Has difficulty speaking, and others find it difficult to understand.		
Spinal	Spinal cord Injury	Spinal cord lesion below neck level (treated)	0.296	Is paralyzed from the waist down, cannot feel or move the legs and has difficulties with urine and bowel control. The person uses a wheelchair to move around.		
Unspecified	Unspecified		0.2		Not from GBD – evaluator's own	Includes cerebral palsy
None	Was assessed in camp and/or services provided but wasn't considered		0			

	person with disability					
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## ***Annex 8 – Assessment improvement scale***

**Table 21 Assessment improvement scale**

	<b>Original description of improvement, from Vaughan and Thapa, 2015</b>	<b>Additional details added for this assessment</b>			
<b>Assessment improvement scale number</b>	<b>Description of improvement</b>	<b>Communication and interaction skills</b>	<b>Training</b>	<b>Activities other than ADL, such as school, social groups/ interaction including SHG</b>	<b>Social security allowance</b>
0	No noticeable improvement seen		Received training but no change in income		Not receiving, or was already receiving prior to intervention
1	Minimal reduction in function limitations, some improvement in social participation, significant further interventions needed. This classification was used for children who are “improving” and perform ADL with supervision.	Improving, basic, etc.	Received training and income increased	Helps, performs with supervision, some participation, etc.	Previously was not receiving but now is
2	Moderate reduction in function limitations, moderate improvement in social participation, moderate further interventions needed. This classification was used for children who have shown “improvement” and can perform ADL independently	Improved, good		Increased participation, good, etc.	
3	Significant reduction in function limitations, significant improvement in social participation, minimal further interventions needed. This classification was used for children who perform ADL	Good, "normal"		Regular attendance/participation including leadership positions	

	independently, have had successful surgeries, attend school and social activities regularly without participation restrictions but continue to receive some support or treatment.				
4	Fully rehabilitated: no functional limitations or restriction in social participation, and no further intervention needed apart from follow-up				

Notes:

- Definition of activities of daily living (ADL): fundamental skills typically needed to manage basic physical needs, including grooming/personal hygiene, dressing, toileting/continence, transferring/ambulating, and eating (Mlinac and Feng 2016, <https://academic.oup.com/acn/article/31/6/506/1727834>)
- Individuals who were assessment but then didn't receive treatment were also scored a 0; they were not removed from analysis because resources were used in the assessment
- There may be some overlap in general description and the additional details added for this assessment columns, but there shouldn't be any contradiction between the two.
- Training provided but not being used = 0
- We cannot account for only seasonal employment
- If there is indication that livelihood status is accompanied by improved social integration in the form of communication and interaction skills, etc., score according to the communication and interaction skills
- Improvements due to social or educational rehab (as opposed to medical) carry a duration of the person's remaining lifetime; otherwise duration of improvement is five years, or remaining lifetime for those deemed fully rehabilitated.

Source for original scale and description of improvement: Author's own; published in Vaughan, Kelsey and Thapa, Aradhana (2015). Cost-effectiveness of a community-based rehabilitation programme in Nepal. Disability, CBR and Inclusive Development (DCID). Vol. 26, No.4. <http://dcidj.org/article/view/457/273>

Source for additional details added for this intervention: evaluators' own.



## Annex 9 – Sample DALYs averted scoring sheet

Part 1 – Information provided by Karuna Foundation Nepal

Batch	VDC	S.No.	Name	Age	Sex	Type of Disability	Diagnosis	Services Provided 2015	Services Provided 2016	Services Provided 2017	Progress/Achievement as of December 2017
2	Sakfara	1	XXX	17	F	Physical	Rt. Shoulder		Disability health screening camp, support to ID card and provided physiotherapy , exercise counseling to parent, vocational training to family	Provided physiotherapy , exercise loan support of family members	Improved physical health after physiotherapy, Going regular to school. Getting positive support from teachers and friends, involved in self help group , participating in saving and credit activities in her family and financial status is same as before
2	Sakfara	2	XXX	50	F	Physical	Rt. Leg Knee amputation		Disability health screening camp, vocational training to family	Sent CBR biratnagar for further investigation and treatment, supported artificial leg	Normal health condition and walking problem is solved, improving in mobility and participation on daily activity, involved in self help group and participating in saving and credit activities and financial status same as before

Part 2 – Scoring done by consultants: baseline code and starting disability weights

Rehabilitated? (Yes/No)	Non-medical interventions only?	Baseline status code 1	Baseline status code 2	Baseline status code 3	Starting disability weight 1 - 2004 weights	Starting disability weight 1- 2016 weights	Starting disability weight 2 - 2004 weights	Starting disability weight 2- 2016 weights	Starting disability weight 3 - 2004 weights	Starting disability weight 3- 2016 weights
No	Yes	Motor_mild			0.381	0.01				

Yes	No	Amputation			0.213	0.061				
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Part 3 – Scoring done by consultants: improvement score, change in disability weights, lifetime/duration of benefits and DALYs averted

Improvement score (0-4)	Notes	Reason for revised improvement score	Revised improvement score	Change in disability weight 1 - 2004 weights	Change in disability weight 1 - 2016 weights	Change in disability weight 2 - 2004 weights	Change in disability weight 2 - 2016 weights	Change in disability weight 3 - 2004 weights	Change in disability weight 3 - 2016 weights	Life expectancy at birth	Correct duration of benefits	DALYs averted - 2004 weights	DALYs averted - 2016 weights
3				0.28575	0.0075					62.0	45.0	12.87095	0.33782
4				0.213	0.061					41.3	5.0	1.065	0.305

## ***Annex 10 – Literature review search strategy***

### **Search Strategy**

Medline search was done via Pubmed from 2<sup>nd</sup> April 2018 to 22<sup>nd</sup> May 2018 without limiting it to any language or years of publication using below mentioned keywords and MeSH terms. However, articles from the 1990s and those written in foreign language, except for English, were later excluded from the study.

1. Prenatal Care
2. Antenatal Care
3. Maternal health Service\*
4. Preconception Care
5. Folic acid supplement\*
6. Folate supplement\*
7. Folic acid fortification
8. 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7
9. Birth defect\*
10. Congenital anomal\*
11. Congenital abnormalit\*
12. Congenital deformit\*
13. Neural tube defect\*
14. Cleft lip\*
15. Cleft palate
16. Anencephal\*
17. Congenital Heart disease\*
18. Orofacial cleft\*
19. Limb reduction defect\*
20. Spina Bifida cystic
21. Encephalocoele
22. Folate sensitive birth defect\*
23. Disab\*
24. 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23
25. 8 AND 24
26. 25 NOT vaccin\*
27. Low and Middle income countr\* OR developing countr\* OR Asia OR Africa OR India OR China OR Bangladesh OR Africa\* countr\* OR \*Asian Countries OR South East Asia
28. 26 AND 27
29. DALY OR Disability adjusted Life Year
30. 29 AND (Folic Acid supplementation OR folate supplementation OR Folic acid fortification)
31. 29 AND Neural tube defect\*

We also further looked into references of the relevant search articles and Lives Saved Tools (LiST) (<http://livessavedtool.org/research/scientific-basis-of-list>) and some of the references suggested by professionals working in the related field.

An overview of search results is provided in Table 22.

**Table 22 Overview of search results**

<b>Source</b>	<b>Search results</b>	<b>Potentially relevant articles reviewed</b>	<b>Articles included in the study</b>
Medline search	494	54	10
LiST (Lives Saved Tool)		2	2
Identified by professionals		3	1
Identified by reference check		4	3

## Annex 11 – Sample HMIS data analysis sheet

VDC/ Indicators	Target pop (U1)	Target pop (U2)	Target expect. live births	BCG	Penta 1	Penta 3	Measles	TT2	TT2+	Growth monitor (new visit)	180 Iron tablets	45 iron tablets	Vit. A to PPM	1st ANC	4th ANC	Inst. delivery	1st PNC	1 <sup>st</sup> new- born care visit	Neon. deaths	Mat. deaths
<b>Batch I</b>																				
Ebhang																				
Erautar																				
Gajurmukhi																				
Jamuna																				
Jirmale																				
Lumde																				
Mabu																				
Maimajhuwa																				
Namsaling																				
Pyang																				
Samalbung																				
Soyang																				
<b>Batch III</b>																				
Chisapani																				
Chulachuli																				
Danabari																				
Deumai Municipality																				
Jitpur																				
Phakphok																				
Siddhithumka																				
Ilam municipality																				
Sangrumba																				
Shanti Danda																				
Soyak																				
Barbote																				
Sakhejung																				
Sulubung																				

Sumbek																				
Suryodaya Municipality																				
Kolbung																				
Pasupati Nagar																				
Shree Antu																				