

ORIGINAL RESEARCH

Cost-effectiveness of a Community-based Rehabilitation Programme in Nepal

Kelsey Vaughan^{1*}, Aradhana Thapa²

1. Director, Bang for Buck Consulting, Netherlands

2. Continuing Education Specialist, University of Washington, USA

ABSTRACT

Purpose: *This study aimed to estimate the cost-effectiveness of a community-based rehabilitation (CBR) programme known as Inspire2Care (I2C), implemented in Nepal by Karuna Foundation Nepal. In the absence of any gold standard methodology to measure cost-effectiveness, the authors developed a new methodology to estimate the programme's achievements and cost-effectiveness.*

Methods: *Financial records were reviewed to determine total expenditure during the period August 2011 - December 2013. Programme records which documented the physical, mental and social status of children and adults with a disability qualitatively before, during and after the intervention were used to determine a starting disability weight and improvement score, which was then converted into a change in disability weight. The disability weight and expected remaining lifespan of each person were used to estimate disability-adjusted life years (DALYs) averted by the intervention. The cost per DALY averted was estimated by dividing the total programme expenditure by the sum of DALYs averted over that same period.*

Results: *I2C cost 204,823 Euros to implement over the period August 2011-December 2013. In total, an estimated 1,065 DALYs were averted from the treatment and rehabilitation components. The cost per DALY averted was 192.34 Euros.*

Conclusions and Implications: *The methodology devised for the study was able to successfully estimate the cost-effectiveness of the I2C programme. Using WHO benchmarks, this programme can be considered highly cost-effective. Other organisations can assess the cost-effectiveness of their programmes by*

* **Corresponding Author:** Kelsey Vaughan, Director, Bang for Buck Consulting, Netherlands. Email: kelsey@bangforbuckconsulting.com

using the assessment improvement score and subsequent conversion to DALYs averted. However, while mental, physical and social gains have been captured, other benefits from I2C cannot be captured in the cost per DALY averted statistic. Further research is needed to develop methods for incorporating these harder-to-measure gains in cost-effectiveness studies with a single outcome measure like the DALY.

Keywords: *Health economics, cost-utility, disability-adjusted life years, disability inclusion, community development, UNCRPD*

INTRODUCTION

About 15% of the world's population lives with some form of disability (Iezzoni, 2011). It is well understood that persons with disabilities face social and environmental barriers to access health services compared to persons without disabilities, and are therefore more likely to suffer from ill health (Iezzoni, 2011). Although the international community has begun to recognise disability as a core issue in development, very little is known about the population and the current programmes to promote inclusion and their well-being (Groce et al, 2011; Croft, 2013).

Nepal, the country where this assessment took place, is in a similar position with regard to the availability of quality data and the provision of equal access to healthcare services. A total of 2% of the population lives with disability (Central Bureau of Statistics, 2012). Their inclusion in services is largely ignored (Schildbach et al, 2012), although it can be argued that the country has made some progress in recent years by introducing and implementing pro-development policies including the Nepal Health Sector Programme (NHSP) (Ministry of Health and Population, Government of Nepal, 2010). NHSP is the national guiding document for the health sector and includes a provision of healthcare for persons with disabilities in the country's Essential Health Care Service package, although it is yet to be costed or implemented. The National Policy and Plan of Action on Disability, developed in 2006, is also an important document that ensures inclusion of disability with priority. To improve the lives of children and persons with disabilities in the country, Karuna Foundation, a Netherlands-based NGO, has implemented the disability prevention and rehabilitation programme 'Inspire2Care' (I2C) together with their Nepal office, Karuna Foundation Nepal, since 2011, in seven Village Development Committees (VDCs) in two districts of Nepal (Karuna Foundation Nepal, 2014a).

The I2C project was conceived as one of the tools to implement the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), a leading international agreement to promote, protect, and ensure the full enjoyment of all human rights and fundamental freedoms by persons with disabilities (Karuna Foundation Nepal, 2014b). The Convention was adopted on 13 December 2006 by the United Nations and signed and ratified by Nepal in 2008 and 2010, respectively. I2C has been designed around the community-based rehabilitation (CBR) Matrix, which consists of five key components: health, education, livelihoods, social context and empowerment, which was developed by the WHO and used by the Government of Nepal for rehabilitation of children and adults with disabilities (Khasnabis et al, 2010).

I2C includes both prevention and rehabilitation components, and focusses on the quality of life, equal rights and opportunities of children and adults with disabilities and their families. Disability prevention activities focus on awareness-raising activities and improving maternal and child health through nutrition interventions. Rehabilitation activities, based on the CBR Matrix components, are customised to address the unique needs of each child and adult.

In keeping with local needs, priorities and resources, the programme is customised and implemented in villages of Nepal. Each village has a Village Disability Rehabilitation Committee (VDRC), a committee mandated by the Government of Nepal to implement rehabilitation activities for persons with disability. In villages where Karuna works, the VDRC recruits a local person to work as a CBR facilitator. The facilitator receives training in rehabilitation, and works with the committee and community to prevent disability and rehabilitate children and adults with disability. CBR facilitators, together with children with disabilities and their families, develop individual rehabilitation plans for each child by focussing on components of the CBR Matrix. Medical rehabilitation activities may include physiotherapy, medical treatment, assistive devices, nutrition rehabilitation and referral to secondary and tertiary levels for required medical care. Educational rehabilitation may include counselling, school enrolment, educational support and linkage to existing scholarship funds to encourage schooling and education. Social rehabilitation can include facilitation to provide government-issued disability identity cards, and counselling and support as necessary to encourage participation in social functions. Furthermore, inclusive child club and self-help group formation and activities, skill development training, livelihood loans, disability awareness, and developing disability friendly public places are part

of the programme. In addition, coordination with local level structures and establishing networks and referral contacts are some key working areas of the facilitators (Karuna Foundation Nepal, 2014a).

Sustainability (financial and managerial) is a key focus from the very beginning. During the first three years, the programme is funded jointly by the community and Karuna Foundation. In the first year, Karuna provides 80% of the direct costs of the programme, reduces this to 50% in the second year and to 30% in the third year. The remaining resources come from the VDCs, which receive funds from the government budget and other local resources including from the people in the community. In the fourth year, the programme is entirely funded by local resources, at which point Karuna only offers technical support for two more years. After the fifth year, the local body and community should be able to continue the programme without external financial or technical support from the Foundation (Karuna Foundation Nepal, 2014b).

Although WHO indicated as early as 1982 that CBR was more cost-effective than institutional rehabilitation (Møller and Huschka, 2008), there are limited studies supporting this (Dawad et al, 2007; Social Policy and Poverty Research Group, 2012). No methodology has been agreed upon for evaluating effectiveness, let alone cost-effectiveness (Finkenflügel et al, 2008; Alavi and Kuper, 2010; Lukersmith et al, 2013), and a review by Robertson et al (2012) documented many methodological problems with existing studies. A letter to the editor of the Asia Pacific Disability Rehabilitation Journal from William Eboh, Federal Ministry of Health and Social Services, Nigeria, noted that “without filling these knowledge gaps [cost, effectiveness including quality and cost-effectiveness] ... it may be difficult to initiate or sustain government interest in CBR” (Eboh, 2000). Particularly in Nepal, where the disability-related components of NHSP are yet to be operationalised and costed, it is imperative to provide evidence about the cost-effectiveness of a CBR programme operating in the country. This study estimated the cost-effectiveness of I2C in terms of cost per disability-adjusted life year (DALY) averted. In the absence of any standard methodology, a new methodology for converting CBR programme effectiveness to DALYs averted was developed and tested by the authors.

Objective

This study aimed to measure cost-effectiveness of a community-based rehabilitation (CBR) programme as implemented over the period August 2011 - December 2013 in Nepal.

METHOD

Setting

The programme was implemented in rural parts of the country, including four villages in Rasuwa district and three villages in Sunsari district. Rasuwa district lies in the central Himalayan region of Nepal, and is one of the remotest areas in the country. Overall the population in Rasuwa has poor health and socio-economic status, with a life expectancy of 55 years (compared to 67 years for the country as a whole), 43% of the population is illiterate (compared to the Nepal average of 34%) and 54% live below the poverty line (compared to the Nepal average of 31%). Sunsari district lies in the eastern Terai region, where the population has a life expectancy of 58 years and illiteracy rates are 30% in rural parts of the district (CBS, 2012). The majority of persons with disability in Nepal lives scattered in rural areas (89%), where there are limited facilities available for persons with disabilities (CBS, 2012; Schildbach et al, 2012).

Study Design

This was a cost-effectiveness assessment, where cost-effectiveness refers to the generic term for economic evaluations comparing the costs and benefits of two or more interventions or programmes and not the specific cost per natural outcome (Drummond, 2005). Cost-effectiveness is measured in terms of cost per DALY averted (also known as cost-utility analysis). The assessment took a programme (implementer) perspective, meaning that only costs and benefits incurred by the implementer are included. Furthermore, only the costs and benefits associated with the rehabilitation side of the programme were scrutinised. The disability prevention component of I2C and the social mobilisation and strengthening the community structure aspects have not been included in this study. The short time frame of the programme and the small sample size made it challenging to assess attribution. Therefore, this assessment does not capture DALYs averted as a result of disabilities prevented, although it is likely that the programme has had an impact there. The study looks at implementation during the period August 2011 - December 2013, which represents the first two and a half years of the five-year programme.

Tools

Programme and financial records were reviewed and relevant information was transferred to Excel sheets created for this study.

Sampling and Sample Size

There were 248 children and 77 adults with disability in the villages included in the programme during the period August 2011 - December 2013. All the available children and adults with disability were included in the assessment.

Data Collection

Expenditure data was derived from various financial audit reports of Karuna Foundation (home office and Nepal) as well as village accounts, and includes Karuna contributions as well as local resources from Village Development Committees (through the District Development Committee's (DDC) budget allocation for disability), district-level organisations like Women and Children Development Office (WCDO), families and others. Karuna expenditure includes direct and indirect expenditure from Nepal as well as the Netherlands. The Nepal expenses were derived from audited expenditure reports which included both contributions to VDRCs as well as other expenses, both in the implementation districts as well as at the country office (CO). For the year 2011, because the assessment period includes only August - December 2011, the total for January to December was multiplied by 5/12 to estimate only the expenditure for August to December (five of the twelve months). Expenses not related to I2C or to the prevention aspect of the programme were excluded. Costs exclusively for I2C were allocated 100% to I2C. Shared expenses (such as office costs, salaries of persons working on both I2C and other programmes) were apportioned to I2C on the basis of percentages suggested by Karuna Foundation staff, which they believe represent the breakdown of work between I2C and a health insurance programme called Share and Care (S&C), taking into account the number of villages each programme was implemented in, by year. In some cases part of the total expenditure was allocated 100% to S&C and the rest allocated on the basis of the above percentages. Karuna's home office (HO) (Netherlands) expenses were allocated to I2C based on the number and size of programmes implemented by the HO.

From HO and CO expenditure, including direct programme support costs at district level, a percentage was removed to account for prevention-related activities (on average 26%). This is based on an analysis by Karuna Foundation Nepal staff of prevention expenditure at village level, and then extrapolated to higher levels.

Direct programme costs were summed with the share of HO and CO expenditure allocated to that district (minus prevention expenditure) for the total Karuna expenditure.

At the village level, I2C is funded on the basis of signed agreements with the Village Disability Rehabilitation Committees (VDRCs). Actual local contributions and expenditure were taken from the audit reports of each VDRC, converted to the January - December calendar year to make them combinable and comparable with the Karuna expenditure.

Karuna Foundation expenditure was summed with non-Karuna contributions at the VDRC level for the total programme expenditure.

Effectiveness data was taken from qualitative reports provided by Karuna Foundation and converted to an improvement score, change in disability weight and number of DALYs averted, as discussed below.

Data Analysis

Based on the qualitative description of services received and the progress/achievement noted, each child was assigned a starting disability weight and the improvement was ranked on the assessment improvement scale. Disability weights (see Table 1) are standardised values derived from multi-country survey data that are assigned to non-fatal health outcomes to capture their severity on a scale of '0' (perfect health) to '1' (equivalent to death), and were taken from the Global Burden of Disease (GBD) 2004, an international project to measure disease burden (WHO, 2008). In some cases the exact condition was not referenced in GBD 2004, so a similar condition was used (see notes).

Table 1: Disability Weights

Condition	Disability Weight	Notes
Amputee	0.213	Average amputee weight of 6 amputee conditions
Burn, > 20% and < 60%, long-term, untreated	0.255	
Cleft lip – cases	0.050	
Cleft palate – cases	0.103	

Cognitive impairment or developmental disability	0.024	
Deafness	0.229	
Dislocation of shoulder, elbow or hip	0.074	Short-term, untreated (long-term not available)
Down Syndrome – cases	0.593	
Epilepsy - cases	0.113	
Fracture, ankle, short-term, untreated	0.196	Used for club foot
Fracture, femur, long-term, untreated	0.272	Used for Genu Valgus
Fracture, hand bone, short-term untreated (long term does not exist)	0.1	
Fractured clavicle, scapula or humerus, short-term untreated (long-term does not exist)	0.153	
Fractured pelvis, short-term (long-term not available)	0.247	
Fractured skull, 0-44 years, untreated, long-term	0.41	Used for physical head injury, post operative
General pain or muscle tightness	0.10	Not from GBD – evaluator's own
Hearing loss, adult onset: mild	0.000	Assumed to have no disability for GBD
Hearing loss, adult onset: moderate, treated	0.040	Assumed similar to mild hearing loss
Hearing loss, adult onset: moderate, untreated	0.120	
Hearing loss, adult onset: severe or profound, treated	0.120	Assumed similar to moderate hearing loss
Hearing loss, adult onset: severe or profound, untreated	0.333	
Injured spinal cord – untreated, long-term weight	0.725	
Injury to eyes – untreated, long-term weight	0.300	
Low vision	0.170	
Macular degeneration: blindness	0.600	
Mental retardation	0.459	

Migraine	0.029	
Motor deficit	0.381	Varies with age and treatment
Neoplasm, malignant, other	0.09	Used half weight for non-malignant (evaluator's own)
Poliomyelitis - cases - lameness	0.369	
Refractive errors: blindness	0.430	Half weight used for blindness in one eye (not from GBD)
Refractive errors: low vision	0.170	
Unspecified physical or neurological disability	0.20	Not from GBD – evaluator's own

Source: WHO, 2008. Some notes are authors' own.

Each child's condition was qualitatively assessed as part of the development of their individual rehabilitation plan (prior to commencing treatment under I2C) and again at the end of treatment or in December 2013, whichever came first. The qualitative assessments were converted to an assessment improvement scale ranging from 0 - 4, as described in Table 2.

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 children who are "improving" and perform activities of daily living (ADL) with supervision.
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.

3	Significant reduction in function limitations, significant improvement in social participation, minimal further interventions needed. This classification was used for children 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: Improvement scale was developed by authors using the International Classification of Functioning, Disability and Health (ICF) domains of functioning (see text for details)

For clarity, the domains of functioning based on the International Classification of Functioning, Disability and Health (ICF) have been used to describe each level of the assessment improvement scale. ICF is a WHO framework to measure health and disability at both individual and population levels (WHO, 2001), but the assessment improvement scale is not based on ICF as such.

It is assumed that each child started at a '0' on the improvement scale, corresponding to no change in their status, which was assumed to be the status before 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 child 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 and changing or upgradation of assistive devices (WHO, 2001). A score of '4' was only given in a few cases (for example, mild physical deformity) where the impairment has been medically/ surgically corrected, and consequently the child has not retained any functional or participation-related restriction. In other cases, the maximum possible score was a '3' to recognise the continued presence of the disability despite treatment. If limited information was provided about the child's improvement but some improvement was noted, the child received a '1' on the assessment improvement scale. In the one case where negative improvement was seen in terms of increased epileptic attacks despite taking epilepsy medication, a '0' was recorded on the assessment improvement scale since the condition

corresponding to the disability weight – epilepsy – was unchanged, even if more frequent attacks were happening.

The scoring was done by a team of two; one researcher made the initial scoring for all children, which was reviewed by Karuna Foundation Nepal staff who were familiar with the children. Some scores were changed based on the second review; these were confirmed by the first researcher on the basis of a detailed written explanation.

The improvement score was then translated to a change in disability weight. Each one-point assessment improvement scale increase (for example, from '1' to '2', or from '2' to '3') represents a 25% reduction in the disability weight; for example, a child whose progress/achievement is rated as '3' reduces the starting disability weight by 75%. If his/her starting disability weight was 0.170 (for example, low vision due to refractive errors), the weight is reduced by 0.1275, and on correcting the refractive error, to 0.0425.

The change in disability weight was then used to calculate DALYs averted, using the prevalence formula: $DALY = YLL + YLD$, where YLL is the Years of Life Lost and YLD is the Years Lost due to Disability. YLL is assumed to be zero, and $YLD = I \times DW \times L$, where I = number of incident cases, DW = change in disability weight and L = life expectancy in years (Mathers et al, 2008). Life expectancy refers to the duration the benefit will be sustained without further investment. This is different for different types of interventions:

1. Educational gains, the ID card and social participation will last a lifetime, so it is assumed the duration of benefits is the child's remaining life expectancy.
2. It is assumed assistive devices have a lifespan of five years (Temple-Bird et al, 2005).
3. For surgeries, it is assumed that the impact gained will last the child's remaining lifetime.
4. For other cases including physiotherapy, the benefits gained will last a lifetime without any additional cost. Some children will also continue physiotherapy at home since parents have been trained to provide it; this is also without additional programme costs. As with the above point, it is assumed the duration of benefits is the child's remaining life expectancy.
5. For children deemed fully rehabilitated, no further services are needed, therefore the duration of benefit is the child's remaining lifetime.

Remaining life expectancy at time of improvement (end 2013) was calculated, assuming the average life expectancy at birth for each child (ranging from 56.6 years for someone born in 1992 to 68 years for someone born in 2012, based on World Bank (2014) data minus years of life already lived (their age) as of 2013). If the age of the child was not available, an average age of 11 was used.

The I2C programme also benefitted adults with disabilities in the form of access to identity cards and allowances, assistive devices, linkages with specialised services and livelihood loans. In Sunsari the average number of adults per village (in each of three villages) was 15, and in Rasuwa there was an average of 8 adults per village (in each of four villages) (estimates provided by Karuna Foundation staff). Without detailed information on these adults, the average reduction in DALY weight per adult was estimated to be the same as the average per child in that district (0.1046 in Rasuwa and 0.0989 in Sunsari). The same process of converting the change in disability weight to DALYs averted was used as described above, based on an average lifetime of 17.6 years, assuming an age at treatment of 31.5 years.

Cost per DALY averted was calculated by dividing the total intervention cost for the period August 2011-December 2013 by the number of DALYs averted during that same time period.

Ethical Considerations

This study used existing financial records and anonymised participant data. No ethical approval was required.

RESULTS

Using this new methodology, the total I2C expenditure (excluding prevention expenditure) was estimated to be 204,823 Euros, including 80,071 Euros (39%) incurred at Karuna head office level, 112,156 Euros (55%) spent at the Karuna country office level (including district implementation) and 12,535 Euros (6%) in non-Karuna contributions at the district level.

An estimated 1,065 DALYs were averted in direct beneficiaries, including 928 in children and 137 in adults.

The cost per DALY averted is 192.34 Euros.

DISCUSSION

A new methodology based on converting qualitative descriptions of health improvement into DALYs averted was successfully developed and used to measure the cost-effectiveness of the CBR component of Inspire2Care. At 192.34 Euros, the cost per DALY averted of I2C is comparable with other available evidence (although methodological differences are likely and reported figures have not been adjusted to 2013 levels), both for disability-related programmes and more generally. For example, a CBR programme in Myanmar for leprosy-affected beneficiaries including medical rehabilitation, housing, micro-credit and livelihood assistance found a cost per beneficiary household of US\$400.80 (Social Policy and Poverty Research Group, 2012), while an NGO-initiated programme in South Africa found a cost per beneficiary per year of R5790 (396 Euros, assuming an exchange rate of 0.068 EUR per 1 ZAR, 17 December 2014). The cost per DALY averted for leprosy clients needing treatment for reactions and ulcers, footwear and/or self-care education was estimated to be US\$7 in a generic setting (Remme, 2006, cited in Van Veen et al, 2009) and US\$110 for those needing reconstructive surgery. Other cost per DALY averted estimates for leprosy include US\$38 for case detection and treatment and US\$1-110 for prevention of leprosy disability (Jamison et al, 2006).

Outside the disability world, there is a wide range of cost per DALY averted estimates for public health interventions in the developing world. In Nepal, NHSP-I estimated a cost per DALY averted of US\$144, while NHSP II was estimated at US\$147 (Ministry of Health and Population, Government of Nepal, 2010). Although the cost per DALY averted of I2C is more than that of interventions implemented under NHSP, it is important to remember that disability rehabilitation has not been implemented by NHSP. Disability prevention is not explicitly costed which makes it difficult to compare NHSP with I2C. The Government of Nepal has already made several notable commitments to disability prevention and treatment, though they have yet to be operationalised on a large scale.

Example cost of DALY averted estimates outside Nepal include US\$1 for prevention of leprosy disability, US\$270 per DALY averted for construction and promotion of basic sanitation facilities in developing countries, US\$120 per DALY averted for preventing and treating coinfection (TB/HIV) in developing countries (Jamison et al, 2006), US\$3.70-11.20 for malaria intermittent prevention treatment in infants (IPTi) in Mozambique and Tanzania (Hutton et al, 2009), and

less than US\$5 per DALY averted for promoting exclusive breastfeeding, measles immunisation, ORT and hygiene in developing countries (Jamison et al, 2006).

Within these findings, the I2C cost per DALY averted is perhaps best compared against the cost per DALY averted findings for leprosy clients in a generic setting needing reconstructive surgery (192 Euros for I2C vs US\$110 for leprosy reconstructive surgeries). However, without knowing which costs were included in the leprosy study and other methodological considerations (including adjusting the leprosy figures to 2013 levels), these findings should be interpreted with caution.

Using the WHO benchmark which compares cost per DALY averted with a country's GDP, I2C as implemented over the period August 2011-December 2013 can be considered highly cost-effective since the programme's cost per DALY averted falls below Nepal's GDP per capita of US\$694.10 or 522.77 EUR in 2013 (World Bank 2013). This study has shown Karuna Foundation's CBR approach to be a cost-effective way of implementing disability-related commitments, including the UNCRPD, when drawing comparisons with WHO benchmarks.

It should be noted that 100% of the claimed DALYs averted have been attributed to I2C, even though some expenditure (like the donated wheelchair) which contributed to averting these DALYs have been excluded from the expenditures calculations. Furthermore, some changes may be the result of a combined effort with families, schools, and other outside partners. It is assumed these efforts would not have happened without the opportunity and coordination provided by I2C, but the authors acknowledge that the programme effect may be slightly overestimated, although the estimated DALYs averted remain valid. If these findings were to be considered as input for a future government policy which may or may not equally rely on donor and charitable funding, the exclusion of outside inputs would need to be reconsidered.

Methodological Issues

The DALY is a commonly accepted indicator to measure health status at the population level, derived by combining population-based epidemiological data on incidence and prevalence along with life expectancy with disability weights reflecting how much a condition affects a person (an individual measure, although it has been subject to criticism in that not all individuals will experience

the condition in the same way, thus making a single weight inadequate) (Voigt and King, 2014). The methodology developed by the authors differs from the standard application of DALYs in that DALYs averted have been estimated at the individual level, but it works since population-based epidemiological data have not been used but rather actual individual assessments of disability and improvement. A similar methodological approach to estimate individual DALYs of participants in a large cancer and nutrition study in the Netherlands was used by Struijk et al (2013).

To make the application to disability relevant, the authors have assumed that severity of disease as noted by the disability weight reflects not only a physical health condition but all the corresponding functional limitations and social implications that can accompany the health condition. In more recent updates to disability weights, there has been an attempt to separate the health-related losses from welfare and social issues (although it has been acknowledged that this is difficult to do; as such, some but not all of the updated weights still include non-health aspects) (Murray et al, 2013; Voigt and King, 2014). This has resulted in a reduction in weights for disability-related conditions targeted by CBR programmes. Given that disability is a multidimensional construct which includes aspects of body, individual and society (Leonardi and Ustun, 2002), the authors believe this is not an improvement in the disability weighting methodology. Consistency in the inclusion of non-medical aspects has been noted as a point for improvement in GBD methods (Voigt and King, 2014).

The authors of the current study have noted that their methodology works well for many disability conditions. However, for cases with severe functional limitation (for example, multiple physical and severe intellectual disabilities) where the condition itself does not have any available therapeutic solution, the methodology, as it is, does not respond as well due to the fact that while the improvement may be significant in the life of the child, it corresponds to a small change on the assessment scale. Measuring improvement after a longer interval from the time of the intervention may show more results on the improvement scale.

Furthermore, recent updates to disability weights which provide a separate weight for the untreated and treated state of a condition may help address this shortcoming (Global Burden of Disease Study, 2012; Salomon et al, 2015). In future applications of their methodology, the authors would therefore suggest that where GBD provides a treated and untreated weight for a particular condition,

the maximum possible improvement could be set to the treated weight (instead of at '3' as they have done) to reflect the continued presence of the disability.

Additionally, new updates to WHO's Disability Assessment Schedule 2.0 (WHO, 2011) provide a generic assessment instrument for health and disability and could be considered in place of the assessment improvement scale.

Additionally, although the methodology developed by the authors for assessing the cost per DALY averted captures mental, physical and social gains made, some of the major benefits or gains from the I2C programme – particularly the community mobilisation around disability, improvements in attitudes of community members towards persons with disability and social cohesion – have not been measured or captured in the cost per DALY averted statistic. This is a problem for CBR interventions like I2C which span broader than the health sector, including all five components of the CBR Matrix (Voigt and King, 2014). In considering other ways to measure the costs and benefits of CBR interventions like I2C, an alternative would be a quality of life measurement, a holistic concept that goes beyond the health dimension, which may capture the impact of gains in the non-health CBR Matrix components. However, quality of life is affected not only by the disability but also by a person's other experiences. It can also be quite subjective, with two persons with a similar disability experiencing it in different ways. And because the cost-effectiveness of health programmes is generally measured in terms of cost per DALY averted, using quality of life measurements instead of DALYs makes it impossible to compare the CBR programme with other programmes outside the disability world, or even other programmes within the disability world which may use different outcome measures. A Social Return on Investment study may be able to capture the value communities themselves place on their increased mobilisation and other less tangible benefits from the programme, although a major drawback of using multiple outcome or effectiveness indicators is the possibility of losing sight of the "big picture".

Also, Parks (2014) notes that *"discounting life in general is problematic, but especially so for people with lifelong disabilities; activists with disabilities make a philosophical argument that their lives should be valued equally to those of people with no disabilities."* However, in response to this valuable argument, the authors of the current study would like to say that their intention of using the DALY was not to devalue the lives of persons with disabilities but rather to reflect the change in health status this population experiences, which is often otherwise ignored, especially in developing countries. Additionally, it provides a commonly accepted way to

measure improvements in health status that can be achieved by programmes such as I2C. Another advantage and reason to use the DALY in this research was that it makes it possible to argue for the cost-effectiveness of such programmes by making them comparable to non-disability programmes.

CONCLUSION

This study found the Inspire2Care programme to be a highly cost-effective model to achieve improvement in health among children with disabilities in Nepal, comparing the cost per DALY averted with WHO thresholds for cost-effectiveness (WHO, 2014). These findings suggest the model may have potential to be adopted in Nepal and beyond by governments and other organisations as a way to implement UNCRPD in a holistic and cost-effective way. The newly developed and tested methodology for converting descriptive changes in health status, participation and functioning into an improvement score, change in disability weight and DALYs averted can be tested (with the changes noted by the authors) by other organisations seeking to evaluate the cost-effectiveness of their CBR programmes. Although not a perfect solution, this technique provides a single metric for measuring cost-effectiveness and also makes comparability with other health programmes possible.

The authors believe there is a strong need for future research to value and incorporate the less-tangible benefits of CBR programmes in a single metric like the DALY.

Limitations

There are a number of limitations related to the assessment. Including only Karuna and VDRC expenditure (see section on excluded expenditure) is a limitation in that it was not possible to know the entire cost of the programme including donated wheelchairs, donated time of VDRC committee members, etc. At the same time, the authors have attributed 100% of the claimed DALYs averted to I2C. It has been assumed that the wheelchair would probably not have been donated without I2C, and that any replication of the programme (for example, by the Government of Nepal) would also rely on these donated items.

The assessment focusses only on the period August 2011- December 2013, although it is recognised that some expenditure (particularly start-up/investment costs) which is in actuality annualised over at least the full five-year duration of

the programme, if not longer, has not been incorporated. This annualisation is likely to improve the cost-effectiveness. Additionally, the assessed period is a pilot phase, and lessons learned during this time may improve the cost-effectiveness of future applications of the programme. At the same time, investment costs were also higher in the pilot phase. Moreover, including the prevention and community mobilisation components of the programme in future assessments will impact on cost-effectiveness, most likely in a positive way.

The shortcomings with the disability weights as provided by the GBD project have been noted in the text.

Finally, the assessment has relied upon progress reports of individual children which were not externally audited in the interests of saving time and money.

ACKNOWLEDGEMENT

This study was funded by Netherlands Leprosy Relief (NLR) and Liliane Foundation. Thanks to Betteke de Gaay Fortman and Merel Schreurs from Karuna Foundation, and Deepak Raj Sapkota from Karuna Foundation Nepal for providing valuable comments on earlier versions of this article.

REFERENCES

- Alavi Y, Kuper H (2010). Evaluating the impact of rehabilitation in the lives of people with disabilities and their families in low and middle income countries: a review of tools. Bensheim, Germany: CBM.
- Central Bureau of Statistics (2012). National Population and Housing Census 2011 (National Report). Kathmandu: National Planning Commission.
- Croft A (2013). Promoting access to education for disabled children in low-income countries: Do we need to know how many disabled children there are? *International Journal of Educational Development*; 33(3): 233-243. <http://dx.doi.org/10.1016/j.ijedudev.2012.08.005>
- Dawad S, Jobson G, Ganie S, Quinlan T (2007). Costing and benefits of comprehensive care offered by the Valley Trust. Available from: <http://www.heard.org.za/downloads/costing-and-benefits-of-comprehensive-care-offered-by-valley-trust.pdf> [Accessed on 31 July 2015]
- Drummond MF (2005). *Methods for the economic evaluation of healthcare programmes*. Oxford: Oxford University Press.
- Eboh W (2000). Need for more comprehensive evaluation reports of CBR programmes. Available from: <http://www.dinf.ne.jp/doc/english/asia/resource/apdrj/z13jo0300/z13jo0314.html> [Accessed on 12 March 2015]

Finkenflügel H, Cornielje H, Velema J (2008). The use of classification models in the evaluation of CBR programmes. *Disability and rehabilitation*; 30(5): 348-354. <http://dx.doi.org/10.1080/09638280701257288> PMID:17852305

Groce N, Kett M, Lang R, Trani J (2011). Disability and poverty: The need for a more nuanced understanding of implications for development policy and practice. *Third World Quarterly*; 32(8): 1493-1513. <http://dx.doi.org/10.1080/01436597.2011.604520>

Hutton G, Schellenberg D, Tediosi F, Macete E, Kahigwa E, Sigauque B, Mas X, Trapero M, Tanner M, Trilla A, Alonso P, Menendez C (2009). Cost-effectiveness of malaria intermittent preventive treatment in infants (IPTi) in Mozambique and the United Republic of Tanzania. *Bulletin of the World Health Organisation*; 87(2): 123-129. <http://dx.doi.org/10.2471/BLT.08.051961> PMID:19274364 PMCid:PMC2636201

Iezzoni LI (2011). Eliminating health and healthcare disparities among the growing population of people with disabilities. *Health Affairs*; 30(10): 1947-1954. <http://dx.doi.org/10.1377/hlthaff.2011.0613> PMID:21976339

Institute for Health Metrics and Evaluation (IHME) (2012). Global burden of disease study 2010. Disability Weights. Available from: <http://ghdx.healthdata.org/record/global-burden-disease-study-2010-gbd-2010-disability-weights> [Accessed on 17 December 2014]

Jamison DT, Breman JG, Measham AR, et al (2006). Cost-effective strategies for the excess burden of disease in developing countries. *Priorities in Health*. Washington, DC: World Bank. Available from: <http://www.ncbi.nlm.nih.gov/books/NBK10258/> [Accessed on 1 February 2016] <http://dx.doi.org/10.1596/978-0-8213-6260-0>; <http://dx.doi.org/10.1596/978-0-8213-6260-0/Chpt-4>

Karuna Foundation Nepal (2014a). Inspire2Care. Available from: http://www.karunafoundation.nl/projecten/inspiretocare_uk.html [Accessed on 10 December 2014]

Karuna Foundation Nepal (2014b). From pilot towards impact: First phase in Nepal (2007 - 2013). Karuna Foundation Nepal, Kathmandu, Nepal.

Khasnabis C, Heinicke MK, Achu K et al (2010). *Towards community-based inclusive development*. Geneva: WHO Press.

Leonardi M, Ustun TB (2002). The global burden of epilepsy. *Epilepsia*; 43(s6): 21-25. <http://dx.doi.org/10.1046/j.1528-1157.43.s.6.11.x>

Lukersmith S, Hartley S, Kuipers P, Madden R, Llewellyn G, Dune T (2013). Community-based rehabilitation (CBR) monitoring and evaluation methods and tools: a literature review. *Disability and rehabilitation*; 35(23): 1941-1953. <http://dx.doi.org/10.3109/09638288.2013.770078>

Mathers C, Fat DM, Boerma JT (2008). The global burden of disease: 2004 update. World Health Organisation. Available from: http://www.who.int/healthinfo/global_burden_disease/GBD_report_2004update_full.pdf [Accessed on 10 December 2014] <http://dx.doi.org/10.1016/b978-012373960-5.00335-x>

Ministry of Health and Population & Government of Nepal (2010). *Nepal Health Sector Programme-II (NHSP -II) 2010 – 2015*. Kathmandu: Ministry of Health and Population, Nepal.

- Møller V, Huschka D (2008). *Quality of life and the millennium challenge*. Heidelberg: Springer Netherlands. http://dx.doi.org/10.1007/978-1-4020-8569-7_1
- Murray CJL, Ezzati M, Flaxman AD, Lim S, Lozano R, Michaud C, Naghavi M, Salomon JA, Shibuya K, Vos T, Wikler D, Lopez AD (2013). GBD 2010: design, definitions, and metrics. *The Lancet*; 380(9859): 2063-2066. [http://dx.doi.org/10.1016/S0140-6736\(12\)61899-6](http://dx.doi.org/10.1016/S0140-6736(12)61899-6)
- Parks R (2014). The rise, critique and persistence of the DALY in global health. Available from: <http://www.ghjournal.org/the-rise-critique-and-persistence-of-the-daly-in-global-health/> [Accessed on 10 December 2014]
- Robertson J, Emerson E, Hatton C, Yasamy MT (2012). Efficacy of community-based rehabilitation for children with or at significant risk of intellectual disabilities in low-and middle-income countries: a review. *Journal of Applied Research in Intellectual Disabilities*; 25(2): 143-154. <http://dx.doi.org/10.1111/j.1468-3148.2011.00679.x>
- Salomon JA, Haagsma JA, Davis A, de Noordhout CM, Polinder S, Havelaar AH, Cassini A, Devleeschauwer B, Kretzschmar M, Speybroeck N, Murray CJL, Vos T (2015). Disability weights for the global burden of disease 2013 study. *The Lancet Global Health*; 3(11): e723. [http://dx.doi.org/10.1016/S2214-109X\(15\)00069-8](http://dx.doi.org/10.1016/S2214-109X(15)00069-8)
- Schildbach E, Mey PD, Dhungana BM, Lamichhane J (2012). Persons with disabilities and their access to healthcare services in Nepal. Kathmandu: The Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ).
- Social Policy and Poverty Research Group (SPPR) (2012). Including people affected by leprosy in mainstream community-based rehabilitation programmes: efficacy and cost-effectiveness. *SPPR Bulletin*; 1(4). Available from: http://www.lift-fund.org/sites/lift-fund.org/files/publication/Vol%201,No.4%20May%202012%20Bulletin_0.pdf [Accessed on 1 February 2016]
- Struijk EA, May AM, Beulens JWJ, de Wit GA, Boer JMA, Onland-Moret NC, Van der Schouw YT, Bueno-de-Mesquita HB, Hoekstra J, Peeters PHM (2013). Development of methodology for disability-adjusted life years (DALYs) calculation based on real-life data. *PLOS ONE*; 8(9). <http://dx.doi.org/10.1371/journal.pone.0074294>
- Temple-Bird C, Kawohl W, Lenel A, Kaur M (2005). *How to plan and budget for your healthcare technology*. United Kingdom: Teaching-aids At Low Cost.
- Van Veen NH, McNamee P, Richardus JH, Smith WC (2009). Cost-effectiveness of interventions to prevent disability in leprosy: a systematic review. *PLOS ONE*; 4(2): e4548. <http://dx.doi.org/10.1371/journal.pone.0004548>
- Voigt K, King NB (2014). Disability weights in the global burden of disease 2010 study: two steps forward, one step back? *Bulletin of the World Health Organisation*; 92(3): 226-228. <http://dx.doi.org/10.2471/BLT.13.126227>
- World Bank (2013). GDP per capita. Available from: <http://data.worldbank.org/indicator/NY.GDP.PCAP.CD> [Accessed on 17 December 2014]
- World Bank (2014). World development indicators database. Available from: data.worldbank.org/indicator/SP.DYN.CBRT.IN [Accessed on 17 December 2014].

World Health Organisation (2001). International classification of functioning, disability and health. Geneva: World Health Organisation.

World Health Organisation (2008). Global burden of disease 2004 update: disability weights for diseases and conditions. Available from: http://www.who.int/healthinfo/global_burden_disease/GBD2004_DisabilityWeights.pdf [Accessed on 15 December 2014]

World Health Organisation (2011). WHODAS 2.0. Available from: <http://www.who.int/classifications/icf/whodasii/en/> [Accessed on 17 December 2014].

World Health Organisation (2014). Cost effectiveness and strategic planning (WHO-CHOICE): cost-effectiveness thresholds. Available from: http://www.who.int/choice/costs/CER_levels/en/ [Accessed on 1 February 2016]

World Health Organisation (no date). Disability weights, discounting and age weighting of DALYs. Available from: http://www.who.int/healthinfo/global_burden_disease/daly_disability_weight/en/ [Accessed on 17 December 2014]