Cost-effectiveness of the Tunafasi programme's community-based rehabilitation (CBR) component

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Table of Contents

Acronyms ii
Executive summary 1
1 Introduction 2
2 Methods 3
3 Findings 5
3.1 Sample characteristics 5
3.2 Expenditures 5
3.3 DALYs averted 6
3.4 Cost per DALY averted 7
4 Contextualizing the results 8
4.1 Affordability 8
4.2 Comparison with other findings 10
5 Recommendations 11
6 Next steps 14
Annex 1: Disability-adjusted life year (DALY) explained 17
Annex 2: Comparator results 26
Annex 3: CHE, 2018 and 2050, by country 27

Acronyms

ADED	Appui au Développement de l'Enfant en Detresse
CBR	Community-based rehabilitation
CBRF	Community-based rehabilitation facilitator
CHE	Current health expenditure
DALY	Disability-adjusted life year
DPO	Disabled People's Organization
DRC	Democratic Republic of the Congo
DW	Disability weight
GBD	Global Burden of Disease
GDP	Gross domestic product
HHS	Household survey
HMIS	Health management information system
I2C	Inspire2Care
ICER	Incremental cost-effectiveness ratio
LiST	Lives Saved Tool
LOE	Level of effort
NCDs	Non-communicable diseases
NGO	Non-governmental organization
NHSP	Nepal Health Sector Programme
PHC	Primary health care
PSI	Population Services International
TA	Technical assistance
UNDP	United Nations Development Programme
WHO	World Health Organization
YLD	Years Lost due to Disability
YLL	Years of Life Lost

Executive summary

Since 2020, the Tunafasi program, a partnership between the Congolese organization Appui au Développement de l'Enfant en Detresse (ADED) and the government, aims to implement the country's community-based rehabilitation (CBR) strategy in Uvira, Democratic Republic of Congo (DRC). The program is modelled after the Inspire2Care (I2C) disability prevention and rehabilitation program, implemented by Karuna Foundation in Nepal since 2007. The CBR program implemented by Tunafasi and ADED are currently funded by Impaction Foundation and its investors and Liliane Fonds, with government paying the salaries of CBR facilitators and the health zone focal person. In early 2022, Impaction Foundation commissioned a cost-effectiveness study to provide evidence for investors to better understand the impact of their investment, and to generate evidence to support the program's lobbying and advocacy efforts with the government.

Considering expenditures based on audited financial statements and results for the rehabilitation component of the program only for the period 1 February 2019 to 31 December 2021, the research found that the program spent €66,329 to assess and treat 530 children and youth with disability ("the sample"). Children and youth assessed but not yet beginning treatment by end 2021 were excluded. Similarly, expenditures corresponding to these children and youth not yet being treated but also related to other CBR pillars or the program's prevention component were also excluded. Through treatment, nearly 250 disability-adjusted life years (DALYs) were averted in these 530 children and youth[1], at a cost per DALY averted of €266. Per person in the sample, this equates to an average of €43 annually. These results are impressive given the given the low levels of expenditure and in light of the many challenges around implementing a project in its infancy years during an unprecedented global pandemic, not the mention that DRC Is an extremely difficult context to begin with.

While tempting to compare the Tunafasi results with results from similar programs[2,3], there are several important differences between the programs and the study methods that limit comparability. Comparing the cost per DALY averted results for Tunafasi with other health interventions implemented in low- and middle income countries like DRC, the Tunafasi program results are well in line: roughly half of interventions likely cost less per DALY averted, while roughly half cost more.

While the cost per DALY averted of the Tunafasi program is still higher than what thresholds of affordability consider acceptable for DRC, the research finds that current project costs are not outside the reach of the government, and advocacy and lobbying efforts should share this as part of their strategy. The consultant considers the investors' five year exit strategy (not counting the preparation year (2019)) ambitious in this challenging context; external financial support will likely be required to sustain some level of involvement from ADED beyond 2024.

The Tunafasi model of implementing CBR through primary health care with support from a non-governmental organization (NGO) and initial external backing is a trendsetter in DRC and likely the entire region. This consultant sees no reason to not move forward with replication in other regions and/or countries, but advises the project to address several areas for concern. This report includes recommendations for improving data availability and quality, staffing, project visibility and funding, and proposes next steps in terms of additional research.

[1] DALYs averted include all benefits achieved with the funds expended during the time period 1 February 2019 to 31 December 2021 (annualized). Benefits may extend beyond 31 December 2021, but can be sustained without additional financial investment.

[2] The pilot assessment found a cost per DALY averted of €197, based on a sample of 248 children and 77 adults. See Vaughan, Thapa and Paudel. Cost-effectiveness assessment of the Inspire2Care program in Ilam. October 2018.

[3] The 2018 assessment found a cost per DALY averted of €384-843 (range reflects use of different disability weights) for batches 1 and 2 in Ilam, based on a sample of 123 children and 491 adults in 10 villages, with findings extrapolated to 20 additional villages. See Vaughan, Thapa and Paudel. Cost-effectiveness assessment of the Inspire2Care program in Ilam. October 2018.

Finally, it is important to note that this study has only captured primarily health-related gains, while some of the major benefits or gains from the program – particularly the community mobilization around disability, skills 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.

1 Introduction

Since 2020, the Congolese organization Appui au Développement de l'Enfant en Detresse (ADED) has been implementing the Tunafasi program in the Uvira health zone of South Kivu province of eastern Democratic Republic of the Congo (DRC), in partnership with Impaction Foundation and its investors, Liliane Fonds and Bezev. The program's overall aim is to enable a positive environment, sustainable autonomy, and equal opportunity for children and youth (under the age of approximately 33 years) with disability and their communities through the integration of the community-based rehabilitation (CBR) program in the state system and with community contributions. There is also a disability prevention component which started in 2021 and aims to strengthen local health facilities to improve the quality of antenatal care, facility-based deliveries and immunizations, among other aspects. The program is modelled after the Inspire2Care (I2C) disability prevention and rehabilitation program, implemented by Karuna Foundation in Nepal.

Together with 20 CBR facilitators (CBRFs), who are government employees and work at 22 different health facilities, ADED officers has compiled a list of children and youth under the age of 33 with a disability who are living in Uvira. Each person the program identifies with a disability is assessed by a multi-disciplinary team from ADED; after diagnosis, a personal plan of rehabilitative assistance is developed. The range of possible support is broad and can include services such as assistive devices, physical therapy, skills training and more. ADED officers and the CBRFs work together to ensure the rehabilitative plans are executed, connecting children and youth with other community organizations to provide therapy and assistive devices where necessary.

The partnership created by the Tunafasi project between ADED and the government to jointly implement the country's CBR strategy, embedding it in primary health care (PHC), is unique[4]. Despite the presence of other national and international non-governmental organizations (NGOs) working on disability in DRC, Uvira is the only health zone in the country known to be implementing all five CBR pillars. Six other health zones in South Kivu (out of 34 total) are known to be implementing the health pillar only; for the country as a whole, 37 out of the country's 517 health zones are known to be implementing the health pillar only[5]. External funding for the project runs through the end of 2024, at which point Impaction Foundation and its investors would like to transition out their support. It is hoped that ADED and the government would be able to continue running CBR and prevention activities without external funding. To better understand the impact of their investment, and to inform future planning, Impaction Foundation and its investors commissioned health economist Kelsey Vaughan to assess the cost-effectiveness of the program's rehabilitation component. This research also provides important evidence to support the program's lobbying and advocacy efforts with the Congolese government.

[4] Programme National de Réadaptation a base communautaire. Document de stratégie réadaptation a base communautaire pour la République Démocratique du Congo. No date.
[5] Personal correspondence between ADED and provincial CBR officer.

This report summarizes the methods for this assessment, the main findings and provides a number of recommendations. Findings are compared with other cost-effectiveness results from DRC and other countries. It concludes with a summary of suggested next steps, including possibilities for future research.

2 Methods

The desk-based assessment covered the period from program initiation through 31 December 2021. The assessment itself was conducted over the period April to September 2022. It followed standard methods used previously to assess similar programs, namely the I2C program in Nepal[6]. In summary, and in consultation with program advisors Betteke de Gaay Fortman and Ram Krishna Thapa, the consultant reviewed budget, expenditure and audit reports to identify all financial costs related to the CBR component of the program which were incurred by four parties[7], namely 1) ADED, 2) the government, and 3) Impaction Foundation and its investors and 4) Liliane Fonds, from startup in February 2019 to 31 December 2021. Expenditures related to prevention-related activities were excluded on a percentage basis considering the proportional focus on rehabilitation as opposed to prevention, which varied by year. CBR expenditures were allocated to the health component as a percentage share of health of all five CBR pillar expenditures, calculated from expenditure records.

Expenditures deemed to be related to CBR's health pillar were then classified into four groups: 1) human resources (including ADED staff and CBRFs salaries which are paid by the government), 2) implementation (meaning direct program costs), 3) running costs (such as office expenditures and bank charges) and 4) other. The "other" category encompasses technical assistance (TA) from the Netherlands, partnership development costs and learning-related costs such as conferences. For shared expenditures such as staff who worked on other activities, or non-health components of CBR, only a partial percentage deemed to correspond to the CBR health component was included. Expenditures associated with preparatory activities for the program, and other investment-type expenditures such as training, whose benefits extended over multiple years, were annualized across the program years (until end 2024) using a 3% discount rate[8]. Costs incurred by families and caregivers, such as transportation to appointments, as well as costs incurred by other organizations, such as those donating assistive devices, were excluded from the analysis. Expenditures are reported in euros (€) of the year in which they were originally incurred.

[6] 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

[7] Bezev was excluded as they focus only on education.

[8] Annualizing refers to dividing up-front expenditures across the years that benefit from the expenditure, and time preferences are accounted for using the discount rate.

The impact of the CBR component of the program was estimated in terms of disability-adjusted life years (DALYs) averted (Box 1), on the basis of a large sample of children and youth with a disability who were assessed by ADED's team before 1 January 2022. The sample was extracted from a database that was being completed and rolled out by ADED immediately prior to the research commencing (April 2022). When the research began in April, ADED had identified over 1,200 persons with a disability as of 31 December 2021, of which approximately 764 had been assessed and a rehabilitative plan developed. The final number of children and youth included in the sample was 530, though we later learned there were an additional 40 individuals who had also received services. The difference between the 530 in the sample and the 764 already assessed includes those only recently assessed (e.g. in 2022, and therefore outside the study period), those lost to follow up (40), deaths (14) and those who were determined to already exist in the database, therefore were duplicate records.

Box 1. What are DALYs?

Disability-adjusted life years (DALYs) are a measure of overall disease burden, expressed as the number of years lost due to ill-health, disability (meaning reduced capacity due to disease) or early death. In the context of CBR, DALYs averted indicate the extent to which CBR activities are improving the health and quality of life in persons with disability. For more information, see Annex 1.

ADED staff provided qualitative information about the disability(ies) of each person on the list (n = 530), classified up to three disability types, each with a corresponding sub-type, using standard categories, provided information on the services received and classified improvement using a standard scale (Annex 1). Services received and improvement were meant to be through December 2021, but because of how the data was collected, the consultant and advisors were unable to verify that ADED only reported on changes prior to 2022. ADED staff, program advisors and this consultant spent considerable time cleaning this data, as the database contained hundreds of incomplete records as well as poor quality data.

Using this information from the database, the consultant assigned starting disability weights (DWs) to each condition and calculated the "gain back" (improvement) in health (DALYs averted) as a result of services received and an improvement in condition. For more information, see Annex 1.

Finally, we adjusted expenditures to reflect the share of the sample of the total population (530/1,200), because the total incurred expenditures also reflect the assessment costs incurred for persons with disability who are not yet receiving services (i.e., n = 1,200 - 530 = 670). This adjustment assumes that persons with disability assessed but not yet receiving services (i.e., n = 670) and persons assessed and receiving services (i.e., n = 530, the sample) incur the same average expenditure per person, as we have no basis to know the differential in average per person cost between persons only assessed but not yet receiving services and persons assessed and receiving services.

Cost per DALY averted was then estimated as follows:

$$\text{Cost per DALY averted} = \frac{\text{Adjusted annualized intervention costs from February 2019 – December 2021}}{\text{DALYs averted in n = 530}}$$

Finally, the consultant reviewed the literature from the last five years to identify comparators against which these results could be reported. Recommendations for improving both cost-effectiveness as well as data availability and quality were co-developed with program advisors to ensure relevance and appropriateness.

3 Findings

3.1 Sample characteristics

The 530 children and youth included in this sample were 45.5% female and 54.3% male (with one respondent classified as "other"). Women had an average age of 15.4 years, men 13.8 years, and the sample as a whole 14.6 years.

In terms of number of disabilities classified per person, 345 persons had a single disability (65%), 153 exactly two disabilities (29%), and 32 exactly three disabilities (6%). Physical disabilities overwhelmingly dominated the sample. The number and percentage of the sample exhibiting each type of disability is shown in Table 1.

Table 1 Types of disability present in the sample

Type of disability	Primary disability (%)	Secondary disability (%)	Tertiary disability (%)
Hearing related	25 (5%)	13 (7%)	0 (0%)
Intellectual	10 (2%)	5 (3%)	0 (0%)
Mental and psychosocial	39 (7%)	11 (6%)	4 (12%)
Neurological	34 (6%)	9 (5%)	2 (6%)
Physical	361 (68%)	134 (72%)	20 (61%)
Vision related	37 (7%)	3 (2%)	2 (6%)
Vocal and speech related	24 (5%)	10 (5%)	5 (15%)
Total	**530 (100%)**	**185* (100%)**	**33 (100%)**

* Includes the 153 with exactly two disabilities and 32 with exactly three disabilities.

3.2 Expenditures

The health component of the CBR program cost €150,180 to implement over the period February 2019 to December 2021 (annualized). Per year, this works out to an average of €51,490. Expenditures were divided between ADED (76.4% of expenditures), Liliane Fonds (13.6%), government (5.3%) and the Netherlands (4.7%). By category, over two-thirds (64%) of expenditures were for direct program implementation, around one-fifth (22%) were for staff, 8% were for running costs and 7% were classified as "other". Table 2, Table 3 and Table 4 present the annualized expenditures by entity, year and category.

Table 2 Total expenditure by entity and year, with and without annualization, 2019-2021 (€)

	Expenditure in euros (€) prior to annualization				Expenditure in euros (€) with annualization			
Entity	2019	2020	2021	2019-2021	2019	2020	2021	2019-2021
ADED	26,136	41,744	59,929	**127,809**	15,926	40,558	58,231	**114,715**
Government	2,100	3,355	2,448	**7,903**	2,100	3,355	2,448	**7,903**
Liliane Fonds	0	0	21,718	**21,718**	0	0	20,489	**20,489**
Netherlands	6,117	5,239	5,032	**16,388**	1,144	2,288	3,641	**7,073**
Total (€)	**34,353**	**50,338**	**89,127**	**173,818**	**19,169**	**46,201**	**84,809**	**150,180**

Notes: "Implementation" refers to direct program costs. "Running costs" include office expenditures, bank charges, etc. "Other" encompasses TA from the Netherlands, partnership development costs and learning-related costs such as conferences.

Table 3 Annualized total expenditure by category and year, 2019-2021 (€)

Category	2019	2020	2021	2019-2021 (%)
Human resources	10,358	13,047	9,261	**32,667 (22%)**
Implementation	5,666	27,889	62,362	**95,918 (64%)**
Running costs	2,001	2,977	6,787	**11,765 (8%)**
Other	1,144	2,288	6,399	**9,830 (7%)**
Total (€)	**19,169**	**46,201**	**84,809**	**150,180**
(%)	**(12.8%)**	**(30.8%)**	**(56.5%)**	**(100%)**

Notes: "Implementation" refers to direct program costs. "Running costs" include office expenditures, bank charges, etc. "Other" encompasses TA from the Netherlands, partnership development costs and learning-related costs such as conferences.

Table 4 Annualized total expenditure by entity and category, 2019-2021 (€)

Category	ADED	Government	Liliane Foundation	Netherlands	2019-2021
Human resources	24,764	7,903	0	0	**32,667**
Implementation	77,406	0	18,512	0	**95,918**
Running costs	9,788	0	1,977	0	**11,765**
Other	2,757	0	0	7,073	**9,830**
Total (€)	**114,715**	**7,903**	**20,489**	**7,073**	**150,180**
%	**(76.4%)**	**(5.3%)**	**(13.6%)**	**(4.7%)**	**(100%)**

Notes: "Implementation" refers to direct program costs. "Running costs" include office expenditures, bank charges, etc. "Other" encompasses TA from the Netherlands, partnership development costs and learning-related costs such as conferences.

When adjusted to reflect only expenditures corresponding to the sample (n = 530), the total annualized expenditures for the period 2019-2021 are €66,329. On an annual basis, this represents an average of €22,742 per year.

3.3 DALYs averted

In the sample (n = 530), a total of 249.34 DALYs were averted, an average of 0.47 DALYs per person. This reflects an average improvement of just over one point (1.27) on the improvement scale, indicating a move, for example, from "slight" to "moderate" improvement. However, there were a large number of children and youth (n=137) in whom no improvement was seen. Of these, 102 (78%) had not yet received services[9]. This means their improvement score was 0 and therefore 0 DALYs were averted. Removing these 102 from the sample, we see a slight increase in the average improvement score and average DALYs averted per person (Table 5).

Table 5 Summary of DALYs averted, total and average per person

Sample size	Average of improvement score (0-4)	Sum of DALYs averted	Average DALYs averted per person

[9] After the research was complete, ADED provided clarification about these 102 children and youth: 21 received medical services but saw no improvement, for 19 it was deemed they do not need medical service at all, 25 are on a waiting list for services, 2 refused medical services and 34 may need medical assistance but are not on the priority list. However, 88 of them received other services like education, vocational training and livelihood support.

Entire sample (n = 530)	1.27	249.34	0.47
Only those who received services (n = 428)	1.58	249.34	0.58

3.4 Cost per DALY averted

Given the adjusted expenditures (€66,329) and number of DALYs averted for the sample (n=530, DALYs averted = 249.34), the cost per DALY averted is €266. Per person in the sample, this equates to an average of €43 annually.

It is hard to predict if these findings will hold over the remaining project period, that is, through end 2024. If Nepal is any indication, however, results should improve as the program matures[10]. However, there are a large number of children and youth who have been assessed and are scheduled to receive services in the coming years. The DALYs averted from successfully completing rehabilitation plans depends largely on staff effort and availability of specialist care, access to assistive devices and the like, as well as overall continued funding, the majority of which is expected to be secured through Impaction Foundation and the consortium of investors as well as Liliane Fonds through end 2024.

On staffing, CBRFs, at their current level of effort (LOE, 1 day per week in 2021), have not been able to properly follow-up on the children and youth with a disability assigned to them, and ADED officers have been spending their time on tasks that should be done by CBRFs, instead of on their assigned roles of supervising and supporting. It is the consultant's assessment that CBRFs, at this current LOE, cannot and will not be able to properly provide services to the persons with disability who should be receiving services under the Tunafasi program. A higher LOE of two days per week would help and has a minimal impact on costs, but may be hard to secure, as CBRFs are stretched with both other CBR pillars other than health as well as other duties at health facilities. As the number of persons with disability receiving services increases, the strain on CBRFs will only increase, and + two days a week LOE is unlikely to be sufficient. Although CBRFs in Nepal were responsible for more persons with disability than the CBRFs in DRC are, both currently and as planned when services are extended to the remaining 764 children and youth, the Nepal program was more mature, CBRFs better trained and the Karuna CBRFs dedicated 100% LOE on this work[11]. Additionally, Nepal CBRFs were paid by the program directly, which gave Karuna Foundation Nepal greater management control over them, whereas Tunafasi CBRFs are paid by the government and payments are reportedly not always made as planned, giving the project little authority over them.

It is also unknown if partners stand ready to provide necessary surgeries, assistive devices and other support, all of which impacts both on expenditures as well as program results. Currently SOZAME and Centre Bethany are providing services to children and youth in the Tunafasi program, and assistive devices are largely provided by the Red Cross. It is estimated that 30% of children and youth receive these services in-kind (at no expense to the person or project)[12]. The project and its partners, namely Liliane Fonds, have invested in strengthening these service providers and fostering the collaboration through an umbrella network of disability-related organizations and a Disabled People's Organization (DPO) in hopes that the relationship will continue.

Finally, the addition of the prevention component has the potential to deliver additional DALYs averted, though it is impossible to predict how many DALYs can be averted. The prevention component also has additional implementation costs that will increase expenditures.

[10] Vaughan, Thapa and Paudel. Cost-effectiveness assessment of the Inspire2Care program in Ilam. October 2018.
[11] Personal communication with Ram Krishna Thapa.
[12] Personal communication with Gilbert Ruturutsa Mututsi.

4 Contextualizing the results

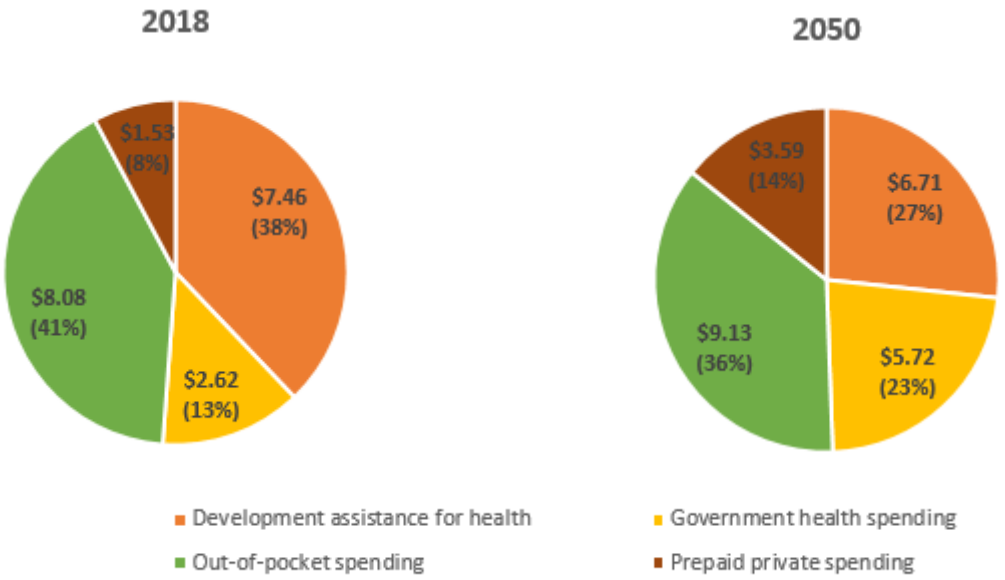
This section contextualizes the results from this study in terms of both affordability of the program in this setting and compares findings with other similar studies and cost-effectiveness results for other health interventions.

4.1 Affordability

It is important to consider how affordable the program is likely to be in coming years for ADED, the government and investors. This depends, of course, on resource availability of these different entities. Overall expenditures on this program are quite low, partly driven by the fact that many resources (such as staff) are shared with other activities. Even a relatively small amount of continued funding will keep the program running.

To consider the feasibility of a scenario where government gradually takes on a large share of costs, and support from ADED and the Netherlands is phased out, project expenditures should be placed in the context of current health expenditure (CHE) in DRC, which quantifies how much development partners, the government and households (both at point-of-service, known as out-of-pocket spending, and through pre-payment arrangements such as insurance) contribute to health, per person (per capita), per year. CHE in DRC was estimated to be US$19.69 per capita in 2018 (2020 US$, €17.24), of which US$2.62 (€2.29, 13%) was paid by government. Both total expenditure and the government's share in absolute and percentage terms are expected to increase by 2050 (Figure 1)[13].

Figure 1 Current health expenditure in DRC, per capita, 2018 and 2050 (US$)



Note: CHE by 2050 reflects the future growth trajectory based on past growth.
Source: IHME. No date. https://www.healthdata.org/democratic-republic-congo.

While health spending in DRC is among the lowest in the world, both as a total and in terms of government's contribution[14], the Tunafasi program's current per capita cost is approximately €0.13 ($0.13) per person per year, given the population of Uvira of 387,421 and assuming the full program expenditure of €51,490 annually. The government's contribution (5.3%) then equates to less than €0.01 ($0.01) per person per year, which does seem feasible given a total government expenditure of $2.62 per person per year. Strictly speaking, even a

[13] IHME. No date. https://www.healthdata.org/democratic-republic-congo. For comparison, CHE in Nepal was estimated to be US$57 per capita in 2018 (2020 US$, €49.90), of which US$14.02 (€12.27, 25%) was paid by government. By 2050, CHE in Nepal is expected to increase to US$105 per capita (2020 US$, €91.93), of which US$23.74 (€20.78, 23%) will be paid by government. For a full comparison, see Annex 3.
[14] World Bank. World Development Indicators. https://data.worldbank.org/indicator/SH.XPD.CHEX.PC.CD

complete government takeover of program financing at a level of €0.13 ($0.13) per person per year is likely possible under current levels of CHE. However, it should be noted that CHE includes both national and sub-national level expenditures, so the entire $2.62 is not expended at local level. Assuming 30% reaches sub-national level ($0.86), €0.13 ($0.13) per person per year would represent over 15% of expenditure on disability, which is likely not realistic. Additionally, the Tunafasi program targets children and youth, thereby excluding nearly a quarter of the population of Uvira from the start[15]. Adjusting the population of Uvira to reflect those aged 33 and under, to 294,440[16], increases the program's current per capita cost to approximately €0.18 ($0.18) per person per year and increases the government's share to just shy of €0.01 ($0.01) per person per year.

It is important to remember that in countries like DRC, development assistance for health is significant. It represented 38% of CHE in DRC in 2018 and supports malaria, HIV/AIDS and TB programming with millions of dollars per year[17,18]. Other disability work in DRC is largely donor funded[19]. Although the program may be able to be largely transitioned to government administration in the short- or medium-term, it may be unrealistic to expect that government will be able to fully fund it anytime soon.

Previously, it was common to compare cost per DALY averted findings with a country's Gross Domestic Product (GDP) on a per capita basis to assess whether the interventions assessed would be considered highly cost-effective, cost-effective or not cost-effective in that setting, but this specific threshold approach has recently been criticized for not taking into account local resource availability (affordability), and has fallen out of use[20,21,22].

There are at least two approaches commonly in use to assess affordability for a health system. The first is to compare findings against a benchmark intervention, that is, against an intervention that a given country has already adopted as the reference for a cost-effective comparator for future analyses. This is the approach used in previous, similar assessments in Nepal, because the cost per DALY averted of the Nepal Health Sector Programme (NHSP) I and II overall was well known[23]. In DRC, there is no such benchmark known to this consultant.

The second option is known as league tables, and refers to comparing results against other health interventions, ranking them into a table according to their incremental cost-effectiveness ratios (ICERs, which compares the numerators and denominators from cost per DALY averted findings, for two alternative interventions, to tell you how much more or less the one intervention costs in relation to the other, and what the difference in DALYs averted is between the two interventions). One would then adopt the interventions

[15] Assuming 76% of the population of DRC is 33 and under, as per World Development Indicator data for 2019, the last year for which this data is available.
[16] IHME. https://ghdx.healthdata.org/record/ihme-data/gbd-2019-population-estimates-1950-2019.
[17] The Global Fund. Democratic Republic of Congo. https://data.theglobalfund.org/location/COD/overview
[18] U.S. President's Malaria Initiative (PMI). https://www.pmi.gov/where-we-work/d-r-congo/
[19] Handicap International's work on rehabilitation in North Kivu, DRC, is currently funded by Luxembourg Aid & Development and Enabel (Belgian Development Agency, previously known as Belgian Technical Cooperation). Handicap International. Country Card. September 2021. https://www.hi.org/sn_uploads/federation/country/pdf/2021-12-Country-Card-DRC-HI-EN.pdf
[20] Bertram, MY, Lauer, JA, De Joncheere, K, Edejer, T, Hutubessy, R, Kieny, M, Hill, SR, 2016. Cost-effectiveness thresholds: pros and cons. Bulletin of the World Health Organization, 94, 925-930. Accessed 19 August 2018. http://www.who.int/bulletin/volumes/94/12/15-164418/en/
[21] Leech, AA, Kim, DD, Cohen, JT, Neumann PJ, 2018. Use and misuse of cost-effectiveness analysis thresholds in low- and middle-income countries: trends in cost-per-DALY studies. Value in Health, 21, 759-761. Accessed 19 August 2018. https://www.sciencedirect.com/science/article/pii/S1098301518300160
[22] Robinson, L, Hammitt, JK, Chang, AY, Resch S, 2016. Understanding and improving the one and three times GDP per capita cost-effectiveness thresholds. Health Policy and Planning, 32, 141-145. Accessed 19 August 2018. https://academic.oup.com/heapol/article/32/1/141/2555408
[23] Vaughan, Thapa and Paudel. Cost-effectiveness assessment of the Inspire2Care program in Ilam. October 2018.

following the established sequence. Two such studies are available for DRC[24,25]. However, in the case of this research, we are not choosing between two comparator interventions, so this approach is not appropriate.

A third approach has been proposed but is not yet widely used. Developed by Ochalek and colleagues, it generates country-specific cost/DALY averted thresholds that reflect health opportunity costs. One proposal used estimated elasticities on mortality, survival, morbidity and DALYs, while also taking into account measures of a country's infrastructure, changes in donor funding, country-specific data on health expenditure, epidemiology and demographics. This information is used to determine the likely DALYs averted from a 1% change in expenditure on health; this is considered the likely health opportunity costs and becomes the threshold. A similar approach is illustrated for South Africa by Edoka and Stacey (2020)[26]. This approach produces thresholds generally lower than the previously used GDP thresholds; for DRC, the generated threshold is US$54-69 (€49-62) per DALY averted (2015 US$/€), which is only 12-15% of the GDP/capita[27]. This lower threshold approach has also been validated by a regression model to calculate cost per DALY averted in low- and middle-income countries, using data about DALYs, per capita health expenditure, human development index score and GDP per capita for 176 countries over the period 2000 to 2016[28]. This approach found the threshold cost per DALY averted was, on average, 0.34 times the GDP per capita in low human development index countries like DRC. For DRC, this would equate to an approximate threshold of US$199 (€168), based on the 2021 GDP/capita of US$584 (€494)[29,30].

It is also important to note that while cost-effectiveness and affordability are important from an economic standpoint, value of particular interventions and their incorporation in, for example, essential health benefit packages guaranteed by government, is normally guided by a wider range of criteria, among others burden of disease, equity and feasibility[31,32].

4.2 Comparison with other findings

It is common to compare findings with results from other studies from similar contexts, and with the costs of other health interventions. 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. Although deemed more cost-effective, it does not mean it will be more affordable or feasible to implement in the given setting.

A literature review of 146 studies synthesized findings about 93 interventions (none related to CBR, however) common in low- and middle-income countries, and found a range of cost per DALY averted of <US$1 to over US$1,000. More than half of the interventions cost less than US$200 (Annex 2). The authors considered US$200 deemed to be an acceptable cost/DALY averted for consideration in publicly funded health care in low

[24] Nutrition International. Cost-Effectiveness of Transitioning from Iron and Folic Acid to Multiple Micronutrient Supplementation for Pregnancy: Policy Brief. April 2020.
[25] Antillon et al. Cost-effectiveness of sleeping sickness elimination campaigns in five settings of the Democratic Republic of Congo. 2022. Nature; 13:1051.
[26] Edoka and Stacey. Estimating a cost-effectiveness threshold for health care decision-making in South Africa." 2020. Health Policy and Planning, 35.
[27] Ochalek et al. Estimating health opportunity costs in low-income and middle-income countries: a novel approach and evidence from cross-country data. BMJ Global Health. 2018.
[28] Daroudi R, Sari AA, Nahzijou A and A Faramarzi. Cost per DALY averted in low, middle and high‐income countries: evidence from the global burden of disease study to estimate the cost‐effectiveness thresholds. Cost Effectiveness and Resource Allocation. 2021.
[29] World Development Indicators. 2022. The World Bank. https://data.worldbank.org/indicator/NY.GDP.PCAP.CD?locations=CD
[30] Exchange rates are from World Development Indicators as of 27 April 2022, for the indicated years.
[31] Horton, S. Cost-Effectiveness Analysis in Disease Control Priorities, Third Edition. In Disease Control Priorities (third edition). Volume 9, Disease Control Priorities: Improving Health and Reducing Poverty, edited by D.T. Jamison, H. Gelband, S. Horton, P. Jha, R. Laxminarayan, C.N. Mock, and R. Nugent. 2018. Washington, DC: World Bank.
[32] Hayati et al. Scoping literature review on the basic health benefit package and its determinant criteria. Globalization and Health (2018), 14:26.

income countries[33], though some interventions above this threshold are likely being implemented with government support in DRC and other similar countries today.

While tempting to compare the Tunafasi results with results from the Nepal I2C assessments[34,35] of the cost per DALY averted of the program's CBR component, there are several important differences between the programs and the cost per DALY averted assessments that limit comparability:

- I2C was significantly more financially capacitated than Tunafasi, both in terms of total expenditures and expenditure per person[36,37].
- While I2C included both children and adults, Tunafasi is largely focused on children.
- The assessment improvement scale used in Nepal was a bit broader than the one used in DRC, in that it specifically incorporated activities of daily living (ADL) and functionality.
- The I2C program was more advanced in its rollout than Tunafasi, even when the I2C pilot was assessed. This maturity brings learnings which can impact on results.
- The data quality in Nepal was overall much better than in DRC.
- The disability weights used in the Nepal assessments were from 2004 and 2016, whereas we have used 2019 weights for the DRC assessment.
- There are differences in the types of disability of persons in the two samples.
- Implementation in DRC may have been impacted by the COVID-19 pandemic as well as security limitations due to violence, both of which restricted travel and accessibility to services in Bukavu and Goma via Burundi.

Finally, it is important to note that this study has only captured primarily health-related gains, while some of the major benefits or gains from the program – particularly the community mobilization around disability, skills 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.

5 Recommendations

This assessment has found impressive results generated by the Tunafasi project, particularly given the low levels of expenditure and in light of the many challenges around implementing a project in its infancy years during an unprecedented global pandemic, not the mention that DRC Is an extremely difficult context to begin with[38]. While the cost per DALY averted is still higher than what new thresholds of affordability consider acceptable for DRC, findings are nonetheless in line with some health interventions likely being implemented with some government support presently in DRC, and if cost per DALY averted patterns follow what was

[33] Horton, S. Cost-Effectiveness Analysis in Disease Control Priorities, Third Edition. In Disease Control Priorities (third edition). Volume 9, Disease Control Priorities: Improving Health and Reducing Poverty, edited by D.T. Jamison, H. Gelband, S. Horton, P. Jha, R. Laxminarayan, C.N. Mock, and R. Nugent. 2018. Washington, DC: World Bank.

[34] The pilot assessment found a cost per DALY averted of €197, based on a sample of 248 children and 77 adults. See Vaughan, Thapa and Paudel. Cost-effectiveness assessment of the Inspire2Care program in Ilam. October 2018.

[35] The 2018 assessment found a cost per DALY averted of €384-843 (range reflects use of different disability weights) for batches 1 and 2 in Ilam, based on a sample of 123 children and 491 adults in 10 villages, with findings extrapolated to 20 additional villages. See Vaughan, Thapa and Paudel. Cost-effectiveness assessment of the Inspire2Care program in Ilam. October 2018.

[36] For the pilot, expenditures totaled €204,823 from August 2011 to December 2013, or €81,929 per year. The total population size was 325, giving an expenditure per person per year of €252. See Vaughan, Thapa and Paudel. Cost-effectiveness assessment of the Inspire2Care program in Ilam. October 2018. Tunafasi expenditures totaled €66,329 over a period of two years and 11 months, equating to an annual cost of €22,742 and €43 per person per year using the sample population of 530.

[37] For Ilam batches 1 and 2, expenditures totaled €740,308 over the period 2014-2017, or €185,077 per year. The total population size was 1,300, giving an expenditure per person per year of €142. See Vaughan, Thapa and Paudel. Cost-effectiveness assessment of the Inspire2Care program in Ilam. October 2018. Tunafasi expenditures totaled €66,329 over a period of two years and 11 months, equating to an annual cost of €22,742 and €43 per person per year using the sample population of 530.

[38] MSF. The daily struggle for survival in the Democratic Republic of Congo. 4 April 2019. https://www.msf.org/daily-struggle-survival-democratic-republic-congo

observed in Nepal, where results improved as the program matured, the cost per DALY averted could realistically fall below the indicated thresholds. Additionally, although both CHE from all sources as well as the government's contribution are very low in DRC, this analysis has shown that current project costs are not outside the reach of the government.

Although this model of implementing CBR through PHC with support from an NGO and initial external backing is a trendsetter in DRC and likely the entire region, the planned complete withdrawal of external funding after less than six years, at the end of 2024, may not be realistic, and other exit strategies should be considered.

This consultant sees no reason to not move forward with replication but advises the project to address several areas for concern, particularly around data availability and quality, staffing, project visibility and funding. A comprehensive list of recommendations follows.

1. Improve data availability and quality.

Data recording needs to be improved to ensure complete, accurate and up-to-date information is available about each child and youth with a disability. Specific recommendations are to:

- Complete remedial training with ADED officers, CBRFs and others involved in collecting and entering data about children and youth with disabilities.
- Reduce the number of fields in the database and convert most/all narrative responses to drop-downs, both to make entry easier for ADED and CBRFs but also to facilitate analysis of the data.
- Build in checks to flag conflicting information entered in different fields for review and correction.

2. Focus on staffing to improve results (DALYs averted).

This assessment has indicated that staffing may not be sufficient, and this may be impacting negative on results. On the one hand, just over 10 percent of the children and youths with disabilities in the sample had not yet started treatment despite being assessed at least six months ago. This may be partly related to restrictions during the COVID-19 pandemic which made traveling for treatment, etc. impossible. However, it was not possible to know from the database if all persons in the sample were being actively followed up in the one day per week that the CBRFs dedicate to the project. Looking forward, a further 764 children and youths have been assessed and are scheduled to start progressing on their rehabilitation plans soon, but CBRFs are unlikely to be able to properly handle these additional persons, even if they double the amount of time they are currently spending. Specific recommendations are to:

- Increase CBRF LOE through advocacy with the government. It is important for ADED to ensure the CBRFs continue to dedicate time to CBR-related activities, which only encompass a portion of their work. Their time spent on this program dropped off in 2021 compared to previous years, while the workload in terms of number of persons with disability under ADED's care is only increasing, so reengaging the CBRFs at a higher level of effort is critical. However, the planned two days a week is unlikely to be enough time, and full-time CBRFs may be preferable, even if that means fewer CBRFs in total. Government is already paying 100% of their salaries, though payments reportedly are not always made or not fully made, so it does not require additional government expenditure, per say. However, government may need to hire new or reallocate existing staff to take over the other responsibilities of the CBRFs that will no longer be covered once the CBRFs are working full-time on disability-related issues.
- Address issues of CBRF motivation. There are also problems reported with CBRFs' motivation, which has been diagnosed as primarily related to CBRF salary payments being delayed by government[39]. Performance-based financial- and/or non-financial incentives offered by the

[39] Terms of Reference for Community Based Rehabilitation (RBC) Facilitators' Sustainable Payment Mechanism Analysis and Definition Workshop. No date.

project and/or reimbursing transportation and/or communication expenses may help sustain and increase their interest. Although performance-based financial incentives have worked to improve outputs in various settings including DRC[40] (though not yet measured for disability, as far as this consultant knows), the project should be careful with the amount of financial resources injected, to prevent creating an imbalance with other local salary levels, fostering a culture where high payments are seen as a pre-requisite for working, and for reasons of financial sustainability. These types of incentives and other approaches to increasing motivation are complex to introduce and the project would benefit from consulting resources such as the publications by Renmans et al[41] and Gupta et al[42].

- As CBRFs devote more time and interest to the project, provide them with additional training on recognizing and assessing disabilities as well as comprehensive training on all five CBR pillars.
- Improve monitoring and evaluation by using the database to clearly track next steps for ADED and CBRFs and the timeline for completing these. This will make it easy to search and know which actions are required for each person with a disability, preventing children and youth from falling through the cracks. That will also make it easy to evaluate the progress and assess the performance of individual CBRFs.

3. Improve project visibility in the country and region.

There is an evidence gap about the implementation and funding modalities as well as the impact of CBR programs, particularly in Africa but more widely in low- and middle-income countries worldwide[43,44]. This project and the example upon which it was modelled, I2C implemented by Karuna Foundation Nepal, are likely quite unique. In the context of CBR, the collaborative partnership and financial arrangements between an NGO, the community, the government and external partners, differs from most other initiatives on the continent[45]. Specific recommendations are to:

- Improve project visibility in the region, as this may attract interest from other governments or partners who can offer options for institutionalizing the model, thereby providing longer-term sustainability.

4. Diversify sources of financing for reasons of ownership and sustainability.

Although there are signs the program is taking root and being accepted and valued by the community – through participation of children, youth and their parents, strengthened self-help groups, young people receiving vocational training and families having access to more income – the financial capacity of the government and community in a low-income country like DRC means the program is unlikely to be able to continue in the short- and medium-term without some form of continued external financing. Some specific recommendations are to:

- Further strengthen this sense of ownership with families and the community through cost-sharing, albeit at very low levels, to help contribute to future sustainability.

[40] USAID. Performance-based financing improves health facility performance and patient care in the Democratic Republic of Congo. Integrated Health Project. January 2017.
[41] Renmans et al. Opening the 'black box' of performance-based financing in low- and lower middle-income countries: a review of the literature. 2016. Health Policy and Planning.
[42] Gupta et al. Approaches to motivate physicians and nurses in low- and middle-income countries: a systematic review. 2021. Human Resources for Health.
[43] CBR Africa. https://afri-can.org/.
[44] CBR Global Network. https://cbrglobalnetwork.wordpress.com/.
[45] CBR Africa. https://afri-can.org/

- Step up lobbying and advocacy efforts with local authorities and other stakeholders to contribute concretely to the improvement of the situation of children with disabilities. A sense of civic pride in supporting vulnerable groups in the community is perhaps as important to sustainability as financial resources. Identifying, training and nurturing community champions who can provide a strong voice for the project as well as manpower on a volunteer or minimally remunerated basis may be useful.
- Continue efforts with provincial and municipal authorities to incorporate Tunafasi project activities in annual plans, thereby securing additional funding for the project (see also below).

5. Consider other options for long-term financial sustainability once the consortium of investors withdraws.

The project's five year exit strategy (not counting the preparation year (2019)) is ambitious in such a challenging context as DRC. Not only was ADED new to disability, the government's CBR strategy is also new, and CBRFs are still learning their role. Support will likely be required to sustain some level of involvement from ADED beyond 2024. There is also no precedent for this type of cost sharing and implementation model for CBR in DRC. Although steps are already being taken to further establish government and community buy-in, including working with government to have some project activities reflected in annual government plans at provincial and municipal levels (presumably with a dedicated government line-item to sustain them, beyond the government's support for CBRF salaries), this process has just started[46]. Given the low levels of CHE, it is advised to consider other options for long-term financial sustainability once the consortium of investors withdraws. Specifically:

- Explore partnerships with larger national and international NGOS and/or development partners already active in DRC and/or Burundi. Successful CBR programs in Bhutan and Myanmar, which like Tunafasi were integrated into the PHC system, were, at least initially, funded by the World Health Organization (WHO) and United Nations Development Programme (UNDP), respectively; Bhutan was co-funded by the government as well[47]. This type of partner could also help ramp up advocacy efforts with government, supporting replication and further institutionalization of the model in other health zones.

6 Next steps

Additional research in the short-term is planned to consider a longer time frame for the present analysis. Specifically, current investors are interested in learn what additional, future benefits may be made possible as a result of their current investment. For example, current implementation in Tunafasi is building the model and partnerships needed to replicate the program in additional areas of DRC. In this replication, the current levels of external support may not be necessary, and the program could be sustained with fewer financial resources. Therefore, the current investments in the program can be seen as facilitating this future expansion. Additional calculations will be made using assumptions about planned replication and its costs, to estimate the possible DALYs averted and cost-effectiveness of the future program, which is enabled by today's investors.

[46] The annual planning in the municipality starts in September each year. First the municipality estimates annual income for the following year from its revenue generating services. To this amount, the Ministry of Budget adds a national-level contribution. Once these two amounts are determined, the municipality develops a budget and presents it to community representatives and other relevant parties, to be amended and approved at each level. It is then sent to the provincial level for final approval by a committee of provincial budget experts. The estimated budget for Uvira for 2022 is 4.2 billion Congolese Francs (approx. US$2.1 million). The municipal budget covers capital expenditures (investments), operating expenses and salaries. Source: personal communication with Gilbert Ruturutsa Mututsi.

[47] World Health Organization (WHO). Compilation of community-based rehabilitation practices in the WHO South-East Asia Region. 2013.

While cost per DALY averted is the single most widely used and accepted metric for assessing cost-effectiveness of healthcare interventions in low- and middle-income settings[48,49], it is not without limitations[50], and may be hard for investors and other audiences to understand[51]. These groups may be used to thinking in terms of return on investment, a methodology gaining some traction in health, particularly in the area of non-communicable diseases (NCDs)[52]. Return on investment studies in health are often presented in the form of an investment case, which systematically examines the economic burden caused by a particular health condition or group of conditions (such as NCDs), including direct and indirect costs, costs interventions to combat the health condition(s) (including clinical, public health, and policy interventions) and estimates the health impacts (DALYs averted) and economic impacts (economic output from increased productivity, averted treatment costs) of these interventions. In this way an investment case estimates the potential returns on investing in policy, public health and clinical interventions, usually considering the short-term (five years) and long-term (ten or 15 years).

An investment case may be considered as a possible solution to one of the current limitations of the DALY, which is that it only captured health gains. An investment case would take a broader range of benefits, considering economic output gained as a result of the health-related improvements in persons with disabilities and the freeing of family members from caregiving responsibilities, though significant assumptions would be required. Like the present research, an investment case would still be unable to address non-monetizable gains from the program, such as increased social cohesion.

Another option for future research could be to explore developing and piloting a single metric which could capture benefits from all five pillars of the CBR matrix. This would need to be done in close consultation with key stakeholders such as the WHO and with support from CBR and/or disability experts. The program's cost-effectiveness is expected to improve if we take a broader perspective and look at impact on family members who may be informal care givers, adverse impacts of discrimination and stigmatization on quality of life, improved educational and employment-related outcomes and the associated improvements in social and economic status, social cohesion (human flourishing rate), personal and community resilience, etc. The major limitations of this option are that it would be applicable only to CBR programs, meaning that results would be not comparable with any other health programs. If such a metric were to gain traction in the international research community, it is likely to be a minimum of ten years before enough comparable results were available to make it useful for comparison purposes.

Finally, although the program's prevention component was excluded from this analysis given that it only started in 2021, and therefore it is too early to assess any impact, it is not too early to be thinking about how future research will be conducted. The originally proposed methodology for measuring the impact and cost-

[48] Feng et al. Using QALYs versus DALYs to measure cost-effectiveness: how much does it matter? International Journal of Technology Assessment in Health Care. April 2020.

[49] Center for the Evaluation of Value and Risk in Health. The Cost-Effectiveness Analysis Registry [Internet]. (Boston), Institute for Clinical Research and Health Policy Studies, Tufts Medical Center. Available from: www.cearegistry.org.

[50] It is important to note that some of the major benefits or gains from CBR programs, particularly the community mobilization around disability, skills 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. See also Annex 1.

[51] GiveWell, an organization which aims to produces research for investors and other donors to direct their giving, often assesses interventions in terms of the cost per life saved. While easy for investors to understand, it fails to capture the non life-saving benefits from interventions, i.e. improvements to quality of life. Additionally, GiveWell often assesses commodities (medicine to prevent malaria, bednets to prevent malaria, etc.), where the intervention is mainly focused on procurement and distribution. For CBR programs like Tunafasi, the main health-related outcome is not lives saved but rather improvements in quality of life. This is both more difficult to implement than procuring and distributing commodities and more difficult to assess.

[52] WHO/UNDP Guidance Note on NCD Investment Cases. UNDP Institutional and Context Analysis (ICA) Guidance Note. Non-communicable disease prevention and control: a guidance note for investment cases. WHO and UNDP. 2019. The consultant is aware of NCD investment cases conducted in Armenia, Bahrain, Barbados, Belarus, Ethiopia, Jamaica, Jordan, Kazakhstan, Kenya, Kyrgyzstan, Mongolia, Thailand, Turkey, Uganda, Uzbekistan and Zambia, among other countries.

effectiveness of I2C's prevention component[53] was a quasi-experimental design relying heavily on two baseline household surveys (HHSs) and an endline survey, combined with data from the health management information system (HMIS) and the mobile data system (Medic Mobile). DALYs and deaths averted were to be estimated using outcome and output-level data with a direct link to evidence-based causality (meaning, interventions that were identified as part of the 2018 I2C research as having a direct impact on preventing disability[54]), plugged in to the Impact Estimator. The Impact Estimator was a tool developed by Population Services International (PSI), based on the Lives Saved Tool (LiST). LiST estimates the number of deaths averted from certain interventions and, then uses data from the Global Burden of Disease study to estimate the corresponding number of DALYs averted.

For the Tunafasi program, it would need to be assessed if the required baseline data is available in DRC, given that the intervention has already been introduced. In the case that this baseline data is not available, an alternate would be to do a modelling study, which could be done with a number of assumptions[55]. Again the interventions to be assessed should be restricted to those with a direct link to evidence-based causality.

[53] KIT, Karuna Foundation Nepal and UBS Optimus Foundation. Disability Prevention and Rehabilitation Program Phase II Impact Study Protocol. No date.

[54] Vaughan, Thapa and Paudel. Cost-effectiveness assessment of the Inspire2Care program in Ilam. October 2018.

[55] Some examples of similar modelling studies: 1) Kahn et al. The cost and cost-effectiveness of scaling up screening and treatment of syphilis in pregnancy: a model. PLOS One. January 2014. 2) Fernandes et al. Cost-effectiveness of intermittent preventive treatment with dihydroartemisinin–piperaquine for malaria during pregnancy: an analysis using efficacy results from Uganda and Kenya, and pooled data. The Lancet. December 2020. 3) Lubinga et al. Potential Cost-Effectiveness of Prenatal Distribution of Misoprostol for Prevention of Postpartum Hemorrhage in Uganda. PLOS One. November 2015.

Annex 1: Disability-adjusted life year (DALY) explained

The disability-adjusted life year (DALY) was developed by Harvard University for the World Bank in the early 1990s as a single indicator for use 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.

The formula for calculating the DALY is as follows[56]:

DALY = YLL + 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:

YLL = N X 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 multiples number of incident cases by the disability weight (DW) for each case by the average duration of the case until remission or death (years):

YLD = I X DW X L

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

YLD = P X DW

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 DALY works by assigning DWs to health conditions. This effectively reflects the loss in health status an individual experiences as a result of his or her condition. We calculated DALYs averted using the most up-to-date weights available from the Global Burden of Disease (GBD) initiative[57], which are from 2019[58]. For each child and youth, their disability diagnosis determines their starting disability weight. For example, an individual with deformity of the right knee, resulting in problems walking, may be assigned the disability "physical", sub-type "motor moderate", which corresponds to the disability weight for "motor impairment, moderate" (0.061). For each disability and disability weight a layman's definition is provided. These were tested to ensure they align to the conditions seen in Uvira and were well understood by ADED officials and were subsequently adjusted. Table 6 provides the classification of types of disability, disability sub-types and English and French definitions of each sub-type, as well as the corresponding DW.

[56] All formulas come from Fox-Rushby, J. A., & Hanson, K. (2001). Calculating and presenting disability adjusted life years (DALYs) in cost-effectiveness analysis. Health Policy and Planning, 16(3), 326-331.

[57] Research suggests that not all health state preferences are universal, meaning that Congolese disability weights may differ from the standard DWs from GBD. However, local weights are not available for DRC. 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.

[58] https://ghdx.healthdata.org/record/ihme-data/gbd-2019-disability-weights.

Table 6 Disability types, sub-types and disability weights, in English and French

English			French translation			Disability weight
Type of disability	**Sub-type for each disability**	**Definition**	**Type of disability**	**Sub-type for each disability**	**Definition**	
Physical	Disfigurement_mild	Has a slight, visible physical deformity that others notice, which causes some worry and discomfort.	Physique	Défiguration_légère	A une légère déformation physique visible que les autres remarquent, ce qui cause une certaine inquiétude et un certain inconfort.	0.011
	Disfigurement_moderate	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.		Défiguration_modérée	A une difformité physique visible qui provoque le regard et les commentaires des autres. En conséquence, la personne est inquiète et a du mal à dormir et à se concentrer.	0.067
	Disfigurement_severe	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.		Défiguration_sévère	présente une difformité physique évidente qui met les autres mal à l'aise, ce qui amène la personne à éviter les contacts sociaux, à se sentir inquiète, à mal dormir et à penser au suicide.	0.405
	Motor_mild	Has some difficulty in moving around but is able to walk without help. May include partial paralysis.		Moteur_ doux	A quelques difficultés à se déplacer mais est capable de marcher sans aide. Peut inclure une paralysie partielle.	0.01
	Motor_moderate	Has some difficulty in moving around, and difficulty in lifting and holding objects, dressing and sitting upright, but is able to walk without help. May include partial paralysis.		Moteur_ modérée	A quelques difficultés à se déplacer, à soulever et à tenir des objets, à s'habiller et à s'asseoir en position verticale, mais est capable de marcher sans aide. Peut inclure une paralysie partielle.	0.061

	Motor_severe	Is unable to move around without help, and is not able to lift or hold objects, get dressed or sit upright. May include partial/full paralysis.		Moteur_ sévère	Elle est incapable de se déplacer sans aide, de soulever ou de tenir des objets, de s'habiller ou de s'asseoir. Peut inclure une paralysie partielle ou totale.	0.402
Mental and Psychosocial	Depression_ mild	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.	Mentale et psychosociale	Dépression_ légère	La personne ressent une tristesse persistante et a perdu tout intérêt pour ses activités habituelles. La personne dort parfois mal, se sent fatiguée ou a du mal à se concentrer, mais parvient tout de même à fonctionner dans la vie quotidienne, moyennant un effort supplémentaire.	0.145
	Depression_ moderate	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).		Dépression_ modérée	La personne est constamment triste et a perdu tout intérêt pour ses activités habituelles. La personne a quelques difficultés dans la vie quotidienne, dort mal, a du mal à se concentrer et pense parfois à se faire du mal.	0.396
	Depression_ severe	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).		Depression_ sévère	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).	0.658

	Schizophrenia	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 person can be forgetful, has difficulty with daily activities, and thinks about hurting himself (or herself).		Schizophrénie	Schizophrénie, état aigu/résiduel. État aigu : la personne entend et voit des choses qui ne sont pas réelles et a peur, est confuse et parfois violente. La personne a de grandes difficultés à communiquer et à accomplir ses activités quotidiennes, et veut parfois se faire du mal ou se tuer. Résiduel : entend et voit des choses qui ne sont pas réelles et a du mal à communiquer. La personne peut être distraite, a des difficultés à accomplir ses activités quotidiennes et pense à se faire du mal.	0.683
	Autism	Some degree of difficulty with social interaction and communication. May exhibit atypical patterns of activities and behaviors, such as difficulty with transition from one activity to another, a focus on details and unusual reactions to sensations.		Autisme	Un certain degré de difficulté en matière d'interaction sociale et de communication. Peut présenter des schémas atypiques d'activités et de comportements, tels que des difficultés à passer d'une activité à une autre, une concentration sur les détails et des réactions inhabituelles aux sensations.	0.011*
Intellectual	Borderline intellectual functioning	Is slow in learning at school. As an adult, the person has some difficulty doing complex or unfamiliar tasks but otherwise functions independently.	Intellectuel	Fonctionnement intellectuel limite	Elle est lente à apprendre à l'école. À l'âge adulte, la personne éprouve quelques difficultés à accomplir des tâches complexes ou peu familières, mais fonctionne par ailleurs de manière autonome.	0.011

	Intellectual disability / mental retardation, mild	Has low intelligence and is slow in learning at school. As an adult, the person can live independently, but often needs help to raise children and can only work at simple supervised jobs.		Déficience intellectuelle / retard mental, léger	Elle a une intelligence faible et est lente à apprendre à l'école. À l'âge adulte, la personne peut vivre de façon indépendante, mais a souvent besoin d'aide pour élever les enfants et ne peut travailler qu'à des tâches simples.	0.043
	Intellectual disability / mental retardation, moderate	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.		Déficience intellectuelle / retard mental, modéré	Elle a une faible intelligence et est lente à apprendre à parler et à effectuer des tâches même simples. À l'âge adulte, la personne a besoin de beaucoup d'aide pour vivre de façon indépendante et élever des enfants. La personne ne peut travailler que dans les emplois supervisés les plus simples.	0.1
	Intellectual disability / mental retardation, profound	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.		Déficience intellectuelle / retard mental, profond	A une intelligence très faible, ne parle presque pas et ne comprend pas les demandes ou les instructions les plus élémentaires. La personne a besoin d'une supervision et d'une aide constantes pour toutes ses activités.	0.2
	Intellectual disability / mental retardation, severe	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.		Déficience intellectuelle / retard mental, grave	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	0.16
Vision related	Complete blindness	Is completely blind, which causes great difficulty in some daily activities, worry and anxiety, and great difficulty going outside the home without assistance.	Lie a la vision	Aveuglement complet	Est complètement aveugle, ce qui lui cause de grandes difficultés dans certaines activités quotidiennes, de l'inquiétude et de l'anxiété, et de	0.187

					grandes difficultés à sortir de chez lui sans aide.	
	Blindness	Is blind in one eye and has difficulty judging distances		Aveuglement	est aveugle d'un œil et a des difficultés à juger les distances	0.017
	Low-vision	Vision loss which cannot be corrected with glasses, contacts or surgery. Limited sight remains but person may experience blind spots, poor night vision and blurry sight, which causes difficulty in daily activities, some emotional impact (for example worry), and some difficulty going outside the home without assistance.		Basse vision	Perte de la vision qui ne peut être corrigée par des lunettes, des lentilles ou une intervention chirurgicale. La vue reste limitée mais la personne peut avoir des angles morts, une mauvaise vision nocturne et une vue floue, ce qui entraîne des difficultés dans les activités quotidiennes, un certain impact émotionnel (par exemple l'inquiétude) et des difficultés à sortir de chez elle sans aide.	0.184
Hearing related	Deaf	Complete hearing loss: 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.	L'audition	Sourds	Perte auditive totale : la personne ne peut pas entendre du tout dans n'importe quelle situation, même les sons les plus forts, et ne peut pas communiquer verbalement ou utiliser un téléphone. Les difficultés de communication et de relation avec les autres sont souvent source d'inquiétude, de dépression ou de solitude.	0.215
	Hearing loss, adult onset: mild	Has great difficulty hearing and understanding another person talking in a noisy place (for example, on an urban street).		Perte auditive, débutant à l'âge adulte : légère.	A de grandes difficultés à entendre et à comprendre une autre personne qui parle dans un endroit bruyant (par exemple, dans une rue urbaine).	0.01

	Hearing loss, adult onset: moderate, untreated	Is unable to hear and understand another person talking in a noisy place (for example, on an urban street), and has difficulty hearing another person talking even in a quiet place or on the phone.		Perte auditive, débutant à l'âge adulte : modérée, non traitée.	Est incapable d'entendre et de comprendre une autre personne qui parle dans un endroit bruyant (par exemple, dans une rue urbaine), et a du mal à entendre une autre personne qui parle même dans un endroit calme ou au téléphone.	0.027
	Hearing loss, adult onset: severe or profound, untreated	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.		Perte auditive, débutant à l'âge adulte : sévère ou profonde, non traitée.	Est incapable d'entendre et de comprendre une autre personne qui parle, même dans un endroit calme, est incapable de prendre part à une conversation téléphonique et a de grandes difficultés à entendre quoi que ce soit dans toute autre situation. Les difficultés de communication et de relation avec les autres sont souvent source d'inquiétude, de dépression et de solitude.	0.204
Vocal and Speech related	Vocal and Speech related	Has difficulty speaking, and others find it difficult to understand.	Lies a la voix et a la parole	Lies a la voix et a la parole	A du mal à parler, et les autres ont du mal à le comprendre.	0.051

* Used same DW as intellectual, since autism is not included in GBD DWs.

ADED staff assigned up to three type of disability, each with a specific sub-type, to each child and youth in the database. ADED staff also assessed improvements seen in the health and condition of each person with disability using an improvement scale ranging from 0-4, with 0 representing no improvement seen and 4 representing full rehabilitation (Table 7).

Table 7 Assessment improvement scale

Assessment improvement scale number	Description of improvement
0	No noticeable improvement seen / same as baseline or worse than baseline.
1	Minor improvement to health.
2	Moderate improvement to health.
3	Significant improvement to health.
4	Fully rehabilitated: no further health-related intervention* needed apart from follow-up

* Health-related interventions include physiotherapy, medicines, surgeries, assistive devices, etc.

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 a "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 DW was then used to calculate DALYs averted using the prevalence formula (YLD = I X DW X L). Life expectancy refers to the duration the benefit will be sustained without further investment. This is different for different types of interventions:

- For individuals receiving non-medical interventions only, it was assumed the benefits would last their remaining lifetime.
- For individuals deemed fully rehabilitated, no further services are needed, therefore the duration of benefit is the individual's remaining lifetime.
- For all other interventions, it was assumed the benefits were to last the program's lifetime (5 years); this was not adjusted to account for the exact remaining program lifetime as the date of the intervention was unknown.

Remaining life expectancy from time of improvement (December 2021) was calculated assuming the average life expectancy at birth for each individual, based on World Bank data (World Development Indicators database) minus years of life already lived (their age) as of end 2021.

These calculations attribute 100% of the claimed DALYs averted to the Tunafasi program even though some expenditures (such as donated medical services or assistive devices) which contributed to averting these DALYs have been excluded from the expenditure calculations.

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 antenatal care (ANC) 4th visit coverage. The DALY is well understood by Ministries of Health, development partners supporting the health sector and other related stakeholders, and presenting a program's cost-effectiveness in terms of cost per DALY averted can be powerful for advocacy purposes.

It is important to note that some of the major benefits or gains from CBR programs, particularly the community mobilization around disability, skills 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 cost-effectiveness is expected to improve if we take a broader perspective and look at impact on family members who may be informal care givers, adverse impacts of discrimination and stigmatization on quality of life, improved educational and employment-related outcomes and the associated improvements in social and economic status, social cohesion (human flourishing rate), personal and community resilience, etc. However, there is not currently a single metric like the DALY which is able to take into consideration this wide range of benefits/impacts[59].

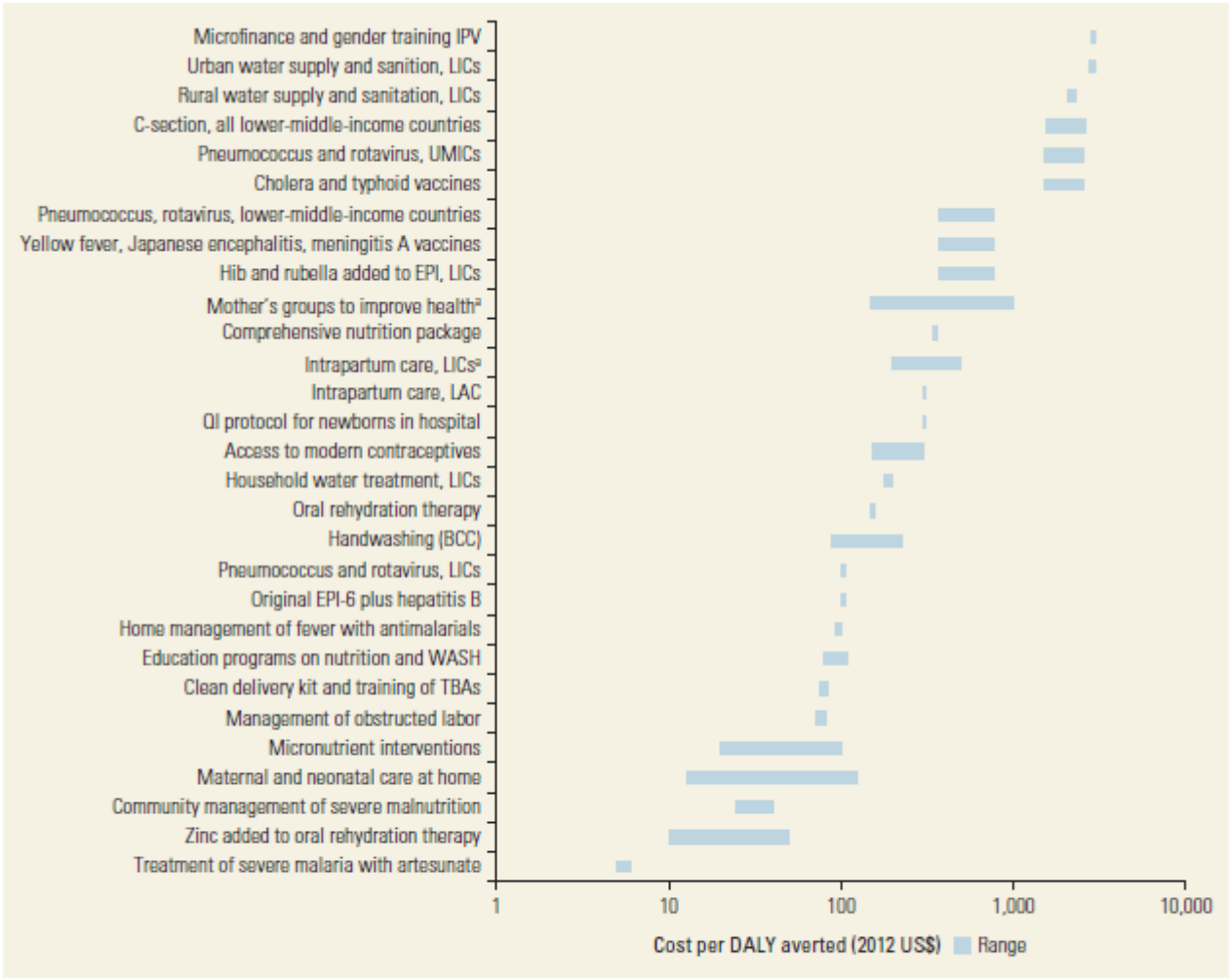
Preventing disabilities and rehabilitating persons with disabilities also helps avert future health care costs which may currently be borne by the government, local or international non-governmental organizations (NGOs) or others. These future savings are also not included in our analysis. Additionally, overall program cost-effectiveness is likely to be improved when the prevention component is taken into account[60]. There is no comparative analysis of prevention vs rehabilitation cost-effectiveness in the field of disability, but studies in other health areas have noted the preventive interventions reduce case incidence, therefore making them integral to a cost-effective response. The same logic is likely to be true for disability, also because many of the disability prevention interventions will contribute to improved health outcomes beyond preventing disability alone.

[59] There is no existing metric like the DALY which can take into account a wide range of benefits/impacts including those outside health. One area of future research would be to develop and test this kind of metric.
[60] Partnership for Prevention, no date. Prevention: A Key Indicator of Quality. Accessed 8 January 2015. https://www.prevent.org/data/files/initiatives/preventionandquality.pdf

Annex 2: Comparator results

A literature review of 146 studies synthesized findings about 93 interventions (none related to CBR, however) common in low- and middle-income countries, and found a range of cost per DALY averted of <US$1 to over US$1,000. More than half of the interventions cost less than US$200. Figure 2 shows the cost per DALY averted results of interventions for children.

Figure 2 Cost per DALY averted of interventions for children



Note: BCC = behavior change communication; EPI = expanded program of immunization; Hib = *Haemophilus influenza* type b; IPV = intimate partner violence; LAC = Latin America and the Caribbean; LICs = low-income countries; QI = quality improvement; TBAs = traditional birth attendants; UMICs = upper-middle income countries; WASH = water, sanitation, and hygiene.

a. Denotes outcome in QALYs (quality-adjusted life years).

Note: results of findings for interventions for adults can be found in the original document.

Source: Horton, S. "Cost-Effectiveness Analysis in Disease Control Priorities, Third Edition." In Disease Control Priorities (third edition). Volume 9, Disease Control Priorities: Improving Health and Reducing Poverty, edited by D.T. Jamison, H. Gelband, S. Horton, P. Jha, R. Laxminarayan, C.N. Mock, and R. Nugent. 2018. Washington, DC: World Bank.

Annex 3: CHE, 2018 and 2050, by country

	Sources	BANGLADESH		DRC		NEPAL		THE NETHERLANDS	
		2018	2050	2018	2050	2018	2050	2018	2050
%	Prepaid private spending	3%	5%	8%	14%	12%	24%	24%	36%
	Out of pocket spending	74%	73%	41%	36%	56%	50%	11%	8%
	Government health spending	18%	18%	13%	23%	25%	23%	65%	57%
	Development assistance for health	6%	3%	38%	27%	8%	3%	0%	0%
	Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**
US$	Prepaid private spending	1.22	4.05	1.53	3.59	6.60	25.17	1,308.08	2,749.59
	Out of pocket spending	33.61	56.02	8.08	9.13	31.55	52.17	584.93	594.51
	Government health spending	7.97	14.03	2.62	5.72	14.02	23.74	3,494.25	4,378.08
	Development assistance for health	2.55	2.24	7.46	6.71	4.50	3.58	0	0
	Total	**45.35**	**76.34**	**19.69**	**25.15**	**56.67**	**104.66**	**5,387.26**	**7,722.18**
€	Prepaid private spending	1.21	4.01	1.51	3.55	6.53	24.92	1,295.13	2,722.37
	Out of pocket spending	33.28	55.47	8.00	9.04	31.24	51.65	579.14	588.62
	Government health spending	7.89	13.89	2.59	5.66	13.88	23.50	3,459.65	4,334.73
	Development assistance for health	2.52	2.22	7.39	6.64	4.46	3.54	0	0
	Total	**44.90**	**75.58**	**19.50**	**24.90**	**56.11**	**103.62**	**5,333.92**	**7,645.72**