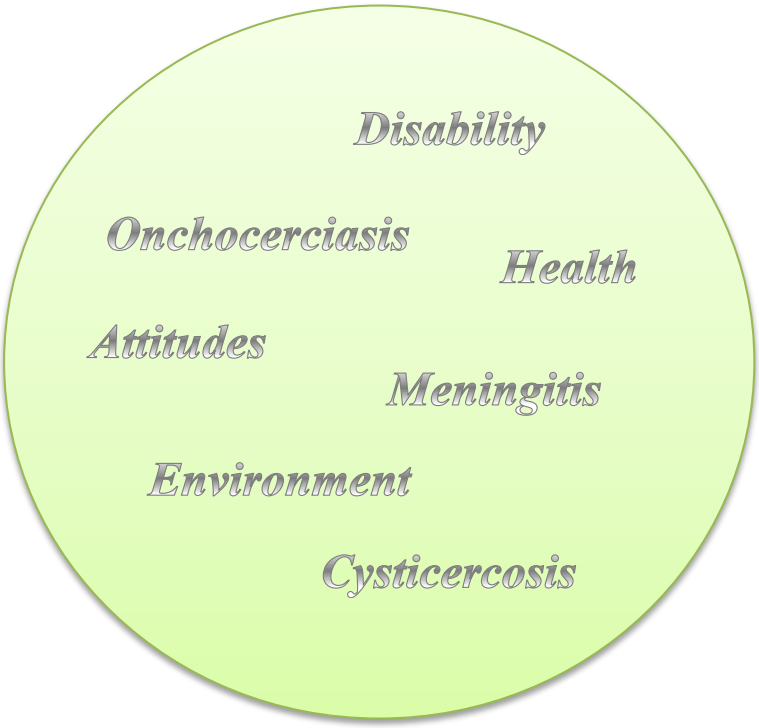
CONSEQUENCES OF DISABLING DISEASES:

How are they included in International development?



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Laura Prince
Studentnummer: 0519448

Foreword

This thesis focuses on *the inclusion of the effects of disabling diseases in Sub-Saharan Africa in International Development*. I chose this topic, because I believed the issue deserved further research. Especially *historical* research could shed more light on the main issues, and the way the different fields (study fields, theoretical and practical fields) and actors had evolved, collaborated or converged.

But as I worked my way through the matter, it became apparent that the topic couldn't be traced historically, at least not sufficiently enough for a thesis research. The issue had received so little attention, that little to no policies; plans (etc.) had been in place. A thorough historical research could not be achieved.

By then, my research was already in such an advanced stage, that we decided to proceed with the work. Particularly, because my study focused on an issue that faced a lack of research and exposure. It therefore deserved more insight on the subject.

Because of this need for more research and exposure, we chose to deviate from a standard (history) thesis format and present the results in a rapport. A rapport is accessible for a wider audience. The rapport can be spread under different actors in the worlds of research; policy-making; International Development; disability; health etc.

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List of Abbreviations

APOC	African Programme for Onchocerciasis Control
CBR	Community Based Rehabilitation
CDT	Community-directed Treatment
CRPD	Convention on the Rights of Persons with Disabilities
DALY	Disability Adjusted Life Year
DGIS	Directoraat-generaal Internationale Samenwerking/Dutch department of development cooperation
DPI	Disabled People International
DPO	Disabled People's Organization
ELISA	Enzyme-linked immunosorbent assay
EMIC	Explanatory Model Interview Catalogue
GBD	Global Disease Study
GDP	Gross Domestic Product
GNP	Gross National Product
HAI	Human Achievement Index
HDI	Human Development Index
HDR	Human Development Report
HPI	Human Poverty Index
ICF	International Classification of Functioning, disability and health
ICIDH	International Classification of Impairments, Disabilities and Handicaps
IGO	International Governmental Organization
IHD	Index of Human Deprivation
IHDI	Inequality adjusted Human Development Index
ILO	International Labour Organization
IOB	Inspectie Ontwikkelingssamenwerking en Beleidsevaluatie/ Inspection development cooperation and policy evaluation
ISMI	Internalized Stigma of Mental Ilness scale
MDG	Millennium Development Goals
MFI	Microfinancing Institution
MPI	Multidimensional Poverty Index
NCC	Neurocysticercosis
NGO	Non-gouvernmental Organization
NTD	Neglected Tropical Diseases
OCP	Onchocerciasis Control Program
OSD	Onchocercial Skin Disease
PO	Partner Organization
PQLI	Physical Quality of Life Index
PWD	Persons with Disabilities
SSA	Sub-Saharan Africa
UN	United Nations
UNDP	United Nations Development Programme
WHO	World Health Organization

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Ibrahim *has a beautiful family with three children. He works very hard to try to support the family by himself, so his children can go to school and not have to work, as is common to many other children in the area. Ibrahim is a self-employed man; he trades in beautiful robes and other textiles. His wife chips in by working as a seamstress, in between taking care of the household. Ibrahim would be very proud if one day his children would be able to take over his business. Yet tragedy struck four years ago, when a meningitis epidemic hit the area. Many inhabitants became infected or even died. His two oldest children (the youngest wasn't born yet) were infected as well. Since then Ibrahim has noticed changes in their behavior, but was convinced some schooling would get them up to speed. Two years after the epidemic a special team came to the area to vaccinate everyone, including his youngest son. The eldest two are currently in school, yet the teacher has told Ibrahim they might have to go to a special school, as they're not able to keep up with the other children. Ibrahim is very happy that his youngest son has received a vaccination, but has no idea what is to come of his two oldest children. It seemed like they aren't growing up; physically they are growing, but mentally they remain toddlers. The local doctor says they will probably always stay this way. Although Ibrahim has managed to maintain a pretty decent standard of living for his family through hard work, he realizes this doesn't go without saying for everyone in their community. He is very worried for the future of his two eldest children. Although he still considers himself lucky, as the son of his brother is not able to do anything anymore after being infected; people aren't even able to communicate in any way with him.*

Aisha *has trouble managing a stable job. She's not sure why, but for some reason her skin itches all the time. It itches so severely, that's she's not able to concentrate on an activity for more than five minutes. These days she's not even able to sleep. Aisha lives at the edge of the village with her mother. Together they struggle to survive as her mother is already old, but in the last couple of years she has also developed visual impairments. Her mother had hoped to be supported by a nice family at her age, but Aisha has yet to be married as nobody in the village wishes to do so. Her skin looks like that of a leopard, and besides being seen as contagious, it also makes her very unattractive. Without knowing, Aisha and her mother suffer from the same disease: onchocerciasis. They have heard that in the next village, near the river where mother used to work, more people experience these symptoms. But in their own village people avoid them. Aisha and her mother don't know who to turn to, as the nearest health care option is a three day travel away, which they can't afford as they already barely have any income to live on.*

Samuel *is to one day take over his father's farm. Although it's very small, it is the best and most reliable source of income one could wish for in his area. The farm consists of a small area of farmland and a couple of pigs, which roam freely on the farm estate. The costs are low as the family itself is able to upkeep the land and the pigs need no attendance as they find their own food in the waste scattered around the farm. Every now and then, new piglets are born and a mature pig is sold. Especially in troubling times, like low harvest, the money from a pig deal functions as an insurance. The pigs are the most important capital of the farm to ensure the family's survival. Yet recently father has started to display weird symptoms. He has frequent headaches, but also experiences seizures like he's possessed by the devil. Samuel has been taking up more and more responsibility on the farm. A health care professional has said that father suffers from a special disease, cysticercosis, and the pigs are involved in the cause of the disease as well. He suggested to get rid of the pigs, if we don't want the rest of the family to get infected. But simply slaughtering the pigs is no option, as this would endanger the family's financial safety. They could try selling the pigs, but it's prohibited to sell infected meat. The pig meat could be sold on the black market, but nobody in the area wants to do business with father anymore, as they believe his seizures are contagious. Samuel is very worried about the future of his family.*

Introduction

The situations for Aisha, Ibrahim and Samuel are very real in Africa, especially Sub-Saharan Africa. The stories don't just apply to people living in the exact same situation and not just just refer to these diseases. Diseases, which have not been receiving enough attention, therefore called neglected tropical diseases, are roaming in Sub-Saharan Africa. But widely known diseases, like meningitis, are also infecting people extensively throughout the area. Some of these diseases may bring about high mortality rates, while others generate severely disabling consequences, like the diseases in the stories. Especially in this region, these disabling consequences can bring hardship for those infected, but also those in their immediate surroundings. The combination of those disabling effects and the poor-living conditions make it, specifically in rural Sub-Saharan Africa, harsh to deal with. These people generally belong to the poorest of the poor. When these disabling consequences of the diseases are experienced in a different surrounding, like a Western context, the experience will be entirely different. It may not be easier, but it will ask for an entirely different approach to deal with the circumstances. Different factors can lead to their poverty, like difficulty in finding a job or being productive, or experiencing exclusion from services or society in general.

International Development has set 'eradicating poverty' as a top-priority goal. While trying to eradicate all extreme poverty, you should have eye for these disabled people living in these circumstances. Within International Development, health is a strong priority. In collaboration with the WHO and other actors, health campaigns for general health care or specific diseases have been initiated. Onchocerciasis is one disease which is being tackled in Africa since the 1970's. But to truly include the before mentioned people in development, the focus cannot lie on health alone. The approach should be directed towards all aspects of life; the combination of disability and poor living conditions affects a diversity of matters. The stories of Aisha, Ibrahim and Samuel show us the diverse barriers that can be encountered. But people with disabilities are not visible on the International Development agenda. Even though 10% of the world is estimated to have a disability. Under the world's poorest people these numbers are even higher: 20%. Of this large group of disabled people, 80% live in developing countries. Despite these facts, they have been excluded from International Development priorities.

Therefore this research will focus on: *How can the consequences of disabling diseases in Sub-Saharan Africa be included in development*?

Where should we focus on to include these effects? And, looking at the last couple of decennia's, which opportunities provide a way to have these people joined in in the development within Sub-Saharan African countries?

For this research three disabling diseases were chosen, each with their own (different) effects on the infected and their surroundings: (meningococcal) *meningitis, onchocerciasis* (river blindness), and *cysticercosis*. The first part focuses on the effects these disabling diseases have on those living in Sub-Saharan Africa. Next, International Development tools and frameworks are tested for their inclusion of these effects. For this, the commonly used Human Development Index and Millennium Development Goals framework serve as the basis. In chapter three an attempt is made to find a new way to make development frameworks more attentive to the effects of the disabling diseases. Lastly, we go back to the persons actually in the situation of dealing with the disabling consequences in the poor living conditions and ways to improve their opportunities. We try to assess the developmental actions which provide the opportunity to escape the hardships they face. Through Dutch examples of development programs and initiatives the possibilities and constrains will be displayed. The conclusion will bring forth what this research could tell us about how to include the effects of disabling diseases in Sub-Saharan Africa included in development.

1

Disabling Diseases in Sub-Saharan Africa: locally destructive

Good health can be essential for living the life you always wanted to live. It enables you to enjoy your life for many years to come. And it offers you the chance to achieve your dreams.

Health is considered one of the most important requirements for living. Yet good health can't be taken for granted; many risks can be encountered which lead to ill-health. Some diseases form a global risk to the health of human beings. These diseases and their consequences often catch the eye of the general public. Yet certain diseases can be extremely disastrous for specific communities, regions or countries. Are the consequences that arise from these diseases, taken into account?

Sub-Saharan Africa is one of the poorest regions of the world. The safety net is minimal, as many people in countries like Burkina Faso already spend their entire income on basic needs. When destructive diseases strike communities here, the consequences can be severe. Development may encounter long term obstruction because of these consequences.

What type of consequences should we think of? High mortality rates can destabilize societies. But especially those diseases leading to wide spread disability within communities ask for a *long-term* adjustment of society and developmental plans. Three diseases of this type are considered: meningococcal meningitis, onchocerciasis and cycsticercosis. The diseases have their own characteristics; they share a destructive and disabling character in Sub-Saharan Africa. What makes them so severe?

300 million people inhabiting the African Meningitis Belt are at risk

Frequently reoccurring bacterial meningitis epidemics in the area led to the term *African Meningitis Belt*. The Belt includes parts of the countries: Burkina Faso, Niger, Nigeria, Chad, Sudan, Benin, Cameroon, Ethiopia, Gambia, Ghana, Mali and Senegal.(A. M. Molesworth et al. 2002) The estimated population of the belt is 300 million people; 100 millions are at risk of getting infected. Because the disease is highly contagious, the epidemics are catastrophic. In 1996-1997 one epidemic killed more than 25 000 people in 10 different countries.(Irving et al. 2012)
The epidemic area has been extending southwards in the last decades, including the Great Lakes Area; thus putting even more people at risk.(A. M. Molesworth et al. 2002; Cuevas et al. 2007)

Figure 1: African Meningitis Belt
Source:http://www.who.int/csr/disease/meningococcal/impact/en/index.html

17,5 million of the estimated 17,7 onchocerciasis infected live in Africa

Onchocerciasis is almost exclusively an African disease. '*Almost all (96%) of the estimated 122.9 million at risk of the disease globally, live in sub-Saharan Africa and 17.5 million of the estimated 17.7 million who are infected live in Africa.*' (Ubachukwu 2006) The vector prefers a certain climate and environment: river basins in savannah or rainforest. Specifically the Savanna belt in West and East Africa is at great risk of onchocerciasis. Geographically the disease can mainly be found in 30 countries Sub-Saharan Africa.(Noma et al. 2002; Kale 1998)

The global estimation of 17,7 million infected may not seem threatening on a global level, but in this region the disease can be catastrophic. In endemic communities it can be the biggest problem for public health and threaten '*the survival of the community itself.*' (Alonso et al. 2009)

'Cysticercosis is probably the single most common cause of acquired epilepsy in the developing world'

The geographical spread of cysticercosis coincides with areas where pig husbandry is performed and hygiene practices are low, because pigs are intermediate hosts.(WHO 2006)

Central and West Africa are acknowledged as endemic regions for Cysticercosis. Cysticercosis is thought to be more urgent in Central Africa than in West Africa (Low prevalence: Burkina Faso, Ivory Coast, Senegal. (Hyper)endemic: Benin, Ghana, Nigeria, Togo, Burundi, Cameroon, Central African Republic, Chad, DR Congo, Rwanda).(S. Geerts et al. 2004) East and Southern Africa were previously not seen as endemic regions, but pig husbandry and pork consumption are increasing here.(Winkler et al. 2009)

The most severely disabling form, neurocysticercosis, is thought to be the most common cause of acquired epilepsy in developing countries and the most common parasitic infection of the central nervous system worldwide. (Mafojane et al. 2003; Engels et al. 2003)According to estimations between 1.3 to 3 million people suffer from neurocysticercosis-related epilepsy in Sub-Saharan Africa. (Mafojane et al. 2003; Phiri et al. 2003)The disease won't cause any rapid international outbreaks, but endemic communities can be greatly debilitated.

Box 1: Meningococcal Meningitis

Course of disease: An infection of the thin lining surrounding the brain and spinal cord, the meninges; caused mainly by viral infection or bacterial infection. 3 most important types of bacteria for bacterial meningitis: Neisseria meningitidis (meningococcus); Streptococcus pneunomiae; and Haemophilus influenza type B. 13 serogroups of N. meningitides have been identified.

The meningococcal bacterium inhabits the mucosal membrane of the nose and throat; where it's usually of no harm. An infection may occur in the body, followed by fever and often a skin rash. Through the bloodstream the bacteria may spread to the nervous system, where inflammation leads to meningitis. Symptoms can develop within a short period of time, leading to death within hours.

Disabling consequences: 5-10% may be asymptomatic, but those consequences experienced can be severe.

Consequences for bacterial meningitis: hearing loss, vision loss, cognitive delay (including mental retardation and learning disability), speech/language disorder, behavioral problems, motor delay/impairment (including gross motor and fine motor impairment, impaired activities of daily living, hypertonia, and paralysis), seizures, and other neurological consequences. Hearing loss seems to be one of the most frequently reported impairments for meningococcal meningitis. Most cases suffer from multiple consequences in different domains, leading to complicated multiple disabilities.

Causes: It's highly contagious. Only humans can be infected by the bacteria; especially children. 4 of the 12 serogroups are known to cause epidemics. Most epidemics can be pointed back to serogroup A

Diagnosis: Diagnosis methods are available. Early diagnosis is important because of the possible rapid course of the disease.

Vaccine: Vaccines for several serogroups (including A) have been available for years. But the vaccine protected for only 3-5 years and wasn't appropriate for infants. Only since 2010 an affordable vaccine is in use which protects 10-15 years and is safe for infants under 1 years old.

Treatment: Treatment with antibiotics is successful, but it's necessary they're provided as soon as possible.

Sources: (WHO 2003; Ramakrishnan et al. 2009; Smith et al. 1988; Chandran et al. 2011; Edmond, Dieye, et al. 2010; Edmond, Clark, et al. 2010; Wireko-brobby 2012; B. Greenwood 1999; A. M. Molesworth et al. 2002; Artenstein & LaForce 2012)

Box 2: Onchocerciasis (river blindness)

Course of disease: Parasitic disease caused by the filarial worm *Onchocerca volvulus*. The female worm, *macrofilariae*, lives in nodules under the skin. (live up to 12 yrs and grow up to 40-45 cm long). When fertilized, she can produce millions of larval worms, *microfilariae*. (live up to 2 yrs and grow up to 0.3 mm long) Contrary to the adult worms, they migrate to the skin and the eye. The death and subsequent disintegration of the microfilariae cause inflammatory reactions. This severe reaction is probably not caused by the larvae themselves, but the bacteria *Wolbachia* which they carry with them. This bacterium is released during the dying stage of the larvae.

Disabling consequences:

- Visual impairment: partially, up to total blindness.
- Onchocerciasis Skin Disease (OSD): wrinkling; thickening; depigmentation (*leopard skin*); loss of elasticity (*lizard skin*); swelling, especially in the lymphatic system; severe itching.

Causes: Blackfly species *Simulium damnosum* are vectors in Africa. Through a bite, the fly ingests the larvae from an infected human. Within the fly, the larvae mature (in ± 7 days). When the fly bites another human, the matured larvae enter the human body through the blood, where they migrate to the subcutaneous tissue and form nodules.

Diagnosis: Good detection methods available.

Vaccine: Not available.

Treatment: Since the 1970's vector control through insecticides spraying on blackfly breading sites in Africa. Since the end of the 1980's mass treatment with *ivermectin.* Ivermectin kills the microfilariae. It does not kill the adult worms, but does prevent them from reproducing, thus stopping the transmission.

Sources: (Adeoye, 1996; Alonso, Murdoch, & Jofre-Bonet, 2009; Basáñez et al., 2006; Boatin et al., 1997; Kale, 1998; Moll et al., 1994; Noma et al., 2002; Samba, 1994; Ubachukwu, 2006)

Box 3: Cysticercosis

Course of disease: Infection with a pork tapeworm (Taenia Solium) in its larval stage. After ingestion of the eggs by a human, larvae are released which can form cysts (cysticerci) in a number of tissues in the human body, preferably the brain, eyes and muscles. The cysts can cause an inflammatory reaction. When located in the central nervous system it leads to neurocysticercosis (NCC). 4 phases can be distinguished for cysts in the brain. After egg ingestion immature cysts form within 1 to 4 weeks (stage 1). Stage 2 marks the maturing of the cysticerci, after about 2 months. This stage can last more than 10 years, mainly asymptomatic. In stage 3 the cysts degenerate leading to intense inflammation. Taking place 2 to 10 years or more after maturing, it is characterized by clinical signs and symptoms. In stage 4 the cysts disappear. Infection with an adult worm, *Taenisis*, has no major health impacts.

Disabling consequences:

- Painful nodules (cysts in muscles)
- Visual impairment (cysts in eye)
- NCC: severe headaches, learning difficulties, convulsion and most frequently epileptic seizures.

Causes: Zoonotic disease; thus transmitted between humans and animals. Pigs are the intermediate hosts; they cannot carry the adult tapeworm, only cysticerci. By eating cysticerci-infected pork meat, humans can get infected with *Taenisis* (only in the human body can the cysticerci develop into adult worms). Pigs get infected through eating the faeces of infected humans who carry an adult worm, as their eggs are passed out with their faeces. Humans ingest the eggs which lead to cysticercosis, through contaminated soil, water or food (mainly vegetables).

Diagnosis: Lack of successful diagnosis because of:

(1) wide variety of clinical symptoms
(2) inaccessibility and expensiveness of diagnostic tools (CT- and MRI-scans).

Immunodiagnostic techniques are possible, but not completely faultless.

Vaccine: No vaccine available for humans. A vaccine for pigs is available and would seem logical as they're intermediate hosts. But mass pig vaccination is a difficult tactic because of the short life of pigs; the vaccine would have to be cheap, mass employable and long-term.

Treatment: No consensus yet on the most successful control. Treatment should include humans (surgical intervention for cysts; general anti-seizure drugs) *and* pigs. Effective drugs for the treatment of *Taenisis* are available, but the cheapest one can cause side effects. And there is no consensus on whether to opt for mass treatment or target treatment.

Sources: (Birbeck & Munsat, 2002; Diop, de Boer, Mandlhate, Prilipko, & Meinardi, 2003; Dorny, Brandt, Zoli, & Geerts, 2003; Engels, Urbani, Belotto, Meslin, & Savioli, 2003; García & Del Brutto, 2003; Gonzalez, García, Gilman, & Tsang, 2003; Lightowlers, 2003; Mafojane, Appleton, Krecek, Michael, & Willingham, 2003; Nash, 2003; Nguekam et al., 2003; Praet et al., 2009; Quet et al., 2010; Sarti & Rajshekhar, 2003; WHO, 2002, 2006, 2009; Winkler, Willingham, Sikasunge, & Schmutzhard, 2009; Winkler, Blocher, et al., 2009)

1.1 Risk factors

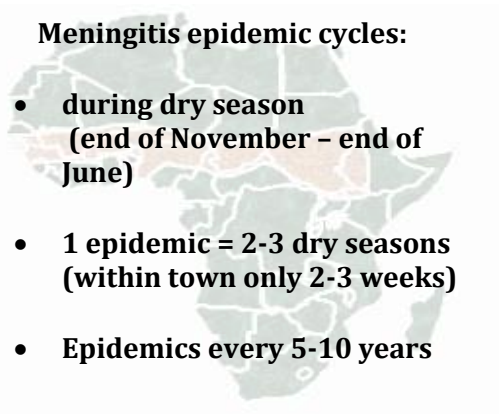
Which conditions accommodate the impact of the diseases?

Meningitis

The disease is highly contagious. The risk for infection increases when surrounded by other carriers. This may seem obvious, but most cases are acquired through exposure to asymptomatic carriers, so quarantine won't be sufficient to decrease the risk of infection.(Wireko-brobby 2012) Humans are the only carriers, so risk control doesn't have to consider other beings.(WHO 2003)

The risks are especially high for children. In Africa, cases are predominantly between the ages of 5-15 years. (Artenstein & LaForce 2012)

The region of Sub-Saharan Africa is specifically a meningococcal meningitis epidemic prone area. Epidemics occur here periodically (A. M. Molesworth et al. 2002):



Meningitis epidemic cycles:

- **during dry season (end of November – end of June)**
- **1 epidemic = 2-3 dry seasons (within town only 2-3 weeks)**
- **Epidemics every 5-10 years**

Four of the twelve serogroups of N. meningitides are recognized to cause epidemics. Most epidemics can be pointed back to serogroup A. (WHO 2003; Greenwood 1999; A. M. Molesworth et al. 2002)

The poor are especially at risk. Poor living conditions and overcrowded housing increase the risk of being infected. Because of the highly contagious nature of the disease these circumstances provide an ideal pool for spreading faster and further. (Artenstein & LaForce 2012) Since these conditions often coincide with poverty, poor people are more at risk.

Onchocerciasis

Living or working near the vector pool increases the risk of infection. The blackflies (the vectors) breed in fast-running rivers and streams in the inter-tropical zone. As they seldom fly very far, these river basins are the most important pools to get infected. Surveys and field studies in river basins have indeed proven the connection between river basins and the disease. It also explains the name river blindness. (Noma et al. 2002; Adeoye 1996; Moll et al. 1994; Kale 1998)

The risk increases with age. Prevalence of infection is supposedly lower during childhood; numbers peak for the population in their 30's. (Innocent et al. 2010; Kale 1998)

Sub-Saharan Africa is specifically at risk. Because of the preference for a certain climate and environment, the blackfly is especially present in this region. (Kale 1998)

The environment can influence the type of acquired impairment. In a savanna environment the numbers for severe visual impairment are high. Yet the numbers for severe visual impairments, like blindness, are lower for rainforest areas. Here, OSD and mild visual impairments seem the more troubling symptoms. (Kale 1998)

Cysticercosis

Higher risk when living near a person who has or had Taenisis. Because human carriers often aren't aware of their T. Solium infection, many people are unaware that they live in an increased risk environment. (J. P. Nguekam et al. 2003)

The risk increases with age. Being exposed to an endemic environment for a longer time, the risk of infection for humans increases with age. Especially since infection with Taenisis often isn't noticed, the risk increases, as there is no action to stop further spreading.(J. P. Nguekam et al. 2003)

The risk is increasing for East and Southern African countries. In West and Central African countries the problem of cysticercosis is widely spread. But in East and Southern African countries it's an emerging problem because pig keeping and pork consumption has increased considerably here in recent years. (Mafojane et al. 2003; Phiri et al. 2003)

Absence of proper supervision on the meat industry. Many African countries have legislation concerning the destruction of infected meat. But the absence of proper meat inspection and the wide-scaled performance of illegal slaughtering, leads to the consumption of infected meat despite this legislation. (Zoli et al. 2003)

Free pig ranging increases the risk. Free pig ranging is the most frequently found method for pig keeping in Africa. The method might not be preferred by governments for developmental plans; not all projects of intensive pig farming have been so successful in Africa. Intensive farming is not preferred by small farmers because it is more production intense; the pigs would need to be fed. With free pig ranging the pigs find their own food. But the risk of ingesting infected human faeces increases greatly with this method. (Lekule & Kyvsgaard 2003)

The poor are especially at risk.(WHO 2006)

- They live *near* the (infected) animals.
- The pigs live in an area with poor sanitary facilities for humans. Combined with free pig ranging, the possibility of consuming human faeces is high.
- The poor eat low quality pork. Infected meat is sold for a lower price, thus it's likely that the poor buy that meat.

Muslim belief does not decrease the risk. Consumption of pork is forbidden according to Muslim belief. But despite the fact that many countries of Central and West Africa have a predominantly Muslim population, the pig population there more than doubled in the last 3 decades. (S. Geerts et al. 2004)

1.2 Impact

What is the impact of the diseases in Sub-Saharan Africa?

Meningitis

The absolute numbers due to epidemics are tremendous. Of the bacterial meningitis types, pneumococcal meningitis is associated with the highest fatality and consequences rates. (Ramakrishnan et al. 2009) But due to the periodical severe epidemics with high impact rates, the impact of meningococcal meningitis is more significant. (Greenwood 1999; Irving et al. 2012)

The burden often can't be carried. Besides serious health consequences, the socio-economic impact is also significant. Countries and households in the poor endemic countries are not able to carry that burden. Research in Burkina Faso at the costs after the 2006/2007 epidemic, proved the enormous burden these epidemics bring for a country and its citizens. The total costs for the country entailed 9428 million US$. (Colombini et al. 2011) For a country where most people spend their entire income on basic needs, saving costs for frequently occurring epidemics is almost impossible. For households, not the health expenses, but the indirect costs of the disease (missing income due to impairments etc.) were the highest. (Colombini et al. 2009)

Vaccine was not suitable for many years. The highly contagiousness of the disease asks for mass vaccination, yet the population of the Belt at risk is too large to be vaccinated with an expensive vaccine. Only recently an affordable and convenient vaccine was introduced. The costs have declined for the vaccine itself and the abolishment of reactive immunization. The new vaccine also enables mass vaccination more fluently. (WHO 2003; Artenstein & LaForce 2012) Before this vaccine, one could use the option of defining specific risk areas for deploying vaccines. Defining an area as epidemic prone or not, has significant policy implications. (A. M. Molesworth et al. 2002) Because of the relation between the epidemics and the climate/environment, climate driven mathematical models could potentially define areas at risk of epidemics. Making these models valid will take a long time though. (Cuevas et al. 2007)

Immediate treatment is necessary. Treatment with antibiotics shortly after infection is crucial; symptoms can develop very rapidly. (WHO 2003) With the huge numbers of infection during epidemics, immediate treatment for all cases is challenging. The impact for society is severe when treatment comes too late.

Multidimensional disabilities ask for a broad spectrum of services. Most cases suffer from multiple consequences in different domains, leading to a complicated disability.(Edmond, Dieye, et al. 2010; Edmond, Clark, et al. 2010) Post discharge care is necessary, yet lacks sometimes in endemic countries. (Edmond, Dieye, et al. 2010)Community Based Rehabilitation programs can play an

important part in the post discharge care. Especially when a large percentage of the community was struck by an epidemic. A multidisciplinary team for these programs is necessary. '*Meningitis requires long-term rehabilitation of various forms of disabilities ranging from intellect deficits to epilepsy, physical disabilities, depression and chronic fatigue.'* (Karthikeyan & Ramalingam 2012) When these services are absent, the long term impact on an epidemic-struck community is felt deeply.

Traditional belief, lack of awareness, and lack of inclusion by meningitis projects of these beliefs, may enhance the impact. Health care programs have to be aware, because some Africans choose traditional healers over clinical treatment.(Colombini et al. 2009) Stigma can also enhance the burden. '(…) *disabled children and adults are hidden from view in many societies, subjected to stigma and neglect.'* (Edmond, Clark, et al. 2010)

Onchocerciasis

The numbers are locally disastrous. Although globally not so impressive, onchocerciasis can threaten the existence of entire communities in the endemic regions. In rural communities it is one of biggest disabling threats to public health and a socio-economic problem of great magnitude. The productivity of a community can decline significantly. In Africa, about 884 000 disability-adjusted life years (DALYs) are lost annually.(Benton 1998; Ubachukwu 2006) People may flee the infection pools out of fear of infection. This depopulation and migration left large amounts of (often fertile) land abandoned. (Alonso et al. 2009; Basáñez et al. 2006; Boatin et al. 1997; Samba 1994)

It is especially an African disease. Like mentioned before, due to the vector, almost all of those at risk and those infected, live in Africa. Nigeria has the highest number of cases in the world. Here 3.3 million people are infected and around 114000 are going blind from the disease. (Okwa et al. 2009) The numbers for Africa may even be an underestimation. *'A complete national survey (1997–2004) in Ethiopia determined that onchocerciasis was much more widespread than originally believed. Nine regions were shown to be endemic, with more than 3 million people already infected and a further 7.3 million at risk.'*(Karunamoorthi et al. 2010)

The burden of the consequences may be underestimated. As onchocerciasis is often referred to as *river blindness*, most people associate the disease with ocular problems. Yet the severity of onchocerciasis skin disease (OSD) cannot be ignored. A WHO research showed that severe itching was often seen as the most troublesome consequences, as it hinders you in every activity, even leading to insomnia. (Ubachukwu 2006) The disability weight of the DALY's is focused on severe visual impairment and severe itching. It may underestimate the burden of less severe visual impairments and other symptoms of OSD. (Kale 1998)

Control programs greatly diminish the burden. Onchocerciasis is seen as an eradicable disease. Two large control programs, targeting several countries, have been directed towards onchocerciasis (Box 4). The Onchocerciasis Control Program targeted the endemic region in West Africa. (Boatin et al. 1997) The African Program for Onchocerciasis Control focusses on other endemic African countries. (Boatin et al. 1997) The OCP and APOC have achieved a great reduction in onchocerciasis.(Samba 1994; B. H. Liese & Marr 1991; Basáñez et al. 2006) The free provision of ivermectin, until termination, by a large pharmaceutical company makes the wide scaled programs affordable. In 2000, ivermectin was received by 20 298 138 individuals in the APOC countries.(Homeida et al. 2002) The programs have brought about very positive changes, but they do have some downsides as well

The burden differs per Eco zone. As mentioned earlier the environment can influence the type of acquired impairment.

Box 4: OCP & APOC

OCP (1974-2000)

Countries: Benin, Burkina Faso, Côte d'Ivoire, Ghana, Guinea Bissau, Guinea, Mali, Niger, Senegal, Sierra Leone and Togo

Method: Vector control through spraying insecticides by helicopters & aircrafts over breeding sites of blackflies.
Late 1980's: introduction ivermectin (provided free by pharmaceutical company) It kills the microfilariae, but not the adult worms; it does prevent them from reproducing, stopping the transmission.

APOC (1995-...)

Countries: Angola, Burundi, Cameroon, Central African Republic, Chad, Congo, Democratic Republic of Congo, Ethiopia, Equatorial Guinea, Gabon, Kenya, Liberia, Malawi, Mozambique, Nigeria, Rwanda, Sudan, Tanzania and Uganda.

Method: Ivermection distribution through community directed treatment (CDT)

Costs: per person treated with ivermectin it is nearly 8,5 times lower than via vector control: US$0.74.

Kale divides the endemic area in four zones, showing the difference in the severity of visual impairment (Kale 1998):
(1) The savanna woodland belt or the northern tropics. The disease is of the blinding type;
(2) The West and Equatorial African rainforest. The disease is characterized as being of the `less blinding' type;
(3) The Zaire basin, with a complex and mixed pattern of severe blinding and `less blinding' onchocerciasis;
(4) The East African highlands extending from Ethiopia to Malawi. The disease is generally of the `less blinding' type

Traditional belief and lack of awareness and inclusion from onchocerciasis projects of these beliefs may enhance the impact. The population nurtures its own beliefs and knowledge of onchocerciasis. One encountered assumption tells that the disease is transmittable from human to human. The diversity in knowledge and conceptions asks for an adaption to the local context, before a large scale treatment program is implemented. (Ndyomugyenyi et al. 2009; Karunamoorthi et al. 2010) The '(…) *disease must be perceived by the affected communities as a severe problem and the benefits of treatment must be appreciated and should outweigh treatment-associated adverse effect.'*(Ndyomugyenyi et al. 2009) The attitude towards the disease and its consequences can enhance the social impact. Like said earlier, not all Onchocerciasis Skin Disease symptoms are included in the Disability Adjusted Life Years (DALY's). Yet specifically those symptoms often carry the most stigma in African communities. The infected are avoided and discriminated by others. The impact for women is even greater, as their marriage prospects diminish or those already married are left or ignored by their men. The stigma has deep psychological effects on the infected themselves. (Ubachukwu 2006; Wagbatsome & Okojie 2004) The stigma can differ per manifestation of the disease. Stigma seems to be more present with skin rashes or lizard skin, than with hanging groin or blindness. Considering that OSD seems to be a more troubling symptom in some regions, and blindness in other regions, the impact of the stigma may also differ per region.

Some damage cannot be reversed. Like mentioned before, onchocerciasis has destroyed entire communities in the past. The OCP proudly showcases its achievements (Samba 1994):

18 million children freed from the risk of blindness

600 000 people prevented from becoming blind

250 000 km2 of abandoned land reclaimed

But disease-struck communities still have to consider the high percentage of disabilities within their community. Community developmental plans have to include this situation.

More than 3 decades ago, in 1981, John Hunter was already concerned about the resettlement of the abandoned lands due to onchocerciasis:

'The planning needs for resettlement are highly complex, involving infrastructural investment and recognition of social systems and land tenure institutions. Questions such as: who owns the abandoned land: the government, stranger-settlers, or indigenous chiefdoms, are delicate, and potentially politically charged.

Governments of the liberate zones have basically three options with regard to resettlement:
(1) to allow spontaneous, uncontrolled resettlement; this happens anyway, and has happened throughout history, subject to local, indigenous, political and social constraints;
(2) the second option is for government to create a "light" infrastructure preparatory to, and in support of, resettlement; this might include the digging of wells and the provision of agricultural extension services;
(3) the third option is "heavy" infrastructure which would include the building of roads, wells, schools, clinics, the measuring of agricultural plots for settlers, even control of crop selection and rotations.'

With vector control, the deserted lands Were cleared of the risk of infection. But the program did not focus too much on the mission at hand. John Hunter realized the problems the redevelopment would generate (see above). (Hunter 1981)

Cysticercosis

Globally no threat, but locally huge impact. In endemic areas the disease causes around 50 000 deaths. (WHO 2006) Especially NCC can have grave effects. Research and estimations describe NCC as the most common cause of secondary epilepsy. NCC is also considered the most important parasitic infection of the central nervous system. (Mafojane et al. 2003; Engels et al. 2003)

Cysticercosis especially affects the poor. The transmission of the disease is tied to poor living conditions. Infection of the disease in both pigs and humans, leads to dual hardship (especially for those with minimal means). (WHO 2006) Both infections lead to a significant loss of income and they often coincide in poor living conditions.

Pig keeping and pork consumption has been growing and still grows. With the risk growing and expanding to new areas, the impact will more likely increase instead of decrease.(Mafojane et al. 2003; Phiri et al. 2003)

There is a lack of good diagnosis and a lack of consensus on control efforts. Both factors should normally be able to decrease the impact, yet with the absence of both, the danger of the disease is very present. (Praet et al. 2009; Diop et al. 2003; G. L. Birbeck & Munsat 2002; Héctor H. García & Del Brutto 2003; J. P. Nguekam et al. 2003) The parasite *T. Solium* has been declared potentially eradicable, yet this target seems far from accomplished. (WHO 2002) These figures show the conditions that trouble the control of cysticercosis in Sub-Saharan Africa (Diop et al. 2003; G. L. Birbeck & Munsat 2002):

Only….

… 129 neurologist in SSA (excl. South Africa)

… 1 neurologist: 1 million people in SSA

… 65 CT-scans in SSA (excl. South Africa)

… 9 MRI scans in SSA (excl. South Africa)

There is a general lack of consensus on the suitable control efforts. Some problems seem specific for this region. The lack of neurologists, CT-scans and MRI-scans is worrying

Box 5: Summary of problems with the control of cysticercosis in endemic regions:

1. **Lack of good diagnosis technique**
   - With variety of clinical symptoms difficult to determine cause is cysticercosis. Especially for the most severe form, NCC, with so few neurologists.
   - Diagnostic tools (CT- & MRI-scan) too expensive and inaccessible. Especially poor affected when dependable on expensive methods.
   - Immunodiagnostic techniques (ELISA). Success for providing correct data questioned
2. **Not for humans, but vaccination for pigs available. But not one adapted to the short life of pigs. Project would need to be:**
   - Cheap
   - Mass-employable
   - Long term
3. **As a zoonosis, both fields of expertise need to be included in control efforts, but they generally don't work together; someone has to bring them together.**
4. **Current available medicine for humans contains some risks for people with cysts.**
5. **Control should go hand in hand with development and education.**

The treatment of cysticercosis also remains debated. Nash mentions five treatment modalities that can be offered (including the problematic drug; surgical interventions against the cysts; and general anti-seizure medication for the seizures) (Nash 2003) But like said, the treatment should also include pigs. Vaccination for only pigs could be a solution as they're the intermediate hosts.

Developmental actions to control cysticercosis, involve: better meat inspection; legislation; strict use of slaughterhouses; better sanitary facilities; facilities to maintain better hygiene; and no free pig ranging. (Gonzalez et al. 2003; Sarti & Vedantam Rajshekhar 2003; WHO 2002) These should go in hand in hand with education. Besides education on cysticercosis itself, especially education on better hygiene is important for the prevention of the disease. Education should also include ways of cooking the pork and washing the vegetables. (Alexander et al. 2012; Gonzalez et al. 2003; Sarti & Vedantam Rajshekhar 2003)

Traditional belief, lack of awareness and lack of inclusion in health care of these beliefs, may enhance the impact. Patients tend to go to traditional healers first. From epilepsy research, it shows that these healers are physically more accessible (close by, no transportation costs) and offer greater cultural and conceptual familiarity. (Baskind & G. Birbeck 2005) Seeing that epileptic seizures may be caused by cysticercosis and are the most frequent feature of NCC, it seems important that traditional healers are involved in the health care system. (Baskind & G. Birbeck 2005; Diop et al. 2003)

According to belief, epileptic seizures are curses. In Africa stigma towards epileptic persons and persons with an intellectual disability is widespread, especially in rural communities (cysticercosis is more present in rural than in urban regions). (Winkler et al. 2009)

Overall, the data and research on the diseases was scarce, especially that with a focus on Sub-Saharan Africa. Most risk and impact information is based on local or regional studies, often there is not enough published for review studies of the entire region.

Meningitis, Onchocerciasis and Cysticercosis ……..

- **No global threat, but destructive locally**
- **Explicitly Sub-Saharan Africa a problematic and endemic region.**
  For meningitis and cysticercosis the endemic region is expanding
- **Risk of infection in Sub-Saharan Africa high, especially for the poor**
- **Endemic countries cannot carry burden of these diseases; but the realization of control efforts display varying degrees of success**
- **Local knowledge and beliefs can enhance the risk and impact of the diseases**
- **Taking into account their disastrous impact, not enough attention has been paid to the disabling diseases**

2

International development indicator tools: missing elements

International development should enhance the quality of life. Quality of life can be read through various dimensions of a person's life. For some, clean water and healthy nutrition may be lacking, for others the shortage of education and employment may interfere with maintaining a decent standard of living. Developmental plans are designed to fill these gaps and improve the overall quality of life. International Development does this through targeting the dimensions of living.

The disabling diseases impose serious complications to the livelihood and survival of single persons, but also certain areas or communities in Sub-Saharan Africa. Sub-Saharan Africa is a poorly developed region and thus targeted by many development plans.

Various tools attempt to summarize and visualize development in general. Have they managed to include all dimensions of human life? The circumstances caused by the disabling diseases may be too rare on a global scale to find them incorporated in international development plans. Are those affected by the disabling diseases included?

Development has transformed from a single to a multidimensional concept. Development used to be assessed as a one dimensional concept, measured through the GNP of countries. In the 1970's the realization arose that development couldn't just be achieved through macroeconomics. The *'(…) expansion of output and wealth is only a means. The end of development must be human well-being*.' (UNDP 1990) Other dimensions, like education and health, were positioned more centrally in development plans in the 1970's. As a reaction to the throwback in the 1980's, where development plans were tied to strict rules of the Structural Adjustment Policies, the UN introduced the concept of *Human Development* in 1990.(UNDP 1990) Largely based on Sen's capabilities approach, *Human Development* focusses on the two sides of development, which should be in balance: the formation of human capabilities and the use people make of their acquired capabilities. (UNDP 1990)

Composite development indicators were developed to monitor progress and serve as a guideline for assessing plans. As GNP couldn't serve as the sole representation of development anymore, other tools were developed. The objective of these tools was two-sided. Firstly, the tools had to measure the state of development. The multidimensionality of the concept entailed the inclusion of various dimensions. Secondly, on the outcome of the new tools, plans and policies were assessed.

The opinions differ on which dimensions and indicators should be included and how much weight should be attached to them. The multidimensional character did not simplify the way to summarize and visualize development, nor did it provide one true approach to do this. Including all dimensions may entail the inclusion of all the capabilities, but might complicate the use on a wider scale. Yet the omission of some dimensions might exclude some people from the development process. And lastly, prioritizing between the included dimensions can have serious consequences; which elements are more important than others?

Is the use of development indicators possible or suitable? The use of international indices in general is being criticized. They can provide false information by deforming very complex data. (Ravallion 2010; Hoyland et al. 2009) The measurability of development, and more specifically Human Development, is questioned. The concept may be too broad. (Kovacevic 2010b)

This discourse on development and tools will reoccur in this chapter on the different tools and frameworks.

2.1 Single indicator tool

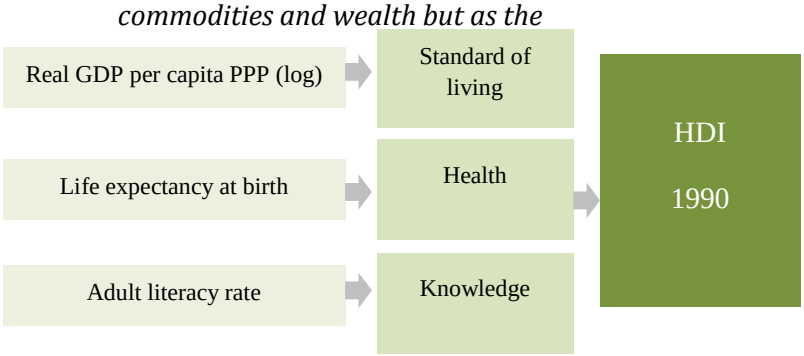
What is included and how much weight is attached?

Single indicator tools summarize and visualize development into one number. GNP used to be the single indicator at hand. Now multiple dimensions and indicators are included to form one index number. (UNDP 1990) The composite indices combine development information to provide an image of the level of development. Reducing the information to one number makes it possible to compare countries or regions. As Hoyland et al. say: '*Their appeal lies in their simplicity*.' (Hoyland et al. 2009) Policy makers can easily get an idea of the current state of development and build their plans around it. Yet the composite indices have been debated on their calculation: what is included, which weight is attributed and how representative are they?

Human Development Index

The best known development index is the Human Development Index (HDI), introduced by the UNDP in 1990. The idea behind the index was '(…) *measuring development not as the expansion of commodities and wealth but as the widening of human choices*.' (UNDP 1990) Following the idea of human development, capabilities were included that can be seen as both input and output (like knowledge); but also capabilities that serve as indicators for other capabilities (like income).(Anand, S. & Sen 2000) The UNDP included only three dimensions. This choice was explained as: (…) *at all levels of development, the three essential ones are for people to lead a long and healthy life, to acquire knowledge and to have access to resources needed for a decent standard of living. If these essential choices are not available, many other opportunities remain inaccessible.'* (UNDP 1990)

Based on critique, the design of the HDI has gone through some revisions over the year. The most significant changes are shown below. Table 9 displays the discourse on the advantages and disadvantages of the HDI. Some factors, like the calculation of income, received more critique and saw more revisions, than others.

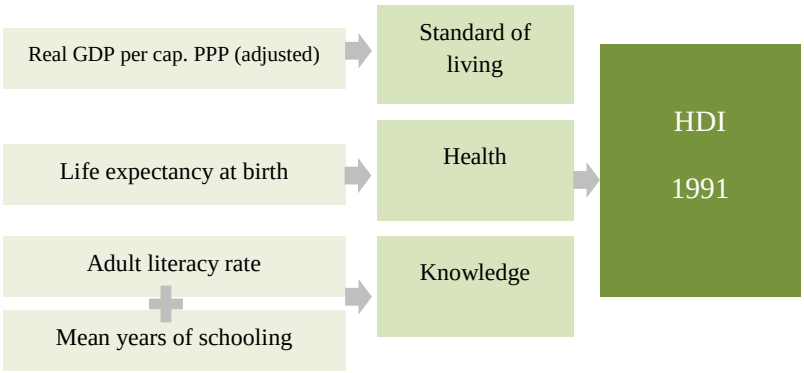


Formula 1990:

Deprivation per dimension = $\frac{\text{Maximum-current status}}{\text{Maximum-Minimum}}$ (observed bounds)

Average deprivation = $\frac{\text{SoL depr.+ H depr. + K depr.}}{3}$

HDI = 1- Average deprivation



Formula change 1991:

1990: Real GDP per capita PPP adjusted with log. Zero weight to income above poverty line.

1991:
Real GDP per capita PPP adjusted with Atkinson formula. Diminishing returns above poverty line.

Knowledge =
⅔ adult literacy rate + ⅓ mean years of schooling

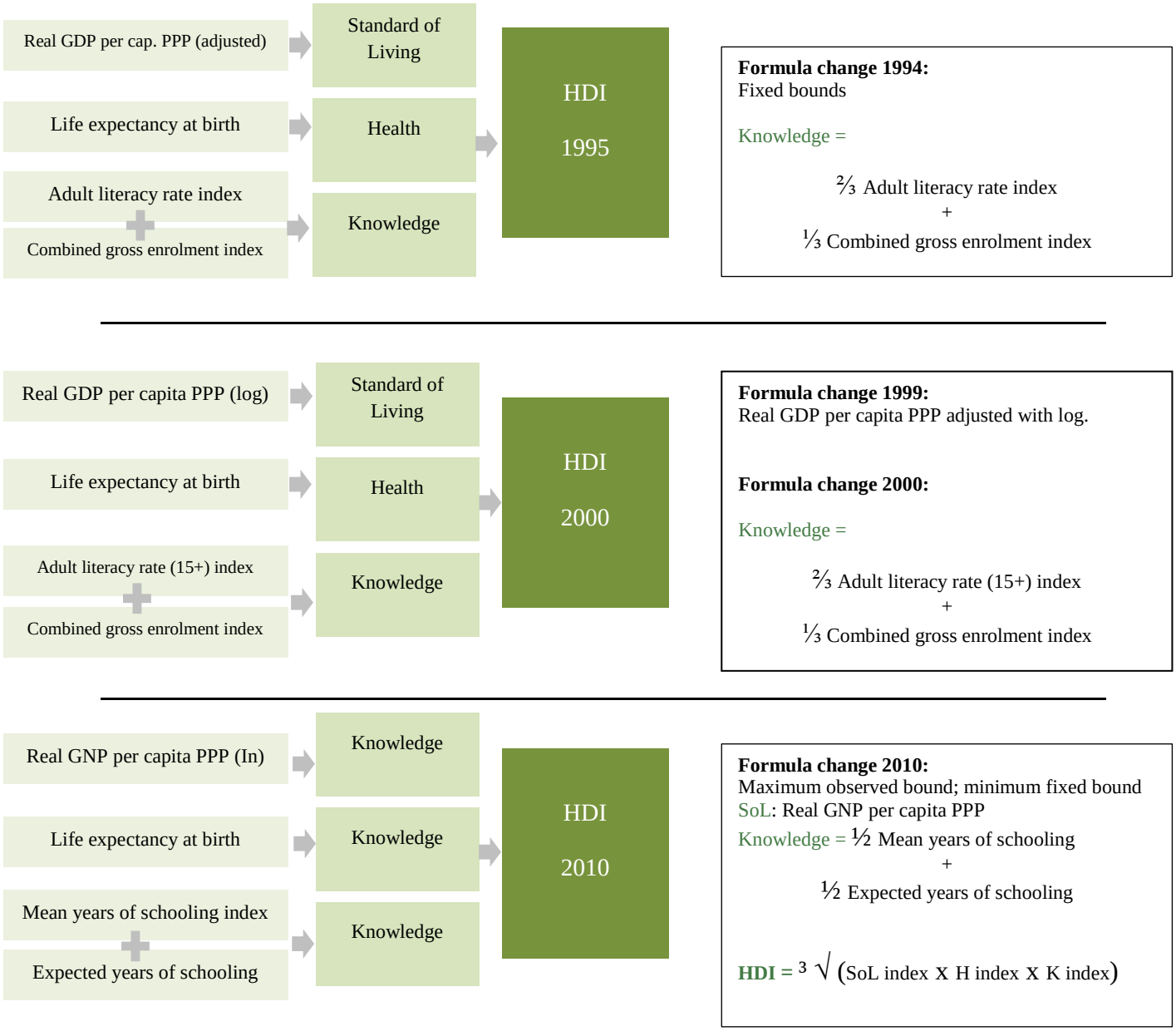


Figure 2: Human Development Index
Sources: UNDP 1990; UNDP 1991; UNDP; 1994; UNDP 1995; UNDP 1999a; UNDP 2000; UNDP 2010

Consequences of disabling diseases missing
Are the consequences for the people and communities affected by the three disabling diseases included in this globally used development tool?

Health during life excluded. In the index the attention is focused on longevity and mortality. But the *quality* of health *during* life should also be included.(Klugman & Choi 2011; Kovacevic 2010a) Especially for people with a disability the quality of health affects their capabilities. This indicator cannot be scaled under another capability like life expectancy or income, but can actually be a very important facilitator or barrier for other capabilities. In this way health could perhaps be given more weight than other dimensions; but the discourse critique only mentions income as a facilitator to attach more weight to. (Noorbakhsh 1998) Strikingly few authors mention health during life specifically as a critique. (Kovacevic 2010; Klugman & Choi 2011; Pritchett 2010)

Locally destructive manifestations are invisible. The distribution of the dimensions within a country isn't clear within the HDI. (Sagar & Najam 1998; Kovacevic 2010a; Grimm et al. 2006; Gaye & Jha 2010; Herrero & Villar 2010)The focus may be on

quantity, but not quantity on a local scale. The local destructiveness of the diseases on the infected, but also on entire communities, remains invisible. Especially since context is omitted. (Graham 2010; Ravallion 2010) In this case context may be very important for development. Stigma can hinder the way capabilities are used; yet services can improve the use of capabilities. The consequences of the invisibility of context are that the HDI can show untrue information but also stimulate the absence of specific policies necessary for the affected regions.

The poor-specific nature of the diseases decreases the importance of the impact within the HDI. The HDI was criticized for including indicators that were applicable to specifically developed or specifically developing countries. (Sagar & Najam 1998; Deaton 2003) Although the standard of living dimension gained a correction for poor and wealthy countries, this distinction was not made for other dimensions. (UNDP 1991) As the three diseases would not thrive as much under developed circumstances, the HDI would need to be more pro-poor, in order to make the consequences of the disabling diseases best visible.

Duration and extension of the impact is invisible. As only mortality is included, the HDI focusses on short term health consequences for a person. The diseases may obstruct development suddenly, during a meningitis epidemic, but overall, the consequences have a long term impact. Especially since comparing ranking over time may not be reliable (as the calculation has changed and the goalposts would need to be fixed), the duration of the impact remains invisible. (Anand, S. & Sen 1994;

Table 1: Human Development Index discourse

Pro's	Con's/critique
Multidimensional, more accurate than just GNP	**Until 2010 dimensions substitutable. In theory, a country could make up for failure in 1 dimension with success in other dimension**
Means *and* Ends ***Capability Poverty Measure* solely ends**	**Dimensions and indicators can represent both, but no structure in components**
Applicable Global Use. (Not context-specific; not controversial or subjective)	**No information political and institutional environment where capabilities exercised. Once acquired, choice how to use capabilities can be context-specific**
Transparency and simplicity, **few dimensions included**	**HDI not so transparent and simple: ranking sensitive to choice of ranges and calculation method** **Dimensions and indicators missing, like state of health *during* life.**
Data needed is available **(for other dimensions might be lacking)**	
Income indicator for other capabilities, with a threshold after which additive income does not result in a significant increase in capabilities	**Not all other capabilities can be included under income.** **The threshold might differ per country; this was built into the formula in later years**
	Focus on quantity instead of quality
***Human Poverty Index* for poor and developed countries designed**	**Not all indicators applicable to all countries (literacy)**
	Mix of stocks and flows -> units not comparable
***Inequality adjusted HDI* designed**	**Inequality within country concealed**
	Changes over time not visible

Sources: *Anand, S. & Sen, 1994, 2000; Cheibub, 2010; Deaton, 2003; Gaye & Jha, 2010; Gaye, 2008; Graham, 2010; Grimm, Harttgen, Klasen, & Misselhorn, 2006; Haas, 2009; Harttgen & Klasen, 2010, 2009; Herrero & Villar, 2010; Hoyland, Moene, & Willumsen, 2009; Klugman & Choi, 2011; Kovacevic, 2010; Noorbakhsh, 1998; Pritchett, 2010; Ravallion, 2010; Sagar & Najam, 1998; UNDP 1990; UNDP1991; UNDP 1992; UNDP 1993; UNDP 1995; UNDP 1996; UNDP 1997; UNDP 1998; UNDP 1999a; UNDP 2000; UNDP 2001; UNDP 2002; UNDP 2003a; UNDP 2004; UNDP 2005;UNDP 2006; UNDP 2007; UNDP 2008; UNDP 2009; UNDP 2010; UNDP 2011*

UNDP 1999a)

The extension of the impact on an entire community is absent, as dependency numbers aren't clear through for instance employment indicators or household finances.

The HDI proved a better alternative to GNP, but in this case it proves insufficient. The advantage that the data is available may be why for instance disability is not included. Yet when you include an indicator it may also give an impulse to the data gathering concerning this subject. The revisions throughout the years have not improved the visibility of the consequences of the disabling diseases. Yet the extra devices and indices that have been designed to support the HDI may be more suitable.

Alternative or supportive indices

Other indices might include the consequences of the disabling diseases in a better way.

Physical Quality of Life Index

The Overseas Development Council created this tool in the 1970's following the trend away from GNP: '(…) *the use of indicators for judging performance under basic needs criteria should concentrate on indicators of outputs or results, rather than inputs.*' (Hicks et al. 1979) The PQL formula included three dimensions:

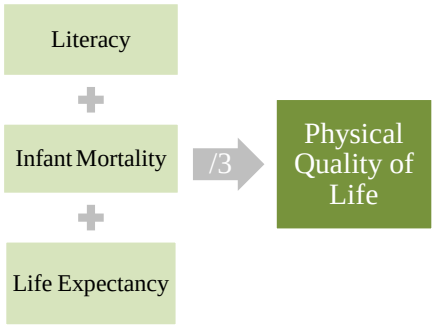


Figure 3: Physical Quality of Life index

For the calculation of the index, raw data was converted into a scale of 1 to 100 for the three dimensions. Those three numbers were added and divided by three.(Larson & Wilford 1979) GNP was explicitly excluded.

The tool provoked critique; some of which can also be found under the HDI critique. Above all, the theoretical foundation wasn't found to be strong enough. No valid arguments could be made why these weight choices were better than alternative indices and why all the dimensions received the same weight. The dimensions that were weighted focused more on quantity than quality of life. (Hicks et al. 1979) Ram suggested the application of the method of principle components on the weight scale and the inclusion of GNP to the index, in order to improve the tool. (Ram 1982) The PQLI resembled a first step, as it included multiple dimensions and excluded context specific information. In this resemblance, the PQLI shows the same shortcomings as the HDI concerning health during life, absence of context or distribution and vulnerability to poor specific circumstances.

Inequality adjusted HDI

The inequality adjusted HDI may help to include the local destructiveness of the diseases. The tool reflects inequality within each of the three dimensions within a country. The higher the inequality within a country, the lower the IHDI will fall compared to the HDI. '(…) *the HDI can be viewed as an index of "potential" human development (…), while the IHDI is the actual level of human development (accounting for inequality).'* (UNDP 2010)

The IHDI does not draw attention to distribution-locality, but focusses on distribution classes within the entire population. It thus cannot make the consequences more visible, not even if more dimensions or indicators were included in the HDI. Especially not since one fault of the IHDI is, that it doesn't show '(…) *whether the same people experience one or multiple deprivations.'* (UNDP 2010) Yet the use of the less traditional data sources may prove an opportunity to include more indicators and dimensions into an equation.

Poverty indices

The development of tools specifically directed to the poor in each community and not human development in general, could be suitable because of the relation between the poverty and the diseases. This perspective is important, because improvements for the

more advantaged people may cloud the image of development and level of poverty within a country. These tools focus on poverty-specific issues, like illiteracy, nutrition, lack of services etc.

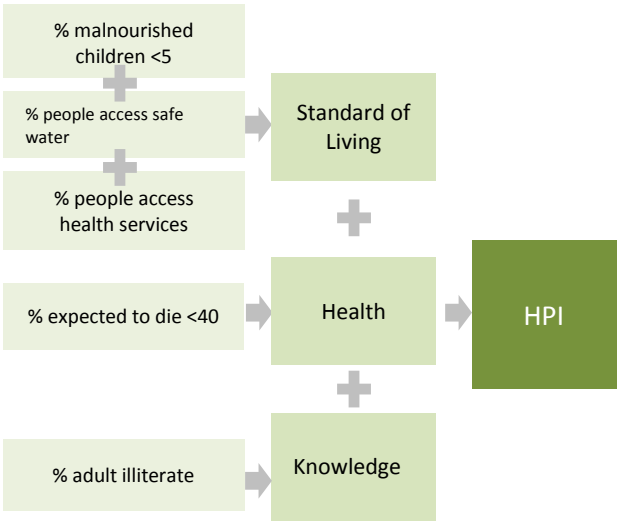


Figure 4: Human Poverty Index

The *Human Poverty Index* was introduced in the 1997 Human Development Report. (UNDP 1997) It includes the same three dimensions, but focusses on different indicators:

The HPI formula encounters some of the same problems as the HDI: the choice of elements, the attached weight. It did choose to avoid income, as the minimum income needed to rise above poverty, can differ per country. They thus chose to focus on '(…) *material deprivation in hunger and malnutrition (…).*' (UNDP 1997)
With an emphasis on poverty issues, this index may include those communities affected by the diseases. It still excludes essential elements though; the health discourse remains focused on mortality. And the index only shows country focusses and cannot identify specific groups. Unfortunately, in 2002 the access to health services was removed from the HPI due to a lack of data. Later on, a specific version for developed countries was designed as well.

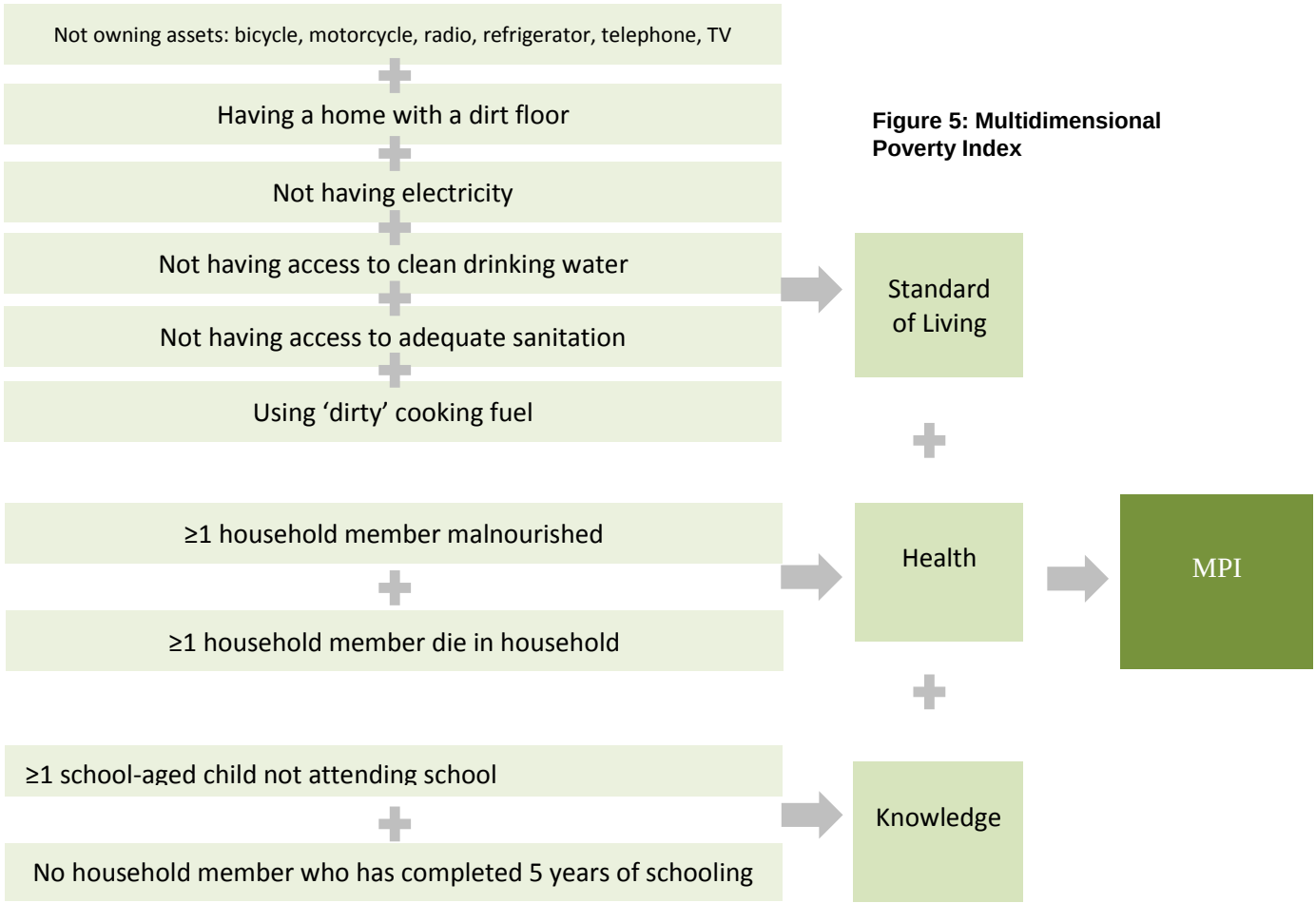


Figure 5: Multidimensional Poverty Index

In 2010 the HPI was converted into the *Multidimensional Poverty Index* (MPI). (UNDP 2010)
In some way this tool combined the HPI and IHDI, as it captures: '(…) *how many people experience overlapping deprivations and how many deprivations they face on average. It can be broken down by dimension to show how the composition of multidimensional poverty changes in incidence and intensity for different regions, ethnic groups and so on—with useful implications for policy.'*(UNDP 2010)The MPI does have some disadvantages, similar to the HDI, like the confusion of ends and means in the elements, use of stock and flow. But it could include the consequences of the diseases better because of its focus on poverty-related issues and within-country differentiation. But once again quality of health during life is excluded. The UNDP even acknowledges that some of the health indicators have poor data coverage. How can they then validate the choice of malnutrition over quality of health during life? (UNDP 2010) One crucial indicator, stigma, is missing from the indices as well.

The last index focusing on poverty related issues was introduced in the 1999 Thailand HDR: the *Index of Human Deprivation* (IHD). (UNDP 1999b) The index includes eight dimensions. These are visualized each in their own index: income; employment; health; education and human resource; housing and environment; transport and communications; consumer goods; women. These separate indices are formed from a multitude of elements. The IHD lends itself for inter-country research and thus differentiation. Although the diseases incidence is included, unfortunately the quality of health during life is absent from the elements.

In 2003 the index was converted into the *Human Achievement Index* (HAI); this index is more related to the HDI. (UNDP 2003b) As Thailand had developed into a middle income country it no longer had to specifically focus on basic deprivation, but on other development processes as well. The HAI preserved five dimensions, but instead of consumer goods and women, it added family and community life; and participation. The dimensions are measured through forty-eight indicators. The index is based on a human life cycle: '(…) *starting with the first essential thing that everyone must have on the first day of his/her life – health, followed by the next important step for every child – education. After schooling, one is expected to get a job, to secure enough income, to have a decent housing and living conditions. Then a person moves beyond him/herself to have a quality family and community life, to maintain contacts and communication with others, and last but not least, to participate as member of a society.' (UNDP 2003b)*

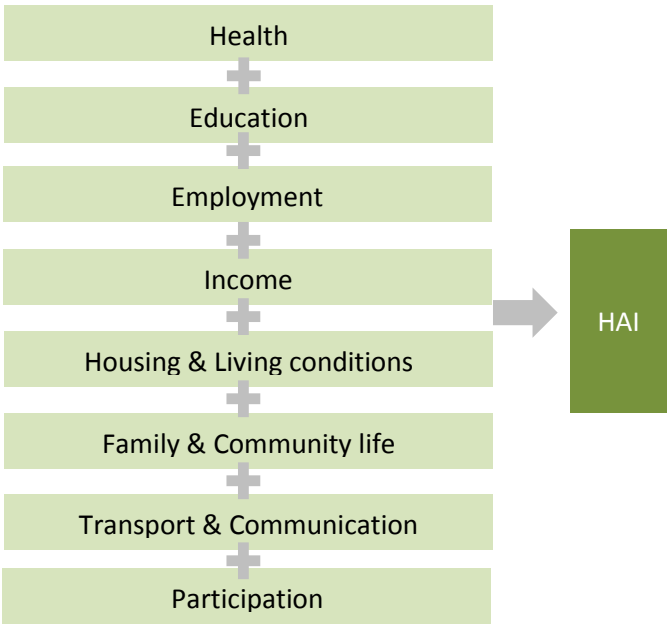


Figure 6: Human Achievement Index

Under the health dimension the HAI measures, for physical and mental illness, the indicators AIDS and mental illness. While the HAI emphasizes how health is the most important component in a human's life, disability is not included as an indicator that could be a facilitator or barrier for other capabilities. But, the HAI includes under family and community life: percentage of disabled persons. The tool is able to hereby include the dependency effect of the disabling diseases on the entire community, not just on those who became disabled. The family and community dimension may have provided the opportunity to include stigma as well, but under community only indicators on crime numbers were included. For global use the

HAI might be too data intensive and complex. (Gaye & Jha 2010)

Missing or alternative dimensions and indicators

Table 2 displays dimensions or indicators suggested by authors or included in other indices. They relate to disadvantages of the HDI, like: the calculation of income; exclusion of quality; missing political and institutional environment; poor-specific or disadvantageous circumstances.

Some dimensions or indicators relate more to the consequences of the diseases than others. The suggestions of the IHD and HAI in the health dimension were already discussed. The effect of disability on the entire community could be captured under family and community life. The political and institutional environment and service delivery could capture the way a context could perform as a facilitator or a barrier. And lastly, participation and exclusion could display the possible stigma within a society. If these dimensions and connecting indicators would be included in development indices, the consequences of the disabling diseases could be less invisible.

Table 2: Missing or alternative dimensions and indicators

Dimensions	indicators	Suggested/ Used
Living Standard	current effective per capita consumption flows	IEWB
	net societal accumulation of stocks of productive resources,	IEWB
	income distribution	IEWB
	Economic security	IEWB
Knowledge/education	average length of employees' schooling	IDIP
	education coverage measured by proportion of the population aged 5-24 years enrolled in schools	IDIP
	, number of employees that have acquired post graduate education per 100,000 employees	IDIP
	number of research and development employees per 100,000 employees	IDIP
	research and development spending as a percentage of Gross Regional Product (GRP	IDIP
	Learning Achievement (includes quality)	Kovacevic (2010)
Health	-Disease incidence -mental illness	IHD HAI
Family& Community life	-% disabled persons	HAI
Service Delivery	Perception of 12 services in education, health, water supply, power supply, sanitation, roads, transport facilities, environment, migration, livelihood, housing, women's safety and position, and overall governance	
Political & Institutional environment		Cheibub (2010)
Law & Order		Noorbakhsh (1998)
Human Rights		Hartgen&Klasen (2010); Herrero et al. (2010)
Peace, security & freedom		Hartgen& Klasen (2010); Harttgen& Klasen (2009); Noorbakhsh (1998)
Participation		HAI
Empowerment	Social empowerment	HEI
	Economic empowerment	HEI
	Political empowerment	HEI
Social Exclusion	Living standard:	HSEI

	- long-term unemployment - % of population below the poverty line	
	Health: % of the population without health insurance	HSEI
	Education: % of the population aged more than 15 years not complete primary education	HSEI
	Participation in society: - % of eligible voters not vote in the in elections - % of the population not participating in activities of social organization	HSEI
	Access to services: % of dwellings without a telephone	HSEI
Migration		De Haas (2009); Harttgen& Klasen (2009)
Sustainability		Sagar&Najam (1998); Herrero et al. (2010)

HAI: Human Achievement Index (Thailand 2003 HDR)
HEI: Human Empowerment Index (Nepal 2004 HDR)
HSEI: Human Social Exclusion Index (Bosnia and Herzegovina 2007 HDR)
LQI: Life Quality Index (Pandey& Nathwani 1997)
IEWB: Index of economic wellbeing (Centre for the Study of Living Standards, 1998)
IDIP: Index of Development of Intellectual Potential (Russian Federation 2004 HDR)
IHD: Index of Human Deprivation (Thailand 1999 HDR)

Sources: Cheibub 2010; De Haas 2009; Hartgen&Klasen 2009; Hartgen& Klasen 2010; Herrero etal. 2010; Kovacevic 2010; Noorbakhsh 2010; Sagar& Najam 1998; UNDP 1999b; UNDP 2003 b; UNDP 2004b; UNDP 2004c; UNDP2007b

2.2 Multiple indicator tool

Have all dimensions and indicators been included and in what way?

Although one index number may offer a simple and clear visual on development, in order to target the right problems, you need more data. Multiple indicator tools portray a more extensive data overview on which policies can be build. The measurement obviously demands more intensive data-gathering though; data which may not always be available.

Millennium Development Goals

The Millennium Development Goals framework is probably the best known multiple indicator tool. It was presented by the UN one year after the Millennium Declaration was signed in 2000. The framework visualized development in several dimensions through goals; attached targets; and matched indicators to measure the progress. The 2001 framework displayed eight goals, eighteen targets and forty-eight indicators. Since 2008, as seen in table 4, the tool contains eight goals, twenty-one targets and sixty indicators. The time dimension for the goals runs until in 2015.

The tool was said to follow the idea of human development, displaying even more multidimensionality than the HDI. (Saith 2006) Yet it solely displays the ends of development and excludes the means. (Andy Haines & Cassels 2004; Vandemoortele & Delamonica 2010) The MDG's have seen extensive promotion leading to globally a wider awareness of development problems. (Manning 2009) But the tool has received considerable critique as well. Table 3 shows the main points in the discourse on the MDG's.

Table 3: Millennium Development Goals discourse

Pro's	Con's
Concreteness (can never cover entire human development field)	**Missing dimensions and indicators.**
Strong Advocacy development problems	
	Structure is wrong (3 health goals, overlapping targets)
Globally achieved goals	**Global targets interpreted as country specific**
Poor-specific	**Development problem solely located in Third World**
	Inequality missing. Especially problematic since PRSP's also top-down approach, not pro-poor.
Motivating fixed targets	**Poorest countries disadvantaged -> demoralizing. Data manipulation to reach targets.**
Responsibility developed countries included, not just developing countries	**Exclusion of global systematic problems in institutions and structures etc. Developed countries not willing to make changes in those areas.**
	Data need too extensive vs. available data
Based on idea human development with multiple dimensions. More than HDI.	**Means are missing. Circumstances needed to achieve goals (like good health systems, peace, good governance etc.) missing; there is a capacity-gap.**
	Too much focus on quantity instead of quality
	Some target programs costs cannot be estimated (violence against women)
	No emphasize on links between goals and targets.

Sources: (Attaran 2005; Easterly 2007; Nullis-Kapp 2004; Fukuda-Parr 2010; Andy Haines & Cassels 2004; Hulme 2010; Jahan 2010; Manning 2009; Saith 2006; Travis et al. 2004; Vandemoortele & Delamonica 2010; Wickstead 2010)

There is a (maybe too) clear focus on health with three separate goals, also including diseases. Health is seen it its own right, but also as a facilitator to other goals. (Andy Haines & Cassels 2004) But one obvious disadvantage is the overall exclusion of quality of health during life. People with disabilities are mentioned nowhere. (Saith 2006) In 2011, a report was published on how to include disability issues in the MDG's. The UN acknowledged that disability is missing from the framework, but they felt there was no more time to adjust the indicators before 2015. (United Nations 2011) The report did explicitly encourage coalitions of DPO's and NGO's to get involved in components of the MDG's, showing the MDG indicators with linked disability indicators.

The MDG's have one goal specifically focusing on diseases, yet the attached indicators don't relate to the three disabling diseases.

Although mentioned as a critique, the MDG's are very poor-specific, which could make the diseases more visible. Yet the data gathering demands are too extensive for those areas, explicitly Sub-Saharan Africa, where the problems are the biggest (and thus data most needed). (Andy Haines & Cassels 2004; Attaran 2005) The data gathering for health especially remains debated, thus excluding quality of health for this reason would be inconsistent. (Attaran 2005)

Unfortunately distribution is not built into the framework, which could hide the local destructiveness. Especially since there remains confusion on whether to interpret the targets on a global, regional, national or local level. (Attaran 2005) (Manning 2009)

As the capacity is excluded, the context also remains invisible. Circumstances like the condition of the health system or stigma can't be found in the framework.

Box 6: Millennium Development Goals (MDGs)

Goals and Targets (from the Millennium Declaration)	Indicators for monitoring progress
Goal 1: Eradicate extreme poverty and hunger	
Target 1.A: Halve, between 1990 and 2015, the proportion of people whose income is less than one dollar a day	1.1 Proportion of population below $1 (PPP) per day[1] 1.2 Poverty gap ratio 1.3 Share of poorest quintile in national consumption
Target 1.B: Achieve full and productive employment and decent work for all, including women and young people	1.4 Growth rate of GDP per person employed 1.5 Employment-to-population ratio 1.6 Proportion of employed people living below $1 (PPP) per day 1.7 Proportion of own-account and contributing family workers in total employment
Target 1.C: Halve, between 1990 and 2015, the proportion of people who suffer from hunger	1.8 Prevalence of underweight children under-five years of age 1.9 Proportion of population below minimum level of dietary energy consumption
Goal 2: Achieve universal primary education	
Target 2.A: Ensure that, by 2015, children everywhere, boys and girls alike, will be able to complete a full course of primary schooling	2.1 Net enrolment ratio in primary education 2.2 Proportion of pupils starting grade 1 who reach last grade of primary 2.3 Literacy rate of 15-24 year-olds, women and men
Goal 3: Promote gender equality and empower women	
Target 3.A: Eliminate gender disparity in primary and secondary education, preferably by 2005, and in all levels of education no later than 2015	3.1 Ratios of girls to boys in primary, secondary and tertiary education 3.2 Share of women in wage employment in the non-agricultural sector 3.3 Proportion of seats held by women in national parliament
Goal 4: Reduce child mortality	
Target 4.A: Reduce by two-thirds, between 1990 and 2015, the under-five mortality rate	4.1 Under-five mortality rate 4.2 Infant mortality rate 4.3 Proportion of 1 year-old children immunised against measles
Goal 5: Improve maternal health	
Target 5.A: Reduce by three quarters, between 1990 and 2015, the maternal mortality ratio	5.1 Maternal mortality ratio 5.2 Proportion of births attended by skilled health personnel
Target 5.B: Achieve, by 2015, universal access to reproductive health	5.3 Contraceptive prevalence rate 5.4 Adolescent birth rate 5.5 Antenatal care coverage (at least one visit and at least four visits) 5.6 Unmet need for family planning
Goal 6: Combat HIV/AIDS, malaria and other diseases	
Target 6.A: Have halted by 2015 and begun to reverse the spread of HIV/AIDS	6.1 HIV prevalence among population aged 15-24 years 6.2 Condom use at last high-risk sex 6.3 Proportion of population aged 15-24 years with comprehensive correct knowledge of HIV/AIDS 6.4 Ratio of school attendance of orphans to school attendance of non-orphans aged 10-14 years
Target 6.B: Achieve, by 2010, universal access to treatment for HIV/AIDS for all those who need it	6.5 Proportion of population with advanced HIV infection with access to antiretroviral drugs
Target 6.C: Have halted by 2015 and begun to reverse the incidence of malaria and other major diseases	6.6 Incidence and death rates associated with malaria 6.7 Proportion of children under 5 sleeping under insecticide-treated bed nets 6.8 Proportion of children under 5 with fever who are treated with appropriate anti-malarial drugs 6.9 Incidence, prevalence and death rates associated with tuberculosis 6.10 Proportion of tuberculosis cases detected and cured under directly observed treatment short course

[1] For monitoring country poverty trends, indicators based on national poverty lines should be used, where available.

Goal 7: Ensure environmental sustainability	
Target 7.A: Integrate the principles of sustainable development into country policies and programmes and reverse the loss of environmental resources Target 7.B: Reduce biodiversity loss, achieving, by 2010, a significant reduction in the rate of loss	7.1 Proportion of land area covered by forest 7.2 CO2 emissions, total, per capita and per $1 GDP (PPP) 7.3 Consumption of ozone-depleting substances 7.4 Proportion of fish stocks within safe biological limits 7.5 Proportion of total water resources used 7.6 Proportion of terrestrial and marine areas protected 7.7 Proportion of species threatened with extinction
Target 7.C: Halve, by 2015, the proportion of people without sustainable access to safe drinking water and basic sanitation	7.8 Proportion of population using an improved drinking water source 7.9 Proportion of population using an improved sanitation facility
Target 7.D: By 2020, to have achieved a significant improvement in the lives of at least 100 million slum dwellers	7.10 Proportion of urban population living in slums[2]
Goal 8: Develop a global partnership for development	
Target 8.A: Develop further an open, rule-based, predictable, non-discriminatory trading and financial system Includes a commitment to good governance, development and poverty reduction – both nationally and internationally Target 8.B: Address the special needs of the least developed countries Includes: tariff and quota free access for the least developed countries' exports; enhanced programme of debt relief for heavily indebted poor countries (HIPC) and cancellation of official bilateral debt; and more generous ODA for countries committed to poverty reduction Target 8.C: Address the special needs of landlocked developing countries and small island developing States (through the Programme of Action for the Sustainable Development of Small Island Developing States and the outcome of the twenty-second special session of the General Assembly) Target 8.D: Deal comprehensively with the debt problems of developing countries through national and international measures in order to make debt sustainable in the long term	*Some of the indicators listed below are monitored separately for the least developed countries (LDCs), Africa, landlocked developing countries and small island developing States.* <u>Official development assistance (ODA)</u> 8.1 Net ODA, total and to the least developed countries, as percentage of OECD/DAC donors' gross national income 8.2 Proportion of total bilateral, sector-allocable ODA of OECD/DAC donors to basic social services (basic education, primary health care, nutrition, safe water and sanitation) 8.3 Proportion of bilateral official development assistance of OECD/DAC donors that is untied 8.4 ODA received in landlocked developing countries as a proportion of their gross national incomes 8.5 ODA received in small island developing States as a proportion of their gross national incomes <u>Market access</u> 8.6 Proportion of total developed country imports (by value and excluding arms) from developing countries and least developed countries, admitted free of duty 8.7 Average tariffs imposed by developed countries on agricultural products and textiles and clothing from developing countries 8.8 Agricultural support estimate for OECD countries as a percentage of their gross domestic product 8.9 Proportion of ODA provided to help build trade capacity <u>Debt sustainability</u> 8.10 Total number of countries that have reached their HIPC decision points and number that have reached their HIPC completion points (cumulative) 8.11 Debt relief committed under HIPC and MDRI Initiatives 8.12 Debt service as a percentage of exports of goods and services
Target 8.E: In cooperation with pharmaceutical companies, provide access to affordable essential drugs in developing countries	8.13 Proportion of population with access to affordable essential drugs on a sustainable basis
Target 8.F: In cooperation with the private sector, make available the benefits of new technologies, especially information and communications	8.14 Fixed telephone lines per 100 inhabitants 8.15 Mobile cellular subscriptions per 100 inhabitants 8.16 Internet users per 100 inhabitants

Source: http://mdgs.un.org/unsd/mdg/Host.aspx?Content=Indicators/OfficialList.htm

[2] The actual proportion of people living in slums is measured by a proxy, represented by the urban population living in households with at least one of the four characteristics: (a) lack of access to improved water supply; (b) lack of access to improved sanitation; (c) overcrowding (3 or more persons per room); and (d) dwellings made of non-durable material.

World development Indicators

The World Bank started gathering data in 1960 for this tool and updates the data, from different sources, several times per year. Through an online database, the World Bank provides us an overview of eighteen dimensions with over three hundred indicators. (Table 5)

The database can be very useful for policy making and research. The tool is extremely data intensive, providing many poverty specific indicators. Yet despite the range of dimensions and indicators, data on quality of health during life is not complete. The discourse is mainly focused on mortality, health care, and maternal and birth data. Indicators on the MDG diseases (HIVA/Aids; malaria; and tuberculosis) are also included. Yet many other diseases and disabilities remain excluded from this development visual. Lastly, the effects of stigma remain invisible.

Indicators are included on dependency within households like unpaid family workers.

Box 7: World Development Indicators dimensions
Agriculture & Rural Development
Aid Effectiveness
Climate Change
Economic Policy& External Debt
Education
Energy& Mining
Environment
Financial Sector
Gender
Health
Infrastructure
Labor& Social Protection
Poverty
Private Sector
Public Sector
Science & Technology
Social development
Urban Development

Source: http://data.worldbank.org/indicator

Level of Living

The last tool may be useful, as it, contrary to all previous tools, *emphasizes* context. The level of living framework was developed in Sweden and still acts as the foundation of surveys on wellbeing in the country. It was first conducted in 1968 and has served as an example for other Scandinavian welfare studies. In 1989 the framework included nine dimensions with twenty one indicators. (see table 6)(Erikson 1989) The dimensions are based on resources, not needs. The director of the project in 1989, Robert Erikson, saw this choice as an advantage: '*We do not necessarily have to decide on which these needs are, the individual is assumed to use them for the best of his interest. On the other hand, we have to decide which the most important resources are and, in so doing, we have to consider for what purpose they can be used.'* (Erikson 1989)

According to Erikson the multidimensionality of the concept and incommensurability of the dimensions ensured that visualization through an indicator was impossible. '*Differences and changes in the level of living must be described for each component.'* (Erikson 1989) But comparability also wasn't the goal of the framework, as the indicators should differ per country. The *'(…) same set of resources is not of equivalent value regardless of the context.'* (Erikson 1989) This framework was specifically designed for Sweden; a country in Sub-Saharan Africa would focus on very different indicators.

This framework thus acknowledged how important a multidimensional tool is and that context can never be excluded. This framework could be adjusted to the Sub-Saharan context.

Box 8: Level of Living framework 1989	
Dimensions	Indicators
Health & Access to health care	- Ability to walk a 100 meters - Various symptoms of illness - Contacts with doctors and nurses
Employment & Working conditions	- Unemployment experiences - Physical demands at work - Possibilities to leave the place of work
Economic resources	- Income and wealth - Property - Ability to cover unforeseen expenses up to $1 000 within a week
Education & skills	- Years of education - Level of education reached
Family& Social integration	- Marital status - Contacts with friends and relatives
Housing	- Number of persons per room - Amenities
Security of life & property	- Exposure to violence and thefts
Recreation & Culture	- Leisure time pursuits - Vacation trips
Political Resources	- Voting in elections - Membership in unions and political parties - Ability to file complaints

Source: Erikson 1989

International development indicator tools ……..

- **Transformation from single into multidimensional tools, following idea of human development**

- **Single indicator tools may be simple;**
  but exclude important elements

- **Multiple indicator tools are more extensive;**
  but suffer from data gathering problems

- **Despite various adjustments to current tools, realization of supportive tools or alternative tools throughout the years;**
  The consequences of the disabling diseases are for a large part still invisible

- **The consequences are invisible, because essential elements are missing:**
  - ***Quality of health during life*. Although actually very important as facilitator for other capabilities. Discourse focusses on mortality or specific circumstances (diseases, malnutrition or health services). Absence of data no reason; applies to other health indicators as well. Inclusion would not only make diseases more visible, but disability in general.**
  - ***Local destructiveness.* Most tools exclude distribution within a country and the inequality adjusted tools often focus on certain groups, not locality**
  - ***Poor-specific issues or a pro-poor focus.* The diseases thrive especially under poor living conditions.**
  - ***Long-term impact.* Comparing over time is difficult and long-term consequence-indicators are excluded**
  - ***The context.* The context may be a facilitator or barrier, through systematic problems (like stigma); (health) system and services etc.**
  - ***Effect on the entire community.* The disabling diseases affect entire communities, not just the cases. Indicators on dependency, household finance etc. excluded.**

3

Including Disabling Diseases in development: new ways

Development intersects several different areas of life. Even if some areas are deemed more important than others, you should have eye for the construct of all the involved areas of life. How else can you respond to change in your life or put improvements in motion?

Human Development concentrates on the different capabilities a person can acquire and use; studied through multiple study fields. These days, International Development combines the fields of social studies, economics, law, international relations, public administration and more fields. Working in the field of development requires wide-scaled expertise. It may be difficult to possess up to date knowledge on all the topics within International Development for one person, but also for one organization or institution. How can it be ensured that all the necessary dimensions and the contemporary ideas on these dimensions are included?

Despite the realization of various tools and frameworks, the consequences of the disabling diseases still have to be included for a large part. Chapter two showed that assessing an International Development framework or tool requires bold choices on what to include and what not. Yet it became obvious that the consequences of the disabling diseases have not become evident enough throughout the years, despite several alterations to the approach of International Development. This chapter will focus on the way towards making the consequences of the disabling diseases more visible in International Development frameworks and tools.

A tool including quality of health is being used by scholars and policy makers. Paragraph 3.1 centers on this attempt to include quality of health during life, in an International Development tool. The described attempt was an important initiative as it tried to integrate the world of health into the world of International Development. Despite its critique, the tool is frequently applied in the work of scholars and policy makers.

Real value can be added to International Development tools by including elements of other fields of study. As the first paragraph concludes that the attempt isn't sufficient enough to include the consequences of the disabling diseases, we step away from the attempts in the field of International Development in the second paragraph. Other fields of study, which link to the different areas of life, are considered. How are some areas of life (which are missing in the International Development tools and frameworks) constructed? And has the approach to these constructs changed?

Combining ideas from different fields can fill the gaps in International Development tools and frameworks. The last paragraph focuses on a new way forward towards including the consequences of the disabling diseases in International Development. the ideas found in other tools and frameworks are summarized and an attempt is made to converge these ideas.

Including quality of health during life

There have been attempts to include dimensions or indicators, which would make the disabling diseases more visible in International Development tools. The most common attempts refer to including quality of health during life; the DALYs are the best known example

Global burden of disease and DALYs

The lack of good methods for providing an estimation of the global state of health, led to the development of the Global Burden of Disease (GBD) study in 1992. The study grew out of a partnership between the World Bank, WHO, Harvard School of Public Health and the Institute for Health Metrics and Evaluation. The World Development Report of 1993 was to focus on health issues; but a good measurement tool was missing, and data was fragmentary and inconsistent.

A framework was needed to integrate health data from all parts of the world; including both mortality and the state of health while living. The measurement unit had to be useful for two tasks:

- measuring the magnitude of premature death and non-fatal health outcomes;
- providing an outcome measure on which methods to reduce the burden could be based.(C. J. L. Murray & Acharya 1997)

The burden of a disease was expressed through one indicator: Disability-Adjusted Life Years (DALY's). A DALY can be seen as one year of healthy life lost. *DALYs are the sum of life years lost due to premature mortality and years lived with disability adjusted for severity*(C. J. Murray & Lopez 1997b)

Box 9 shows the DALY formula. The DALYs are calculated on the principle that all should be treated the same and non-health characteristics of the individual are excluded, except for age and sex which are general to all communities and households, to avoid discrimination. (C. J. L. Murray & Acharya 1997)(C. J. L. Murray & Acharya 1997)(C. J. L. Murray & Acharya 1997)(C. J. L. Murray & Acharya, 1997)(C. J. L. Murray 1994; C. J. L. Murray & Acharya 1997) There is thus no distinction between the regions of the world; the same ideal life expectancy is used; and the same disability weight is used for all found cases (excluding the social context). The DALY's measure incidence instead of prevalence, because death is an incidence number. Lastly, a 3% age weight is taken into account to incorporate the different social roles throughout life. Less weight is given to the years lived at a young age or at an old age.(C. J. L. Murray 1994)

The indicator measures a reduction in human functioning; partly indicated by the disability weight. This weight factor reflects the severity of the disease on scale from 0 (perfect health) to 1 (equivalent to death). Six disability classes are distinguished along the scale. (Anand & Hanson 1997) Unfortunately there was no disability weight ranking available yet, thus a new one was designed for the GBD study. A group of independent experts from diverse backgrounds chose the disability weights. The weights were revised by a group of experts in 1995, this time using the person-trade-off method. (C. J. L. Murray & Acharya 1997) There were separate weights assigned to the treated and the non-treated diseases. (D. D Reidpath 2003)

Box 9: Formula DALY

DALY= YLL+ YLD

YLL = years of life lost due to premature mortality in the population
YLD = years lost due to disability

YLL = N x L

N = number of deaths
L = standard life expectancy at age of death in years

YLD= I x DW x L

I = number of incident cases
DW = disability weight
L = average duration of the case until remission or death (years)

Source:
http://who.int/healthinfo/global_burden_disease/metrics_daly/en/en

The first study included more than 100 diseases and injuries. The data was updated in 2002, also including risk factors this time. At the end of 2012 the data of the 2010 GBD study was published. Table 7 displays the discourse on the GBD and DALYs in specific. Some of the points specifically relate to the consequences of disabling diseases:

The tool provides a broader perspective than mortality; but part of the burden remains excluded. The consequences of the disabling diseases don't just manifest in impairments. The DALY's exclude the burden on household members of the cases and the community in general. The burden also excludes barriers (like stigma) and facilitators (like personal factors or services).

Scale of the burden in Sub-Saharan Africa is emphasized; yet the picture of the burden for the poor may be distorted. The GBD studies show how troublesome the state of health is in Sub-Saharan Africa. '*In 1990, nearly 90% of the worldwide burden of disease occurred in developing regions, where only 10% of healthcare funds were spent. In terms of overall worldwide burden of disease, sub-Saharan Africa and India had the largest proportions (21.4% and 20.9%, respectively) but very small proportions (0·7% and 1·0%) of health expenditure.'* (C. J. Murray & Lopez 1997b) It also showed some trends for poor countries, Sub-Saharan Africa in particular. The non-communicable diseases are mostly present in developed countries and the communicable diseases represent the biggest burden in poor countries. (Arnesen & Kapiriri, 2004) *'The burden of these largely preventable or inexpensively curable diseases of children is far larger in Sub-Saharan Africa (43 percent of all DALYs lost) than anywhere else (…).'* (World Bank 1993) And lastly, '(…) *22.9% of DALYs were caused by infectious and parasitic diseases, but (…) 42·5% in sub-Saharan Africa.'* (C. J. Murray & Lopez 1997b)

But despite clear pictures on the world's poor countries, this picture may be distorted due to the formula.

- The included age-weight follows the pattern of developed countries. In developing countries people are productive from 4 years old till a very late age. (King & Bertino 2008)
- Secondly, because context was chosen to be excluded, the burden is based on an average social milieu. Resources will thus be allocated according to this average social milieu, even though the milieu in developing countries is much worse. The gap between rich and poor will grow even further. (P. a Allotey & Daniel D Reidpath 2002)

Context is fixed and excluded. Even though context has been shown to be very important with disability in general and the disabling diseases specifically, the DALYs exclude context. The DALYs formula isn't useful without context, as disability weight cannot be assigned without context. Individual and social resources can compensate for impairment and help functioning. The burden thus shows a distorted picture, as context interactions result in a different impact. The impact of especially the disabling diseases depends on a facilitating or opposing environment (climate; living conditions; stigma; services). Besides, country or local analysis by use of the GBD data is useless, because of a fixed context. The local destructiveness of the diseases also remains invisible.

The burden of especially these diseases is underestimated. Some of the diseases, like cysticercosis, show a variety of symptoms, which are disaggregated included in the GBD as they're not recognized as one disease. And secondly, multidimensional disabilities are invisible in the tool, mostly in the disability weights. Yet the disabling diseases often display multiple consequences.

The DALY's do not seem suitable for making the disabling diseases more visible. The tool has highlighted the quality of health, but especially the disability weights and exclusion of context are debated (table 4).

Table 4: Global Burden of Diseases and DALY's discourse

Pro's	Con's
Broader health perspective than just mortality	**-Part of burden still excluded (**social costs of factors like disfigurement or dysfunction; burden on family, friends and the society at large; the way an individual copes with limitation) **-Still expert dominated discourse**
Single global metric for all health conditions, where all diseases excluded from non-health characteristics and context	**-Represents medical model, as context is excluded** **-Country analysis useless because of fixed context** **-Standard life expectancy not applicable all countries; standard rate much higher than currently in developing countries** → distorted image these countries **-Included age factor not general, so why not include other non-health characteristics**
Comparing between countries and over time possible	**not comparable across very different countries; context interactions result in different impact**
Importance of diseases mapped for regions and countries to asses policies	**-More focus on aggregative quantity than on lowering the burden.** Data is good, but context needed for policy assessment. **-stimulation of focus on health programs with vertical approach** **-When resources are allocated according to the average social milieu (as context is excluded), the gap between rich and poor will grow, as the burden is harder on the poor.**
Simple because of one indicator for disease and consequences	**Use of single indicator guarantees limited number of dimensions, while disability is multidimensional**
Data can show distinction between type of diseases and regions	**DALYs do not account adequately the burdens associated with specific diseases or in specific populations**
Social roles incorporated through age weight	**-Age weighting doesn't represent social roles** (useless without indication context), but more capital production weight → may lead to favoring treatment certain ages **-Age weight follows patter of developed countries.** In developing countries people productive from younger till later age
Measures a reduction in human functioning largely through disability weight	**-Disability weight cannot be assigned without context.** Individual and social resources can compensate for impairment and help functioning **-PTO-method (introduced in 1995) for assigning disability weight is offensive.** Life of PWD seems worth less. And although used in economics as objective tool, assigning disability weight remains subjective **-Weights portray multiple disabilities not sufficiently**
Goal was not to give *exact* data for entire world	**Data not neutral and correct, yet policy makers may not be aware of this**
	Burden of neglected tropical diseases underestimated →symptoms disaggregated because not diagnosed as symptoms NTD; many NTD's multiple disabilities which disappear

Sources: (C. J. Murray & Lopez 1997b; C. J. Murray & Lopez 1997a; C. J. Murray & Lopez 1997c; Murray, C J & Lopez 1997; World Bank 1993; Anand & Hanson 1997; C. J. L. Murray & Acharya 1997; Barker & Green 1996; Anand & Hanson 1998; T Arnesen & Nord 1999; C. J. L. Murray 1994; P. a Allotey & Daniel D Reidpath 2002; P. Allotey et al. 2003; D. D Reidpath 2003; Trude Arnesen & Kapiriri 2004; King & Bertino 2008; C. J. Murray et al. 1994; Cooper et al. 1998)

3.2 Frameworks and tools from connecting fields

What can be learned?

The dimensions and indicators that have been missing in the tools, refer to certain areas of life, which have been studied in other fields. But they have not been specifically adjusted for developmental purposes.

Disability frameworks

To include all dimensions relevant to the presence of disability in a development framework, the elements incorporated in a disability framework can be used. But when you wish to use ideas from this study fields, you should be aware that both the concept of disability and disability frameworks have evolveduring the last decades.

Disability is a changing concept and not a definitive abstract phenomenon. It can be envisioned as a physical construct or as a social-political construct. Throughout the years the definition has changed and the different approaches have been captured in models. Box 10 displays the four most influential and relevant models.

Some models have prevailed over others; especially the social model has radically changed the approach to disability among a wide audience. Despite its critique, it is still the most favoured model in many circles. But in some groups or societies, the medical or charity model persists. For instance in the DALY's, like mentioned above, the medical model is present.

Scholars have mainly agreed that a mix of the above mentioned models would be ideal, but it has proven difficult to transform this into a framework. In an attempt to create frameworks which include all the dimensions, the next four frameworks show the changes in this process up until this day.

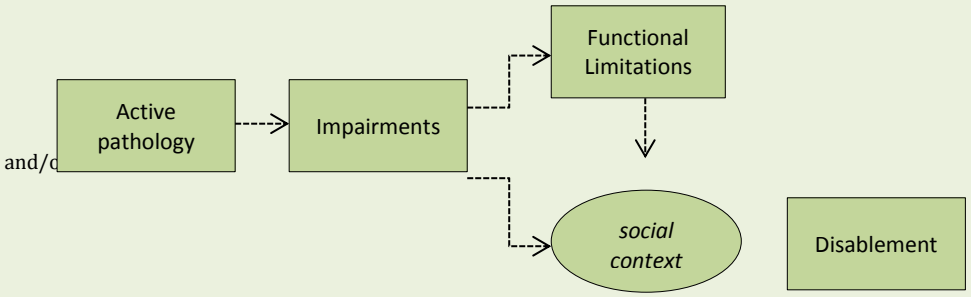
Nagi's framework

Most frameworks before the 1980's were based on the medical model, where impairment was seen as the reason for being disabled; with a one-way link from impairment to disablement. Frequently they were even seen as synonymous. (Masala & Petretto 2008) The limitations were mainly physical or activity limitations.

Nagi developed a framework in the 1960's showing first signs of ideas that are included in the social model (Box 11). Impairments *can* be a consequence of active pathology, and *can* produce effects in terms of functional limitations *and/or* in terms of disablement. (Masala & Petretto 2008) '*According to Nagi, disablement would be the expression of functional limitations in the social context, i.e., the product of the interaction between the individual and the environment that poses demands to individuals*.' (Masala & Petretto 2008)

Source: Masala & Petretto 2008

Box 11: Nagi's framework



Active Pathology = '*A state of the body's defenses and coping mechanisms*' (Masala&Petretto 2008)
Impairments = '*A loss or abnormality at the tissue, organ, and body system level*'(Masala&Petretto 2008)
Functional limitations = limitations to perform tasks & obligations of usual roles and normal daily activities (seeing; walking; listening)
Disablement = limitation in performing socially defined roles (employment; self-care)

Box 10: Theoretical models on Disability (Sources: Albert 2004; Bickenbach etal.1999; Hoppe etal. 2011; Edmonds 2005; Handicap International/CBM 2006; Hughes 2007; Katsui 2008; Katsui 2006; Linton 2010; Masala & Petretto 2008; Shakespeare 2010; Shakespeare 2006; UN 2006; WHO 2011)

Model	*When*	*Construct/domain*	*Main view*	*Implication*	*Associated terms*	*Pro's*	*Con's*
Medical	‹ end 1970's	Physical	Impairment disables	- Disability in self - Disability a biological deficit - Fix/correct disability - Special Care - PWD are different and thus separated	- Disabled - Handicapped - Impaired	- Good health treatments for PWD - Eye for individual (medical) needs	- Exclusion from disability discourse (solely specialists) and society (through residential institutions and special schools) - Not everything can be fixed - Low self-esteem since disability within self
Social	end 1970's - Mid 1990's	Social-political-cultural	Society disables	- Disability within society - PWD oppressed group - Remove environmental barriers (physical barrier; stigma; absence good services & regulations) - Mainstreaming	- People with Disabilities (PWD)	- Inclusion - Builds self-esteem PWD	- Strict division impairment and disability, but biological core important as well → opinions differ on the ontological question of disability - Physical cannot be ignored - Barrier free world is Utopia - Generalization while model actually mainly applies to physical impaired (focus on decision process excludes intellectual or psychiatric disabilities) - No attention individual needs
Rights	1990's	Social-political-cultural	Empowerment necessary because of denied rights	- PWD oppressed group - Focus rights& needs PWD because of basic universal human rights - Self-organization of PWD		- Awareness raising; especially in countries where not much attention for PWD (attention necessary before removing barriers) - Self-involvement PWD	- Not all societies/cultures emphasize the importance of rights; may collide with collectivism
Charity		Physical	People with disabilities (PWD) are victims	- PWD need to be taken care of - Specialized aid organizations - PWD separated	- Special people /children - Physically challenged - Handicapable - (innocent) Victims	- Attention for special needs; not all disabilities can be seen as one - Society should always include some form of 'caring solidarity' and PWD will always have specific needs	- Psychological effect of idea that disability is in its essence negative - PWD become long-term dependent

ICIDH

The International Classification of Impairments, Disabilities and Handicaps (ICIDH) was developed at the end of the 1970's by the WHO. (Bickenbach et al. 1999) They tried to include ideas of the social model (Box 12).

According to the model, impairments *can* affect a person's activities, but not automatically; this doesn't need to turn into a disability when a person isn't expected to be able to do that activity. PWD will only be handicapped or '(…) *disadvantaged in a social, cultural or attitudinal environment in which having impairments and disabilities (or being perceived to) typically brings disadvantageous consequences*.' (Bickenbach et al. 1999) The ICIDH was a major step forwards at the time of publication, but has received a considerable amount of critique since then (Table 6).

Box 12: ICIDH framework

Impairment = any loss or abnormality of psychological, physiological, or anatomical structure or function.
Disability = any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being
Handicap = a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual
Source: Bickenbach etal 1999

Table 6: ICIDH discourse

Pro's	Con's
Ideas social model incorporated. Environment included	**-Elements linked on a progressive scale.** No two-way interaction between social context & health condition **- Unchangeable environment**
	No classification social world
	Term *handicap* controversial

Sources: Bickenbach eta.l 1999; Dahl 2002; Masala & Petretto 2008

DPI framework

Disabled People's International (an important organization in the social model movement), adapted the framework of the Union of the Physically Impaired Against Segregation (UPIAS) in response to the ICIDH, one year after its publication. (Bickenbach et al. 1999)

Box 13 shows the DPI framework of disability; it included two elements. Disability is imposed by society on top of the impairments. (Bickenbach et al. 1999) Table 7 shows there were more disadvantages than advantages found to the approach of the DPI.

Box 13: DPI framework

Impairment = functional limitation within the individual caused by physical, mental or sensory impairment.
Disability = loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers

Source:Bickenbach etal. 1999

Table 7: DPI discourse

Pro's	Con's
Follows social model. Society disables, not impairment. Handicap term excluded.	**Impairment left out of disability.** Impairment is different from other socially created disadvantages (like race & gender) because it contains a health factor. Without including it, it's hard to analyze the social world. By ignoring the factor, physical & biological aspects are downplayed
	The link between the elements is unclear. Without mentioning impairment in the disability element, it seems there is no link at all
	Not included that impairment doesn't necessarily lead to disability. In the ICIDH this option was included

Sources: Bickenbach eta.l 1999; Dahl 2002; Masala & Petretto 2008

ICF

The International Classification of Functioning, disability and health (ICF), published in 2001, was the update by the WHO of the ICIDH (Box 14). The ICF is a multi-dimensional model linking the elements in multiple ways. The framework doesn't just focus on the problems in functioning (disabilities) but also indicates the neutral aspects of functioning.

'A person's functioning and disability is conceived as a dynamic interaction between health conditions and contextual factors.'(WHO 2001) The ICF has embraced the earlier critique of the immeasurable and unchangeable environment. The environmental and personal factors can have a positive (facilitators) or negative (barriers) influence on all three elements of the functioning component. Problems in one element can, but do not necessarily have to, lead to problems in another element.

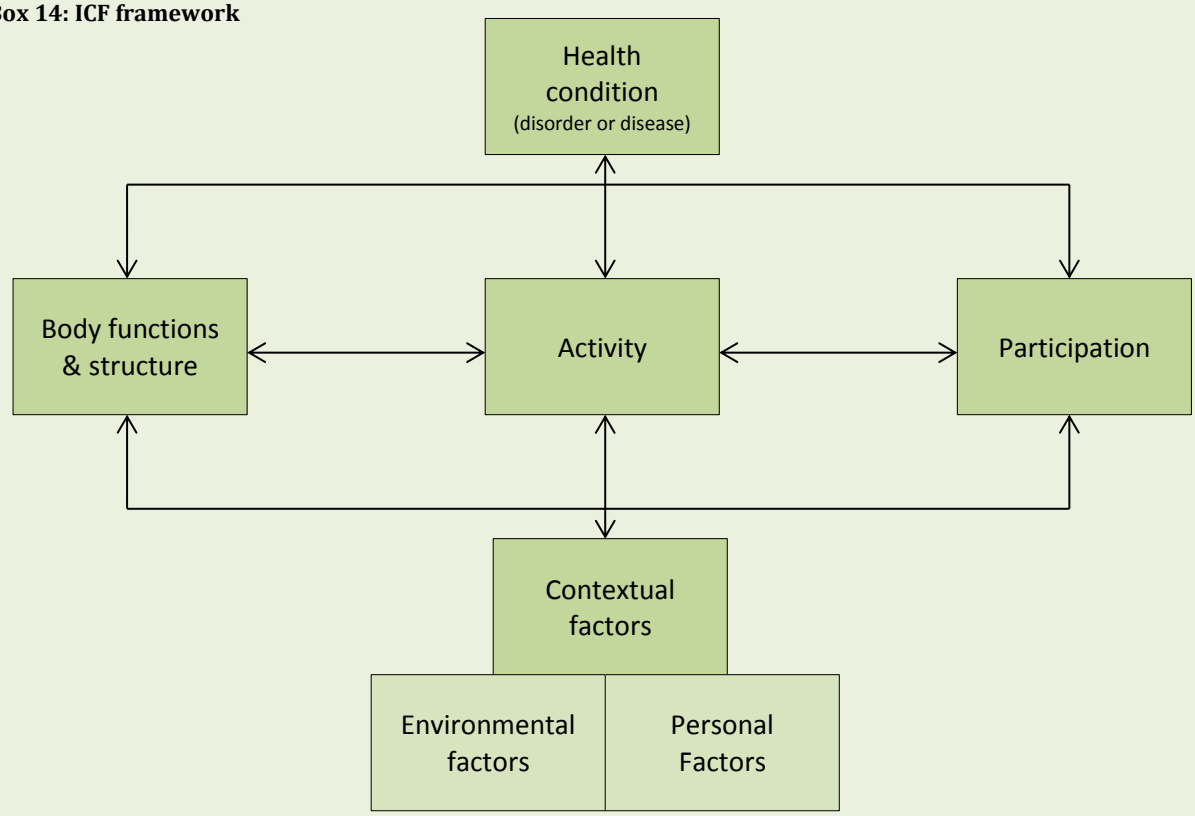
Table 8 displays the discourse on the ICF. Compared to earlier frameworks, the advantages have started to outweigh the disadvantages. The complexity of the framework could potentially make it difficult though, to easily incorporate the ICF in International Development frameworks

Table 8: ICF discourse

Pro's	Con's
Operational for multiple purposes	
Define disability as an interaction instead of an attribute of a person	
Includes variety of impairments; physical/bodily aspects; contextual aspects	**-Classification personal factors excluded** **-Perception of PWD themselves excluded**
	Distinction between activity and participation too vague

Sources: Albrecht & Devlieger 1999; Anthony 2011; Bickenbach et al. 1999; Dahl 2002; Dijkers 2010; Jelsema 2009; Levasseur et al. 2004; Leonardi et al. 2006; Lipson & Rogers 2000; Mbogoni 2003; McDougall et al. 2010; Miles 1996; Whiteneck et al. 2004; Schuntermann 2005.

Box 14: ICF framework



Functioning:
Body functions = physiological functions of body systems (including psychological functions)
Body structure = anatomical parts of the body (organs; limbs; and their components)
Activity = the execution of a task or action by an individual. (basic activities one could perform on a deserted island: running; sitting; or eating)
Participation = involvement in a life situation. (life situations in which one can experience participation restrictions: mobility; employment; education; or social life) Participation focusses on the performance of a person, as can be observed by an outsider

Context:
Environmental factors = the physical, social and attitudinal environment in which people live and conduct their lives. These factors focus on two different levels in a person's life:

1. the individual level, or more specifically the immediate environment;
2. the societal level, the formal and informal social structures, services and overarching approaches or systems in the community or society that have an impact on individuals.'

Personal factors = the particular background of an individual's life and living. They comprise features of the individual that are not part of a health condition or health states. (Gender; race; social background; self-efficacy)

Impairments = problems in body function or structure, such as a significant deviation or loss
Disabilities = impairment + activity limitation + participation restriction

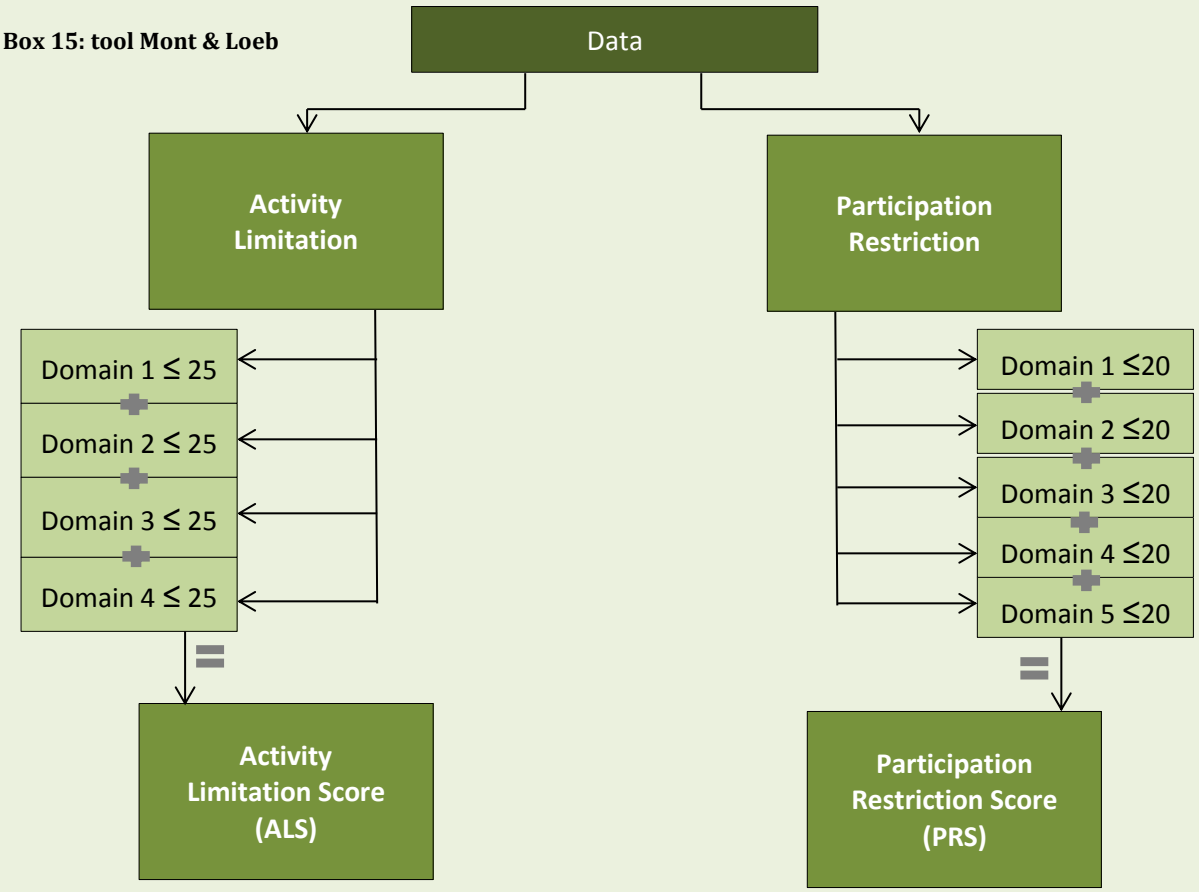
Source: WHO 2001

Tool of Mont & Loeb

In 2008 Mont and Loeb proposed an alternative method for the DALY's (Box 15). '*DALYs do not reflect the change in people's functional status or well-being if they receive rehabilitation services, assistive devices, accommodations, or live in a society that has become more open and accessible to individuals with functional limitations'* (Mont & Loeb 2008) DALYs specifically aren't suitable for developmental purposes; only health actions that 'cure' the disabilities can be recognized by the DALY's. (Mont & Loeb 2008) They based their tool on the International Classification of Functioning,

Disability and Health of the WHO. Even though the ICF provided a clear framework for disability, it remained difficult to adapt it to surveys to gather the right information. Especially adapting it to local language and culture, where the perception can differ, was a challenge. (Lipson & Rogers 2000; Devlieger 1998; Anthony 2011; Miles 1996; Mcewan & Butler 2007; Bickenbach et al. 1999; Mbogoni 2003)

Box 15: tool Mont & Loeb



Activity Limitation measurement = 18 basic activities without the benefit of assistive devices of any kind whether technical or personal). Each measured activity item is scored on a 5 point scale from (0) no difficulty (1) mild (2) moderate (3) severe difficulty to (4) unable to carry out or perform the activity.
Participation restriction measurement = 22 complex activities according to how the individual performs in their usual environment (where they normally live, work or play and with the benefit of assistance). Each measured activity item is scored on a 5 point scale from (0) no difficulty (1) mild (2) moderate (3) severe difficulty to (4) unable to carry out or perform the activity.
Domains = Activity items classified under domains weighted in order to equalize domain effects(reach max. score 20/25)
ALS & PRS = Scaled from 0-100

Source: Mont & Loeb 2008

According to Mont, the goal of assessing data may also determine the disability-approach within the tool:

- *Monitoring data for comparison*: body functioning more suitable; activities and especially participation are not comparable across cultures
- *Designing service provision*: very detailed functioning and contextual factors; including support from within family and community and many environmental factors
- *Assessing the equalization of opportunity:* basic activity questions; participation includes a subjective dimension which could distort the question. (Mont 2007)

Mont perceives the last goal to be important for developmental ends, as it focuses on the inclusion (or exclusion) of PWD. (Mont

2007)Yet the DALY's solely focus on the first two goals.

Looking at the analyses of the tool, the more the scores on the ALS and PRS approach 100, the '(…) *less capacity to perform basic functions and more difficulty in carrying out complex activities'* (Mont & Loeb 2008) By giving each domain an equal weight, Mont and Loeb stayed away from the disability weight discourse. But it might be necessary: *The development of an appropriate weighting scheme would have to empirically examine the importance of each activity domain on outcomes of interest, such as employment or poverty. That goes beyond the scope of this paper.'* (Mont & Loeb 2008) The discourse on the tool can be seen below in table 9. Unfortunately good review of the method of Mont and Loeb are still lacking.

Table 9: Mont& Loeb tool discourse

Pro's	Con's
Suitable to study relation health care interventions & disability scores. Not just focus on *curing* disability.	
measure improvements in functionality that result from interventions (such as rehabilitation services) that do not change an underlying diagnosis	Choice of weights
Separation activity limitations from participation restrictions; correlation 2 scores shows influence environment.	
Reduce the degree of counting particular activity limitations more than once;	
Weight different domains equally, instead of by the number of individual items within a domain.	More detailed investigations need to address the appropriate weighting of the various sub-components of the ALS and PRS, taking into account those subcomponents influence on outcome variables of interest
Allow for the variability in functional capacity of people with the same medical diagnoses;	
Implicitly weigh functional domains	

Sources: Mont 2007; Mont & Loeb 2008

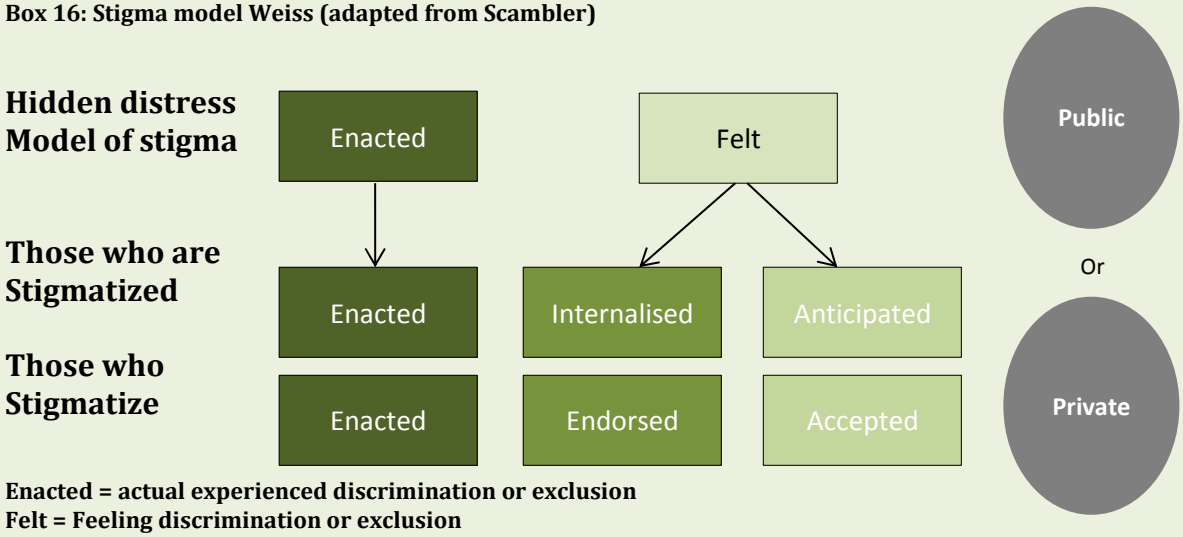
Stigma frameworks

The research on stigma is quite extensive. It also contains a number of health-related stigma studies. (Van Brakel 2006) But with the exception of leprosy, there has not been much research on stigma related to tropical diseases. (M. G. Weiss et al. 2006)

Stigma has been defined in very different ways. (Link & Phelan 2001) The conceptualizing changed in a direction similar to the concept of disability: from a concept within a person, to lying within in social space. (Yang et al. 2007) Stigma should be seen as a process; a multidimensional concept with various elements and links.

Different types of stigma can be distinguished. Weiss included these in a model (Box 16). Manifestations of stigma can be found in a public or in a private context.

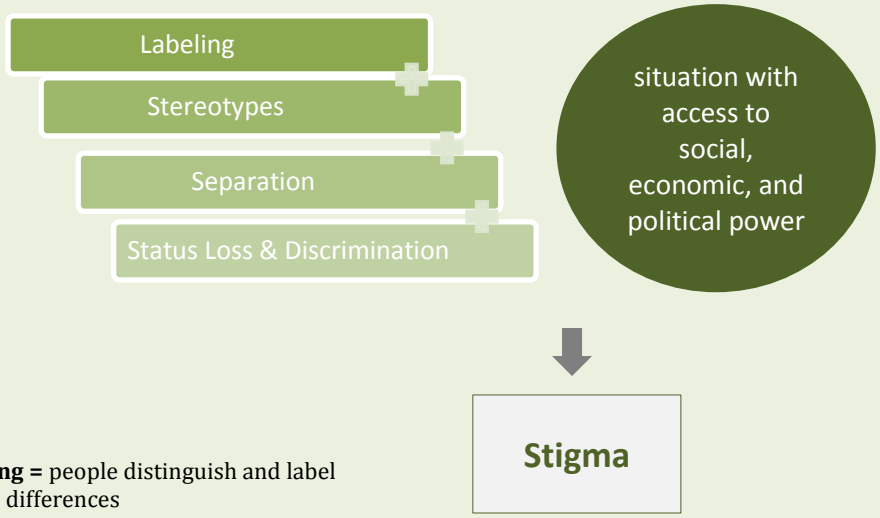
Box 16: Stigma model Weiss (adapted from Scambler)



Enacted = actual experienced discrimination or exclusion
Felt = Feeling discrimination or exclusion
Internalised = Self stigmatization because of assumed stigmatizing conceptions in society
Anticipated = Assuming stigma present
Endorsed = Justifying and supporting exclusion, but not practicing
Accepted = Condemning stigma, yet do nothing about it

Source: Weiss1997

Box 17: Stigma model Link & Phelan

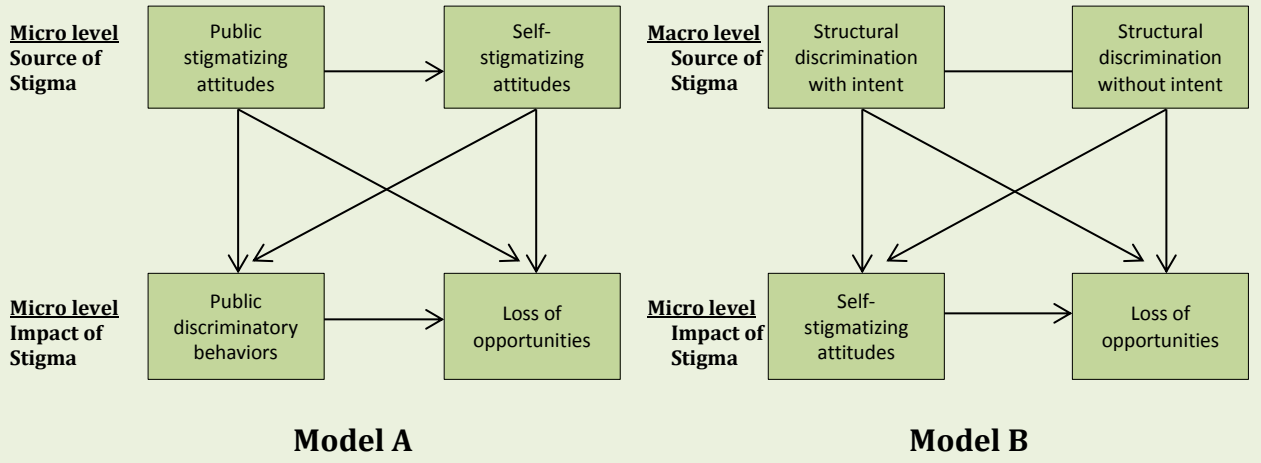


Labeling = people distinguish and label human differences
Stereotypes = dominant cultural beliefs link labeled persons to undesirable characteristics
Separation = labeled persons are placed in distinct categories so as to accomplish some degree of separation of "us" from "them"
Status loss & Discrimination = labeled persons experience status loss and discrimination that lead to unequal outcomes
Link& Phelan 2001

Link and Phelan developed a multidimensional model, describing the process *towards* stigma (box 17). They included the element of power to the construction of stigma. The more power the stigmatizers have, the higher the experienced stigma can rise. '(…) *we apply the term stigma when elements of labeling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold.'* (Link & Phelan 2001)

These models mainly focus on the micro level of stigma. When the macro level is included as well, the importance of structural stigma can be acknowledged. Corrigan et al. show us (box 18)(Corrigan et al. 2004) the type of model used very often in research: a micro-level model (model A). In model B they include structural discrimination, which takes place on a macro level. In the case of the disabling diseases, structural discrimination can refer to the denying of good health care or specific services.

Box 18: Stigma models Corrigan etal.



Structural Discrimination = processes that typically represent collective and macro-level units rather than individuals
Source: Corrigan etal 2004

Stigma Measurement

Including stigma in International Development tools can be based on existing approaches to measuring stigma. What should be taken into account when measuring stigma?

Quantitative or qualitative research. Most research has incorporated a combination:

- Quantitative research: the amount of stigma; length or degree to which stigma is posing as a barrier on lives
- Qualitative research: the content of the stigma; what is being said or believed?

Qualitative research could be more important to help develop plans to tackle stigma or lower the barrier. Especially when it concerns a certain disease with specific prejudices and stereotypes attached to it.

Focus of research. As shown above, different types of stigma can be measured. These types also relate to different focus groups: those experiencing stigma; those practicing; but also all the people living in a stigmatizing environment, without directly encountering stigma themselves. So *what type* of stigma is being measured and *who* is included? Most research on health related stigma has focused on personally experienced stigma and public health stigma. (M. G. Weiss et al. 2006). But for the disabling diseases, the research also needs to include secondary targets: household members of the cases, other community members or entire communities (like in the case of onchocerciasis). Tools do exist for measuring: the attitude of health care personnel; general public attitude; socio-economic rehabilitation; and discrimination. These tools can be generic or could focus on specific diseases or disabilities. (Van Brakel 2006)

Focus on participation according to ICF? Some authors claim that when measuring health-related stigma, the research should focus on the participation arena, as described in the ICF framework. Van Brakel claims that stigma also affects other aspects of life, like '*well-being or quality of life, self-esteem and emotions.'*(Van Brakel 2006) Yet, as the stigma related to the disabling diseases does not just manifest

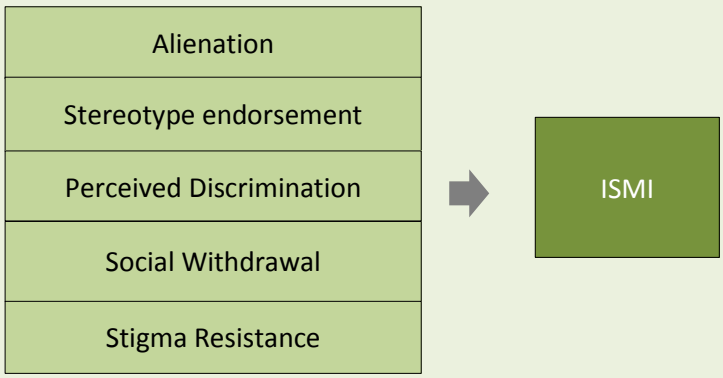
in the cases, but also in secondary targets, and is not just related to the disabling nature of the diseases, the participation dimension is not sufficient enough for the stigma measurement of the disabling diseases.

Use of transcultural, global measurement tool. Opinions differ on the use of one tool for measuring stigma. Van Brakel believes it's possible to develop such a tool. *'Despite enormous cultural diversity, the areas of life affected by stigma are remarkably similar in different countries and health conditions.'* (Van Brakel 2006) These areas are: marriage, interpersonal relationships, mobility, employment, access to treatment and care, education, leisure activities and attendance at social and religious functions. Weiss et al. disagree with van Brakel: '*A single scale or instrument is likely to be inadequate to fulfill the needs for disease-specific and culture-specific studies of stigma.*' (M. G. Weiss et al. 2006) He prefers a cultural epidemiological approach with anthropological and epidemiological frameworks and methods. This way the research will not lose eye for local concepts and categories; which are most important in stigma research, as can also be seen from the stigma on the disabling diseases. Vlassoff et al. claim that in attitudes towards a stigmatizing illness, parallel trends can be noticed. But: '*Stigma is experienced in different ways by those affected by a disease than by those who perceive it as something foreign or removed from themselves. It is also experienced differently by men and women.'*(Vlassoff et al. 2000)

Which tools are most commonly used in health-related stigma research?
In the field of health relkated stigma, some of the earliest research was actually on mental disabilities. (Van Brakel 2006)

A good tool to measure the stigma as seen by the infected of disabling diseases, is the **ISMI** (Internalized Stigma of Mental Ilness Scale). This tool assesses the *subjective experience* of stigma through five sub-scales (box 19). (Yanos et al. 2008; Brohan et al. 2011; Van Brakel 2006) Within these subscales, the participants are asked to value twenty-nine statements (items) between a range of strongly disagree to strongly agree. (Ritsher et al. 2003) The ISMI provides five clear dimensions of internalized stigma, which can also be adapted to other health problems than mental illness. But the tool only tests the view of those experiencing or perceiving stigma themselves, excluding the macro world of stigma (secondary targets, policies & services etc). Weiss et al. see the need for: '*studies of stigma considering points of view of patients, populations, health care providers and other special groups, and general policy interests.'*(M. G. Weiss et al. 2006)

Box 19: ISMI



Source: van Brakel 2006; Brohan ertal. 2011; Ritscher etal. 2003; Yanos etal. 2008

In the epilepsy research field there has been a significant concentration on internalized stigma and self-esteem, but scales have been developed for parents as well. (Van Brakel 2006) Research on HIV/Aids-related stigma has made use of population surveys. '*The extensive interview includes queries about interactions with persons with AIDS, symbolic contact, beliefs about transmission, attitudes towards people with AIDS, trust in authorities and experts, HIV mandatory testing, feelings toward people with AIDS, perceptions of persecution, and the effect of concerns about stigma on HIV testing.'* (M. G. Weiss et al. 2006) Besides a variety of views included, eye for contextual factors seems important in the case of the disabling diseases as well.

The **EMIC** (Explanatory Model Interview Catalogue) seems to reflect both an inclusion of all those concerned with stigma, and of context. The tool embraces multiple research fields (epidemiology; anthropology; psychiatry etc.) Stigma is only one part of the tool, as it focusses on the entire illness experience. As Weiss explains:

'The EMIC is a catalogue of explanatory model interviews based on an adaptable, operational framework and the experience acquired from their use; it is not a single instrument for generic use irrespective of particular clinical and cultural contexts.'(M. Weiss 1997)

The interview is conducted in five areas (see box 20). The interviews produce both quantitative and qualitative information. The interview section focusing on stigma, can be transformed into a stigma scale. Table 10 shows the advantages and disadvantages of the use of the EMIC stigma scale for stigma research.

Table 10: EMIC stigma scale discourse

Pro's	Con's
Simple	
Adaptable to multiple (health) conditions	**Excludes certain areas of life:** responsiveness to change; stability

Box 20: EMIC

Sections

Patterns of Distress	•*Full range of problems associated with respondent's condition*: Illness-related problems & concerns; name of illness, symptoms, anticipated outcome; psych.soc.econ. impact; stigma, disclosure & self-esteem; marriage prospects & marital relations
Perceived Causes	•*Ideas of respondent why and how affected:* Foods; psych. factors, psychosoc. stressors, victimization; sanitation, hygiene, contamination & healkth habits; infection, prior illness, constitutional factors; humoral imbalance; magico-religious forces; Heredity; sexual experience, retribution previous deeds
Help Seeking & Treatment	•*Choices respondents make among various options:* Family support & home remedies; private practioners & public clinics; western-styled health professionals, para-professionals, specialists; trad. healers of various types; past experience & current preferences
General Ilness Beliefs	•*Understand broader context of ideas illness in general:* Explanatory models of illnesses other than current problem; focus on ilnesses within a range of cultural meanings; relationship between mind & body
Disease-specific Queries	•*Ideas about the illness affecting the subject, but distinct from personal experience of presenting problems*

Source: Weiss, 1997

Examples of adaptation of the EMIC stigma scale also include research on Onchocercal Skin Disease (OSD) The Pan-African study group on Onchocercal Skin Disease used the entire EMIC tool for assessing the experience of suffering. They constructed a stigma scale around ten indicators which referred to life areas. (Pan-African Study Group on Onchocercal Skin Disease 1995) From questions within these ten groups, quantitative analysis (percentage of low self-esteem) and qualitative analysis (which reactions precisely to disease) were done.

Brieger et al. adapted the framework of the Pan-African Study Group by adding three items, which make the tool even more specific (Box 21). (Brieger et al. 1998)

These ideas, frameworks and studies from the fields of disability and stigma have great potential to make the consequences of disabling diseases more visible when included in development frameworks and tools.

Box 21: stigma scale for Onchocercal Skin Diseases

Indicators

- Disclosure
- Esteem
- Leadership
- Heterosecual relationships
- Pity
- Avoidance
- Shame
- Mariage
- Sexual functioning

- Embarrassment b/c itching
- Perceptions others of person
- Perceptions others of family

Source: Brieger etal 1998

3.3 A new way forward

What should this look like?

After reviewing International Development tools and frameworks, and tools and frameworks focusing on issues related to the disabling diseases, it can be concluded that one good approach for having the consequences of the disabling diseases included in International Development, is lacking. But, an opportunity lies in combining ideas from different fields.

Dimensions and indicators missing

In an attempt to assess a way to make the consequences of the disabling diseases more visible, we first go back to what remained invisible in the popular International Development tools, like the Human Development Index and the Millennium Development Goals. Despite critique, the last decades showed no significant development in trying to include these missing elements in the tools:

Quality of Health during Life

The focus lies mainly on mortality. Although the Millennium Development Goals did include three targets on health, one of which specifically focused on diseases, the overall focus on quality of health remains invisible. There is no mention of disabilities.

Local Destructiveness

Distribution is excluded. Within region or especially within-country differentiation remains invisible, even when this affects development greatly.

Poor-specific Issues or Pro-poor Focus

The HDI doesn't consider a differentiation between life situations; thus no eye for poor-specific issues. Yet the MDG's showed a significant improvement in this area, by including very poor-specific goals like 'eradicate extreme poverty and hunger'.

Long-term impact

The long-term impact of the disabling diseases remains invisible. Comparing over time is difficult and long-term consequence-indicators are excluded.

Context

The context is completely excluded in both frameworks. As they both function as international tools, they deliberately excluded context. But context cannot be excluded while focusing on development, because it can serve as a facilitator or as a barrier.

Effect on entire community

In the HDI, dependency indicators were absent; the MDG's did include some form of dependency through employment to population ratios. But it hereby only focused on the economic aspect of the effect on the entire community. The effect on development for the entire community (not only just for those infected), remains invisible.

Dimensions and indicators from other tools and frameworks

The last decades have seen the development of other tools and frameworks that can help in assessing the visibility of the disabling diseases. Table 11 displays a summary of the useful ideas and lessons learned from other tools.

Table 11: Ideas from other tools and frameworks

Ideas/Lessons learned	Tool/Framework
One indicator tools are too narrow	MDG; WDI; LoL
Multiple dimensions in tool/framework	IHD; MDG; WDI; LoL
Poor-specific indicators	HPI; MPI
Make sure life conditions, patterns and areas relate to area (cannot be universal)	DALYs
Include context: to see if facilitator or barrier for development political& institutional environment; service delivery; law& order; human rights; peace, security& freedom	Cheibub (2010); Hartgen& Klasen (2010); Harttgen& Klasen (2009); Herrero et al. (2010); EMIC; Noorbakhsh (1998)
Different framework/indicators for different countries: different context	LoL
Include distribution	IHDI; MPI
Include perceptions/point of views of all involved	ICF; Stigma frameworks
Health needed as first capability in life	HAI
Include quality of health during life	ICF; DALYs
Disability weights too subjective to use universal	DALYs
Make sure variety of symptoms of health condition visible	DALYs
Include not just health actions that can cure, but also those that facilitate (in adaptation)	ICF; Mont& Loeb
Include entire experience disease	EMIC
Relate context and stigma to health conditions	EMIC
Include participation or exclusion	Van Brakel (?); HAI; HSEI
Include different types of stigma	Weiss (?)
Include micro and macro structure stigma	Link & Phelan (?)
Include dependency (and not just economically)	HAI; MDG
Include quantitative and qualitative research	Stigma frameworks

A new framework

The multidisciplinary nature of making the consequences of the disabling diseases visible in International Development, may explain why a consequent tool or framework has been lacking. The ideas on development and the tools accompanying them, have transformed significantly in the last decades. Ideas on health issues and disability have also seen big changes in the last decades. Research on stigma has linked the changes in the health field to the research on the health experience, by including the macro world and its effects. But real breakthroughs in linking the changes in the health field and the field of development have remained absent. The DALYs characterized a bold attempt. But in this attempt the most important changes, in the last decades, from the field of health and disability remained excluded: the ideas of the social model and the rights approach.

Problems with choosing the right format for a framework (single or multiple indicators); including and excluding certain dimensions and indicators; and making it applicable and usable for development in all regions and life-situations, have been discussed.

Box 18 displays a suggestion for a framework which includes the ideas of human development, but also attempts to include the consequences of the disabling diseases. The framework combines the elements missing from the HDI & MDG's, and the ideas and lessons learned from other tools and frameworks.

The framework contains several characteristics:

Multiple indicator framework with few dimensions, but many indicators. The framework remains simple and transparent, but shouldn't exclude essential dimensions and indicators.

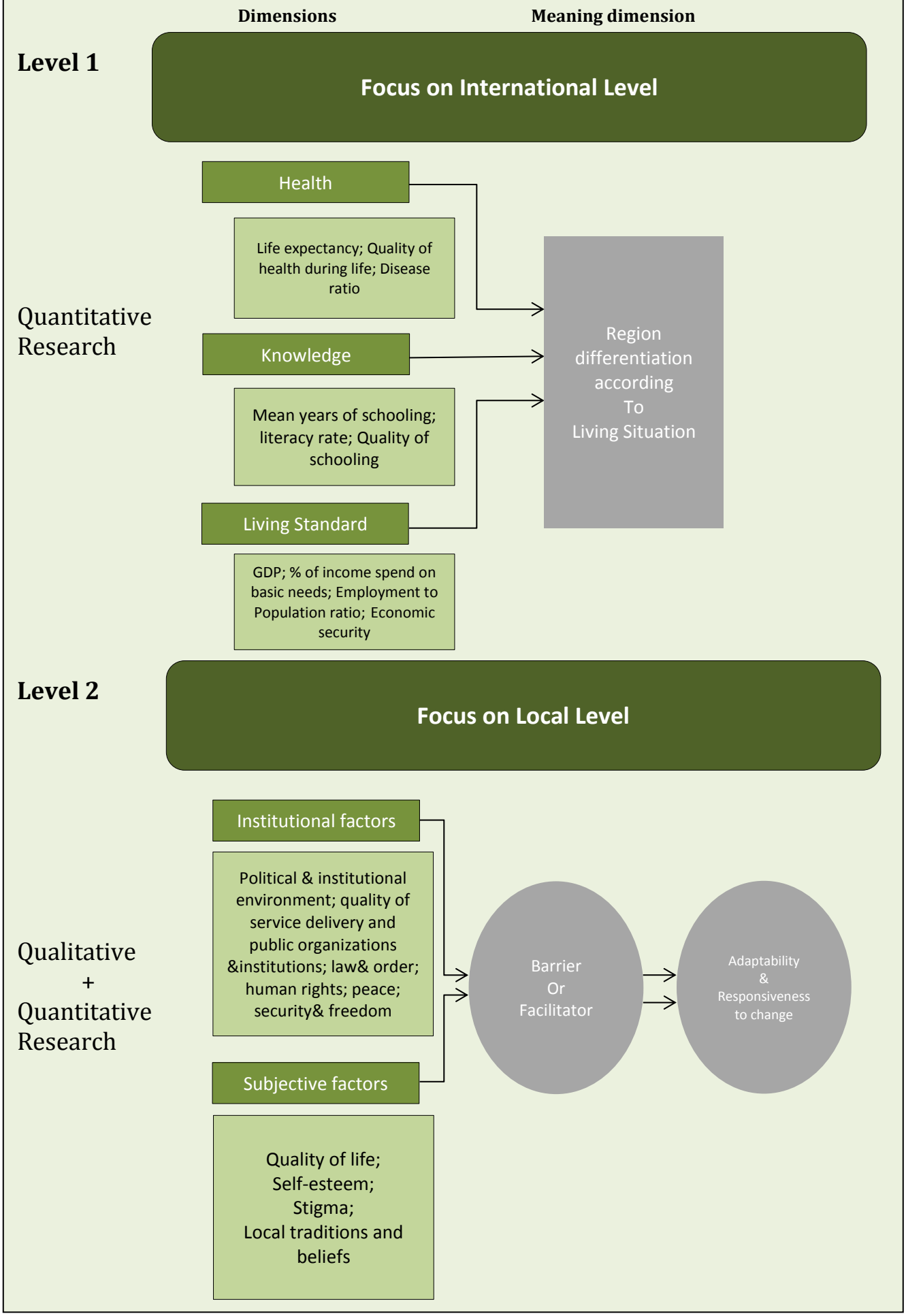
A focus on two levels. The framework displays a two level assessment: the international, or macro, level and the local, or micro, level. Hereby the framework moves away from the generalizing line of several International Development tools, but does show a clear focus and approach (contrary to some multiple indicator frameworks like the World Development Indicators).

Context included without losing eye for transnational developments. Without context, development will never succeed. But to ensure that the focus of development would follow a bigger line, local context will not be weighed before the second level. One type of context seemed important to include in level 1, to avoid complete generalization. Living situations differ significantly between rich and poor regions. A general assessment of living situations in regions helps determine which indicators are appropriate for quantitative research of the three dimensions.

The meaning of dimensions needs to be assessed for development purposes. Simple data analysis of the indicators is not sufficient enough for a development tool. The previously studied tools and frameworks have shown that numbers, situations and institutions do not sufficiently show the concept of human development, where humans make use of the formed capabilities. That's why the framework includes a category where the dimensions are weighted in which way the dimensions are truly capabilities they can use (region differentiation according to life situation) and in which way they can make use of them (barrier/facilitator; adaptability & responsiveness to change).

Quantitative and qualitative research necessary. The research on disability and stigma, showed that quantitative and qualitative research should both be valued for developmental plans.

Box 22: A new International Development framework (including consequences of disabling diseases)



As said, the framework contains few dimensions, but many indicators. These choices can be explained.
Level 1:

- **Health**. Following the idea of HAI, health was included as essential for the life path of development for a human. Quality of health was included, but also the disease ratios. Aside from the critique on the DALYs, the idea of including some form of disease ratio, more elaborate than disease incidence (in the IHD), seems sensible. The disease ratio could focus on density instead of incidence, sketching the destructiveness like that.
- **Knowledge.** Another essential capability and also a capability which can advance other capabilities. The living situations can determine here which indicators to focus on, as literacy isn't suitable for many rich countries.
- **Living Standard.** This dimension should not only include the GDP as this number may disguise some dimensions of living standard. Here, a dependency factor can be built in through employment to population ratio and economic security.

Level 2:
The ideas on disability and stigma have shown how human development does not just lie within one's self. The way capabilities are used, can be influenced by contextual factors.

- **Institutional factors.** These factors relate to structural characteristics, either in our direct environment (local care-giving) or in the society we live in. Which characteristics are seen as a barrier or as a facilitator, may be controversial (as discussed in the HDI critique), but can have a crucial role in the development process.
- **Subjective factors.** These factors may be the most difficult to grasp for developmental purposes. But as seen for the disabling diseases, can severely limit a person's or a community's development.

The framework faces some disadvantages. One problem, reoccurring throughout the entire development discourse, remains operationalizing the framework. Especially data gathering will need a structured, yet complex approach. Especially for level two, one would need extensive data, since qualitative research is needed as well. But the advantage of the two-level system is that the framework can be seen as a two-step tool, where level 2 is adaptable to all countries and can be researched per country.

The framework has managed to include most of the dimensions and indicators missing from the HDI and the MDG's. But one dimension difficult to include, was the long-term effect. This can be overcome by including expectancy-ratios.

But the framework can include people living in different situations in different regions. The consequences of the disabling diseases would be a lot more visible for development purposes through this framework.

Important in the way towards new International Development frameworks and tools, will be, to make sure this field stays up to date with the changes and developments within the fields they cross their paths with. And that may not always be the fields 'traditionally' linked to International Development.

A way forward ……..

- **Attempts to include the missing elements of the consequences of the disabling diseases, have not been sufficient**

- **Other study fields, focusing on areas of life which should be included in International Development, can help in constructing International Development frameworks. Currently, some fields (like disability and stigma) and the developments within these fields are omitted.**

- **It is difficult to operationalize a framework including all the necessary elements**

- **Changes and progress within all the connecting study fields need to be integrated into International Development**

4

Development Aid for the infected: developmental efforts in practice

International Development may be designed around tools and frameworks, but it's the results that make it count. Critics of the results of developmental efforts have emphasized the lack of progress or sustainability in some parts of the world or in some thematic areas. It can always be questioned whether certain approaches induce the best results. But the last couple of decennia, the different actors within International Development have been triggered to find innovative ways to work towards better and more sustainable results.

If International Development is able to help the victims of the disabling diseases; where do the opportunities lie? How should these efforts be put into practice? The disabling diseases have demonstrated to affect disparate areas of life. A simple and one-sided approach seems insufficient. And when we know which factors to focus on, will there be barriers to achieving successful results? Developmental efforts concerning the consequences of the disabling diseases, will be considered, in order to map ways in which effective and sustainable results may (or may not) be achieved.

The pressure of better and sustainable results has risen within the International Development world. Besides including the effects of the disabling diseases in International Development tools and frameworks, we need to see approaches to accomplishing developmental results in the lives of the people affected by the disabling diseases. From the ideological changes and a focus shift at the beginning of the 1970's, to an even greater strictness towards exchanging donor money for results in the 1980's, the pressure rose even more in the 1990's when accountability became very important. Extensive reports and evaluations had to account for every penny spend. This led to a focus on short-term concrete results, instead of long-term change with unclear results within a set term. But in order to really evaluate the effects of Development Aid, the results into account. That's why the focus in this chapter lies on approaches put into practice with important developmental results.

The combination of the consequences of the disabling diseases and the poor living conditions, troubles the development of the infected. It's more difficult to attain better and more sustainable developmental results for the infected, because of the difficult circumstances they live in. Paragraph one will analyze their difficult living situation and the relationship between the consequences of the disabling diseases and the poor living conditions.

Different approaches exist to ensure developmental efforts for the infected. The second paragraph will elaborate on the different approaches and tactics chosen to ensure development for the infected. First literature will show what *types* of approaches are in place to ensure development for the infected. Secondly the developmental efforts will be studied. To ensure we stay close to the research framework and tools, the analysis in paragraph two works through the construct of the life dimensions of the infected. To ensure focus in my research, I chose to include among the examples of developmental efforts, mainly Dutch approaches, organizations, institutions and initiatives. Naturally research can also be conducted on other approaches, organizations institutions and initiatives.

This chapter will show what can be done to ensure inclusion of persons affected by disabling diseases in International Development in practice, instead of in tools and frameworks.

4.1 The vicious circle of disabling diseases in Africa

How is it linked?

The vicious circle

As mentioned before, not much research has been published on the effects of the disabling diseases on people living in sub-Saharan Africa; especially not on the relation between the effects of the diseases and the living conditions. It has been established that poor living conditions raise the risk of gaining the diseases and enlarge the impact of the diseases.

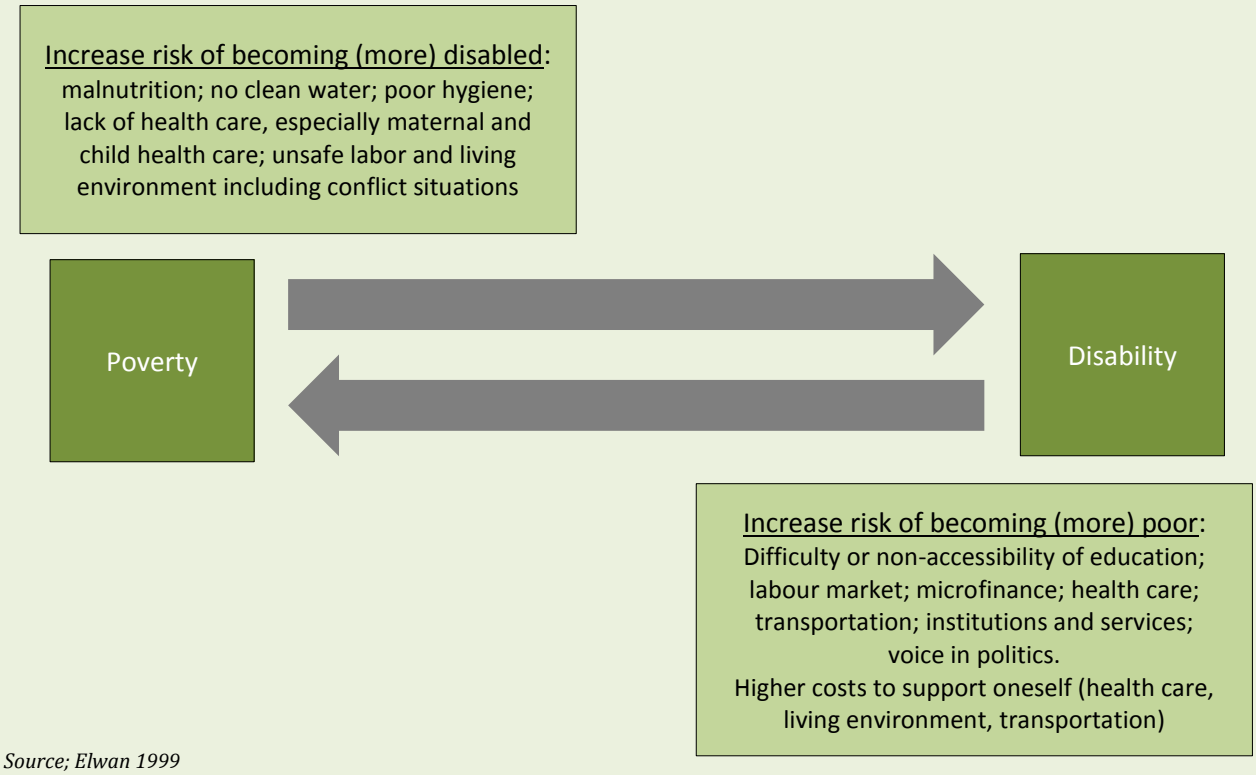
The research on the relation between poverty and disability in general, is scarce as well. (Mitra et al. 2011; Yeo & Moore 2003; Grut & Ingstad 2005) Although the association between the two has often been stated; disability research has not provided enough proof of the real impact of disability on the economic wellbeing of PWD and the households they live in. (Braithwaite & Mont 2008) On the other hand, poverty scholars have not sufficiently recognized the role of disability in the poverty concept; disability is often seen as an isolated issue. (Rogerro etal. 2006; Saunders 2006) The research that has been done on the relation between the two concepts, has mostly been confined to high income countries. (Barnes & Sheldon 2010; Mcewan & Butler 2007; Palmer 2011; Yeo & Moore 2003; WHO 2011)

Recently the discourse has been including middle- and low-income countries.(Mcewan & Butler 2007; Palmer 2011)

The available research compared PWD to non-disabled and found signs of poverty among the disabled: less assets; low employment rate; low school attendance (and thus not prepared right for the job market); fewer working hours; low paid jobs; no access to microfinance; no access to services; bad living conditions. (WHO 2011; Kett et al. 2009; Filmer 2005; DFID 2000; Grut & Ingstad 2005; Mitra et al. 2011; Loeb et al. 2008; Mwenda etal. 2009; Eide&Kamaleri 2009; Rogerro etal. 2006) Yet most of the published research is not conclusive on the direct links. (Mwenda et al. 2009; Kett etal. 2009)

Most scholars refer back to the work of Elwan, in 1999 one of the first who specifically targeted the link between disability and poverty (Box 23). He wrote about the two roads in the relation between poverty and disability: the path from poverty to disability, and from disability to poverty. (Elwan 1999)

Box 23: Elwan's two road relation between poverty & disability



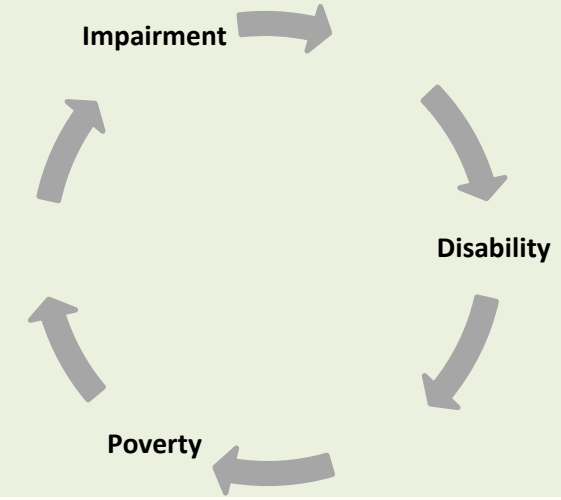
Source; Elwan 1999

While Elwan, and many authors in his footsteps, wrote about the two way relation between poverty and disability, Yeo took this link a little further in 2001. She described the relation as a **vicious circle**.

Figure 1 displays the vicious circle of poverty and disability. Yeo described the same factors as described above in the two pathway of Elwan, but she also claimed that this leads to an ongoing slide downhill. '*Excluded from mainstream social, economic and political opportunities throughout their lives, disabled people frequently fall further and further into chronic poverty and have little opportunity to come out of this cycle*.' (Yeo 2001) Looking at figure 7, poverty can lead to higher risks of becoming impaired. The impairment can lead to becoming disabled because of exclusion, which then can lead to increasing poverty. (Yeo 2001)

Yeo's vicious circle can refer to the situation the infected of the disabling diseases find themselves in specifically, thinking back to the stories of Ibrahim, Aisha and Samuel. Every story, every disease, every environment brings about different factors; yet these can all be inserted into this vicious circle. The circle represents how this hardship of living with the disabling effects in Sub-Saharan Africa actually persists.

Figure 7: Yeo's vicious circle of poverty &disability



4.2 Escaping the vicious circle

Where do the opportunities lie?

The vicious circle does not entail that the infected in Sub-Saharan Africa have to be trapped forever. Developmental efforts can provide opportunities to escape this circle. This can be of crucial importance, especially when other people in their surrounding are starting to enjoy more prosperity through developmental efforts. When the effects of disabling diseases are not considered in development, the gap between those affected and others will grow even further.

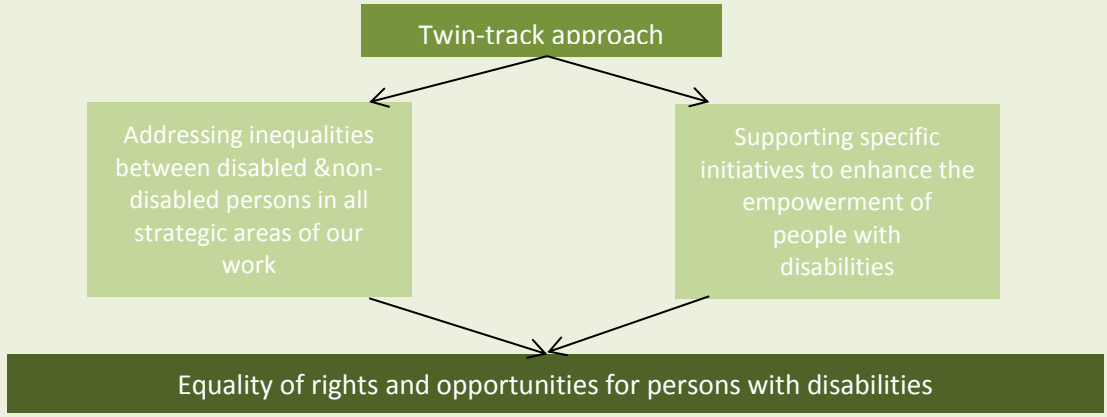
Developmental efforts

When we wish that the effects of the disabling diseases are taken into account by International Development, we should regard which tactics to use.

The field of disability can provide us with three tactics which can be found in developmental plans these days. The first approach is a **special targeting approach**. In this case, this would entail that the infected would be targeted through special projects or programs, focused on their specific needs. They would be treated as a vulnerable or disadvantaged target group with special needs. Secondly an **inclusion approach** can be applied, where the issues are *actively* considered in mainstream development work. The mainstream projects or programs should be arranged in such a way that the infected disabled are included as well. Lastly the DFID introduced the idea of **a twin-track approach** to disability and development, copied from their tactic towards women's development. (Box 24) (DFID 2000) This, '(…) *entails the inclusion of an active consideration of*

disability issues in the mainstream of development co-operation work, and looking for opportunities to support more focused activities, including direct support to organizations of disabled people and to initiatives aimed specifically at enhancing the empowerment of people with disabilities.'
The tactics will come about while analyzing the different life areas.

Box 24: DFID's twin-track approach *Source: DFID 2000*



Escaping the circle

The last three chapters have displayed which dimensions in the lives of those who are affected by the disabling diseases, are important. The chapters have also shown which factors especially have to be taken into regard within these dimensions, when considering the effects of the disabling diseases. All these dimensions are captured within the vicious circle. But within every one of these life areas, an opportunity may lie to escape the circle. This section will provide a complementary analysis to the theoretical research in the previous chapters. An analysis of the barriers a person infected with a disabling disease in Sub-Saharan Africa faces in real life will be discussed for each life dimension.
Next, the ways in which development is put into practice in one such area is analyzed. These developmental efforts can represent an escape to the vicious circle.

Standard of living

Those dealing with disabling consequences in Sub-Saharan Africa may have trouble sustaining a decent standard of living. The difficulties experienced by the infected in the work & income field:

Difficulties standard of living	Employment rates already low in Sub-Saharan Africa
	In rural areas the work may be more physical than in urban areas
	Stigmatizing views from employers; co-workers; employment institutions & services
	Especially difficult to find and keep employment with visual & hearing impairments; epilepsy; and mental disabilities (Elwan 1999)

All the above reasons impose a certain degree of dependability upon the infected. They often have to depend upon those in their immediate surroundings (family members; extended family; community members) to survive. People with disabilities would much rather achieve economic inclusion.

Self-employment

Since they're experiencing so few employment opportunities, many people with disabilities turn towards self-employment, especially in developing countries. (Handicap International 2006; de Klerk 2008; WHO 2011) '*Although many would prefer to have a job with a regular income, self-employment is often the only option available*.' (De Klerk 2008)

As Marije Koeman, program worker at the Liliane Fonds (a Dutch NGO focussed on disabled children), mentions: entrepreneurship is a very popular subject in the mainstream International Development world these days. Often through microcredits from microfinance institutions (MFI's; financing institutions that focus specifically on the poor and poor countries) self-employment is encouraged to further development under the poor.

But this enthusiasm cannot be applied to people with disabilities in developing countries:

There is no consensus (yet) on how to approach the subject of self-employment and how to guarantee successful self-employment, including micro financing, for people with disabilities (PWD's).

The lack of agreement seems to be caused by two factors:

1. People with disabilities are generally excluded from the general entrepreneurship and microcredit programs and do not have access to MFI's. (Handicap International 2006; de Klerk 2008)
2. Within the *disability and development* research field there is not much literature nor discourse on work and income. Organizations who work with *disability and development* in practice are not yet specifically and systematically focussing on the processes within the work & income theme in general, let alone self-employment or micro financing.

Box 25

Invisibility PWD's in MFI programs:

- ✓ **MFI's do not target 'poorest of poor', but 'middleclass poor'**
- ✓ **MFI's are not willing to provide microcredit to people without experience in economic activities**
  - ➔ **often PWD's don't have that experience**
- ✓ **MFI's lack understanding of the capabilities/possibilities of disabled people**
  - ➔ **PWD's are often seen as too great of a risk**
- ✓ **PWD's and Disabled People's Organizations (DPO's) lack understanding of the micro financing operations**
  - ➔ **Think preconditions are too demanding**

Sources: Handicap International 2006; de Klerk 2008)

Because PWD's experience extra barriers in acquiring official employment, the first factor is a real problem for people with disabilities. Box 25 shows the reasons why people with disabilities are not part of the programs of MFI's.

The first issue is not just a problem of disabled people. The MFI's have received a considerable amount of critique in the last couple of years that they're not reaching the poorest-of the-poor, the most vulnerable groups in developing countries, which includes persons with disabilities. The idea of social inclusion is on the move within the microfinance-industry these days; so there has indeed raised some form of awareness within this industry. Some MFI's have begun to specifically target this excluded group, so this could improve the opportunities for PWD's.

But according to Ton de Klerk, access to MFI's is still very hard to achieve for disabled people. Ton de Klerk, a former freelance consultant on emergency aid and rehabilitation programs (also including income generation and microfinance), is

currently a voluntary advisor for the Liliane Fonds in the field of work and income. He previously engaged in a large scale research for Handicap International on economic inclusion of PWD's in developing countries. He shared, how (seven years after the results of the research for Handicap International were published), he has not encountered any initiatives in the field that have led to real progress. The last three issues of Box 21 come down to raising awareness between the two parties and a willingness to work together. This appears to be very hard to achieve in the field.

On a macro scale though, Handicap International has been lobbying very intensively. International partnerships have been established to ensure the economic inclusion of people with disabilities in developing countries. One result Handicap International managed to accomplish through their advocacy, is the integration of disability in the discrimination code of the *Smart Campaign*. The Smart Campaign aims to unite microfinance leaders around the common goal of keeping clients as the driving force of the industry and thus serving the world's poor. This campaign is one of the signs of increasing social awareness in the micro financing sector. The campaign has '*Client Protection Principles to help microfinance institutions practice good ethics and smart business*.' [3] Among the 'fair and respectful treatment of clients' principle, it is also stated not to discriminate. The campaign is led by a committee of leaders in the microfinance industry from diverse regions and institutions. By ensuring the integration of people with disabilities in the discrimination code, some form of awareness is created and with this in mind, MFI's might be more inclined to provide microcredits to PWD's. The road towards economic inclusion is taken.

There are various ways to encourage and enable self-employment for disabled people. Box 26 shows the possible financing instruments and the way they can be provided:

[3] http://www.smartcampaign.org/about-the-campaign/smart-microfinance-and-the-client-protection-principles

Box 26: Financing Instruments

	What?	Pros'	Con's	Provided by
Grants	Funds provided by an agency to a beneficiary, who is not required to reimburse them	-better accessible poor PWD's especially for start-up -simple program set up -donors are willing to finance grants	-reinforce charity idea -no real effort from PWD b/c no pressure -Grant alone cannot lead to sustainable business -Provision of grants depends on money of donors	-NGO's -DPO's -community based saving & lending groups
Loans	An arrangement in which a lender provides money to a borrower and the borrower agrees to repay the original amount (principal), along with interest fees (the cost of borrowing), at some future point in time	-Ensure more sustainability than grant system -better commitment to business b/c of debts to repay	-No access to loans -Low income earning capacity may trouble ability to repay loan	-MFI's -other financial institutions -governments -community based saving & lending groups
Subsidized loans	An arrangement in which a lender provides money to a borrower and the borrower commits to returning the amount borrowed without paying full interest fees on the loan (i.e. the borrower reimburses the amount of the loan, but does not pay 100% of the cost of borrowing). In this case, the lender or some external agency bears the rest of the cost (called subsidy)	-better accessible poor -no 100% charity idea and some pressure for commitment, so ensures more business sustainability than grant -By help of NGO or DPO access to MFI or other specialised financing institution, where otherwise excluded -> when business sustainable and can afford normal loan, already have access MFI	-still not 100% sustainable -dependable on money of donors -High risk for NGO or DPO	-NGO's -DPO's Or the NGO's/ DPO's bears extra costs and loan goes through specialised financing institution, like MFI's

Source: (Handicap International 2006; de Klerk 2008)

After knowing the problems for enabling self-employment for disabled people and the ways to make it possible; what would lead to the best results?
According to Ton de Klerk, it should be a combination of methods.

- Because the MFI's often don't support people without experience in economic activities, and PWD's often are newcomers, small grants should be available to those who need it.
- The grant should represent the first small push in their business, and thus come in a very small amount. After the grant, the PWD's should apply for loans through professional financing institutions, in order to make the business sustainable.
- During the road - from making a business plan, receiving the start-up grant, investing the grant-money in the right way, accessing the professional financing world- the disabled person should be mentored, coached, trained and advised thoroughly and consistently.

The Liliane Fonds had previously scrapped grants from their activities, as (like many other examples) they did not lead to sustainable businesses. But Ton de Klerk

has made sure grants are once again included in the new work and income policy guidelines for the organization. He's convinced that:

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the problem doesn't lie with the financing instrument but with the lack of guidance.

Exactly in this field of guidance, lies the role of preferably disabled people's organizations (DPO's), or otherwise organizations *for* PWD's. Ton de Klerk prefers DPO's because of the strength of self-organization. People, who are in the same situation, can be of great support. Especially when you can organise yourself as a group, a sense of empowerment can rise. The organizations build the self-esteem of people with disabilities, which (as discussed in chapter 3) can often be very low. A raise of self-esteem is important for various dimensions in the life of a disabled person, like maintaining a decent standard of living.

Integration in the employment field

But Marije Koeman raised the question if self-employment is for everyone? Ton de Klerk also came across this problem, as he now works with youngsters at the Liliane Fonds, for who it may be harder to start up their own business. Developmental efforts should thus not only be focussed on self-employment but also on economic inclusion in the formal employment field.

As mentioned earlier, by Ton de Klerk, within the field of *disability and development* the process of work and income isn't a major topic. According to Ton de Klerk, traditional disability organizations like CBM, Leonard Cheshire disability, or in the Netherlands the Leprastichting, do not have work and income as a specific theme. When they focus on it, it consists of vocational training etc. and there is no real guidance towards pinpointing the opportunities in the job market and actually finding a stable job. There is thus not much knowledge and therefore neither much knowledge exchanging on the subject.

At the Liliane Fonds they have only recently made it one of its themes. They work through the approach of *Job Development*, guiding people with disabilities towards formal, stable and sustainable employment. One program example, which is currently being put in place, is a restaurant in India where PWD's serve in the restaurant and work in the kitchen. This concept is well known in the Netherlands, but not implemented there. The partner organization of the Liliane Fonds sets up the restaurant. The disabled people receive '*on-the-job-training'* to prepare them for the job market in the restaurant business. The partner organization is responsible for creating and maintaining a network within this business. In this way they're able to prepare and integrate the PWD's in a smooth way into employment within the restaurant business. The link between the training and potential job-market and employees is an essential part of the job development idea. According to Ton de Klerk, too often disabled people are provided with vocational training but have no clue where the opportunities lie for them to find and maintain a decent standard of living. The idea of job development ensures more sustainability.

On a macro level, not just organizations like Handicap International are working on economic inclusion. The International Labour Organization has also been active in the field of economic inclusion as well. '*The ILO's Disability Programme promotes equality of opportunity and treatment for persons with disabilities in vocational rehabilitation, training and employment, as reflected in Convention No. 159 concerning Vocational Rehabilitation of Employment of Disabled Persons, 1983, and the ILO Code of Practice on Managing Disability in the Workplace adopted in 2001. It works to increase knowledge on the training and employment of people with disabilities, by carrying out applied research relating to policy and practice, compiling and disseminating information, publishing guidelines and manuals, and sponsoring other research and reports.'* [4]The ILO doesn't just focus on the work environment and job-

[4] http://www.ilo.org/global/topics/skills-knowledge-and-employability/disability-and-work/lang--en/index.htm

training; it also has projects on self-employment. Among their work was a project on self-employment among women in Ethiopia, one of the countries in Sub-Saharan Africa where the disabling diseases occur. The project does not just aim women with disabilities, but also those who have to support a disabled family member. The project was implemented by two Ethiopian DPO's. The ILO published a situational analysis in preparation of the project. Here it became clear that the project had to target the whole area of self-employment Ton de Klerk was referring to. This included: vocational training, market opportunities, business plans, providing of training and guidance, microcredit etc.(ILO Disability Programme 2003) This project shows that besides raising awareness on a macro level for the right practices in economic inclusion, it also does good work by supporting programs targeting the whole arena of self-employment through DPO's.

But whether it concerns self-employment or integration in the job market, how exactly should a DPO or other local organization, focusing on PWD's, approach the guidance towards economic inclusion? Ton de Klerk prefers a holistic approach. He performed an impact study on a DPO in Bangladesh, (Bangladesh Protibandhi Kallyan Somity: BPKS) in 2008 and this organization put an extraordinary approach into practice. The organization was active on national level (lobbying with government) but also very present on a provincial and local level, with local departments.(Kalimullah & De Klerk 2008) Box 27 shows their wide range of activities and services.

For instance, in the field of self-employment, the organization provided very small grants, but a large percentage of the members in the local communities received loans from specialized financial organizations.(Kalimullah & De Klerk 2008) According to Ton de Klerk, an organization should take an holistic approach in their activities and services, but know where to draw its lines. In that way the risks for the DPO remain low. It should not develop into a professional microfinance organization. Like the Liliane Fonds encourages, an organization should focus on *creating a network* for specialized services like financing of microcredits.

Within the approach it should also take into account where they're operating. In the rural parts of Africa, where most of the victims of the disabling diseases in this research live, the opportunities lie more in agricultural self-employment than integration in a diverse job market. But once again, the role for DPO's can lie in helping the disabled persons discover where the exact opportunities for economic inclusion lie.

Box 27
Activities and services BPKS

- ✓ **Addressing basic needs of its members, through provision of physical therapy, assistive devices etc.**
- ✓ **Assisting them to secure access to basic services such as health, enrolment in schools, government allowances, access to training and development programmes of the government and other NGO's, access to financial services of Government Banks, Social Welfare Department, microfinance institutions etc.**
- ✓ **Developing self-confidence and self-esteem of its members, through group formation, leadership training, awareness of disability issues and their basic rights, and equal participation in social and economic life.**
- ✓ **Looking to social, cultural as well as economic aspects of life**
- ✓ **Creating disability awareness in the community**
- ✓ **Lobbying and advocacy in order to ensure the rights of its members**

Sourxce: Kalimullah & de Klerk 2008

Box 28 concludes the lessons learnt for developmental efforts in the standard of living dimension.

Box 28: Lessons learnt

Standard of living	✓ Disabled people encounter barriers in economic inclusion, in the fields of formal employment *and* self-employment ✓ Guidance of disabled people is very important for both for formal employment and self-employment → that's the best way to ensure sustainability ✓ DPO's should fulfil this role of providing guidance. They should do this through an holistic approach, but create a network, like for specialist services.

Inclusion is very well possible. Improvements have to be made in this field of expertise though, because there is still a lack of consensus and knowledge exchange on the subject.

Knowledge

In order to develop, knowledge is a very important dimension in life. Generally speaking, people with disabilities have difficulty acquiring education. The disability factor can even weigh stronger than other factors associated with vulnerability: '*The correlations for both children and adults between low educational outcomes and having a disability is often stronger than the correlations between low educational outcome and other characteristics – such as gender, rural residence, and low economic status.'*(WHO 2011)

With epilepsy (a disabling sequelae of cysticercosis), research showed that most people would not allow a child with epilepsy to go to school. Reasons for not allowing this were: the child's life might be endangered if seizures occurred on the way to school (65.9%); such a child is mentally subnormal, thus unsuitable for schooling (54.0%); danger of infecting other children (11.2%); child would frighten or disturb other children if a seizure occurred during class (8.4%). (Rwiza et al. 1993)

Difficulties knowledge	Absence of possibilities to acquire an education: no suitable transportation towards school; no suitable learning material; lack of abilities teacher; impassable school building
	Absence of willingness to provide an education: Stigma from the school, teachers or parents; exclusion from general educational services

Like within the story of Ibrahim, many disabled children have been sent to special schools. Even though this approach has proven to be more expensive and also extremely excluding towards the disabled person.(WHO 2011)

Depending on the severity of the disability, an inclusive approach is favored. This approach can strictly mean that all children with disabilities are being taught in regular classrooms. But it may also refer to a differentiating model where the approach for the child may differ. '(…) *education may take place in a range of settings – such as special schools and centres, special classes in integrated schools or regular classes in mainstream schools – following the principle of "the least restrictive environment*.' (WHO 2011) But in any event, attention should be paid towards children with disabilities, so the low education rate can go up and the children are at least receiving *some* form of education.

Research has shown that especially primary education is essential for poor people. Universal primary education is one of the prime Millennium Development Goals. But the more a country develops, the more the returns of primary education diminish. (IOB 2011a) As education should be available to all, a national education system, or at least an approach at national level is important. The Dutch government used to support these educational plans through their Development Aid.

Bilateral cooperation

Education has since long been part of the development programs of the Dutch department of development cooperation (DGIS) within the Ministry of Foreign Relations. This involvement in education has been guided by two principles:

- a human rights argument (education for all) and
- the link between education and development. (IOB 2011a)

In practice this meant that (like in the other fields within DGIS)) the education aid was provided through sectorial or general budget support. The financing went towards the budget for education or the central budget of a partner country of the Netherlands. Experts at the Dutch embassy engaged in policy discussions with the foreign ministries and other donors about education reforms.

Through email contact with BUZA, it was stated that up until now, in their bilateral cooperation, an inclusive approach was maintained. All children, including those most disadvantaged and vulnerable, should be able to get an education. Within the policy discussion with the partner countries ministries, inclusion was on the agenda. But the Dutch international development program did not contain any programs specifically targeting children with disabilities.

Nongovernmental organizations

The sectorial approach, has, in the period 1999-2009, been accompanied by support through nongovernmental organizations (NGO's). The added value of working with NGO's at country level was: '*To develop innovative, alternative interventions with the aim of improving access to education, education quality and the relevance of education, specifically in relation to hard-to-reach target groups*.' Children suffering from the effects of disabling diseases can experience problems with accessibility of education and may be assigned to these hard-to-reach target groups. In the 1999 education policy, the objective entailed reaching excluded, disadvantaged children. (IOB 2011b) The Dutch DGIS supports local organizations in their partner countries, but also Dutch ngo's through the co-financing system. One of the supported Dutch ngo's who works in the field of disability and education is the Liliane Fonds.

It remains difficult to conclude whether the specific targeting of disadvantaged or vulnerable children, has also sufficiently targeted the children infected by our disabling diseases. The IOB evaluation concludes that target groups which were not being reached by the public education system because of their geographical or social isolation, did enjoy improved access to education. But the approach also had downsides: *'Several evaluations noted that there was no clear*

strategy to reach intended target groups. As a result, there were no clear guidelines for student identification and selection. The danger of this was that the most vulnerable children would continue to be excluded, and it also ran the risk of creating tensions within communities. Evaluations noted that attention should be paid to the effect of demand-side interventions on other children in the same school, family or community.' (IOB 2011b)

What then was found to be a successful approach in providing education for the disadvantaged children? Through non-formal schooling the NGO's managed to reach the biggest amount of these children. This entailed community and mobile schools; residential and non-residential education centers; and bridging courses and accelerated learning programs to reintegrate students who have dropped out back into the public systems. The last tactic may especially apply to those children of schooling age who are suddenly struck by a disease and left with the disabling effects. The non-formal schooling programs were effective because of their flexibility and possibility to adapt to local contexts. It did proof difficult though to integrate innovations into the public schooling system and to safeguard the sustainability of the interventions.(IOB 2011b) The tactics implemented by these NGO's do need to ensure that, in this instance, children struck by the disabling diseases in the future, will also be able to enjoy the same opportunities.

Not knowing exactly to what extent the work of the NGO's in general affected those living with disabling diseases and what was successful, the Liliane Fonds provides a better insight in the work in the field targeting disabled people specifically. Although the Liliane Fonds is an organization which specifically targets people with disabilities between the ages 0-25, it works through the twintrack approach. They want to mainstream the children as is best possible, yet they also acknowledge the importance of specialist care. In the field of education this means that: '*The Liliane Foundation promotes inclusive education when the cultural, socio-economic, legal and infrastructural circumstances of the country allow that*.' (Liliane Fonds 2011) As Marije Koeman, a program worker at Liliane Fonds, concluded: regular where possible; special where needed.

They mainly work through small-scale direct assistance for a child or youngster with a disability.
Box 29 gives an idea of the activities Liliane Fonds works on within the field of education:

Box 29 Liliane Fonds activities financed in education field

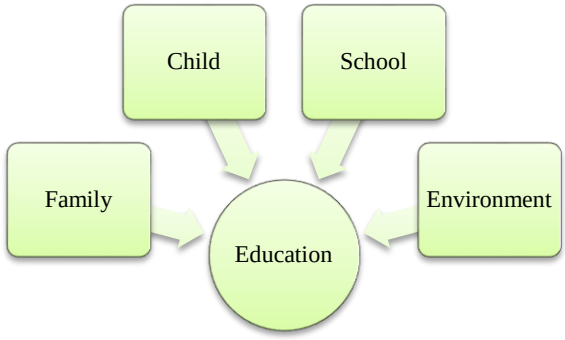
- ✓ **Direct contributions to a child (school fees)**
- ✓ **Supports partner organizations in :**
  - **buying educational assistive devices(study books in braille)**
  - **supplying non-educational assistive devices or services in order to ensure to be able to learn (hearing devices); transportation to/from and in school (wheel chair, bus transportation)**
  - **Providing training to teachers, school personnel for education inclusion of children with disabilities**
  - **Establishing educational facilities (special education centers)**
  - **Enabling enrollment in vocational training or higher education after school**

Sometimes the circumstances in a country indeed are not suitable for inclusive education. Marije Koeman mentioned the foundation of a school for blind and visually disabled children in Burkina Faso (financed by the Liliane Fonds), where children from the entire country were enrolled. No doubt, among these are children affected by onchocerciasis, as Burkina Faso was one of the endemic countries.

According to Marije Koeman it's difficult to approximate the determining factor for successfully ensuring an education for a disabled child. Figure 8 shows the factors influencing the success or failure. The four actors (school, child, family,

environment) can act as facilitators ensuring a successful education or as barriers denying the child a good education. Sometimes the parents refuse to see the opportunities lying ahead for the child or are afraid of what the rest of the community will say. Other times the child has internalized all the stigma it encountered and can't believe in its own potentials.

Figure 8: Factors influencing the education of a child with disabilities



Marije Koeman encountered situations where the child and parents where very enthusiastic, but when they arrived at the school, they were simply omitted entrance. They were told by the school that they would receive papers, but never received those. The environment can also be very facilitating. Marije Koeman came across a boy who was awaiting a wheelchair (which was still being adjusted), so he could go to school. Yet the school year had already begun. So his friends put him on the back of a bike and while holding him, walked him to school and back every day.

International Organizations

Aside from NGO's, like the Liliane Fonds, the Dutch DGIS also cooperates with international organizations with in the field of education. Here the same policy as the Dutch government shines through. The current Unicef-program Education & Peace Building and the Global Partnership for Education (GPE) all support and work towards inclusion, but have no programs specifically targeting disabled children.

In 2012, a member of the Dutch Parlement called for an inclusive approach in the Dutch development cooperation in general, where, according to him, in a field like education this could lead to major progress. Yet the state secretary of development cooperation, Ben Knaapen, concluded this subject was no longer current, because of the changes in the Dutch development cooperation agenda. After a longtime Dutch presence in the field of education, education is crossed of the Dutch development agenda after 2014, except for the Netherlands Initiative for Capacity development in Higher Education (NICHE) and the Netherlands Fellowship Programme (NFP). Educational experts will no longer engage in discussions in the field of education in the partner countries nor be present at the embassies. This is unfortunate, because according to the former director of Unicef and current president of the GPE the Netherlands was the number one donor in the field of basic education. [5]

Despite claiming an inclusive approach, the dismantling of the Dutch support in the field of education is counterproductive in funding sustainable developmental efforts. It seems the only support (besides the NICHE and NFP) from the Dutch government which can reach disabled children, will now go through an organization like the Liliane Fonds which is very small scale though, or through international projects from organizations like Unicef, where the effects for disabled children aren't visible enough.

Box 30 concludes the lessons learnt for developmental efforts in the education dimension:

[5] http://www.viceversaonline.nl/2013/05/hoe-nederland-verdwijnt-uit-onderwijs/

Box 30: Lessons learnt	
Education	✓ Inclusion when possible; Special when needed ✓ Keep in mind the 4 factors influencing the success of education as barriers or facilitators ✓ When you claim to have an inclusive approach, ensure it's truly visible your projects are inclusive ✓ NGO's can play a part in specific targeting children for ensuring some form of education (preferably inclusive, otherwise special)

Health

Health is a crucial dimension, as the infected acquired their disabilities through a disease, not through some other misfortune like accident or war. For disabled people in general health represents an important field. An enabling environment is crucial for being included, yet the health aspect of a disabled person may never be ignored.

The health dimension can be seen through two focus points: *general state of health* and *health care*. Once again, difficulties are encountered within this field:

Difficulties health	High risk to lower general state of health, because of low hygiene (like bad sanitational facilities); no clean drinking water; malnutrition
	Absence or inaccesibility of health care (like facilities and services)

The encountered difficulties actually apply to all the inhabitants of the region. But the infected may experience them as higher barriers, because of their lower income, lower mobility, and especially because of their higher needs.

General state of health

The first focus point, general state of health, is being targeted by several development programs in the Sub-Saharan countries. The risks to a lower state of health can be found in the relation between disability and poverty. Very important within the programs targeting these risks, is to wonder whether disabled people are included? Does the provision of clean drinking water also apply to the infected? A blind person may still experience difficulty in acquiring this water, when the facilities are inaccessible. The biggest results here can be achieved by raising awareness among governments, International governmental organizations (IGO's) and nongovernmental organizations (NGO's). A sense of awareness and knowledge will enable them to ensure the inclusion of people with disabilities in the programs and projects. Awareness raising will come about in the section on the macro world later on.

Health care

The second focus point, health care, can entail more of a twin-track approach. A big part of the health focus of International Development turns to "***primary health care for all***". For these general programs, the care for the infected should also be taken into account. New regional health care facilities may not be as convenient, when there is no special knowledge of epilepsy or skin diseases.

The Dutch Development Aid has been active in the health sector for some decades now. The same guiding principles that applied to the education field, also apply to health: a human rights argument and the link between health and development. (IOB 2002)

The Dutch development programs of the DGIS focused on health have followed international trends. In the 1980's the focus lay on health services, while in the 1990's the focus shifted towards institutional improvements in the health sector of developing countries. Specific themes have been in line with the internationally set Millennium Development Goals, like reproductive health and Aids/HIV. These international goals are of course developed and promoted for a reason. And it also once more emphasizes the importance of concluding the effects of the disabling diseases in these frameworks. But it may be debated if the approach was effective, when it was concluded that the choice of specific health support areas was not based on a needs analysis in the countries themselves, but on international policy trends.(IOB 2002) Especially the local destructiveness of the diseases may have been ignored when this approach was applied by the Dutch government.

This actually is contrary to what was stated in a conversation with an employee of the health department at the DGIS. It was confirmed that (like with education), the specific agenda on health aid is determined in the partner countries and runs through the embassies. But the IOB report mentions that there are some specific themes throughout the entire Health agenda of Dutch foreign aid. (IOB 2002)The employee of the DGIS said disability is not a priority, but it is anticipated to gain in prominence, as the Dutch government intends to ratify the Convention on the rights of persons with disabilities this fall. Yet after the ratification the whole process of planning how to organize the convention in their policies, how to implement etc., will need to be lifted off the ground. So the actual importance of disability within the aid agenda, may still take a couple of years. It was obvious that disability was in no way very present within the health agenda, also not in a general inclusive way. This was even more emphasized by the fact that the targeting of vulnerable groups also lies with the embassies, according to the employee of the DGIS. She did claim that (like with education) the Ministry targets these groups through NGO's, especially the Liliane Fonds and Terre des Hommes.

The Liliane Fonds, with their focus on specialized care, indeed very actively target disabled people (although just till the age of 25). In this strategy they chose to combine the good aspects of both the medical and the social model on disability (see chapter 3) and not to ignore the health aspects of being disabled. Within their work in the field of health, they focus very specifically on the *symptoms* of disability for the child. Although the organization does acknowledge the importance of preconditions in order for them to do their job, they do not support actions towards making health care nationwide and accessible to all. Some of these preconditions, like the high prices of medicines, have to be tackled on a macro scale and will come about later in this paragraph. The Liliane Fonds also doesn't finance activities on prevention, as they work on the *symptoms*, not *causes* of disability.

Box 31 presents the activities financed by the Liliane Fonds in the field of health:

Box 31 Liliane Fonds activities financed in health field

- ✓ **Treatments (surgery; medical check-ups; provision of medications and therapies)**
- ✓ **Providing assistive devices (wheelchairs, prostheses, adjusted bikes, hearing devices, glasses, braces, crutches, orthopaedic shoes)**
- ✓ **Access to medical rehabilitation services that address the usage of the (para-) medical equipment and devices**

In practice, according to Marije Koeman, the health activities are all practiced through the idea of *Community Based Rehabilitation*(CBR). When needed though, specialized care is arranged for in a big hospital. In 2010 the WHO published new CBR guidelines. The next part on the micro life dimension will further elaborate on Community-Based Rehabilitation.

The "***specific targeting of the disabling diseases***" can be seen as the other component of the second focus point, *health care*.

The 2002 IOB evaluation could not provide any proof of attention for the effects of the disabling diseases. The employee of the health department of DGIS confirmed that disabling diseases are not a priority within the field of Health or the general Dutch aid agenda. It also probably won't become a priority post 2015, after the end of the Millennium Development Goals period. It is quite striking that this could already be guessed since the agenda isn't in place yet and the lobbying to put disability on the agenda is still in process. She also stated that it was very difficult to attain results or proof of programs involving people infected by one of the three disabling diseases. She suspected that the embassies (where decisions were made on the programs in the separate countries) also would not be able to provide me with any information on the subject.

But we are aware of the involvement of the Dutch government in specific targeting programs for the diseases. It is striking though, that: *'With the exception of malaria control, no special guidelines have been drafted for disease control programmes.'* (IOB 2002)This was confirmed by the employee at the Health Department of DGIS. According to her, the guidelines of the financed specific disease targeting programs by third partners, all differentiate. This is quite striking, when the IOB evaluation rapport later claims*: 'Over the past twenty years, providing support to essential drugs programmes has been an important component of Dutch development aid.'* (IOB 2002)

Mali is one of the countries part of the Meningitis Belt. In 2002, the country hosted the African Cup of Nations; the biggest sport event of the continent. With epidemics already having disastrous effects upon the population; during such a massive event which extracts an innumerous number of people, the consequences would be catastrophic. The championship was also planned in the months in which the risks for an epidemic are the highest. The ministry of Health of Mali had thus organized a vaccination campaign. They had asked the Netherlands to fund this campaign. Mali is one of the countries the Dutch government has a long relationship with in development aid. The Dutch government thus invested 6.5 million gulden in the campaign to hopefully prevent an epidemic during the tournament. The number of cases did remain low in Mali that year, while neighboring country Burkina Faso was hit pretty severely that year.

These days a global health project, the Meningitis Vaccine Project, is being implemented in several countries on the Meningitis Belt. This project first developed the new low-cost long-lasting vaccine, which would be effective for the endemic area; ready for use in 2010. Successful partnerships with players from different fields and sectors helped make the project and vaccine development possible. The Dutch DGIS has no part in this big vaccination project, but among the partners was a Dutch biopharmaceutical company Synco Bio partners. (DSW & Policy Cures 2012) They helped with the development of the vaccine. Up until now, the campaign has brought about incredible results: the lowest

case numbers in years.[6] The target is for all 26 countries in the 'meningitis belt' to be vaccinated by 2016. (DSW & Policy Cures 2012)

The African Program on Onchocerciasis Control (APOC) is one global health program which specifically targets a disease, for which the Dutch government did contribute funding. The Netherlands were even one of the initial supporters of its predecessor, the Onchocerciasis Control Program (OCP), in 1975, as former minister of Development Aid, Jan Pronk, tells. But, very recently, the Dutch government has eliminated this funding. According to Luc Coffeng, who (commissioned by the program itself) analyzed the health impact of APOC, the program has been a great success up until now (it runs till 2016). Several aspects came about which ensured a strong program: they possessed the needed expertise; local connections in the program countries; collaboration between the public and the private sector; and the operational and scientific field worked well together.

The APOC (and its predecessor OPC) are often invoked in the success story of the road towards elimination of onchocerciasis; as one of the most successful, international, cost-effective, major health projects. According to Luc Coffeng, APOC is broadly supported and its importance is recognized within the world of onchocerciasis expertise and tropical diseases. But despite being used as an example of a success story, it remains difficult to generate attention for the problem of onchocerciasis and the control program tackling this, APOC. The paper of Luc Coffeng on the health impact of APOC, generated absolutely no attention in the Dutch press; no newspaper was willing to pick it up.

Even though the recent *London declaration on neglected tropical diseases* established the need for more attention towards these diseases, the issue may still seem too much of a distant reality here in a country like the Netherlands. Especially since the funding for APOC by the Dutch government was thus recently suspended as well. Despite these signs of disinterest for the diseases, the Dutch development cooperation department (DGIS) is a large donor for poverty-related and neglected diseases R&D according to a recent report. But most of the investment (around 75%) actually goes to the big three Millennium Development Goal diseases: HIV/Aids, malaria and tuberculosis. (DSW & Policy Cures 2012) The country also houses a historically renowned research institute in this field: the Royal Tropical Institute. But this institute was confronted with heavy cutbacks recently. In 2011 the Dutch Ministry of Foreign Affairs decided to completely eliminate the annual structural financing of 20 million euro as of 2013. This subsidy constituted half of the yearly budget of the institute.[7]

In general, it can be concluded that there is no conclusiveness within the governmental Dutch development aid on the existence of an inclusive approach, a twin-track approach or a special targeting approach for those affected by the disabling diseases and disabled people in general. It can be interpreted that the infected and disabled people are not visible enough, or not visible at all. Specific targeting examples on a small scale (through the Liliane Fonds) or on a macro scale (by large control programs) do seem to be successful. Despite these special programs and growing global concern for these neglected diseases, the disabling diseases still remain invisible for a large part within the general health policy of the Dutch development cooperation department (DGIS). It also remains debated if the accessibility to general health care on a national or global level isn't the most sustainable solution for the infected and people with disabilities in general.

Box 32 concludes what should be kept in mind for developmental efforts in the education dimension

[6] http://www.who.int/csr/don/2013_06_06_menin/en/index.html

[7] http://www.kit.nl/kit/Reorganisatie_nodig_voor_toekomst_KIT

Box 32: Lessons learnt	
Health	✓ Inclusion in general state of health and national health care project is important ✓ Specific results can be seen in small scale targeting or specific diseases ✓ It is still difficult to generate attention for diseases that are not on the international agenda → the disabling diseases need to be on the post-2015 development agenda

Micro world

In his or her immediate surroundings (the micro world), the infected have to deal with the consequences of the disease as well. Here they may experience difficulties in their close relationships. The fact that they have to depend upon family members, the extended family, or even the whole community, may be hard to deal with.

Difficulties Micro World	Dependancy upon others, which may lead to unequal relationships
	Stigma (enacted, anticipated and internalised stigma) in immediate relations and/or community

Besides this dependency, it may also be difficult to indulge in a close relationship. The infected may be stigmatized by others, like women with a skin disease. But most often, internalized stigma leads to low self-esteem (see chapter 3). Because of this, the infected may find trouble upholding close relationships, but also may not wish to engage in social gatherings anymore. This low self-esteem also affects the other life dimensions.

Examples of these barriers came about in projects financed by the Liliane Fonds. A boy was provided a wheelchair. But a while after he had received this wheelchair, the boy was still found in the same dark corner of his house. His parents didn't see the use of going outside with him, as their view of his potentials had not changed. Or the parents were afraid that the whole community would make fun of them if they went outside with their son.

The micro world dimension might actually be one of the most difficult areas to target. Overall inclusion would be the end result, where the disabled person is no longer living in isolation and/or in an outsider, dependency position. But, to accomplish true inclusion, the mindsets need to be addressed first. This process of mind changing is not just difficult to realize, it's also a long-term project. It's difficult to show concrete results with programs within this field.

To realize changes within this life area, specific targeting seems appropriate, in order to realize inclusion. The targeting can focus on the two factors that lead to isolation and dependency.

Firstly one can focus on those in the immediate surroundings of the infected. Research has shown that lack of knowledge

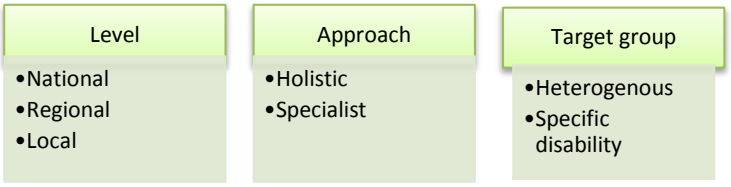
is the main cause of enacted, endorsed or accepted stigma. In this specific case, education on the diseases and its disabling consequences may decrease stigma. Health education has been known to improve the knowledge concerning the condition and change the way the diseases are viewed. Tchounkeu etal. report this change of perception thanks to the Community Directed Treatments of the African Program of Onchocerciasis Control. '(…) a *mass treatment programme like CDTI is necessary to reduce the impact of social, physical and economical discrimination due to stigmatization.'* (Tchounkeu et al. 2012) Where earlier awareness raising training for Micro Finance Institutions in the standard of living field and training for teachers in the education field came about, awareness raising training can also focus on the social segment of the community. Although the Liliane Fonds focuses more on direct child assistance, it has also financed applications for awareness raising campaigns.

The second factor to target is the self-esteem of the infected themselves. Building the self-esteem, to ensure more inclusion, can be done through concrete training and coaching. Earlier employment training or business training came about. But building self-esteem can also be done by improving his or her physical functionalities through revalidation or assistive devices.

But in the disability world, the emphasis in this field the last couple of years has been on empowering projects, following the rights model. Disabled people form groups to support each other; to collaborate; to lobby for more rights, services and opportunities etc. These organizations are called Disabled Peoples Organizations (DPO's). The DPO's come about in different forms:

They can be active on the national, regional or local level, or on multiple levels. They can focus on all the dimensions of the lives of people with disabilities and thus take a holistic approach in their strategy. Or they can focus on specific aspects of life, like work and income, or rights for persons with disabilities. Because of all the different types of disabilities, the concerns may be so far apart, that persons with a specific type of disability (like visual impairments) may choose to come together. But DPO's may also focus on the entire group of disabled persons. Figure 9 shows these differences:

Figure 9: Differences in DPO's



DPO's have been known to greatly improve the self-esteem of the disabled people themselves. The members of the DPO Ton de Klerk researched in Bangladesh mentioned this as one of the best impact results. The organizations have also brought about significant changes in attitude among non-disabled persons.

Work on local level through NGO's

How should these difficulties, which are experienced on a local level by the disabled person, be targeted in practice?

In the world of Development Aid, NGO's (northern, southern or international) have since long been seen as the actors within the development field that can work on such a local level. (Lewis & Kanji, 2009). The Liliane Fonds is one of the organizations that has a very specific community focus; even more so than other well-known general NGO's like Oxfam or disability-focused like Handicap International. The Liliane Fonds does not wish to join the global debate or lobby among different players. Figure 10 displays the mission and core activities of the Liliane Fonds:

Figure 10: Core of the Liliane Fonds

Source: Liliane Fonds 2011

The organization might not be ideal to remove all the barriers in the micro surroundings of a disabled person. Their work is primarily focused on the revalidation aspect, and less so on empowerment activities. Their activities can generate results in this last arena though: The earlier mentioned school for the blinds and visually disabled, which was set up in Burkina Faso is one example. Children were coming from all over the country to the school, as there were no other opportunities in their own nearby communities. Instead of applying for a dormitory for those kids, the partner organization initiated a plan with foster parents. The children would be housed with families in the near communities. In collaboration with the community, several families had been identified as foster parents. This plan was meant to ensure that the children also experienced the family life and encountered other people than just those attending the school for the blind and visually disabled. But besides achieving this effect and thus taking away barriers for the children themselves to engage in their micro world, it also had its effect on the community. Where the foster families in the beginning received a small amount to finance the stay of the child within their homes, they were refusing this subsidy after some time. The child had become part of the family and accepted as such.

Through the approach of Community Based Rehabilitation organizations are on purpose working on a very local level to ensure the inclusion of people with disabilities. It is also a good example of a twin-track approach. '*In the beginning CBR was primarily a service delivery method making optimum use of primary health care and community resources, and was aimed at bringing primary health care and rehabilitation services closer to people with disabilities, especially in low-income countries.'*(WHO 2010) CBR has come across some critique after its rise to popularity in the 1980's. According to Grech, its institutional practices and attitudes were simply relocated to the community. And the projects underestimated the support of the family and community already present.(Grech 2009) But CBR has evolved with time. In the 1990's the need for a multi-sectorial approach was recognized. In 2004 the CBR matrix was developed to provide a common framework for CBR programs (figure 11):

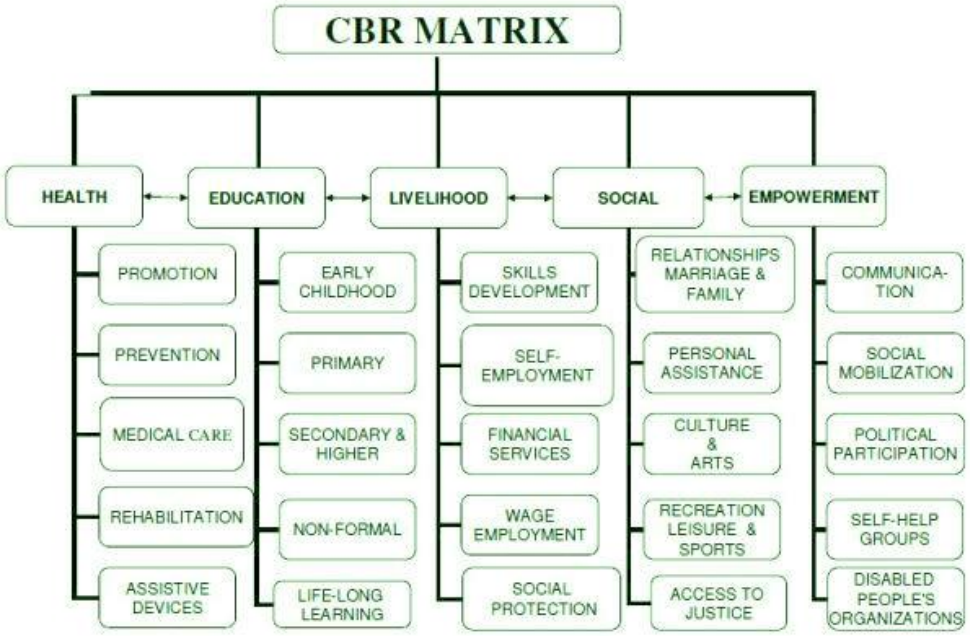


Figure 11: CBR matrix
Source: WHO 2010

The matrix entails five main components (health, education, livelihood, social and empowerment components) with each of them containing another five elements. The first four components refer to development sectors key to PWD; the last refers to the empowerment of PWD, their families and their communities.(WHO 2010) The matrix is designed in a way, that not all the components and elements are implemented, but to '(…) *select options which best meet their local needs, priorities and resources*.'(WHO 2010) The CBR approach is implemented worldwide by different organizations. Like mentioned before, the Liliane Fonds works through the CBR approach as well.

The Dutch department of development cooperation (DGIS) indeed ranks the Liliane Fonds as the type of NGO which can reach those on a local level in the field. At the education and the health department, Liliane Fonds was appointed the job of reaching the vulnerable groups (disabled in particular), which the general policy of the DGIS would not focus on, together with one or two other NGO's. They are indeed being subsidized by DGIS for a program application targeting vulnerable children, in an alliance together with two other NGO's (Terre des Hommes and Kinderpostzegels).

Work on local level with diverse cultures
One very important point which was raised both by former Dutch Minister of Development Aid Jan Pronk and by the program worker of the Liliane Fonds: You should be aware, especially when you're targeting the mindsets of the people, that you are then truly entering the field of local traditions, ideas and cultures. Especially when you are trying to bring about changes, in the way people approach things through awareness raising. Developmental interference, especially from a Western party, may not always be appreciated here. Crucial mistakes have been made in this field. When dealing with disabling diseases or disabilities, where beliefs in stigma or traditional healers can be very common in Sub-Saharan Africa, it can be even more delicate. Marije Koeman shares an example of a blind men, who was given a white cane for blind people. In the Netherlands, blind people find great help in these sticks. But after using the cane, the blind man in Sub-Saharan Africa actually felt miserable and alone. Beforehand, he always had someone to follow to get around or someone who would lead him by holding him. That was a very important way to be connected with society for the blind man. The white cane didn't work in that culture, because by losing this connection, he had lost his relations to others, which is such an

important part of their culture. It defines who you are.
In order to ensure that the targeting of the local culture is approached in a right way, the involvement and responsibility of the local people is very important. The Liliane Fonds ensures this by only working through strategic partners from the countries they work in. Figure 12 shows the connection between the Dutch organization and the children they target:

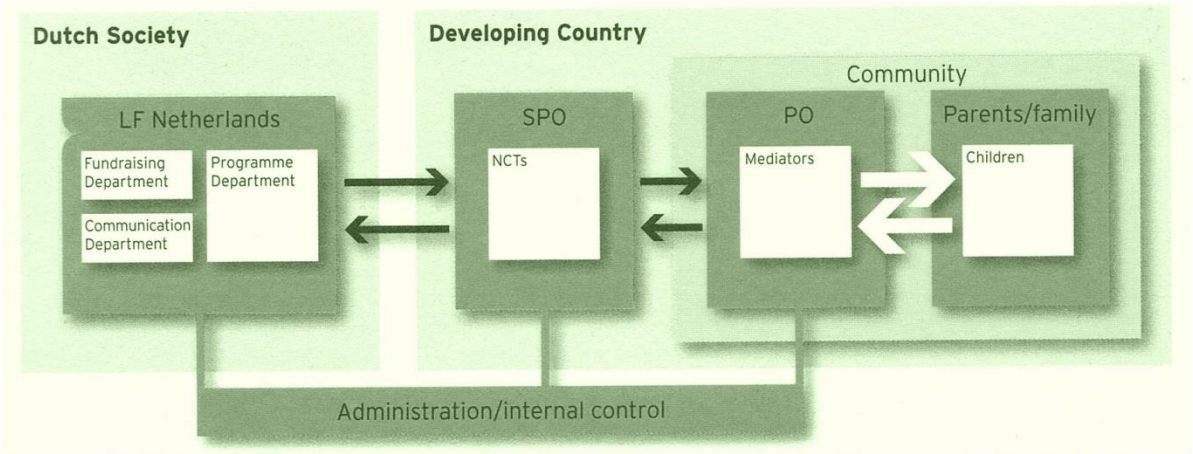


Figure 12: Stakeholders chain Liliane Fonds
Source: Liliane Fonds 2011

Their strategic partner organizations work with local partner organizations (PO's). The local PO's send out mediators into the field, who stay indirect and close contact with the children and parents of these children. This contact comes very naturally as the mediator is a local and thus already part of the community. The Liliane Fonds is working towards a model where almost all of the responsibility lies with the strategic partners. The ambition is that in 20 years the Liliane Fonds should be redundant.

Does it work then, when you really are in touch with the local people, circumstances and cultures? The Liliane Fonds experienced an example where using the local circumstances to your advantage towards the goal of inclusion, proved to be extremely successful. There was a need for locally produced wheelchairs and prosthesis. And unemployment rates were very high among disabled youth. But orthopedic shops rose, where these disabled youngsters started working. The concept actually worked so well that other people started to admire the disabled people working there. The profession assured a certain status, where previously disabled people perhaps were looked down upon.

The best way to ensure changes from within the local culture itself, instead of laid upon to achieve complete inclusion of people with disabilities in society, is probably though the DPO's. Not only can DPO's realize changes within the lives of disabled people and those surrounding them on a local level, changes are also being realized on a regional and national level by these organizations, through lobbying and engaging in partnerships with other organizations. The organizations can also spread change horizontally by DPO's popping up after a disables person being inspired by such an organization in a nearby community.
Box 33 concludes what should be kept in mind for developmental efforts in the micro world dimension:

Box 33: Lessons learnt	
Micro World	✓ To ensure inclusion in the micro world, specific targeting of the ideas of people in the immediate surrounding or the self-esteem of disabled people ✓ The self-esteem is best targeted through DPO's ✓ Targeting should take place on a local level, not through bilateral or international aid. This is best done through NGO's who preferably work through the CBR approach ✓ Removing barriers in the view points on a local level, should be done through using local context, instead of forcing Western ideas upon them

Macro world

The structural barriers within the macro world have come about in several of the earlier discussed dimensions. We can try to include those dealing with the effects of the disabling diseases, or target them specifically with developmental efforts, but when they still face structural barriers in the macro world, these efforts will never be sustainable.

Difficulties Macro World	Institutional barriers within Sub-Saharan African countries itself: discriminating laws, regulations & policies; absence or inaccesibility of services and institutions; denying of rights
	Structural barriers on a global level: lack of attention for (rights of) disabled people; unequal trade regulations& structures; unfair health provisions (expensive medicines, only cures for 'Western diseases' etc.)

This dimension is of specific importance for the long-term attention towards the infected, so they won't be excluded from developmental progress in sub-Saharan countries.

The difficulties experienced in the macro world are divided between inter-country barriers and barriers on a global level (although this distinction often isn't that clear). A general lack of attention for the (rights of) people with disabilities can trickle down towards national policies and global structures.

How can these barriers be tackled in a sustainable manner? Through advocacy and empowerment, the mindset of the people can be challenged. These changes can appear through different tactics: a bottom-up approach, with local organizations by and for (for instance) disabled people trying to trigger change within the communities; a national coalition of different local organizations triggering local change and at the same trying to gain influence on a national level; or a national representing organization trying to generate change at those making the important decisions for the country population. In the case of the infected, and people with

disabilities in general, the disabled people's organizations (DPO's) should play these parts.

National level

Firstly, inter-country level advocacy and empowerment activities can be supported by donor countries by either subsidizing the organizations in the countries themselves. Or (when the grounds still have to be laid for advocacy and empowerment) subsidizing an international NGO that tries to unite the disadvantaged, so they can form

a joint front in the developing country. Human rights are one of the main thematic focus points within Dutch development aid. The IOB evaluation concludes that from 1998-2002 the number of human rights activities in Africa was by far the largest compared to other regions. (IOB 2005) It seems rather obvious, that when you wish to tackle the difficulties experienced by the infected, they experience specific human rights barriers which need to be dealt with.

Table 13 shows the way priorities were set within the human rights policy of the Dutch Development Cooperation department DGIS:

Table 13 Year	**Priorities Dutch human rights agenda** Priorities
1979	No specific themes and/or target groups
1991	-rights of women
1997	-rights of the child -rights of women -indigenous people -asylum & refugees policy -rights of minorities Abolition of capital punishment
2001	-freedom of religion -control of racism -elimination of torture -rights of the child
2012	-rights of women -rights of homosexuals, lesbians, bisexuals & transsexuals

Sources: IOB 2005; IOB 2012

The first specific human rights policy document of 1979 mentioned no specific themes or target groups. This could be logic, as it collides with equal rights for all. But these *were* set later on from 1991. Disabled people in general, and those struck by disabling diseases specifically, do not seem to be included in any of the priorities throughout the years. Even though 2006 saw the adoption of a specific UN convention on the rights of persons with disabilities. Women and children are the only other groups, for which such a document has been brought about, and they are well represented in the priorities. But the convention still hasn't generated enough attention though; perhaps future ratification will.

The choice of specific themes or target groups does not necessarily seem to be based on the most urgent problems. According to an IOB evaluation, priorities mostly come about from pragmatic considerations, where the international agenda is taken into consideration. The choices for these themes aren't sufficiently clarified. (IOB 2012) The Dutch DGIS thus does not seem to be one of those international donors sponsoring DPO's financially or helping disabled people to organize themselves.

It is essential though that the empowerment and advocacy on a national level is practiced by the people in the country themselves, preferably by the specific target group. When you wish to generate changes on a national level, within the policies, rules, regulations and laws of a national government on a delicate subject, a foreign actor preferably should not be involved. Disability has a great deal of stigma surrounding it, which makes it one of those delicate subjects to deal with. Just like women's rights can be a very delicate subject for a Western actor to discuss with the government of a Muslim country.

In an interview with former minister of Development Aid, Jan Pronk, he emphasized that the subject has to be handled with care. You have to approach the situation from the situation in the country itself. He mentioned two difficulties which the barriers, faced by the infected, bring about*:*

- *a lack of interest from the national government*
- *the cultural context* (like within the micro world).

In case of the DGIS, both difficulties make trying to tackle these problems through the national government of the African country (the Dutch government cooperates with) difficult. It's hard to emphasize a theme, when the government there isn't interested in it, because they claim there are more urgent problems to deal with. And the cultural context also has to be handled with care. You can't come running in, trying to generate change from your own point of view. Even when the necessity can be proven, acceptance can still remain difficult.

Berkvens explained in his paper the difficulties he encountered trying to introduce mental health care into general health care in Ethiopia, even though the Dutch were *asked* to play a part in this. It took some twenty years before the project was generating a developmental effect. (Berkvens 1990) That's why these problems should be targeted by (also mentioned by Jan Pronk) subsidizing local and international civil organizations.

And when governments do indeed start providing the needed services (like general health care or specialist care concerning disabilities), those organizations can become redundant. The Liliane Fonds experienced in Brazil that the legislation was more advanced than in Sub-Saharan Africa and that the government was already providing many of the services. So the Liliane Fonds is slowly pulling out of the country. And in India, the government has introduced a disability card. With this card disabled people have the right to discounts on certain services. But especially in the focus region of this research, Sub-Saharan Africa, in countries like Sierra Leone or Togo, the needs are still very high. Even if legislation is in place, it might not be implemented. Or corruption can stand in its way.

International level

But will this be sufficient enough to generate change on the highest level? Perhaps the problems, like lack of attention, have to be tackled on an international level. Perhaps a local or national approach cannot be sustainable.

In the **field of disability**, such changes have not been brought about sufficiently enough. The exclusion of disability from the original Millennium Development Goals and their revision in 2008 unfortunately proves a persisting lack of attention.

This might seem surprising, considering that the issue has been on the agenda several times since the foundation of the United Nations in 1945, as table 14 shows:

Table 14
UN attention for disabled people

1950	**Conference** to discuss coordination specialized agencies in field of rehabilitation persons with disabilities
1969	**Declaration on Social Progress & Development** ➔ emphasized need to protect the rights and welfare of persons with disabilities
1971	**Declaration on the rights of Mentally Retarded Persons**
1975	**Declaration on the rights of Disabled Persons**
1981	**International year of disabled persons**
1982	**World Program of Action concerning Disabled Persons**
1983-1992	**UN Decade of Disabled Persons**
1993	**Standard Rules on Equalization for opportunities for Persons with Disabilities**
2006	**Convention on the Rights of Persons with disabilities**

Source: http://www.un.org/disabilities/

Yet the attention has not been grasped by those working on a macro level outside of the field of disability and development.

But with the plans for a new development agenda post-2015 approaching, definite action is being undertaken to ensure that people with disabilities will not once again be omitted from the International Development frameworks. '*As discussions regarding the post-2015 agenda gains momentum, the international community has before it a critical opportunity to ensure the inclusion of disability in the emerging global development agenda*.' [8] To ensure the inclusion in this agenda several meetings are being held.

[8] http://www.un.org/disabilities

These meetings should produce what should be on the agenda and how this can be incorporated:

Figure 13: UN meetings disability post-2015
Source: http://www.un.org/disabilities/

The meeting in September 2013 '(…) *will result in a concise, action-oriented Outcome Document*.' [9]

The new development agenda will show whether all the lobbing will bring about the aspired results. Meanwhile, the number of countries signing and ratifying the convention on the rights of persons with disabilities is rising consistently though. Once countries have ratified the convention, they are legally bound by the terms of the Convention. Yet the Netherlands is one of the countries demonstrating the long process until all the right laws, regulations and policies are in place to ensure these rights aren't denied. They signed the treaty in 2007 already, but have up until this day failed to ratify the Convention. The employee of the Health Department of the DGIS said the ratification is on the agenda for this fall 2013. Yet, like Marije Koeman from Liliane Fonds said: some countries may have ratified and have the right laws and regulations in place, but the lack of implementation of these laws and regulations still leads to exclusion of people with disabilities.

But in the **field of health**, real changes (relevant to those dealing with the effects of the disabling diseases) have been taking place on the highest level.

The attention for global health is enormous these days. This attention has resulted in three out of the just eight Millennium Development Goals (MDG's), targeting health issues. The attention isn't just confined to actors in the field of International Development. Global health is a field that has grown explosively in multiple sectors. Partnerships dedicated to different global health goals have been popping up all around. These partnerships are formed by actors from different fields (health personnel; health research; pharmaceutical research & development; medicine & vaccine large scale production; health care distribution) and different sectors (governments, ngo's igo's, private firms, private initiatives).

Because of the MDG's, the biggest examples of partnerships engaging in a global health campaign are those directed towards HIV/Aids and Malaria. But large campaigns targeting the disabling diseases, with several actors involved, are in place in Sub-Saharan Africa for onchocerciasis and meningitis.

The Netherlands is actively engaging in the fight against global and poverty-related diseases. On governmental level the Dutch DGIS is a big subsidizer of Research and Development (R&D) for poverty-related neglected diseases (DSW & Policy Cures 2012):

But these numbers can show a distorted picture, especially for the disabling diseases. According to the rapport 75% of the EU funding, including the above mentioned Dutch funding, goes towards only three diseases: the MDG diseases HIV/Aids, malaria and tuberculosis. And (as mentioned) earlier the Dutch DGIS has seen making major cutbacks in its budget since 2010, including at the important research institute Royal Tropical Institute (KIT).

The Netherlands is especially active in supporting *partnerships* within the field

[9] http://www.un.org/disabilities

of poverty-related neglected diseases. It especially supports the Product Development Partnership model (PDP). '(…) *which leverages the expertise and resources of government, industry and philanthropic institutions, resulting in increased time and cost efficiencies*.' (DSW & Policy Cures 2012) The European Union is already the biggest funder within this field and among the EU countries 26% comes from the Netherlands, making it the second largest funder of the EU. (DSW & Policy Cures 2012) The Dutch government is a donor of the GAVI Alliance. This is a public-private global health partnership committed to saving children's lives and protecting people's health by increasing access to immunization in poor countries.[10] The Dutch Royal Tropical Institute engages in several partnerships in the field of global health and poverty related diseases, like: '(…) *identification of TB biomarkers to be used in future diagnostic development.'* (DSW & Policy Cures 2012) In this project the Leiden University in the Netherlands and the non-profit Foundation for Innovative New Diagnostics (FIND) are also included. The Dutch government was included in one of the partnerships targeting one of the disabling diseases: African Program for Onchocerciasis Control (APOC), and previously the Onchocerciasis Control Project (OCP). In these projects the private sector played a large part as well, with the free provision of the medicine Ivermectin, which is being produced in the Netherlands at MSD.

In the fight against meningitis a Dutch private actor was involved as well. The Meningitis Vaccine Project was founded and a partnership of the WHO, PATH (a international non-profit organization) and funded by the Bill and Melinda Gates Foundation. The development of the vaccine also came out of a partnership of several players:

- *'SynCo Bio Partners, a Dutch vaccine manufacturer, supplied the technology for one of the main components of the vaccine, and played a key role in meeting the price per dose target*
- *Aérial, a French company based in Strasbourg, provided expertise in the formulation of the vaccine.*
- *The U.S. Food and Drug Administration donated a technology critical to creating a more effective vaccine and provided technical support*
- *The Serum Institute of India, one of the world's largest producers of vaccines, agreed to manufacture the new vaccine at a cost that no manufacturer in the developed world could match. (…)The vaccine was also tested and licensed in India.'*(DSW & Policy Cures 2012)

The campaign has been very successful up until now and has led to the lowest case numbers in years.[11]

2007-2010:

- ✓ **Annually ± €21 million**
- ✓ **0,0035% of GDP**
- ✓ **Third largest absolute donor in EU**
- ✓ **Fifth largest % of GDP donor in EU**

This shows how successful these global partnerships can be. It also shows how important it is though, that the global community takes an interest. Without enough attention, these global health projects would not be in place. The canceling of the financing of the APOC project by the Dutch government provides the perfect example, as it still has a disease like HIV/Aids very high on the agenda. But there is interest, funding and expertise in the Netherlands for the fight against diseases in poor countries on a macro level; in both the Dutch public *and* private sector.

Yet the role of the private actors has been debated throughout the years. European companies are very dominant in the poverty-related neglected diseases field: '(…) *Europe has led the way in integrating*

[10] http://www.gavialliance.org/

[11] http://www.who.int/csr/don/2013_06_06_menin/en/index.html

the private sector into the PRND R&D landscape. Europe-based companies account for two-thirds of global industry PRND R&D investments, and invest far more of their annual revenues in PRND R&D than their U.S. counterparts.' (DSW & Policy Cures 2012) For the disabling diseases we have seen the involvement of Dutch companies as well.

But one initiative has generated some real change in the private sector of pharmaceutical companies. In 2003/2004 Wim Leereveld, founded the *Access to Medicine Index*. This index has, up until now, seen 3 versions: in 2008, 2010 and 2012. The index maps:

- *In what way the multinational pharmaceutical companies are ensuring that their medicines are accessible to all, including those living in poor living situations.*

Before this index was put in place, these companies were receiving major critique. It seemed that no positive attention was given to what these companies were actually doing *right* (like working on new medicines, vaccines etc.)

To formulate the index (see figure 14), the foundation first goes into debate with the diverse stakeholders: from the big financial investors, to governments (Western and developing countries), universities, international organizations to find out what they want from these companies.

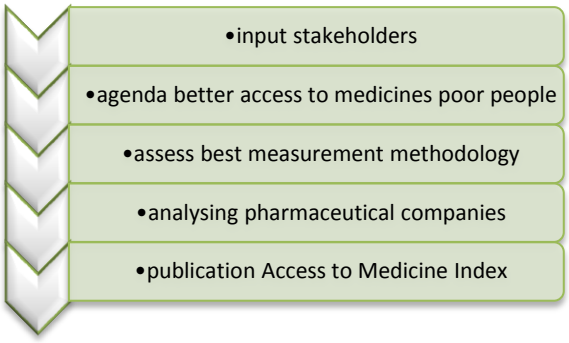
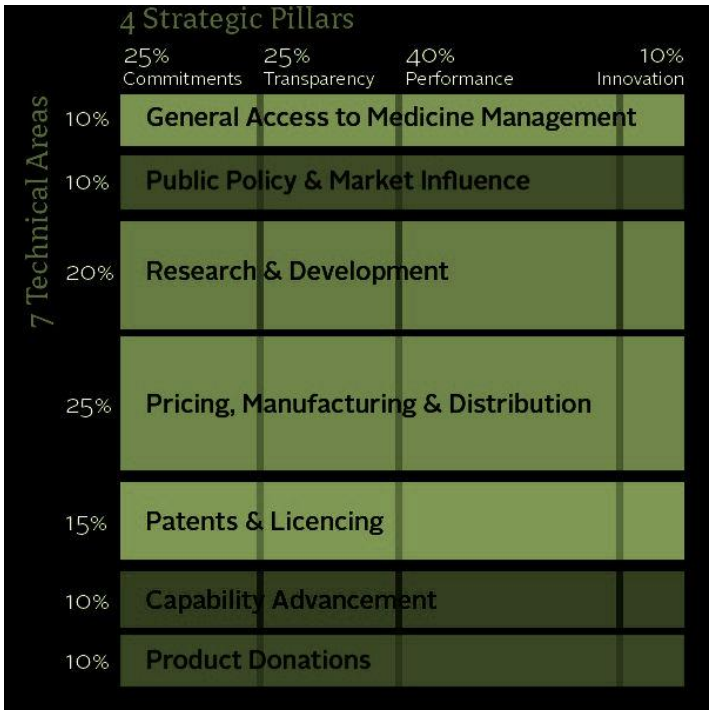


Figure 14: Process of the Access to Medicine Index *(Source: www.accesstomedicineindex.org; interview W. Leereveld)*



Box 34: Analytical framework Access to Medicine Index *(source: http://www.accesstomedicineindex.org/methodology-0)*

The summary of all these opinions leads to an agenda of what can and should be done. Next, the different companies are tested on their performances in the different agenda-points. These can range from lower medicine prices or diversity in prizing within a developing country.

Which macro effect has this index brought about? The companies actually care about this index. Before, the companies themselves also had no idea what was exactly being done. Now the companies are ranked on their performance and the ranking has generated real attention and real long-term changes within the companies.

Box 34 shows the framework by to which the companies where ranked in the 2012 index:They're now working very hard to improve the accessibility to medicines for the poorest of society. It hasn't just brought about changes within the separate pharmaceutical companies, but also created more partnership in the field. The success of the ranking constitutes in bringing together the opinions of the different stakeholders, which generates more partnership. The independency of the index, as the agenda doesn't just represent the opinion of one single NGO, makes it a credible tool. For its

research it has included high expertise from the field of health and evaluation. Although the companies remain rivals, they were all represented at the collaboration for the London declaration on neglected tropical diseases. Wim Leereveld received the compliment that the access to medicine index contributed in a great way to this collaboration.

The index represents how changes in the macro structure can be brought about, here specifically in the field of health. Although this approach is still very new and young, initiatives in other fields, like a food index with the big food companies, have also been developed.

But, like with the partnerships on global health subjects, these types of initiatives still depend on the amount of attention they can generate. If the Dutch society wasn't committed to Development Aid, then this project would not have received its funds to make a start of. And the support of Bill Gates generated even more funds and wider attention. But still, the project represents how changes on a higher level can have a significant impact on the effects of the disabling diseases in Sub-Saharan Africa.

Box 35 concludes what should be kept in mind for developmental efforts in the micro world dimension:

Box 35: Lessons learnt

Macro World	✓ The human rights of PWD's can be tackled within a country, but you need to ensure the issue is on the agenda (country itself + the donor). It's best to let this be done in the country itself, by DPO's ✓ On a macro level there is not enough attention for disability & development, but extensive lobbying is taking place to include it in the post-2015 agenda ✓ Within the field of health real changes have taken place with big campaigns through global partnerships (which include different expertise + different sectors) → But you do need to ensure the disease is on the global agenda, otherwise no action ✓ The role of the private sector within targeting disease is important. The access of Medicine Index has raised awareness and changes are taking place on macro level

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A holistic approach – combining all the life dimensions

Obviously it would be most profitable if changes in all these dimensions could be produced. A health project shouldn't stop at providing cheap medicines. We should also keep in mind that developmental efforts may be focused on different social sectors, but that this doesn't automatically generate poverty alleviation. This was proven by an IOB evaluation on the Dutch development aid in Tanzania where social improvement which targets all the life dimensions included in the state of wealth.

occurred without the necessary raise in income to sustain these improvements in the future. (IOB 2004)

The focus should be on an

An overall holistic policy aimed at inclusion in all aspects of life

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This holistic approach is part of mainstream International Development as well. The aim is to raise the general state of wealth through a human development approach

Obviously this general inclusion policy is missing in the Dutch development cooperation department DGIS. Perhaps the

ratification of the Convention on the Rights of Persons with Disabilities might change the approach within DGIS. But not only the Dutch government lacks an overall inclusion approach, some Dutch mainstream development organizations also see disability as a specialist area and rather leave the work to an organization like the Liliane Fonds. The *Dutch Coalition on Disability and Development* tries to encourage the inclusion of people with disabilities in the overall Dutch development cooperation. The coalition has a wide network of actors within the Dutch development cooperation world. Through lobbying, encouraging networking, and knowledge management it hopes to further the inclusion process in the Dutch development cooperation world.

But how can we expect the Dutch government and organizations to structurally implement an inclusive approach, when the International Development agenda lacks an inclusive approach. This paragraph showed that the development aid provided by the Dutch government frequently follows the International Development agenda trends, like the Millennium Development Goals. Like the MDG's, the Dutch agenda thus lacks the inclusion of people with disabilities. This emphasizes the importance of inclusion of the effects of the disabling diseases in the International Development frameworks and tools. Otherwise big changes will not occur in the developmental efforts in practice.

There are plenty of examples of countries that have realized an inclusive approach in their development department though. Countries like Australia, Norway, Sweden, the United Kingdom and the United States display varying degrees of inclusion approaches, but they do prove that the International Development agenda doesn't have to regarded as an unconditional manual.

This chapter showed that the infected can become stuck in a difficult situation because of the relation between the consequences of disabling diseases and poor living situations. But techniques for developmental efforts can be guided towards ensuring an escape from this downward vicious circle.

Infected of disabling diseases going along in development ……..

- **Those dealing with the effects of the disabling diseases in Sub-Saharan Africa find themselves in a <u>downward vicious circle</u>,**
  - **➔ due to relation between consequences disabling diseases & poor living situations**

- **They can escape this vicious circle through developmental efforts.**
  This can be done through different tactics: inclusion; specific targeting or twin-track approach

- **Changing the experienced difficulties can take place on different levels: local (through civil society organizations or NGOs); national (through governments) or international (through collaborations)**

- **Examples of successful developmental efforts for the infected were specifically found:**
  - **➔ on the local level, with the involvement of people with disabilities themselves**
  - **➔ on the international level, with partnerships**

- **Barriers remain for developmental change.**
  Especially <u>advocacy</u> of the importance of the issue remains a difficult matter
  ⟶ not just in the field of development, but also in other fields like global health

Conclusion

Millions of people in developing countries are living with disabilities. Among those people are millions who have suffered from disabling diseases; diseases that are specifically disastrous in the Sub-Saharan region.
This research focused on the consequences of the disabling diseases in Sub-Saharan Africa. **Are these consequences included in development**? The analysis included the theoretical field of development (International Development frameworks and tools) and the work done in the field (developmental efforts). Other fields of study, relevant to the consequences of the disabling diseases, were connected to the field of development to make the consequences more visible.

Lesson learnt

Which lessons can be learned from the analysis?

1, Disabling diseases can be disastrous in Sub-Saharan countries

The studied diseases did not cause global distress. But on national, regional and local level, they led to very serious consequences for those living in Sub-Saharan Africa. Why are the problems so severe in this region? The problems are caused by a combination of:

- ✓ getting sick and having to live with severe or multiple disabilities
- ✓ poor living conditions (lack of/exclusion from basic needs & services)
- ✓ difficult attitudes towards disability and health care

This combination results in a very tough life for infected, spiraling downwards into a vicious circle.

The problems aren't necessarily so severe for everyone. Conditions aren't the same everywhere and disability and environment (including attitudes) don't have to pose as a barrier.

2. The field of International Development does not provide a way out of these tough situations for the millions of people living with the consequences of disabling diseases in Sub-Saharan Africa

These people are not on the agenda, because the consequences are excluded from tools and frameworks. International Development should be designed to lift people out of tough situations and to raise the well-being. Through an improvement in the capabilities of human beings and the use they make of them, the level of development can rise. But the capabilities composite of people living with the consequences of disabling diseases, or disabled people in general, can look entirely different from the composite of others in Sub-Saharan Africa. How they're able to make use of these capabilities, can be extremely influenced by personal or environmental factors as well. But without attention for the available capabilities and factors that brought them in these tough situations, the people living with the consequences of the disabling diseases, and disabled people in general, can fall seriously behind compared to others living in Sub-Saharan Africa.

Lesson learnt

3. Despite continuous evolvement in the theoretical field of International Development, the field has failed to include fields of study essential for the lives of millions living in Sub-Saharan Africa

There has been considerable research on factors which are associated with the consequences of the disabling diseases, like disability and stigma. But development scholars haven't had eye for these fields of study. At the same time, disability and stigma scholars have failed to make a connection with the field of International Development and failed to ensure inclusion of their fields in development research.

The contextual element which is crucial within the fields of disability and stigma, could be seen as an obstacle to including the ideas in International Development frameworks and tools. But it is possible to include the concepts from these fields into development frameworks, while maintaining its international character.

4. The International Development agenda does in fact influence the developmental efforts put into practice in various ways. The exclusion of the consequences of the disabling diseases from the international agenda hereby has direct results for an infected person living in a Sub-Saharan country

The research has shown that policies are indeed based upon this International Development agenda. This can be expected from international organizations like the UN, who initiated the Millennium Development Goals. But the bilateral aid of governments, big international health projects and donor money also let their priorities be guided by the international agenda. The International Development agenda priorities may be derived from extensive research and input from stakeholders, but they're also the result of extensive lobbying. If this wasn't the case, the *disability and development* world wouldn't see the need to be lobbying so vigorously for the post-2015 International Development agenda.

But there is the risk of international priorities seriously overlooking local problems. The disabling diseases in particular cause problems in one certain region (Sub-Saharan Africa) and can be destructive on a very local level. This locality is not just caused by climate preference of the region, but also by the state of other capabilities. As eye for context and local distribution of capabilities often isn't included in International Developmental frameworks and tools, abiding to this agenda may collide with the real problems at hand.

5. Good and sustainable results can be achieved by working on an international level

Despite the objections in the previously lesson, trying to set priorities on a macro level can also lead to good changes for a large group of people. These changes on a macro level often ensure more sustainability than many actions on the local level. The research on developmental efforts in on macro level has provided several examples of significant results for the people living with the consequences of the disabling diseases or people with disabilities in general. The initiative for these macro changes doesn't just have to come from the world of disability (like national DPO's or organizations like Handicap International). The Access to Medicine Index or the global partnerships for specific diseases show how changes can be initiated in other fields as well.

Lesson learnt

6. Attention for the consequences of the disabling diseases, but also for disability in developing countries, remains crucial for large scale action and donor money funding this

The example of the African Program on Onchocerciasis Control represents the crucial importance of advocacy and awareness raising. The program is often paraded by representatives of the field of global health and donors (like the Dutch government), because of its successful results and successful partnership (including the different sectors). But apart from this success story, the issues of onchocerciasis (river blindness) do not generate much attention at all. In that way it can still be seen as a 'neglected tropical disease'. Several examples from the developmental efforts (disease control; microfinance, human rights) demonstrated that , despite the urgent character of the issue, not much can be accomplished if attention isn't generated for the issue.

7. Working on a local level on the consequences of the disabling diseases and disabled people in general, can generate better and especially more clear results than the work on a national/bilateral level

If a government (donor or African) claims to work through an inclusive approach, the evidence for this inclusive approach often couldn't be demonstrated easily. In the case of the consequences of the disabling diseases and disabled people in general, NGO's, organizations for disabled people and disabled people's organizations (DPO's) showed very concrete results. Because of the locality and contextual character of the issues, the local approach seemed to work very well. Especially when the activities stayed close to the local community (through local partners, situated in the communities itself) and the community's culture, traditions and ideas.

8. The involvement of the disabled people themselves ensures better results, more sustainable results and also secondary results

Developmental efforts are not based on a charity approach anymore. The activities should not culminate in dependency but in empowering the person to make the best use of his or her capabilities. This especially goes for people with disabilities, who often are already dependable upon others. These people need to be fully included in their communities as active members. The best way to acquire this inclusion, is by generating it yourself.

By self-organization the people with disabilities realize they're not the only ones living in a certain situation. The disabled people organizations (DPO's) give them the courage to do activities they might never imagined. And most importantly: disabled people themselves are best equipped to know which activities are necessary to improve the living situations of disabled people. The DPO's can focus on all the different life dimensions of people with disabilities through a holistic approach, because the ICF model (chapter 3) showed that all factors in life influence each other. Through networking and building partnerships (not just a popular term on a macro level), they can facilitate the inclusion of their members in society and acquire specific expertise of others when needed.

The research also brought about some issues to keep in mind. The different actors within the field of development, disability and development, disability, stigma and disabling diseases should stay focused on these areas:

- **There seems to be a definite separation of causes and symptoms of disability**

Organizations like the Liliane Fonds or DPO's often only work on the symptoms of disability. But from the field of health, the specific disease programs only target the prevention or cure of the diseases. The Onchocercial Control Program showed this lack of attention for the issues after the implementation of the control efforts. The field of global health often seems to lack any attention for contextual factors or how the environment can influence the physical functioning as well. The WHO contributed in a great way to this issue with the publication of the ICF. But perhaps the disability world is afraid of concentrating too much on the medical model? For some reason connecting health and social issues, still seems challenging.

This lack of connection is problematic if you wish to focus on the consequences of the disabling diseases though. The issues touch ground with the causes *and* the symptoms of disability. For my research, people and organizations from different fields of expertise had to be approached, but none of them seemed to be knowledgeable on the entire subject.

The developmental efforts showed how this separation was obvious in development put into practice. But the separation also has effects for the attention for the consequences of the disabling diseases in the development discourse. This may pose serious problems on the long term, because of the connection of the theoretical field to the international agenda and policies. If you want inclusion of the consequences of the disabling diseases, but also of disabled people in general, you need to bring the two together. There cannot remain a gap between the social expertise and the health expertise. The DALYs represented a good attempt from the field of health to include disability in the international health agenda and a possible method to include disability in the development agenda. But the framework collides with ideas from the field of disability, it lacked crucial characteristics of the social model. But at the same time, the field of disability has not been able to get any closer to theoretically incorporating disability ideas in development tools or frameworks. A large amount of the material on disability and development focusses on practical guides for inclusion in developmental activities.

- **The solution to successful developmental efforts seems to be on a crossroad between local & in practice versus global & in policies**

Firstly, the problem of the consequences of the disabling diseases seems to be locally, but still affects a region which represents a large part of the world; a part of the world where International Development is most focused on because poverty rates are at its highest. So within the problems of the consequences of disabling diseases already exits some tension for the positioning of the problem. Where exactly lays the essence of the problems? On a local, regional, national or global level? The developmental efforts show this lack of concession on how to approach the problems as well. In the world of International Development in general, questions persist: which approach generates the best result? Is it the work of NGO's with their specific targeting on a local level? Is it through bilateral support, so the changes can come from within the countries' governments itself? Or should changes be made to global structures and through global partnerships?

In this research the local level actions seem to generate very clear results, and when performed correctly (like through DPO's or close to the communities) very sustainable. The global actions may not display direct results for the infected or disabled people in general, but do reach larger groups of people. And they generate more sustainable results for such large amounts of people. Which approach should developmental efforts focus on? This question should be taken into account by the actors involved in this field. Perhaps a combination of approaches will work the best. But a lack of concession will never be beneficial for a solution to the problems of the consequences of the disabling diseases. Exchanging of knowledge and a discourse should be put in place to ensure people, organizations, institutions and governments are not carrying out the same or counterproductive work.

Despite the conclusions that could be drawn from this paper, it could not include all the factors that deserved attention. Nor could it include all the different developmental efforts. Because of the choices made for the focus of this research, the research presented two downsides:

- The results are not representative for *all* developmental efforts. Mainly Dutch examples were used. Organizations, institutions, governments, companies and initiatives from other countries will display different patterns and approaches. But as a country where the government is not one of the forerunners on the subject of *disability and development*, and with the ratification of the CRPD at hand, it was interesting to use Dutch examples.
- The research displayed a considerable focus on disability in general. The reasons for this attention for disability were: Firstly, the effects, programs etc. on the disabling diseases and the infected are hardly registered at the Dutch department on Development Cooperation (DGIS) and at NGO's. It was hard to finds signs of the infected and the diseases in the work of these institutions and organizations. Besides this lack of material in development in practice, there was a lack of attention for the developmental efforts towards the infected in literature as well. Most literature focused on the diseases itself, the disabling consequences and the control efforts. Secondly, many NGO's, DPO's etc, mainly focused on the disability *symptoms*. The way they acquired the disability doesn't really matter. Thus there is no attention for the diseases, but a focus on how to live with the acquired disabilities. For a disease like lepra, more material is available though.

This paper is not a practical guideline for organizations, institutions or governments how to include the consequences of disabling diseases. It is an extensive analysis of the up-to-date main concerns in all the different fields that touch ground with the consequences of disabling diseases. An analysis integrating all of these concerns in these different fields, is lacking.

Statements have been made claiming that disability in general, has been excluded from International Development frameworks, tools, agenda's etc.

Due to this lack of integration of the different fields and inclusion of disability, my analysis aims to fill these gaps. Its relevance lies in:

- An extensive analysis of the wide number of International Development tools and frameworks from the last two decennia. The analysis includes if the consequences of the disabling diseases are taken into account, but can also be used to see if disability is included.
- An attempt to combine frameworks focused on development work with ideas from the fields of disability and stigma, which is lacking.
- An analysis of the relation between the consequences of disabling diseases and poor living conditions (in Sub-Saharan Africa), which is lacking. The literature is also rare on the relation between disability and poor living conditions
- An analysis which is focused on the frameworks *and* the work in practice. The relation between the two is discussed as well.
- An analysis focused on all the aspects of life. These included aspects of life are based on current ideas in the development discourse, which should make it more accessible to those working in the field of development. This approach was chosen to further the goal of including the consequences of the disabling diseases and disabled people in general, in the field of development.

Further research can be done on the connecting of other fields of study to the field of development. This can ensure that no dimensions of life are excluded or underestimated within developmental research, agenda's and work. Future research can also focus on other diseases and other examples of developmental efforts. This research could not provide a complete overall view of the word of disabling diseases, disability and development; this would require extensive research. But it especially requires scholars stepping out of their comfort zone and connecting different fields of study, or scholars from different fields working together.

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Meningitis

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