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# The impact of Neglected Tropical Diseases, and their associated stigma, on people's basic capabilities

Emma Jane Wilsher

## Abstract

Neglected Tropical Diseases (NTDs) are a group of diseases prevalent in developing countries. It has been estimated that collectively they may account for a health burden, in terms of years of life lost to disability, close to that of malaria, tuberculosis or HIV/AIDS. Stigma, in part, accounts for this high disease burden. However there is little literature on why NTDs are highly stigmatised, how the infected individual and their family are affected by stigma, and how this may manifest as either an entry into poverty or a deepening of poverty; in terms of both economics and capabilities.

This thesis combines the capabilities approach, as theorised and developed by Amartya Sen and Martha Nussbaum (1993), and NTDs in order to assess NTDs' impact on poverty in terms of reducing people's ability to choose a life that is valuable to them.

A conceptual framework has been devised, linking health, poverty and capabilities, in which to place NTDs. Using the capabilities approach as a basis for analyzing NTDs is useful, as it is a well-established paradigm, which inspired the creation of the UN's Human Development Index (HDI). Therefore combining the high profile paradigm of the capabilities approach with the lower profile NTDs may help to raise NTDs' profile, as well as creating a way in which to assess their impact on poverty that does not concentrate on monetary losses or mortality rates alone. It is hoped that this new direction will reveal major gaps in the current literature and initiate new research directions.

*The impact of Neglected Tropical Diseases,  
and their associated stigma, on people's  
basic capabilities*

Emma Jane Wilsher

Masters by Research

Department of Geography  
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2011

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January 2011

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## Abbreviations

BBC	British Broadcasting Cooperation
DAC	Development Assistance Committee
DALYs	Disability Adjusted Life Years
DCL	Diffuse Cutaneous Leishmaniasis
DOTS	Directly Observed Treatment of Tuberculosis
GDP	Gross Domestic Product
GNNTDs	Global Network for Neglected Tropical Diseases
GNP	Gross National Product
HAT	Human African Trypanosomiasis
HDI	Human Development Index
HDR	Human Development Reports
HIV/AIDS	Human Immunodeficiency Virus/ Acquired immune deficiency syndrome
LCL	Localised Cutaneous Leishmaniasis
LDC	Least Developed Countries
LF	Lymphatic Filariasis
MDA	Mass Drug Administration
MGD	Millennium Development Goal
NTD	Neglected Tropical Diseases
ODA	Official Development Assistance
PKDL	Post-Kala-Azar Dermal Leishmaniasis
PLoS	Public Library of Science
SSA	Sub Saharan Africa
STH	Soil Transmitted Helminth
TB	Tuberculosis
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
US	United States
USAID	United States Agency for International Development
WHO	World Health Organisation

## Chapter 1

### Introduction

Neglected Tropical Diseases (NTDs) are a set of infectious diseases, prevalent in developing countries, thirteen of which are described in appendix one. They are often referred to as 'poverty promoting chronic infectious diseases' as they thrive in, and deepen poverty (Neglected Tropical Disease Coalition). Despite their effects on poverty, NTDs are relatively unheard of and are neglected in a number of ways. The impact of NTDs on poverty is often overshadowed by the 'big three' tropical diseases: HIV/AIDS, tuberculosis (TB) and malaria (Manderson *et al.*, 2009). This is partly due to their high mortality rates in contrast to NTDs, which have comparably low mortality rates, but high incidences of resultant disability, disfigurement and social isolation, and thus high disease burdens.

This thesis explores the link between NTDs and poverty *via* the mechanism of assessing the choices infected individuals lose during their illness. This loss of choice is explored *via* the notion of capability deprivation, in turn derived from the capabilities approach which emphasises substantive freedoms as an alternative way of applying welfare economics (Sen, 2000). Capability deprivation results in individuals being forced into decisions, and this lack of choice acts to reduce their life satisfaction, and as a consequence can further hinder capabilities. It is widely recognised that ill health and poverty are inextricably interlinked, and the presence of one state functions to generate risk for acquiring the other. A large percentage of those living in poverty within developing countries recount that ill health was a significant factor in their decline to poverty, thus adding more conviction to the previous statement (Harper, 2004; Krishna, 2007).

Poverty has, in the past, been characterised by economic measures alone, such as Gross National Product (GNP), and Gross Domestic Product (GDP) per capita. However, reliance on economic changes when assessing ill health can be misleading, as not only is a decrease in economic productivity seen, but people's social experience is also altered. This alteration often results in a change in what people are actually able to do, that is, they lose the capability to generate certain events. The notion of capabilities thus differs from looking at what people achieve, as it incorporates the options that people possess and therefore the choices they can make (Sen, 2000). The element of choice is considered to be essential to people's ratings of life satisfaction, and a fundamental aspect of being human. Amartya Sen (2000) and Martha Nussbaum (2000) define poverty in terms of capability deprivation, as opposed to economic deprivation, where the loss of the ability to choose is

the defining aspect of poverty. Although the loss of capabilities has a close association with the loss of income, due to decreased earning opportunities, Sen stresses that economics should not be the means by which poverty is measured (Sen, 2000). The capability approach enables a more accurate portrayal of the experience of poverty in everyday life, and highlights that even wealthy people can suffer from a form of poverty if they are unable to live their life as they wish to do so (Nussbaum, 2000; Sen, 2000).

Sen's capability approach is useful for conceptualising poverty in terms of health, as ill health can result in the loss of many capabilities. NTDs have not previously been assessed in terms of capability deprivation and doing so would aid the understanding of NTDs as significant barriers to development. Moreover, the inherent social limitations and lifelong physical problems associated with NTDs effectively generate diminished choice as framed within a capabilities approach.

Many of the social problems faced by people suffering from NTDs result from stigma. In the case of NTDs, social problems contribute to a high proportion of the disease burden, and must be combated in order to retain the capabilities of infected individuals. However, minimal research has been carried out on NTDs, their stigmatising features, and their relationship with poverty, and even less on how stigma may impact on their basic capabilities. Where research has taken place, it has mainly focused on etiology, transmission mechanisms, treatments and vaccines, as opposed to research into the social propagation and social impact of NTDs. This is exemplified by Stienstra *et al* (2002) who claim that their paper is the first to discuss the social impact of Buruli Ulcer (one of the thirteen NTDs identified by the World Health Organisation (WHO)). This, together with the fact that most social research into infectious disease has focused on the big three diseases, further justifies the use of the term 'neglected'.

Nonetheless, there is an emerging interest in not only why NTDs are highly stigmatised, but how the stigmatised individual and their family are affected by this social change (Weiss, 2008). Understanding the social impact of NTDs is of great importance, as social problems and exclusion increase the likelihood that a family will enter, remain and transfer poverty, as well as causing delays in seeking health care and decreased adherence to treatment (Hotez *et al.*, 2006a; Hotez, 2008b; Weiss, 2008). This delay can cause a number of problems, including: increased transmission potential, increased likelihood of the disease becoming chronic, and an increased chance of developing a disability or disfigurement (Hotez, 2008b). NTDs therefore promote poverty by acting as a social and economic shock as well as a physical health shock.

This thesis contributes to the gap in the NTD literature by building a conceptual framework linking health, poverty and capabilities in which to place NTDs. Evaluating NTDs through the lens of the capabilities approach can help to further identify areas where current knowledge is lacking, and where future empirical research is needed. The capability approach will help to illuminate the poverty experience felt by those affected with NTDs. The focus must therefore be on increasing people's capabilities and this will inevitably lead to improved financial well-being, as people will be able to build up their own financial stability due to increased opportunities (Sen, 2000). A nation's developmental progress should therefore be measured in terms of their citizen's capabilities rather than their economic development, as capability measurements generate a more accurate portrayal of the poverty experience, and indicate the opportunities people are provided with.

The overall aim of this current research is to evaluate NTDs through the lens of the capability approach in order to help assess the poverty experience felt by those affected with NTD infection. A greater understanding of the pathways through which discrimination and stigma occur, and an enhanced appreciation of methods by which poverty is generated *via* NTDs, will ultimately help identify new methods to prevent, cure and reduce the stigma of NTDs, which would lead to a better quality of life for sufferers. This thesis aims to increase understanding and act as a key starting point for further research into these connections.

The thesis offers a particular exploration of one of the ways that the impact of NTDs on poverty may be mediated, that of stigma. I focus, in part, on the stigma of NTDs, because there is a growing literature concerning the additional impact that stigma has on the burden of disease. Many academics believe that stigma heightens the burden of disease that the NTD sufferer experiences significantly, and is therefore an area of great relevance to my thesis. It may even be considered impossible to investigate NTDs without mentioning the devastating effects of stigma.

Many NTDs have been explored in terms of biology and stigma, but without relation to the capabilities approach set out by Sen (2000). Thinking about poverty in terms of capability deprivation, as opposed to purely economic deprivation, is becoming mainstream for assessing the poverty status of individuals, households and countries. This approach can be applied to NTDs to assess their impact. However, stigma is not the sole cause of the problems resulting from NTDs as sometimes implied, and should be considered with caution (Muela Ribera *et al.*, 2009). The capabilities approach can help counter the tendency to exaggerate stigma's role in increasing the burden of disease, as it

does not focus on one capability as being more important than any others, and demands attention to other co-existing issues.

Assessing NTDs in relation to the capabilities approach will not only boost their recognition status, as the capabilities approach is relatively high profile, but may also help to improve the efficacy of control programmes *via* a better understanding of what prevents people from seeking healthcare for example. Capabilities constitute what is valued by individuals, so addressing people's lack of capabilities will drastically improve their lives, without necessarily improving their economic status or even their disease state.

### *Overall Aim*

The aim of this thesis is to explore the link between NTDs and poverty by employing an innovative method to assess the choices infected individuals lose during their illness by applying the capabilities approach. The role that stigma plays in this debilitating loss of capabilities is a major theme in this thesis and I aim to assess its contribution to the enhancement of poverty.

### *Objectives*

To address this aim, the research will:

- 1) Develop an understanding of NTDs, their neglected status and their broad contribution to global disease
- 2) Generate a conceptual framework of health, poverty and capabilities in which to place NTDs
- 3) Assess NTDs in terms of the conceptual framework, paying significant attention to the effect of stigma on people's capabilities, and consequently adding this NTD specific field into the framework
- 4) Identify gaps in the relevant literature which hinder the connection between NTDs and capability reduction and suggest future empirical research to close this gap

Table 1 states each objective and identifies specific tasks to aid completion of each. I have then considered what information will be needed in order to undertake each task and briefly summarised how this information could be sourced.

Table 1: Objectives, tasks and strategy

<i>Objectives</i>	<i>Tasks</i>	<i>Information Needed</i>	<i>How to Source this Information</i>
1) Develop an understanding of NTDs, their neglected status and their broad contribution to global disease	To review the literature in order to:	Journal articles on NTDs that look into distribution, importance, research and stigma	Search online databases, specific journals, poverty institutes and the library catalogue
	determine NTDs global distribution and how this affects their international 'importance'	Maps identifying geographical location	Search organisations such as the WHO to find distribution information
	understand the various reasons why NTDs are neglected	Theoretical literature on stigma	
2) Generate a conceptual framework of health, poverty and capabilities in which to place NTDs	assess the stigma attributed to NTDs and why		
	To develop a general understanding of the three literatures (health, poverty and capabilities)	Journal articles looking into health and poverty	Search online databases, specific journals, poverty institutes and the library catalogue
	To detail the relationship between health and poverty	Theoretical literature on the capability approach	
	To uncover any controversies		
	To justify the use of the capabilities approach		
3) Assess NTDs in terms of the conceptual framework, paying significant attention to the effect of stigma on peoples capabilities, and consequently adding this NTD specific field into the framework	To establish how capabilities can be applied to health and poverty		
	To assess NTDs in terms of the conceptual model developed	Detailed information on all 13 NTDs in order to choose three to concentrate on	Search online databases, specific journals, poverty institutes and the library catalogue
	To select three NTDs and justify this selection	Journal articles that look specifically at the three chosen NTDs	Search organisations such as the WHO to find distribution information
4) Identify gaps in the relevant literature which hinder the connection between NTDs and capability reduction and suggest future empirical research to close this gap	To compare them in terms of how they affect people capability sets		
	To justify the foundation created by the conceptual framework	Need all previous literatures and any examples of other diseases that have been analysed in terms of poverty and capabilities	Search online databases, specific journals, poverty institutes and the library catalogue using different search criteria such as HIV/AIDS
	To identify techniques for further empirical research		

## *Research Methods*

In the process of creating this thesis, I will build a conceptual framework in which to place NTDs. The thesis will conclude with research questions for future empirical research. My research is based on examining and analysing existing data, mainly in the form of journal articles.

The ‘methods and rules’ used to generate a literature review allow the controlled collection and analysis of literature (Hart, 1998:28). I have largely drawn on the traditional method of creating a literature review rather than the systematic approach. The ideas taken from the traditional approach are those of summarising a body of literature (or literatures in my case), whilst critiquing sources and drawing conclusions from them (Cronin *et al.*, 2008). I used an initial literature search to help refine and adjust my research question, leaving it flexible to new ideas, angles and serendipity. I did not begin with a precise and definitive research question, but let it evolve as I read around the selected topics.

Literature was sourced from:

- Online databases
  - Google Scholar, PubMed and Science Direct
- Specific online journals
  - PLoS Neglected Tropical Diseases
  - Emerging Infectious Diseases
  - Tropical Medicine and International Health
- Poverty Institutes
  - Brooks World Poverty Institute, Manchester
  - Chronic Poverty Research Centre
- Publications
  - WHO
- The library catalogue
- The references of key journals

By entering combinations of key words such as: ‘Neglected Tropical Diseases’, ‘Leishmaniasis’, ‘Trachoma’, ‘Trypanosomiasis’, ‘stigma’, ‘social impact’, ‘discrimination’,

'exclusion', 'health', 'well-being' and 'capabilities' into searches I gathered a large amount of literature. Using synonyms of words was important in order to gather all the papers possible within the field. This then led to a snowballing effect whereby I took advantage of the 'related articles' panel, on the PubMed database, for example, as well as scanning key bibliographies for additional useful references. I only considered papers written or translated into English; this may be a limitation as many of the countries I am looking at are not English speaking, so some un-translated papers may be missed.

### *Organisation of the thesis*

The thesis comprises five chapters. This first chapter has outlined the basic ideas behind the thesis, on which the subsequent chapters will be built.

Chapter two consists of an account of the controversies involved in defining NTDs and a justification of the definition I have chosen to use in my thesis. This is followed by a detailed explanation of why NTDs are neglected and how this neglect is represented.

Chapter three firstly looks into the relationship between poverty and health, it then goes on to explore the concept of the capabilities approach. A conceptual framework is developed which combines these three literature bases before an explanation of the model is provided.

Chapter four initially details the concept of health related stigma. This concept is utilised, along with other ideas, to place NTDs into the conceptual framework that was developed in the previous chapter. Three NTDs are then chosen, and assessed in terms of the conceptual model.

Chapter five concludes by identifying the gaps in the literature and establishes ways in which this research could be carried out. It also highlights what impact this future research may have on the way NTDs are looked at by both academics in the field and the lay public.

### *Conclusion*

This chapter has summarised the basis of my thesis and outlined the main gap in the literature I aim to begin to close. The concepts I have outlined here will form the basis of my arguments, and help me develop my own conceptual framework to create a different

lens through which to look at NTDs. The chapter has outlined the benefits that are possible from combining NTDs with the capabilities approach, and explained the contribution this thesis aims to make. This contribution will be at the forefront of current research as NTDs and their associated stigma will be assessed in terms of the capability approach, a paradigm never previously explored in relation to NTDs. This will inevitably strengthen the connection between NTDs and poverty as previous research outlining the link between economic poverty and NTDs could be combined with this new approach detailing the link between NTDs and capability deprivation poverty. Combining these two aspects will give a more comprehensive view of the problems caused by NTDs and therefore help determine how best to alleviate both the prevalence of NTDs and their debilitating social effects. The capabilities approach itself is both current and high profile, and using this approach in combination with NTDs may not only aid understanding but also generate advocacy and awareness of NTDs.

The literature used herein will be critically analysed and where appropriate further empirical work will be suggested in order to clarify the arguments presented.

This chapter is suggesting an alternative way in which to look at, and assess, the problems caused by NTDs, with the aim of showing that people's lives can be enhanced with the introduction of secure basic capabilities.

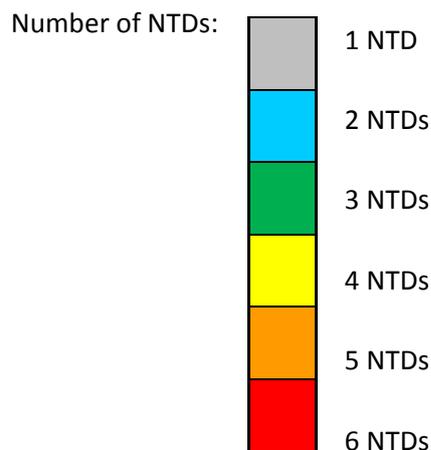
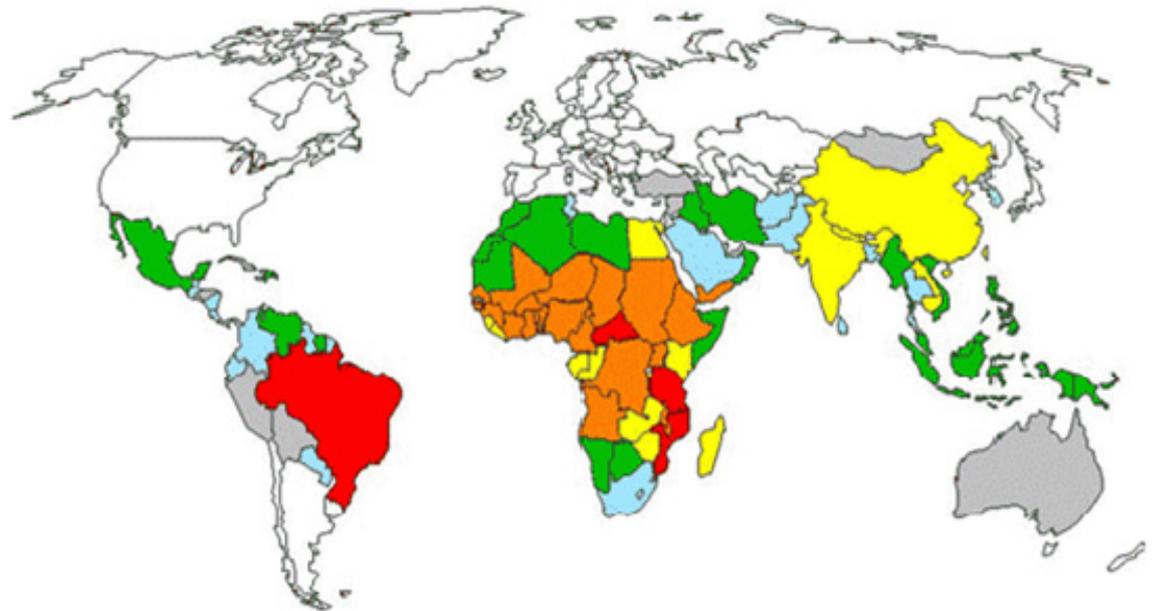
## Chapter 2

### Neglected Tropical Diseases

Neglected Tropical Diseases (NTDs) are a set of infectious diseases that are prevalent in tropical developing countries. Figure 1 shows the location of these NTDs on a world scale, as well as the number of NTDs within each affected country. The map clearly shows that the world's poorest nations suffer the greatest concentration of NTDs. NTDs are therefore often referred to as 'poverty promoting chronic infectious diseases' due to their ability to both thrive in poverty, and deepen it (Neglected Tropical Disease Coalition), as a result of their negative impacts on economic productivity and the social dynamics of communities. However, it can be difficult to unpick the cycle linking poverty and NTDs, as they are heavily intertwined and mutually reinforcing. I therefore aim to disentangle the relationship in stages.

This chapter will explore the importance of NTDs, and how controlling, and eliminating them, may help to lessen the burden of poverty. Determining how and why NTDs are neglected is an important step toward understanding how this set of diseases may impact on people's basic capabilities. This will be the first step towards assessing NTDs through the lens of the capabilities approach in order to evaluate their impact on poverty. This chapter firstly explains the controversies involved when defining NTDs in order to justify the definition I have chosen to employ in my thesis. Secondly, the advantages and disadvantages of grouping these diseases, under the umbrella term NTDs are discussed, with the aim of defending the justification for their grouping, and therefore their study as a group. Lastly, an explanation of why NTDs are termed neglected is presented, which includes neglect in terms of location and finances, the Millennium Development Goals (MDGs), disease burden measurements, and finally in terms of the media.

Figure 1: Geographic Overlap of endemic Neglected Tropical Diseases Source: Molyneux *et al* 2005



*Definitions:*

“There is no standard global definition of neglected diseases” (Caines, 2004:4) which can cause problems when outlining which diseases come under the NTD umbrella term, and thus their contribution to the collective burden. Being unable to determine a collective burden will cause difficulty, as it is this measure that is often used to press for political action to define new policy in favour of deploying resources to NTD control. Without a specified definition it will be difficult to rally support for, and confidence in, NTD control programmes. The umbrella term Neglected Tropical Disease is used to promote comparable, but varying agendas, depending on which definition is utilised in the study (Liese *et al.*, 2010).

According to Liese *et al* (2010) there are two ways to formulate a definition of NTDs. The first type of definition adopts neglect as the central point, whilst the other defines NTDs in terms of the features they share with one another, and their correlation with poverty (Liese *et al.*, 2010). Originally, construing NTDs in terms of neglect was the predominant definition type, but, as NTDs have gained further recognition, funding and international priority, the emphasis has moved toward the second type of definition, that of the relationship with poverty and the shared features of NTDs. For example, the UN bases its work on the WHO definition (Caines, 2004; Hunt, 2003), that NTDs “affect almost exclusively poor and powerless people living in rural parts of low-income countries” (WHO, 2003b:106). This mostly overlooks the problem of neglect, as the notion of neglect is only inferred from the mention that diseases affect the poor in rural settings, as the definition instead focuses on the relationship with poverty and location. Caines (2004:9), on the other hand, states that “these are diseases affecting principally poor people in poor countries, for which health interventions – and research and development – are regarded as inadequate to the need”. This, unlike the definition used by the UN, incorporates both the issue of neglect and the link to poverty. It is therefore important to combine both definition types to define NTDs in order to shortlist which diseases should be focused on in programmes and policies. For example, malaria, even though one of the big three diseases, could be categorised as an NTD on the basis of its distribution within predominantly developing countries and the fact it principally affects “poor and powerless people” (WHO, 2003b:106). Using only the first definition type, which excludes the neglected aspect of NTDs, malaria would be considered an NTD. Malaria is, however, not an NTD due to the large amount of investment into its control, its international recognition and awareness, and its high priority within global public health agenda. Malaria is mentioned explicitly within the Millennium Development Goals as one of two main diseases to combat, it does therefore not fit the definition of an NTD if neglect was taken into account (UN). The definition, therefore, requires the aspect of neglect in order to filter out diseases such as malaria.

These differing approaches to defining NTDs denote that there is no singular accepted definition, but many related, yet different, definitions (Liese and Schubert, 2009). Table 2 outlines the diverging sets of NTDs that are used for differing purposes, and thus when talking about NTDs it is essential to specify which set of diseases are being taken into account, and for what purpose.

Table 2 highlights the variety that can occur between NTD lists as a result of their varying goals. Lists range from including 7 to 37 diseases, for example, Molyneux includes seven NTDs, three soil transmitted helminths (STHs) (hookworm, ascariasis and trichuriasis), lymphatic filariasis (LF), schistosomiasis, trachoma and onchocerciasis. These diseases are similar in terms of geographical location, prevalence and could potentially be controlled simultaneously (Molyneux *et al.*, 2005). The aim of this list is to identify the NTDs that can be controlled *via* an integrated rapid impact package; he does not claim that the list is exhaustive, but does maintain that these seven diseases should be of top priority due to their possible integrated control. The ease of control stems from the fact that all seven can be targeted by four drugs; albendazole/ mebendazole, praziquantell, ivermectin/ diethylcarbamazine and azithronmycin (Hotez *et al.*, 2009). This type of categorisation is therefore very useful when it comes to identifying control methods for NTDs, as it can highlight the ways in which control can be integrated and thus how to enhance the economic viability of their control. A brief evaluation of the integrated approach is provided within the next sub section.

Table 2: List of NTDs from: Public Library of Sciences Neglected Tropical Diseases - *PLoS NTDs* (PLoS), World Health Organisation - *WHO* (WHO, 2007), Global Network for Neglected Tropical Diseases – *GNNTDs* (GNNTDs), Neglected Tropical Disease Program USAID – *USAID* (NTDCP), Peter Hotez and colleagues – *Hotez* (Hotez *et al.*, 2009; Hotez *et al.*, 2007; Hotez *et al.*, 2006c) and David Molyneux – *Molyneux* (GNNTDs; Molyneux *et al.*, 2005)

<i>Disease</i>	<i>PLoS NTDs</i>	<i>WHO</i>	<i>GNNTDs</i>	<i>USAID</i>	<i>Hotez</i>	<i>Molyneux</i>
Amoebiasis						
Balantidiasis						
Chagas Disease						
Giardiasis						
Human African Trypanosomiasis						
Leishmaniasis						
Taeniasis-cysticercosis						
Dracunculiasis						
Echinococcosis						
Food-borne Trematodiasis						
Loiasis						
Lymphatic Filariasis						
Onchocerciasis						
Schistosomiasis					**	
Soil-transmitted Helminthiasis			*		*	*
Toxocariasis and other Larve Migrans						
Dengue						
Japanese Encephalitis						
Jungle Yellow Fever						
Other Arboviral Infections						
Rabies						
Rift Vally Fever						
Viral Haemorrhagic Fevers						
Bartonella						
Bovine Tuberculosis in Human Beings						
Buruli Ulcer						
Cholera						
Enteric Pathogens						
Leprosy						
Leptospirosis						
Relapsing Fever						
Trachoma						
Treponematoses						
Mycetoma						
Paracoccidiomycosis						
Scabies						
Myiasis						
Yaws						
Anthrax						
Brucellosis						
Anthroponotic Leishmaniasis						

The dark green boxes represent the diseases on the NTD lists for each organisation. The WHO's categorisation method differentiates 'tool ready diseases' (dark green) and 'tool deficient diseases' (light green) (WHO, 2007).

\* = States that the organisation has specified the three STHs (hookworm, trichuriasis and ascariasis).

\*\* = Specifies the two forms of schistosomiasis (urinary and hepatobiliary)

The WHO identifies 'tool ready' diseases, i.e. diseases which have existing, inexpensive, effective and easy to administer drugs and vaccines, where expansion rather than developmental research is the priority (WHO, 2007). This is in contrast to 'tool deficient' diseases, where diagnosis, medicines and other tools, such as pesticides, are expensive and can be difficult to administer and maintain. This is well characterised by Leishmaniasis treatment, which involves a long course of toxic injections incurring high rates of resistance, which can force the use of more toxic treatments and produce serious side-effects. Side effects include the development of diabetes, chemical pancreatitis and cardiovascular toxicity (WHO). Some Leishmaniasis treatments require a hospital stay of 15 to 30 days, where the patient must be monitored closely whilst being treated intravenously. This is inevitably very costly to the country and the patients, and something which many affected countries cannot administer on a scale large enough to treat all infected people (WHO, 2010c). This is why Leishmaniasis is placed in the tool deficient category, as it is in need of having its treatment further researched and simplified to make it cheaper and easier to administer, maybe even at a community level. Again, the WHO does not claim that this list is exhaustive, and they emphasise that there are significant regional and national variations so each region is encouraged to make its own specific list which includes diseases of national importance. For example, the European list includes tularaemia, a bacterial zoonotic infection which usually manifests as lesions and is spread by animals such as rabbits. Differentiating between tool ready and tool deficient is very useful, as not only does it highlight the 'most neglected' diseases in terms of medical technology, but it also prioritises diseases in terms of regional significance.

Conversely, Hotez (2009; 2007; 2006c) focuses on thirteen NTDs (Appendix One), which he and his colleagues deem the most prevalent of the neglected diseases. Focusing on these thirteen NTDs, allows them to create collective statistics. The cumulative mortality of these NTDs is circa 534,000 deaths annually, and they account for, by some estimates, 56.6 million disability adjusted life years (DALYs) (only 12/13 diseases are included as Buruli Ulcer has an undetermined DALY measurement) (Hotez *et al.*, 2007). The DALY measurement is a quantification of the disease burden in terms of the number of years lost

to ill health or premature death and will be discussed further when considering neglect in terms of inaccurate disease burden measurements. The DALY estimations are, however, merely approximations resultant of the hypothesis that the DALY values for NTDs are grossly underestimated, and therefore require substantial evidence to clarify them (King and Bertino, 2008). As Hotez and colleagues have used the most prevalent neglected diseases in their list and generate many collective statistics, I have decided to focus my studies of NTDs on their list. Hotez's work often revolves around the link between NTDs and poverty, which is an important theme in my thesis and thus further justifies my use of his classification of the most important NTDs. The high prevalence of the diseases listed in Hotez's thirteen also means that there is likely to be sufficient literature available in order to compile my thesis. I have decided against using the PLoS NTDs and the WHO's expansive lists of NTDs due to the vast number of diseases listed, the large range between the disease prevalences, and the possibility that literature on the less prevalent diseases will be sparse.

The differing agendas which result in the compiling of alternative sets of diseases are often similar and related. Many people want to connect diseases of the developed world to the NTDs of the tropics (Hotez, 2009a), in order to rally more enthusiasm for their control. This comparison requires all-encompassing country specific NTD lists in order to draw on the similarities. For example, Chagas disease is endemic in deprived Hispanic populations living within the US, and is thought to be dependent on poverty conditions (as opposed to immigration). The presence of an NTD in such a wealthy country should warrant more research and funding from the US into diagnosis, vaccines, cures and addressing the apparent social problems within their own country (Hotez, 2009a). These technologies, and lessons generated from the developed world, could then be transferred to developing countries where Chagas is also endemic. The extensive lists contrast the shorter lists developed by USAID and Molyneux (2005), which aim to show the promise of the integrated approach and preventative chemotherapy, a method of control which involves mass drug administration (MDA).

### *Why are NTDs grouped?*

A major question when it comes to NTDs, is why have these very diverse diseases, including three bacterial infections, eight helminth infections and two protozoan infections (Hotez *et al.*, 2007; Liese and Schubert, 2009; Reddy *et al.*, 2007) been grouped together?

The primary reason for grouping NTDs is to generate recognition and advocacy from governments and organisations to support funding, research and awareness campaigns. The concept of NTDs was therefore developed, in order to rally support for investment in new drugs (Alvar *et al.*, 2006). In this section I aim to present the evidence for and against the umbrella term and ultimately justify the grouping of NTDs.

It can be perceived as illogical to group these very diverse diseases; however the shared features of these diseases in terms of their impact on the infected individual, community and the country as a whole are comparable. Molyneux (2008:509) considers all NTDs true 'allies of impoverishment', and therefore they are often collectively referred to as 'poverty promoting chronic infectious diseases' (Neglected Tropical Diseases Coalition). Many NTDs result in permanent physical disability, such as blindness (trachoma, onchocerciasis), disfigurement and scarring (Leishmaniasis, leprosy, Buruli ulcer) and elephantiasis and hydrocele (lymphatic filariasis). And others result in impaired growth and cognition in children (STHs) and fatigue (schistosomiasis, human African Trypanosomiasis). Although diverse, these disabilities create very similar social, economic, political and mental problems within a family household.

HAT transmission mainly occurs in rural areas of Africa, where the tsetse fly thrives, often concentrated around animal reservoirs (Fèvre *et al.*, 2008; Stich *et al.*, 2002). Like HAT, many NTDs prosper in rural locations and are therefore likely to affect agricultural production, a profession which requires good physical health. The first stage of HAT, occurs when the trypanosomes (the infective agents) multiply in the blood and lymphatic system, and induces fatigue, depression, fevers, headaches, anaemia, tachycardia and a rash (Cox, 1996). When the trypanosomes cross the blood brain barrier to move the disease to the second stage, motor weakness, sensory problems, sleep disturbances and deterioration to coma are observed (Fèvre *et al.*, 2008). These symptoms directly affect livestock management, and both the infected person and their carer are prevented from working, meaning less physical labour is available. Secondary income earning may also be compromised thus reducing income diversity, a result which will render the family vulnerable to subsequent shocks. Education may also be jeopardised, as children are removed from schooling to either to care for the individual, tend to the house or to provide income for the family (Swallow, 2000). A HAT outbreak in the rural community of Burma (Democratic Republic of Congo) from 2000-2002 implicated 21% of households (57 patients) (Lutumba *et al.*, 2007). It was discovered that the cost to each household represented five months income for each household's normal income. This finding holds

for all NTDs, as most NTDs affect poor rural communities that are situated far from health services, thus making treatment costly and time consuming which has repercussions in terms of household compromises (Hotez and Kamath, 2009; Hotez, 2008a).

Stigma produces much of the social problems associated with NTDs, whether it be because of physical disfiguration (Hotez, 2008b), the association with the supernatural, or the diseases relationship with poverty (Robays *et al.*, 2007; Stienstra *et al.*, 2002). In the instance of HAT, the loss of respect due to unusual and out of character actions (aggression, excessive talking and change in personality) predisposes stigma which often remains after an individual has been successfully treated. Not only does the unusual behaviour contribute to a decrease in employment opportunities as a result of social isolation, as well as the patient's own shame and hiding, but it also increases the burden of disease and effects the seeking of treatment, often resulting in a delay (Hotez, 2008a; Stienstra *et al.*, 2002). This is predicted to be due to a lack of understanding of the disease, its transmission and the shortage of suitable treatments (Stienstra *et al.*, 2002). The stigma attributed to NTDs can extend after successful treatment, this can be due to long-lasting visible disability, poverty or the perception that an individual is tainted (Cross, 2006). The on-going stigma associated with HAT, results from the loss of normal mental functioning during the illness, meaning they are seen as untrustworthy and feared as they "came back", which refers to the regained mental functioning (Robays *et al.*, 2007:293). A decreased social network can lead to the inability to draw on community resources to help the household recover from shocks. This social isolation is worsened by the fact that many are subsequently unable to marry or retain care of their own children as a direct result of stigma (Hotez, 2008a). This generates vulnerability and in Uganda can increase the prospect of unfavourable marriages, where the individual may be exploited (Lwanga-Ntale, 2003).

Stigma can also affect the other household members *via*, what can be termed, courtesy stigma. This can cause the recipient to suffer from social problems that are very similar to those faced by the sick or impaired individual themselves. For example, the siblings may also be unable to marry as they too are seen as unclean or tainted due to their relationship with the disabled family member (Lwanga-Ntale, 2003; Yeo, 2001).

The problems faced by HAT and other NTDs demonstrate the shared features of NTDs, which facilitate their persistence through poverty (WHO, 2006). If we consider the two forms of NTD definition, we can deduce that NTDs are grouped on the basis of their neglect, their poverty promotion and their shared features. Therefore, the advantage of

grouping NTDs is that advocacy and collective burden measurements carry more weight and raise the profile of NTDs both nationally and internationally (WHO, 2007). However, advocacy can also be complicated by the fact that NTDs are a collection of diseases, and so the message conveyed may be confusing and misleading (Liese *et al.*, 2010). Although NTDs are diverse in their symptoms, they are all heavily and extensively intertwined with poverty and thus the key to controlling or eliminating each is the same – scale up existing tools, replace inadequate tools, improve cost effectiveness, and combat stigma (WHO, 2007). For this reason, advocacy has tended to concentrate on their shared connection with poverty and the fact that many can be incorporated into an integrated approach, as opposed to focusing on the details of each disease and what more needs to be done to combat them separately (Liese *et al.*, 2010).

Efforts to exploit these shared features *via* the integration of selected control activities will generate more efficient use of economic resources. In Berlin and Geneva (2004 and 2005 respectively), the WHO and its partners developed a framework which moves away from disease centred approaches and toward integrated approaches (WHO, 2006). These shared features and the integration of control have attracted attention, with the Bill and Melinda Gates Foundation giving a series of grants to expand the integrated approach (Lammie *et al.*, 2006; Liese *et al.*, 2010). This is precisely the effect that the term NTD aimed to generate, and therefore even though controversial, the grouping of these diseases has been a success.

#### Evaluation of the integrated approach:

In this section I aim to provide a brief overview of the successes and failings of the integrated approach, in order to gauge whether the fact that some NTDs can be tackled simultaneously in an integrated approach, can help further justify the grouping of NTDs. Uganda is endemic for six out of the seven NTDs (with the exception of trachoma) identified by Molyneux in table 2 as diseases that could potentially be controlled *via* an integrated approach (Kolaczinski, 2006). Individual control programmes for these six NTDs have been shown to be successful, but in order to increase financial viability and coverage, an integrated approach has been piloted and implemented in some areas (Kolaczinski, 2006; Kolaczinski *et al.*, 2007). Integration of disease programmes has recently received a plethora of attention, as it is seen as cost effective, practical and realistic, so is intuitively appealing (Kolaczinski *et al.*, 2007). Co-implementation of disease control programmes claims to save up to 47% on costs, making it very economically inviting

(Molyneux, 2010). As well as economic viability, integration provides improved quality of care, strengthened vector control and enriched surveillance and monitoring systems. Nevertheless, there are still many challenges including the 'geography, epidemiology and ecology of different NTDs', and therefore their suitability to fit into an integrated disease control package (Kolaczinski *et al.*, 2007:485). The advantages and disadvantages of existing single disease programmes must also be considered, as a single disease system that is already economically viable and efficient may not benefit from integration with other programmes (Kolaczinski *et al.*, 2007).

Even with the great prospects of integrated NTD control, there have been some failures. For example, it was found that community drug distributors in Uganda found it hard to integrate onchocerciasis control in addition to their previous commitments for other disease control programmes (Kolaczinski, 2006). This difficulty is likely due to the varying guidelines given by different disease programmes (Richards *et al.*, 2006). Nigeria also faced problems, as the mapping of schistosomiasis was restricted by strict guidelines, which made it complicated to map, and thus hindered its integration with two already successful disease programmes, LF and onchocerciasis (Richards *et al.*, 2006). Saying this, when integrating other health measures with an already established ivermectin delivery programme in a multi-country study in Africa, their success was greater than if they were implemented alone. The study trialled the integration of four interventions, vitamin A supplementation, insecticide treated bed net distribution, directly observed treatment of TB (DOTS) and home treatment of malaria (WHO-TDR, 2008). The number of interventions in each area was built up gradually, until all five were running in conjunction after three years, and this was compared to control areas, where programmes were delivered separately (WHO-TDR, 2008). Integration proved successful with the exception of DOTS, which was not enhanced but equally, was not hindered. The collaboration was very cost effective, as no additional funding was provided, but a higher coverage was achieved. Despite these successes, there was a slight community loss in some cases, as community health volunteers had to donate more time to the integrated programme and therefore had less time to partake in other commercial or social activities (WHO-TDR, 2008). This problem is, however, likely to resolve as health workers become practised in integrated control as in the multi-country study, it was found that with training and adequate support, community workers could indeed implement interventions effectively and efficiently, and were keen and willing to continue the integrated approach (WHO-TDR, 2008). In order to gauge whether the success of the integrated programmes in Uganda and Nigeria detailed

previously will increase with practice and training they will have to be continually assessed over a number of years. The lessons learned during these studies could then be incorporated into future integrated approach projects.

In central Nigeria, successful integration of bed net distribution with mass drug administration (MDA) resulted in an elevated ownership, and use of bed nets, for protection against both malaria and LF, without compromising the efficacy of the MDA programme which was already in place (Blackburn *et al.*, 2006). Another success occurred when two programmes, LF elimination and schistosomiasis control, were integrated with an established onchocerciasis programme, again in central Nigeria (Hopkins *et al.*, 2002). It was thought that the initiative to eliminate LF could effectively exploit the existing structure of the onchocerciasis programme (African Programme for Onchocerciasis Control, APOC), as well as helping to make APOC more economically sustainable, increasing awareness of the programme (Hopkins *et al.*, 2002). Additional benefits occur from the use of the combination of drugs, as other STHs can be treated unknowingly, or their intensity reduced, which will have positive health effects for the community (Hopkins *et al.*, 2002).

Despite successes, Liese *et al* (2010) claim that calls for the integration of control may not be feasible, as diseases differ in origin, geographic coverage, epidemiological goals, funding and governance, meaning that integration will be challenging. This, however, does not mean that NTDs should not be grouped. For even though integration is challenging, some disease programmes with overlapping locations, similar drug distribution methods and epidemiological goals can be integrated, and many more have the potential for integration, especially as new, simpler drugs are being created. This research would not be possible without the funding generated from the promotion of NTDs produced by grouping them. In conclusion, even if some believe that NTDs do not deserve to be grouped, this grouping has generated funding that can help develop more treatment and prevention schemes, making them easier to integrate, and thus further justifying the grouping of these diseases.

#### *Why NTDs are termed 'neglected'*

A problem arises as to what the term 'neglect' means in the context of NTDs. It seems obvious, in terms of the definitions above, that neglect materialises as inadequate health interventions, research and development. However, NTDs are 'neglected' in many

other ways, namely: in terms of finances, within the MDGs, in terms of the DALY measurement, within the media and in terms of recognition and awareness. These sources of neglect are outline below.

### *Neglect in terms of location and finances*

In the instance of geographical location, neglect refers to NTDs' disproportionate prevalence in developing countries, in comparison to wealthier nations (as seen in figure 1). Hence, this is also why the term tropical is used, as it refers to countries which are mainly located between the tropics. These countries happen to include the world's poorest countries and NTDs act as an additional and unnecessary extension to the diseases suffered throughout the world (Chitsulo, 2005). Saying this, some countries where NTDs are endemic offer little in the way of funding towards their research. This is partly due to the lack of political voice the poor marginalised communities possess, but where NTDs flourish (Liese *et al.*, 2010). Governments are therefore not under threat or under pressure to assist in the development of control programmes for these diseases. As well as the lack of pressure, a lack of economic resource is also blamed for the neglect of NTDs within countries with high a prevalence.

The low mortality rates of NTDs mean they have low recognition status among wealthy nations. This, together with the fact that travellers to tropical countries face a low risk of contracting an NTD, decreases the market for NTD research and development within developed countries (Hotez *et al.*, 2006a; WHO, 2006). This is problematic, as these wealthier nations do have the economic and technological resources to help treat and prevent these diseases in developing countries (Boutayeb, 2007). Many pharmaceutical companies feel that, as NTDs occur in countries unable to buy (or buy at full price) the drugs they develop, they are not a feasible and worthy investment (Chitsulo, 2005). The low purchasing power of endemic countries generates a high level of risk for researchers and developers, who are mainly profit driven (Trouiller and Olliaro, 1999). There is also the problem of the information gap, due to the discrepancies in what constitutes an NTD, there is a low consensus on which diseases need funding (Moran *et al.*, 2009). Therefore, donors willing to provide funding are ill informed, and can miss opportunities to invest in diseases which really need the money. This means that "research funding is highly concentrated and has little correlation with burden, as measured in DALYs" (Moran *et al.*, 2009:145).The gap

has been partially closed by the NTD list dividing tool ready and tool deficient NTDs, but more needs to be done in order to secure funding for NTDs (WHO, 2007).

Considering the burdens in terms of DALYs of HIV/AIDS (84.5 million), malaria (46.5 million), TB (34.7 million) and NTDs (between 19.4 and 56.6 million (Hotez *et al.*, 2009)), Official Development Assistance (ODA) for health does not reflect this burden (Liese and Schubert, 2009). ODA is a statistic assembled by The Development Assistance Committee (DAC) to measure funding given to certain aspects of welfare. Health specific ODA calculations are compared to the DALYs measures and presented in table 3.

Table 3: Calculations for % of health specific ODA allocated to the big three diseases and NTDs compared to the relative percentage of DALYs Source: Liese and Schubert (2009)

Calculations for % of ODA allocated compared to the relative percentage of DALYs						
	% ODA	% for NTDs, HIV/AIDS, Malaria and TB only	DALYs (millions)- lower NTD estimate	DALYs %	DALYs (millions) – higher NTD estimate	DALYs %
<b>NTDs</b>	<b>0.6</b>	<b>1.4056</b>	<b>19.4</b>	<b>10.4808</b>	<b>56.6</b>	<b>25.4611</b>
HIV/AIDS	36.3	85.0117	84.5	45.6510	84.5	38.0117
Malaria	3.6	8.4309	46.5	25.1216	46.5	20.4678
TB	2.2	5.1522	34.7	18.7466	34.7	15.6095
Other <sup>1</sup>	57.3	-	-	-	-	-

<sup>1</sup> Includes infectious disease control, health sector development and population policies (family planning, sexual health and reproductive health care). This is included in the table to show what the other health specific ODA is spent on but the main table focuses on comparing the big three diseases and NTDs.

Table 3 clearly displays the allocations discrepancies between NTDs, HIV/AIDS, malaria and TB. Take for example the highlighted NTD row, even though the DALY percentages are between 10% and 25% of the burden of the four diseases, less than 1.5% of health ODA (when only taking into account the four specified categories) is allocated to NTDs. The overall ODA funding increased from 8,731 million in 2003, to 14,377 million in 2007. This is an average annual growth rate of 10.5%. Individually NTDs, HIV/AIDS, TB and

malaria have had average annual growth rates of 9.9%, 18.0%, 20.3% and 29.6% respectively (Liese and Schubert, 2009). The additional funding has clearly not been distributed evenly, thus showing that NTDs are neglected in terms of funding allocations. The funding allocation may in fact be smaller than calculated, as the NTD figures 'represent the upper bound for possible NTD control ODA' as they also comprise commitments that include both non-NTD and NTD control and those that have an unspecified purpose (Liese and Schubert, 2009:143). These statistics undoubtedly show that in terms of DALYs, NTDs are worthy of a greater share of the money put into infectious disease research, development and implementation. It is becoming increasingly necessary to allocate resources to treatments with the best value for money (Doran *et al.*, 2010). Many NTD treatments would already fit this criterion, such as STHs, which simply require an annual inexpensive pill.

#### *Neglect in terms of the MDGs*

Within the Millennium Development Goals (MDGs), a set of eight goals designed to combat poverty, the NTDs were only heedlessly referred to in the collective 'other diseases' in MDG 6 ('Combat HIV/AIDS, malaria and other diseases' (WHO, 2003a)), reiterating their perceived low importance (Boutayeb, 2007). This has led to these 'other diseases' being overlooked in favour of the named diseases, HIV/AIDS and malaria. However, many consider the targets of MDG 6 unachievable if the focus remains solely on the well-known diseases and if the NTDs are ignored by policy makers (Molyneux, 2008). Fenwick *et al* (2005) go a step further, and claim that 7 out of the 8 MDGs need to involve the control of NTDs in order to reach their targets. Molyneux (2008) believes that the MDGs' success relies upon a 're-evaluation of what can be done with the tools available now' and those tools are the simple, efficient and cost-effective NTD treatments and eradication plans of tool ready diseases.

For example, in the case of dracunculiasis, otherwise known as guinea worm, the infection can be prevented easily without anthelmintic drugs or vaccines, but *via* simple measures such as filtering drinking water, applying larvicide to ponds, educating communities and encouraging them not to enter sources of drinking water whilst infected, or alternatively, providing wells (Barry, 2007; Hopkins, 1998). In Uganda, elderly men are employed as pond caretakers to ensure that people with emerging worms do not enter the water and release eggs into the water (Barry, 2007). Many national programmes used

education rather than providing wells, as it is cheaper because local volunteers were hired, educated and served to diagnose, report and share their knowledge with infected people, which halted the spread of the larva (Hopkins, 1998). When comparing the cost of the eradication campaign to the benefits of reduced dracunculiasis prevalence in 1997, the economic rate of return ranged from 11% to 44%, depending on whether the average length of economic incapacitation was 4 or 6 weeks respectively (Kim *et al.*, 1997). This provides evidence that NTDs do adversely affect economic development, and that their control can strengthen the economy.

It may therefore be easier to reduce disease prevalence in the poorest billion people by concentrating on NTDs, rather than the harder to tackle diseases such as HIV/AIDS (Molyneux, 2008). NTD treatments are often so cheap that no additional monetary resources need be found, just a minor reworking of the existing financing system (Molyneux, 2008). Molyneux (2008) feels that policy makers are ignoring the ‘low hanging fruit’ by not putting more efforts into combating NTDs. Policy makers are therefore encouraged to rapidly implement these ‘quick fix’ programmes in poverty reduction schemes (Fenwick *et al.*, 2005). NTD control is an easy target, it can be cheaply and effectively tackled, but breed huge improvements in the lives of the affected populations. The difference in cost for the big three and NTDs is presented in the radar plots (Figure 2), which assess the varying costs between countries as well as between diseases.

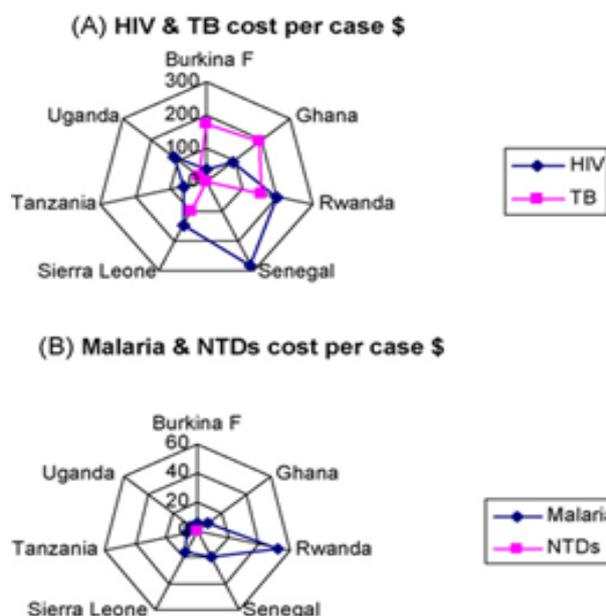


Figure 2: Plots of costs per case over 3-year funding period of (A) HIV and tuberculosis (TB) and (B) malaria and neglected tropical diseases

Source: Molyneux 2008

The cost effectiveness of each NTD in terms of \$ per DALY averted, are compared to the big three diseases in figure 3.

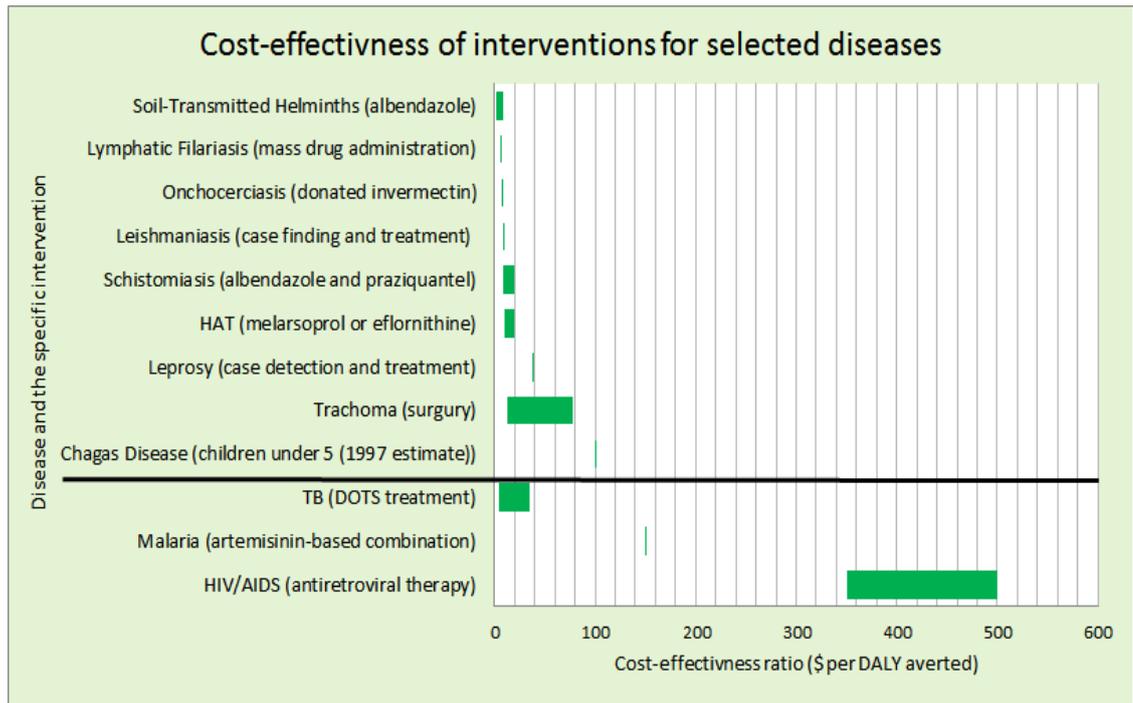


Figure 3: The cost effectiveness of interventions for NTDs and the big three diseases in developing countries

Source: Data from (Baltussen *et al.*, 2005; Laxminarayan *et al.*, 2006; Liese and Schubert, 2009; Ottesen *et al.*, 2008; Remme, 2006).

Problems with figure 3:

The graph created in figure 3 has a few inherent problems. Firstly, I have chosen to focus on one cost – usually that of the drug treatments. Although useful, other costs are involved, especially in HIV/AIDS prevention and control. For example: mother to child transmission prevention, opportunistic infection treatment, blood and needle safety, condom promotion and distribution, counselling, and education programmes for high risk groups (Laxminarayan *et al.*, 2006). This may lead to an overestimated cost-effectiveness ratio and disease control may in fact be much less cost effective. Soil-transmitted helminths on the other hand have very little added control and prevention programmes with simple, effective treatments that can be administered at school together with basic hygiene education.

It will always of course be difficult to directly compare the cost-effectiveness of disease control due to the varying nature of different diseases and therefore different methods of control; for example trachoma surgery is used in the graph as it is the most common cure as opposed to a drug therapy.

Another problem may be the number of cases. NTDs collectively create a burden that rivals any one of the big three (Hotez *et al.*, 2007) but individually they have a much a smaller burden. This therefore may affect the costs of drug production (a relatively small amount may be more costly per person than it would be if the burden was much higher).

Not all the data comes from the same source, which may create differences in the time of the data collection. For example, the information on chagas disease was collected in 1997, which is now out of date.

Saying this, this simple graph does illustrate the relatively low the costs involved in controlling NTDs, compared to the cost of treatments for the big three.

Figures 2 and 3 clearly show that NTD treatment is generally much cheaper than all three of the big diseases, with soil-transmitted helminths being the cheapest intervention in terms of DALY averted cost-effectiveness. And according to Molyneux 'the incidence of HIV, TB and malaria is not declining despite infusions of significant sums' (Molyneux, 2008:516), a shift towards including NTD treatment and prevention in health programmes warrants consideration. This is especially significant as in 2005 it was estimated that 25% of DALYs could be attributed to NTDs, and therefore a small infusion of money could potentially decrease DALYs significantly (Fenwick *et al.*, 2005). As mentioned previously, NTDs prevent achievement of at least the first 6 MDGs (Hotez *et al.*, 2009). In my opinion all the MGDs are either affected by, or affect NTDs. This means that NTDs can prove to be

very important if the MDGs are to be achieved, as the cyclical effects of NTD involvement will inevitably be important. In other words, controlling NTDs will help accomplish goals, and the achievement of other MDGs will help control NTDs, consequently further impacting on the MDGs. The MDGs and their sub targets are outlined in table 4.

Table 4: The Millennium Development Goals and their sub targets

Source: UN website: <http://www.un.org/millenniumgoals/poverty.shtml>

MDG	Goal	Sub targets
MDG1	Eradicate extreme poverty and hunger	<ol style="list-style-type: none"> <li>1) Halve the proportion of people living on less than \$1 a day</li> <li>2) Decent Employment for Women, Men, and Young People</li> <li>3) Halve the proportion of people who suffer from hunger</li> </ol>
MDG2	Achieve universal primary education	<ol style="list-style-type: none"> <li>1) By 2015, all children complete a full course of primary schooling, girls and boys</li> </ol>
MDG3	Promote gender equality and empower women	<ol style="list-style-type: none"> <li>1) Eliminate gender disparity in primary and secondary education preferably by 2005, and at all levels by 2015</li> </ol>
MDG4	Reduce child mortality rates	<ol style="list-style-type: none"> <li>1) Reduce by two-thirds the under-five mortality rate</li> </ol>
MDG5	Improve maternal health	<ol style="list-style-type: none"> <li>1) Reduce by three quarters the maternal mortality ratio</li> <li>2) Achieve, by 2015, universal access to reproductive health</li> </ol>
MDG6	Combat HIV/AIDS, malaria and other diseases	<ol style="list-style-type: none"> <li>1) Have halted and begun to reverse the spread of HIV/AIDS</li> <li>2) Achieve universal access to treatment for HIV/AIDS</li> <li>3) Have halted by 2015 and begun to reverse the incidence of malaria and other major diseases</li> </ol>
MDG7	Ensure environmental sustainability	<ol style="list-style-type: none"> <li>1) Integrate the principles of sustainable development and reverse loss of environmental resources</li> <li>2) Reduce biodiversity loss, achieving, by 2010</li> <li>3) Halve, by 2015, the proportion of the population without sustainable access to safe drinking water and sanitation</li> <li>4) By 2020, to have achieved a significant improvement in the lives of at least 100 million slum-dwellers</li> </ol>
MDG8	Develop a global partnership for development	<ol style="list-style-type: none"> <li>1) Develop further an open, rule-based, predictable, non-discriminatory trading and financial system</li> <li>2) Address the Special Needs of Least Developed Countries (LDC)</li> <li>3) Address the needs of landlocked developing countries</li> <li>4) Make debt sustainable in the long term</li> <li>5) In co-operation with pharmaceutical companies, provide access to affordable, essential drugs</li> <li>6) In co-operation with the private sector, make available the benefits of new technologies, especially information and communications</li> </ol>

## MDG1: Eradicate extreme poverty and hunger

The first sub target is to halve the proportion of people living on less than \$1 per day. NTD control could potentially support the accomplishment of this target, as a reduction in any disease will increase 'healthy time', and therefore increase the economic productivity of the household and the country (Grossman, 1972). Iron deficiency anaemia can cause an extensive drop in productivity and is a feature of many NTDs, including hookworm infection and ascariasis. This link was quantified, as haemoglobin status (in grams per decilitre) was found to correlate with both work time and work output (Basta *et al.*, 1979; Guyatt, 2000). For instance, on a plantation in West Java, Indonesia, 88% of adult males were infected with hookworm and more than 45% of them were anaemic (haemoglobin below 13/100ml) (Basta *et al.*, 1979). As these rubber tappers were paid according to their output, the workers' wages could be used as a proxy for work output. Income from rubber tapping presented a linear correlation with haemoglobin levels as can be seen in figure 4.

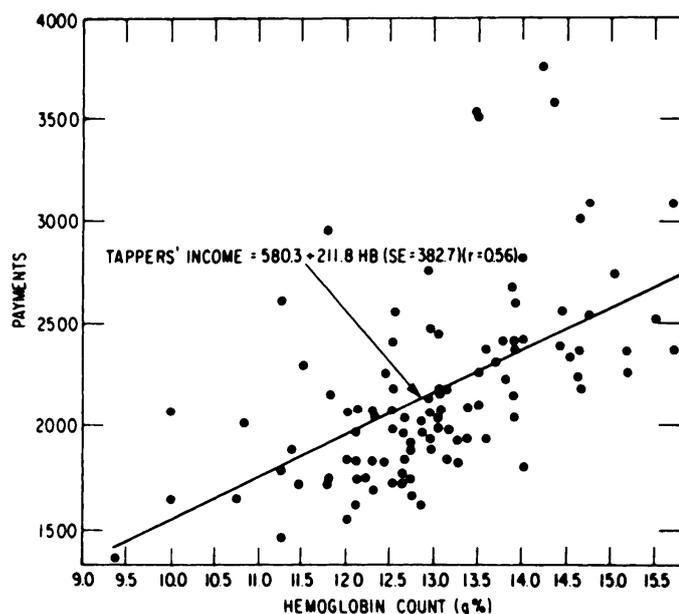


Figure 4: Haemoglobin levels and their relation with worker output, as dictated by their income.

Source:(Basta *et al.*, 1979)

Figure 4 shows that if haemoglobin iron saturation was improved as a result of ridding the workers of hookworm, each individual would earn more as their work output improved. This can be further proven as supplementation with ferrous iron, plus a small incentive payment, showed greater improvements in worker output than a placebo with the same payment (Basta *et al.*, 1979). The beneficial effects that did materialise when the placebo was taken are attributed to the ability of the individual to buy more iron rich foods with the additional money they were given, as when payments were removed the placebo

group showed a decline in haemoglobin saturation to pre-payment levels (Basta *et al.*, 1979).

Intestinal nematodes that are acquired during childhood can have negative effects on growth and cognitive function and, consequently, can have repercussions for adult productivity (Guyatt, 2000). A small stature is associated with decreased wage-earning ability in developing countries due to the physical requirements of many rural jobs (Guyatt, 2000). Guyatt (2000) also suggests that concentration, specifically within school, can be hindered by anaemia. Ill health not only impedes educational performance, but can also decrease attendance, completion rates and enrolment, meaning that the opportunity to be educated is lost (del Rosso and Marek, 1996). This constraint will thus render individuals unable to reach their intellectual potential and secure well paid employment. Therefore, a population free of NTDs would be more productive, especially in terms of physical labour. Eradication would mean that households have generally higher incomes and this opportunity would be passed down to their children, as they would also receive a better education. NTD control would thus bring developing countries closer to meeting the target of halving the proportion of people living on less than \$1 per day as a result of more productive physical labour and schooling.

The second sub target, to achieve decent employment for women, men and young people, may also be aided by controlling NTDs. Many factors involved in being infected by NTDs will reduce the likelihood of employment, including physical, social and psychological problems. Physical problems include blindness (trachoma and onchocerciasis), hydrocele (lymphatic filariasis), swelling of the spleen (visceral leishmaniasis), anaemia (STHs and schistosomiasis) and chronic pain (dracunculiasis) to name a few. The victims of many NTDs, such as onchocerciasis, primarily affect young working age communities (ages 35-45) and, when severe visual impairment has set in, approximately 70% of people discontinue employment (Evans, 1989). People with visual impairment are not incapable of work, but often cannot continue in their old occupation as it requires physical work.

The social problems resultant of NTDs can result in the exclusion of infected individuals from employment, even if they are capable of working or have undergone successful treatment. Therefore the NTDs themselves, or their associated stigma, must be resolved in order to meet this target. Stigma will be discussed in more detail in chapter four. The disabling psychological problems congruent with NTDs affect self-confidence and self-perception, and therefore the ability to seek employment successfully. This can be a

consequence of self concealing, or the fact that they are kept hidden by family members in order to prevent embarrassment or discrimination.

Halving the proportion of people who suffer from hunger is the final sub target of MDG1 and could involve controlling the numerous helminth infections that make up eight of the thirteen NTDs. Intestinal worms, such as hookworm and trichuriasis, can result in both iron and protein-deficiency anaemia (Guyatt, 2000), and can cause weight loss, as the food eaten is not utilised efficiently, meaning the infected individual may become malnourished (Neglected Tropical Disease Coalition). Helminths mainly affect and cause the most severe effects in children, so control would certainly help reduce the prevalence of underweight children (Hotez *et al.*, 2006b). As these nematodes mainly affect children, vital stages of physical and cognitive development are threatened, a process which is irreversible if the disease is not treated early. As mentioned earlier, poor health will decrease work output and consequently income, meaning that further under-nutrition and health problems may result as nutritious food can no longer be afforded, actualising a vicious cycle of poor income and poor health (Appleton, 2000).

Some cultures may also ban infected individuals from eating certain foods during the course of their illness, due to traditional superstitions. For example, 60% of the inhabitants of a Nepalese village believed that sour food should not be consumed by people infected with leishmaniasis (Koirala *et al.*, 1998). The outcome of some foods being culturally excluded is that a less nutritious diet may be had by infected individuals, not only implying they may suffer from protein, vitamin or calorie deficiencies, but also that recovery from infection may be interrupted.

#### MDG2: Achieve universal primary education

NTDs, although non-possessing of high mortality rates, are the main cause of educational problems in developing countries (Reddy *et al.*, 2007). Therefore, the target to guarantee children complete primary schooling by 2015 can be reached in part by controlling NTDs. As previously stated, children directly suffering from NTDs often enrol late, drop out early and achieve less from education (Appleton, 2000; Molyneux, 2008). Therefore, NTD control and eradication would mean that children may benefit from better utilisation of the education system.

Parental NTD Infection has also been proven to affect children's schooling, by means of reducing the household income so that schooling is no longer affordable. This loss of income within a large family will cause difficult decisions to be made in terms of

resource allocation. Within developing countries, funding allocated to education is often biased in favour of sending males to school, as they are believed to have greater employment opportunities. Therefore, the control of NTDs will increase economic stability and enable gender equality to ensue in the context of primary education. The illness of a breadwinner may require children to be removed from school in order to look after the home, or work, to compensate for the time and money (Appleton, 2000).

### MDG3: Promote gender equality and empower women

The same principles of gender inequality apply to secondary education, as the probability of a female being schooled is more dependent on the cost of schooling than it is with males (Marinda 2006). Females also suffer from high dropout rates due to cultural biases including early marriages, and biological differences, where poor sanitation means they cannot cope with the onset of menstruation. To improve the attendance of girls, NTDs could also be considered. Illness, which results in a loss of household income, often means that not all children can be educated and many households choose to send a boy to school rather than a girl as he is predicted to become more economically productive later in life. Reducing NTDs, and thus maintaining income, will make education more equally available in terms of gender, as income will not be reduced. A study found that girls residing in Peru tend to suffer from ill health more often, but have less money spent on their healthcare in comparison to males (Messer, 1997). This problem is amplified for many tool deficient NTDs, as they can have expensive treatment, which is often therefore delayed and can lead to chronic disease states. This is notably more severe in females, who have, on average, a more extensive period of illness before treatment commences due to their low social status (Ahluwalia *et al.*, 2003; Alvar *et al.*, 2006; Bern *et al.*, 2008). NTDs and gender therefore have a cyclical relationship. Women suffering from NTDs are less likely to get adequate treatment, and are more likely to suffer for longer due to gender inequality. And an earning family member (of either gender) suffering from an NTD, can decrease household income, and therefore the family may be forced to make the decision to take a girl out of schooling rather than a boy.

The promotion of gender equality and empowerment of women will in turn, help to improve the control of NTDs. With women being more equal in terms of schooling, and having more power in the household, NTDs are more readily recognised and treated, as when the money is controlled by women it is more likely to spent on children's education and health (Haddad *et al.*, 1998). Marinda (2006) found that in rural Kenya, a mother's

education, income, healthy time and nutrition all have major positive effects on the children's nutritional status and their health.

#### MDG4: Reduce child mortality rate

Many NTDs affect children under the age of five and, if they are left untreated and become chronic, can be fatal (Hotez *et al.*, 2006b). Additionally, NTDs affecting pregnant women can cause pregnancy and birth complications, which increases the probability of the child dying after birth (Brooker *et al.*, 2008). Even though NTD fatalities are rare, they increase the likelihood that the child may suffer from another life-threatening condition, such as additional infection or malnutrition. For example, females who contracted urinary or genital schistosomiasis, are up to three times more likely to contract HIV due to the presence of lesions (WHO, 2010a). Within a group of Zimbabwean women who had urinary schistosomiasis, 33.3% of them were HIV positive whilst for women without schistosomiasis, the prevalence was 25.6% (Ndhlovu *et al.*, 2007). This HIV infection can be passed from the mother to her child through pregnancy or breastfeeding. It was discovered that half a million under 15 year olds in Sub Saharan Africa (SSA) were living with HIV in 2007, and 95% of these children had acquired the infection from their mothers; 330,000 of these infected children died of AIDS in the same year (Homsy *et al.*, 2010). It is therefore believed that controlling NTDs will help fight the big three diseases, as all NTDs lower the immune systems of children, meaning other, more fatal, infections can be acquired easily.

It has also been found that congenital schistosomiasis infection can occur (Friedman *et al.*, 2007), meaning that the NTD can be directly transferred to the child and possibly lead to mortality, or an increased opportunity for HIV to be contracted (Hotez and Ferris, 2006). The contraction of HIV will have inevitable consequences on child mortality when that child comes to bear their own children.

#### MDG5: Improve maternal health

As mentioned previously, helminth infections, particularly hookworm, can cause anaemia, which contributes to the rates of maternal morbidity (Bánhidý *et al.*, 2010). In Pakistan, women affected by anaemia are five times more likely to die during child birth than non-anaemic women, due to a decreased tolerance to haemorrhage and infection (Rizwan *et al.*, 2010), and it is estimated that 20% of all African maternal deaths are directly due to anaemia (Hotez, 2009b; Hotez *et al.*, 2006c).

Improving maternal health, as well as decreasing mortality rates, will mean that mothers can care for their children, and are more likely to recognise illnesses and appropriately deal with them, including NTDs. Therefore, meeting the goal of improving maternal health will have direct benefits for other MDGs, principally those of reducing child mortality and combating disease.

#### MDG6: Combat HIV/AIDS, malaria and other diseases

It is obvious that NTDs come under the heading of 'other diseases' and therefore any reduction in NTDs will help achieve this goal. However, as a consequence of providing large sums of money to combat HIV/AIDS and malaria, has left the 'other diseases' underfunded (Maudlin *et al.*, 2009). This is despite the fact that NTDs have large disease burdens and generate life-long disabling conditions and the fact that they can increase the likelihood of one of the big three diseases being contracted (Vogel, 2006). For example, there is evidence that deworming can reduce the severity and death toll from malaria, due to a reduction in anaemia (Molyneux, 2008). Therefore, not only will combating NTDs directly support the specific aims of this goal, but it will also positively impact on the incidence of HIV/AIDS and malaria.

To reduce the number of malaria cases, the target of providing all children with bed nets by 2015 was introduced. These nets will also reduce the incidence of vector borne NTDs, such as lymphatic filariasis, Leishmaniasis, Trypanosomiasis and Buruli ulcer (Brady *et al.*, 2006). Furthermore, the associated benefits for NTDs, would aid the distribution of additional bed nets *via* 'NTD distribution channels' (Molyneux, 2008:515), which in turn will help further reduce malaria cases creating a mutually beneficial system of distribution.

#### MDG7: Ensure environmental sustainability

Fulfilling the target of halving the number of people without sustainable drinking water and effective sanitation will inevitably decrease the transmission of NTDs. Trachoma is transmitted by flies which gather in unsanitary areas and can carry the infection on their bodies (Cox, 1996; Kuper *et al.*, 2003). Trachoma is accordingly known to spread faster in poor, unhygienic areas (Markel, 2000), therefore improving sanitation will inevitably reduce trachoma prevalence. Improving the supply of safe drinking water undoubtedly helped eradicate guinea worm, as wells meant that people no longer had to stand in the water they were collecting (Hopkins, 1998). Environmental change was the only way to control

Guinea Worm, as there is no effective drug or vaccine, so efforts included health education, providing safe drinking water and vector control, as they were the only means of eradication (Barry, 2007). The high profile of the guinea worm eradication programme, has augmented the provision of safe drinking water, and has thus facilitated the progression of this goal (Barry, 2007). The eradication efforts for guinea worm have therefore led to improved water supply and sanitation, and the introduction of this infrastructure has led to the reduction in guinea worm.

There is an obvious association between the control of NTDs, and improving the lives of slum dwellers, as NTDs persist in poor urban areas as well as in rural communities (Hotez and Kamath, 2009). It has also been revealed that in households where the male head is in poor health, there is an increased likelihood that children will be forced onto the street, and therefore become more likely to suffer from an NTD themselves (Strobbe *et al.*, 2010). The control of NTDs could therefore decrease the prevalence of street children as well as improve the lives of those that remain.

A further sub target of goal number seven is to reverse the loss of environmental resources and reduce the damage to biodiversity. Onchocerciasis is transmitted by the blackfly and the disease can achieve extremely high prevalences within rural communities. When the incidence gets unacceptably high, whole communities are forced to relocate and re-establish their lives in a new location. This involves the abandonment of productive river plains and the destruction of other habits in order to create agricultural land (Remme *et al.*, 2006). Therefore, the control of NTDs that are determined by insect vectors could prevent the unnecessary destruction habitat.

#### MDG8: Develop a global partnership for development

There are difficulties, both physical and financial, in delivering drugs and bed nets to landlocked countries (Molyneux, 2008) as transport costs are much higher and depend heavily on the surrounding countries' transport infrastructure (Collier, 2007). This means, in terms of NTD resources, that transporting small items, such as tablets for the treatment of helminths, are much more economically viable than bed nets for the control of malaria (Molyneux, 2008). Thus the eighth goal will help make delivering these much needed resources easier and cheaper, as having a better and more predictable trade system will decrease the price and length of delivery. And, conversely, the need to deliver NTD drugs may accelerate infrastructural development in both landlocked countries and those surrounding them.

NTDs can also help to address the individual needs of the Least Developed Countries by encouraging them to generate their own specific lists of problematic diseases.

#### *Neglect in terms of the DALY measurement*

A major challenge within NTD research is quantifying their disease burden, and the lack of dependable measures has hindered awareness campaigns and requests for funding (WHO, 2007). "DALYs are the most widely accepted quantitative indicator of burden of disease" (Moran *et al.*, 2009:145) and were designed to support the fair allocation of resources (Gold *et al.*, 2002). However, the DALY measurement is speculated to be a source of neglect. DALYs were designed to be a comprehensive health measure that could overcome the challenge that 'what cannot be counted simply doesn't count' (Hoos, 1979:3).

DALYs combine the years of life lost as a result of premature mortality with the number of healthy years of life lost due to disability (Fèvre *et al.*, 2008; Maudlin *et al.*, 2009; Reidpath *et al.*, 2003). DALYs use the life expectancies of 82.5 years for women, and 80 years for men, as the WHO has developed these as the international standards, regardless of country specific life expectancy, on the grounds that everyone has the potential to achieve these average life expectancies with the right conditions (Gold *et al.*, 2002). The number of years lived with disability is calculated by multiplying the duration of the disease by the disease prevalence. This is then multiplied by the disability weight, a measurement determined by experts, to numerically quantify the disease's impact. Finally, the figure is multiplied by the age weighting, which attributes a higher burden to the illness of young adults, as illness at this age is likely to have greater social and economic consequences (King and Bertino, 2008). This disability weighting is then added to the number of years lost due to premature mortality.

However, the overreliance on DALYs has been criticised, as it has been claimed that DALYs 'underestimate the burden of NTDs' (King and Bertino, 2008:1); resulting in the neglect of NTDs in policy planning (Maudlin *et al.*, 2009). NTDs are underestimated by the DALY measure for a number of reasons: they can cause disability even after successful treatment; local contexts are not taken into account; DALYs use westernised ways of calculating burdens for different ages; data are difficult to obtain and there are problems measuring disease co-morbidity.

Firstly, NTDs can cause disruption to life for many years, even after the infection has been successfully treated (King and Bertino, 2008). Many NTDs often initiate on-going socio-cultural problems, yet data on this are scarce (Wynd *et al.*, 2007). Appendix 2 offers some suggestions about how the impact of each of the 13 diseases may continue beyond treatment and cure. For example, in the case of HAT, the loss of decorum resulting from the change in personality during infection may result in continuing stigma. Scars are inevitable after infection with either cutaneous or mucocutaneous leishmaniasis, and can also be a source of lifelong stigma (Alvar *et al.*, 2006). This scarring, and the social problems that may manifest as a consequence, are not included in the DALY measure.

Secondly, DALYs fail to take into account the context in which the disease occurs, as the DALY is an average disability ranking which extends to all geographical areas (King and Bertino, 2008). Therefore, because disease perceptions, and thus their consequences, vary geographically, DALY estimates must be context specific (Wynd *et al.*, 2007). Each disease is however, given a disability weight determined by experts that is unchanging over social, cultural or environmental contexts (King and Bertino, 2008; King *et al.*, 2005; Reidpath *et al.*, 2003). This means that being blind in the UK has the same disability weight as being blind in Niger, even though it is much easier to live in the UK when blind due to interventions such as brail, specialised schooling and structural devices, such as textured surfaces at road crossing points (King *et al.*, 2005).

The average length of a disease's course is used to determine the DALY figure. However, in poor rural areas of developing countries, where treatment is not always readily available, the disease's course may in fact be much longer than elsewhere (Gold *et al.*, 2002). The lack of cultural specificity acts to further reduce the accuracy of the DALY measurement.

Thirdly, the superior infrastructure and availability of resources in developed countries results in more accurate epidemiological data on disease (King and Bertino, 2008). In developing countries the limited health care facilities mean that not all cases will be picked up by the system and thus not included in disease prevalence figures (King and Bertino, 2008; Maudlin *et al.*, 2009). It is often a lot easier to deal with a disease in a developed country due to the resources, infrastructure and care available, and the fact that the main type of employment doesn't involve physical work. DALYs do not take the differences between the lives of people in different societies into account, and therefore cannot provide accurate measurements for assessing the impact of NTDs.

DALYs do take into account the fact that an illness affecting an individual at working age will have a larger impact than if the disease materialised at a young or old age (Gold *et al.*, 2002). However there are flaws with this design. Initially, there is the issue that this form of assessment devalues the lives of the retired or the young, which can appear insensitive and unjust. Secondly, different cultures have differing norms of what the term 'working age' encompasses, and in many developing countries people tend to work from childhood up until they can physically work no longer. This generates a developed country bias, whereby disease burdens of the developing world are underestimated (King and Bertino, 2008). This developed country bias will mean that NTDs in working children and older people will not be assigned a fair DALY measure.

Another major problem is that the DALY measurement cannot assess diseases when co-morbidity occurs, which is a common, rather than a rare occurrence (Pullan and Brooker, 2008; Singer and Ryff, 2007), as the geographical distributions of NTDS heavily overlap (Molyneux *et al.*, 2005). For example, Tanzania is host to 6 NTDs, meaning that people can suffer from more than one disease, either at the same time or within their lifetime (Brady *et al.*, 2006; Reddy *et al.*, 2007). This co-morbidity often results in a poorer prognosis and higher financial costs (Valderas *et al.*, 2009). Therefore 'the poverty-promoting potential of the neglected tropical diseases must consider the reality that they do not occur in isolation' (Hotez and Ferris, 2006: 5791). However, when using DALYs, one of the most widely accepted measures used to determine funding allocations (Gold *et al.*, 2002; Moran *et al.*, 2009), problems can arise when trying to disentangle individual disease burdens from the collective burdens of co-morbidity. Firstly, polyparasitism disrupts the measuring of DALYs of separate diseases, as some more common symptoms may be overlooked in either of the disease calculations, such as anaemia and diarrhoea. It can also be unclear whether a co-morbid set of diseases creates an additive or a synergistic effect.

It has been speculated that the interaction between co-present helminths can result in either additive anaemia or synergic anaemia. Synergism occurs when the effects of polyparasitism are greater than the mere addition of the effects of each individual infection (Ezeamama *et al.*, 2008; Pullan and Brooker, 2008). Due to this discrepancy, DALY disability weightings cannot consider all illnesses occurring within one person, meaning only one disease can be assessed per individual (Gold *et al.*, 2002). Individual disease burdens must be added together for co-morbid patients and the synergistic effects that may be present are easily missed.

Co-infection with helminths is common in communities with many endemic helminths (Howard *et al.*, 2002), but few studies have documented the morbidity implication of polyparasitism (Mupfasoni *et al.*, 2009). In a population sample of 260 people in Côte d'Ivoire, two thirds of inhabitants possessed three or more parasites (Raso *et al.*, 2004). Little is known about how helminths interact biologically, but some inferences can be made (Ezeamama *et al.*, 2008). A study looking into low intensity disease co-infection, found that polyparasitic infections were associated with up to an 8 times higher chance of developing anaemia, compared to singular low intensity infections or no infection (Ezeamama *et al.*, 2005). This chance was similar to that of possessing one or two medium to high intensity infections. Previous studies have discarded low intensity infections as having no morbidity and have therefore not taken into account the synergistic effects of polyparasitism (Ezeamama *et al.*, 2008). However, as co-morbidity is extremely common in endemic areas synergism needs to be reconsidered, as many low intensity multiple infections may be overlooked even though they can cause severe anaemia when combined with further low intensity infections (Ezeamama *et al.*, 2008; Pullan and Brooker, 2008). Conversely, alternative research revealed that the association between low intensity polyparasitism and anaemia was not significant (Ezeamama *et al.*, 2005; Ezeamama *et al.*, 2008; Pullan and Brooker, 2008). Mupfasoni *et al.* (2009) therefore believe that it is best to target high infections whether polyparasitic or not. Due to the uncertainty of the relationship between polyparasitism and anaemia, it is recommended that both low intensity infection and medium to high intensity infections are further researched and both targeted for intervention.

Ezeamama *et al.* (2008) found synergistic parasite interaction in co-infections of hookworm and *S. japonicum* (schistosomiasis), and hookworm and trichuris as they predicted. 60% of the anaemia in children infected with both hookworm and *S. japonicum* is credited to biological interaction, and 40% to the individual anaemic effects of each individual infection (Ezeamama *et al.*, 2008). This may be because of the differing mechanisms by which anaemia is created; for example, hookworm associated anaemia is caused by intestinal blood loss (Hotez *et al.*, 2004), whereas schistosomiasis associated anaemia, is caused by blood loss, the holding of red blood cells in the spleen, and anaemia of inflammation (where inflammatory cytokines stimulate a number of sequential molecular stages, which prevents iron stores from being released (Nemeth *et al.*, 2004; Pullan and Brooker, 2008). These differing mechanisms will all be present in a sufferer of hookworm and *S. japonicum* co-morbidity, so anaemia can be generated in a number of

ways which may interact to generate synergetic morbidity (Pullan and Brooker, 2008). The presence of synergistic morbidity may, however, be a result of experimental error. For example, it has been found that severe anaemia resulting from polyparasitism is greatest in communities where iron intake is inadequate. This means that apparent synergism may be the result of the added effects of a poor diet (Brito *et al.*, 2006). It was also found that co-infection of hookworm and trichuris led to an increased chance of anaemia compared to hookworm alone, even though individually, trichuris is not associated with anaemia (Ezeamama *et al.*, 2008). This is therefore likely to be due to biological interaction.

Many NTDs can result in symptoms such as malabsorption, anorexia, blood loss (Pullan and Brooker, 2008) and wasting, and therefore it is also common to see additive and multiplicative burdens for these individual symptoms (Booth *et al.*, 1998; Mupfasoni *et al.*, 2009). It can be challenging to determine the direction of this association, however, as malnutrition may precede helminth infection in developing countries, and thus further investigation is required (Pullan and Brooker, 2008).

The inaccuracies inherent within the DALYs are problematic, as policy makers utilise the measure to determine where funding should be assigned. This reliance can generate mistakes as policy makers make two main assumptions; one, that the experienced disability is constant in all regions and countries and, two, that there is a consistent association between the money invested in a disease and a reduction in the disease burden (King and Bertino, 2008). It is therefore essential that funding decisions reflect other factors alongside DALYs. Comparing cost-effectiveness per DALY averted should not be the sole indicator sourced when allocating funding, as economic efficiency should not be the only criterion used when distributing resources (Gold *et al.*, 2002). Cost-effectiveness will inevitably be underestimated if the DALY measure is undervalued and consequently the treatment of NTDs may be viewed as less economically viable (Conteh *et al.*, 2010). This is detrimental to the allocation of resources as higher cost effectiveness is likely to spawn more funding.

### *Neglect in terms of the media*

It is in fact the case that the issue of the media neglecting NTDs, has itself been neglected, with a 2008 paper claiming to be the first published study on the lack of NTD coverage in the media (Balasegaram *et al.*, 2008). NTDs are neglected within the media, as very few cases make the headlines (Balasegaram *et al.*, 2008). This is perturbing as media

coverage can initiate action towards policy change and increased awareness This holds true for all types of media; print and electronic (Holder and Treno, 1997). Some articles that were found to be specific to NTDs as a collective, or singularly, only referred to the problems they created within the western world, such as a threat to the American blood supply and the danger to US troops (Balasegaram *et al.*, 2008). Journalists who were interviewed about NTD news stories often claimed that they were not newsworthy, because the public did not warrant them as important, or interesting, news story (Balasegaram *et al.*, 2008).

NTDs often have names which some people find difficult to pronounce have not allowed them to be brought to the attention of the lay public of some developed countries (WHO, 2006). When NTDs are presented in the media, journalists often use colloquial terms such as sleeping sickness as opposed to Human African Trypanosomiasis, thus highlighting the need to simplify disease names in order to reach a wider public (Balasegaram *et al.*, 2008). When the celebrity Ben Fogle contracted Muscutaneous Leishmaniasis, headlines included 'Fogle catches a flesh-eating bug', which was placed in the entertainment section of British Broadcasting Cooperation (BBC) news online, as opposed to the health section (BBC, 2008). In many headlines similar to these, neither the term Leishmaniasis or Oriental Sore (a local name for the disease) were used. Therefore it is evident that more accessible terms are needed. If advocacy for NTDs is to be increased, then a strategy to increase media coverage is urgently needed (Balasegaram *et al.*, 2008).

### *Conclusion*

In conclusion, I feel that although NTDs are still highly neglected, there have been important advances in the field in recent years to increase their advocacy. This is exemplified by the Bill and Melinda Gates Foundation giving a series of grants to be used in NTD research, and the implementation of control programmes (Lammie *et al.*, 2006; Liese *et al.*, 2010). It has been shown in the MDGs subsection, that NTD control and elimination could play a critical role in achieving these poverty reduction goals, and therefore must be considered of great importance. As we shall see in the next chapter, poverty is appraised, not only in terms of monetary poverty, but also as a lack of basic freedoms or choice. This can include, for example, the ability to attend school (the *ability* is the important aspect here, not the actual attending of school), which features in MDG2. To achieve this goal people must have the ability to attend school in the first place, and the suffering of an NTD

can diminish this capability in a number of ways, the specifics of which will be discussed in chapter four.

The complications with using DALYs to measure the burden of disease are particularly potent, as they are the primary criterion used to determine the funding allocated to different health programmes. With NTDs being neglected within this measure, funding is likely to be directed away from them, due to their apparent low burdens and mortality rates, as well as poor cost effectiveness estimates. A lack of funding means infected people can find themselves suffering additional, and more severe, complications such as blindness as disfigurement. These long term problems as a result of lack of education on the suffers part, an inability to access health centres, lack of economic resources to pay for treatments, or social exclusion rendering the individual unable to seek care (all infringements of a person's basic capabilities), can lead to further capability loss. Again, this will be discussed further in chapters three and four.

This chapter has therefore laid the groundwork for the rest of the thesis to be based and built upon, and highlights some areas that need to be developed and further researched, such as a rethinking of the DALY measure so as to include all aspects of the NTD burden.

## Chapter 3

### Poverty, health and capabilities, building a conceptual framework

As NTDs have not been analysed with respect to the capabilities approach, I offer a conceptual framework linking health to both poverty and capabilities, in which to place NTDs in a later chapter. Analysing NTDs in terms of the capabilities approach is useful, as the capabilities approach is a well-established paradigm for policy debate in terms of human development. The capabilities approach inspired the creation of the UN's Human Development Index, a widely used measure in terms of assessing the human welfare. Therefore, combining the high profile paradigm of the capabilities approach, with the lower profile NTDs, may help to raise their profile, as well as creating a way in which to assess their impact on poverty focuses on the opportunities available to those infected. This is in contrast to welfare assessments which only document mortality rates and monetary losses. This chapter begins with an analysis of the association between poverty and ill health; and a conceptual framework proposed combining these within a capabilities approach. Chapter four will then use this framework to evaluate NTDs as a specific area of ill-health.

#### *Poverty and health*

There is ample literature regarding the relationship between ill health and poverty, and this section details the mechanisms by which ill health acts as a driver of poverty, and how it affects the intergenerational transmission of poverty. I have also included a description of the relationship between disability and poverty, as many NTDs can lead to disabling conditions. The literature on disability and subsequent poverty is vast, and can often be transferred to explain the problems faced by people in ill health. The mutually perpetuating relationship between ill health and poverty is well known, especially in terms of the loss of income and increase in expenditure, during a period of poor health. This, together with the increased risk of impairment and illness due to the unfavourable conditions that poverty creates, spawns a vicious cycle of ill health and poverty. As summarised by Grant (2005:4): 'ill health can be a catalyst for poverty spirals and in turn poverty can create and perpetuate poor health status'. This relationship is especially prominent when it comes to chronic poverty, which is defined by the Chronic Poverty Research Centre as: 'poverty experienced by individuals and households for extended periods of time or throughout their entire lives' (Addison *et al.*, 2008-09:130). Ill health is

more pronounced when it comes to chronic poverty, because the illness draws upon high amounts of household resources. The subsequent conditions of poverty render the household increasingly vulnerable to additional health shocks, and thus the cycle continues until chronic poverty is entrenched. Chronic poverty increases the chance that poverty will be passed between generations, due to the lack of transfers of different forms of capital, such as human capital (Moore, 2001).

Economists are becoming more interested in health as a form of human capital, and one which is essential for economic growth and development (Kimhi, 2003). According to Moore (2001), the transfer of human capital is based around responsibilities. The obligation to provide for family members that are young, old, ill or disabled is one example of the transfer of human capital. The nature of this responsibility is inherently intergenerational, and affects the capabilities of both those receiving the transfer, and those passing it on. This intergenerationality needs to be the target of health and poverty programmes, instead of focusing on one generation in order to prevent poverty becoming embedded within multiple generations.

### *Drivers of poverty*

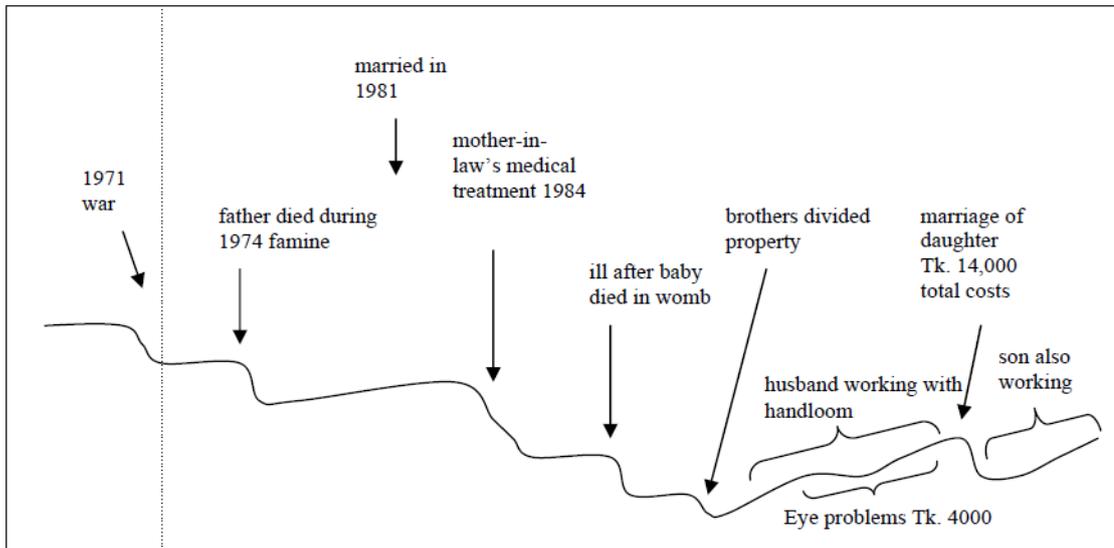
Firstly, I will look into how poor health may facilitate the entry into poverty. The causes of entering and remaining in chronic poverty are multi-faceted, overlapping, and involve influences from the household level, up to the global level (Grant *et al.*, 2004-05). Some aspects of illness are drivers (those that force the slide into poverty) and some are maintainers (those that maintain the state of poverty). In this subsection I will focus on the drivers of poverty. These drivers can be referred to as 'shocks', and when people have few assets and little financial, social or emotional support, these shocks can be the means by which poverty is entered. The descent into poverty usually occurs due to a build-up of these shocks, so arises gradually (Harper, 2004; Krishna, 2007). 71% of households descending into poverty in central and western Uganda reported a health based decline, highlighting that ill health is a major stimulus for increasing the likelihood that a household will experience poverty (Krishna, 2007).

The physical body is many poor people's most productive and valued asset, with most paid labour involving physical work. It is, however, the most fragile asset, and can easily 'slide from being an asset to being a liability' (Krishna, 2007:7). Ill-health or injury

causes a decrease in 'healthy time' (Grossman, 1972:223), where healthy time equals earning time. Grossman assumes that, with investments of health care and nutrition, the quantity of healthy time can be increased. However, without adequate health care and nutrition, an individual's health stock may never increase, but only decrease with the onset of old age. This will subsequently decrease agricultural output, both in terms of physical labour and managerial abilities, which will lead to a lowered earning potential (Ulimwengu, 2009). It has been noted however, that there is little decrease in earnings from farming itself, suggesting that the decrease in farming activities has been counteracted by the introduction of child labour, and that non farming secondary income sources have instead decreased (Ulimwengu, 2009). It was indeed discovered that child labour was twice as high in families that were affected by ill health, in comparison to healthy families (Ulimwengu, 2009). However, introducing child labour, and lessening the diversity of income, although a coping strategy, can have extremely detrimental effects on the maintenance of poverty; a concept which will be covered in the next section. The death of a productive member of the household is the ultimate loss of healthy time and a major shock to a household. Ulimwengu (2009) believes that death is costly, not only due to a decreased income, funeral expenses and the increased ratio of dependants, but also the loss of agricultural knowledge that could be passed down through the generations.

The fall into poverty denotes an increase in household vulnerability, and thus reduced resilience to another episode of ill health (Bird and Shinyekwa, 2005; Davis, 2006). Additionally, when social protection is not provided, which involves income support, free basic services and emergency relief, the effects of the shock, or succession of shocks, vastly increase household vulnerability (Grant *et al.*, 2004-05). This can be shown diagrammatically using a 'saw tooth trajectory' diagram (Davis, 2006:18), as depicted in Figure 5. As can be seen in this trajectory, there is a general decline with little recovery until the husband starts work using a handloom. This connotes that shocks occurring after the 1974 famine occur within already disadvantaged circumstances, as any recovery has not restored the level of wealth to the state in which the first shock occurred. Periods of illness play a prominent role in the progression of poverty establishment, including the mother in law's treatment, the death of an unborn child and eye problems.

Figure 5: Saw tooth trajectory of decline into poverty: (TK is the currency in Bangladesh, where 1TK is equivalent to £0.01). Source: Davis (2006)



Poverty outcomes are highly dependent on which member of the household is affected by illness. It is not surprising that an illness affecting the breadwinner is the most common driver of poverty as illness affecting the principle earner will result in the largest single loss in household income (Grant *et al.*, 2004-05; Harper, 2004; Krishna, 2007). The family however, are likely to prioritise earners for expensive treatment, to minimise the effects on the economic stability of the household (Grant *et al.*, 2004-05). Subsequently, the heads of household are more likely to have good health status. Illness of any adult (not simply to the breadwinner) creates another dependant, meaning other members of the family may need to stop earning, education or household work to look after them (Grant, 2005).

37% of children living on the streets of Zambia are forced out of their homes because the male head of household is affected by ill health (Strobbe *et al.*, 2010). Strobbe *et al* (2010) therefore suggest that because of the detrimental economic effects and the risks to children's health, education and shelter, there would be major benefits in targeting the male heads in health programmes, as the benefits would filter down to the whole household. This is likely to apply in other countries where the economic stability of the household is largely dependent on a male breadwinner. On the other hand, Grant's 2005 study in Bangladesh suggested that targeting women and giving them more responsibility within the household, in terms of resource allocation, leads to different aspects of life being prioritised. For example, in the hands of women, earnings were more likely to be

spent on health care and education for the children, irrespective of the gender of the child (Begum and Sen, 2005). Therefore, illness affecting the female may not only mean that the money is in the hands of the male, and consequently not prioritised for health care and education, but it may also diminish the source of secondary income, and affect the household's potential coping strategies by reducing the diversity of productivity.

Conversely, the illness of a child or elderly family member, already dependant on their family, is likely to result in a less severe impact in terms of the household's decline into poverty. This can portend less hastily sought treatment, therefore prolonging an illness, and there may be consequences later in life, such as intellectual impairment and poor growth depending on the disease (Harper, 2004). The adverse circumstances become more severe with chronic illness, as opposed to short term ill health, as treatment costs mount up, and earning time remains restricted. It must be decided whether or not to treat the individual, for example, a young earner or potential earner would be favoured for expensive treatment over an older person, due to their larger set of capabilities and social and economic value (Grant, 2005). Conversely, it has also been found that a female headed family with many young dependants may delay treatment for adults in order to treat ill children, which can have negative consequences for the adults' long term health and ability to care properly for their children (Grant, 2005; Harper, 2004).

The above discussion shows that illness of different members of the family can have varying effects on the economic stability and capabilities of the family unit, thus affecting their vulnerability to poverty. The differing opinions concerning which member of a family in poverty to target for help indicates that the issue is complex. Disparities in the allocation of help between countries may be largely affected by national and regional factors such as demographics, employment structure and health care provision.

### *Stigma as a driver*

Although stigma is a consequence of other drivers of poverty, such as a physical ailment, a mental limitation, poor nutrition or poor shelter, it can be classed as a driver of poverty in itself. This is because the added stigma may increase the disease burden so much so as to actually facilitate the decline into poverty, whereas without stigma poverty may be non-existent or less severe. The next chapter will illustrate this with some specific examples involving NTDs.

### *The intergenerational transmission of poverty*

Intergenerational transmission of poverty requires that poverty be chronic, i.e. maintained over time, with time being the primary factor of a person's experience of chronic poverty (McDonough *et al.*, 2005). McDonough and colleagues (2005) argue that short term and long term poverty have such majorly different causes and consequences that the health outcomes related to each must also differ. For example, they found that long term poverty is more heavily associated with premature death, in comparison to short term poverty (McDonough *et al.*, 2005). Maintaining poverty over time therefore increases the probability that chronic ill health will ensue, which in turn deepens poverty, a cyclical association which is difficult to interrupt.

The transmission of poverty between generations is bidirectional; usually parents transfer poverty on to their children, but they can also transfer it to their parents (Smith, 2006). The intergenerationality of poverty transfer from the older generation to the younger, and how this will go on to affect the transmission of poverty from that younger generation onto their own children, will be the focus of this sub section. Therefore, instead of Strobbe *et al.*'s idea of targeting the household male head, it may be more beneficial to interrupt the cycle at the point of childhood poverty. Adults are less at risk of becoming poor if they themselves were not poor as children (Harper, 2004). Accordingly, intervening at childhood may tackle both childhood poverty, and intergenerational poverty.

The transfer of poverty between generations does not merely involve the lack of monetary transfers, but also the lack of social, human and physical transfers (Grant, 2005). Chronic poverty is multidimensional, and encompasses malnutrition, illiteracy, poor health service access, social isolation, exclusion, exploitation (Grant *et al.*, 2004-05), poor nurture and inappropriate protection (Harper, 2004). These diverse features of poverty can all be transferred to children. In order to determine the risk factors for intergenerational poverty, the maintenance of poverty must firstly be investigated.

At an international and national level, poverty is maintained by low economic growth, failed states (where there is a lack of health care and social protection), weak international aid cooperation, and geographical disadvantages (Grant *et al.*, 2004-05). A local maintainer of poverty is that of social exclusion, whereby the discriminated are forced out of social networks and into exploitive employment, or unemployment, anchoring them to poverty (Scambler, 2009; Van Brakel, 2006). Therefore coping strategies, for example

exploitive or dangerous employment, challenge their well-being and impact on their ability to escape poverty. Intergenerationality is defined as 'persistent impoverishment is not only a symptom of past deprivation, it is also the cause of future destitution' (Grant *et al.*, 2004-05:15). A Zimbabwean states that 'poverty lays eggs', reiterating the ease with which poverty is passed onto the next generation, and the difficulty involved in reversing it (Grant *et al.*, 2004-05:3). Therefore the best way to tackle chronic poverty may be to attend to the intergenerational transmission of poverty, thus breaking the cycle (Harper, 2004).

The next sub section explores the literature surrounding ill health and the transmission of poverty. The link between disability and poverty will then be investigated; disability is relevant to my research for a number of reasons: firstly, some NTDs, if inadequately treated or not treated at all, can result in disability, including sensory disability, (Cook, 2008; Evans, 1989; Hopkins *et al.*, 2008; Markel, 2000), and limb amputation (Stienstra *et al.*, 2004). Secondly, the range of problems faced by people with disabilities can be very similar, and have comparable consequences to those generated by ill health. For example, if a member of the household is ill or disabled assets will be utilised to pay for treatments, and using these assets will render the household vulnerable to shocks (Grant, 2005).

#### *In terms of ill health*

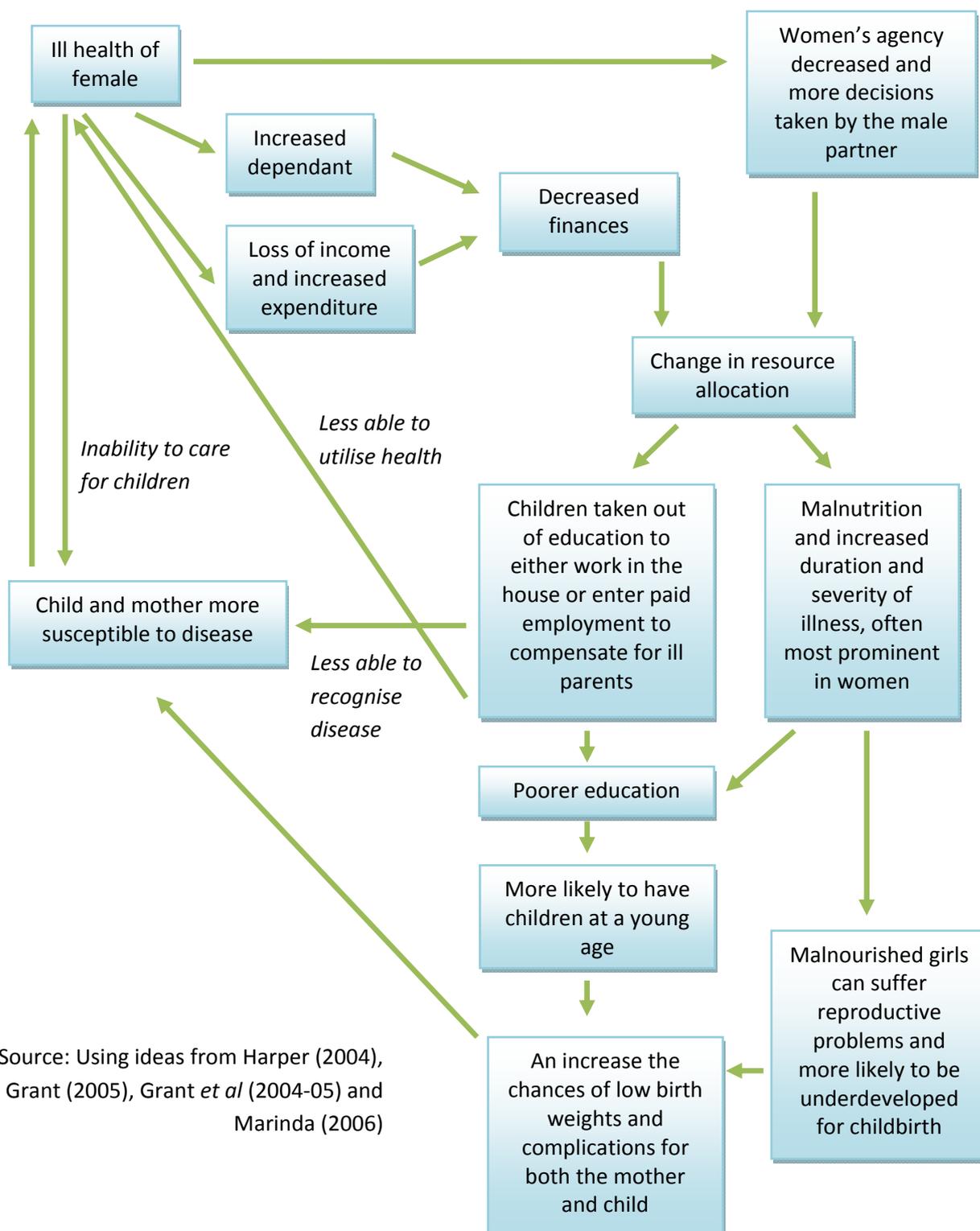
There is a strong negative relationship between chronic poverty and poor health (Grant *et al.*, 2004-05). The link is so strong that it has been thought that 'health measures themselves could be used as a direct measure of chronic poverty' (Lawson, 2003:2). The nature of illness, as either a sudden shock or a prolonged problem, can cause the household to function adversely as an economic compound due to either the unexpected, or long-lasting treatment payments. This stress may cause a breakdown in family structure as well as causing financial loss (Grant, 2005).

Lawson (2003) measured the correlation between health and poverty by using two data sets from Ugandan household surveys, from 1992 and 1999. He used health status of the household head as an indicator of household ill health, relying on the Beckerian model where the head of the household is altruistic and shares resources equally among members. However, the bread winner will usually get health care priority within the family (Nussbaum and Glover, 2007; Thomas, 1990), leaving the old, disabled and other dependants more likely to suffer from, gain impairments from, and have a slow recovery

from illness. This is the argument of the Pareto Efficient, whereby a change to make one household member better off, must make another member worse off (Thomas, 1990). This implies that using the health status of the household head as an indicator for household health may be biased toward the reporting of less ill health within the family. Saying this, Lawson (2003) did find some useful correlations; the health status of the head in 1992 had an influential role in determining the level of household poverty, in 1999. Illness of the household head therefore had the effect of making households move into poverty and remain there.

Household heads are usually male, and the consequences of illness affecting the mother will differ from those mentioned above. The relationship between mother and child, as seen in Figure 6, is extremely close, meaning her illness can have a wide range of consequences for the family. The diagram shows how a vicious cycle of underinvestment in women, where they are given less priority of resources, perpetuates poverty through generations. This lack of resources throughout life can mean that the transmission of poverty can begin before birth (Grant, 2005). This may be partially due to women's limited agency, and the subsequent decreased ability to be well nourished (Begum and Sen, 2005). Increasing the woman's role in decision making, and increasing her power in the household, has beneficial effects on both the mother and child's health. If she is able to allocate herself sufficient nutrition before, during and after pregnancy, her child will not be malnourished at birth and the cycle of malnutrition may cease (Begum and Sen, 2005). This is due to the fact that an underweight and malnourished baby has lower cognitive ability, as well as worse physical health and immunity (Grant, 2005; Harper, 2004). This would therefore impact on school achievement, choice of occupation and therefore their income, meaning an escape from poverty is made more difficult and poor health is more likely to ensue. A poor education means health facilities are less well utilised which increases the probability that disease will be left untreated and become chronic or disabling (Harper, 2004). An increase in women's agency will, as previously mentioned, generate the ability to prioritise the child's health, nutrition and education, irrespective of gender, and thus prevent the transmission of poverty conditions (Begum and Sen, 2005). These findings implicate another point in the cycle where interventions could be successful: women's health and agency.

Figure 6: Transmission of poverty *via* ill health of women:



As can be seen from Figure 6, poor education is a major factor in the transmission of poverty. Ill-health of a working adult decreases household income, and thus may limit

education. The link between ill health and education is cyclical, as it has been found that the average duration of illness is increased if the household head is illiterate, with the average duration being 49 days, compared to 31 days when the head is literate (Asfaw, 2003). Not only does malnutrition affect the physical health of the child, but it also affects their cognitive ability. This means that what little education children do receive may not be utilised to its full potential (Appleton, 2000; Harper, 2004; Ulimwengu, 2009). Reduced cognitive ability, together with an increased incidence of child labour, disconnects children from the education system; this is more prevalent among girls. Consequently, these children are more likely to be ill, due to poor nutrition and poverty conditions, more likely to stay ill for longer as a lack of education contributes to poor treatment seeking, and their future children are more likely to suffer from ill health as they cannot care properly for them (Ulimwengu, 2009). Education provides women with the knowledge about different illnesses, and consequently they are more able to spot ill-health in their own children, and take preventable measures such as good hygiene, to protect their children from disease (Appleton, 2000). Educated women are also less likely to have children early, which carries its own risks of low birth rate and complications for both mother and child, meaning the child is again more likely to suffer from ill health (Grant *et al.*, 2004-05; Marinda, 2006).

In rural western Kenya, an experiment was conducted to ascertain whether school children could relay the health education they learned in school to their parents (Onyango-Ouma *et al.*, 2005). They taught children things such as how to construct a 'leaky tin', which acts as a wash basin. Although this example looks at knowledge transfer from the young to the old, it also has connotations for the ability of these children to transfer knowledge to their own children in the future. It has been previously mentioned that children that come from a family where the parents have been educated have a lower risk of preventable death, as the parents are better at recognising illness (Appleton, 2000). Appleton (2000) states that in Sub Saharan Africa life expectancy rises from 51.2 years, with uneducated parents, to 65.2 when the parents have been schooled to secondary level. Education is therefore another good point in which to enter, and interrupt the cycle of poverty, as children are more impressionable than adults (Onyango-Ouma *et al.*, 2005). Educating children is a cost effective way of changing the health behaviours of the whole community, and the next generation. Not only will this initiative generate the ability for children to influence their own, and others' health, but it will also help to motivate them to want to do so, and this will be long lasting, sustainable and intergenerational (Onyango-Ouma *et al.*, 2005). Money is unfortunately required in order to provide 'conditions of health', such as

clean safe housing and materials to make leaky tins, but the ideas can be maintained and put into practice when funds were available (McDonough *et al.*, 2005:1795). This study is a good example of the philosophy that a missed or underutilised education can hamper the efforts of other poverty reduction programmes, such as initiatives to combat poor hygiene and the provision of health care, as without education, people may be unaware of the importance of such programmes or be unsure of how to best utilise services (Harper, 2004).

Another reason to break the poverty cycle at children is because adversities early on in life, such as poor growth, inadequate education and ill health, can result in lifelong consequences which are irreversible when they enter adult life; thus these problems must be tackled at a young age in order to prevent them becoming poor adults (Harper, 2004).

#### *In terms of Disability*

It can be considered that 'disability feeds on poverty and poverty on disability' (Lwanga-Ntale, 2003:1), much like the relationship between poverty and ill health. The disabled have different needs and problems to face than the rest of the population, and within developing countries the majority face chronic poverty (Lwanga-Ntale, 2003; Yeo, 2001). Disabled individuals are often considered 'specialist' in terms of policy, so many NGOs and government policies shy away from including them specifically, therefore they face chronic poverty but are provided with no help to facilitate an escape (Yeo, 2001). For example, The Ugandan Poverty Action Plan does not include any reference to disability, even though there were as many as 3 million disabled people living in Uganda in 2003 (Lwanga-Ntale, 2003).

Yeo defines disability as 'a complex system of social relations imposed on people with impairments resulting in a denial of rights and equal opportunities' (Yeo, 2001:3). This means it is not the impairment that warrants disability, but the environment in terms of the physical world, policy, and the attitudes of people around them (Grant *et al.*, 2004-05). The discrimination by the human infrastructure of the physical world has been described as apartheid by design (Imrie, 1996; Yeo, 2001), highlighting the exclusion felt by the disabled, and the feeling that the physical world designed to cater for the able bodied is an unnecessary barrier to a normal life. It is widely accepted that discrimination and deprivation overlap, and social exclusion can often be used as an indicator of poverty. Due to the huge amount of stigma often attached to disabled people, they may be difficult to

reach and research, as the family may deny their existence and keep them isolated from society, especially when the disabled individual is a child (Yeo, 2001). People rationalise the discrimination of the disabled in many ways, from beliefs they are the objects of witchcraft, and therefore dangerous, to the belief they are incapable and should therefore be protected from challenges (Grant *et al.*, 2004-05). The lack of exposure to decision making situations can render the individual a disempowered adult, and result in a lack of confidence thus further hindering their employability, which inevitably maintains their state of poverty (Lwanga-Ntale, 2003).

Because the disabled are comparatively invisible, they are often left out of research, and thus not incorporated effectively into policy. This is controversial as they are a major source of intergenerational poverty. Poverty will never be eradicated, and development targets never met without including the disabled in rights based movements, and without targeting them specifically *via* policy (Yeo, 2001). Their invisibility also causes another problem: their peers will be unaware of them, their problems, abilities, and rights, meaning they may be feared and taunted as they have not had experience involving disabled people. A lack of knowledge may breed false beliefs about contagion, thus generating ignorance and further exclusion, even among medical professionals, who are often ill trained (Lwanga-Ntale, 2003), creating a vicious cycle of stigma and invisibility.

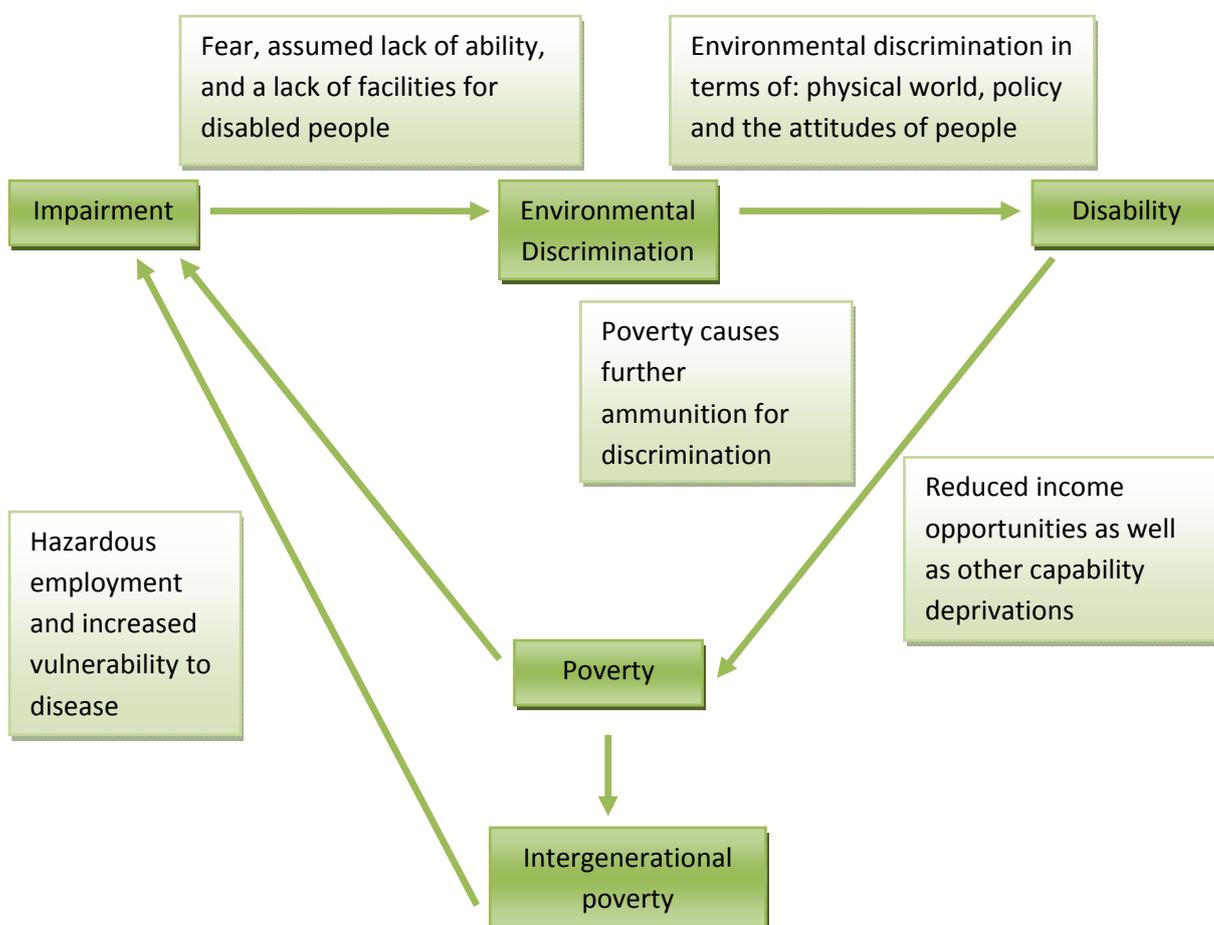
Disabled children are often prevented from attending school, as they are thought to be less able to cope, even if their physical state does allow them to travel to a school. This may be due to inadequacies within schools; including the lack of specialist resources and teachers, such as Braille and teachers who can use sign language. Social problems also facilitate non-attendance by making the disabled individual feel unwelcome and reducing their desire to attend school. Another potential problem is courtesy stigma; if disabled children are sent to school the whole community will know of their disability, meaning the family may begin to suffer from a courtesy stigma (Goffman, 1963; Herek *et al.*, 1998; Weiss *et al.*, 2006). Siblings may even be unable to marry as they are seen as unclean or tainted, due to their relationship with the disabled family member (Lwanga-Ntale, 2003; Yeo, 2001). This may cause the family of a disabled individual to prevent them from attending school in order to protect the social status of the family.

In Uganda, a child bearing a disability is seen to be the fault of the mother. This leaves her very vulnerable to divorce, and renders her socially excluded and susceptible to poverty, especially as she is likely to be unemployed in order to look after her disabled child (Lwanga-Ntale, 2003). A physical or mental disability, combined with the fact that

extremely high proportions of disabled people have had no formal education, deems many unemployable, so much so that around 90 percent of the disabled are unemployed according to the chronic poverty report of 2004-05 (Grant *et al.*, 2004-05). Unemployment may also be a result of a self-fulfilling-prophecy, whereby society looks upon disabled people as less worthy and able to carry out jobs, thus reducing their self-confidence and making them conform to their stereotype. This may induce reluctance to find employment due to the fear that they will underperform. Non-disabled children are therefore seen as a 'better investment' in terms of education, so often receive educational priority over their disabled siblings as a result of their lowered earning potential (Yeo, 2001:24). This may also be the case in terms of nutrition and health care. Due to reduced skill levels, many disabled people cannot access loans, further limiting their capabilities and chances of escaping poverty (Lwanga-Ntale, 2003). This, together with the fact that disabled children rarely inherit land from their parents, as it may be better used by able bodied siblings, subjects them to a life of poverty, and increases the chance they will project this poverty onto their own children. To reiterate the vicious cycle of impairment and poverty, I have constructed a simple diagram (Figure 7). The quote: 'one sure way of entrenching poverty in your household, particularly if you are a disabled man yourself, is to marry a disabled woman' (Lwanga-Ntale, 2003:16) is appropriate, as it demonstrates that the high impact that disability has on producing poverty and its perception by disabled people themselves.

Figure 7: The cycle of disability and poverty

Source: Ideas from Yeo (2001) and Grant *et al* (2004-05)



This section has highlighted the multifaceted nature of poverty, and its intergenerational transmission *via* the medium of ill-health, and resultant disability, as well as highlighting the interactions between health and other fields, such as education and nutrition. Solutions to the health crisis may therefore lie in other areas, such as education and environmental management. This association may also work in reverse, so, for example, programmes specifically tackling health will have positive effects on education (Appleton, 2000; Harper, 2004; Ulimwengu, 2009) and agricultural production (Ulimwengu, 2009). As many programmes have ramifications outside their own sector, policy makers must consider the multiple aspects of poverty to generate new effective policy. For example, the very prominent link between agriculture and health must have coordinated policies in order to combat the overlapping problem effectively (Ulimwengu, 2009).

As we have seen, it may be advantageous to attack poverty at different points in the cycle, namely children, women (mothers) and household heads, using education and health interventions. It will be important to consider sequencing when implementing education and health initiatives, as the health sector would benefit greatly from the education system being implemented first, in order to increase proper usage of health facilities when they are later put in place (Harper, 2004). This however, can be argued against as the health of individuals will affect their ability to concentrate, learn and even attend educational facilities (del Rosso and Marek, 1996), meaning it may be the case that educational facilities would prefer the health services to be implemented first.

On a global scale, health allows people to benefit more from economic growth, (Harper, 2004) and good economic growth has a positive effect on health (Kimhi, 2003). To be in good health is therefore not only a valued aspect of life for individuals, but it also has a major impact on the economic growth and development of a country as a whole.

#### *The capabilities approach*

Sen developed the capabilities approach in the 1980s to generate a new angle on welfare economics, which aims to define poverty in terms of capability deprivation rather than income deprivation, or what Rawls terms resources (Garnham, 1999; Sen, 2000). This angle puts focus on what an individual is able to do, and the life they are able to lead (DeJong, 2003). This is in contrast to many approaches which focus on monetary deprivation, due to the philosophy that a region's economic growth will not always benefit the very poor, and will inevitably detract attention from their problems, as inequalities are ignored in place of overarching prosperity (Nussbaum, 2010). Although the loss of capabilities has a close association with the loss of income, focusing on capabilities allows a more relevant portrayal of how poverty is experienced in everyday life by those who face it (Sen, 2000). People facing poverty struggle to achieve a life that is full, and meaningful to them as well as being economically deprived (Nussbaum, 2010). The Human Development Reports (HDR) mention that the wealth of a country is principally its inhabitants, and therefore rather than economic growth being the target of development, development should aim to generate opportunities for people to enjoy long, healthy, meaningful lives, thus realising their potential (Watkins, 2006). This is reflected in the MDGs which strive to encourage gender equality, health and education, among other things, as these are some of the most basic capabilities (Nussbaum, 2010; Watkins, 2006). As we have seen

previously in Chapter 2, NTDs can have a large impact on MDG achievement, thus further justifying looking at them through the lens of the capabilities approach.

The founder of the approach, Amartya Sen has slightly differing ideas to Martha Nussbaum, a philosopher who collaborated closely with Sen on the approach (Nussbaum, 2000). Both Sen and Nussbaum claim that the purpose of the capabilities approach is to generate a space in which to compare quality of life (Nussbaum, 2000). However, Nussbaum (2000) aims to build on this by assessing how capabilities can be formulated into principles, which the population can demand from their governments. She also puts less stress on complete capability equality, and more emphasis on everyone reaching certain capability thresholds (Nussbaum, 2000). The biggest difference between the two capability theories is that Sen has never made a list of what he classes as central capabilities, whereas Nussbaum's theory is based on her ten central capabilities; life; bodily health; bodily integrity; senses, imagination and thought; emotions; practical reason; affiliation; other species; play and control over one's environment, which will be discussed in more detail later on in this chapter.

The capabilities approach originates with a simple question; what are people actually able to be and do (Nussbaum, 2010)? The capabilities approach arose in response to a critique of welfare economics; utilitarianism and Rawls' theory of primary goods (Garnham, 1999). Firstly, utility is the satisfaction generating from the consumption of goods, and economic activities can be explained in relation to attempting to increase utility (Marshall, 1961). Utility is therefore seen to correlate with want, and can be measured by the price an individual will pay to fulfil their want (Marshall, 1961). The utilitarianism viewpoint doesn't account for varying ideas, as the population's satisfactions are grouped together, it also aggregates aspects of life, such as health and bodily integrity into one term, satisfaction (Nussbaum, 2010). The utility measurement also does not put any emphasis on agency, the ability to be an active participant in your own life, where people may be better off when they are in control of their own decisions, even though they may end up with less (Nussbaum, 2010). However, Sen stresses that some functionings do not involve agency, especially in the realm of health based capabilities (Garnham, 1999). Garnham (1999) gives the example of freedom from malaria being an extremely sought after basic functioning, but cannot be based on agency. I believe that this is only partially true as, to some extent, people can take measures to avoid infection by correctly using insecticide treated bed nets. This obviously depends on bed net supply, socio-cultural norms and malaria education and awareness. . Agency itself can be seen as a functioning,

so an end in itself, so Sen considers it as separate to the other functionings it has helped to obtain (Garnham, 1999). Another criticism is that it's not the person's capabilities that are taken into account, but also their mental response, and these responses can be regulated to coincide with their expectations, for example a person educated to UK secondary school level may be satisfied with their education but be unaware of what their life may be like had they had further education (Garnham, 1999; Nussbaum, 2010). This is applicable even in the realm of health, whereby an individual may get used to feeling weak, hungry or fatigued and therefore may state they are satisfied with their health, but not know what it is like to be in full health, and what this could mean for their quality of life (Nussbaum, 2010).

Secondly, the theory of primary goods was built as a response to the main criticism of utilitarianism, that of its focus on psychological states. Rawls' answer was to move away from mental functions, towards actual primary goods, which, in terms of Rawls' theory of justice, are seen as things that every sane person is expected to want (Amdur, 1977); namely, social primary goods: rights, opportunities, income and self-respect, and natural primary goods: health, intelligence and imagination (Rawls, 2003). Self-respect is the most important social primary good as the other goods rely upon it to make them possess value (Amdur, 1977). Rawls' second principle of justice states that inequalities in the distribution of primary goods are justified only when they improve the lives of those in poverty, compared to when distribution is equal (Rawls, 2003). Otherwise he argues for equal distribution of primary goods.

The capabilities approach on the other hand is based on "capabilities", a measure of an individual's real freedoms in terms of choices, and the ability of that individual to convert these capabilities into the valuable activities ("functionalities") that make up a person's life (Gasper, 2002; Sen, 2000). Therefore capabilities and functionings replace the concepts of mental states and primary goods in the two preceding theories (Garnham, 1999). The term capability can be used to specify what *can* be done, what a person can *be* or what a person can *have* (Gasper, 2002; Nussbaum, 2010). Functionings therefore can be classed as what has been done, what a person is and what a person has (Garnham, 1999). Hence, capabilities can be defined as alternative functionings that the individual has/ had the potential to accomplish (Garnham, 1999; Gasper, 2002). The capability set of an individual depends on many factors, including personality and social arrangements, which can either hinder or extend their capability set and the ability of realising those capabilities (Sen, 1993). Capabilities are therefore the freedoms that people actually value such as the

ability to live to old age (DeJong, 2003), the ability to go without shame (Smith, 1793), the ability to escape morbidity, the ability to achieve self-respect and the ability to take part in community life (Garnham, 1999); as opposed to utilities or primary goods. The subsequent functionings derived from the capability set are what makes up the person's life (Garnham, 1999).

The capability approach stresses that development policies should be evaluated in terms of their impact on increasing capabilities and the consequent ability to attain functionings, as opposed to evaluation in terms of increases in income or ability to satisfy utility *via* the purchase of goods (DeJong, 2003), or the presence of basic primary goods as depicted by Rawls (Rawls, 2003). Like Rawls' theory of justice, the capabilities approach also has a focus on distribution, thus making sure that the poorest people get noticed and measures are not agglomerated (Nussbaum, 2010).

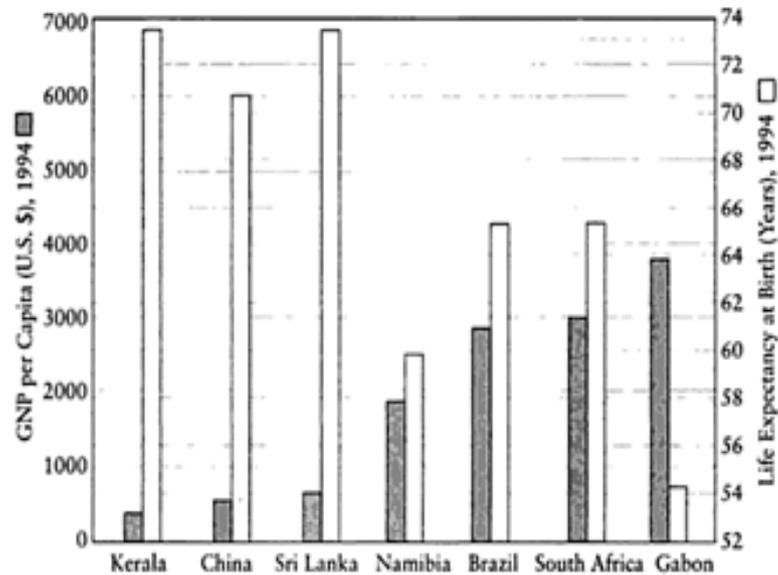
The capability approach is in keeping with the notion of cultural relativism, which ascribes individual beliefs and activities to a particular culture (Nussbaum and Glover, 2007), meaning diverse cultures will value individual capabilities differently. For example, in eighteenth-century England it was deemed necessary to own leather shoes, in Scotland this was only applicable to men and in France they were deemed unnecessary (Smith, 1793). This means that not having leather shoes in some cultures would generate shame, whilst in others, the capability to appear in public without shame would be intact even without leather shoes. The ability to convert monetary resources into capabilities (for example by the purchase of leather shoes to combat the feeling of shame (Smith, 1793)), varies between communities and households. People affected by diseases or disability will have a lesser ability to use the same monetary resources to meet the same ends as a family unaffected by disease. This is due to the increased expenditures and higher dependency ratio within the household, meaning more resources are needed in order to reach the same capability level (Garnham, 1999; Sen, 2000). What people gain from certain goods depends on certain personal features, such as health, therefore a move away from Rawls' primary goods construct is necessary, in order to properly assess individuals as different people need differing amounts of certain primary goods in order to satisfy the same needs (Garnham, 1999; Nussbaum and Sen, 1993).

In the capability approach the development status of the society is judged on the freedoms its citizens possess, rather than the traditional measurement of their utilities (Sen, 2000). Sen is therefore trying to get people to understand poverty "in terms of a different informational base" (Sen, 2000). This takes into account, for example, that not

only does unemployment decrease household income, but it also has detrimental effects on the social status, confidence, freedoms and health of the individual and their family (Sen, 2000). In Kuklys's (2005) book describing Sen's capabilities approach, it is proposed that the more attributes of welfare that are included in the measurement of poverty, the better our understanding of the situation. This is emphasised by the fact that there are large differences between, for example, gross national product (GNP) and life expectancy for the same region or country (Figure 8).

Development can therefore be classed as the expansion of people's freedoms, with the gaining of freedoms being both the ends and the means of the development process (Sen, 2000). This will of course further economic development, as enhanced capabilities naturally will increase a person's ability to earn, but, in Sen's view, economic gain should not be looked upon as the end of development (Sen, 2000). It is however helpful to know that it is possible to drastically affect the growth of the economy *via* the introduction of social opportunity in the form of increasing people's capability sets. This goes against the view of many, who believe that in order to increase these social opportunities you must first of all have economic resources to do so. Thus it is believed that the development of human resources is only possible in rich nations. This can be disproven using the example of China and India. When these countries attempted to move towards being market economies education and health care were well established in China, in comparison to India where only half the population were literate. Consequently, China adapted much quicker to the economic change due to the already established social network (Sen, 2000). India, on the other hand, believed that economic development must precede the development of human resources, and subsequently the economic advances were not smoothly integrated and did not benefit the entire population. Figure 8 adds more evidence to the hypothesis that nations do not have to wait until they are economically developed to lay down a good education and health care system by comparing life expectancy to GNP for seven countries and states.

Figure 8. GNP per capita (US dollars) and life expectancy at birth, 1994 Source: Sen (2000)



Health care and education increase life expectancy and these facilities can be inexpensive in some developing countries as they are labour intensive rather than economically intensive. Therefore, even in states such as Kerala, where GNP is extremely low, life expectancy is in the 70s and vice versa in Gabon where GNP may be the highest out of the 7 countries and states, but life expectancy is only 55 years. This therefore means that a nation's capability can be expanded without extensive economic provision, and that these capabilities can aid economic development in the future. The increase in both capabilities and economic prosperity can therefore further increase capabilities and lessen poverty providing a cycle of positive feedback.

Health is both a functioning and a capability. The opportunity to be healthy may be available from society, but society also provides the choice to lead an unhealthy lifestyle, therefore even though the opportunity for good health exists, the functioning of good health may not be realised (Nussbaum, 2000). Being in good health is seen as an end in itself, but it also provides the capability of choice (Gasper, 2002), and influences the ability to possess other capabilities. Although freedom from ill health is considered a capability, this freedom must also be evaluated in terms of functionings This is because being healthy (functioning) means having freedom from psychological and physical ill-health (Gasper,

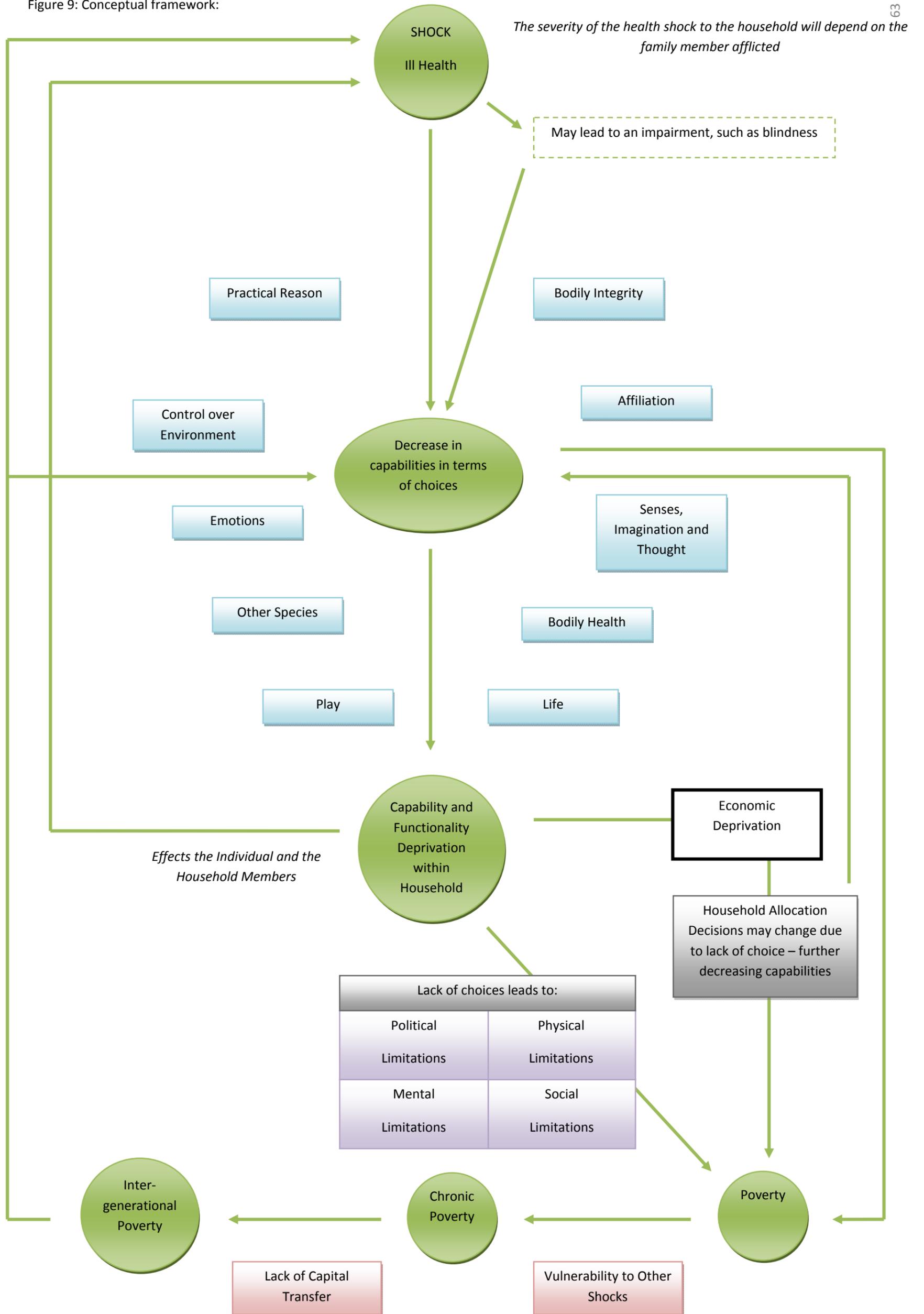
2002). Furthermore people should not only have the opportunity for good health, but have the opportunities to utilise their healthy bodies in ways that they value (Gasper, 2002).

Contrary to the Beckerian model mentioned earlier, it is believed that capabilities, such as that of the capability to have good health, cannot be judged at a family level as there are many inequalities within households, such as the unequal distribution of health care resources (Thomas, 1990). This means that some people in the household may not have the same opportunities to maintain a healthy body, or the same opportunities to utilise their healthy bodies. This relates to the section on the role that women's underinvestment plays in the maintenance of poverty (Figure 6), and the study by Lawson (2003), where it was contested whether relying on the health status of the household head to determine the family's health status was appropriate.

In conclusion, the political goal of the capabilities approach is ultimately to generate and sustain capabilities, rather than the functionings themselves, as it is important that people have the option to choose (Nussbaum, 2000). For example, healthcare in developing countries must be improved to give people the option to live a healthy lifestyle and be treated for disease, but others still may choose to lead an unhealthy life. A healthy lifestyle, where people make a good use of the services provided, cannot be enforced upon them as the act of choice is a capability in itself (Nussbaum, 2010). It is stressed that the most important aspect of this approach is that of capabilities, and that although functionings are important, and easier to measure, they can be deceptive (Garnham, 1999). Take for example the functioning of adequate nutrition; the lack of this functioning may imply both the presence and the absence of the capability of nutrition: fasting and famine respectively (Garnham, 1999). Due to these discrepancies it is agreed that even though notoriously difficult to measure and compare, capabilities should be the aspect of welfare evaluated (Garnham, 1999).

Figure 9 is an assemblage of the three bodies of literature discussed in this chapter. This conceptual framework will act as a means by which to assess NTDs' burden and detrimental influence on poverty in the next chapter.

Figure 9: Conceptual framework:



### *Explanation of model*

I begin my diagram (Figure 9) with the health shock itself, but it could have alternatively been started with poverty, due to the cyclical processes connecting ill health and poverty. The health shock itself or a resultant disability can affect the individual's basic capabilities. I have used the ten capability categories identified by Nussbaum (2000), to which all capabilities relate, to represent the capabilities approach within the diagram (Table 5). This is because they cover all basic aspects of human life, whilst leaving space for people to pursue other valued functionings (Nussbaum, 2000; Nussbaum, 2010).

Table 5: Nussbaum's ten basic capabilities

Source: Nussbaum (2000)

Capability	Explanation
Life	Being able to avoid premature death and maintain a life that is of value
Bodily Health	To have the ability to maintain good health, nutrition and shelter
Bodily Integrity	To be able to move freely, be free from violence and have opportunity for sexual satisfaction
Senses, Imagination and Thought	To be able to use the senses, to imagine, and to think in a human way informed by education, to have freedom of expression and to avoid non-beneficial pain
Emotions	To be able to develop emotions without fear
Practical Reason	To be able to form conceptions of what is good and to think rationally about one's own life
Affiliation	To be able to live with, and show concern for, others as well as having self-respect and non-humiliation
Other Species	To be able to live in concern for other living things
Play	To have the ability to enjoy recreational activities
Control Over One's Environment	To be able to participate politically and hold property to the same rules as the rest of the population

If any one of these ten capabilities is missing in an individual's life, then he or she may not be able to live life as they may personally want, and a lack of one capability cannot be counteracted by the presence of more of another (Nussbaum, 2000). At an extreme, the absence of a capability may render a person 'not really a human being at all'

(Nussbaum, 2000:73). This means that individuals can suffer from capability deprivation poverty even if, financially, they are wealthy. The list is undoubtedly a set of separate components, but they are also heavily interlinked. For example, Nussbaum (2000) states that an effective way of helping increase women's right to political participation (an aspect of the ability to have control over one's environment) is to promote literacy (the ability to use the senses, imagination and thought). Education can also lead to increased employment opportunities, which has been proven to lessen the probability that ill health will be experienced. The increased social status of women can help them to protect themselves from violence and sexual assault, an important aspect of the ability to maintain bodily integrity. The interlinked nature of these capabilities is another reason to avoid the promotion of one capability alone and neglecting the others (Nussbaum, 2000).

Nussbaum's capability set is intended to be cross cultural, and aims to represent a consensus between people with differing life values, as each capability can be given different weights according to different societies' beliefs (Nussbaum, 2000; Nussbaum, 2010). Therefore, it is an appropriate set with which to discuss NTDs, as it can apply to developing countries as well as developed countries. Nussbaum does, however, state that even though her capabilities approach is designed to be universal, specific country contexts must be explored in order to realize the approach within a certain country (Nussbaum, 2010). She also states that the list is not a 'complete theory of justice', but only provides the foundation for determining a 'decent social minimum' (Nussbaum, 2000:75). The relationship that these capabilities have with ill health is outlined below.

Firstly, the most basic of capabilities, life, comprises the ability to live to old age, and to avoid a life that is so reduced in other capabilities, and devoid of value, that it is considered no longer worth living (Nussbaum, 2000). This is inextricably intertwined with health, as life relies on being free of life shortening illness. An illness may also render an individual so lacking in capabilities that they feel their life is not worth living. The incapacitating illness, or premature death of an adult prevents human capital from being transferred to the next generation, and therefore the cycle of ill health and poverty can continue to embed itself in their lives (Grant *et al.*, 2004-05; Ulimwengu, 2009).

The second capability, bodily health, includes the ability to possess good health, to have sufficient nourishment and to have adequate shelter (Nussbaum, 2000). It is obvious that ill health will eliminate the ability to possess good health, but it is not so obvious how ill health will affect nourishment and shelter. This capability is normally indirectly affected by ill health; ill health can decrease the ability of the infected individuals, and their family,

to cultivate land, thus not only decreasing their agricultural productivity but also decreasing household income (Ulimwengu, 2009). Decreased productivity relinquishes the family's ability to generate income, as well as the ability to be self-sufficient. This reduced income may denote that food quantity may be favoured over nutritional quality, meaning important food groups, such as protein, may be excluded from the diet, as meat products tend to be more expensive. By decreasing the amount, and nutritional content of food, families become more susceptible to disease due to the impact of low nutrition on the immune system (Loevinsohn and Gillespie, 2003). Malnutrition is the most widespread predisposition to immunodeficiency in the world, with protein energy malnutrition causing problems, such as 'significant impairment of cell-mediated immunity, phagocyte function, complement system, secretory immunoglobulin A antibody concentrations, and cytokine production' (Chandra, 1997:460). The multitude of adverse effects on the immune system, as a result of malnutrition, contribute heavily to intergenerational poverty, as having a poor diet can lead to a health shock, and that health shock can contribute to the introduction of a poor diet for the next generation, and thus the cycle continues.

Ill health can also directly affect the standard of nutrition, as certain diseases may impact on the absorption or initial appetite of infected individuals, for example, people with HIV/AIDS require up to 50% more protein than uninfected individuals in order to meet the same level of nutrition (Piwoz and Preble, 2000). This is because HIV/AIDS increases the concentration of certain metabolic hormones, which metabolise carbohydrates, proteins and fats and therefore accelerating their metabolism (Piwoz and Preble, 2000). Lowered income, as a result of the onset of an illness, can also affect the upkeep, and initial purchase, of sufficient shelter. This therefore can reduce the ability to maintain adequate shelter, an important aspect in human existence and survival.

Bodily integrity is the third of Nussbaum's ten capabilities, and involves the ability to move and travel to places, to be safe from violence and assault, and to have the ability to satisfy sexual and reproductive needs (Nussbaum, 2000). Ill health can affect the movement of people in terms of a diminished physical ability and, in some cases, a lack of social ability to move from place to place. The inability to move due to social reasons can originate from discrimination, which leads to an inability to use transport, or visit the intended destination (Van Brakel, 2006). There is also a mental aspect to mobility, as a fear of potential discrimination, or a feeling of shame (Scambler, 1998; Scambler, 2009), may cause people to choose not to be mobile, meaning they don't have the ability to convert the capability of travel into a functionality due to a mental limitation.

In developing countries, it is sometimes the case that ill and disabled people are vulnerable to violence, sexual abuse and mental assaults, even from medical professionals (Heijnders and Van Der Meij, 2006). For example, in India a 38 year old 'hospital ward boy' disclosed he was HIV positive to fellow employees and they now avoid him and remark, 'Look, he is the HIV fellow', this is a perfect example of discrimination in a work place which should be highly understanding and tolerant of disease (UNAIDS, 2000:26).

The ability to effectively use the senses, to imagine and to think in an informed way is an essential aspect of being human (Nussbaum, 2000). This therefore requires that education is available and utilised so thought can be an informed process. It has already been discussed how ill health can prevent education from being obtained or effectively exploited, and this lack of education prevents the development of informed thought. This capability also involves the ability to use imagination and thought freely, and to be protected under laws of freedom of expression and religious choice (Nussbaum, 2000). However, ill health and resultant poverty may reduce an individual's political assertion, and within developing nations marginalised populations often do not benefit from the same levels of protection from the law. The senses can of course be compromised in certain diseases, such as diabetes related blindness, meaning individuals may lack a sense vital to the full experience of life (Icks *et al.*, 1997). 'Normal' imagination and thought can also become abnormal with the onset of mental illness (Andreasen, 1997).

Emotions, another highly regarded capability, involve the ability to care for others and make social attachments, along with the ability to develop emotionally in a safe and unrestrictive environment (Nussbaum, 2000). As mentioned previously, people suffering from ill health, and those with disabilities, can be taken advantage of and even abused; this can generate fear and therefore suppress an individual's emotional development. Most research into the suppression of emotions has centred around child abuse (Leitenberg *et al.*, 1992; Wolfe, 1999), but may be applicable to health discrimination. The ability of an individual suffering from ill health to show and construct emotions may be diminished due to social stigma and exclusion (Parker and Aggleton, 2003; Weiss *et al.*, 2006). This is because any experience of physical or mental abuse may represses an individual's emotional development. The emotional impact of stigmatisation and exclusion can have physical, psychological and social repercussions (Weiss *et al.*, 2006), such as, an increased susceptibility to additional health problems , a loss of self-esteem and a diminished ability to marry or maintain an existing marriage (Weiss *et al.*, 2006).

Practical reason entails the ability to formulate conceptions of what is good and to be able to reflect about life (Nussbaum, 2000). Again, the ability to think clearly may be compromised by the onset of mental illness and the conception of what is good may be impaired. Memory may also be affected by illness, which will diminish the ability to reflect on life. Practical reason is highly valued, and an essential aspect of human existence. People with impaired practical reasoning can be feared, a concept which will feature heavily when discussing the capabilities affected by late stage Human African Trypanosomiasis.

Affiliation necessitates the ability to live with others and to show concern for them, whilst being able to imagine the life of another, as well as taking part in social contact (Nussbaum, 2000). This can be impacted on by ill health, as a physical impairment may not allow the social interaction, due to an inability to be present at places of social interaction, or the inability to use body language to interact. For example, diabetes related blindness will impair eye contact so people do not feel that they are communicating fully with a blind individual (Argyle and Dean, 1965). Secondly, affiliation involves having self-respect and the ability not to be humiliated, but to be treated as an equal to others (Nussbaum, 2000). Nussbaum identifies the grounds of race, sex, sexual orientation, ethnicity, caste, religion, national origin and species, on which non-discrimination should be based, but fails to mention that of ill health or disability (Nussbaum, 2000). Ill health and disability can be an instigator of humiliation and discrimination and so can also affect this basic capability, and should therefore be included within Nussbaum's list (Ablon, 2002; Egers, 2009; Scambler, 2009; Weiss *et al.*, 2006).

The ability to be able to live with, and have concern for, other species (Nussbaum, 2000) could have specific implication when it comes to zoonotic or vector borne diseases. The transmission of many NTDs involves mammals and insects and they therefore pose a particular problem in terms of this capability, and one which will be further explained within the next chapter.

Play is a key capability and involves the ability to laugh and take part in recreational activities (Nussbaum, 2000). Without a fully functioning body or mind this may become challenging. For example, if social acceptance is an issue, simply getting the opportunity to play with peers may be challenging for children. Any physical manifestation of illness may similarly prevent the opportunity to play materialising, especially if a child is the one affected by disease.

Finally, the tenth capability; having control over one's own environment, means having the ability to participate in political choices that affect an individual's life, as well as the ability to have property and have equal property rights in comparison with others (Nussbaum, 2000). This also involves the ability to seek employment on equal terms to others. The ability to participate politically may depend on attending meetings within the community, and if physical access is a problem then this basic capability may not present in the individual's capability set. The ability to attend meetings would also be complicated by stigma and the act of exclusion on the grounds of ill health. The other aspects of this capability will be discussed in more depth in relation to NTDs.

These effects on people's basic capabilities act to generate limitations, most obviously physical limitations as a consequence of the physical symptoms of the disease, for example: decreased mobility, pain or a sensory deficit. The infected individual may also suffer from social limitations. These limitations are a result of the loss of social capabilities and are generated by environmental discrimination, as opposed to the symptoms of the disease itself. The three main types of environmental discrimination are those of the physical world, policy, and the attitudes of people (Grant *et al.*, 2004-05). Grant *et al* (2004-05) use this theory in the context of disability, whereby the environmental discrimination of an individual with an impairment leads to that person to suffer from a disability, as depicted in Figure 7. This theory can also be applied to ill health, where the disease burden is increased by the impacts of environmental discrimination. Psychological limitation is usually derived from self stigma and the subsequent loss of self-esteem; self stigma occurs when discrimination becomes internalised, and the individual feels a lack of self-worth and confidence (Goffman, 1963). This can lead to a mental limitation so that the individual may find it difficult to get a job, even though they are physically capable, through lack of self-esteem and subsequent failure to apply for a job. This may also manifest as a social limitation as the individual avoids social situations thus isolating themselves (Scambler, 2009). As previously detailed, a lack of political capabilities will inevitably lead to political limitations, where an individual is unable to contribute to the political choices that affect their lives.

The limitation directly affecting the household of an infected individual is that of social limitation (Rafferty, 2005). This occurs as the stigma attributed to the ill individual is passed on to their family members (Rafferty, 2005). This therefore may limit the family's social interactions and social support network as they too are ostracised from society. This topic is covered in more detail in the next chapter.

The lack of capabilities, and ultimately functionalities, can result in economic deprivation, thus adding to the already burdened, capability deprived, household. Economic deprivation affects the household's allocation of educational, nutritional and health directed resources. When these basic rights are unaffordable, poverty becomes more severe and more capabilities are lost. This feeds back to the top of the diagram with economic deprivation leading to additional capability loss. A decrease in capabilities, as well as economic losses, means the household becomes more vulnerable to consequent shocks, such as another bout of ill health. The household may then enter a state of chronic poverty, meaning poverty will persist for an extended period of time as the household has no means of escape. A state of chronic poverty will further impact on a family's social status and acceptance within the community, and thus social, political and mental limitations will be further increased. This state of chronic poverty leaves the family with little in terms of capital (human, socio-cultural, socio-political, financial/material or environmental/nature (Moore, 2001)) to transfer to the next generation. This therefore increases the likelihood that poverty will persist in the next generation and that they too are vulnerable to health shocks.

Another way in which resources may be allocated differently is in terms of time. The time diverted from normal activities in order to care of an ill individual, or to counteract their lack of productivity may be compensated for by the extraction of children from education into paid labour or house and caring work thus beginning the transmission of poverty to the next generation by depriving them of the ability to learn (Ulimwengu, 2009). The lack of, human, socio-cultural, socio-political, financial and material capital leaves the next generation in a state of poverty, which has its own risk factors, such as poor sanitation, lack of education to identify and treat disease, lack of finance to purchase any treatments and lack of social support. These will increase the likelihood that a health shock will occur, and therefore the likelihood that poverty will be deepened.

This chapter has created a framework in which to assess the impacts of NTDs in terms of capability deprivation. The suggested targets of interventions will be useful to consider when exploring NTDs, as many have a disproportionate prevalence among children, and women often suffer for extended time periods in comparison to men. In the next chapter I will therefore extend these ideas and look at how NTDs specifically act to reduce people's basic capabilities, and how the extent of this loss will depend on who is affected, in terms of: age, gender and position within the household.

## Chapter 4

### Identifying the poverty pathways that result from diminished capabilities as a consequence of NTDs

Following on from the previous chapter, this chapter aims to place NTDs within the conceptual framework that was outlined for ill health as a general condition. NTDs may pose different problems to other ill health conditions due to their neglected status and because people who develop them are highly stigmatised. The reasons behind the neglected status of NTDs were outlined in chapter two, as well as the consequences this neglect had on: accurately assessing their disease burden, new research into treatments and prevention, the achievement of the MDGs, and people's awareness of NTDs. This chapter will firstly examine and review health-related stigma in order later to apply this concept to NTDs. The main body of the chapter will detail how NTDs can be assessed through the lens of the capabilities approach, using three specific NTDs as case studies; cutaneous leishmaniasis, trachoma and late stage Human African Trypanosomiasis (HAT). These three diseases were chosen because each has a differing mode of transmission and each affects a different part of the body; the skin, the eyes, and the brain respectively. The first aim is to discover whether these diverse diseases have different effects on capabilities, or if they impact on different capabilities altogether.

According to Van Brakel, the 'consequences of stigma are remarkably similar in different health conditions, cultures and public health programmes' (Van Brakel, 2006:307). Therefore, by analysing the three NTDs I will examine the strength of this statement. On the presumption that Van Brakel's statement is accurate, although stigma may be attributed to different features of a disease, it still has very similar consequences for the individual and the household in terms of economic, social, mental and political limitations. This chapter will therefore explore this idea further as well as identifying the capability-depriving features of each disease.

#### *Health-Related Stigma*

It is common for members of a defined social group to stigmatise what is different, as this is how a community produces its collective identity. Determining who is different enables them to label themselves as 'insiders' and justify themselves as 'normal' (Falk,

2001). However, what is considered a deviation from the norm in one society may in fact be considered normal in another (Jones *et al.*, 1984). The application of this difference to another human being can be carried out without ever having met an individual with the 'different' attribute. This implies that people can make false assumptions, which are often congruent with the view held by a society or sector of society. For example, the assumption that individuals with a mental illness are dangerous is often made before any direct experience of mental illness has been encountered (Link *et al.*, 1999). Stigma can therefore result from a collective opinion, meaning a person within the society can feel prejudice towards others either because that is what society has embedded in them, or because of fear of being rejected by that society for not conforming to the beliefs of the majority (Jones *et al.*, 1984).

The term stigma stems from a Greek word used to describe the mark burnt on to certain people's skin in order to make their social status visible. These were often slaves and meant they could be identified and returned if they ever escaped (Falk, 2001; Goffman, 1963). The word stigma later became used to indicate a 'mark of disgrace or physical disorder' (Hotez, 2008b:1). Now the term stigma refers to a feature of an individual that is discredited by their peers, which detracts from viewing the person as a whole (Falk, 2001). The assignment of stigma is developed through a number of stages. Firstly, there is an element of social selection as many human differences are overlooked and only some become the focus of stigma and discrimination (Link and Phelan, 2001). This also applies to health-related stigma, where some medical conditions are considered less socially acceptable than others, for example, skin cancers are not as stigmatised as schizophrenia (Link and Phelan, 2001). Secondly, this labelled difference must then be associated with negative stereotypes, such as the belief that people with psychological illness, such as schizophrenia, are dangerous (Goffman, 1963; Link and Phelan, 2001). When this distinction and association with a stereotype occurred, a separation of us and them may transpire. This separation can justify for 'us', the discriminatory treatment of 'them' and the difference that warrants the discrimination can become the master status of the individual (Link and Phelan, 2001). The transfer of difference from an aspect of their person to a master status means the individual is now defined by their difference, as opposed to their difference being a mere feature of the person as a whole. Stigma resulting from any human difference can lead to social exclusion, and thus affect other aspects of the individual's life. A group of people possessing a discriminated master status hold low amounts of social power, thus limiting their ability to stigmatise others with any conviction,

furthering their feeling of isolation (Link and Phelan, 2001; Weiss *et al.*, 2006). This lack of social power can mean that stigma leads to further stigmatising conditions, for example, a socioeconomic stigma may lead to a poorer health environment, which predisposes poorer health. A further health-related stigma can ensue, which can in turn lead to further socioeconomic suffering (Weiss *et al.*, 2006).

Erving Goffman (1963), a prominent figure in the field of stigma, identifies three aspects of difference that may lead to someone becoming stigmatised: 'abominations of the body' (physical deformities), 'blemishes of individual character' (mental disorders) and 'tribal identity' (such as, race, sex or religion). However, in relation to health-related stigma, Weiss and colleagues (2006) identify some limitations of Goffman's original work for use in health policy for a modern audience, especially within developing countries. Firstly, the language Goffman uses is dated and difficult to apply to the definition and division of applied health policies. Secondly, given his aim was to make the term stigma of broad meaning, he does not explicitly address health-related stigma, therefore the specifics of this experience are still to be elaborated. Thirdly, his concept of a dominant norm can become problematic when doing cross-cultural research, as it hinders the recognition of successful multicultural societies. This is because deviance from the dominant norm does not necessarily result in stigma or discrimination within multicultural societies.

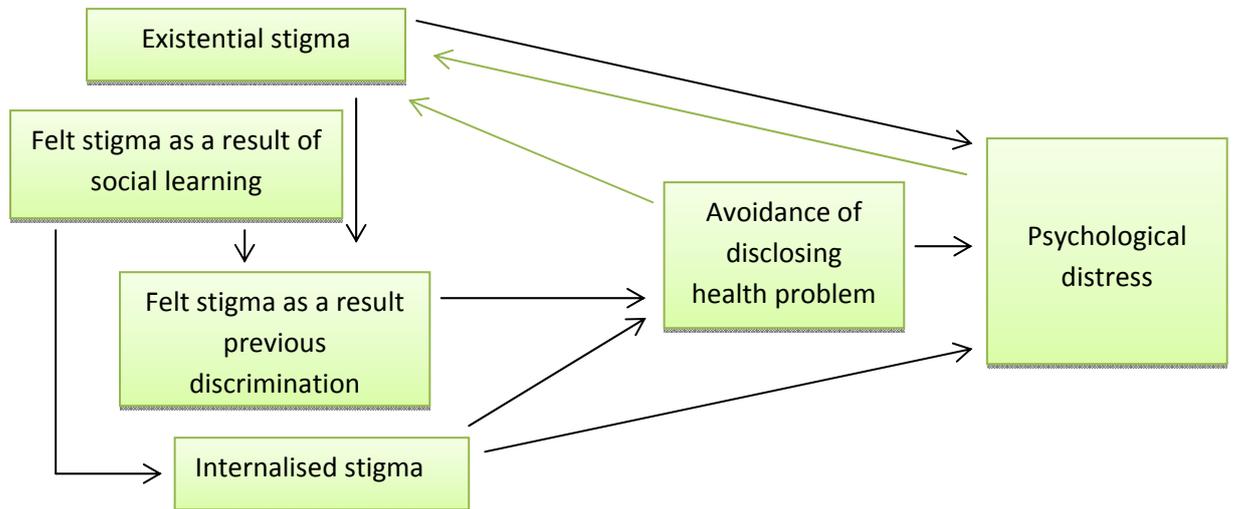
Increasingly, studies have elaborated on health-related stigma and the surrounding issues (Arole, 2002; Chaturvedi *et al.*, 2005; Hotez, 2008b; Link and Phelan, 2001; Van Brakel, 2006; Weiss *et al.*, 2006). Stigma greatly adds to the burden of disease, for example, it has been claimed that labelling a mental disease directly affects the extent of the disease burden. The increased stereotyping associated with the label can result in an increase in unusual behaviours, so as to effectively conform to the stereotype (Scambler, 2009). The progression of a disorder's severity can be exacerbated if the responsibility of becoming, or remaining, in a state of ill health is attributed to the patient, as opposed to it being attributed to chance or the environment (Littlewood, 1998). It is this self-blame that can lead to the internalisation of stigma, which is defined as the acceptance of the stigma as valid (Steward *et al.*, 2008). It has been found that to combat this feeling of being at fault, a high proportion of disabled people are religious, or seek social support, in order to relinquish responsibility, and attribute the illness to a higher power (Johnstone *et al.*, 2007). The ascription of blame to an entity beyond their control decreases the disease's mental burden, and therefore ultimately increases the individual's quality of life.

Van Brakel (2006) defines four forms of health-related stigma, all with differing debilitating effects: existential stigma; perceived or felt stigma; internalised stigma; and stigma produced by health services, policy and the media. Existential or enacted stigma involves the direct experience of discrimination, or exclusion, in the context of certain social activities, as a consequence of the characteristics that render the individual contaminated, reprehensible, and socially unacceptable (Scambler, 2009). The stigma experience can be further intensified by the addition of felt stigma. Felt stigma is generated either by the fear of already experienced existential stigma, or the perception that existential stigma could occur, even though discrimination has yet to be encountered directly. The fear of stigma without actually having encountered direct discrimination is a result of social learning, whereby the experiences of others are relayed to potential sufferers of stigma *via* the medium of storytelling. Felt stigma differs from the third form, internalised stigma, which is often a consequence of felt stigma (Steward *et al.*, 2008). Internalised stigma is directed toward the self, and the stigmatised status is accepted and believed to be justified and deserved (Scambler, 2009; Steward *et al.*, 2008). This is unlike felt stigma alone where an individual may fear potential existential stigma, but does not feel that this stigma is deserved or warranted.

A particular problem with both internalised and felt health-related stigma is that it can affect people's health-seeking behaviour and treatment adherence, and thus hinder the progress of disease control programmes. The problems of low treatment adherence and poor health-seeking behaviour can therefore result from the fear that enacted stigma may be experienced either on the journey to a health centre, at the centre itself, or when a course of treatment has commenced. Another scenario is that treatment may not be sought as the individual feels so deserving of the health problem they are suffering from that they, for that reason, feel undeserving of any treatment. The final form of stigma may also heavily influence the decision to seek treatment. This is the stigma produced not by the lay public within the community, but by health professionals and policy makers. The stigma generated by these professionals can be eminently damaging to the success of health programmes as the very people who are there to help can no longer be trusted by the stigmatised individual. Figure 10 shows how these different forms of stigma interact to produce psychological distress, as well as how they influence each other, using the example of HIV, a highly stigmatised disease that a lot of health-related stigma literature has centred on (Steward *et al.*, 2008). In addition to Steward *et al.*'s linkages, another connection can be added into the diagram, that of the effect that internalised stigma and the avoidance of

disclosure have on enacted stigma. Avoiding disclosure can generate anxiety when talking to others, and the infected individual may come across as timid or anxious, potentially leading to further discredit and existential stigmatisation.

Figure 10: Theoretical framework linking the facets of stigma, avoidance of HIV serostatus disclosure, and psychological distress



Source: Adapted from Steward *et al.* (2008)

An early study by Shears and Jensema (1969) illustrated the characteristics that they believed lead to stigma; people were asked how much social interaction they were prepared to have with others with different conditions. They identified six dimensions which determined the levels of interaction people were prepared to have:

- Visibility
- Communication interference
- Associated stigma
- Reversibility prognosis
- Incapacity extent
- Difficulties in everyday life.

The most acceptable disabilities were found to be those that were clearly visible, such as amputations or blindness (Shears and Jensema, 1969). This is thought to be because there is no need for the impaired person to explain their problem, and the person interacting with them knows what to expect (Shears and Jensema, 1969). This notion

however is contested and contradicts the findings of other studies, which lead to the hypothesis that if the impairment can be concealed, less stigma is attached to the individual (Jones *et al.*, 1984). These two distinct and opposing findings may be a result of the use of different diseases in the investigations. For example it may be that case that concealing an extremely stigmatised disease such as HIV/AIDS would decrease stigma but the concealment of a more socially acceptable condition may not benefit the individual due to the added anxiety resulting from concealing an illness and possible lack of additional support. Secondly, any interference with communication, such as, speech problems, memory problems, and a lack of appropriate eye contact, is likely to result in an increased stigma. This is likely to be a result of the awkwardness associated with impaired communication, and the fact that people tend to avoid awkward situations as they can be a propellant for anxiety. Thirdly, people often stigmatise differences they have never encountered due to the culturally determined stereotypes that are seen as the norm. The more culturally unacceptable a condition, the more stigmatised it will be, even among those who have never had direct experience of an individual possessing that difference.

In Shears and Jensema's study (1969) respondents were asked to state whether they would be happy to associate with people with varying conditions at differing levels of intimacy. When asked about very intimate relationships such as marriage and close friendship, the prognosis, extent of incapacity and the difficulties in everyday life were considered more important than the previously discussed criteria; visibility, communication interference and the associated stigma. This means that a hereditary or incurable condition, a highly incapacitating condition or a condition causing a large amount of difficulty in everyday tasks would be more highly stigmatised, and close relationships would be avoided with individuals possessing conditions with those features (Shears and Jensema, 1969).

Jones *et al* (1984) have generated a slightly different set of six stigma dimensions; can it be concealed, can it heal/ be cured, does it affect social interaction, what does it look like, how did it come about and does it pose any dangers? All of these factors can determine the level of direct discrimination and the feeling of otherness both by society and the individual possessing the stigmatising feature. An important aspect in determining if enacted stigma takes place according to Jones *et al* (1984), is whether the potentially stigmatising feature can be concealed, as if the condition goes undetected then the individual cannot be discriminated against (Ablon, 2002; Jones *et al.*, 1984). This is known as 'passing', and depending on the nature of the illness can be either easily done or it can take large

amounts of effort to 'pass' as normal (Scambler, 2009). However, even though enacted stigma may not be experienced if the condition is hidden, self or internalised stigma is still likely to be felt by the individual. Having to disguise a condition may result in anxiety, due to the fear that it may be accidentally revealed, the inability to decide whether to reveal or not, or the guilt associated with being ashamed of their condition and keeping it from close friends and family (Ablon, 2002; Goffman, 1963; Jones *et al.*, 1984). This was shown by the fact that people with concealed blemishes were more awkward around people who did not know of their potentially stigmatising feature, than when they were in the company of people who were aware (Jones *et al.*, 1984). This awkwardness in itself may in fact evoke stigmatising and avoidance behaviours from others as they try to avoid potentially embarrassing and difficult situations, akin to the avoidance of people with communication problems as discussed previously.

The second determinant of stigma, according to Jones *et al.* (1984), is whether the illness can be cured, as if irreparable, a higher stigma may endure. If curable, the stigma suffered is likely to be less severe; this may not be purely due to the fact that the disease is curable, but also because the behaviour of the infected individual is likely to differ depending on their prognosis and thus may have the potential to be stigmatised.

The extent to which an illness is destructive to social interaction is a major determinant in the presentation and severity of stigma. In the case of a physical deformity the stigmatiser faces a conflict, that being whether to stare at the mark as they may want or to not stare so as not to be rude. This conflict, it has been speculated, results in 'normals' avoiding those with a physical mark in order to avoid this distressing conflict (Jones *et al.*, 1984). The more aesthetically unpleasing a person may look due to deformity, the more they may be seen to be stigmatised as they may not be regarded as a whole human being. Jones *et al.*, like Shears and Jensema, believe that assaults on the physical features required for communication can hinder social interaction, such problems that prevent speech, eye contact and hand gestures for example. These communication problems will be looked at in more detail when considering NTDs.

Another very important aspect determining the extent of stigma is that of the condition's origin. As was mentioned earlier, attributing personal responsibility to a mental illness resulted in a worse prognosis for the patient, as their internalised stigma was greater (Littlewood, 1998). Heightened existential stigma is then likely to occur as an act of self-preservation, meaning that people will stigmatise an illness as the fault of the beholder, so as to assure themselves that it cannot happen to them, as they have done nothing wrong

(Jones *et al.*, 1984). This differs slightly from Shears and Jensema's view that hereditary conditions are most highly stigmatised. Jones *et al.* (1984) found that not only are hereditary diseases additionally stigmatised at the level of intimate relationships, but conditions that imply an undesirable personality trait will also be avoided at the level of close personal association. For example, the risky behaviours associated with HIV/AIDS, such as promiscuity and drug use, could be associated with the reduced willingness to form personal relationships with infected individuals. This is in opposition to hereditary diseases, where the individual is not at fault and has not taken part in any stigmatising behaviours, therefore may be subject to reduced stigma in terms of close friendship, an idea that was not supported by Shears and Jensema. This will be discussed in more detail when looking into the stigma of NTDs due to differing modes of transmission and differing false transmission beliefs. This difference may not be total contradiction as Shears and Jensema explained that this view mainly occurred when it came to describing whether normals would have a close relationship, such as a marriage, with people with hereditary conditions. This is because the hereditary condition would directly affect decisions to have a family with that individual.

Lastly, the idea of a posed danger can exacerbate stigma, either through contagion, violence, the possibility of a courtesy stigma or an evoked anxiety about the fragility of our own human bodies (Jones *et al.*, 1984). This can occur even if the danger is false, such as in the case of leprosy contagion (Arole, 2002; Weiss *et al.*, 2006), as detailed in the next section.

I will use these dimensions as a framework for assessing the stigma of NTDs in the next subsection, where existing literature is less available. Discussing the amount of stigma attributed to certain diseases will allow me to more accurately assess the extent to which capabilities (specifically social and mental capabilities) are affected in sufferers of NTDs.

Stigma not only contributes to individual disease burdens, but to poverty as a whole (Alvar *et al.*, 2006; Stienstra *et al.*, 2002; Vlassoff *et al.*, 2000). It is therefore important that the issue of stigma is addressed, as well as tackling the disease itself, as stigma has a dramatic effect on the success of intervention programmes. Stigma has indirect effects on public health interventions as it increases the chances of the disease progressing to a clinical level and heightens the risk of the development of disability (Van Brakel, 2006). This may be due to either perceived or actual stigma causing fear of going out in public due to embarrassment, and apprehension of public feedback. Because of these effects on health-seeking behaviour, stigma is a serious problem as it means that

diagnosis, and thus treatment, are delayed which will, without doubt, result in a worse prognosis and an increased time frame when disease transmission can still occur. Due to the multifaceted nature of stigma, an equally complex system of differing interventions is required, as simply educating the 'normals' is not enough to eradicate a health-related stigma (Cross, 2006). This is because other dimensions, such as felt stigma resulting from storytelling, may not be eradicated by the education of potential stigmatisers alone.

### *NTDs, Capabilities and Poverty*

In this section I assess NTDs through the lens of the capabilities approach by placing them into the conceptual diagram generated in the previous chapter. Muela Ribera *et al.* (2009) briefly mention the interaction between NTDs, stigma and the capabilities approach by stating that the stigma attributed to NTDs acts to produce social inequalities. They then quote Sen, stating that an inability to "mix with others might directly impoverish a person's life, and also, additionally reduce economic opportunities that come from social contact. Indeed, quite often different aspects of capability deprivation and social exclusion may go together" (Muela Ribera *et al.*, 2009:1). This chapter aims to build on this linkage further by firstly assessing NTDs as a health shock and explaining the severity of this shock in terms of physical, social, mental, political and economic limitations using the conceptual framework. I will consider how stigma, among other things, can reduce the capabilities of people living with NTDs in more detail, paying specific attention to the effects they have on reducing or eliminating the ten most basic capabilities, as outlined by Nussbaum (2000).

NTDs, like any other disease or health problems, act as health shocks and may drive a family into poverty either short or long term. NTDs are often physically and socially life changing, meaning they are also subjected to high levels of stigma, which further impacts on people's capabilities and can drastically heighten the severity of the health shock. Due to their relative rarity, and the lack of new research into alternatives, the treatments available can be more expensive and long term than treatments for less neglected diseases, therefore requiring a higher amount of economic expenditure and commitment to fulfil treatment needs (Caines, 2004). The specific requirements of NTDs can therefore lead to the generation of a large health shock.

The degradation of people's basic capabilities as a result of NTDs will firstly be discussed on a general level, and then more specifically for dermal leishmaniasis, Human African Trypanosomiasis and trachoma. As noted in chapter 2, NTDs can have

incapacitating physical problems, including: blindness (trachoma and onchocerciasis), hydrocele (lymphatic filariasis), swelling of the spleen (visceral leishmaniasis), anaemia (STHs and schistosomiasis), malnutrition (STHs), scarring, disfigurement and loss of a limb (cutaneous leishmaniasis, leprosy and Buruli ulcer), itching (HAT and onchocerciasis) and chronic pain (draculiasis). All these features are debilitating in some way and will restrict, if not eliminate some basic capabilities. A physical condition alone can eliminate the right to bodily health, the ability to use the senses, to play and even to lead a valued life. Due to the physical aspects of disease, the capability of choice is also compromised. For example, the inability to walk long distances due to a heavy and cumbersome hydrocele, a result of lymphatic filariasis, decreases the ability to weed for long periods of time, and thus this functionality is not observed. From this we can deduce that the infected individual no longer possesses the capability to choose their working hours due to the physical limitations of the hydrocele, and consequently must rely on other family members to provide for them financially (Gyapong *et al.*, 2000). Blindness, as a result of trachoma and onchocerciasis, among otherwise fit and healthy adults also prevents individuals from working efficiently, compromising their productivity (Hotez and Brown, 2009)(Hotez *et al.*, 2009). This can cause more severe problems for subsistence farmers who, when they have reduced capability to work on their own land, cannot afford to pay others to work for them (Hotez *et al.*, 2009). This leads to a reduced harvest and therefore NTDs may contribute to the world food crisis (Hotez and Thompson, 2009). In addition, when diseases such as onchocerciasis become prevalent within agricultural communities, villagers may be forced to relocate to often poorer soils in order to escape disabling disease, further affecting agricultural productivity and stability (Remme *et al.*, 2006). These people may feel they have lost the capability to choose where they live, together with the loss of ability to have adequate nutrition, shelter and to be free from disease.

These physical limitations mean that NTD sufferers often require their family to look after them. As a consequence, the family may become economically limited and changes to the allocation of resources may transpire. To add to the resultant financial strain of a reduced household income, treatments are often extremely expensive for some NTDs (den Boer *et al.*, 2009; Moore and Lockwood, 2010). Accessing health care can lead to 'catastrophic financial payments' which can push households into or towards poverty (Xu *et al.*, 2003:111). The cost of treating Buruli Ulcer in Ghana for the poorest quartile represented between 193 and 315% of their annual earnings, a figure that would drive even well off households into economic poverty (Conteh *et al.*, 2010). The treatments for

visceral leishmaniasis are also costly and include sodium stibogluconate and amphotericin B, both costly, prolonged treatments of 20 and 5-30 days respectively, and the shorter term courses of liposomal amphotericin B and the oral drug miltefosine, both expensive treatments (Moore and Lockwood, 2010). Visceral leishmaniasis treatment is therefore extensive and costly, and often causes severe side effects, such as cardiac problems, renal complications, liver conditions, diabetes and vomiting, adding to the costs of aftercare. If visceral leishmaniasis is left untreated however, or if treatment is ceased prematurely, the disease can lead to death (den Boer *et al.*, 2009). Where patients do not conform to the full treatment course, drug resistance can also develop and this new strain can then be passed on to others, generating primary resistance and thus a more severe health shock in subsequent sufferers (den Boer *et al.*, 2009; Moore and Lockwood, 2010). Visceral leishmaniasis is however one of a few exceptions, as many NTDs do not result in death, but do lead to life-long disability and poverty. Although many NTDs have low mortality rates, the health shock they generate may be extensive, and plunge the household into poverty more rapidly, or for a longer period of time, as is the case with Buruli Ulcer in Ghana (Hotez and Brown, 2009).

Several NTDs affect the economic potential of households as they affect the health of children; STHs and schistosomiasis impair growth and fitness, whilst hookworm and schistosomiasis generate anaemia. Anaemia can impact children before they are born, as anaemia in the mother leads to low birth weights and increased mortality (Hotez *et al.*, 2009). This may not eliminate specific capabilities, but it may reduce them, for example they may have a diminished ability to play with others as they are less physically developed and easily fatigued but they can engage in some forms of play. This notion is in keeping with Nussbaum's idea of capability thresholds whereby differing capability levels can be reached. As well as the obvious effects of the physical limitations generated by NTDs on the ability of children to attend school, some NTDs result in diminished cognition and memory, the main culprit being hookworm (Harper, 2004; Sakti *et al.*, 1999). The association between hookworm and reduced cognitive performance intensifies with age (Sakti *et al.*, 1999), highlighting the importance of deworming at a young age. Early treatment denotes less severe physical, social and economic problems and even the reversal of already associated limitations (Brito *et al.*, 2006). For example, deworming in Kenyan schools resulted in reduced absenteeism from school by a quarter, and was therefore the cheapest way to boost school attendance (Miguel and Kremer, 2004). This study highlights that the often simple measures of controlling NTDs can have a huge effect on generating and

preserving capabilities, which will inevitably decelerate the cyclical effect of ill health and poverty. Not only is the ability to attend school relinquished, but they are more likely to reach their full academic potential, due to the cognitive benefits of being infection free. This generates a good start in life, which is essential to becoming a successful adult and staying out of poverty. In other words, a large set of capabilities in childhood will help to maintain a large capability set through to adulthood, and thus minimise poverty in terms of capability deprivation. This will also have an intergenerational effect, as a parent with a high capability set is likely to produce and raise a child with a similar standard of capabilities. Not only do the physical aspects of disease generate capability deprivation, but the social effects can be equally, if not more, important in terms of exacerbating capability deprivation.

There is an emerging interest in, not only why NTDs are highly stigmatised but how the stigmatised individual, and their family are affected by this social change, i.e. how their capability sets have been modified and how this is dealt with. The added stigma of some diseases can further increase the intensity of the health shock. Diseases are more likely to have a higher stigma if the condition is rare, as with NTDs, due to a lack of exposure, subsequent lack of knowledge and the absence of time to become tolerant of a condition (Jones *et al.*, 1984). Stigma can lead to a more multi-dimensional state of poverty making it harder to escape, and more likely to be maintained. On top of this there is also the stigma resulting from NTDs' link to poverty and productivity reduction, which generates another basis for discrimination and exclusion (Hotez and Ferris, 2006). Saying this, little research has been carried out in the field of NTDs and their stigmatising features, and even less on the how stigma may impact on their capabilities. There are a number of reasons why the social effects of NTDs have been under-researched, as where research has taken place, it has focused on etiology, transmission mechanisms, treatments and vaccines, as opposed to the social impacts and ways to beat social stigma to lessen the burden of NTDs. *The Thematic Reference Group on Social Sciences and Gender: Annual Report 2009 Draft* (2009) states that understanding the social dynamics and impacts of tropical diseases has become of great importance, because these infectious diseases can persist as social processes. Nonetheless, Stienstra *et al.* claim that their 2002 paper is the first to discuss the social impact of Buruli Ulcer. This justifies the need to continue to research the social aspects of NTDs, especially in terms of stigma, in order to control and eliminate the problem of NTDs effectively, as merely providing a treatment service will not ensure people will make use of it and will not eliminate the social problems faced after an infection has cleared.

Stigma greatly adds to the burden of disease, especially when the disease is highly visible or disfiguring, such as the NTDs Mucocutaneous Leishmaniasis, Leprosy and Buruli Ulcer (Hotez, 2008b). An infected individual may not be stigmatised by the infection itself, but by the resulting disfigurements that are a product of the disease, even if the person has been cleared of active infection (Cross, 2006). Taking the example of leprosy, despite its disfiguring consequences and painful appearance, is in fact relatively painless and difficult to catch, and thus the diagnosis of this highly stigmatised disease may be a lot more distressing than the symptoms themselves (Arole, 2002; Weiss *et al.*, 2006). Diagnosis can lead to an increased level of felt stigma and subsequent concealment of the disease, even from the medical profession (Scambler, 2009). The fact that leprosy lesions look extremely painful, but are in fact not, may also increase stigma towards the infected individual, as it is seen as unusual, something to be wary of and even supernatural (Cross, 2006). The diagnosis and consequent stigma may be a worse burden than the physical disease, due to the negative consequences that often result from leprosy stigma, such as the entry into vertical control programmes (separate from the general health system), and ostracism from society due to fear of contagion (false beliefs that minimal contact can pass on the disease or a belief that as victims of witchcraft they could transmit the disease). All of this can lead to fear of existential stigma or internalised stigma, a 'self-destructive acceptance of relegation as a second-class member of society' (Ulrich *et al.*, 1993:445). The resulting fear, shame and diminished self-esteem (Arole, 2002; Ulrich *et al.*, 1993) can drastically affect the life of a person living with leprosy, and can diminish their well-being to the extent that they no longer value it, a loss of one of the most basic and important capabilities as detailed by Nussbaum (2000).

Falk (2001) believes that incurable diseases lead to the greatest amount of stigma, as they are associated with death, a very stigmatised event. How then is leprosy so stigmatised when it can be easily and effectively cured (Rafferty, 2005; WHO, 2010b)? It may be due its history as a highly feared and disfiguring disease, mystified by the fact that there was no known method of transmission or cure. This belief and fear may still be prevalent due to the extremely large impact leprosy had on sufferers' lives in the past. The stigma of leprosy can therefore be seen to be a driver of poverty as opposed to the disease itself, as if proper treatment is sought when symptoms are first experienced the physical problems can be minimal. Leprosy lesions can look like many other diseases such as cutaneous leishmaniasis, syphilis, yaws, mycosis fungoides and lupus vulgaris, which are often less stigmatised even though they may have similar presentations (BMJ, 2010; Ulrich

*et al.*, 1993). The stigma therefore should be similar for these diseases before a diagnosis, but post diagnosis the label of leprosy can generate a more severe stigma with more severe consequences (Ulrich *et al.*, 1993). The social identity of a person suffering from leprosy changes, and they are not considered as a person with leprosy but as a leper, their illness becomes their 'master status', as opposed to something they have (Ablon, 2002; Falk, 2001:50). This therefore means that the distinction between us (non-infected individuals) and them (people infected with leprosy) has been made, as well as the justification of ill treatment (Link and Phelan, 2001). The stigma from leprosy is perfectly reflected in a quote from Nelson Mandela, "The stigma is something that kills human beings - sometimes far more than the disease" (cited in (Egers, 2009:1). The stigma is so great that that the term leprosy is used as a metaphor to describe stigma (Cross, 2006), and is often considered alongside HIV/AIDS in the stigma literature (Frist, 2000; Heijnders and Van Der Meij, 2006; Van Brakel, 2006).

However the removal of the stigma may not reverse the effect it previously had on the individual's self-esteem, as the internalised negativity can reach beyond that purely directed towards the stigmatising feature and become a negativity applying to the whole self, which can generate a spoiled identity (Jones *et al.*, 1984). This means that as well as campaigning to prevent 'normals' from stigmatising people with NTDs, programmes also need to address the effects of self-stigma on the infected individual themselves. To regain a full set of capabilities after infection by a potentially stigmatising NTD the physical limitations, social stigma and self stigma all must be addressed, a hard feat within resource poor countries. This is especially problematic when it comes to NTDs as these diseases are primarily found in the poorest areas of developing countries (WHO, 2003).

In conclusion, the added stigma of NTDs, due to their association with poverty and fear, will bring further losses to the individual's and household's basic capabilities. The capabilities that will be most affected by stigma are social capabilities, such as affiliation and play (Nussbaum, 2000). These social limitations may also increase an individual's mental limitations, mainly *via* a loss of self-esteem as a result of experienced stigma. As mentioned previously, an inability to get to community meetings will reduce a person's political capabilities. Again, stigma can generate political limitations as people may not be accepted into meetings, or may not be able to leave the house through fear, meaning yet again social limitations have compromised another aspect of the person's life. The high impact of stigma is evident, as it can affect every other aspect of life, generating further capability losses.

However attributing much of the adversities suffered by victims of NTDs to stigma may overstate the case, and just because it is the current trend in research, and the easy answer to problems, such as low health-seeking behaviour, many other factors contribute to behaviour and should not be ignored (Muela Ribera *et al.*, 2009). The overemphasis on stigma may be unbeneficial to improving health care because it detracts from problems of infrastructure and affordability of treatments, meaning that the improvement of health care systems themselves may be overlooked. It is therefore useful to look at stigma's contribution to poor health outcomes, together with other important factors. Non-attendance is a coping strategy for dealing with the repercussions of the physical aspects of disease or the stigma attributed to them. This can be a lack of money, an inability to stop earning to make the trip, inaccessibility, fear about the treatments themselves or embarrassment and shame. Logically, stigma should in fact encourage treatment seeking, so the stigmatising illness is quickly treated in order to reduce the stigma and subsequent additional burden (Weiss, 2008). Stigma however is often the main reason attributed to poor health seeking behaviour. The fact that non-attendance due to stigma is self-destructive and illogical has been mainly ignored or overlooked (Muela Ribera *et al.*, 2009). This is a very strong argument against using stigma as the sole reason for issues such as a lack of health seeking. The label of stigma may actually detract from the fact that people feel that there is no incentive to seek a diagnosis if treatment is unavailable to them due to high costs for example.

Another reason why stigma cannot always be relied on as the sole cause of additional suffering, is that many people may feel prejudice towards people in ill health but do not actually discriminate against them. They therefore may have a stigmatising belief but the infected individual may be unknowing of that (Jones *et al.*, 1984). There are two reasons why people keep infected individuals hidden from society. As mentioned in the previous chapter, people may try and shield disabled people from difficult challenges, as they are thought to be incapable and in need of protection (Grant *et al.*, 2004-05). This may also be the case for people in ill health, and infected people may be hidden away and 'protected' from the world. This is a form of stigma, as although it might be thought by some as kind and a protection from existential stigma, the person is actually powerless and seen as incapable of making their own decisions, therefore their capabilities are as severely compromised as those who are inflicted by typical forms of discriminatory stigma. The second reason behind the isolation of infected individuals is to avoid stigma by association, which would drastically decrease the capabilities of all household members. The main

capability lost in both instances is that of choice itself, an extremely important aspect of human existence.

The following sections detail how the effects of three specific diseases, cutaneous leishmaniasis, trachoma and HAT, correspond to the conceptual framework. Their differing physical ailments will be considered and how these contribute to specific physical limitations, as well as looking at the social aspects of each, paying particular attention to the importance of the affected area to everyday life, i.e. the skin, eyes and brain.

### *Cutaneous and Mucocutaneous Leishmaniasis*

Leishmaniasis comes in three primary forms; Visceral, Cutaneous and Mucocutaneous (Cox, 1996; David and Craft, 2009)(Appendix One). The visceral form is a systemic infection which, among other things, causes the spleen and liver to swell (Ahluwalia *et al.*, 2003; Cox, 1996; Moore and Lockwood, 2010). This differs from the cutaneous and mucocutaneous leishmaniasis, which are dermal and mucosal membrane infections respectively, with the species of protozoa and the host's immune response determining the disease's severity (David and Craft, 2009). A secondary form of leishmaniasis can also occur, termed post-kala-azar dermal leishmaniasis and is a cutaneous condition resulting from previous infection with visceral leishmaniasis (Gasim *et al.*, 1998). In all primary cases the parasitic protozoa *Leishmania* is passed to humans *via* the female phlebotomine sandfly vector, the protozoa cannot pass between people directly. Some strains can be housed in reservoirs of zoonotic hosts, including dogs, which contributes to the fact that the diseases are more prevalent in rural areas where people are in close contact with animals (Cox, 1996; Reithinger *et al.*, 2007). Many people are unaware of the disease's incubation within mammals, so continue to sleep in the same rooms as them, meaning they are more exposed to both the sandfly vector, which thrives around animals, and the animals themselves which house the disease (Cox, 1996). Due to a lack of education, it was found that many people also did not know that the sandfly was the vector and instead believed that it was passed between people (Ahluwalia *et al.*, 2003; Kassi *et al.*, 2008). The forms of leishmaniasis I am focusing on in this section are the cutaneous and mucocutaneous forms, which manifest as skin lesions, the lesions can spread to the mucosal membranes around the face in the mucocutaneous form.

Cutaneous leishmaniasis is not life threatening, but inadequate treatment can lead to the development of mucocutaneous leishmaniasis, a potentially life threatening

condition if untreated (David and Craft, 2009). Alternatively mucocutaneous leishmaniasis can be the original infection. These infections act as the health shock, the first step in the conceptual model, and may contribute to the loss of a number of Nussbaum's ten capabilities (Nussbaum, 2000). Firstly, either condition can eventually result in a loss of the most basic capability, the ability to live a full life. They may also affect other aspects of the capability of life *via* the impact they have on other capabilities, which may in turn diminish the value of their life to the extent that they no longer feel it to be valuable to them.

The ability to maintain bodily health is eliminated with the onset of a dermal leishmaniasis, as the body enters a state of ill health. Health is defined by the WHO as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (WHO, 1948). However this definition has been critiqued, for example Üstün and Jakob (2005) suggest that this definition is 'inflexible, and unrealistic' due to the use of the word 'complete', which has the implication that people are rarely in a state of good health. It also does not account for age or culture, for example some cultures may consider spiritual health and the health of their community as a whole to be just as important as personal physical health (NHMRC, 1996). However, in the absence of a 'perfect' definition of health this definition does address the main health concerns which are consistent throughout cultures. It is also widely understood and accepted and is therefore the most suitable definition to use for the purposes of this thesis. Care will have to be taken however to make sure other culturally specific aspects of health are not overlooked.

Using this definition means we cannot restrict the scope of 'the ability to maintain bodily health' to physical health alone, and bodily health can constitute mental, spiritual and social health as well. Physically, sufferers of cutaneous leishmaniasis can have mild symptoms restricted to a lesion at the site of the bite only (localised cutaneous leishmaniasis – LCL), more severe symptoms that result in multiple nodules which do not become ulcerous (diffuse cutaneous leishmaniasis – DCL), or the most severe manifestation, involving the destruction of the mucosal tissues around the nose and mouth (mucocutaneous leishmaniasis) (Reithinger *et al.*, 2007). The lesions may look extremely uncomfortable and raw, but in fact are often not as painful as they appear (Ashford, 2000; David and Craft, 2009). Enlargement of the lymph glands may also develop as the protozoa spreads in the lymphatic ducts (Ashford, 2000). This enlargement can occur without any ulcerative presentation and can cause pain or tenderness (Barral *et al.*, 1995). Not only does this affect an individual's bodily health but it also eliminates their ability to avoid non-

beneficial pain, a component of the ability to use the senses, imagination and thought in a purely human manor (Nussbaum, 2000); a capability I will discuss in more detail when describing mucocutaneous leishmaniasis.

Mucocutaneous leishmaniasis can begin as nasal congestion and ulcers around the mouth (David and Craft, 2009; Reithinger *et al.*, 2007). Very late stages result in destruction of the oronasopharyngeal mucosa and cartilage in the face which can cause infection, obstruction of the airway and disfigurement (Ashford, 2000; David and Craft, 2009). Unlike cutaneous leishmaniasis, mucocutaneous leishmaniasis cannot heal spontaneously and can potentially be fatal if left untreated (Reithinger *et al.*, 2007). The pharynx, larynx and soft palate can become affected (Marsden, 1990; Reithinger *et al.*, 2007), which can be detrimental to speech, food consumption and breathing. Speech may become hoarse, as vocal cords become less moveable, and as more damage is done to the larynx sound production will worsen (Marsden, 1990). Speech is the most important method of communication as it facilitates and maintains social interaction. Compromising the ability to communicate normally is likely to increase the severity of stigma suffered by the individual (Jones *et al.*, 1984), as people will avoid the experience of an awkward conversation and the embarrassment of potentially misinterpreting information. This effect on speech may reduce or eliminate several key capabilities that are important for social well-being; specifically affiliation and play (Nussbaum, 2000). The ability to form affiliations with other people relies on normal social interaction. With impaired speech this normality is lost and individuals with mucosa damage affecting the sound producing organs may find it difficult to interact with others without the ability to speak clearly or at all. This together with the fact that speech may become painful further increases the likelihood that social interaction will not only become difficult but be avoided, thus reducing the opportunity to play and have pleasurable conversations.

As well as speech, mastication can become painful and, to the extent that it is avoided (Cascio *et al.*, 2000), can lead to inadequate nutrition (Taranto *et al.*, 2000), an insult to another component of the ability to retain bodily health. The third problem generated through damaging the organs of the throat is that of breathing difficulties. Damage done to the larynx can cause suffocation as it can collapse and close, one of the commonest causes of death among people with this condition (Marsden, 1990) and the loss of the most basic capability, life.

The capability to use the senses, to imagine and to think are functions that make human beings different from other organisms, and the option to perform these functions in

a 'truly human way' is considered an important capability (Nussbaum, 2000). It has been mentioned that non-beneficial pain reduces this ability for cutaneous leishmaniasis sufferers. Progression to mucocutaneous leishmaniasis however can compromise another aspect of this capability, the ability to use the senses. Mucosal destruction around the nose and mouth can result in restricted airflow, rhinosinus and opacification of the sinuses (Vincenzo, 2002), which can hinder the sense of smell (Hong *et al.*, 1998), an important sense in the experience of taste, the detection of spoiled foods, and even in courting. The sense of smell may also be compromised by the continuous experience of a 'fetid smell' emanating from sore lesions (Romero *et al.*, 2001). A continuous foul smell detracts from the experience of other smells, and the foul smell can be especially prominent if the lesion is on the face, such as is the case in mucocutaneous leishmaniasis. Not only will this smell change the infected individual's experiences, but it may also cause more social problems as people may avoid a person who generates a foul smell. This can cause the patient embarrassment and reduce their self-esteem which may develop into a mental limitation whereby feelings of negativity towards the self, result in the inability to carry out daily tasks.

In some more severe cases vision can be threatened, the scarring of the eyelid as a result of a lesion can disable the lid's ability to close (Saltici *et al.*, 1998), which means that the eye can more easily harbour infection, suffer scratches and dry out, which can lead to poor vision. A third sense can be affected by the common first line treatment, pentamidine; a common side effect is the development of a metallic taste in the mouth, which can decrease the enjoyment of food and act as a constant irritant (David and Craft, 2009). The five main senses allow people to perceive the world around them, without which the human experience may be inferior. The senses are therefore established as an essential component of people's capability sets, the loss of a sense being a very distressing outcome of disease.

To think in an informed way, as developed during adequate education, is an important aspect of the capability to think (Nussbaum, 2000). As covered in the previous chapter, illness of any family member can prevent a child from attending school due to monetary constraints, as an effect of both a lowered income and increased expenditures in terms of health care. In addition, children suffering from cutaneous leishmaniasis themselves may not attend school due to the inability to afford school necessities such as uniforms, social problems, or the family's fear that relatives may begin to suffer from a courtesy stigma (Herek *et al.*, 1998; Kassi *et al.*, 2008; Weiss *et al.*, 2006). Stigma suffered in

a school environment may be more severe with cutaneous or mucocutaneous leishmaniasis due to the disease's high visibility so the ability to pass as normal is compromised. Lack of schooling can hinder the development of informed thought and the evolution of informed thought is restricted for either the infected person or their families. In circumstances where the ill health of a parent compromises the capability set of their child is an example of the intergenerational transfer of capability deprivation poverty. This is likely to result in the presence of risk factors which will lead to the maintenance of this cycle.

To evaluate the effects of a dermal leishmaniasis on the social capabilities of an individual the predispositions and consequences of stigma must be analysed. Cutaneous leishmaniasis has more stigma attached to it than other common illnesses. This was demonstrated by a study where a woman from Kabul, Afghanistan, covered her ulcerated nose when guests came round and explained this strange behaviour by claiming she was ill. This false illness did not lead to discrimination but when the lesion was accidentally revealed the guests immediately left the house (Reyburn *et al.*, 2003). This study provides useful information, as it illustrates the extent of leishmaniasis stigma in comparison to a more common illness that is directly contagious. Because the ulcer or scar is often found on exposed parts of the body i.e. the arms and face, it can be extremely difficult to disguise. It is thought by some that if the lesion can be concealed easily by clothes then an individual's body image may not be adversely affected. This was demonstrated by a study where people with cutaneous leishmaniasis lesions were asked to rate their satisfaction with their body and were assessed for psychological disorders (Yanik *et al.*, 2004). Yanik *et al.* (2004) discovered that mental disorders, such as depression, anxiety and poor body image were more common in people who exhibited exposed lesions, often on their hands and faces. This is in keeping with the notion that visibility plays a huge a role in the severity of enacted stigma experienced (Ablon, 2002; Jones *et al.*, 1984). Saying this, as previously revealed, concealment cannot prevent stigma entirely, as self or internalised stigma is likely to be felt by the individual and prevent or hinder similar capabilities (Ablon, 2002; Goffman, 1963; Jones *et al.*, 1984). This internalised stigma may also result in depression, and consequently reduce the individual's quality of life even if the lesion can be concealed (Kassi *et al.*, 2008; Yanik *et al.*, 2004). Psychological problems are more likely to affect women as they are, more than men, considered undesirable for marriage and may have their children removed from their care, breaking their relationships and reducing their ability to affiliate with others (Kassi *et al.*, 2008). Resulting depression affects the emotions and can render a

person unable to think normally about people outside themselves, reducing their ability to think rationally, control their emotions, affiliate with others, carry out practical reasoning and empathise with others.

The need to affiliate with others is an innate desire, and thus humans have the ability to imagine the situation of another in order to respond emotionally to them, and facilitate relationships (O'Connor *et al.*, 2002). It has been speculated that people suffering from depression are less empathetic, and therefore perform fewer acts of altruism towards others in need (O'Connor *et al.*, 2002). However, it has later been found that depressed people tend to have normal levels of empathy, but instead they often misinterpret emotions in others, and attribute others' negative emotions to something they have done (O'Connor *et al.*, 2007). This, could be interpreted as self-centred, an unappealing characteristic when forming relationships with others. The confusion of emotions severely reduces the ability of people affected by depression, as a result of cutaneous leishmaniasis, to make social attachments with others, a basic human need. The problems associated with, and generated by, the visibility of leishmaniasis can be seen to lead to poverty. This is because the social limitations generated by stigma can affect the physical, psychological, social and economic well-being of infected individuals (Kassi *et al.*, 2008; Rafferty, 2005).

Jones *et al.* (1984) also identified that the curability of a disease has an impact on the severity of stigma. Although cutaneous leishmaniasis is curable, and can often self-heal without any medical intervention, a scar is generally left whether treatment is sought or not (David and Craft, 2009; Reithinger *et al.*, 2007). The scar indicates that the individual has had the disease, and it will always act as a reminder to others that even though 'cured', the once infected individual will never be free from the lasting effects of the disease. There can be disastrous consequences for an individual who possess a scar, for example, a 28-year-old woman from Pakistan with cutaneous leishmaniasis scars could not marry and is now considered old within her community (Kassi *et al.*, 2008). In many rural communities within developing countries marriage is an essential step in the development of a person and a crucial source of economic security. She illustrates her future by saying that other girls with leishmaniasis scars married late, to either physically or mentally disabled men, and that her fate must be the same (Kassi *et al.*, 2008). This will undoubtedly compromise her ability to make choices about reproduction, as she does not have the ability to choose a partner. This impairs her right to bodily integrity, as she is not only unable to choose who she marries but also may gain no sexual satisfaction from that marriage. The scarring has also caused her ability to choose a life which she values, in terms of a marriage partner, to

be abolished. Choice is a major component of quality of life; without choice people's lives are controlled by external (or in the case of internalised stigma, internal) forces and thus carry less value than if they were able to choose their life course.

Mucocutaneous leishmaniasis, on the other hand, can be life threatening, and treatment is required, as opposed to being optional (Yanik *et al.*, 2004). This treatment does however have its risks, including the closure of the airway (Marsden, 1990). Both this risk of death, and the scarring, act to remind non infected individuals that human beings are fragile, and that death is imminent for all, an idea that doesn't sit easily with most people as death is a heavily stigmatised event (Falk, 2001). People therefore choose to avoid people who remind them of this fragility in order to avoid this conflict of a living person representing death. This inevitably has consequences when it comes to social capabilities, particularly affiliation and play. The act of being avoided may hinder the infected individual's ability to show concern for other human beings. It may become challenging to empathise with others as they may not understand why they are being avoided and take the view that as others show no concern for them, why should they show concern for others. This notion is reliant on the infected individual not internalising the stigma held towards them, and thus not feeling they are worthy or deserving of that stigma. This point links into the capability to feel and interpret normal emotions as discussed previously in terms of health related depression, which inevitably leads to capability deprivation, the loss of functionalities and the descent into poverty.

The many beliefs held concerning cutaneous leishmaniasis, predominantly involving its method of transmission, is an important dimension in the assigning of health-related stigma (Jones *et al.*, 1984). It was found that many people in Pakistan did not know that the sandfly vector was the mode by which leishmaniasis was transmitted to people, and instead believed that it was passed between people *via* direct contact (Kassi *et al.*, 2008). Similar findings were obtained from the Northwest Pichincha Province in Ecuador, where even some previously infected individuals claimed that they had had no contact with the sandfly vector (Weigel *et al.*, 1994). Those who think that cutaneous leishmaniasis spreads *via* human contact are more likely to socially exclude and avoid those with the disease unnecessarily, due to fear of contagion (Kassi *et al.*, 2008). A number of people surveyed in Kabul, Afghanistan, believed that merely talking to someone infected with leishmaniasis could spread the disease. These people were likely to distance themselves further from infected individuals (Reyburn *et al.*, 2003), rendering them even more socially isolated as a direct result of this belief. Another explanation for the transmission of

cutaneous leishmaniasis is poor hygiene. This further justifies the social exclusion of an infected individual, as not only are they infected by a disease, but they caught that disease from being unclean and unsanitary, a stigmatised characteristic in itself (Reyburn *et al.*, 2003). Yanik *et al.*'s (2004) study suggests that stigma may be more severe as it links individuals with a poor rural lifestyle and connects them to the poor, undesirable regions of the country.

Those who believed cutaneous leishmaniasis was transmitted by an insect vector thought the insects were attracted to unclean environments and dirty water (Reyburn *et al.*, 2003), again justifying further discrimination to the discriminators. Indeed, poor housing and a lack of good environmental sanitation do increase contact with sandflies (Alvar *et al.*, 2006) so there is 'truth', and potential justification for this added stigma. Dogs were also implicated in the transmission of cutaneous leishmaniasis by locals (Reyburn *et al.*, 2003), and they have been found to be one of the main reservoirs of the disease. However, the fact that animals and insects play a crucial role in the transmission of this disfiguring disease may render people's capabilities compromised, namely the ability to live with, and have concern for animals. These animals and insects may be feared, and not treated with respect as a result of this fear. Not only may this compromise the animal's treatment, but the ability to live in peace with animals is a basic human capability, which brings satisfaction to human beings as well as additional labour, food and companionship. Another belief for the contraction of cutaneous leishmaniasis is that of a punishment from God. This breeds its own specific problems as family members may believe the infected individual has committed a sin that has warranted the development of disease. This belief can be the reason for social exclusion as opposed to the disease itself but can cause similar social problems (Reyburn *et al.*, 2003).

Finally stigma can be generated from the anticipated danger associated with the bearer of an undesirable characteristic. Cutaneous leishmaniasis poses no danger from aggression for example, but there is, however, the danger that associating with that individual may result in a courtesy stigma towards the non-infected individual. This can lead to the family trying to conceal a member's lesions so other members of the community do not judge the family as unclean, much in the same way as disability is concealed (Yeo, 2001). Although this may protect the family from discrimination the infected individual's capabilities are additionally compromised. Their right to move freely (an aspect of bodily integrity) will be diminished as their movements are now controlled by the wishes of their family.

The different debilitating aspects of leishmaniasis as described here, can lead to poverty and the propagation of the poverty and ill health cycle. The details of capability deprivation poverty have been discussed with regard to which capabilities have been affected and to what extent. It has also been discussed, where relevant, the loss of capabilities faced by the family members of the infected individual. All these aspects generate a lack of choice and a set of limitations which result in capability deprivation poverty. In terms of economic poverty, many of the physical and social aspects of disease lead to unemployment. Even if a person is physically able to work, which is often the case with a dermal leishmaniasis, stigma faced by the sufferers of cutaneous leishmaniasis can lead to people not seeking employment due to fear of rejection (Reyburn *et al.*, 2003). Employers may also judge someone with a lesion to be unacceptable for work, diminishing their ability to be treated equally when seeking employment (Nussbaum, 2000). Jobs such as the sale of food or clothes pose a specific problem, even if the sufferer is self-employed, as the association with poor hygiene can mean people are unwilling to buy produce sold by someone with a lesion, meaning they can no longer run a viable business (Reyburn *et al.*, 2003). The financial pressure and social exclusion, both in the home and the work place, can be enough to make infected people contemplate suicide, as their lives have got to the stage where they no longer feel that life is worth living (Reyburn *et al.*, 2003). This is an insult to the most basic of human capabilities and in some cases can be seen as worse than the loss of life itself (Nussbaum, 2000). As mentioned before, the stigma can be more severe than the disease itself; this has been shown to be the case for cutaneous leishmaniasis, where lesions are relatively pain free and often spontaneously heal, yet the disease acts as an extensive and devastating health shock.

To overcome the struggles of health shock induced poverty many families adopt coping strategies. However some coping strategies carried out by infected individuals and their families inhibit their capabilities further, as opposed to restoring or maintaining them, thus deepening poverty. For example, in Kabul people with cutaneous leishmaniasis often socially isolated themselves in order to prevent hurtful experiences, and retain one basic capability, the ability to avoid humiliation (Nussbaum, 2000). This isolation, however, prevents the possession of more capabilities than it maintains, including play, affiliation, bodily integrity and in extreme cases, life. Political control over one's environment may also be compromised as the act of remaining in the house to avoid social interaction means that people may not be able to take part in political choices that require leaving the home, such as voting and attending community meetings. I therefore feel that in addition to Reyburn *et*

*al.'s* (2003) observed economic, social and emotional limitations, political limitations can also be generated both *via* social stigma and the coping strategy of self isolation. These limitations, together with economic poverty, generate a multi-dimensional state of poverty, which is harder to escape due to the number of interventions needed in order to restore financial stability as well as the household's capabilities. This can therefore lead to chronic poverty as the household is vulnerable to subsequent shocks deepening their poverty. A lack of capital is thus passed to the next generation so their own family will be more vulnerable to ill health and the cycle maintained by the initial infection.

### *Trachoma*

Trachoma is the most prevalent cause of preventable blindness in the world with 10% of the global population potentially at risk of becoming blind *via* multiple trachoma infections (Hopkins *et al.*, 2008). Trachoma is the recurrent infection of the *Chlamydia trachomatis* bacterium which causes conjunctivitis early in life (Bailey and Lietman, 2001) (Appendix One). Although this infection is treatable with antibiotics, reinfection is almost certain without community programmes to change the environment and behaviour of the inhabitants (Bailey and Lietman, 2001). Regular reinfection dictates the disease's progression to trichiasis and inflammation which can cause permanent damage. Trichiasis is the process by which the eyelashes invert and grow into the eye, impairing vision, which can eventually result in blindness if left untreated (Hopkins *et al.*, 2008; Smits, 2009). This eventual blindness is a result of the inflammatory response, where ulceration of the eye leads to the formation of scar tissue on the cornea, preventing light passing through the lens correctly and so rendering the patient blind (Markel, 2000). It is obvious that bodily health is compromised when trachoma infection is present. As in the case of cutaneous leishmaniasis, this can result in problems with poor nutrition and psychological problems *via* the direct results of capability deprivation and economic poverty.

Trachoma is passed between people either by direct contact (touching an infected eye or its secretions, followed by touching an uninfected eye), or indirect contact, *via* clothing for example (Hopkins *et al.*, 2008). The rural settings where this disease flourishes contribute to the transmission of trachoma *via* the abundance of flies (Cox, 1996; Hopkins *et al.*, 2008). This mode of transmission is directly linked to poor hygiene as the flies (*Musca sorbens*) breed mainly in human excrement on the surface of bare earth, and smaller flies can be seen to emerge from animal faeces (Emerson *et al.*, 2001). It is therefore known to

spread faster in poor, rural, unhygienic areas, generating an additional socioeconomic stigma congruent with that suffered during cutaneous leishmaniasis infection.

The loss of vision can be devastating to already poor communities, as it further limits their already compromised capabilities. As well as total blindness, the visual impairment caused by trichiasis before the onset of blindness should be considered a large burden, as it too can lower the economic production of the household by taking the individual and the informal carer out of employment or reducing their productivity (Frick *et al.*, 2003). As with cutaneous leishmaniasis I will look into the effects of blindness on the ten basic capabilities as outlined by Nussbaum (2000).

The most prominent capability affected as a result of blindness and visual impairment is the assault on the senses. The loss of vision will impact on every area of a person's life and diminish their capabilities and independence. Visual impairment may even induce the feeling of not being totally human due to sight's importance in communication as well as perception of the world. The ability to use all the senses in order to have truly human experiences, is one aspect of the capability to use the senses, to imagine and to think (Nussbaum, 2000). Sight has often been considered the most important of the five senses, and a loss of sight may be mourned, a reaction akin to that of grief, and may even lead to suicide (De Leo *et al.*, 1999). This study was carried out in Australia and so may not directly apply to other countries due to the possibility of different cultural norms concerning the importance of sight. However it offers an important insight into the negative emotions that can be generated by the lack of sight even within countries which have strong support services for visually impaired people, such as specialist schools. Depression, anxiety and suicide are in fact more likely to occur among partially sighted people who have the prognosis of blindness due to the fear of losing a vital sense (De Leo *et al.*, 1999). Some people no longer feel that their life is of value without the capacity for sight or the inevitability of blindness, as not only will they feel less like a human being, but they will also suffer in terms of other basic capabilities, thus limiting the choices they have in life. The lack of control may be a contributing factor in lessening their perceived life value, as people are more likely to value things they have chosen, with the act of choice being the most important factor. This diminishment of life to the point that they believe it is not worth living is the loss of the most primitive capability, life.

Visual impairment often results in a loss of independence, both economically and socially (Taylor *et al.*, 1991). The ability to work, especially in a rural setting where much of the work is physical, is compromised by both the visual impairment, and the pain suffered

by the in-growing eyelashes. The consequent declining or absence of income, further reduces an individual's capability set rendering the individual less able to escape poverty and more likely that they will pass this poverty on to their children. The progression of trachoma often starts in young children and therefore generates an unstable beginning in life, making it difficult to gain and maintain capabilities as an adult. A girl from Southern Sudan reports that because of the pain in her eyes she was unable to play with friends outside, and had to sit in the shade with elderly relatives (Vision2020, 2009), due to the fact that heat aggravates the condition (Wall, 1934). This seemingly insignificant occurrence actually eliminated two important childhood capabilities, the ability to live without non-beneficial pain, and the ability to play with peers. The social interaction associated with play is crucial to normal child development, and interacting with people of a similar age is beneficial in adulthood, as it aids 'cognitive, physical, social and emotional well-being' (Ginsburg *et al.*, 2007:182). Play is therefore vital to children's development, and is considered so important that it has become recognised as essential by the United Nations Commission for Human Rights (Ginsburg *et al.*, 2007), which draws on the ideas developed by the capabilities approach. Play can also help develop self-confidence (Ginsburg *et al.*, 2007), which will better equip people when it comes to finding employment and making social affiliations, aside from its impact on other aspects of life it is an important feature of a valued life.

Another barrier for visually impaired individuals is stigma. Trachoma disease is highly visible, as it is worn on the face and brings about an unpleasant appearance, which is concentrated around a very personal feature of a person, the eye (Markel, 2000). This disfigurement in women can render them unable to marry, since as with other disfiguring diseases, they are no longer seen as attractive, and can therefore become a burden on their family (Vision2020, 2009). Blinding and disfiguring trachoma, if occurring during marriage, can justify divorce. Women are often not in control of the household money so they commonly delay the treatment of their trichiasis and others' needs are prioritised (Vision2020, 2009). This lack of household decision making is likely to increase with the onset of disease, as they may be deemed unable to make good decisions (Taylor *et al.*, 1991). These restrictions will inevitably lead to the progression of trachoma, an easily treatable disease, and thus increase the likelihood of divorce and subsequent poverty.

The eyes are very important when communicating with others, so both blindness and the distasteful appearance of the eye hinders social interactions and can result in exclusion. 'Without eye contact, people do not feel that they are fully in communication',

as eye contact allows people to judge others' reactions and evaluate the meaning of the relationship, whether it be sexual, friendship or status driven for example (Argyle and Dean, 1965:289). Not only can this lead to exclusion of the blind individual due to their awkward nature of communication without eye contact, but this exclusion can also contribute to the negative emotions held by the visually impaired individual. In fact social exclusion may also contribute to the suicidal feelings and loss of self-esteem mentioned earlier. Blinding trachoma therefore creates a double-strength social burden, as social exclusion is combined with the loss of a vital human sense. The inability either to maintain or make affiliations can also represent the loss of a vital coping strategy. Where chronic poverty is prevalent, having social contacts is essential in times of need, as they can provide loans, food, and emotional support that can prevent a household's fall into poverty and thus generate the opportunity to increase its capabilities (Addison *et al.*, 2008-09). Not only can a lack of affiliation diminish a family's ability to survive, but it can decrease the household's quality of life, occasionally to the extent that they feel it is no longer worth living as social contact is a valued aspect of being human. Being accepted within a social community builds self-esteem, increases available services, increases political power and allows people to enjoy pleasurable experiences, all fundamental properties of a fulfilled human life.

As well as the visibility of trachoma, stigma may also be a result of beliefs which implicate witchcraft. For example, the family of a 15 year old girl in Niger believed that a spell had been cast on her in the form of trachoma (Vision2020, 2009; Wall, 1934). A magician was subsequently paid to remove it, a costly treatment that failed. However there were no economic resources left to seek an alternative treatment (Vision2020, 2009). A family member reported that she was a burden to the household as she requires a lot of one to one care, and is unable to attend school or carry out household chores (Vision2020, 2009). This link to witchcraft and the supernatural can be problematic when it comes to social affiliation, since people may be avoided because of the belief that the spell can be transferred to them. Alternatively, the belief that the transmission of trachoma is due to a lack of hygienic behaviour and therefore may pass directly between people may also generate stigma (Markel, 2000).

Not only does visual impairment cause disability, but a study looking into mortality rates among the blind in Tanzania concluded that people who were visually impaired were more likely to have a shorter life expectancy (Taylor *et al.*, 1991). A premature death is the ultimate undesirable functionality from which we can deduce that their ability to live to a

desired age was compromised. Taylor *et al.* (1991) did not find any increase in suicide rates among the visually impaired population in Tanzania, unlike De Leo *et al.*'s (1999) study mentioned previously, and instead found that they died from events or diseases very similar to the sighted population, such as dysentery and malnutrition. This difference could be because of disparities between Tanzanian and Australian perceptions of becoming blind as sight may carry varying levels of importance in each nation. Alternatively experimental error could account for this disparity where either not enough subjects were assessed over a long enough period of time or inadequate data was collected due to differential recordings of deaths. Premature death and the loss of other capabilities as a result of visual impairment may be partly due to the inability to seek health care for other diseases when visually impaired. Firstly, health centres are often far from rural communities, meaning transport costs are incurred as well as the loss of potential income (Melese *et al.*, 2004; Oliva *et al.*, 1997). It is also likely that another person with good vision would have to accompany a visually impaired person to a health centre, especially if they are a long distance away (Melese *et al.*, 2004). Women in Ethiopia and Tanzania attending health centres for their eye operations were required to be accompanied so that they had someone to walk with and provide nutrition for them during their stay, although they found this requirement difficult to obtain (Oliva *et al.*, 1997; Zerihun, 1997). This is mainly required in the late stages of the disease where total blindness has occurred, so intervening early may mean that people going to health centres with eye problems will not need accompaniment (Melese *et al.*, 2004). Although these studies looked into people attending health centres as a direct consequence of their eye condition, it is likely that a visually impaired person with another health complaint would be just as unable to find anyone to accompany them to the health centre, meaning their lives may be at risk. In Tanzania 14.3% of women stated that the main reason for not accepting free surgery was because they had no one to accompany them and 23.5% said that if they did have someone to accompany them then they would get eye surgery (Oliva *et al.*, 1997). An accompanying relative, however, means that an additional cost is endured, as not only is the patient's income (if they are able to earn one) prohibited for the time they are in hospital, but so is that of the accompanying person, and potentially another carer will be prevented from working to look after any children left at home (Lewallen and Courtright, 2001). The inability of a woman to find someone willing to accompany her to surgery may be because of prior losses of capabilities. For example, the act of finding someone willing to look after things at home while they are away will be hindered by a lack of ability to affiliate with others, as a

lack of social connections made within the community will render the individual unable to find a willing carer. This possible inability to form affiliations may have resulted from social stigma, generating a cyclical process whereby stigma hinders curative surgery and that lack of curative surgery leads to further social stigma.

Visual impairment can restrict movement, as affected individuals have to rely on others in order to exercise the functionality to move freely from place to place, an important aspect of having bodily integrity. This inability to move independently may generate further capability losses, for example, the ability to participate politically may be diminished if the individual is unable to attend meetings, elections, or protests as a result of their visual impairment. This participation is essential to quality of life as the ability to choose one's own path and make decisions regarding their future is often more important in life satisfaction measurements, than the course of life itself. It was found that in China, political participation of any kind, even a general interest, increases life satisfaction, even if their interests lie outside the communist party (Song and Appleton, 2008). This is an interesting finding as the authors expected that an interest in policy outside of the communist party may increase discontent with the current regime and thus lowered life satisfaction. This finding, however, points to the fact that choice in political matters does actually increase life satisfaction, irrespective of the party favoured. This however could be contested, as happier people may be more likely to participate in political matters than people who are unsatisfied; therefore we cannot be sure of the directionality of this statement. We can however be sure of the link between life satisfaction and political participation.

As trachoma can often be a lifelong disease in rural areas of developing countries, the insults on infected individuals' capabilities, and those of their household, can be compromised for entire lifetimes. Even if their trichuriasis is cured or they undergo corrective surgery they may still face a life of reduced capabilities as they are unable to regain lost capabilities. For example, as mentioned earlier, existential stigma faced by some individuals may not only make them think of their illness in an extremely negative way, but this negativity could be attributed to the whole self. Self-loathing or a lack of self-confidence can therefore persist even after vision is restored, which may impact on their mental health, ability to travel to and from places, emotional attachments, practical reasoning, affiliation, control over the environment and play. This therefore means some individuals, whether cured or not, will face a lifetime of capability deprivation poverty as well as economic poverty as result of the inability to work, the need for carers and high

expenditures. The absence of these functionalities leads to us to believe that visually impaired individuals have a reduced capability set. This generates capability deprivation poverty as well as economic poverty which can become chronic and consequently intergenerational.

### *Human African Trypanosomiasis*

Also known as sleeping sickness, Human African Trypanosomiasis (HAT) is characterised by distinct stages (Appendix One). The trypanosomes (usually *Trypanosoma brucei rhodesiense* or *Trypanosoma brucei gambiense*) are transmitted *via* the tsetse fly vector, and thus infection is concentrated in the Tsetse belt, which spans Sub Saharan Africa (Cox, 1996). At the site of the bite, the closest lymph nodes inflame, termed lymphadenopathy (Stich *et al.*, 2002), and the trypanosomes are circulated in the lymphatic fluid and the blood (Cattand *et al.*, 2006). The first stage of generalised infection presents itself as an erratic fever, followed by myocardial complaints, and sometimes a faint rash. The late stage of the disease arises when the trypanosome parasites cross the blood-brain barrier, where it invades the central nervous system, causing meningoencephalitis, which is characterised by headaches and changes in personality (Cattand *et al.*, 2006). This causes the patient to eventually enter a permanent state of drowsiness, leading to coma and finally death, resulting in the disease commonly being known as sleeping sickness (Stich *et al.*, 2002).

This disease, if left untreated, will inevitably impact on an infected individual's bodily health, and the increased likelihood of suffering a premature death will compromise their ability to live to old age. However, even if treatment is sought, and the proper course adhered to, there is still the risk of spontaneous death in 2-8% of cases (Papadopoulos *et al.*, 2004; Stich *et al.*, 2002). The deaths associated with medical intervention can make others sceptical of seeking treatment, which may lead to an increased mortality rate, as without treatment death is inevitable (Robays *et al.*, 2007). Death from the side effects of treatment can occur in previously asymptomatic people, resulting in the belief that these unusual deaths are a consequence of witchcraft. It is thought that the influence of witchcraft is much greater when the disease is revealed to the public, meaning individuals may choose not to disclose their HAT status (Robays *et al.*, 2007). This can be problematic as not only are health-seeking behaviours likely to be compromised, but the individual may develop anxiety due to the fear of an accidental disclosure. Reinfection can also occur after

treatment as no immunity occurs, meaning that getting treatment for HAT does not mean that you cannot die from another HAT infection at a later date, adding to the fear and reluctance to seek health care (Cattand *et al.*, 2006). The associated witchcraft is detrimental to the individual in terms of stigma, and this stigma can be transferred to family members who may also be excluded or feared. This is a result of the fact that much of the presumed witchcraft is thought to originate from an extended family member. If medical treatment is sought and works then the relative will be considered innocent, but if the treatment results in death then this may be attributed to the relative. This belief can reduce the capabilities of the relative in terms of life, bodily integrity, emotions, affiliation and play.

HAT's effect on the brain can change the personality of individuals with late stage disease and aggression, emotional disorders, excessive talking and insulting behaviours becoming more persistent (Haller *et al.*, 1986; Robays *et al.*, 2007). The disease has altered the individual's concept of what is good behaviour, and in doing so has restricted their ability to perform practical reasoning. It may also affect their ability to form emotions normally, and feel for those around them, as an aggressive behaviour may represent a loss of understanding for others' feelings and emotions. This inability to take others' emotions into consideration, or to have no notion that they are behaving badly, can have repercussions when it comes to the ability to affiliate with others. People are likely to lose patience with the individual and avoid their company.

Due to HAT's impact on the brain, and thus mental functionings, many people often consider this disease a psychiatric disorder. This can be detrimental to the sufferer, as in many marginalised communities in developing countries most psychiatric disorders have a stronger association with witchcraft and sorcery than HAT (Robays *et al.*, 2007). This means that not only is the person perceived differently due to personality changes, but also has the added problem of being feared due to the association with the supernatural. Robays *et al.* (2007) also state that due to the loss of normal behaviour during the course of their illness, even after they have been cured, they will most likely suffer long term stigma and won't lose the shame they brought on themselves and their family. Stigma experienced during the illness will result in a social scar or psychological damage, and therefore the stigma of possessing a previous stigmatising feature can be long lasting (Jones *et al.*, 1984). This is especially prominent with mental disorders as the label of being a former psychiatric patient is very much undesired. Falk (2001) suggests that this is because the ability to think rationally is one of human kind's basic capabilities and is seen

as a necessity within society of most countries. The inability to think rationally can be seen as a threat to the development of civilisation as individuals unable to think rationally may not be able to contribute to development such as scientific discovery and social cohesion within a community, two essential factors for societal development (Falk, 2001). Falk (2001) also suggests, that as well as terminally ill people, people with mental disorders remind 'normals' that life is fragile, thus increasing the likelihood these people will be avoided to evade the anxiety generated by this concept. This stigma towards people with psychological problems occurs irrespective of how the disorder occurred, whether it be parasitic, viral, trauma, genetic or social, meaning that HAT may not be thought of as any different to another purely mental disorder. The stigma experienced for HAT is therefore a result of differing capability losses compared to the previous two diseases, with practical reason being more highly compromised in people with HAT.

A six month rest period to avoid complications after treatment is required, meaning a long period of dependency without income. To avoid complications within the six month period, patients in The Democratic Republic of Congo are traditionally expected to avoid hard labour, sex, heat, fire, hot water, spicy food, and oranges (Robays *et al.*, 2007). Any complications that do happen to occur are therefore blamed on the patient and attributed to them disobeying one of the rules. The blaming of the patient in this way can lead to further loss of capabilities, mainly in the form of mental limitations, a problem previously covered in the stigma section at the beginning of this chapter in relation to mental disorders.

HAT can have lifelong consequences, many of which may not be included in current DALY measurements and are therefore often neglected. What using the capability approach has aimed to do is to highlight the capability losses that may have been missed in conventional disease burden measurements. For example the social health of a previous sufferer of HAT may never fully recover as many fear the individual due to their previous psychological change and the present return to normal (Robays *et al.*, 2007). It is therefore obviously not enough to only offer a cure for HAT without any additional social and emotional support.

### *Conclusion*

This chapter has shown how specific NTDs can be assessed by the capabilities approach, and how numerous important aspects of life are negatively affected by NTDs. It

has been shown that NTDs are not merely physical disorders, but can manifest as social, mental, political and economic disorders as well. The effects on health go beyond that stated in the WHO's definition of good health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (WHO, 1948), with political and economic health also being considered. Using the capabilities approach allows the whole disease experience to be illustrated, and thus the real burden of these neglected and feared diseases deciphered. Not only should the physical and social consequences of NTDs be taken into account, but the loss of other basic capabilities, such as political participation, both during the course of the illness, and after the infection has been cleared, as these deprivations can be long lasting and life altering. Constricting the capability set not only reduces specific capabilities, but also removes the ability of individuals to choose the direction of their lives, such as the inability to choose marriage partners and levels of education. Choice can be seen as the most important aspect of life, with someone who chooses to skip a meal, for example, being less deprived in terms of capabilities than someone who was forced to skip a meal, even though the functionality and the consequences of not eating that meal may be the same. This is because they had the ability to nourish themselves and even though they did not take this opportunity the opportunity was there for them to take. It is a human right to have the ability to choose and 'when a man cannot choose he ceases to be a man' (Burgess, 1962:67). The capability set is therefore what should be measured as opposed to the functionalities that actually occur, as measuring these alone will not provide a picture of what people are actually able to do; only what they have done. The observation of functionalities can, however, lead to the deduction of the individual's capability set, a process that will be detailed in the next chapter.

For some NTDs the stigma suffered is so great that it can remain and affect the individual after the physical symptoms have been successfully treated. They have regained their bodily health but are restricted from using their healthy bodies to rebuild their capability sets. Affiliation remains a problem as, for example, the label of being a former mental patient, or equally a former HAT sufferer, carries social stigma even if the symptoms have been eliminated (Falk, 2001). The capabilities that stigma reduces after a cure are not considered within the DALY measurement for that disease. This lack of recognition means that little funding is allocated to aftercare and education. Aftercare may help affected individuals and their families rebuild their capability sets as well as their physical assets, and education to whole communities may reduce the loss of capabilities

suffered by people with, or who have previously had, an NTD, from the onset of their condition. This support would drastically aid their treatment seeking, recovery, and quality of life both during the course of the illness and after the infection has been successfully treated.

It has been shown that the consequences of differing stigmas are remarkably similar. For example, the lasting scar on a person who previously suffered from cutaneous leishmaniasis can result in exclusion patterns that are similar to the lasting stigma suffered by people who have been cured of HAT. This occurs despite the differing effects which the diseases have on the physical body and the different reasons for the attribution of stigma. Although these differences appear vast, the effects of the attributed stigmas generate similar limitations and capability losses for infected individuals. This holds true even after the diseases have been effectively treated, as the stigma of previously being infected is present. Typical effects of being a previous patient are: unemployment, an inability to marry and decreased opportunities for other family members due to courtesy stigma, an increased dependency ratio and a reduced household income. It has also been found that NTDs reduce the capability sets of children, which suggests they are unlikely to regain these capabilities to possess a complete set in adulthood. I therefore conclude that Van Brakel's statement, that the 'consequences of stigma are remarkably similar in different health conditions, cultures and public health programmes', does hold true for NTDs and that the predominantly rural prevalence of NTDs adds to the similarities (Van Brakel, 2006:307).

## Chapter 5

### Future Research

#### *Overall aims*

The aim of this thesis was to explore the link between NTDs and poverty by assessing the choices infected individuals lose during their illness as detailed by the capabilities approach.

To address this aim, I have:

- 1) Developed an understanding of NTDs, their neglected status and their broad contribution to global disease
- 2) Generated a conceptual framework of health, poverty and capabilities in which to place NTDs
- 3) Assessed NTDs in terms of the conceptual framework, paying significant attention to the effect of the enhanced stigma on people's capabilities, and consequently added this NTD specific field into the framework

This chapter first summarises the thesis and its findings, focusing on linking the chapters together and detailing the pathways by which NTDs lead to poverty. I will revisit the conceptual framework and detail the pathway of discrimination development for HAT as well as NTDs in general. Secondly, I address the fourth objective and identify gaps in the literature and suggest future empirical research that could begin to close these gaps.

The objectives of this thesis were to discover what links had already been made between NTDs and poverty, to identify any gaps in this research and to determine areas and methods for future research. To begin the search for these linkages I firstly had to discover how NTDs were neglected and why this was occurring. One main reason for neglect was the fact that the link between NTDs and poverty did not have enough experimental evidence to justify the hypothesised extent of the link. This lack of substantial and convincing evidence contributes to many areas of neglect including the lack of media coverage, funding, adequate disease burden measurements and inclusion on global health agendas. The arguments for a revised DALY measure, for example, are based on little empirical data, so to strengthen the argument that NTDs have a wider impact and a higher burden than currently reported, more research into their physical, social and political

effects need to be carried out, as well as research into the links between these effects and poverty exacerbation. The underrepresentation of disease burdens can mean that NTDs are not at the forefront of political agendas to prevent poverty, whereas in reality they are a major source of poverty, both in terms of capability deprivation and financial instability. Not only is the link to poverty under researched, but all areas of research were relatively sparse, including research into treatments, prevention, social impact and psychological impact. These areas, although stand alone, also contribute to our understanding of both capability deprivation poverty and economic poverty, thus indicating a substantial gap in the NTD-poverty literature. Funding to carry out this research is however unlikely to be allocated to NTDs, as firstly they have low public recognition status and little political advocacy, and secondly, their adverse effects on a country wide scale have not been adequately researched. This creates a vicious cycle whereby without funding advocacy generating research will not be carried out, but without advocacy essential funding towards research is unlikely to be awarded.

Preliminary research into the link between NTDs and both capability deprivation poverty and economic poverty would generate much needed advocacy, in order to increase the likelihood that funding will be provided for control and elimination through the development of culturally suitable and sustainable treatment and prevention programmes.

Chapter two also highlighted the debate surrounding the grouping of NTDs under an umbrella term. It has been criticised that this grouping reduces the importance of each individual disease, but on the other hand has been praised for highlighting the large collective impact of NTDs and for increasing awareness for the group. The argument for grouping diseases can be partially justified by the introduction of the integrated approach. Although a good idea in theory, research is often lacking for specific locations and collections of diseases. Extensive testing into different drug combinations is required to ensure compatibility, safety and economic benefit. This research is already underway and is vital for generating advocacy and the knowledge that, economically, the treatment of NTDs is viable.

The principal research gap revealed in chapter two is therefore the underrepresentation of NTDs' global importance in terms of their exacerbation of poverty. Research into the discovery of the real burden of NTDs, within the different contexts in which they occur, will begin to close this gap and a snow-balling effect may occur. The disclosure of the true disease burden will initiate increased media interest and thus generate greater awareness and advocacy. This media coverage is likely to induce pressure

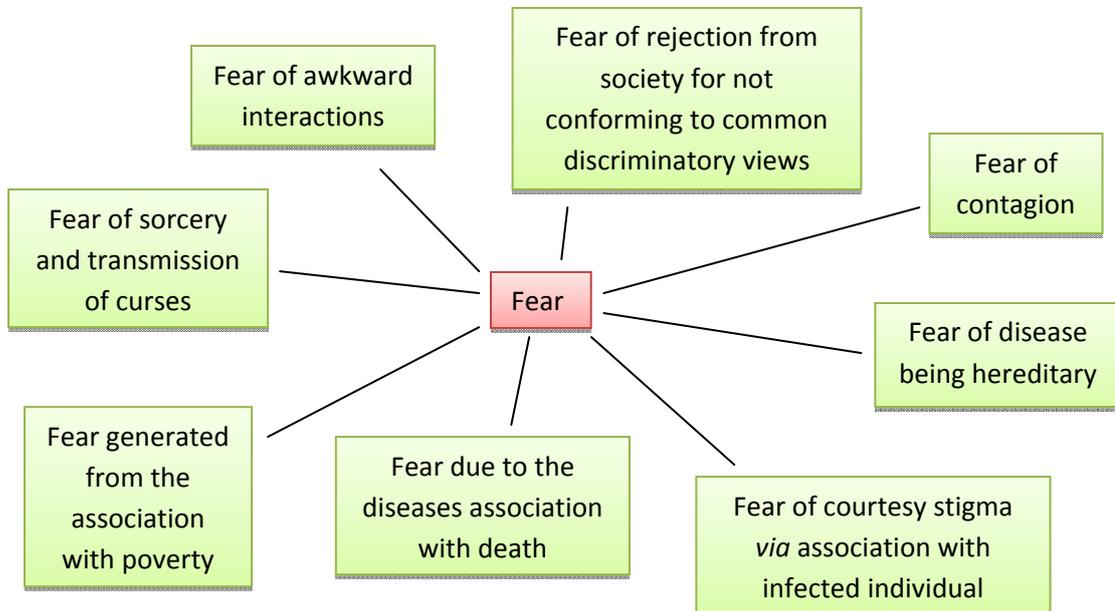
to provide the financial backing and the addition of NTDs into the global health agenda. As well as NTDs' impact on capability deprivation poverty, the impact that NTDs have on the economic status of a country is also hypothesised to be large. If we understand the effects that NTDs have on the economy, as well as on quality of life, then it is possible to estimate the benefits of controlling them to the economic development of an individual, a community or a country (Conteh *et al.*, 2010). Recognition that NTDs are a major barrier to economic development will put them higher on the priorities of the global health agenda and will encourage investment in the belief that revenue will be generated from the positive economic impacts of NTD control.

The third chapter develops the conceptual framework by linking three bodies of literature, health, poverty and capabilities. This was necessary because of the shortage of literature linking poverty and NTDs *via* the capability approach, so links had to be made using already developed concepts in which to later place NTDs. The links between ill health, the subsequent abatement of capabilities and consequent poverty were found to be extensive and cyclical. A theme which continued when NTDs were analysed using the framework in the fourth chapter, which drew on the unique features of NTDs discovered in chapter two and used this information to assess them effectively in terms of the framework. Without the previous knowledge regarding the neglect of NTDs, their analysis within the framework would not have been so forthcoming.

One area where NTDs did seem to differ from other diseases was the effect that stigma played on maintaining the cycle detailed in the framework. Stigma was often one of the problems that generated the highest disease burden in terms of quality of life, especially when the disease itself was not hugely traumatic for the sufferer, such as localised cutaneous leishmaniasis. Discrimination as a result of the possession of an NTD, or a previous infection, can occur *via* a number of pathways depending on the aetiology, transmission or cultural context of the infection. However, the general formula by which discrimination evolves is similar for all stigmatised conditions. The first stage in the development of existential stigma is others' knowledge of the disease (Jones *et al.*, 1984; Shears and Jensema, 1969). This could be a result of purposeful disclosure by the infected individual themselves, a breach of confidentiality, or the visual presence of the disease. If the disease is highly stigmatised it is likely that the infected individual fears existential stigma even before it is directly experienced, and therefore they are already experiencing a form of stigma from the point of contraction or diagnosis. Once disclosed however, the

specifics of the disease induce fear in the potential stigmatisers. This fear can be generated from a number of sources as shown in figure 11.

Figure 11: The sources of fear

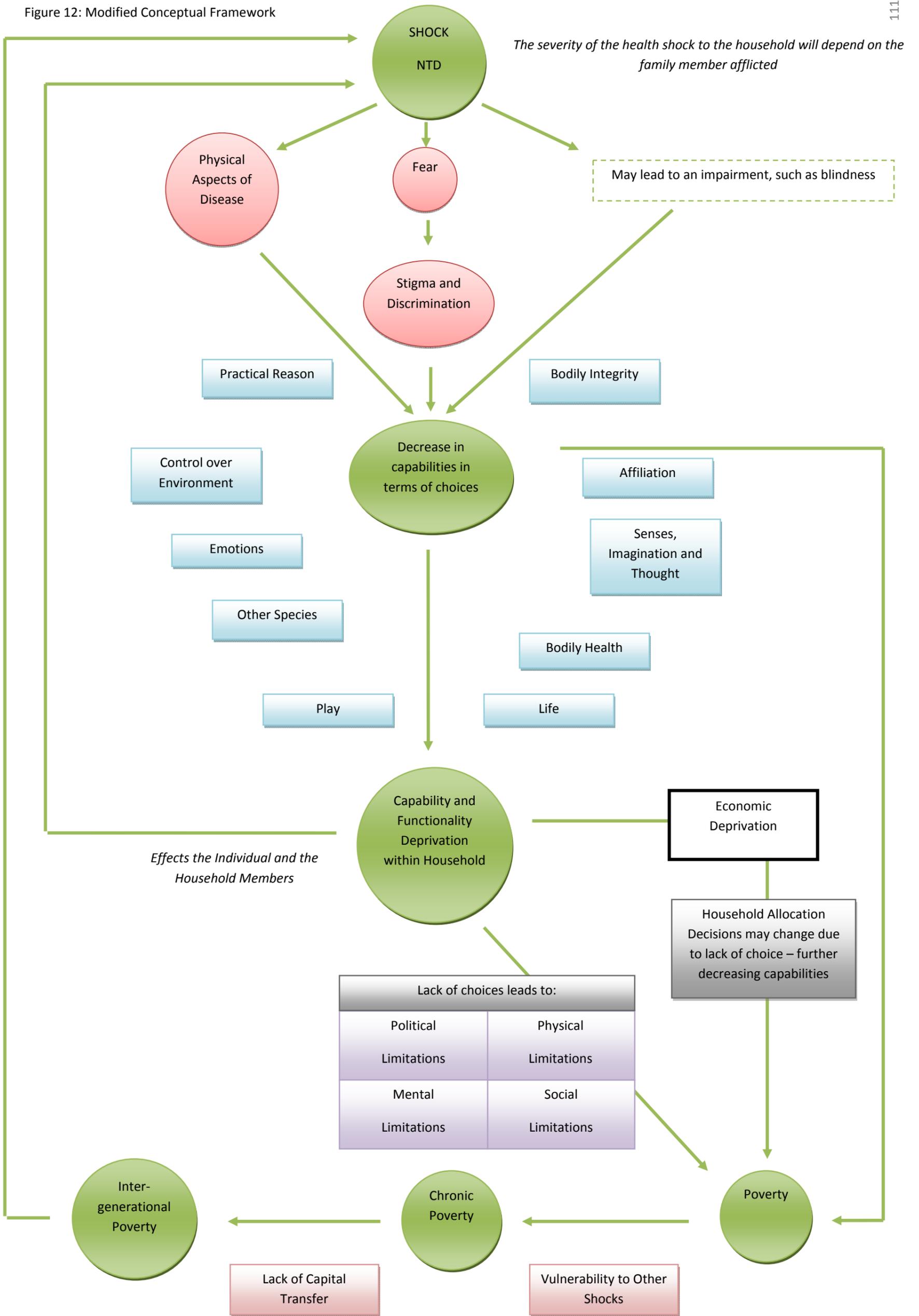


This fear then leads the potential stigmatisers to actively exclude or to discriminate against an individual with an NTD. This can occur *via* social exclusion whereby the infected individual is unable to take part in social activities within the community, unable to take part in political decisions, and made to feel uncomfortable in, or even excluded from, their own homes.

Discrimination can also occur as a result of the belief that an infected individual is mentally weak. This can lead to exploitation, such as unfair housing and employment contracts, whereby the infected individual and their family are tied into contracts which they cannot extricate from (Scambler, 2009; Van Brakel, 2006). Exploitation in the workplace can also occur as reduced pay for the same job, as the infected individual is led to believe that they are lucky to have obtained the job at all as no other employers would consider employing them (Scambler, 2009). This type of discrimination does not directly result from fear but is linked to it. The existential stigma faced by the infected individual as a result of fear renders them vulnerable in terms of self-esteem and self-belief and they are therefore easily exploited. Thus, without the previous pathway of fear leading to discrimination, the exploitive pathway would not be so prevalent.

This discrimination, together with the physical effects of disease, drastically decrease an individual's capabilities. They therefore suffer capability deprivation poverty, a state that can compromise quality of life and the ability to choose, thus reducing their life satisfaction. This satisfaction may reach unacceptable levels and result in the capability to live a valued life being compromised as their life may no longer be valued and they may feel it is not worth living. As stigma and discrimination were found to be extremely important in the perpetuation of the cycle detailed in the conceptual framework, they have subsequently been incorporated into the conceptual framework to specify it towards NTDs. This modified framework is detailed in Figure 12.

Figure 12: Modified Conceptual Framework

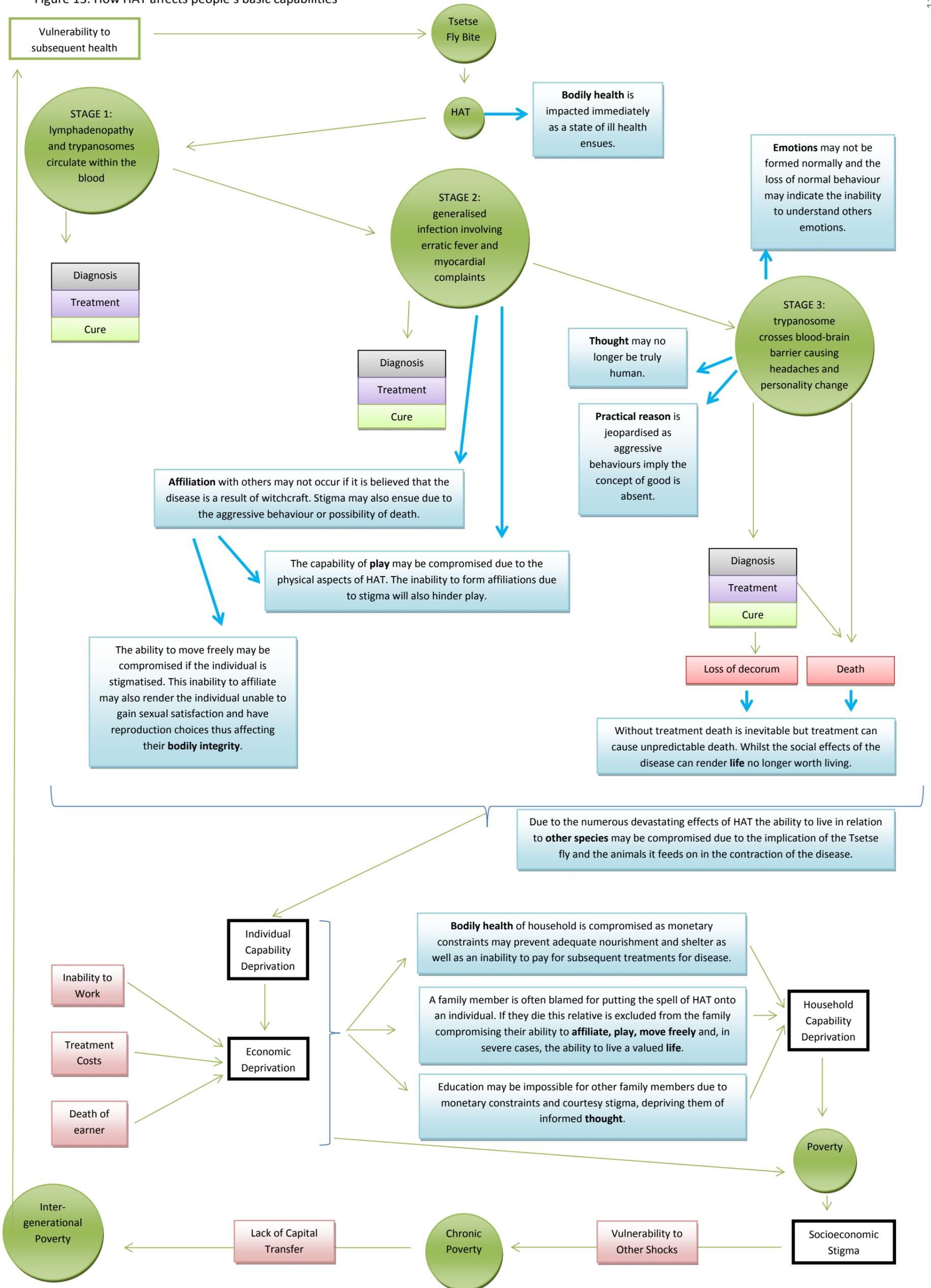


Taking the example of HAT, the symptoms, diagnosis, and treatment are all feared stages of the disease. The most feared symptom occurs at the stage when the trypanosomes cross the blood brain barrier and generate personality changes (Cattand *et al.*, 2006). This is because personality defines us as individuals whilst also associating us with the human race. A change in personality can therefore remind people of their own fragility and bring about the feeling of fear. Due to the often aggressive nature of people with late stage HAT, the new personality itself may also be feared as the person has become dangerous and someone to be wary of. In many developing countries HAT also has a strong association with witchcraft, with some cultures believing that HAT results from a curse originating from a family member (Robays *et al.*, 2007). This association also spawns fear as this curse could potentially be spread and affect other members of the community.

The diagnosis of HAT often carries more fear than the symptoms of early stage disease. This is because a diagnosis would also bring the possibility of death, either *via* progression of the disease or as a result of the lengthy and toxic treatment (Papadopoulos *et al.*, 2004; Stich *et al.*, 2002). Diagnosis also implies a six month period of rest after the treatment has been administered, a long period of time to act as a dependant within the household, with work and physical activity banned. The disease is therefore heavily associated with poverty thus generating a further source of stigma and reason for exclusion.

As with other stigmatised diseases, associating with an individual affected by HAT can lead to the suffering of a courtesy stigma. Fear is therefore generated from the possibility of being burdened by this stigma and consequently the infected individual is avoided. The feared aspects of HAT are numerous and result in high levels of stigma being faced by infected individuals, thus compromising their capabilities. These effects on people's capabilities are outlined in the Figure 13, the blue boxes detail how each capability is affected and their positioning indicates the disease stage where they begin to be affected. It also details how these individual capability losses can contribute to the deterioration of the household's capability set.

Figure 13: How HAT affects people's basic capabilities



As the burden of stigma greatly affects most NTDs it must be given numerical value if it is to be recognised in disease burden measurements such as DALYs, which rely on the agglomeration of numerical data. This will be challenging as stigma varies according to culture, individual personality, gender, and disease severity. However, this research could be based on qualitative methods used previously to assess the social burden of other diseases. For example, UNAIDS (2000) developed a protocol to measure the discrimination suffered by people living with HIV. The results identify specific discriminatory practices and show that the disease burden has dramatically increased due to stigma. UNAIDS (2000) documented 37 discriminatory situations within ten areas of social life. These included practices that took place within health care, employment, the justice and legal system, administration, social welfare, housing, education, family life, financial services, and access to other public services. Figure 14 depicts the situations assessed within health care.

Figure 14: Assessment criteria for documenting discrimination in health care. Source: UNAIDS (2000)

Area	Required by law	Required by internal regulations or procedures	Occurring in practice
<b>I. Health Care</b>			
1. Refusal to treat on grounds of HIV/AIDS status.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Different treatment on grounds of HIV/AIDS status.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Testing without knowledge.			
4. Refusal to inform a person of the result of an HIV test.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Health controls, quarantine, compulsory internment, and/or segregation in hospital, clinic, nursing home etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Compulsory notification of HIV/AIDS status to sexual partner(s) and/or relative(s).			
7. Non-confidentiality: supplying names of individuals found to be HIV-positive to any other party, or knowingly or negligently allowing confidential files to be consulted.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Figure 14 shows that there could potentially be disparities between what levels of discrimination are against the law and what is occurring in practice. For example, the law states that breaching confidentiality is a crime, but people who test positive for HIV may be subjected to a breach of confidentiality and their status spread throughout the community. The same format of collecting information from law, and using questionnaires to determine actual practice, could be used for the assessment of stigma and discrimination towards those suffering from NTDs. A numerical indicator can then be calculated using the following expression:

$$\frac{\text{Number of non-discriminatory practices/ rules identified}}{37 \text{ (the number of assessed situations)}} \times 100$$

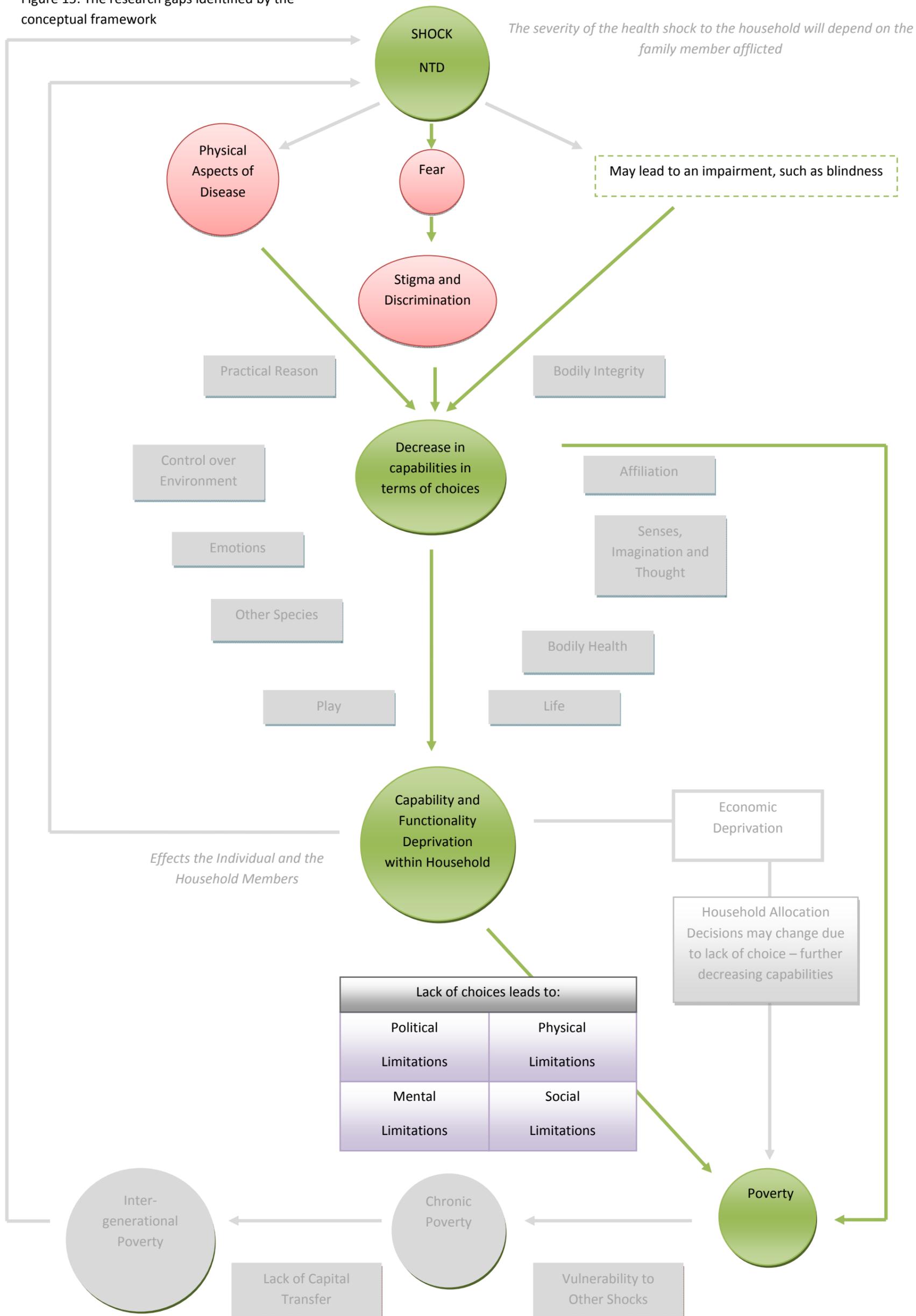
This is not an exhaustive list, but an indication of the stigma intensity for HIV/AIDS and which areas of life are most problematic. When dealing with NTDs, the list of potentially discriminating practices must be specific to a disease and location, with preliminary investigations and questionnaires acting as the basis for the development of the criteria. This measure alone does not take into account self or internalised stigma, both very difficult to measure numerically, as measurement would rely on self report, a method fraught with inaccuracies due to personality differences and differing education levels. However, psychological testing could also be carried out and added into the discrimination indicator.

The conceptual framework highlighted that NTDs lead to poverty in terms of both capability deprivation and economic poverty, as income opportunities are reduced, and expenditure increased. As this hypothesis was formed from the collation of different literatures as opposed to the collection of primary data, the ideas generated herein need to be backed up by empirical research, and thus the conceptual framework expanded and clarified. The framework has provided a new way to address research gaps that were already apparent within the literature, as well as highlighting new gaps in research. For example, the lack of evidence for NTDs link to poverty could be researched using already developed methods, or it could be analysed using the capability deprivation poverty paradigm.

Figure 15 highlights the main gaps in knowledge that need to be addressed within the framework. The masked areas in grey are those that already have been researched: the link between NTDs and lifelong impairments, Nussbaum's set of ten capabilities and their interchangeable nature depending on circumstances and culture, the stages of poverty from transitional poverty to intergenerational poverty, the link between poverty and future

ill health and the links between capability deprivation and economic poverty. The link between capability deprivation poverty and economic poverty, although a well-known concept, requires further exploration in relation to NTDs as funding allocation for NTDs will depend heavily on the exploration of the economic benefits of controlling them. The highlighted areas on the other hand illustrate the main links where little or no research has taken place. Firstly, the link between the health shock of an NTD and a decrease in capabilities as dictated by the capabilities approach has never been specifically explored. Secondly, it has not been ascertained how these capability deprivations lead to specific limitations which deepen poverty. There is also a gap in knowledge about if, and precisely how, capability deprivation can be passed from an individual on to their families. In the next section I will explain the difficulties of measuring capabilities and suggest ways in which to measure capability deprivation among NTD sufferers.

Figure 15: The research gaps identified by the conceptual framework



The main gap in the literature is the link between NTDs and the capabilities approach. There are obvious difficulties measuring the impact of NTDs on people's capabilities as these cannot be directly observed. However, the capability set of an individual is the 'ultimate space of evaluation' for determining people's level of poverty, compared to their economic situation or analysis of their functionings. It is thus important to find methods that are able to measure capabilities in terms of what choices are open to people. To do this, people's alternative functionings must be ascertained.

However, before the evaluation of choices can begin, the process of selecting which capabilities make up the dimensions of poverty needs to be addressed. There is also the issue of assigning weight to the chosen capabilities, as even though Nussbaum's list is often used as a universal list of basic capabilities, Sen argues that these capabilities will differ in importance between populations (Alkire, 2007). Preliminary studies must therefore be carried out in order to add culture specific weightings to the capability set. One simple way to gather this information would be to observe the daily lives of people in order to gauge which aspects of life are prioritised within the day. For example, it may be observed that prayer occurs every day for a certain amount of time despite other commitments and thus freedom to religious practice may be of great importance to that population. In-depth interviews could then be carried out to assess whether the observed activities were down to choice, or whether they were partially or entirely motivated by a lack of choice. For example, if a high proportion of the day was spent indoors, this may indicate that the choice to remain indoors is of high importance, but on further investigation *via* interview, it may be discovered that this choice was forced by social exclusion and discrimination.

It has been suggested that the community being studied should be the ones to decide on the weightings of each capability (Robeyns, 2006). There may however be some discrepancy between the weightings given by people who are unaffected by NTDs and those already affected by NTDs. For example, individuals or households that have been directly affected by an NTD may frequently report the most important capability as the ability to maintain bodily health, a capability which has been lost, or conversely they may prioritise a capability that they have preserved, such as social affiliation for example.

When both the capabilities to be assessed and their weightings have been determined it is necessary to decide whether capabilities will be assessed directly, or if functionings, with the intention of speculating the preceding capabilities, will be the focus of research. One possible way of attaining information regarding an NTD sufferer's

capabilities directly is to ask them to discuss their options. Anand and van Hees (2006) chose the phrase 'taking all things together, I think my options are...' and asked participants to complete the sentence (Anand and van Hees, 2006:271). This allows the participant to fully describe what choices they believe they possess in all areas of life. The question could also be targeted to a specific area of life by the researcher, such as educational choices. However there are flaws in such an approach; people may not be aware of all their capabilities or state some capabilities that are unattainable. This disadvantage is common in self-report based studies so to increase accuracy a high number of participants would be required. However, it could potentially be argued that it is the choices that the participant believes that they possess, or do not possess, that impacts on their life satisfaction, as if they feel that they have chosen their life course they will be more satisfied than if they feel that they had no choices. This point stresses that it is important that people are aware of their choices in order to feel in control of their lives

There are also major differences between groups of people, for example, Anand and van Hees (2006) declare that ethnic minorities in England reported higher satisfaction with their capability sets. This may be because different groups of people rate satisfaction from different 'benchmarks', thus suggesting minority groups do not take their capabilities for granted and are more appreciative of the ones they have. This discrepancy, although not problematic for ascertaining which capabilities are present, may alter satisfaction ratings. The capabilities approach has gained a reputation of being unworkable and of little practical significance as a result of the difficulties in measuring it (Robeyns, 2006). Because of the difficulty in measuring people's capabilities, especially in large country wide studies, many researchers choose to focus on functionings and make assumptions about people's choices. For example, it is assumed that people with the financial ability to nourish themselves will do so. Therefore, everyone who lacks the functioning of adequate nutrition is assumed to lack the ability to nourish themselves. This is of course untrue of anorexics or people on religious fasts. Differences in intrinsically desirable functionings, such as adequate nourishment, are however, unlikely to be down to choice and more likely attributed to differences in capabilities (Robeyns, 2003). This implication means that, in some instances, capabilities can be deduced from functionings. For example, in terms of nourishment, shelter or education, when two similar groups of people have significantly different functionings, it can be deduced that this may be because of differing capability sets, as opposed to the choice of different functionings (Robeyns, 2003). Focusing on less essential functionalities can however generate data collection problems, as the presence of

a functionality shows only that one capability existed and it does not provide information as to whether other options were available or if this was a forced choice.

The capabilities approach is an individualistic theory, meaning the assessments made should be in terms of individuals, as opposed to communities, households and countries. The approach does still take into account societal factors, meaning that individuals' capabilities are considered dependent and linked to other people and the wider society (Robeyns, 2003). For example, a family with small children may be limited in their choices. Individually, the parents may have the same ability to be employed but whilst caring for the children only one of them can realise this individual capability (Robeyns, 2006). This presents the argument for looking into both the capabilities of the individual, and the functionings of that individual, to determine their individual capabilities and the constraints posed by others or the society.

In-depth community assessment may be needed in order to determine the services present and the ability for everyone to use them. For example, in the case of NTD sufferers, a school may be present but it may be too far away for someone with a large hydrocele, or the fatigue generated from STHs to travel to. Another potential barrier is the social stigma faced by the sufferer, which may prevent them from attending the school. This can be judged by observation, and interviews assessing both the view of the NTD sufferer and the sufferer's view of the stigma directed towards them. The sufferer can also report on the levels of felt stigma and internalised stigma in order for us to gauge whether mental limitations are also hindering school attendance.

A further barrier to education is likely to be financial, especially if the NTD treatment is expensive or lengthy, and therefore the family may be unable to send children to school as they have no money to pay for it, or, if it is free, no money for transport, uniforms or books. Identifying the differing barriers to attaining the ability to attend school, for example, will inevitably help when structuring programmes to increase education for NTD sufferers, or those with an affected family member, as the mere presence of a school is not always enough to induce this capability.

One way of researching the capabilities lost by those suffering from NTDs is to compare the lives of people before the onset of the disease, during the disease and after it has been cured or controlled. By comparing the lives of the individual and their family before the onset of disease, to when the NTD took hold, we can deduce which capabilities were affected by the NTD itself. This is important, as many people who suffer from NTDs are already poor and living in poor conditions, meaning their capability sets are already

reduced. Focusing on the individual at the time of the disease in isolation may therefore generate a bias, as the lost or reduced capabilities that define their quality of life may have already been reduced or non-existent before the onset of disease, and these may be mistakenly attributed to NTDs. For example, people suffering from poverty may already be stigmatised due to their low social status. The onset of an NTD may increase this stigma but will not account for its introduction, and thus stigma cannot be entirely attributed to NTDs. The effects of NTDs can be life-long, even if they are cured. Therefore comparing the capability set during the course of the disease, and after successful treatment, will show whether any capabilities have been regained, remained the same, or have been further reduced. This investigation could in part be done by using census data, if available, on aspects such as changes in the number of people within a family attending school, housing standards and deaths.

### *Conclusion*

It has been found that applying the capabilities approach to NTDs in order to assess their impact on poverty may be advantageous for a number of reasons. NTDs rarely result in mortality, but instead devastate lives through on-going disability and social disqualification. This means that mortality rates do not adequately depict the impact of NTDs and other methods of assessment must be employed. Using the capabilities approach is an invaluable way to assess the impact of NTDs on welfare, both on a person centred and country wide scale. Even though notoriously difficult to measure numerically, capability sets can be ascertained through the combination of a number of methods. These include the methods previously discussed: observation, investigation of services, determination of level of education, in depth questionnaires and psychological assessments. The subsequent determination of capabilities can provide us with information regarding how better to educate people about the options they have regarding all aspects of life. This is important because the act of choice is the most valuable aspect of life and heavily contributes to the level of life satisfaction experienced.

By assessing the impact of NTDs through the lens of the capabilities approach I have come to the conclusion that the current disease burden measurements underestimate the damage that NTDs do to individual lives, communities and countries. I believe that due to the drastic loss of capabilities, economic instability and loss of life satisfaction that NTDs

propagate they need to be taken more seriously and be more generously funded and recognised in poverty reduction programmes.

If time was not a constraint during the creation of this thesis, I would have liked to have carried out some of the preliminary empirical research in order to begin to understand more fully the pathways of poverty transmission *via* the medium of NTDs and subsequent capability losses. I would carry out observations and interviews as well as distributing simple questionnaires within a community where an NTD, or several NTDs were prevalent. I have a specific interest in discovering how people's perceptions of a disease change as it moves through different physical stages, such as in the case of HAT. I hypothesise that different capabilities are affected depending on the stage of disease, and would also like to discover whether an early diagnosis and treatment would result in the same social capability losses as the entry into the third stage of the disease as a result of anticipated symptoms. I would do this by documenting the changes in the capability sets of infected individuals by conducting interviews. I aim to discover the differences between individuals who received early treatment and those who entered the most stigmatised third stage of the disease. However, to get to this stage of research would require extensive background studies to tailor the capability set to the culture and location, and assign the correct weightings to each capability. This could be done *via* the methods previously outlined in the chapter, such as letting the community itself decide on the importance of each separate capability.

The capabilities approach is a well-established paradigm for policy creation in terms of human development, and so combining it with lower profile NTDs may help raise their recognition status and thus their likelihood of being awarded essential funding. If time permitted, I would like to carry out a small study within my local area, asking the citizens and local politicians what characteristics of a disease they believe to be important in the generation of advocacy and public awareness. This would be of great benefit to future NTD research, as areas of most importance to developed countries could be initially researched to generate further advocacy. This would hopefully result in additional funding for research into prevention and control mechanisms drawing on the social research of previous studies.

It is hypothesised that understanding the effects that NTDs have on the economy, and therefore estimating the economic benefits of controlling them, is an important aspect when trying to generate advocacy and compete for funding (Conteh *et al.*, 2010). This will become ever more important as the global economic crisis persists, as developed countries

that donate money for research and control programmes will be more interested in ideas that will cost minimal amounts for maximum reductions in poverty. NTDs already have very cheap prevention and treatment programmes. Melinda Gates speaks on behalf of the Bill and Melinda Gates Foundation about NTDs stating that: 'For governments, corporations, NGOs and individuals, there is little else during this global economic crisis that provides such a significant return on investment while also reducing suffering and saving lives' (The Bill and Melinda Gates Foundation, 2009). For example, STHs often require a single annual tablet, with costs below a pound per treatment, and trachoma prevention is primarily down to education involving facial cleanliness. Both are cheap and simple mechanisms which will have a large positive impact if implemented correctly. The good investment potential has resulted in several major companies including GlaxoSmithKline, Pfizer and Merck making major new investment commitments (The Bill and Melinda Gates Foundation, 2009). These investments will not only provide a good financial return for the donor companies, but will also improve the lives of many people with or at risk of contracting NTDs.

It is important that the social propagation and social impacts of NTDs are thoroughly detailed in order for prevention and control programmes to be utilised and successful. Research into the propagation of disease *via* the capabilities approach will aid our understanding of the social, physical, mental, economic and political limitations of infected individuals. This knowledge will provide reasons for poor treatment-seeking behaviour and this information will in turn be essential in developing effective prevention and control programmes. In conclusion, for effective policy to be established, a far greater nuanced and situated understanding of the social contexts of NTDs is required.

Appendix One

The thirteen NTDs, their DALYs, methods of transmission, symptoms, treatment and causes of stigma

NTD	DALYs	Transmission	Symptoms	Treatment and Prevention	Stigma
Leishmaniasis	2.4 (Benderley, 2009) OR ≈2 (Schriefer, 2009)	A natural sandfly vector ( <i>Phlebotomus papatasi</i> ) that carries the parasite <i>Leishmania</i>  Animal reservoirs include dogs and rodents (zoonotic hosts) (Cox, 1996)  Cannot pass directly between humans (Cox, 1996)	CUTANEOUS: sore at the bite site – heals unaided but leaves a scar (can progress to the other forms)  MUSCUTANEOUS: Permanent disfiguring lesions – spreads to other tissues especially the nose and mouth  DIFFUSE CUTANEOUS: widespread skin lesions resembling leprosy  VISCERAL: fever, enlarged spleen and liver and blackening of the skin	Pentavalent antimonials are facing resistance in India  Amphotericin is now the drug of choice	Disfiguring scars as well as a change of perception towards oneself can lead to severe psychological disorders  Sufferers are ostracised from society and find it hard to marry  It can be wrongly perceived to be transmitted from person to person, which generates further stigma (Kassi <i>et al.</i> , 2008)

NTD	DALYs	Transmission	Symptoms	Treatment and Prevention	Stigma
Trachoma	2.3-4.0 (Smits, 2009)	<p>Caused by a <i>Chlamydia</i> bacteria</p> <p>Children are the main reservoir of the disease</p> <p>Spread by direct or indirect contact</p> <p>Flies gathering around the eyes can also transmit infective discharges between people (Cox, 1996)</p>	<p>Trichiasis occurs when eyelashes grow back towards the eye, causing discomfort and visual impairment, which can lead to blindness (Smits, 2009)</p> <p>Resultant inflammation, scarring and ulceration mean the eye becomes covered by scar tissue (Markel, 2000)</p>	<p>Azithromycin, oral drug</p> <p>Eyelid surgery</p> <p>Maintain environmental hygiene and facial hygiene (Smits, 2009)</p>	<p>Evidence of high amounts of stigma towards people infected with trachoma when they emigrated to the US</p> <p>The distasteful appearance, treatment difficulty, and contagious nature of the disease add to stigma</p> <p>Known to spread in poor areas with poor hygiene meaning stigma can also result from the link to low social status (Markel, 2000)</p>

NTD	DALYs	Transmission	Symptoms	Treatment and Prevention	Stigma
Human African Trypanosomiasis (HAT) (Sleeping Sickness)	1.54 (WHO 2009 (in 2002))	Protazoan parasite called trypanosomes are transmitted <i>via</i> the tsetse fly vector (Cox, 1996)	<p>Two forms caused by morphologically indistinguishable subspecies</p> <p>Clinically distinct stages: at site of bite a trypanosomal chancre appears and regional lymphadenopathy occurs</p> <p>First stage of generalised infection includes fever, myocardial complaints, a faint rash</p> <p>Second stage occurs when the trypanosome crosses the blood brain barrier and invades the central nervous system. Encephalopathy (headache and mental changes) occurs and the patients eventually enters a terminal somnolent state (Stich <i>et al.</i>, 2002)</p>	<p>Diagnosis requires skilled professionals</p> <p>Melarsoprol, which is toxic, or Eflornithine, which is difficult to administer, or Nifurtimox, which is cheap, and can be administered orally (Legros <i>et al.</i>, 2002)</p>	<p><b>Low attendance at screenings may suggest that people are socially excluded so feel they cannot be seen in public</b></p> <p><b>Carries stigma as a mental disease and in many communities psychiatric problems are often associated with sorcery</b></p> <p><b>Due to personality changes it is inevitable that people will perceive the infected person differently</b></p> <p><b>Even after a cure former patients cannot be taken seriously due to loss of decorum during the disease, which generates long term stigma and shame</b></p> <p><b>Unexpected deaths and unpleasant side effects of the treatment lead to people avoiding treatment (Robays <i>et al.</i>, 2007)</b></p>

NTD	DALYs	Transmission	Symptoms	Treatment and Prevention	Stigma
Schistosomiasis	1.8-4.5 (Smits, 2009)	Genus <i>Schistosoma</i> (blood fluke)  Laval stages develop in aquatic snails, these are shed and penetrate any skin in contact with infected water  Larvae make their way to the intestine or bladder (Cox, 1996)	Impaired growth and cognition in children  URINARY SCHISTOSOMIASIS: Hematuria (red blood cells in urine), renal failure, and bladder cancer  INTESTINAL SCHISTOSOMIASIS: Diarrhoea and disturbed liver function (Smits, 2009)	Praziquantel  Use molluscicides to kill snails, together with water management (Smits, 2009)	Female genital Schistosomiasis is a prominent social problem, as it may lead to infertility and extra uterine pregnancy. It may also facilitate the spread of some Sexually Transmitted Diseases such as HIV/AIDS, which can generate severe social problems such as ostracism and the inability to marry (Okwa, 2007)

NTD	DALYs	Transmission	Symptoms	Treatment and Prevention	Stigma
Onchocerciasis (river blindness)	0.5-1.0 (Smits 2009)	Nematode worm ( <i>Onchocerca volvulus</i> ) transmitted by <i>Simulium</i> (blackflies) feeding on human host (Cox, 1996)	Disfigurement of the skin, and visual impairment, which can lead to blindness (Smits 2009)	Invermectin Indoor residual spraying and bed nets (Smits 2009)	Social rejection, isolation and divorce The beauty of the skin is culturally and socially important so disfigurement can lead to social rejection (Okwa 2007)
NTD	DALYs	Transmission	Symptoms	Treatment and Prevention	Stigma
Lymphatic Filariasis	5.6-5.8 (Smits 2009)	Caused by <i>Wuchereria bancrofti</i> , <i>Brugia malayi</i> and <i>B. Timori</i> nematode worms which are transmitted by mosquitoes. The nematodes live in the lymphatic system (Cox, 1996)	Acute adenolymphangitis and lymphatic obstruction, oedema of the legs, and psychiatric illness (Smits 2009)	Diethylcarbamazide or Invermectin plus Albendazole (Smits 2009) Mosquito nets	Social rejection, isolation and divorce lead to feelings of shame, fear, embarrassment and suicidal thoughts (Okwa 2007)

NTD	DALYs	Transmission	Symptoms	Treatment and Prevention	Stigma
Soil Transmitted Helminths - Ascariasis	STHs collectively 4.7-39.0 (Smits 2009)	Infection with a large roundworm <i>Ascaris lumbricoides</i> from contaminated soil or food The eggs are passed to soil in faeces (Cox, 1996)	Impairments in physical, intellectual, and cognitive development Larvae burrow through intestine, reach lungs, and are re-swallowed which may cause inflammation, fever, diarrhoea, spleen enlargement, pneumonia, nutrient deficiency, and bowel obstructions (Baird <i>et al.</i> , 1986)	Ascaricides e.g. Mebendazole, block the worms uptake of glucose Piperazine paralyses the worm so it is passed out in faeces	Curtale <i>et al.</i> (1998) found that there was no stigma associated with worms due to the fact that they are extremely common  They also found prevention methods were common knowledge, such as washing hands and foods, this could have two impacts on stigma:  1) People could be heavily stigmatised for having worms as it shows them to be unclean and unhygienic  2) People would not be stigmatised as there is no fear associated with the infection and transmission is easily prevented

NTD	DALYs	Transmission	Symptoms	Treatment and Prevention	Stigma
Soil Transmitted Helminths - Trichuriasis	STHs collectively 4.7-39.0 (Smits 2009)	<p>Infection by whipworm, <i>Trichuris trichiura</i></p> <p>Inhalation or ingestion of soil contaminated with faeces or infected food (Stanford)</p>	<p>Impairments in physical, intellectual, and cognitive development</p> <p>Worm resides in the large intestine, rectum, appendix and upper colon</p> <p>Usually mild symptoms, but can cause diarrhoea, necrosis of the colonic mucosa and sub-epithelial haemorrhages, severe anaemia, and weight loss (Arfaa, 1984)</p>	<p>Treat excrement with ovicides, maintain good sanitation, treat food before consumption, and mass chemotherapy (Arfaa 1984)</p> <p>Oral treatment with mebendazole for 3 days is commonly used in symptomatic infections</p>	<p>Curtale <i>et al.</i> (1998) found that there was no stigma associated with worms due to the fact that they are extremely common</p> <p>They also found prevention methods were common knowledge, such as washing hands and foods, this could have two impacts on stigma:</p> <ol style="list-style-type: none"> <li>1) People could be heavily stigmatised for having worms as it shows them to be unclean and unhygienic</li> <li>2) People would not be stigmatised as there is no fear associated with the infection and transmission is easily prevented</li> </ol>

NTD	DALYs	Transmission	Symptoms	Treatment and Prevention	Stigma
Soil Transmitted Helminths - Hookworm	STHs collectively 4.7-39.0 (Smits 2009)	<p>Caused by infection of one of two roundworms, <i>Ancylostoma duodenale</i> or <i>Necator americanus</i></p> <p>These are passed out through faeces and hatch in the soil, the larvae then bore through the skin (Cox, 1996)</p>	<p>Impairments in physical, intellectual, and cognitive development</p> <p>Local pruritic, erythematous, and a papular rash known as "ground itch"</p> <p>Infection with <i>A. braziliense</i> third-stage larvae results in cutaneous larva migrans, or "creeping eruption," a self-limited dermatologic condition characterized by burrows, 1 to 5 cm long</p> <p>Vomiting, pharyngeal irritation, cough, dyspnea, and hoarseness</p> <p>Severe intestinal blood loss causes anaemia (Hotez <i>et al.</i>, 2004)</p>	<p>Proper sanitation and footwear</p> <p>Benzimidazole anthelmintic, single dose, available at low cost</p> <p>School based de-worming is favoured (Hotez <i>et al.</i>, 2004)</p>	<p>Curtale <i>et al.</i> (1998) found that there was no stigma associated with worms due to the fact that they are extremely common</p> <p>They also found prevention methods were common knowledge, such as washing hands and foods, this could have two impacts on stigma:</p> <ol style="list-style-type: none"> <li>1) People could be heavily stigmatised for having worms as it shows them to be unclean and unhygienic</li> <li>2) People would not be stigmatised as there is no fear associated with the infection and transmission is easily prevented</li> </ol>

NTD	DALYs	Transmission	Symptoms	Treatment and Prevention	Stigma
Buruli ulcer	0.1 (WHO, 2002)	<p><i>Mycobacterium ulcerans</i></p> <p>Research suggests aquatic organisms can harbour the disease and transmit it to animals, but this is not certain as Australian data implicates the mosquito (WHO, 2007)</p>	<p>First stage involves a non-tender nodule</p> <p>The subcutaneous fat is then affected followed by the bone, this results in a necrotic ulcer with deeply undetermined edges, which is usually painless</p> <p>Can develop scarring and permanent disabilities</p> <p>In some cases rapid oedema of limb occurs and the whole area may ulcerate (Johnson <i>et al.</i>, 2005)</p>	<p>Large ulcers are treated surgically but relapse may occur</p> <p>Drug therapy has been considered ineffective, but combined anti-micro-bacterial antibiotics are able to kill the bacteria (Johnson <i>et al.</i>, 2005)</p>	<p>Common perceived causes are witchcraft and curses which are highly stigmatised</p> <p>The mysterious nature of disease and lack of knowledge of the mode of transmission adds to the stigma burden</p> <p>Whole families can be stigmatised as they are thought to have brought the disease to the community (Stienstra <i>et al.</i>, 2002)</p>

NTD	DALYs	Transmission	Symptoms	Treatment and Prevention	Stigma
Leprosy	0.177 (WHO, 2002)	<p>Bacterial infection of <i>Mycobacterium leprae</i></p> <p>Most common mode of transmission remains unclear, but it can be contracted by inhalation, bites, wounds, food or drink (Cox, 1996)</p>	<p>Can result in a small asymptomatic macule with no sensory impairment or widespread infiltration can cause large plaques generating the loss of sensation, muscle weakness and atrophy</p> <p>Severity is dependent on the individuals immune capacity</p> <p>Often leads to permanent disability and deformity (Cox, 1996)</p>	<p>In the 1970's resistance to dapsone was widespread so multiple drug therapy was utilised combining dapsone, clofazimine and rifampicin</p> <p>However this combination is expensive (IDRI 2007)</p>	<p>Social rejection, isolation and divorce</p> <p>The word leprosy is used as a metaphor for stigma (Cross, 2006)</p> <p>Leprosy has been associated with stigma throughout history and on all continents, however in different locations there are different beliefs about cause and transmission, which generate differing levels of stigma</p> <p>Leprosy generates many cases of self-stigma (Arole, 2002)</p>

NTD	DALYs	Transmission	Symptoms	Treatment and Prevention	Stigma
Dracunculiasis (Guinea worm)	0.1 (WHO, 2002)	<p><i>Dracunculus medinensis</i> – a Guinea worm</p> <p>Caused by drinking water containing fresh water crustaceans infected with the larvae, ingested larvae then penetrate the stomach wall (Cox, 1996)</p>	<p>Larvae penetrate stomach wall and move to subcutaneous tissue causing pain, they then emerge through the skin producing oedema, blistering and an ulcer</p> <p>Fever, nausea, vomiting (WHO, 2009)</p>	<p>Pass water through a fine cloth (Cox, 1996)</p> <p>No treatment or vaccine available and people must extract the worms themselves</p> <p>The exit wound generates the possibility of secondary bacterial infection</p>	<p>Women are unable to meet husbands sexual needs due to the pain which can result in divorce and social exclusion (Okwa, 2007)</p>

NTD	DALYs	Transmission	Symptoms	Treatment and Prevention	Stigma
Chagas' disease (American Trypanosomiasis)	0.676 (Urbina and Docampo, 2003)	<p>The parasitic protozoan <i>Trypanosoma cruzi</i> is transmitted in the faeces of blood sucking insects of the Triatominae subfamily</p> <p>Can also be spread by blood transfusions, eating uncooked meat or food contaminated by faeces</p> <p>Occasionally congenital (Cox, 1996)</p>	<p>Early phase is asymptomatic (usually a lesion at entry site), but is occasionally fatal</p> <p>Can progress to heart abnormalities, intestinal malfunction, and enlargement of oesophagus and colon (Cox, 1996)</p>	<p>Drugs are only available against early stages</p> <p>Nifurtimox and benznidazole have side effects (Remme, 2006)</p> <p>Insecticides and housing improvements are therefore favoured (Cox, 1996)</p>	<p>Disease used to be associated with poor rural families, resulting in socioeconomic stigma, but now poverty in urban areas has made the disease more widespread</p> <p>People must declare they have the disease when applying for jobs, this acts as a discriminatory mechanism and people are either rejected or are put into jobs with precarious contracts (Briceño-León and Méndez Galván, 2007)</p>

## Appendix Two

The thirteen NTDs and how each may impact life after the infection has cleared and how DALYs can be underestimated

*Disease*                      *Impact after the infection has been cleared and how DALYs can be underestimated in other ways*

Human African Trypanosomiasis	<ul style="list-style-type: none"><li>• The loss of normal behaviour and change in personality during a period of illness will inevitably change people's views of the infected person.</li><li>• This may last even after the person has been cured as they won't lose the shame they brought on themselves and their family at the time of the illness (Robays <i>et al.</i>, 2007).</li><li>• HAT carries the stigma of a mental disorder which can be associated with sorcery (Robays <i>et al.</i>, 2007).</li><li>• This loss of decorum will not be included within the DALYs as DALYs do not account for social disability (Fèvre <i>et al.</i>, 2008).</li><li>• HAT prevalence clusters locally therefore causing the whole community problems but it is considered within the DALY measure as any other disease that does not cluster (Lutumba <i>et al.</i>, 2007).</li><li>• DALYs also do not consider the different protozoa or the differing stages of HAT infection and give the same weighting to early and late stage symptoms (Fèvre <i>et al.</i>, 2008).</li><li>• There is also some evidence of long term physical problems resulting from the <i>.gambiense</i> infection such as a decreased weight, stunting and later development of puberty which will not be included in the DALY measurement (Aroke <i>et al.</i>, 1998).</li></ul>
Leishmaniasis	<ul style="list-style-type: none"><li>• Cutaneous and Mucocutaneous Leishmaniasis involve the infected person having lesions on their body (cutaneous) and these can spread to the facial tissue around the nose and mouth in the mucocutaneous form (Cox, 1996).</li><li>• After the infection has cleared these lesions leave large scars, which can cause lifelong social problems and shame.</li><li>• The visceral form of Leishmaniasis, even after successful treatment, can lead to a secondary disease several months or years later. This is termed post-kala-azar dermal Leishmaniasis (PKDL) and occurs when infected with <i>Leishmania Donovanii</i>, PKDL manifests as many small lesions on the face and body which may disfigure the skin (Gasim <i>et al.</i>, 1998).</li><li>• This secondary infection will not be included in the DALY measure as it does not always occur and so may be classed as a separate disease, when in fact it is a symptom of visceral Leishmaniasis.</li><li>• There is limited information regarding incidence and impact of Leishmaniasis, meaning DALYs for Leishmaniasis are out of date (Maudlin <i>et al.</i>, 2009;Reithinger, 2008).</li></ul>

Ascariasis	<ul style="list-style-type: none"> <li>The soil transmitted helminth infections (STHs) DALY measure is continually changing. Due to the very high number of people infected with STHs, very small changes to the disability weightings of the infections can generate huge variations in DALYs. For example, in 1990, STHs and schistosomiasis combined produces a DALY figure of 18 million, compared to 4.7 million in 2001(Hotez <i>et al.</i>, 2006).</li> </ul>
Trichuriasis	<ul style="list-style-type: none"> <li>Burdens may be underestimated due to the fact that they don't include the whole scale of morbidity e.g. anaemia, pain, diarrhoea and under nutrition (Hotez <i>et al.</i>, 2006), which all have consequences in later life after the infection has been cleared. For example, under nutrition during childhood can cause cognition problems leading to a decreased achievement level at school and thus a continuation of poverty, but this later impact will not be included in DALY measurements.</li> </ul>
Hookworm	<ul style="list-style-type: none"> <li>Hookworm receives the largest DALY measure but the burden of anaemia may still be underestimate even though it can cause developmental and behavioural problems in pre-school children as nutrition problems in childhood affect growth and mental ability and these cannot be made up in adulthood.</li> <li>It is not exactly known whether the DALY measure takes into account these deficiencies (Hotez <i>et al.</i>, 2006) but it almost certainly will not account for the social and economic problems in adulthood.</li> <li>A more thorough assessment of pregnant women who are vulnerable to anaemia could render the DALY estimates even more underestimated as not only would this affect the mothers but also the children who would not be included in the DALY measure.</li> </ul>
Schistosomiasis (urinary)	<ul style="list-style-type: none"> <li>It is doubted that experts can assess chronic diseases in terms of DALYs and some age specific estimates were very similar those for to facial vitiligo, a face discolouration which has no symptoms other than discolouration (Murray and Lopez, 1996).</li> <li>Schistosomiasis can also be recurring, which is not included in the DALY measure as it occurs after an initial successful treatment and is therefore counted as a separate disease rather than related to the first (King <i>et al.</i>, 2005).</li> </ul>
Schistosomiasis (hepatobiliary)	<ul style="list-style-type: none"> <li>As mortality only occurs in very few people with extreme and prolonged infection, it is not included in the DALY (King <i>et al.</i>, 2005).</li> <li>Low intensity infection is associated with some forms of morbidity, such as inflammation, so the DALYs should not overlook mild infestations as being without disability (King <i>et al.</i>, 2005).</li> <li>King <i>et al.</i> (2005) estimate the disability resulting from schistosomiasis to be 4 – 30 times higher than that given in the Global Burden of Disease project in 1996, as this separated the infection from associated morbidities such as anaemia.</li> </ul>

## Lymphatic Filariasis

- LF is characterised by elephantiasis and hydrocele, which are enlargements of the limbs and scrotum due to a nematode worm dwelling in the host lymphatic system (*Wuchereria bancrofti*, *Brugia malayi* or *Brugia timori*) and consequently damaging the system often *via* blockages (Cox, 1996).
- Advanced elephantiasis is irreversible, meaning the consequences of LF may be for the rest of people's lives (Cox, 1996).
- It can be thought that women suffer a double burden when infected by symptomatic LF because, as their identity and well being is based on marriage and childbirth, and they have poor marriage prospects due to the probability of the diseases reoccurring or the deformities they will have for their entire lives (Wynd *et al.*, 2007).
- The inability to marry will not be incorporated into DALYs. The DALY also does not incorporate the impact of acute fever attacks that are ongoing in sufferers (Wynd *et al.*, 2007).
- Hydrocele is thought to place a greater psychological burden on men (Gyapong *et al.*, 2000).
- The burden of hydrocele is often a hidden one as men are unwilling to disclose a sexual dysfunction and may often cause their partners pain during intercourse (Wynd *et al.*, 2007). This pain felt by others will not be incorporated into the DALY measure and therefore leaves out an important aspect of household problems.

## Onchocerciasis

- Currently the DALY estimates for onchocerciasis does in fact include blindness, visual impairment and itching but doesn't take into account the mortality associated with heavy infection with *Onchocerca volvulus*, the causative agent (Little *et al.*, 2004; Pion *et al.*, 2009).
- Onchocerciasis also can cause disfigurement resulting from the scratching of the skin infection and this is also unlikely to be included in the DALY measurement and this may have long-lasting effects after the infection has been cleared (Njepuome *et al.*, 2009).
- Although skin itching is included in the DALY measure of onchocerciasis, other skin complaints are not featured, including reactive skin lesions and onchocercal skin disease (WHO-TDR, 2002).

## Dracunculiasis

- Dracunculiasis can affect very large numbers of people within a community (as much as 30%) which has implications for harvests and planting (Hopkins, 1998).
- This large prevalence within a small community may cause problems with DALY estimations. DALYs cannot account for the disproportionate burden to those communities who suffer very high prevalence.
- This means that a person within a community where they are the only sufferer have the same DALY estimate as an infected

individual within a village where the prevalence is extremely high and will cause problems for the entire community in terms of agricultural production. This problem with agricultural production will inevitably generate problems later on in terms of calorie and micronutrient malnutrition as well as exacerbating economic poverty due to the need to buy in extra food.

Trachoma	<ul style="list-style-type: none"> <li>• The DALY measurement does not adequately assess the burden of trachoma before the onset of visual impairment such as the itching and pain of trichiasis (ITI, 2009; Mariotti <i>et al.</i>, 2003).</li> <li>• Left untreated, trachoma leads to blindness. This will have obvious post infection consequences, including the inability for the same standard of work as compared to before the blinding.</li> </ul>
Leprosy	<ul style="list-style-type: none"> <li>• Leprosy skin lesions are relatively harmless and painless but complications can lead to blindness, infertility, disfigurement and sensory and motor disability (Remme <i>et al.</i>, 2006) which may not be included within the DALY measurement.</li> <li>• And as a direct consequence of diagnosis, or the visible lesions, many leprosy patients have severe social and psychological problems (Remme <i>et al.</i>, 2006). It has been reported that DALYs underestimate the impact of leprosy as a mental as well as a physical disability and people without visible signs of leprosy may be stigmatised just due to people knowing they have contracted the disease (Remme <i>et al.</i>, 2006).</li> <li>• Stigmatisation can last even after successful treatment as leprosy is such a stigmatised disease and can leave deformities; this aftermath will not be included within DALYs unless there is significant physical disability.</li> </ul>
Chagas Disease	<ul style="list-style-type: none"> <li>• Chagas can be asymptomatic for years before it presents itself so is very difficult to estimate prevalence which is a contributor to the DALY measurement (Maudlin <i>et al.</i>, 2009).</li> </ul>
Buruli Ulcer	<ul style="list-style-type: none"> <li>• It is claimed that in 2008 there were no DALY estimates for Buruli ulcer due to lack of information (Moran <i>et al.</i>, 2008).</li> <li>• Buruli ulcer has very different manifestations such as the loss of a limb, decreased joint movement and no visible contractures (Stienstra <i>et al.</i>, 2004). It is believed therefore that the DALY measure is inadequate for assessing Buruli ulcer as it is not based on self-assessment as different people will suffer differently from varying complications (Dadzie, 2005).</li> </ul>

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