

Disability adjusted life years in a Regional  
and Cultural Perspective  
Who Should weight the disabilities?

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<p>Sammanfattning</p> <p>Begrebet Disability Adjusted Life Years (DALY) kom frem i starten af 1990'erne som et redskab til at måle sygdomsbyrde. DALY kombinerer sygdomsbyrden med hensyn til for tidlig død og år levet med handicap. Megen kritik af DALY er rejst fx i forhold til etiske aspekter. Denne opgave fokuserer på manglen på kontekst i DALY-konceptet fordi instrumentet anvender en universel standard for alle sygdomme på tværs af lande. Ét formål med opgaven er at beskrive hvorledes regionale og kulturelle sammenhænge influerer synet på handicap og dermed er i modstrid med de bagvedliggende antagelser i DALY-konceptet. De regionale og kulturelle forskelle er illustreret ved eksempler som paraplegi. Publicerede sygdomsbyrde studier gennemgås i sammenhæng med regionale eller kulturelle overvejelser. Analysen konklusion er, at regionale og kulturelle hensyn ikke indarbejdet i DALY tilgangen.</p> <p>Det andet formål med opgaven er at diskutere, hvem skal vurdere handicappedes liv. Som følge af udviklingen af befolkningernes sundhedstilstand har opfattelse af helbred og adgang til sundhedsvæsenet ændret sig. I bedømmelsen heraf ligger en implicit vurdering af handicap blandt såvel lægfolk som sundhedsprofessionelle. Hvis man anvender DALY som generelt mål for sygdomsbyrden og prioriterer på baggrund heraf, så diskuteres hvem der skal deltage i værdisætningen af vægtene, der indgår i beregningerne. En model for samarbejde omkring vægtene beskrives. Konklusionen er, at lægfolk bør involveres i processen med støtte af udefra kommende konsulenter.</p> <p>Overordnet viser opgaven, at udviklingen af DALY er et seriøst tiltag på et simpelt værktøj til at forstå og prioritere komplekse udfordringer i folkesundheden. For indeværende er der behov for en dagsorden for videreudviklingen af kontekstrelateret DALYs.</p>				
<p>Nyckelord</p> <p>Folkesundhed, Disability Adjusted Life Years, DALY, kontekst, kultur, samarbejde, konsulent</p>				

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<p>Abstract</p> <p>The concept of disability adjusted life years (DALY) came forward in the early 1990's to be used as a measurement of the burden of disease. The DALY combines the burden with regard to premature death and years lived with a disease. Much criticism has been raised since then with regard to e.g. ethics. This thesis focuses on the lack of contextual aspects of the DALY-concept because the measurement has a universal standard for all diseases in all countries.</p> <p>One aim of the study is to describe how regional and cultural context influence the view of disability and therefore contradicts with the underlying approaches of the DALY-concept. The regional and cultural differences are illustrated by examples like paraplegia. Published burden of disease studies are examined for contextual considerations. The conclusion of the analysis is that regional and cultural issues are not taken into account when using the DALY-approach of health assessments in public health.</p> <p>The second aim of the study is to discuss who should value the life of disabled. Following the transition of health, different views of fair health have developed and the need of health care. Underlying this assessment is an implicit valuation of disabilities among lay-people and health care professionals. If one uses DALY as a general measurement for the burden of disease and prioritising resources for disabled it is discussed who should be involved in the calculation of disability weights and a model for the collaboration is described. The conclusion is that lay people must be involved in a facilitated process.</p> <p>Overall the thesis show that the development of DALY is a serious attempt to give a simple tool for understanding and prioritise the complex challenges in public health. At present, an agenda for development of contextual DALY's is needed.</p>				
<p>Key words</p> <p>Public health, disability adjusted life years, DALY, context, culture, collaboration, facilitation</p>				

# Disability Adjusted Life Years in a Regional and Cultural Perspective

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# The Concept Disability Adjusted Life Years

The concept of Disability Adjusted Life Years (DALY) occurred the first time in World Bank's World Development Report "Investing in Health" in 1993<sup>1</sup>. The DALY is a time-based measure accounting for years of life lost due to premature mortality and healthy years of life lost due to disability. This burden of disease study initiated a discussion for the basis of DALY-concept grounded on the purpose that any health policy arguments must begin with the assessment of the magnitude of the health problems.

The DALY-concept has been considered very controversial because of the political and economic forces of the institutions behind the burden of disease studies. The potential implications of the use of DALYs with regard to dictate priorities for action and funding in regions with poor national health policies are obvious. And from different aspect of the academic world criticism has been raised on several issues and at numerous occasions<sup>2 3 4 5 6 7</sup>. Some of them will be referred in the articles of the thesis.

Nevertheless the DALY-concept also has its supporters. The concept was launched as having the potential to revolutionize the way in which one measure the impact of diseases, how to intervene and how to track success and failures of interventions<sup>8</sup>. It was believed to be among the most significant developments in public health for decades.

And indeed the burden of disease approach contributes to a very significant and complex formulation of the problem of solving the needs of disabled or diseased people. In the current version it must still be seen as being in a premature state because the DALY-concept focus on ambitious goals like all people living as long as Japanese women and uses calculations like discounting years which all can be modified and refined without increasing the complexity to an extend where the results are overwhelming. It will be argued that the use of a universal measurement does not accomplish the requirement of local founded and understood DALYs.

A similar situation appeared in the early 1980s in Denmark with regard of using Diagnosed Related Groups (DRG). The conclusion at the time was that under the circumstances it would not be possible to make advantage of the DRG-system<sup>9</sup>. No further examinations were done until the mid 90s where The Ministry of Health started using the NordDRG-grouper for productivity analysis<sup>10 11</sup>. Status at the present time is that the Danish DkDRG-system is used as the basic funding system and applied for all kind of analysis<sup>12 13</sup>.

The main course for this development is the Ministry of Health's methodology in intersectorial collaboration between doctors, economists and statisticians. By this approach the main interest groups contributed in the ongoing process and by the way accepted the new framework. A similar situation will hopefully come forward over the coming years with the opinion about DALY. Until now few scientists have worked with this measurement of the burden of disease and little has been published concerning Danish circumstances<sup>14 15 16 17</sup>. In a Scandinavian context a burden of disease study has been car-

ried out for the Stockholm region, but foremost has the main papers being critical contributions from the Norwegian Institute of Public Health and the University of Oslo on various aspects<sup>18 19 20 21 22</sup>.

The purpose of this thesis is to balance the discussions between the two extremities being for or against the DALY-concept. The criticism raised is right, but has so far not contributed in the development of the techniques behind the DALYs. Unfortunately have especially the Nordic countries not invested resource in the DALY though there is a lot of experience in the field of health economics from working with e.g. Quality Adjusted Life Years and DRG. Along with a longstanding tradition of tracking diseases in central databases there is a large potential for further development in the DALY-concept in the Nordic countries which have to be encouraged. The thesis should be seen as a contribution to the debate where it is emphasized that there are some missing links in the current version of DALY-concept, but in stead of a total rejection of the thinking behind the measurement, it will be discussed how to continue the progress of the DALYs.

The thesis consists of two articles. The first article will focus on why a universal DALY-concept cannot apply for every region or country. It will further be discussed why the regional and cultural perspectives should be incorporated in the DALY-concept in order to achieve a measurement for the burden of disease where the local conditions are expressed in the disability weights. The paper emphasizes the importance of cultural and regional context not as determinants of health states like social and environmental parameters but as a determinant of the severity and impact of these health states. The building of regions and the influence of culture is presented and discussed in relation to the beliefs of sickness and health care. To support the discussion, ranking of disabilities carried out by other authors is analyzed in combination with a determinant of regional differences, and a determinant of cultural differences. Examples of how the life of paraplegic is valued under different conditions are presented to help understanding the limits of universal disability weights. Finally, burden of disease studies based on the DALY approach are examined for regional or cultural considerations. The purpose is to see to which extent the use of local disability weights has been applied in burden of disease studies.

The article demonstrates that based on the analyzed data there are no general relationship between the economic conditions per capita and the presumption of disabilities. Instead it is argued that regional initiatives can contribute to the change in people's opinions about the assessment of disabilities. The data presented in this study contradicts a number of assumptions underpinning the DALY in its current form. The regional and cultural contexts in which a health condition occurs influence the impact of that condition. An appropriate estimation of the disability weight for a health condition requires that this contextual information is included. In regard to public health matters one wants to find those elements of the context that effect populations not individuals. There is no definitive answer to the question of what defines a single context. Different countries will be more or less homogenous on a range of different regional and cultural factors.

The second article focuses on two issues. First, it presents how health and health care have developed over time and it is discussed how the view of different groups on disability and need are in relation to relieve the situation of the sick and disabled according to the experience of the group with a given health condition. Following this, it emphasises the challenges of estimating disability weights given the different approaches from professionals, patient and lay-people when these persons are asked to make the assessment prior for a burden of disease study. A model for the process is shown to express the categories which have to be considered in the collaboration within one or more focus groups. The purpose of this is to stress the challenge in collaboration about a complex task involving people of all sorts of personal and professional background.

The article concludes that trustful collaboration between the driving forces of DALY-concept and local actors are crucial for the acceptance of future burden of disease calculation. There have to be established a consensus among interested partners of burden of disease studies, that mutual believe in the values of the DALYs is vital. The previous discussions of the DALY-approach indicate a challenging task for synthesising all the contributions. Trust building built based on incremental successful implementation of modest collaborative initiatives should be the preferred strategy. In situations requiring the collaborating organizations to be more ambitious, managing the associated risk is seen as an integral component to trust building and to coping with lack of trust. Poor contexts may indeed be overcome by appropriate facilitation.

Overall, the articles show that the development of DALY is a serious attempt to construct an instrument with a simple measure for understanding and prioritise the complex challenges in public health. It is a good general tool for global health assessment and acknowledgement of trends in disease patterns. But it has some serious shortcomings in addressing regional and cultural based consequences of diseases.

Using universal disability weights in DALY-calculation does not give the right detailed answers to questions of health assessment, health planning or prioritising health initiatives whether for specific diseases nor for reallocation of resources. But the DALY-concept has proven valuable by giving an estimate of the burden of disease and by forcing health planners to focus on effective programmes for health development.

The DALY-concept at the present state should be seen as an interesting work in progress to be used with caution. More than 10 years after the publication of the global burden of disease it has been demonstrated, that for the time being there is almost no research that looks at this aspect of health outcomes. But ignoring the problem is not the solution. At present, we need an agenda for the burden of disease estimation which trustfully takes all the criticism over the years into account, including the lack of regional and cultural context.

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# Disability Adjusted Life Years in a Regional and Cultural Perspective

## Introduction

The continuously rising in economic wealth over generations has contributed to the evolution in medical care in the western countries. As a consequence there has been a rise in the numbers of years of life expectancy although there seems to be a lower growth now.

There is still avoidable death in the western countries and public health plans thus focus on that matter. But as a consequence of the trends in duration life expectancy, the target for the public health plans in the Nordic countries have also focused on healthier years lived<sup>1 2 3 4</sup> or life lived without disabilities.

Trend in the duration of life lived with disability that accompany the epidemiological transition have been subject to different theories put forward to explain the changes in disability that accompany mortality decline.

One argumentation is that with the improvements in survival, the prevalence of disability will decline and therefore the proportion of the lifespan lived in a disabled state will decrease<sup>5 6 7 8</sup>. Another argument is that the proportion of lifespan lived with disability will increase as mortality declines. The suggestion is that as the survival of individuals with chronic conditions improves, the prevalence of these conditions must rise. In another way, will the medical intervention improve survival for more frail individuals who will subsequently experience higher incidence rates of disability and increase the prevalence of disability<sup>9 10 11 12 13?</sup>

No matter which of the arguments is right, it raises crucial questions for the public health on how to monitor the progress. No matter how specific the political goals are – the programmes in the Finnish public health plan are the only ones which are possible to operationalize whereas the programmes in the other Nordic public health plans are much more policy oriented – it is of great importance to have the ability to follow up on the issues. One answer to this could be the use of Disability Adjusted Life Years (DALY).

The DALY is a time-based measure accounting for years of life lost due to premature mortality and healthy years of life lost due to disability<sup>14</sup>. The years of life lost for a given health state,  $i$ , are calculated as:

$$DALY_i = YLL_i + YLD_i$$

where  $YLL_i$  is the years of life lost in a population due to premature mortality attributable to health condition  $i$ , and  $YLD_i$  is the healthy years of life lost in a population due to disability attributable to health condition  $i$ .

The purpose of this article is to see if it is possible and relevant to develop a regional DALY-system to help with setting public health service priorities; in setting health research priorities; in identifying disadvantaged groups and targeting of health interventions; and provide a comparable measure of output for intervention, programme and sector evaluation and planning.

Here the focus is on the valuation of the morbidity issue in the DALY, namely the disability weight and the role of the cultural and regional context in which it is developed. Even though there has been criticism of the DALY approach, only few have commented on the problems accessing the disability weights and they have tended to be part of a more general critique<sup>15 16 17 18 19</sup>. Until now the debate has been limited regarding the challenges that arise from a burden of disease measure that excludes the very context in which the diseases occurs.

## Aims and methods

Given the ambition of the fathers of the DALY approach, it is important to stress the concern about the validity of the DALY in its current state and therefore question the application of the DALY in the public health field and in policymaking. This paper seeks to emphasize the importance of cultural and regional context not as determinants of health states like social and environmental parameters but as a determinant of the severity and impact of these health states. The building of regions and the influence of culture is presented and discussed in relation to the beliefs of sickness and health care.

To support the discussion, ranking of disabilities carried out by other authors is analyzed in combination with a determinant of regional differences, GNI pr. capita, and a determinant of cultural differences, religion. GNI per capita is the gross national income, converted to U.S. dollars using divided by the midyear population. The data is downloaded from The World Bank respective the CIA Fact Book.

Furthermore the current burden of disease studies based on the DALY approach are examined for regional or cultural considerations. The purpose is to see to which extend the studies pay attention to differences between the inherent opinions of local needs and the context less thinking of the DALY.

## The disability weight

The disability weight associated with each health condition is currently fixed across all social, cultural and environmental contexts<sup>20</sup>. Hence blindness in the Denmark, Norway and Sweden has the same disability weight as blindness in Kampuchea, Laos and Viet-

nam in spite of structural interventions in the Scandinavia that make living with the disability less severe than in South East Asia.

Given the equation

$$YLD_i = D_i * I_i * L_i$$

where  $D_i$  is the disability weight associated with the health condition  $i$ ,  $I$  is the incident number of cases for condition  $i$  and  $L$  is the average number of years in which condition  $i$  lasts, it is possible to calculate the effect of the disability weight to the DALY.

The disability weight is a measure of the impact of a health condition and the calculation of it is based on preferences for each health state relative to death and full health. The preferences have a value between 0 and 1, where 0 indicates indifference between the health condition and full health, while 1 indicates no difference between the health condition and death. As a consequence in the DALY approach there is no morbidity which is valued worse than death. In general, each health state has a single associated disability weight.

With a few exceptions, the disability weights were elicited by a panel of health experts. Twenty-two of the health states, the “indicator conditions”, were assessed with a “Person Trade-off technique”. The disability weightings for the majority of the conditions were elicited with a rating scale. For the rating scale exercise, there is no description of the methodology used, no health state descriptions other than the diagnosis, and no explanation of how the treatment effects were established and described<sup>21</sup>. Originally the panel were asked to restrict their consideration to those aspects of health conditions that applied to the International Classification of Impairments, Disabilities and Handicaps<sup>22</sup> and by this ignore the context in which the impaired (disabled, handicapped) lived<sup>23</sup>. In the rethinking of the DALYs some information about the context in which the lives were lived was taken into account, so that the panel should be aware of the functional loss associated with the health state and the impact average conditions of individuals and social responses or average social milieu would have on persons living with that e.g. handicap.

Socio-medical indicators for the assessment of physical and psychological conditions like DALY have become increasingly popular as accessories to the traditional epidemiological and clinical measures of public health. The indicators have mostly been developed in the USA or Great Britain and considerable problems occurs from attempts to use them in other cultures. The measures themselves can be considered culture specific<sup>24</sup>. The ambiguity inherent in the terms “health”, “sickness”, “illness” and “disease” is compounded cross-culturally by different interpretations depending on cultures, values, expectations and development. Consideration of cultural differences must precede any attempt to transform existing instruments for use in another culture or within a subgroup whose members were not included in the development process<sup>25</sup>.

It should be recalled that associated with each health condition is a disability weight intended to capture the impact of the health condition on life in an average global con-

text regarding all factors external to the disability or disease. Thus, when estimating the disability weight for a specific health condition, the panel of judges estimating the disability weight should consider of both the functional loss associated with the disability or sickness and the impact that the average conditions of individuals and social responses would have on life lived with that specific condition. The problem with using the average social economic environment of an entire population is that the average person who has a disability will not be the average person in the population. The disabled will not be exposed to the average social conditions in the population as a whole, but to a different version of the population's social response. Given that poor health is commonly associated with poverty, the average social condition of those with poor health will not be the same as for the general population. The use of global disability weights is therefore vague.

### The contextual approach

For everyday health planners it seems obvious that context is important to the impact of a health state and that a disability weight which remained constant concerning contexts would be unusable practical purposes. However, there has been a reluctance to differentiate the disability weights because of the risk to reduce the “objectivity” of the DALY, thereby making it largely worthless for comparisons between countries or regions according to the founders of the DALY-concept. The inclusion of context in the measurement of the burden of disease complicates the task. Secondly, the inclusion of context misses the point that the focus ought to be on those factors that are intrinsic to the individual and result directly from the pathology of the diseases. Finally, those who claim the important of context have misunderstood the intention of the DALYs so that only uniform disability weights seem to apply for the purpose of using DALYs.

The first argument against context is that context is problematic because it adds a level of complexity to the issue of modelling population health. The added complexity requires not only empirical data to support it, but also some significant theoretical work. While it may be true that a rich model of health requires the inclusion of context, a simpler model of population health may be adequate for most purposes, including resource allocation and priority setting. Taking the notion of context to the extreme, every non-fatal health outcome is unique. Consequently, there would need to be a separate disability weight for every person with a health condition, because each person embodies a unique context, making the inclusion of context untenable.

In relation to public health issues, there has to be a balance between the assumption that the entire world is one context, and that each individual belongs to his or her own unique context. It is necessary is to find those elements of the context that affect populations, not individuals. There is no absolute rule about what effects should be characterised as contextual. Different countries will be more or less homogenous over a range of different social economic and cultural factors. This should be viewed as a challenge for health research and not an overwhelming barrier. There is almost no research that looks at this facet of health outcomes. By ignoring the problem, the burden of disease studies does not improve in quality.

One proposal, to avoid the consideration of context, is to focus on health dimensions such as impairments and functional limitations that are central to the person, and ignore the interaction of social economic and cultural factors of the individual<sup>26</sup>. This, in effect, would result in the description of a disease process that would be fairly uniform and standardised, based on the condition and ignoring any other influences on how the disease may be experienced. But there are major problems with the evaluation of the impact of a health condition in the absence of any contextual information. If the aim is to provide a measure of the burden of disease in populations, then it is important that the burden is measured, as good as possible, as it really occurs. The impact of the health conditions to the population are necessarily an interaction between the disabled persons and their interaction with the social economic and cultural contexts in which they are living<sup>27</sup> as discussed in the following sections.

## The regional perspective

The effect of the state of economic development has implications for the calculation of burden of disease that is done on a country and regional level. In the less developed countries the burden of disease will be greater than the estimates, and in the more developed countries, it will be less than the estimates because of the possibilities of health care institutions in the respective areas. Hence, allocating resources on the basis of a global disability weight would therefore further exacerbate inequalities between developed and developing countries.

First there is a need for a definition of “regional”. Thus so far the interpretation of what is a region has not been discussed. A region is characterized by being either “a large area of land with definite boundaries, which is one of the parts of a country that has been divided up for administrative purposes” or “a large area of land which has no definite boundaries but which has some feature or quality that makes it different from other areas”<sup>28</sup>. It is an intellectual construct created by the selection of features relevant a particular problem and the disregard of other features considered to be irrelevant<sup>29</sup>. Given these characteristics one might argue that the definition by the WHO is like “a large area of land with definite boundaries which typical have some feature in common that makes it different from other areas”.

Because the DALY is universal there is no regional difference inherited or no obligation taken to local conditions. There are no regional characteristics or features built in the rating scales mentioned above.

The construction of regional boundaries, agencies alliances etc. are not only an exclusive UN or WHO phenomenon. Despite the interpretation of region used according to the WHO how is the construct of region applied in other matters? In Europe alone over 100 cross-border ventures are identified, of which several involves the Nordic countries<sup>30</sup>. In a Nordic and a health related perspective the most interesting regions are the Baltic Sea Region<sup>31</sup> and the Øresund Region<sup>32</sup>.

*The Baltic Sea Region* concerns eleven countries covering a large European area around the Baltic Sea: Denmark, Estonia, Finland, Latvia, Lithuania, Poland, Sweden, Germany, Norway, Russia and Belarus. The areas in the region share many of the same problems and challenges, and by working together and sharing knowledge and experiences it is hoped that a sustainable and balanced future will be secured for the whole region. The Programme's geographical focus mainly aims at overcoming the East-West and North-South divide. Its strategic objective is to strengthen economic, social and spatial cohesion by focusing on disparities between different territories in order to reach an increased level of integration in Baltic Sea Region and to form a sustainable part of Europe.

One of the projects spinning of the Baltic Sea Region is the "Baltic eHealth". The objective of Baltic eHealth is to counteract rural migration in the Baltic Sea Region. Baltic eHealth will promote the use of eHealth in rural areas of the Baltic Sea Region by creating a large trans-national infrastructure for eHealth, the Baltic Sea Healthcare Network. As a pilot project, electronic communication over the Baltic Health Network will be tested in two different medical specialities: eRadiology between the Funen hospital (Denmark) and the East-Tallinn Central Hospital (Estonia) and the Vilnius University Hospital (Lithuania), and eUltrasound between Norrlands University Hospital (Västerbotten County Council - Sweden) and the St. Olav's Hospital (Mid-Norway).

The second health related off spin of the Baltic Sea Region is the "eHealth for Regions". The objectives of the eHealth for Regions are to enhance the attractiveness of the regions by using eHealth as an instrument for regional development; to improve the accessibility and quality of health care available to citizens in urban and rural areas; to share knowledge and resources through transnational transfer, standardisation and localisation of eHealth solutions; to promote the acceptance of patients, doctors and other actors in the health care sector with regard to eHealth services; to build a transnational, cross-sectoral network and develop a business model promoting co-operation in the field of eHealth in the Baltic Sea region and to experience the transnational network and to co-operate in the field of telecardiology and other fields<sup>33</sup>.

The purpose of the *Øresund Region* project is to give the inhabitants of the Øresund Region the possibility to exploit all the resources in the region, even though the national border divides the population. Through co-operation projects people, companies and organisations should discover new possibilities and learn from each other's experience. Barriers should be minimized and networks, institutions and structures that can be jointly exploited should be stimulated. One of the initiatives emerging from the Øresund Region is the Øresund Science Region and especially the Medicon Valley Academy in regard to health care.

The strategic areas of Medicon Valley Academy<sup>34</sup> include research within diabetes, cardiovascular diseases, proteomics, neuroscience, immunology, cancer, and stem cells, and. There are more than 300 research groups, 20.000 students and 34.000 employees active in life sciences in Medicon Valley. The region also has 26 hospitals, 6 science parks, 12 universities, 115 biotech companies, 130 medicotech companies and 70 pharmaceutical companies. The main research centres are located at various universities,

hospitals and institutes (e.g. Lund University, Technical University of Denmark, Malmö University Hospital, University of Copenhagen, Lund Institute of Technology, and Danish Centre for Stem Cell Research) in the region.

With emphasis on the health care and the binding of cross border health care systems another way of building regional collaboration and getting common values regarding medical standards is establish and thereby giving the inhabitants a new understanding of accessibility to health professionals and provision of the right health service.

The Baltic eHealth ties rural and remote areas with others part of the Baltic Region constructing a new virtual region. It offers the inhabitant the possibility of specialized diagnostic which otherwise were not accessible. With that the possible treatment improves and the expectations regarding living with non-treated diseases or impairment changes among the health professionals and the population in general.

Not only provides the establishment of the Øresund Region an economic development and therefore a higher demand for health care, but living in the Øresund Region gives the possibility of access to several university hospitals within one hour of transport. Given the fact that more than 50.000 people are involved in the health sector, combined with the wealth of the region it contributes to the public opinion of what is considered a decent life and how disabilities should be relieved.

The above examples of regional building using joint capacity and infrastructure give possibilities beyond the local potential. As it becomes recognised by the public, the expectations changes and extends the definition of a good life. And as a consequence the implicit consensus of the disability weight must change according to this trend.

Despite the mentioned definitions, in the following the use of region or regional perspective will mean “an area of land which might have either definite boundaries and be part of a continent or an area of land which have no definite boundaries but which have some cultural, economic or religious characteristics that makes it different from others areas”. As the interpretation of the first part of the definition is clear, the interpretation of the second part should be seen in the light of e.g. the area dominated by the Kurdish people in stead of seen them as inhabitants of Turkey, Iraq, Iran and Syria.

In that sense the estimation of regional disability weights would take into account the socio-economic context and therefore require an explicit assumption about the area considered in the use of the weights. In relation to the Nordic context the region could be Stockholm, Sweden or Scandinavia depending on the expected reliability and validity.

## The cultural perspective

Health social scientists such as medical anthropologists, medical sociologists and health psychologists concerned with the social and cultural ramifications of illness and health from a cross-cultural perspective have dealt extensively with the cultural variation in the interpretation and experience of illness, and the social coping mechanisms around dis-

ease-related impairment. To identify potential variation in health state valuations, the focus is placed on cross-cultural determinant like the perception of illness and health risks, the social consequences of illness and in the notion of time that could generate different outcome in the assessment of disability weights.

Nations and cultures show considerable differences in value patterns<sup>35</sup> and to some extent these values are not stable. The valuation of a health state is shaped by individual values and attitudes towards health in general and the individual's health state in particular. These values may either reflect exclusively individual preferences or culture- or society-specific notions of good or ideal health. The classification and ranking of the values may change over time as a result of external changes<sup>36 37</sup>.

As mentioned earlier, health state valuations are built upon Western notions of risk and probability which may not be fully shared outside this sphere. The perception of risk and risk behaviour is considered as socially and culturally depended in the sense of subjective or perceived risk and not only as an objectively measurable value<sup>38</sup>. The perception and assessment of risk is seen as a social process determined by cultural norms and values of the local community. Norms and values, grounded in the community's physical and social environment, guide the social construction of reality. Both influence the perception and assessment of what is considered dangerous or not and reflect cultural knowledge<sup>39 40</sup>.

The concept of illness shapes an individual's coping mechanisms, i.e. illness behaviour. It has been shown that i.e. mobility, pain and discomfort, and work capacity are universally aspects of the quality of life concept and therefore interpreted as an indication of health being a universal domain of quality of life<sup>41</sup>. But this does not imply that quality of life evaluations are the same across cultures and the disability weights to be constant.

The effects of disease and disability are highly variable across cultures. The society's understanding of disability or impairment due to illness and attitudes towards disabled persons is largely shaped by social and cultural values<sup>42</sup>.

Assumed, expected, or known economic and social consequences of an illness may have a central impact on an individual's health state valuation. Impairment may in certain cultures not be interpreted in utility terms, i.e. in terms of loss of working ability or time loss, but rather as a chronic or permanent loss of a person's ability to participate in community or household discourse and activity<sup>43</sup>. When a disease is known to inflict social stigma, to disturb social life, or results in the patient being a burden to his social environment, a disease state may be evaluated according to the societal and cultural consequences that the disease is believed to have. The consequence is that there might be tremendous differences between what lay people has of perceived burden and the burden which can be calculated using statistics from i.e. the International Classification of Disease (ICD).

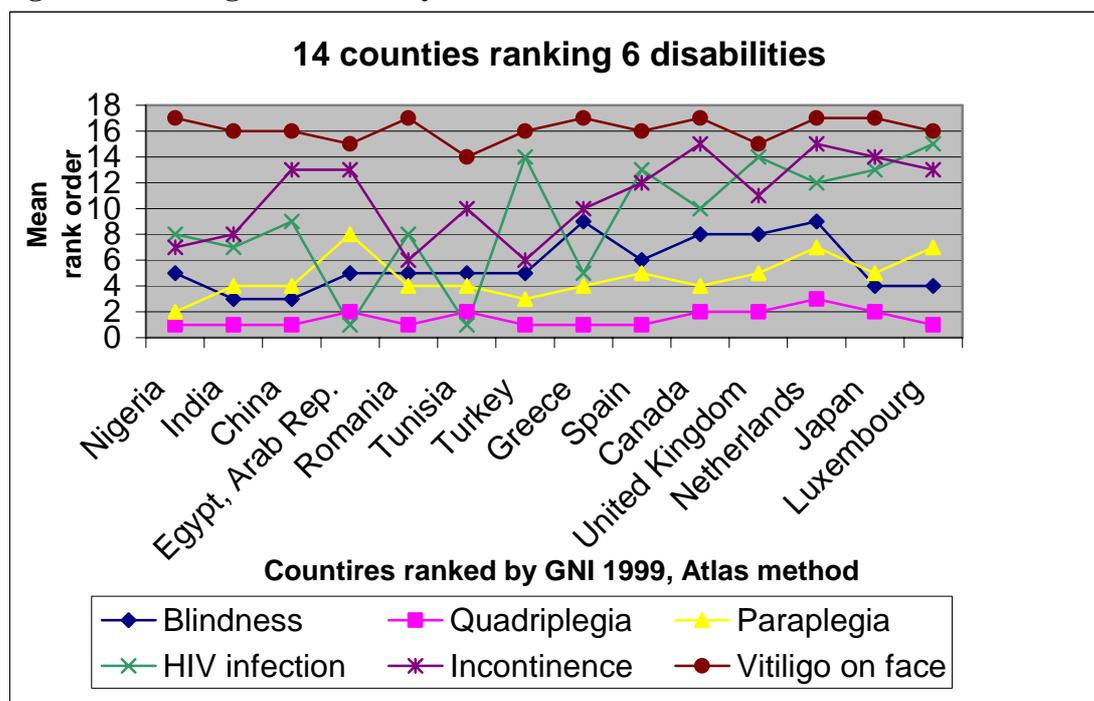
A crucial factor in accessing disability weight is the concept of time and the perception of time. The Time-Trade-Off model presents the respondent with the task of determining what amount of time they would be willing to give up to be in a better versus poorer

health state<sup>44</sup>. Concepts of time, however, are culturally constructed and vary widely across societies and cultures. The Western concept of time as neutral emerged in industrializing Europe in the 19th and 20th centuries<sup>45</sup> and has been criticized in its assumptions as a cross-culturally valid method for the evaluation of social programmes<sup>46</sup>. At present time, there seems to be no evidence concerning cross-cultural concepts of time and time preference with respect to an individual's health discounting.

## Contextual perspectives

To illustrate the challenge of valuing disabilities according to their origin the following figures are drawn based on a study of ranking different health conditions in 14 countries<sup>47</sup>. The figures illustrate the ranking of 6 disorders sorted out by having the 3 highest (HIV infection, incontinence and blindness) and 3 lowest (vitiligo on the face, quadriplegia and paraplegia) standard deviations amongst the respondents.

**Figure 1 Ranking disabilities by income**



In figure 1 the health conditions are ranked by gross national income pr. capita (GNI – Atlas method\*)<sup>48</sup> in 1999. The figure shows good agreement at the extremes of the disability scale, quadriplegia and vitiligo on the face whereas there seems no consensus regarding the others condition. In order to establish a relation between income and ranking of disabilities a regression analysis is performed. Table 1 shows the parameters of the results.

The analysis of paraplegia, HIV infection and Incontinence came out with reasonable statistical values indicating a correlation between the economic effort of the inhabitants

and the ranking of diseases. For the remaining diseases there seem to be no statistical significant relation to income.

**Table 1 Regression results of disability by income.**

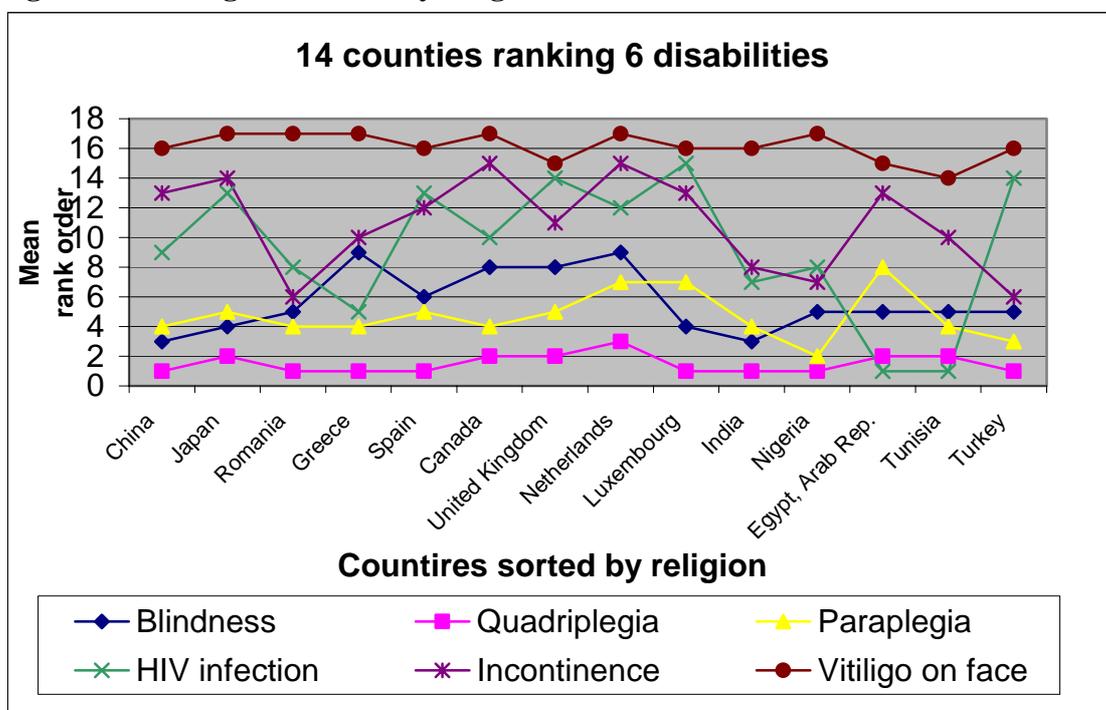
Disability	R-squared	Constant	P-value	GNI pr. capita	P-value
Blindness	0,06	5,17	< 0,001	3,60E-05	0,38
Quadriplegia	0,11	1,31	< 0,001	1,48E-05	0,25
Paraplegia	0,25	3,97	< 0,001	5,66E-05	0,07
HIV infection	0,42	6,57	< 0,001	0,00021	0,01
Incontinence	0,38	9,16	< 0,001	0,00014	0,02
Vitiligo on face	0,04	15,97	< 0,001	1,34E-05	0,48

The impression of the regression is that the ranking of paraplegia 4 by an income of zero GNI pr. capita and it rises by 1 for every ca. \$ 18.000 on average. The original ranking of paraplegia by the United Kingdom is 5 and the model predicts 5,3.

If one assumes religion to be an adequate determinant for cultural beliefs, it is possible to put up the ranking according to the state religion or the major religious belief<sup>49</sup> in the countries. According to this procedure China is categorized Atheist; Japan as Buddhist; Nigeria as indifferent; India as Hindu; Canada, Greece, Luxembourg, Netherlands, Romania, Spain and United Kingdom as Christian and Egypt, Tunisia and Turkey as Muslim countries.

Figure 2 illustrates rankings of the 6 disabilities by religion as a determinant of culture.

**Figure 2 Ranking disabilities by religion**



Again it is the extremes which are ranked constant. But there are a striking lack of agreement between and within the religions, e.g. incontinence and HIV infection. There are cultural dependent rankings, but there seems to be no common pattern according to the available data.

Given the illustrations one conclusion could be that it is not possible just to breakdown disability weights in regional areas as defined by WHO or social-economic factors. There has to be a more narrow focus challenging the universality of the current disability weights used.

In the following section paraplegia will be further accentuated with regards to the burden of disease in the regional and cultural context. Paraplegia is chosen because it combines the best consensus of the original ranking with the relation to income. In an exploratory comparison between Cameroon and Australia<sup>27</sup>, the contextual influence on burden for paraplegic is examined and referred below. It seems possible to combine the experience of the study above with this study in so far that regional socio-economic and environmental conditions of Cameroon are very much alike in Nigeria as both countries have a GNI pr capita below \$ 1.000 although there is some differences in the religious belief<sup>48 49</sup>. Similarly Australia comes very close to wealthy Christian countries like e.g. Canada. Both Australia and Canada have approximately a 70 % Christian population and a GNI pr. capita in the range of \$ 20-21.000.

From a regional perspective the main themes are the environmental and social condition for relieving the disabled. Paraplegic in Cameroon expressed that they were the “lucky” ones since they were still alive. The general life expectancy following injury for people with paraplegia is about two years. Many die from septicaemia because of untreated pressure sores. In some cases paraplegic would have to live in one room only furnished as kitchen, bedroom, sitting and toilet. As the sanitary circumstances are rather bad, e.g. the room smells very mush, the stigmatisation and social isolation increases.

There were a clear country differences in the way that the infrastructure and the aid were considered (e.g. paved roads and wheelchairs) to improve mobility. So there is a gradient of disability, with severity lessening as the level of development of a country improves. Australian paraplegic also reported some problems, but these related mainly to stigmatisation and difficulties negotiating access to facilities that were provided by government and community groups<sup>27</sup>.

When focusing on the gender issue some women described the difficulty of carrying a pregnancy and taking care of children. That being eight months pregnant with paraplegia makes mobility harder than not being pregnant with paraplegia is certain. But in order to accomplish the cultural norms, the role was important for them, in line to maintain some respect and self-esteem within the community.

The edges between functional limitations that are inherent or extrinsic to the disabled disappear as those limitations are examined in different contexts. In Australia, as in Scandinavia, people with paraplegia have wheelchairs and often, the wheelchairs are even motorised so the loss of mobility is further reduced. In Cameroon as well as in

most developing countries, many people with paraplegia do not have wheelchairs, and their mobility is severely limited. Wheelchairs has nothing to do with the pathology of the disease; thus, it is the interaction between the individual and things extrinsic (i.e. the wheelchair) that improves the mobility. The current DALY approach implies that provision of a wheelchair amounts to the treatment and therefore relates to the intrinsic nature of the condition. But wheelchairs themselves are of no use unless the environment is designed to support their use. Australia has like Scandinavian countries building codes and laws covering equity of access for people with disabilities, which have improved the access to buildings and public spaces for people in wheelchairs. In Cameroon, the basic infrastructure to support the free movement of a wheelchair does not exist. So the provision of a wheelchair in one context would not have the same therapeutic outcome that it would have in another context. This is a classic example of the effect of the development gradient on the burden of disease. The sole focus on pathology necessarily excludes a range of potential interventions to reduce the burden of disease.

There has been a failure to recognise that two different types of social determinants of the burden of disease exist. First, there are the social determinants of the incidence of the disease and second there are the social determinants of the impact of the disease. For instance, poverty is a determinant of or a risk factor for paraplegia and would also affect the options of the disabled for engaging in the social life. Likewise poor contact to health services, if accessible at all, would also contribute to the burden.

In order to estimate the burden of disease in a defined area, the DALY must suit their circumstances taken into account the stage of medical advance and the opinion of the people living there. In certain cultures it will be difficult to estimate a reliable the disability weight because the impaired are not living long enough. As in the example of paraplegia citizens of developing countries may be unfamiliar with the disorder or perceive them differently because the prevalence of paraplegic is low as they soon die after the injury. Or because the paraplegics are stigmatised and not mobile they have no social contact and the rest of the society does not recognize their standard of living.

The opposite situation causes attention in the developed countries because it might be impossible to weight disabilities like living with malnutrition for years causing several deficiencies or disorders with infectious origins like malaria. Even diseases commonly known all over the world, are interpreted different. In the case of HIV, it is now a treatable illness but living with HIV is highly dependent on the access to medicine. So while HIV still is inevitably fatal in the developing countries; in the western hemisphere the infected is living with a chronic disease. These facts are supported by the ranking shown in Figure 1 and the result of the regression analysis concerning HIV.

## Local Burden of Disease studies and contextual approaches

The Global Burden of Disease Study (GBD) initiated the first weights and in the following years. As it can be seen from Table 2 only a few regional studies have been carried out. It is crucial that most of the published studies have been done in developed, western economies. This might be due to the fact that the DALY-approach mostly fits the way

of the thinking in these areas, the access of reliable and valid data and perhaps foremost the fact that here are established research environments in health economic base.

The Dutch Disability Weights Study followed a modified version of the GBD valuation protocol. In short, most diseases were subdivided into disease stages considered homogeneous with respect to functional status, treatment, and prognosis. The 175 disease stages were valued by 3 panels of medical experts. First, 16 disease stages were valued in day-long panel sessions by person trade-off methods. These so-called indicator conditions were selected because their expected valuations should evenly cover the total range, from the best to the worst imaginable health. Furthermore, they should have a sizable public health impact and they should be relatively easy to recognize and interpret. The mean disability weights for these indicator conditions were then used to construct a disability scale on which the remaining 159 disease stages were interpolated. This task was conducted by the same medical experts in an individual postal procedure.

Generally, disease stages were valued by assuming duration of 1 year. However, some of the selected diseases (e.g., influenza) have only a brief duration and are followed in most cases by full recovery. Those diseases were valued as an “annual profile” (e.g., “a healthy year including a 2-week episode of influenza”), and the disability weight was multiplied by the (yearly) incidence of the disease— not by the point prevalence—to arrive at YLDs.

**Table 2 Burden of disease studies**

Study	Year	WHO region and mortality stratum	Area	Regional revisions	Cultural revisions
Murray & Lopez <sup>21 50</sup>	1993	All	The world	÷	÷
Vos et al. <sup>51</sup>	1995	Afr-D	Mauritius	÷	÷
Lozano et al. <sup>52</sup>	1995	Amr-B	Mexico	÷	÷
Bowie et al. <sup>53</sup>	1997	Eur-A	South West Region	?	?
Petterson et al. <sup>54</sup>	1998	Eur-A	Stockholm	+	+
Stouthard et al. <sup>55</sup> <sup>56 57</sup>	1997	Eur-A	Netherlands	+	+
Victorian Department <sup>58</sup>	1999	Wpr-A	Victoria	+	+
Mathers et al. <sup>59</sup>	1999	Wpr-A	Australia	+	+
Schopper et al. <sup>60</sup>	2000	Eur-A	Geneva	÷	÷
Ministry of Health <sup>61</sup>	2001	Wpr-A	New Zealand	(+)	(+)
Ministry of Health <sup>62</sup>	2001	Afr-E	Zimbabwe	?	?
Kominsky et al. <sup>63</sup>	2002	Amr-A	Los Angeles County	÷	÷
Bradshaw et al. <sup>64</sup>	2003	Afr-E	South Africa	(+)	(+)

÷ Use of GBD panel weights; + Local panel weights; (+) Use of local weights from other study; ? Unknown.

To calculate YLDs on the basis of the prevalence data for the disease as a whole and the disability weights for its separate stages, it was necessary to combine the disability weights of the disease stages into 1 disease disability weight. Therefore, the average disability weight of a disease was calculated, to which the stage disability weights contributed according to their share in the disease prevalence. The required distribution of the prevalence over the disease stages was obtained through consulting experts for each disorder and, in some cases, by additional modelling.

In the Stockholm burden of disease study population-based inpatient registers, national survey information and expert judgements on the prevalence of morbidity were used to calculate YLDs in combination with the original GDB-weights.

The Australian and the Victorian Burden of Disease Study used actual or derived weights from the GDB and from the Dutch disability weights for calculating the DALY. Although many different sources of information were used to calculate YLD, sometimes data were not available and expert judgement was relied on. For most disease and injury groups, Australian experts were consulted during the development and revision of YLD-estimates.

The South African Burden of Disease Study used the ratio off YLL/YLD in the GBD study. This was done for illustrative purposes and to have some preliminary figures for DALYs in South Africa. South Africa falls into the AfroE region and hence these estimates were considered to be most appropriate for the country. As the South African Burden of Disease Study list did not correspond exactly with the GBD cause list, if necessary ratios for causes that appeared on the lists of other DALY-studies like the Zimbabwian, Mauritian and the Australian were used.

In the absence of country specific values (social preferences for health states), The Burden of Disease Study for New Zealand used Dutch disability weights. Where a Dutch weight was not available because the condition concerned had not been included in the Dutch valuation exercise, either the Global Burden of Disease Study weight was used, or a multiplicative regression model was applied to interpolate weights between indicator conditions.

The other studies do not report any contextual initiatives. From the description of the regional burden of disease studies there has only been the Dutch Disability Study which has made a real contribution to the further development of disability weights in a contextual sense.

Beside the reported studies, several studies are published using the techniques of the DALY-approach focusing on specific diseases like asthma, cancer, obesity etc.

## Conclusion

The development of DALY is a serious attempt to construct an instrument with a simple measure for understanding and prioritise the complex challenges in public health. It is a good general tool for global health assessment and acknowledgement of trends in disease patterns. But it has some serious shortcomings in addressing regional and cultural based consequences of diseases.

It has been shown that there are no unequivocal cultural dependent presumptions of disabilities. Based on the results shown in Figure 1 and Table 1 it is not possible in general to conclude if there should be a relationship between the economic conditions per capita and the presumption of disabilities because one half of the regressions are significant whereas the other half are not. Instead it has been argued that regional initiatives can contribute to the change in people's opinions about the assessment of disabilities. Indeed there are differences in the ranking of disabilities and therefore it is necessary to decompose the areas examined whether in regard to a defined region or to a specific cultural environment.

But ranking of disabilities is not sufficient because ranking follows a cardinal scale whereas the disability weights are estimated on a nominal scale. While the ranking of diseases only implies the succession of the burden and even though varies arbitrary, the weighting of the disabilities must be assumed to be almost impossible without knowing the specific context in which they should be regarded.

In the development of the DALY one of the aims was to reinforce objectivity in epidemiology used for health assessment and health policies. The correct measurement of the burden of disease, would remove the opportunities for advocacy, and decision making could then be based on an independent analysis presented in a comparable measure.

The data presented in this study contradicts a number of assumptions underpinning the DALY in its current form. The findings are not surprising, and the criticisms of the use of a global severity weight for disaggregated units such as country, culture, age, and sex reinforce the view that the support from a particular perspective drives the features of the DALY's development.

The regional and cultural contexts in which a health condition occurs influence the impact of that condition. An appropriate estimation of the disability weight for a health condition requires that this contextual information is included. But the inclusion of contextual information in the estimation of the disability weights will increase the level of complexity to the task of calculating the global burden of disease.

Nonetheless, there has to be a balance between the assumption that the entire world is one context, and the treatment of each individual as belonging to their own unique context. In regard to public health matters one wants to find those elements of the context that effect populations not individuals. There is no definitive answer to the question of what defines a single context. Different countries will be more or less homogenous on a range of different regional and cultural factors. More than 10 years after the publication

of the global burden of disease it has been demonstrated, that for the time being there is almost no research that looks at this aspect of health outcomes. But ignoring the problem is not the solution.

\*GNI per capita (formerly GNP per capita) is the gross national income, converted to U.S. dollars using the World Bank Atlas method, divided by the midyear population. GNI is the sum of value added by all resident producers plus any product taxes (less subsidies) not included in the valuation of output plus net receipts of primary income (compensation of employees and property income) from abroad. GNI, calculated in national currency, is usually converted to U.S. dollars at official exchange rates for comparisons across economies, although an alternative rate is used when the official exchange rate is judged to diverge by an exceptionally large margin from the rate actually applied in international transactions. To smooth fluctuations in prices and exchange rates, a special Atlas method of conversion is used by the World Bank. This applies a conversion factor that averages the exchange rate for a given year and the two preceding years, adjusted for differences in rates of inflation between the country, and through 2000, the G-5 countries (France, Germany, Japan, the United Kingdom, and the United States). From 2001, these countries include the Euro Zone, Japan, the United Kingdom, and the United States.

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# Who should weight the disabilities in Burden of Disease Studies?

## Introduction

The development of Disability Adjusted Life Years (DALY) is a serious attempt to construct an instrument with a simple measure for understanding and prioritise the complex challenges in public health. It supports the purpose for global health assessment and acknowledges the trends in disease patterns. But it has some serious shortcomings in addressing regional and cultural based consequences of diseases.

The regional and cultural contexts in which a health condition occurs influence the impact of that condition. The proper estimation of the disability weight for a health condition requires that this contextual information is included. However, the inclusion of contextual information in the disability weights will increase the level of complexity to the task of calculating the global burden of disease.

More than a decade years after the publication of the global burden of disease there has been almost no research that looks at this aspect of health outcomes. Ignoring the problem is not the solution. In stead further attempts ought to be done to examine and develop local disability weights whether with regard to techniques or with regard to the individuals involve in the process.

## Aim

This article focuses on two issues. First, it present how health and health care have developed over time and by the help of a static model it is discussed how the view of different groups on disability and need are in relation to relieve the situation of the sick and disabled according to the experience of the group with a given health condition. Secondly, it emphasise the challenges of estimating disability weights given the different approaches from professionals, patient and lay-people when these persons are asked to make the assessment prior for a burden of disease study. A model for the process is shown to express the categories which have to be considered in the collaboration within one or more focus groups.

## Background on contributing factors for health development

Why involve other than medical professionals and especially why should the assessment of disability weights not rely only on the values of doctors? There are three major components fundamental to the health development, which are the health determinants, the demographic component and the development in therapeutic<sup>1</sup>.

The main driving force includes the underlying social, economic, political and cultural factors which determine health and are responsible for the health transition. Of major importance has been the achievement of modest level per capita income and widespread literacy, especially for women<sup>2</sup>. Some changes, such as urbanisation and the associated changes in behaviour, occur with industrialisation followed by for example nutritional changes and the increase in cigarette smoking. An increasing frequency of these risk factors in the population leads to increases in age-specific deaths rates. Also included in this component are the public health interventions which aim to reduce the population's exposure to health hazards, for example, immunisation and focus on occupational health.

The demographic component refers to the worldwide ageing of populations as a result of declining fertility and to declining death rates, particularly in children. The ageing of the population results in the emergence of non-communicable diseases of adulthood which have a long latent period and become more frequent with increasing age. As populations get older, the absolute number of these diseases will predictably increase, although the age and cause-specific death rates decline.

The therapeutic component includes factors that tend to reduce the risk of dying once a disease has become established. Effective health services are crucial for the achievement of good population health and interact with the independence of women and higher educational levels. The most effective health services are not necessarily those which are technologically advanced, but rather those which are either free or inexpensive and easily reached. From a historical perspective, this contribution to the health transition has in general been small because of the minor effect of most medical interventions. The therapeutic component has been of greatest importance in poor countries and has contributed to the major decline in child mortality that has taken place in these countries over the last few decades.

As a consequence of the components different economical, occupational and technical elements to the health transition it is obvious that not only the medical professions, especial the doctors, have contributed to the development in the general health condition of the society. Engineering have at least a similar influence. Therefore it is important to acknowledge and recognise other's than doctor's opinions in regard to the severity of the life as disabled.

## Understanding different view of disabilities

In valuing the disability weights of diseases the individuals implicit express the view for the care needed by the diseased. Knowledge of the health condition to be evaluated can cause different valuations among different groups of respondents. A distinction can be made between respondents without knowledge of the condition to be assessed as many members of the general population tend to be, and those with knowledge of the condition to be valued. The latter may further be broken down into those who have experienced the condition themselves or are still living in this state – disabled or patients; and

those who have gained knowledge of the health state through their work like professional health care providers.

This raises the question about “what is need?” Until now the concept “need” has been used without considering whose need and what kind of need is to be taken into account. By the assessment of disability weights it is crucial to distinguish between demand for public health services and need.

An individual or a group of individuals might have the need for a service but are ignorant and do not demand the service. Conversely there might be individuals or group of people without any need, who seek public health care. Stating this there is an implicit assumption saying that need is a value-added normative notion connected to goals applied and for which the services are necessary<sup>3</sup>. Others than the individual seem to judge to which intend the individual or the public is in need for public health care services. The other respondents in assessing the need are medical experts and the society as such expressed through legislation, public health plans, state subsidized insurances or community members.

The different view of the appropriate offer can be illustrated by the following simplified example<sup>4</sup>. The example focuses on sickness but could in practice include any public health issue. Sickness is assumed a dichotomy variable “healthy – sick” disregarding the varying degrees of illnesses and diseases.

There are three respondents, society, medical experts and the individual, who separately are given the questions:

- a) Is the individual sick?
- b) Is the individual in need of public care?
- c) Does the individual demand public care?

The last question is answered by observing the individuals who contact the health services to be diagnosed or threaten and who are willing to wait if access is limited at the time. Figure 1 shows the more interesting possible combinations of different view of the need for health care and is not mathematical exhaustive. If the yes-answers are shown as *S*, *M*, *I* and the no-answers are illustrated by *S*, *M*, *I*, the results can be shown as follows:

Case 1 shows justified demand in agreement with society and medical experts. The cases 2, 3 and 11 represent latent need with society and medical experts in agreement. In the cases 5, 6, 8, 9, 12 and 13 there is a latent need for service but with disagreement between society and the medical experts. Cases 10 and 14 represent unjustified demand with society and medical experts in agreement. The answers to the two first questions depends on knowledge and valuation, but they tough different informative problems. The problems considers to which extend it is possible to convert latent need to demand on the one hand and how it is possible to avoid unjustified demand. A well informed public will not demand the services unless they are in need<sup>5</sup>.

Finally the cases 4 and 7 represent demand with society and medical experts in disagreement. If case 4 is regarded as justified active demand it shows the difficult problem having doctors to ordinate appropriate care. If case 7 is considered as unjustified demand it stresses the problem of over consumption of health care.

**Figure 1 Need and demand for medical care**

Is the individual sick?	Is the individual in need of public care?	Does the individual demand care?	Case	
SMI	SMI	Yes	1	
		No	2	
	SMI	No	3	
	SMI	Yes	4	
		No	5	
	SMI	No	6	
	SMI	Yes	7	
		No	8	
	SMI	No	9	
	SMI	Yes	10	
	SMI	SMI	No	11
		SMI	No	12
		SMI	No	13
	SMI	SMI	Yes	14

The above description of health assessment and determination of need for health care is simplified for illustrative purposes. In reality the reliability and validity of the respondents answers are seriously dependent on several conditions.

If the respondent is the *patient or disabled*, the valuation will be restricted to the person's own health state. Health profiles and utility measures can be applied. Doubt has been raised about the appropriateness of patients' responses. Empirical studies have shown that disabled and former patients adapt to their own health state and rate this as less severe than non-patients<sup>6 7 8</sup>. Furthermore, the knowledge of ex-patients and their family and friends extends to only a limited number of health states<sup>9</sup>.

It is also argued that when a societal perspective is considered best for studies concerning health care resources in the public interest, the best articulation of society's preferences for particular health states should be gathered from a representative sample of fully informed members of the community. This also includes the argument that patient characteristics do not necessarily follow that of the community. As a consequence, patient preferences alone should not be used for valuing health states in the context of resource allocation decisions. On the other hand, the total needs of patients should be considered in the planning and provision of different services<sup>10</sup>.

When the respondent is a *medical expert or health professional*, the valuation may refer to a wide range of hypothetical health states. Health professionals have been seen as credible sources of preference scores because they have witnessed a particular condition or health state in many patients and are able to provide a reasonable judgement about the long-term effect of the health condition for a patient. They may be involved in the description of health profiles, as well as in valuing health states by utility measures. It can be argued that health professionals may give too much weight to functional status and inadequately take into account more subtle and subjective influences of an illness like emotional problems, pain and discomfort, when valuing impairment. Additionally, health professionals do not make up a representative cross section of the general public with regard to age, income and socioeconomic class, and therefore systematic bias may be built into these preferences. Using health professionals to directly value health states is regarded as an unsatisfactory method of obtaining preferences.

If the respondent is a *social representative or community member*, the valuation may also refer to a wide range of hypothetical health states. As this involves lay people who are not knowledgeable enough to assess and classify the various physical, social and psychological domains related to a health state, they can only directly value health states based on existing health profiles.

Although efforts can be made to provide in-depth descriptions of health states, lengthy descriptions can result in cognitive overload, and the health states, even if described in detail, remain hypothetical. On the other hand it has been examined that that people can visualize at least some specific health states relatively well<sup>11</sup>. Utility measures based on statistical or objective probability confront subjective or personal considerations of probability. In populations with low levels of formal education, another problem may arise from using numbers and thus translating lay knowledge, attitude and experience into a single numerical value. A quantified estimation is never a 'value free' act. It is based on lay-peoples interpretations of numbers, statistics and probabilities, or the epidemiology of lay-people<sup>12</sup>. The question is to which degree is the population's relative degree of numeracy developed? Does a population understand and accept a numerical expression of risk and uncertainty?

So far need has been described as an absolute quantity but this it not the right unless you explicit define who you assume is in need and who is not. The term "need" depends on cultural and social factors. As these factors are not constant in time and space there is reason to believe that the definition of need should change as well. An individual's valuation of a certain health state, to a large extent, reflects values, assumptions and be-

liefs about health and illness in general, and 'lived' experience with actual episodes of ill-health, impairment and handicap in particular. In valuation surveys, lay peoples' emphasis on these qualitative features of illness and disability are, therefore, neglected at the benefit of a numerical value. Social and cultural values and beliefs, on the other hand, are not 'stable' cognitive phenomena; they reflect cultural orientation as well as social and socioeconomic positions within a society and can change over time. The concept need is dynamic.

The use of community preferences coincides with the more theoretical point of view, that the best articulation of society's preferences for particular health states should be gathered from a representative sample of fully informed members of the community.

### Assessing disability weights

The group of parties involve in weighting disabilities therefore has to suppose a concept of need which is ought to be assumed consistent in the period of time where the disability weights are used. New diseases like the recognition of HIV/AIDS in 1980's or medical technologies will change the general assumption of which need to be fulfilled. In the case of HIV/AIDS the level of stigmatisation in some societies negatively affects the lives of those who are HIV positive and thus increases the severity of the condition. Those living in more stigmatising societies would warrant a higher disability weight than those living in less stigmatising societies. Stigmatisation also drives the disease underground and makes it harder to deliver health promotion and safe-sex messages, which in turn increases the population's risk of infection.

Need for public health care is not only valued between different diseases but also in relation to satisfy the need for other issues like sanitation of development of employment. It is not possible to accomplish all need and therefore it is necessary to prioritize the different needs within the given resources. The satisfaction of need does not have to be the technically or clinical most effective treatment but might be the solutions where - in an economical term - the marginal utility compared with the marginal cost is highest. The way of threatening the patients might have a little physiological effect in a given state of condition and therefore supposed ineffective but in the actual situation it can still be worth doing it if the patient receives utility from the caring, as opposed to the curing, aspect<sup>13</sup>. This is indeed one of the reasons why it is not relevant to have universal disability weights. Much of the health care in the developed world concerns the palliation of chronic disorders to improve the health status of the disabled. In contrast to this contribution, most of the countries in the developing world are in a transition from morbidity and mortality caused by merely infectious diseases to a situation whereas these countries have to deal with life style related diseases, too.

To get reliable and contextual disability weights one way would be to settle a number of focus groups like the WHO has done with the estimation of the global disability weights. Though, here the participants are lay-people in a health perspective but professionals and specialist in many other issues of life. A facilitator or a group of facilitators

should be assigned to help the participants to team up and get ownership of the process and the results.

The participant in the focus groups can be seen as members of an intersectorial collaboration of multidisciplinary teams. Everyone contributes to the assessment of the disability weight in his or hers own way according to the individuals sex, age, beliefs, professional training, working experience etc. However, a multidisciplinary team is a fragile and volatile form of organisation which needs a constant nurturing in order to achieve its goals<sup>14</sup>.

## Facilitating the process

In order to comply with these demands of the process it seems appropriate to facilitate the practice in the focus groups. Facilitation is a way of providing leadership without taking the reins, managing the process and leaving the “content” to the participants. Facilitation can also be expressed as “How you do something” (process) rather than “What you do” (content)<sup>15</sup>. It is about moving something from one point to another and making this as easy and convenient as possible. Compared to the bio-medical sciences facilitation can be seen as a catalyst. The active components are still the same; the people are the same; the catalyst speeds up the process - facilitation is a technique where one person makes things easier for others<sup>16</sup>.

Within the concept of helping and enabling, the focus of facilitation can encompass a broad spectre, ranging from the provision of help to achieve a specific task to using methods which enable individuals and teams to review their attitudes, habits, skills or ways of thinking and working<sup>17</sup>.

The facilitator is a person who contributes to the structure and process and to interactions so that groups are able to function more effectively and make better quality decisions. The facilitator is a helper and enabler whose role is to support others in achieving better performance. The aim is also to get others to assume responsibility for their task and to take the lead.

The facilitator is a process guide similar to the chairperson of a majority-voting model committee, guiding a group of persons through co-operative processes, including collective decision-making .

A facilitator can come from inside of an organisation, or from outside. The choice of internal or external facilitation should depend on the task . It is important to distinguish between the role of a local opinion leader and a facilitator . The leadership (of the local opinion leader) is “the degree to which an individual is able to influence other individuals’ attitudes or overt behaviour, informally, in a desired way with relative frequency”, while the facilitator role is to make things easier by helping, encouraging etc.

The facilitator has different kinds of authority: A *tutelary*, where the facilitator has mastered some knowledge and skills and under appropriate procedures are passing it on; a

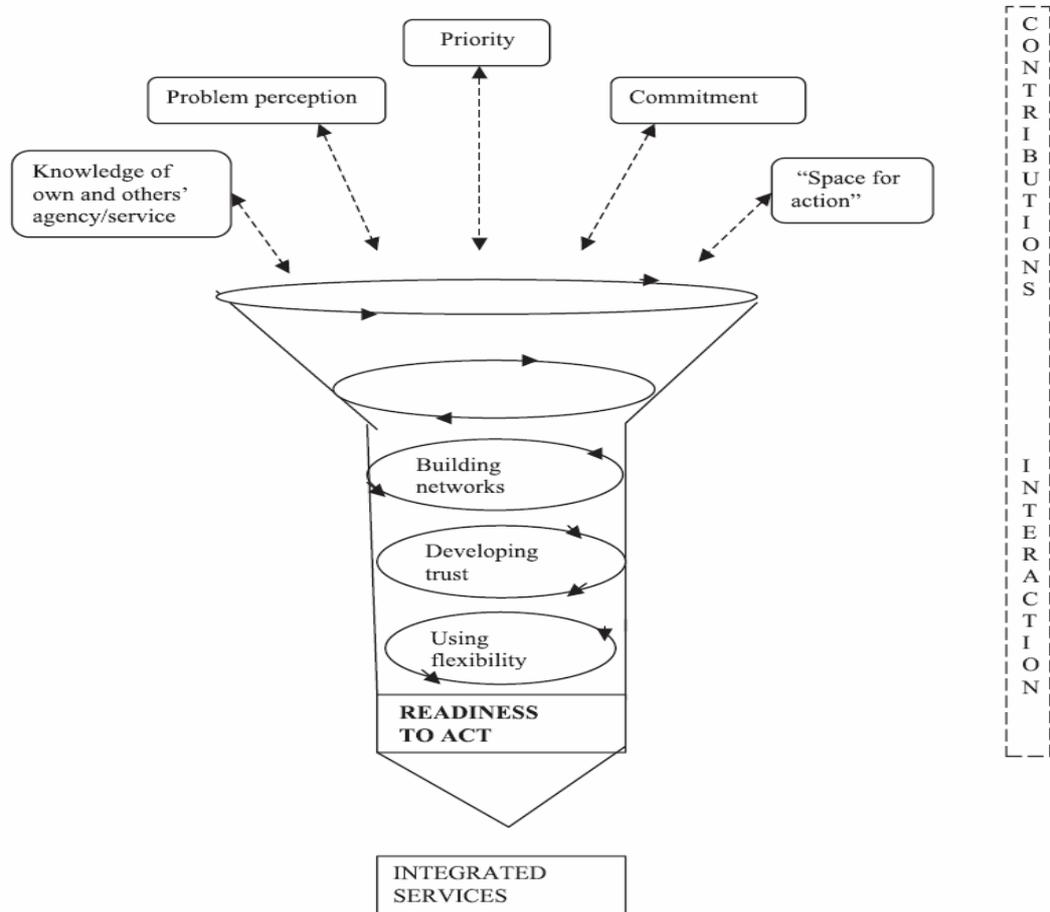
*political*, where the facilitator makes decisions that affect the whole programme of learning, involving the content, methods and timing of learning; and a *charismatic*, under which the facilitator influences learners and the learning process by virtue of their presence, style and manner, they empower people directly by the impact of their way of being and behaving<sup>18</sup>. The facilitator needs to analyse and plan what his role should be in any particular situation, to tailor his role to the task.

By engaging those involved in identifying disability weights it may be possible to devise tailored action plans that will lead to more successful interpretation and later on implementation. Thus the strategy for focus groups would be different in a group of participants that are used to e.g. poor leadership and measurement practices than in a group in which the representatives embraced a lifelong learning philosophy.

The process for forming the group of participants for the facilitator can be divided in two different aspects of collaboration<sup>19</sup>. One can be regarded as the participant's contribution to the team; the second is the participant's interaction in the team as illustrated in figure 2. The group members are the lay-persons using their occupational (professional) as well as personal experience with public health, disabled and attitudes toward these issues. With few exceptions, they are not supposed to professionals in that sense that that are salaried health professionals. But by change members of the group might be health professionals. It is an intrasektoriel assignment with a common theme which includes communication and cooperation between actors<sup>20</sup>.

Five categories clarify the participant's contributions: Knowledge of own and other's service, problem perception, priority, commitment and space for action. These contributions might vary depending on the individual case. Three other categories demonstrated characteristics of the participant's interactions within the collaboration: Building networks, developing trust and using flexibility. These categories are essential to hold the collaborative process together over time. All the emerging categories appeared to influence each other in a dynamic evolving process. The core category is the participant's 'readiness to act' and all the other categories are related to this central explanatory concept.

**Figure 2 The participant’s contribution and interaction in interprofessional collaboration**



The dynamics of the model above is like conducting a fluid through a funnel. This shows how the distinct contributions and interactions can be combined through the collaboration process into a whole, facilitating integrated services in a multidisciplinary team.

**The participant’s contributions**

*Knowledge of own and other’s service* represent primary tasks, organizational structures, support, boundaries and perceived opportunities/limitations. These concepts deal with the procedures, tasks and organization of the different services. For the group participant it is important to explore the boundaries regarding opportunities and limitations of the other participants in so far they have knowledge of specific types of services available and what type of support may be expected for disabled.

The Facilitator's role will be to introduce the case and give attention on the various competences of the team members. The purpose is to enable the group to get to know what resources are at hand for the coming work. The facilitator has to fit in to a flexible role where on the one hand he has to influence the process just with his presents as a catalyst and on the other hand he has to pass on his own knowledge and experience in the field.

*Problem perception* relates to professional background and personality and represents professional's knowledge of the DALY-concept and disabilities in general, their specific professional orientation, their experience, personal values, views and style. The participants in these focus groups not only embody different professions, but has in addition adopted different theoretical 'schools' and approaches. It is important to know the team members different possibilities with regard to communication, access to information and use of procedures in order to establish a common understanding of each others everyday<sup>21</sup>. Some might not have a formal professional education, but everyone will have different kinds of experiences, including experiences from their own private life, which influenced their perception of challenges for disabled persons living in their surroundings.

How their perception of a disability emerges and how the group members relate to this depend on the communication between the collaborating persons. As peoples identities are affected of membership of linguistic, regional and ethnic groups, this background creates problems for intercultural communication<sup>22</sup>. But rather than see this as a hurdle for the intersectorial group, the "languages" and cultures within the group should be seen as dynamic sources for the further interpretation and possible implementation of the DALY-concept.

One of the main tasks for the facilitator might be to give co-counselling and make the group task meaningful. The objective is to create a common platform and obtain motivation for coping with the difficulties ahead.

*Priority* is a category consisting of the characteristics of the phases and progression in the assessment, comply with the complexity and timing. Priority setting is crucial for the succession of the groups work. As there is only a limited time left for the participant the priority of resources have to be clarified at an early stage. Following this *Timing* is very close connected to priority. Timing describes the co-ordination of the various actions. Who does what at which time and at what tempo? Timing is about how the process is optimised in order to achieve an outcome from the focus group so it is possible to act further concerning the DALYs.

This is one of the strategic core phases of the cycle of the focus group. As part of the strategy, a framework and schedule have to be established. The authority of the facilitator will continuously change being tutelary, charismatic or political in order to stick to the time table. And at the same time, use the appropriate tactics to enable and encourage free discussions at the right moment, so the necessary clarification occurs for the work to come.

*Commitment* embodies the member's involvement in a specific phase, position in the group, perception of responsibility and ethics and use of initiative. Mutual goals and responsibility are of great importance for the collaboration<sup>23</sup>. Everyone in the team have to assume ownership of the group's tasks. Persons used to the abstract thinking in their daily life might be most engaged as their perceptions are relative best. The complexity of the DALY-concept will challenge the group's relative power structure and mutual relations.

To achieve a mutual commitment of the group the facilitator has to use his own prestige in the project so the participants see him as having part and responsibility for the team's progress and results, too. By this the facilitator stands forward as robust and reliable. Being committed him self, the facilitator have greater opportunity to impose the mutual goals and responsibility for the team as a whole.

The category *space for action* explains the participant's freedom to adopt creative solutions, and opportunities to respond to the other individual needs in coping with the different disabilities and finding new solutions. The level of many hundred determinants of variance in health state valuations in combination with understanding of the nature of particular health states by members of the general public or by others, who are not experiencing the health state, is not always accurate and can be heavily influenced by how the assessment procedure is done<sup>24</sup>. New ways of describing or illustrating the nature of the daily life of the disabled have to be taken into account.

It is important to find forms of collaboration which apply to that specific problem to be solved<sup>25</sup>. In this example, an inhomogeneous group of people have to give the answers to a very complex set of question and therefore they need to know that their effort to estimate disability weights will be acknowledged. The member's contributions to multidisciplinary collaboration might vary from disability to disability depending on conditions related to the participant's potential. The personal component is particularly important as it represents a potential force for communication and willingness to stretch boundaries of the schedule phases. There will be a need for the 'space of action' to respond to unpredictability of group progress and a possibility to create alternative solutions.

The primary role for the facilitator in this stage is to acknowledge the cognitive and personal obstacles in the perception of disability weight. As the group is a fragment of the general public they may have only the vaguest notion of e.g. the daily life of a blind, incontinent or paraplegic person. Some may have the experience with a relative or a friend with that disease or just know that it is an illness which is severe for the individuals and hinder them in having a normal life. Because the information gap may be huge, the group members have to be taught about the consequences of living with each disease stage. In some cases illustrations by video may help the group further; in other situation the facilitator in accordance with the participants may have to change the applied valuation method.

## The interaction of the participants

Three categories are essential to how the collaboration is kept together. *Building networks* stretch the ability inside the focus group to establishing channels for communication, finding format for collaboration, building relations, accessibility, acknowledge mutual contribution, and continuity. This relates to the framing and structure of the interaction to make a functional network among the collaborating members. There have to be regular meeting points in time and space according to the schedule. In addition, there should be opportunities to contact each other by phone or mail, using smaller and informal meetings between the arranged meetings. The more often the members can be in contact with each other the more likely it is to establish the group as a committed team.

The objective for the facilitator is to motivate interpersonal relation. This can be done by securing the right facilities physically and technically. But foremost the facilitator must encourage communication among all participants, so they get the feeling of being a team. The facilitator has to empower the individuals which else would keep low profile and push them to be integrated in the network outside the time spent in the scheduled settings.

*Developing trust* also influences interaction and includes the acknowledging of various contributions, sharing experiences, support, recognition, transparency and loyalty. Trust is needed to make the collaboration successful<sup>26 27 28</sup> although mutual trust does not have to be present at the start but can be built during the process. This category illuminates some of the difficulties and challenges in dealing with this challenge of assessing disability weights. It is a complex task and in advance there are no obvious solutions. It is important to share various experiences and discuss approaches and support each other's efforts even if they are not successful, nevertheless representing a new begin.

The facilitator has to be aware of this second major strategic category and bear in mind a cyclical trust building process. Because even in situations when collaboration is well under way and a good degree of trust is present, continuous effort is required to sustain sufficient levels of trust. The participants need acknowledgement to continue so they do not give up after what seems to be personal defeats. The collaborating partners need feedback and supervision that require a confident and open atmosphere. They also have to be confident that when they are making mutual decisions, the other members involved will stand by the ranking of disabilities, the values of the disability weights etc.

The loop building function is further developed to illustrate the dynamics and evolutions in the collaboration of the focus group. The trust building is accelerated through the funnel. The members of the teams will by coming through the funnel go from being a team of unidisciplinarity to a transdisciplinary unit in order to objectively achieve better qualified disability weights<sup>29</sup>.

*Using flexibility* includes division of responsibility, negotiations and reflection, use of power, generosity and openness to change. This category shows the balance of give and take between professionals as they assess the disability weights. They have to be able to discuss and disagree and try to complement each other. The participants also have to re-

spond to unpredictability results of their discussions regarding the values of the calculated weights.

Flexibility is heavily emphasised so the group is able to respond to individual experiences and carry out new rankings. The establishment of commitment and trust inside the group is crucial for the group's ability to be flexible. Achieving such an inter-personal and interprofessional consensus will be difficult in settings where each individual remains rigidly attached to inherited and uni-professional modes of thinking and working<sup>30</sup>.

The facilitator has to use his political authority to stress that the flexibility is not a matter of revising the valuation methods or likewise technical issues for the calculation as discussed in the "space for action" category. Here the purpose for the facilitator is to keep focus on critical reflection and use the commitment and trust in the team to enable an open discussion on how close the disability weights seem to reflect the quality of life in its broadest sense.

The category labelled *readiness to act* can be related to all the categories presented and serves as a unifying proposal. With this 'readiness to act' the focus group is able to respond to the purpose of identifying local disability weight taking into account the current regional and cultural context. "Readiness to act" is dependent on both the member's contributions as well as the member's interactions as a dynamic merging process. According to the model in figure 2 'readiness to act' facilitates integrated contributions of lay-people to get actual and valid disability weights representing the values of the society in which they will be used for estimating the burden of disease.

In this final stage the facilitator has to ensure that the team remain faithful to the results and maintain the consensus achieved in the earlier phases. Drawing on all kinds of authority and personality the facilitator must present the estimated disability weights and the effect on the burden of disease in a way that no member back out of the group. For the group as well as for the facilitator this is the point where the intersectorial collaboration can be appraised

The key message is that collaborative structures need to be understood as an ambiguous, complex and dynamic process in order to understand the enormous challenges which teambuilding and collaboration presents. Achieving collaborative advantage for all but the simplest of collaborative purposes requires major resource investment, together with significant managerial skill and patience from each of the individual group members. The goodwill both of these individuals is also essential. An experienced and competent facilitator or group of facilitators is a fundamental asset, but cannot be expected to carry out the collaboration without the appropriate level of resource and support from the commissioners.

## Conclusion

Using universal disability weights in DALY-calculation does not give the right detailed answers to questions of health assessment, health planning or prioritising health initiatives whether for specific diseases nor for reallocation of resources. But the DALY-concept has proven valuable by giving an estimate of the burden of disease and by forcing health planners to focus on effective programmes for health development.

As a measurement the DALY-concept has been used to draw attention to neglected disorders like psychiatric ones and pushed research and funding like in the case of malaria. In a world of limited resources DALYs would be a useful instrument for resource allocation to comply with the individuals at most need, but still lack sufficient robustness in terms of being the tool to reallocate resources from one topic to another.

The DALY-concept at the present state should be seen as an interesting work in progress to be used with caution for the time being. Though tables are presented for various diseases cross country and economic examinations can be carried out it will take a long time before DALYs are used for reallocation between defined cultures, regions or countries. First, there is a need for local estimated disability weights based on local needs and possibilities of support and not a further development in a universal DALY.

Trustful collaboration between the driving forces of DALY-concept and local actors a crucial for the acceptance of future burden of disease calculation. As in the example in this paper of a collaborative process in assessing local disability weights, there have to be established a consensus in general among interested partners of burden of disease studies, that mutual believe in the values of the DALYs is vital.

Most successful collaboration would seem to occur when evidence is high; the milieu is receptive to change with sympathetic cultures, appropriate monitoring and feedback mechanisms, and when there is suitable facilitation of the process. Little change happens in the process without key drivers, be they defined as opinion leaders or facilitators. Facilitators as defined in this paper are typically external experts in the management of change who work with teams to help them introduce new research based practices. The previous discussions of the DALY-approach indicate a challenging task for synthesising all the contributions.

Trust building within which trust is built incrementally via successful implementation of modest collaborative initiatives would be the preferred strategy. In situations requiring the collaborating organizations to be more ambitious, managing the associated risk is seen as an integral component to trust building and to coping with lack of trust. Poor contexts may indeed be overcome by appropriate facilitation.

Seminars like the European Biomed Study of Rotterdam or The Global Programme on Evidence for Health Policy Conference in Marrakech, both in 1999, contribute to the process in developing DALYs. However the process does not seem to have the appropriate preconditions and therefore arrangements like the mentioned seminar gives not sustainable contributions for burden of disease studies. The seminars seem more to be a

forum where the actors in the field can give their opinions, but unfortunately it is not part of the agenda to achieve mutual methods or goals for the future burden of disease calculations. At present, we need an agenda for the burden of disease estimation which trustfully takes all the criticism over the years into account, including the lack of regional and cultural context.

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