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## **MMS Bulletin #133**

*Faire avancer la lutte contre les maladies tropicales négligées*

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### **The need for a transversal approach in Community Based Rehabilitation programmes**

## **Stigma - a special Problem of NTDs**

De Ingrid Mason und Lobke Dijkstra

*Neglected Tropical Diseases (NTDs) disproportionately affect poor people in developing countries. Many of the NTDs can potentially cause severe and often permanent disabilities. Disfiguring NTDs such as Buruli Ulcer (BU), yaws, and leprosy are frequently associated with social stigma, increasing the burden of disease on the individual and family.*



Kamerun (Foto: Simon B. Opladen / © FAIRMED)

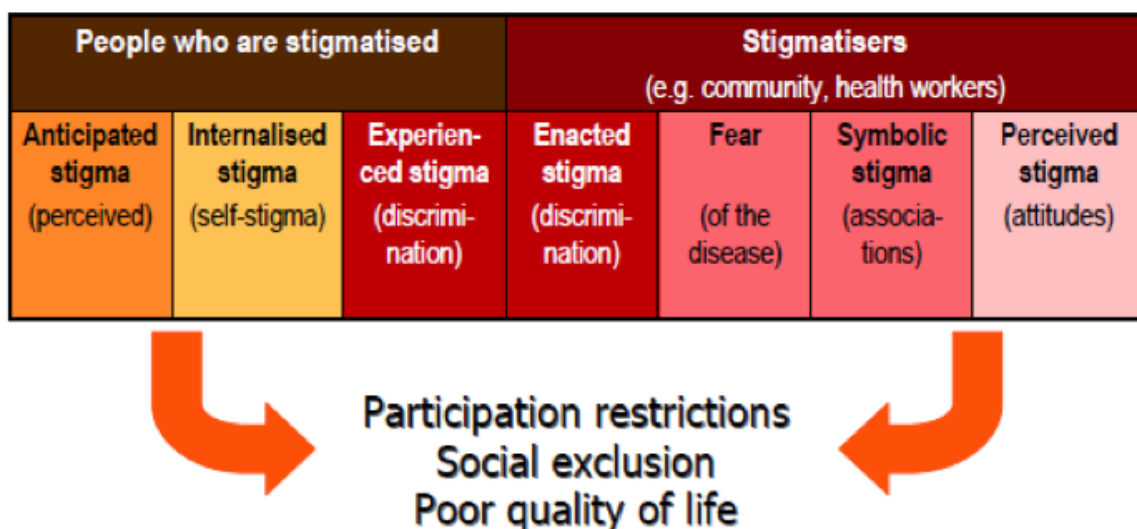
Stigma reducing practices described throughout literature are mainly framed within health related topics, addressing issues like delayed health seeking behaviour of affected people and inadequate provision of health care. The World Health Organization (WHO) Community Based Rehabilitation (CBR) strategy, which is widely used in NTD affected areas, reinforces the importance of a comprehensive approach connecting health, education, employment, social and political aspects of life. Stigma reducing practices should be regarded as a transversal topic to be most effective. Evidence of best practices documented in the health domain could be applied to other domains; paying particular attention to awareness raising and education of all stakeholders engaged in CBR.

## Definition of stigma

As with many social phenomena, the definition of stigma has changed over time. A commonly used definition of health-related stigma formulated by Professor Weiss at the Swiss Tropical and Public Health Institute (2006): as `a social process or related personal experience characterised by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular problem`.

Different types of stigma are described by van Brakel, Weiss and other authors, distinguishing different processes from either the perspective of people who are stigmatised, or of the stigmatisers. Not only enacted and experienced, but also internalized stigma can lead to persons with disabilities restricting themselves from participation, social exclusion and hence a poorer quality of life.

## Types of stigma



Model modified from Mitchell Weiss, STI, Basel

Figure 1: Types of stigma.

## ***Stigma, an additional burden for people affected by NCDs***

Stigma has surrounded NTDs over centuries, strongly related to traditional perceptions of aetiology, transmission, treatment and prevention. Besides medical and economic factors, stigma adds a social element to the burden of disease. Despite obvious differences between several NTDs, stigma related literature often describes cutaneous disfiguring NTDs as a group since they hold similarities in stigmatising factors. Several authors suggest addressing social stigma associated with BU, leprosy, onchocerciasis, lymphatic filariasis and cutaneous leishmaniasis in joint interventions rather than disease specific (Alonso and Alvar, 2010; Wilsher, 2011).

Whereas fear of transmission is mentioned as the basis of many stigmatising processes (Alonso and Alvar, 2010), feelings of shame, embarrassment, low self-esteem, low body-satisfaction, resulting in concealment, and precipitation of psychological disorders are all seen as personal consequences arising from stigma and causing a decreased quality of life. On a social level, reduced marital prospects as well as less employability, restriction in social participation, and denial of electivity for leadership roles are mentioned as consequences of stigmatisation.

### ***Further consequences of stigma***

Several studies show that stigma causes delay in seeking health care services (Weiss, 2008; Alonso and Alvar, 2010). The social consequences of stigma for the individual and family are complemented by problems in accessibility, affordability, reachability and acceptability of services. Late reporting may lead to suffering from deformities and disabilities and increases the chance of transmission in the community, complicating control of the diseases (Hotez, 2008). Besides delay in diagnosis and treatment, non-adherence to treatment is also reported to be related to stigma. Other factors such as geographical location, poverty, gender, and preference to attend traditional health care providers may adversely influence conventional treatment compliance. Temporary or definitive drop out from school or work due to long-term treatment processes is a factor of concern, especially with leprosy and BU where treatment is prolonged and intensive. Although in some cases in-house education is provided, there is little data available about school (re)attendance after discharge, nor about drop-out primarily due to stigma.

### ***Stigma reduction interventions and their impact on poverty***

Stigma-reducing interventions should be targeting individuals, families, communities, and duty bearers. Health education amongst medical professionals and people affected by NTDs is crucial to increase their knowledge and to break down the barriers surrounding NTDs. Public health programs can seek to change communities whereas smaller scale interventions may address specific issues and cultural practices in a given setting. Culture-specificity seems an obvious condition for health education programs to be effective; van Brakel however mentions the consequences of stigma to be remarkably similar in different health condition, cultures, and

public health programs (Van Brakel, 2006). Weiss (2008) argues for the establishment of health policies that are not only attentive to biological and medical issues, but also to the social and cultural aspects that contribute to and underpin a change in health seeking behaviour.

NTD endemic areas are often isolated and of low priority in health budget disbursements. Furthermore, poverty is strongly linked with NTDs and vice versa: prevalence rates are higher among poor populations and NTDs may be an entry point for affected persons and their families into poverty or a deepening of already existing poverty. Affected individuals and their families often face catastrophic (health) expenditures and loss of income generating activities which directly impact the availability of monetary resources. Morbidity and disability also impact the ability of affected people to choose a life that is valuable to them, while suffering from NTD and from associated stigma. This refers to the capabilities approach of poverty which was first described by Sen and Nussbaum in 1999 and forms the basis of the UN's Human Development Index (HDI). Reinforcement of capabilities and resulting increase in social and economic productivity will empower people affected by NTDs and support the development of individuals and families, as well as the communities in which they live. Therefore stigma reduction practices do not only return the dignity and humanity for the affected persons, but also target poverty reduction.

### ***Community Based Rehabilitation (CBR) – a tool to improve the quality of life***

The Community Based Rehabilitation (CBR) strategy introduced by WHO in the 1970s has since undergone further development, but has been widely accepted by development organisations as a tool to improve the quality of life of people with disabilities, their families and communities. CBR facilitates or reinforces participation and inclusion of (marginalised) persons in all aspects of life through multi-sectoral interventions. CBR sits within a human rights framework and supports the dignity and capability development of individuals and communities.

Five columns: health, education, livelihood, social and empowerment (figure 2) represent the key domains in life. Each column holds five elements, breaking down the main items within the respective domains.

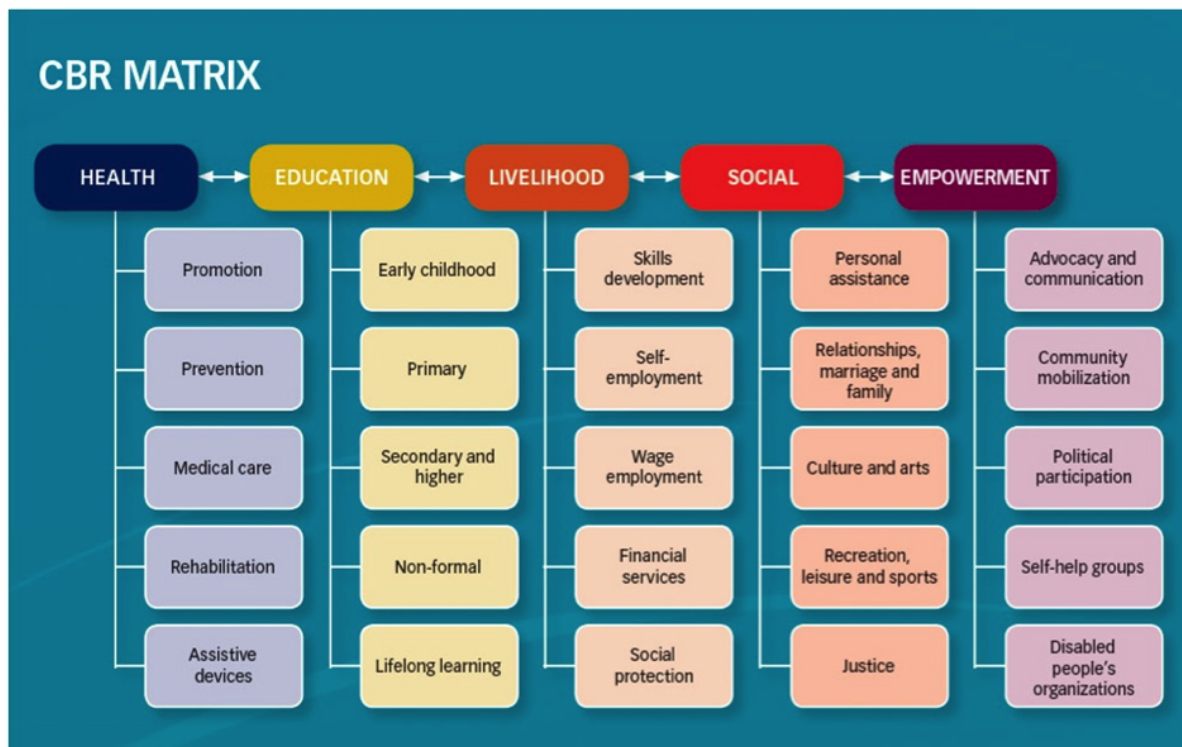


Figure 2: CBR matrix.

CBR is implemented through the combined efforts of people with disabilities, their families and communities, and relevant governmental and non-governmental stakeholder in the respective domains. Recognising the insufficient numbers of professional workers, CBR stimulates the use of volunteers originating from and working within their community, supported and coordinated by professional individuals or organisations. CBR follows a bottom-up approach addressing the actual needs coming from the community, aiming at increased social coherence and inclusion, and connecting multiple stakeholders through its horizontal sector wide approach. The strength of a sustainable CBR programme is seen through the openness and willingness of the stakeholders to network and learn from each other whilst retaining the beneficiary as the focal point. WHO recognized the CBR approach as a poverty reduction strategy (ILO, UNESCO, WHO 2004). Hence, for stigma reduction to be effective it should go beyond the health domain and be seen as a truly transversal issue that is taken up by stakeholders in the other domains of the CBR matrix. A situation in which successful stigma reduction leads to improved health, but not to improved access to i.e. education, employment, or community acceptance due to remaining attitudinal barriers should be avoided.

### ***Building capacity beyond the health sector***

In summary, CBR has been widely taken up as a strategy to improve social inclusion of people with disabilities, facilitating the empowerment of individuals and communities to take an increasing role in their own development. Stigma reduction practices through CBR should comprehensively aim at improved equality of services and opportunities for persons who are stigmatised due to NTD-related disabilities. This, in turn, would contribute to the achievement of the Sustainable Development Goals (SDGs).

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