

# STIGMA AS BARRIER TO THE IMPLEMENTATION OF THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES IN AFRICA

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## Summary

*A major social challenge to the implementation of the Convention on the Rights of Persons with Disabilities (CRPD) in Africa relates to the widespread stigma attached to the characteristics of disability and those who embody them. The article (a) discusses the phenomenon of social stigma as an underlying contextual lens around Africans with disabilities; (b) examines how stigma generally impacts the lives of Africans with disabilities; (c) applies (a) and (b) to the illustrative examples of stigma related to the treatment of people with albinism in Tanzania, persons with leprosy in Nigeria, and general perceptions of disability in Kenya; and (d) suggests several ways forward to diminish and eventually eradicate the significant damaging effects of stigma attached to disability characteristics and the Africans who live with disabilities, thereby paving the way for increased and more effective implementation of the CRPD in Africa.*

## 1 Context

For people with disabilities, there has been a significant transformation over the past 20 years from viewing disability based on a medical model to that of a more socially-oriented model. Historically, the medical model of disability viewed disability and its manifestations as a medical and clinical

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phenomenon intrinsic to the individual; something to be examined, diagnosed, managed and 'cured' where possible. Characteristically, this model recognised disability not only as a phenomenon intrinsic to the individual, but concomitantly emphasised the constraints imposed by disability in relation to non-disabled persons. In the medical model, therefore, the health and related professions sought ways of ameliorating these difficulties by accommodating the disability (to a greater or lesser extent) so that the disabled would better fit in with a society based on normalcy. In so doing, the medical model, predictably, classified persons according to their disability and its severity, essentially dividing the world into those with and those without disabilities or, stated differently, the abnormal and the normal. Furthermore, this divide attributed to those with disabilities a palpable sense of being incapable and dependent. The manifestations of these *sequelae* are often visible in the layperson's perception that people with disabilities are either to be pitied for their disabling condition or celebrated as brave and resilient in overcoming their lot in life. Furthermore, this model implies that the individual is responsible, by happenstance, for bearing the burden of the disability, thereby abrogating society from any responsibility to close the abled versus disabled divide. In sum, this view holds that disability tends to become central to the individual's identity rather than as adjunct to peoples' innate humanness and personhood and the notion that they have more, not less, in common with their non-disabled counterparts.

Not surprisingly, the disability community has viewed the medical model as restrictive and unresponsive to their needs. While those with disabilities do not seek to ignore or refuse medical and other assistance related to their condition, they often perceive medical outlooks as socially exclusionary and sometimes degrading. Consequently, they view the necessary support and resources as disproportionately misdirected inward (that is, to their disability) versus outward (that is, to making society more accommodating and inclusive for them despite their disability).

More recently, and in direct response to the shortcomings of the medical model of disability, a social model of disability has become the accepted norm in unpacking issues related to disability and society. The model emphasises the notion that disability is a social construct. That is, all human beings reside on any number of continua related to their physical, psychological and emotional makeup, creating unique individuals with an unlimited array of personal characteristics that transcend compartmentalisation and fixed categories. Put another way, the social model of disability de-emphasises the actual disability to a tangential rather than central influence. Thus, the decentralised social model of impairment replaces the centrality of disability in the medical model. That is, while some human characteristics may cause impairment (being blind or deaf, using a wheelchair, and so on), these characteristics

are not the ultimate definer of the person in whom they reside, but rather adjuncts to their individuality akin to any other human characteristic.<sup>1</sup>

As such, the social model of disability assumes acceptance of the reality of impairment and requires a social willingness and ability to implement those vectors that will provide for fully-inclusive communities at every level. It was to this end that the United Nations Convention on the Rights of Persons with Disabilities (CRPD)<sup>2</sup> was devised.

## **2 Convention on the Rights of Persons with Disabilities**

An examination of the CRPD reveals a set of criteria devised to address issues related to discrimination on the grounds of disability and the fundamental human rights of persons with disabilities the world over. What is immediately clear is that all these criteria assume that the starting point of any government or country is the goodwill and capacity of both the government and its citizens to implement the CRPD as effectively and efficiently as possible. However, such assumptions can be pragmatically challenging. For example, does the government in question have the political will to drive its effective implementation? Does the government have organisational and other structures to implement the CRPD, and are citizens well prepared for even a basic understanding, such as disability awareness, as outlined in the CRPD?

In the article, it is suggested that the issue of disability stigma often undermines the efforts of the CRPD and member states to the Convention.

## **3 The phenomenon of social stigma as an underlying contextual lens around Africans with disabilities**

In terms of barriers to the implementation of the CRPD, it is submitted that a fundamental concern, and of particular importance to Africa, relates to the notion of stigma and its *sequelae* in how Africans with disabilities are considered by their non-disabled peers. Indeed, stigma seems to be a fundamental underlying cause of discrimination against Africans with disabilities in most settings, transcending national, ethnic and political boundaries. This stigma has repeatedly been acknowledged as significantly impacting, for example, public health interventions. Thus, unless the idea of stigma and its real world consequences are examined and addressed, the

1 A Stone-MacDonald & G Butera 'Cultural beliefs and attitudes about disability in East Africa' (2014) 8 *Review of Disability Studies: An International Journal* 2.

2 United Nations Convention on the Rights of Persons with Disabilities (2008).

implementation of the CRPD is likely to be much less successful than where such stigma has been significantly weakened or eradicated.

### 3.1 Concept of stigma

The term 'stigma', originally from the Greek describing a physical marking to clearly identify societal undesirables, has a long and notable history in both philosophy and, more recently, in psychology and related research. In the modern sense, its progenitor may be traced to Durkheim, who identified stigma as a broad social phenomenon distinguishing between socially-acceptable and unacceptable behaviour.

In the modern era, unpacking the meanings and implications of stigma is usually ascribed to Goffman who, as others, saw stigma as a characteristic that was both an undesirable and discrediting factor to whom it was applied, thereby lowering the status of the person so labelled.<sup>3</sup> Or, in Goffman's words, stigma is

the phenomenon whereby an individual with an attribute which is deeply discredited by his/her society is rejected as a result of the attribute. Stigma is a process by which the reaction of others spoils normal identity.

Stated differently, 'stigma is a socially constructed reaction to deviance from an agreed-upon set of norms, and in the case of disability, is mediated by perceptions rather than functional limitations'.<sup>4</sup>

In my discussion, I use the framework of stigma as laid out by Link and Phelan<sup>5</sup> to explain the phenomenon, before turning to how stigma operates among the treatment of people with albinism in Tanzania, persons with leprosy in Nigeria, and general perceptions of disability in Kenya.

#### 3.1.1 Link and Phelan

Link and Phelan<sup>6</sup> define stigma as

the convergence of interrelated components. Thus stigma exists when elements of labelling, stereotyping separation, status loss, and discrimination occur together in a power situation that allows them.

3 M Heijnders & S van der Meij 'The fight against stigma: An overview of stigma-reduction strategies and interventions' (2006) 11 *Psychology, Health, and Medicine* 353.

4 CL Saetermoe, D Scatone & KH Kim 'Ethnicity and the stigma of disabilities' (2001) 16 *Psychology and Health* 699.

5 BG Link & JC Phelan 'Conceptualising stigma' (2001) 27 *Annual Review of Sociology* 363.

6 As above.

This definition also acknowledges that, depending on social contexts, stigma may be a matter of degree, ranging from mild to severe.

A brief explanation of these definitional concepts follows.

### ***Component 1: Labelling and differences***

The roots of stigma begin when people distinguish among and label human differences. However, not all differences are labelled equally; many are usually ignored as being socially irrelevant because these differences have little, if any, broader social consequence (for instance, a person's name). However, other differences are conspicuously labelled as socially significant (for instance, skin colour, sexual orientation), thereby leading to varied forms of social grouping based on perceptions of difference, usually negative. It is clear that social grouping requires, at the very least, significant generalisation of the labelled, even while ignoring obvious variability within the labelled group (for instance, consigning peoples' skin colour to 'black' or 'white'). Furthermore, social phenomena chosen for labelling and grouping vary according to place and time (for example, in the nineteenth century, small foreheads and large faces were regarded as ape-like and, therefore, likely represented someone with criminal proclivities). In sum, stigma generates negative labels that become affixed to a group of persons who over time are oppressed or ignored based on the designated negative label.

### ***Component 2: Associating human differences with negative attributes***

Here stigma is formed when labelled differences are tied to a set of undesirable characteristics that comprise a stereotype. Researchers have recently started to address the nature of underlying cognitive processes that support the use of categories and how these categories are connected to stereotypes. Findings have demonstrated that categories and stereotypes are often made by people in split-second and probably unconscious decisions which, at least initially, serve as 'shorthand' to pass judgments about the labelled group.

### ***Component 3: Separating 'us from 'them'***

The third component of stigma relates to its ability to separate groups of people into antagonistic categories of 'us' versus 'them'. Here, the abovementioned connection between stereotypes and undesirable characteristics becomes the justification for the perception that 'them' are so essentially different from the 'us' that the 'them' are completely different types of people almost entirely irreconcilable with the 'us'. This, in turn, raises the probability that 'them' are so qualitatively different from the 'us'

that they may not even be considered human, thereby justifying many ways of treating 'them' poorly or abusively.

#### ***Component 4: Status loss and discrimination***

As the sequence of components 1 to 3 accumulates, the labelled person or group begins to encounter a significant loss of social status and concomitant higher levels of discrimination. The targeted person or group will consequently be devalued, rejected, and even harmed physically, emotionally or psychologically. For example, this may lead to a significant reduction in the capacity of interacting with the labelling groups, resulting in the curtailment of basic human rights (for instance, the rights to freedom from harassment, to earning a living wage, to taking advantage of educational and other life-enhancing opportunities, and so forth). As would be expected, the previous components inevitably lead to a downward status spiral on any number of hierarchal continua. In sum, in the real world the loss of status generates very significant inequalities.

Following on from the abovementioned is the concept of discrimination. Labelling and stereotyping lead to overt discrimination against the labelled and stereotyped. Such discrimination is evident in various subcomponents, such as structural discrimination (that is, institutional discrimination via institutionally-accumulated practices that disadvantage the 'them' group even if individual discrimination is absent).

#### ***Component 5: Stigma and power***

As the overarching glue holding the concept of stigma together, Link and Phelan note further that stigma relies on social, economic and political power to achieve its stigmatising aims. Clearly, this power resides in the stigmatisers ('us') used against the stigmatised ('them'). Thus, what matters in terms of stigma is that the 'us' group's perceptions and actions prevail over the 'them' group in all aspects of private and public life. Inevitably, therefore, collateral damage to the stigmatised means that they are often unable to rectify discrimination because of their powerlessness.

We now turn to the notion of stigma and Africans with disabilities.

## **4 Impact of stigma on the lives of Africans with disabilities**

According to the United Nations (UN), there are approximately 85 to 90 million Africans with disabilities. Similarly, the World Health Organization (WHO) has broken down the overall prevalence, showing that approximately 40 per cent of Africans have disabilities, among whom 10 to 15 percent children of school-going age. Overall, therefore, there are

approximately 300 million African children with disabilities, almost all of whom are excluded from schools and other educational structures. Further, adults with disabilities are routinely excluded from proper (or any) employment, from social, political and economic life in general, and, by extension, excluded from being citizens fully participating in their communities. Furthermore, Africans with disabilities are much more likely than their non-disabled counterparts to suffer abuse, especially if they are disadvantaged in several ways (for instance by disability, being female, being a child, and so forth).

There are at least two foundational reasons undergirding the stigma of people with disabilities in Africa: First, there is a considerable lack of information regarding the causes of disabilities and their resulting characteristics. Second, the notion of including persons with disabilities as fully-participating citizens is anathema to the perceptions of many, if not most, Africans.<sup>7</sup>

#### **4.1 Cultural beliefs and values**

There is little doubt that across the continent, many cultural attitudes and beliefs negatively affect the way in which persons with disabilities are perceived, although positive perceptions are not unknown (for instance, among the Chagga in East Africa, those with physical handicaps are seen as pacifiers of evil spirits; in Benin those with physical handicaps are often selected as law enforcement personnel; the Turkana of Kenya perceive children with disabilities as a gift from God to be well taken care of, or else they risk the wrath of the deity). However, negative connotations attached to disabilities are likely to be much more prevalent. For example, in Ghana, Ashanti men with physical disabilities are prevented from becoming chiefs, and non-disabled chiefs can be destooled if they become disabled. Furthermore, children with visible disabilities are often killed or abandoned. In many African contexts, a child with a disability is perceived as a curse upon the whole family and a cause of shame and embarrassment. Other negative cultural beliefs connect disability to immoral behaviour by the mother or as punishment for immoral behaviour by other family members. Others attribute disability to a general sense of evil or otherworldly powers meting out disability as punishment for some perceived wrong or a generic sense that the cause of disability results from breaking social taboos (for instance, having sexual intercourse during pregnancy), witchcraft, magic, and other supernatural forces.<sup>7</sup>

7 AH Eideet et al 'Development process in Africa: Poverty, politics, and indigenous knowledge' (2014) 3 *African Journal of Disability* 1.

## 4.2 Disability and poverty

There is no doubt that disability and poverty are closely linked in a downward spiral trapping Africans with disabilities, especially females, children and young persons, in a web of hopelessness and despair. Indeed, almost half of all impairments of persons with disabilities are preventable and are linked directly to poverty.<sup>8</sup> This link can occur in several ways. For example, economic poverty may lead to poor or no medical care (either preventative or responsive) increasing maternal and child disease rates. Or, the very poor are likely not to have access to rehabilitative services or medical devices that may assist in ameliorating their condition (for instance, wheelchairs), and they are often perceived as an economic drag on their families and the community as because they require additional resources but are often unable to contribute to the economic common good. In this regard, children and the youth seem to suffer most in this regard. In terms of needed services, poor communities are often the least accessible, making the provision of even basic services challenging, if not impossible.

## 4.3 Education

Education is generally viewed as a pivotal aspect in raising social and economic status, and is exponentially more important to people with disabilities who are often shunned from the workforce for no other reason than the perception that their disability means that they are unable to perform as employees. The United Nations Educational, Scientific and Cultural Organisation (UNESCO) estimates that more than 90 percent of children with disabilities in the global south do not attend school, and of the 10 percent that do attend school, only half of these complete their primary education.<sup>9</sup> This state of affairs results in literacy rates for adults with disabilities at around 3 percent. This dismal state of affairs is even more starkly realised by the fact that children and young persons without disabilities have a two or three times the likelihood of attending school.<sup>10</sup>

## 4.4 Disability and gender

Given that in Africa stigma is not only associated with disability but gender, females who are disabled are doubly disadvantaged (and triply so if they are children or young persons) and are far more likely to be the victims of domestic and communal abuse and to live in extreme poverty than either their non-disabled peers or males with disabilities. Female

8 P Parnes et al 'Disability in low income countries: Issues and implications' (2009) 31 *Disability and Rehabilitation* 1170.

9 K Koszela 'The stigmatisation of disabilities in Africa and the developmental effects' (2013) *Independent Study Project Collection Paper* 1639.

10 Parnes et al (n 8 above).



infants with obvious disabilities are also more likely to be abandoned or killed at birth, and in many places they have higher mortality rates than their male counterparts. They are also employed at rates far lower than men with disabilities. These issues can be complicated, for example, by caring for a family member with a disability, a task almost always left to females of the household and the community.

#### **4.5 Employment**

Generally, the unemployment rates of Africans with disabilities are twice that of their non-disabled peers, and in developing countries approximately 80 per cent of people with disabilities are either unemployed or underemployed. Those who are fortunate enough to be employed often face discrimination, abuse and marginalisation by non-disabled colleagues and managers who believe that the employee with a disability is automatically less capable and less productive than non-disabled workers.

#### **4.6 Marginalisation, exclusion and discrimination**

Given the above vectors, it is not surprising that the vast majority of Africans with disabilities are marginalised, discriminated against, and almost always excluded from the societies and communities in which they live. This, of course, means that they are denied many of their basic human and legal rights and other, more pragmatic vectors, such as access to education, health care, full civic participation, and the denial of hope for a better life. For example, families having members with disabilities are viewed negatively and appear less accepted in their communities.<sup>11</sup> Acceptance may also depend on how well the individual with a disability is able to conform to the behavioural and ritualistic norms of the community, with more acceptance being granted to less impaired individuals and less acceptance being shown to persons with more severe disabilities. Marginalisation, exclusion and discrimination are obviously part of the everyday lives of Africans with disabilities. For example, in Kenya it is unlawful for people with visual or hearing problems to become President, as the Constitution stipulates that the President should read English and Kiswahili without Braille or sign language; deaf children in Uganda are often seen as burdens to their family and are consequently hidden from public view to avoid the shame and embarrassment that having such a child is likely to engender in the wider community.

Given the aforementioned, we now turn to three illustrative cases of stigma among Africans with disabilities, namely, (a) people with albinism

11 Stone-MacDonald & Butera (n 1 above).

in Tanzania; (b) persons with leprosy in Nigeria; and (c) general perceptions of disability in Kenya.

## 5 Illustrative examples related to persons with disabilities in Africa

### 5.1 People with albinism in Tanzania

Generally speaking, the stigma of albinism in Tanzania starts with the birth of the child who is evidently and immediately different, given that the parents are black and the child white.<sup>12</sup> In many African minds, the characteristics of albinism are believed to be caused, among others, by the mother having had an affair with a white person, having shaken hands with a person with albinism, or having shared a meal with someone with albinism.<sup>13</sup> Furthermore, albinism is often seen as a curse on the family and, in many instances, babies with albinism, especially among the Maasai, are either killed or abandoned to die. In other cultural communities, for example, the Digo of North Eastern Tanzania, babies with albinism are subjected to an elaborate 'death ritual' whereby an infant is dropped into a lake to see if it will survive, its subsequent death being proof of its sub-humanness.<sup>14</sup> Other misperceptions hold that persons with albinism are not human, but rather ghosts. Should people with albinism be allowed to live, they are often regarded as witches, the cultural belief being that the sun makes their eyes red. They are also often regarded as lazy as they avoid working in the heat of the day to protect their vulnerable skins from the sun. However, in some Tanzanian cultural communities (for instance, the Sekuma of North Western Tanzania), persons with albinism are allowed to grow to adulthood, some of whom are then designated to be buried alive with a deceased Sekuma chief.<sup>15</sup>

The maltreatment of Tanzanians with albinism garnered international attention in 2008 with high-profile international reports that these people were being killed or maimed for various body parts ostensibly to be used for good luck charms or as ingredients in potions thought to have magical qualities. However, the killing of Tanzanians with albinism started earlier, in October 2006, in and around the city of Mwanza on the shores of Lake

12 M Thuku 'Myths, discrimination, and the call for special rights for persons with albinism in sub-Saharan Africa' (2011) *Under the Same Sun* 3.

13 AE Cruz-Inigo 'Albinism in Africa: Stigma, slaughter and awareness campaigns' (2011) *29 Dermatologic Clinics* 79.

14 Under the Same Sun 'History of attacks against persons with albinism' (2013) (PWA) <http://www.underthesamesun.com/sites/default/files/History%20of%20Attack%20against%20PWA.pdf> (accessed 25 August 2015).

15 Under the Same Sun (n 14 above).

Victoria. It is also worth noting that this region of Tanzania has the highest *percapita* number of witchdoctors in the country.<sup>16</sup>

By 2008, the spate of killings had finally reached proportions that could not be ignored by the nation. The Tanzanian government scrambled to deal with the problem once its extent had become known and in response to pressure from the international community. In a significant symbol of solidarity with Tanzanians with albinism, President Kikwete appointed a woman with albinism, Al-Shymaa John Kwegyir, to the National Parliament as a way of raising awareness of the albinism problem and to give Tanzanians with albinism a political voice at the highest level. Furthermore, in January 2009, Kikwete's government, in an attempt to end further killings, banned all traditional healers and witchdoctors from practising their trade. This last gesture, well-meaning as it was, was difficult to enforce given that traditional beliefs and perceptions around albinism were (and are) so deeply entrenched in the communal psyche. Subsequent to the banning of witchdoctors, the Tanzanian government declared the killing of persons with albinism a capital crime.<sup>17</sup>

It is worth noting that the targeting of Tanzanians with albinism focuses on an already-marginalised and excluded group whose isolation makes it easier for them to be the targets of mutilation and killing. This exacerbates an already dire set of circumstances for this population which encompasses, among others, (a) serious health issues, especially related to sun exposure and skin cancer; (b) their voluntary or involuntary withdrawal from the community as a result of ostracism or as a result of psychological or physical abuse; (c) a concomitant sense of low self-worth and a deep sense that society devalues them; (d) discrimination against their family and friends for being associated with the person with albinism; (e) the inability to participate fully (or even partially) in broader social settings; (f) a denial of the right to marry; (g) discrimination in employment; and (h) a concomitant denial of their most basic human, educational and legal rights.

## **5.2 Persons with leprosy in Nigeria**

The stigma attached to leprosy remains a global phenomenon, especially in the developing world. In many countries, stigmatising attitudes towards persons with leprosy are as high as 80 percent of the general population. Significantly, the literature in this area also reveals that, while there is often a high level of understanding of the real causes of and treatment for leprosy, this understanding does not necessarily correlate with more

16 CP Dave-Odigie 'Albino killings in Tanzania: Implications for security' (2010) 3 *Peace Studies Journal* 68.

17 S Bucaro 'A black market for magical bones: The current plight of East African albinos' (2010) 15 *Public Interest Law Reporter* 131.

positive attitudes towards and acceptance of those who have the disease. There are generally four mediating factors related to the fear of leprosy, namely, (a) visible deformities; (b) perceived incurability and chronic course of the disease; (c) perceived infectiousness; and (d) perceived 'bad origin of disease'. Furthermore, given the fact that leprosy is also a 'visible' disease, it follows that persons with leprosy are among the groups most likely to self-isolate and to be reluctant to seek treatment for the condition.<sup>18</sup>

As in the case of stigma attached to albinism in Tanzania, the stigma attached to leprosy in Nigeria reveals similar areas of misperception, oppression, and a denial of human rights. While many Nigerians reveal a greater or lesser accurate view of leprosy and its causes, the stigma attached to leprosy is still undergirded by traditional negative beliefs. For example, some Nigerians believe that leprosy is caused by supernatural forces or as a result of a witchcraft curse preempted by the breaking of some form of social taboo (for instance, having sex with a menstruating female). Other negative perceptions of leprosy include reduced chances of marrying someone with leprosy or increased divorce rates when a spouse contracts the disease, or the perception that the condition is hereditary. Furthermore, the very nature of the disease, especially in more advanced cases, engenders prejudicial perceptions and reinforces the notion not only of 'us versus them', but also that those with leprosy are less than human and are to be shunned in any number of ways. Perhaps the greatest fall-out here is that persons with leprosy might delay seeking medical treatment, having self-isolated due to their diminished social and human status.

A significant finding related to stigma and leprosy is related to how the disease is viewed among different religious groups in Nigeria. For example, there is evidence that the stigma attached to leprosy is higher among Nigerian Christians who generally perceive leprosy as a punishment for sin, and lower among Muslims who accept leprosy as being part of God's will. Further, as with many medical and other disabilities, the stigma attached to leprosy is not limited to the person with the disease, but is often extended to the entire family, thereby further complicating social status within the community.

As may be expected, general attitudes towards Nigerians with leprosy means

devaluation, distancing hatred, rejection by family, exclusion, and labelling ... [and] fear was often found to be the root of these negative attitudes, eg, fear of exposure to the disease, fear of being infected, fear of association with a person affected by leprosy.

18 ML Wong 'Designing programmes to address stigma in leprosy: Issues and challenges' (2004) 15 *Asia Pacific Disability Rehabilitation Journal* 3.

This leads to a wide array of missed opportunities, especially those related to (a) acquiring life and employment skills; (b) employment; (c) participation in family and community life; (d) access to preventative and treatment healthcare; (e) access to and participation in educational pursuits; and (f) rejection by the family and the wider community; and so forth.<sup>19</sup>

### **5.3 General perceptions of disability in Kenya**

Approximately 10 percent of the Kenyan population embodies some form of disability.<sup>20</sup> Of this number, approximately 25 percent are children of school-going age, accounting for fully one-third of all out-of-school children. This translates into of the estimated total special needs school age population of 750 000, while only approximately 90 000 have been assessed as in need of special education.<sup>21</sup> Furthermore, this means that only 5 percent of children with disabilities are enrolled in educational institutions.<sup>22</sup> This state of affairs is further complicated by the fact that, while some special education is offered via private schools, this is expensive and, therefore, usually not available to the average Kenyan. If special education is offered at public institutions, it is more likely to be found in urban areas, meaning that children with special needs have to be boarded, making even state education prohibitively expensive. This also raises another barrier to access as many children with disabilities are unable, due to their disability, to travel long distances to get to their schools, and even if they are able to do so, there is no guarantee that the school will be able to provide the necessary physical and educational accommodation. Another complicating factor arises when parents have to decide, due to financial and other constraints, in which child they should invest with whatever education is available. Predictably, this usually means that a child with disabilities is not designated for formal education.

In terms of the entire Kenyan population with disabilities, there are no accurate statistics gauging the extent of disabilities and, therefore, how they might be supported, but an approximation indicates that the special needs population is approximately 3.5 million people countrywide. The absence of accurate census efforts, especially in remote areas, is severely problematic.

19 WH van Brakel & BM Galarza 'Infectious diseases: A case study of leprosy-related stigma' (2013) *American Psychological Association* 139.

20 B Ingstad & L Grut 'See me, and do not forget me: People with disabilities in Kenya' (2007) SINTEF Health Research.

21 K Matua & BB Swadener 'Semiotics of disability in Kenya: The convergence of culture and post-coloniality' (2013) 5 *PowerPlay: A Journal of Educational Justice* 518.

22 NA Hsieh 'Of curses and cows: Barriers to the realisation of special needs education in Kenyan Maasai communities' (2015) <http://www.bluekitabu.org/bluekitaburesearch-institut/nathaniel-hsieh-maasai-spec.pdf> (accessed 13 August 2105).

As is the case with albinism and leprosy, disability in general in Kenya is viewed as being caused by any number of negative forces. For example, many Kenyans believe that a disability is a curse from a supernatural or mysterious otherworldly force,<sup>23</sup> or as a result of witchcraft spells placed either upon the family or the individual with disabilities.<sup>24</sup> In the larger social context, there is the widespread belief that taboo activities, such as adultery or incest, can result in a child born with disabilities. In addition, traditional medicine practices hold, for example, that incorrect or no 'massaging' of an infant at birth is likely to result in ill health. Others believe that disability is simply the deliberate plan of an unseen deity. Also, there is the widespread belief that disability can result from some broken taboo by the mother (for instance, eating eggs during pregnancy) or by other closely-related family members.<sup>25</sup> Some beliefs resulting in stigma are even more specific: For example, among the Nandi, killing an animal without provocation during a wife's pregnancy is believed to cause disability in the newborn child, while among the Abagusii, children born with cleft palates are thought to be the result of parents making fun of someone with a disability.<sup>26</sup> However, it must also be noted that, as is the case in Tanzania and Nigeria, not all traditional beliefs are negative. For example, many families of children with disabilities take good care of these children and do all they can to advocate for their rights in the family and the community. Furthermore, in many instances, people with disabilities are allowed to take part in important ritual events, which in turn increases social standing in the community. In other communities, it is the disability itself that ensures that the community cares for and values the person with disabilities. For example, certain tribes believe that a person with a disability is the sacrificial lamb to evil spirits, and that taking care of said person ensures that no other evil will befall the community. Others, such as the Turkana, believe that children with disabilities are actually a gift from God and that they should be well taken care of to avoid the wrath of the supernatural for not taking care of their disabled charges.<sup>27</sup>

Other Kenyans believe that disability is a punishment meted out to the parents of children with a disability. In this regard, studies conducted among the Maasai reveal that mothers often see their children with disabilities as defective and have been known to expose their infants to harsh conditions to precipitate their demise.<sup>28</sup> Other stigmas are attached to both family and community perceptions of disability. For example, a

23 NO Ogechi & SJ Ruto 'Portrayal of disability through personal names and proverbs in Kenya: Evidence from Ekegusii and Nandi (2002) 3 *Wiener Zeitschrift für Kritische Afrikastudien* 63.

24 J Monk & J Wee 'Factors shaping attitudes towards physical disability and availability of rehabilitative support systems for disabled persons in rural Kenya'(2008) 29 *Asian Pacific Disability and Rehabilitative Journal* 93.

25 As above.

26 Ogechi & Ruto (n 23 above).

27 Stone-MacDonald & Butera (n 1 above).

28 Hsieh (n 22 above).

person with a disability is often viewed as less able to contribute to the greater economic good of the family and community. Such persons are, therefore, not only seen as a financial and resource liability internally, but also by the larger community, resulting in the shaming of the family with a member with disabilities and a concomitant probability that the family member with a disability is kept isolated from the larger community based on shame and loss of social status. This is reflected in surveys of Kenyans with disabilities who feel discriminated against within their own families and by the wider society.

As noted above, such levels of stigma seriously affect Kenyans with disabilities to fulfil their human potential and to fully participate as citizens of their country, similar to the state of affairs found in Tanzania and Nigeria.<sup>29</sup>

Given the conditions related to the stigmatisation of people with disabilities in Tanzania (albinism), Nigeria (leprosy) and Kenya (general disability issues), it is imperative that strategies be developed to mitigate the considerable influence of stigma.

## **6 Ways forward to more effective implementation of the CRPD in Africa**

The CRPD provides an extraordinarily clear blueprint for addressing the needs of persons with disabilities worldwide. However, the CRPD is likely to be ineffective if it cannot be implemented to its fullest degree because of barriers to its implementation, in this case, the formidable barrier of stigma attached to disability across the entire African continent. In this part of the discussion, I examine the shaping and development of macro- to micro-forces necessary to eliminate the stigma surrounding disability and in its place to generate the willingness not only of African governments, but among Africans themselves, to more fully accept and include people with disabilities.

Heijnders and Van der Meij<sup>30</sup> provide a useful analytical framework of stigma-reduction strategies at several levels from micro to macro: (a) intrapersonal (treatment, counselling, cognitive-behavioural therapy; empowerment; group counselling; self-help; advocacy; and support groups); (b) interpersonal (care and support; home care teams; community-based rehabilitation); (c) organisational/instructional (training programmes; revised policies); (d) community (education; contact; advocacy; protest); (e) governmental/structural (legal/policy interventions; rights-based approaches).

29 Ingstad & Grut(n 24 above).

30 Heijnders & Van der Meij (n 3 above).

## **6.1 Intrapersonal level interventions**

At this level, the primary focus is on changing individual behaviour via knowledge, encouraging more positive self-perceptions, personal empowerment, and economic support to reinforce and maintain positive attitudes and behaviour. The literature in this regard is mixed as to efficacy, with some studies reporting efficacy under certain conditions, while other studies indicate limited efficacy overall. Self-help, advocacy and support groups seek to provide support among people with disabilities to develop positive self-identity, self-esteem, and an array of coping skills. As with other aspects, the literature in this area is very limited, but generally tends to indicate that these interventions are effective, at least to some extent.

## **6.2 Interpersonal level interventions**

Here the idea is to modify the environment in which people with disabilities reside, especially in terms of the impact of social support and networks on health status and behaviour. For care and support, generally assumed to be positive and helpful, there is some research indicating that people receiving such care and support may actually run the risk of emphasising the negative aspects of disability. Home care teams are generally viewed as helpful, especially in terms of modifying positive behaviour towards the person with a disability being cared for. However, there is no research specifically establishing efficacy or inefficacy of the home care team idea. Community-based rehabilitation uses community development to rehabilitate and equalise opportunities for the social integration of people with disabilities. Again, the research literature here is scant with only vague indications that community-based rehabilitation engenders positive outcomes for people with disabilities.

## **6.3 Community level**

Here the aim is to increase knowledge related to specific disability conditions and to address stigma within specific community groups. Education is usually the first strategy, singly or in combination with other strategies, to reduce the stigma attached to disability. Clearly, 'educational strategies' cover a wide variety of approaches and the literature here, as in other areas where literature exists, reveals mixed efficacy results. In addition, the notion of contact refers to encouraging positive interactions between the public and persons with disabilities at the point of contact to reduce the stigma attached to disability. The limited literature here shows some positive findings, while also noting that there are some dangers involved; for example, that disclosing one's disability status could have negative follow-on effects. Advocacy programmes and strategies seek to promote the rights of persons with disabilities at the national and



governmental level by advocating changing laws and policies that are unfavourable to persons with disabilities. Apparently there is no literature that has examined the effects of advocacy at this level. Finally, the idea of protest is to actively suppress disability stigma of individuals, groups, and organisations/governments by peaceful protest and public opposition to these stigmas. There is no literature addressing protest efficacy in improving the lot of persons with disabilities.

#### **6.4 Governmental/structural level**

Here strategies are aimed at intervening in the legal and policy arenas to concomitantly reduce discrimination against and oppression of persons with disabilities while increasing the enforcement of the legal and human rights of people with disabilities. The literature here does not address issues of efficacy. Aside from these general areas, which appear to be empirically unsupported, several other steps forward are suggested to reduce disability stigma and increase the chances of the effective implementation of the CRPD.

#### **6.5 Obligation of African governments**

The coming into being of the CRPD was, rightfully, hailed as a major international advance in addressing the plight of the billion or so people with disabilities worldwide. Many governments, including those in Africa, were eager to ratify the Convention as a very visible and tangible gesture to their citizens with disabilities and to demonstrate their solid commitment to improving the lives of these citizens. This is reflected in the actions of Tanzania, Nigeria, and Kenya, all of whom have ratified the Convention and its Protocol.

However, ratifying these important documents is only the very first step towards the implementation of the CRPD, a task that is complicated in Africa by the restraints of inadequate resources, poor organisational structures and, perhaps, the lack of sheer political and humanitarian will of governments to address the issue.<sup>31</sup> In other words, signing the CRPD does not automatically guarantee full or even partial implementation. Furthermore, even the most vigorous attempts at implementing the CRPD are likely to be significantly muted when they run up against the spectre of disability stigma, because no matter the efficacy of implementation, these attempts will largely be wasted in a social milieu that views persons with disabilities as at best an underclass and, at worst, worthy of abuse or death. Clearly, without the full force of each government's inclination to prioritise the issue of stigma reduction, the implementation of the CRPD is likely to be uneven or even impossible. While there is little doubt that addressing

31 Koszela (n 9 above).

the issue of stigma is a grassroots challenge, it must be acknowledged that governments wield tremendous power that can make a very real difference at all levels of society. Perhaps the most notable recent example of this is the very successful ABC/AIDS reduction strategy in Uganda.<sup>32</sup> Each government must address and incorporate important external aspects to support implementation by working closely with national and regional disability organisations and non-governmental organisations (NGOs) who are in the frontlines in confronting stigma, as well as with international bodies, such as the UN CRPD Secretariat, UNESCO, the WHO, the World Bank, and so forth.<sup>33</sup>

Finally, the above critique does not imply that African governments are uniformly neglectful of their citizens with disabilities, but argues that, at whatever level of support and assistance governments are already providing, much remains to be done at almost every level.

## 6.6 Educational programmes to alleviate stigma

There is little doubt that educational programmes to erase stigma attached to disabilities must take into account as a first premise the role of cultural perceptions, beliefs, values, and actions that feed the disability stigma in the first place, and how these vectors influence the course of programmatic goals and objectives,<sup>34</sup> and that stigma-reduction educational programmes must be carefully matched to the unique culture, community, and mindset of the population to which it is applied.

Of particular interest here is building a corpus of research around effective and empirically-tested knowledge-based strategies, that is, strategies that provide a major pushback against disability stigma, replacing them with empirically-based knowledge. However, this is easier said than done. For example, in Nigeria, once medical interventions proved highly effective in treating and preventing leprosy, it was assumed that the stigma surrounding the disease and those who carried it would diminish. However, this turned out not to be the case. Similarly, 'health education' efforts – educating people about the true medical causes and *sequelae* of disease – did not necessarily translate into lower levels of stigma, most certainly because these campaigns were either too generic or failed to take into account local social and normative nuances in the communities in which they were introduced.<sup>35</sup>

32 EM Murphy et al 'Was the "ABC" approach (abstinence, being faithful, using condoms) responsible for Uganda's decline in HIV?' (2006) 3 *PLOS Medicine* 1443.

33 Koszela (n 9 above).

34 Stone-MacDonald & Butera (n 1 above).

35 Z Gussow & GS Tracy 'Stigma and the leprosy phenomenon: The social history of a disease in the nineteenth and twentieth centuries' (1970) 44 *Bulletin of the History of Medicine* 425.

There are other documented examples of well-meaning but ultimately unsuccessful strategies related to disability. For example, the historic use of a biomedical approach of 'early detection and cure' (or management of the disability) was not successful in many areas, probably, as noted above, because it did not take into account cultural factors related to stigma and disability.<sup>36</sup> Another example holds that in developing countries, including Africa, many health professionals hold negative, stereotypical and mythical views of disability despite their medical training. Such negative biases mean that those with a disease, especially in more advanced and visible stages, may be turned away from hospitals and clinics, or subjected to insensitive treatment.

Other sigma-reduction strategies include, for example, (a) encouraging and using non-discriminatory language, beginning with people-first language (person with a disability versus a disabled person, and so forth); (b) integrating services for people with disabilities into the general health care system rather than having these services in separate (and often unequal) settings; (c) encouraging the mass media to provide less negatively-biased and sensational reports about persons with disabilities; (d) teaching self-advocacy skills to people with disabilities; (e) changing negative language to more positive and accurate representations (for instance, changing the term 'leprosy' to its medical term 'Hansen's disease'); (f) providing medical and psychosocial counselling to people with disabilities to increase their self-help and self-advocacy skills; (g) conducting emancipatory research (that is, encouraging people with disabilities to have more prominent roles in the research process); (h) integrating disability awareness into all public institutions (for instance, schools, government departments, the public health sector, and so forth); and (i) encouraging community self-support groups, and so on.

Overall, however, there is very little empirical research evaluating the many programmes assumed to reduce the stigma attached to disability in Africa and even less attention being paid to identifying gaps in this rather meagre database.<sup>37</sup>

## **6.7 Non-governmental organisations and other grassroots organisations**

Historically, church missionaries and religious institutions, later working alongside NGOs at the eradication of the stigma attached to disability, have dominated services and support for Africans with disabilities. However, these well-meaning efforts were often seen as not taking full account of local perceptions, beliefs and communal knowledge of

36 Van Brakel & Galarza (n 19 above).

37 Wong (n 18 above).

disability, a first step to starting a conversation that will eventually reduce disability stigma.

## **6.8 Need for more empirical research**

There is a need for more empirical research around disability stigma across a wide array of topics (for instance, research about the impact of traditional beliefs and stigma; conducting censuses for establishing an accurate picture of the extent of disability countrywide; research on the extent of resources for every aspect of every disability; the connection between illness and attached stigmas; physical versus intellectual disabilities; mild versus severe disabilities; the bi-directional relationship between disability and poverty, and so forth) in every African country. Generally, the research base is scattered and unfocused, although pockets of fairly deep research do exist (for example, research related to specific diseases causing medical and other disabilities; research on certain social aspects of disease and disability). Perhaps of immediate concern is the fact that there is very little or no research related to the stigmatisers, the available literature being overwhelmingly in favour of studying the victims of stigmatisation. Additionally, there needs to be an emphasis on a holistic research approach to stigma reduction which incorporates relevant theoretical, behavioural, psychosocial, and cultural models as a means of providing a comprehensive framework for deeper investigations.

Building empirical research databases will have the cumulative effect of providing meta-answers to vexing problems in the area of disabilities and is also entirely necessary in order to form the undergirding sound base upon which national policy can be devised, articulated and implemented.

In terms of research design, given the heavily embedded nature of stigma attached to disability, a combination of quantitative and qualitative approaches seems best, as well as the incorporation of a transdisciplinary approach to examine stigma from a variety of interconnected methods and disciplines. Furthermore, qualitative and other ethnographic approaches may best be suited to the uncovering of deep understandings of stereotypical perceptions and attitudes, their contribution to disability stigma, and in explaining the complex interactions at work psychologically, emotionally and intellectually among both the stigmatised and stigmatisers. In terms of quantitative research, there is a significant need for randomised controlled trials to establish which stigma-reduction strategies work better than others and also to establish the validity and reliability of any formal assessment quantitative instruments.

## **6.9 Advocacy**

By definition, the stigma attached to persons with disabilities means that they are invariably seen as having a low or no social status. Clearly, the full

participation in civic life is a major path towards empowerment and higher social status. Perhaps the most effective way of enhancing social status and fuller inclusion in society is the ability of disability advocates, persons with disabilities themselves and their organisations to advocate for their unqualified inclusion at all levels of society. Over time, such advocacy will allow these entities to gain and build on political power to the point that they will have a national influence on those who are able to provide support and resources for those with disabilities, including their governments and international entities offering such support.<sup>38</sup>

Such advocacy, of course, is only attained incrementally and is especially taxing among Africans with disabilities who have, over the course of their lifetime, been socialised into accepting their lowly lot in life and who often do not possess the requisite tools to make the transition from being oppressed and downtrodden to being empowered and politically influential. That said, there are encouraging signs that the advocacy movement continues to grow and is ever more vocal in the demands for equals rights, treatment, and societal participation (for instance, the Secretariat of the African Decade of Persons with Disabilities (SADPD), the Southern African Federation of the Disabled (SAFOD), and Disabled People's Organisations (DPOs), etc).<sup>39</sup>

## **6.10 Socio-economic rehabilitation**

Africans with disabilities are almost always among the most poverty-stricken in society, because they are discriminated against, ostracised, denied entry or advancement in the workforce and, generally, have to rely for survival on the kindness of others or on begging. Socio-economic rehabilitation refers to the notion of people with disabilities, or those generally in poverty, becoming empowered enough to engage in economic activity that enhances their lives and allows them to provide for themselves and even for others. This, in turn, boosts self-esteem, a goal-directed sense of self-efficacy, and reciprocally enhances the status of the person with a disability among non-disabled members of the community.

## **6.11 Collaborating with religious leaders**

Van Bakel and Galarza<sup>40</sup> suggest that another avenue for combating disability-related stigma is to collaborate with religious leaders in the community, given that these leaders usually have significant standing in their communities and, therefore, may well be able to influence and change social attitudes towards persons with disabilities. While it is true

38 Koszela (n 9 above).

39 Ingstad & Grut (n 35 above)

40 Van Brakel & Galarza (n 19 above).

that some religious leaders may reinforce negative disability stereotypes, particularly related to the causes of disability, it is equally true that these leaders can promulgate positive attitudes (for instance from biblical or Koranic texts) and valid information related to disabilities to end many of the myths surrounding disability. Equally, concerted efforts must be made to reduce the influence of traditional healers and witchdoctors who perpetuate damaging myths, stereotypes and fear of disability by all means possible.<sup>41</sup>

## 7 Conclusion

The CRPD is a significant and progressive set of ideas, strategies and policies that, if properly implemented, are likely to immeasurably improve the lives of Africans with disabilities across the continent. However, no matter how well-meaning implementation plans might be, they may be derailed by the very real, entrenched and change-resistant phenomenon of stigma. Given that stigma, either overtly or covertly, underlies and forms perceptions about Africans with disabilities, it must, as a matter of course, be significantly reduced or completely eliminated as a precursor to the implementation of the CRPD. Clearly, with most African governments already having ratified the CRPD and, therefore, already obligated to implement the CRPD in the coming years, they will face considerable challenges in doing so, given that reducing stigma has largely not been addressed. Furthermore, a careful examination of extant strategies designed to reduce stigma reveals that these are, at best, partially effective, ineffective, or devoid of enough empirical evidence to make solid decisions as to which strategies should be used and which should be discarded.

41 Under the Same Sun (n 14 above).