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The Stigmatization of Disabilities in Africa and the Developmental Effects

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The Stigmatization of Disabilities in Africa and the Developmental Effects

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Summer 2013

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Abstract

Stigmatization still exists in large scale and leads to exclusion and continued poverty and poor standard of life for persons with disabilities, especially for those living in Africa. The main cause of stigmatization in Africa is a lack of education about disabilities and the needs of persons with disabilities. The unknown creates fear in society and exclusion for persons with disabilities, prohibiting them from obtaining decent education, proper health care and having access to jobs and financial support. Since the Convention for the Rights of Disabled Persons (CRPD) in 2006 societal education has been supplemented by implementation of development programs as a means of inclusion in education, health and employment programs, but there is still a ways to go. There is a gap between many countries’ ratification of the CRPD and execution of these programs. Those who are working for inclusion are primarily specialized organizations and NGOs. Issues faced by persons with disabilities need to be mainstreamed for true change to occur. This comes in the form of the Post 2015 Millennium Development Goals, which still do not fully acknowledge the marginalization of persons with disabilities. The focus needs to be on specific programs and assessments and better coordination between international and national governments.
Preface

I came to choose this topic because of my experience in Patriensa, Ghana two summers ago. While I was there I became aware of the stigmatization and taboo nature of discussion regarding persons with disabilities. It broke my heart to see the neglected care and misunderstood nature of these people. They were left to fend for themselves with little aid from communities or governments. While Ghana is not exclusive in these practices, and persons with disabilities face discrimination and hardships in many parts of the world, there is very little research done so far regarding the numbers of disabled and programs focusing on persons with disabilities for those living in Africa except in South Africa due to lack of funding. As an area with a particular interest for Millennium Development Goals due to the high levels of poverty compared to many other areas of the world, this paper is written to bring special attention to these people.
Acknowledgements

This paper has been an incredible opportunity to explore a topic of interest and expand my knowledge of international development. Many thanks are due as part of this opportunity. First off I want to thank Dr. Gyula Csurgai and Dr. Alexandre Lambert from the School of International Training for organizing this program and guiding me along the way. I would also like the thank Professor Leigh Linden at the University of Texas at Austin for the beginning of my formal education in Development Economics, the seed that allowed for the growth of this topic. It is essential that I also thank all of the interviewees for their expertise and input in this paper. Finally I would like to thank the friends and colleagues I have made in this program for their moral support and motivation. And particularly, thank you to my mom for her unconditional support and provision in making my dreams a reality, for sending me on this program and allowing me to follow my big ambitions.
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Introduction

Why Important

15 percent of the world’s population experience some form of disability and 1/5 of these people experience a significant disability, an estimated total of 110-190 million people.\(^1\) When this statistic is paired with the blatant status of poverty 1.94 billion people or 22 percent of those living in developing countries already face\(^2\), persons with disabilities in developing countries are condemned to unrelenting difficulties and a poorer quality of life. They are more likely to have poorer health, experience poverty, less education, fewer employment opportunities and higher rates of abuse than those without disabilities.\(^3\) For a world whose international community has become increasingly dedicated to aiding the hurting and marginalized with the spread of globalization, ignorance towards the adversities faced by persons with disabilities is a gross injustice.

In 2006, the Convention on the Rights of Persons with Disabilities (CRPD) was proposed as a legal framework to defend and reinforce the human rights for people with disabilities. The CRPD aims to promote advocacy and awareness of the struggles faced by persons with disabilities and foster the implementation of integration and inclusion programs for countries. Even though many countries have ratified the CRPD, there is still a gap in the implementation process of programs to facilitate inclusion and reentry into society by persons with disabilities. Solutions for the needs of persons with

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disabilities cannot be delayed any further in light of the impending Post 2015 Millennium Development Agenda. If poverty is to truly be eradicated worldwide and the achievement of the goals laid out in the current Millennium Development document is to be accomplished, persons with disabilities must be included; an entire group of people cannot be excluded.

Key Research Questions and Paper Objective

The intention of this paper is to shed more light on the struggles faced by persons with disabilities in Africa due to stigmatization and exclusion and to advocate for stronger inclusion of persons with disabilities within society and the international development sector. Publications by various NGOs and United Nation Associated organizations, such as CBM, UNICEF, World Bank and International Disability Alliance have been detailed a similar theme, but have not focused on persons with disabilities in Eastern and Central Africa in relation to stigmatization. Through interviewing experts in the field of disability and development and extensive researching, this report is designed to assess why stigmas are present for persons with disabilities and the adverse developmental effects they have in two key development areas, education and employment. This paper does not aim to say that these are the only two areas of difficulty for persons with disabilities, because the challenges extend much further, but for brevity and focus, a brief overview of programs in compliance with CRPD in each of these two key development areas is given. Each of these programs are essential for the genuine inclusion of persons with disabilities if they are to receive their full human rights and are designed to allow persons with disabilities the chance to escape the marginalization that they have been subjected to up to now. This paper concludes with a look at the remaining issues and proposes recommended solutions for further inclusion of persons with disabilities and better overall international
development as the enhancement of the Millennium Development Goals approaches in
2015.

**Disabilities in Africa**

*Stigmas*

“Prejudices held by society, family and individuals can act as a barrier to people with
disabilities exercising their right to full participation in society” ⁴ Stigmas against
children with disabilities come from two main components: lack of information regarding
what causes disabilities and what a child can achieve with a disability⁵. First, lack of
information creates a barrier in society. Often times blame is placed on the mothers for
having a child with disabilities, but in reality impairments can be caused by poor
maternal health or a lack of services for mothers during pregnancy. For example, Amber
Rosier from AbleChildAfrica said that in East Africa she heard many times that a woman
gave birth to a disabled child because she ate snakes during pregnancy, an odd myth
given that there aren’t many snakes in East Africa. Religion also plays a role in the
interpretation of what it means for a child to have a disability. Depending on the region
and type of disability in Africa, children with disabilities are either seen as a gift or a
punishment from God for doing something evil during pregnancy. Epilepsy for example,
can be construed as the child being possessed or part of a divine intervention in many
East African countries. In a study conducted by CBM, “70% of people [in Nigeria]
believe mental disabilities are caused by evil spirits.” ⁶ Many people do not believe that
psychosocial disorders are like every other illness. In the same study conducted by CBM

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⁶ Emeka Nwefoh Chinweuba. CBM. Personal Interview. (July 14, 2013).
it was concluded that, “60% of people believe that persons with mental disabilities cannot be treated medically, they need to be treated by pastors.”

Secondly, many disabled children are hidden away and kept in the house because of the stigmas that are placed on them and the embarrassment or harassment that may be shown to the mother, so societies have very little experience and few examples of what children with disabilities are able to accomplish, leading them to assume they are incapable and therefore should not be included.

Discrimination and Exclusion
Stigmatization of persons with disabilities leads to exclusion from society and as a result ostracism of persons with disabilities from developmental programs that have the intention of betterment of a person’s quality of life and future. “Inequalities not only lead to their exclusion and discrimination, but combined with the general absence of social protection measures, almost unavoidably lead persons with disabilities (and their families) to situations of poverty and extreme poverty, which can even result in risk to their lives”. This leads to a perpetuation of exclusion and lack of access to fundamental developmental services, causing greater vulnerability and reinforcing the cycle of poverty.

Discrimination and marginalization of children with disabilities does not intrinsically come from the fact that they have a disability but because society does not understand that disability the result is fear and lack of accessibility. “Inequalities faced by persons

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7 Emeka Nwefoh Chinweuba. CBM. Personal Interview. (July 14, 2013).
with disabilities result from a large number of barriers, including physical and institutional communicational barriers as well as attitudinal barriers and stigma, which often lead to persons with disabilities being invisible and considered as unable to participate in society, and in particular in decision-making processes.”  

The main problem is the invisibility process. Societies are not used to having relationships with persons with disabilities; they do not know how to interact with them so many communities of people feign that persons with disabilities do not exist and act as if there is not enough space for persons with and without disabilities to live together.  

Alleviating the gap between programs for children with disabilities and programs for children without disabilities is a matter of political as well as community will. Communities play a key role in helping these children. The trouble with a child being isolated due to fear of the unknown and lack of education in society about what causes a disability is that the child is prohibited from peer influence, and denied in part the chance for progression.  

The Need to Educate Communities about Disabilities  
Before progressing further in the argument of this paper it is essential to note that education about disabilities is the key if progress and development is to be made. Education for communities regarding what causes disabilities and the rights and needs of persons with disabilities is crucial for the elimination of stigmas and inclusion in society of persons with disabilities. Stigmas are created out of a lack of understanding; by addressing the knowledge gap and helping all people to have a better understanding about disabilities persons with disabilities are in effect more likely to be accepted. As a means 

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11 IDA Secretariat Staff Member. International Disability Alliance. Personal Interview. (July 16, 2013).
of educating communities about disabilities to reduce stigmas and exclusion from life improving programs, people, in particular children, with disabilities must be given a chance, otherwise the invisibility cloak they are currently under will remain secured and no progress will be made. “Only by showcasing benefits of kids, what they can achieve, will change occur.”\textsuperscript{13} This is the foundational mentality behind all of the inclusion programs and policies laid out in the remainder of this paper.

\textit{Theoretical Framework}

In conjunction with awareness education and inclusion programs, advocacy at the political level is necessary to effectively remove the marginalization of persons with disabilities. The international goal of poverty eradication and greater development worldwide requires governmental cooperation and voice. There are four models for understanding disability within the international community:\textsuperscript{14}

- **Charity Model**—people with disabilities are viewed as objects in need of charity; they are seen as victims without the capabilities to help themselves
- **Medical Model**—people with disabilities are seen as patients in need of curing; they are seen as broken in need of fixing
- **Social Model**—states that the problem is a disabling society, that people are disabled not by their own impairments but by attitudinal (fear influenced by lack of understanding and religion), environmental (lack of accessibility) and institutional (exclusion from legal rights) barriers; the social model proposes education and awareness, access and rehabilitation into society

\textsuperscript{13} Amber Rosier. AbleChildAfrica. Personal Interview. (July 12, 2013).
• **Rights-Based Model**—emphasizes the lack of equality and opportunities for participation for persons with disabilities as the disabling factor not solely their impairments; advocates for empowerment of persons with disabilities through the right to health care, education and employment and accountability of institutions to legally and socially implement these rights

According to the International Classification of Impairments, Disabilities and Handicaps (ICIDH) generated by the WHO defines impairment as the physical situation of a person, disability as the restriction of capabilities due to the impairment, and handicap is used as a term to express a person’s limited participation in a social role, such as holding a job, given the compounded nature of the impairment and disability. To mitigate disabilities and handicaps according to this definition inclusion in development programs as well as advocacy for the rights of persons with disabilities are necessary. This idea is in line with the social model and rights-based model. As part of these models the Twin-Track Approach has been developed, stating that disability should be both mainstreamed within general development initiatives, and where appropriate, addressed through disability-specific efforts targeting hard to reach populations

**Current Policy Work**

On December 13, 2006 the Convention on the Rights of Persons with Disabilities was laid out and adopted. On March 30, 2007 it received 82 signatures and one ratification, and commenced operation in 2008. In March of 2013, 170 countries had signed the CRPD and as of June 2013 131 of these had ratified it, equating the convention rulings with national law. The CRPD is a legal framework to defend and reinforce the human

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rights for people with disabilities. Ratification and adoption of Convention on the Rights of Persons with Disabilities has encouraged a closer look at the needs for people with disabilities. It incorporates many dimensions of development and human rights for persons with disabilities with the aim to ensure their fundamental freedoms. The CRPD aims to promote advocacy and awareness of the struggles faced by persons with disabilities and foster the implementation of integration and inclusion programs for countries. This has led to the creation of development programs in line with the twin-track approach and social and rights models in order to allow for the full inclusion and participation in society by persons with disabilities. Some of the key CRPD Articles include:

- **Article 24**—discusses the right to education for persons with disabilities
- **Article 27** recognizes the right of persons with disabilities to have the opportunity to gain a living by working
- **Article 32**—states that once a country signs the convention it has to include people with disabilities in its international cooperation and development program.\(^\text{16}\)

In order to monitor the implementation of the framework and policies of the CRPD, there is a body of 18 experts that composes the Committee on the Rights of Persons with Disabilities. All UN member states who have ratified the CRPD must submit a report to the Committee within the first two years of ratification and every four years after that.

It is the Committee’s job to analyze the implementation of the policies via the States’ reports and offer recommendations for the forward movement and progression of the CRPD statements.

**Education**

UNESCO and Human Rights Watch confirm that one third of the 67 million children who are still not in school are children with disabilities. UNICEF states that only 10% of all children with disabilities are in school, and only half of these complete their primary education. Children with disabilities are often denied access to education…or have to leave schools prematurely because of inaccessibility, inadequately trained teachers, and lack of awareness among parents and school staff,” explained Vladimir Cuk from International Disability Alliance. Lack of primary education causes long term effects for financial stability and self support as an adult. “Studies on human capital formation affirm that there is a loss of GP in low-income countries as a result of lack of education of persons with disabilities and their consequent non-participation in the economic workforce.”

In East Africa, the education system mandates that children take an end of the year exam each year; if they pass the exam they are allowed to go on to the next grade, if they do not they must repeat the grade. For children with disabilities one of two things typically happens: the child is left to repeat the same grade year after year because they do not understand the test and have not been given the proper attention to learn the material, or

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the teacher automatically passes the child onto the next grade under the assumption that
they would not pass the test anyways so there is no expectation for them to learn\textsuperscript{20}. Either
way this creates an ineffective education for the children and often they just drop out or
go through their schooling never having been properly included and taught.

In recent years as part of the Article 24 of the CRPD framework and UNESCO’s
Education for All program Inclusive Education has gained recognition as a beneficial
response to the issue of children with disabilities not receiving education. Inclusive
Education involves transforming the education system to incorporate all children under
the belief that education is a basic human right. It is intended to facilitate a positive
environment for children with disabilities, ensuring that the education system as a whole
enables children with different needs and learning abilities to receive schooling. It is
intended to allow children with disabilities and teachers to feel comfortable and be
enriched. Inclusion is accomplished through teacher trainings and certification of
accessible infrastructure for children with disabilities.\textsuperscript{21}

UNESCO worked with intellectual disabilities’ programs starting in 2002, and developed
the Flagship program but there was not much work done from 2008-2011. Now
UNESCO’s Education for All Program is working with UNICEF in line with the CRPD
framework. This occurs in the form of advocacy from taskforce on education (UNESCO)
and taskforce on accessibility (UNICEF). These taskforces are designed to prepare
initiatives to bring to the High Level Meeting in September regarding Millennium
Development Goals; will move forward after that. Some of that work will be to ratify
CRPD to ensure implementation of inclusive programs to help provide equal

\textsuperscript{20} Amber Rosier. AbleChildAfrica. Personal Interview. (July 12, 2013).
\textsuperscript{21} UNESCO. Open file on Inclusive Education. p 19-21.
opportunities for children with disabilities. Work is currently under way with the
Washington group to get desegregated data to fill in the knowledge gaps and know how
to move forward. This data will help map the educational situation for children with
disabilities using statistics such as dropout and enrollment rates at school. Currently
UNESCO’s work is only at a global level, but as progress is made there will most likely
be delegated taskforces driven by member’s priorities that could work at the national
level for Inclusive Education

One option that currently exists for education for children with disabilities is to send them
to institutions, or specific schools designed only for children with disabilities. Many
times families are not willing or able to take care of a child with a disability given the
added resources (money and time) it demands, so they are sent away to institutions to be
taken care of and abandoned by their families. There are many accounts of horrific
conditions existing within these institutions. Many Nigerians believe persons with
disabilities are violent even if they are not, so they will chain them up and lock them in
rooms, forcing them to stay there and eat so they do not endanger the rest of the
community. This is a huge human rights issue of abuse. There are misperceptions about
how to care for a child with a disability, how to open their spirits, within institutions and
many times there are not enough care takers and providers to effectively run the
institutions

Inclusive education is intended as a better alternative option for children with disabilities
than institutions. contain issues that need to remedied in order to be effective options or
solutions for children with disabilities. For inclusive education, the issue is that disabled

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22 Mariana Kitsiona. UNESCO Education for All Taskforce. Personal Interview. (July 5, 2013).
23 Emeka Nwefoh Chinweuba. CBM. Personal Interview. (July 14, 2013).
children are now placed in classes with more students and teachers who may not be properly trained so the children receive less attention and less personalized education, causing them to have a hard time and teachers to get frustrated. As a result many disabled students simply drop out, contradicting the idea of inclusive education in the first place. For institutionalized education, the issue is that there are not standards for the operation of institutions, so each varies; some are in very poor condition based on funding or lack of care and do more harm for children with disabilities than good, while some are well kept and operate in such a way as to provide all the intended benefits to children with disabilities. The problem is that if governments create standards for these institutions many of the poorly kept institutions would have to shut down, and for some communities they may be the only source of education for disabled children regardless of the costs, but if standards are not set who is say what quality of education is required.
Employment

“According to the World Report on Disability the unemployment rate among people with disabilities is twice the level of the non-disabled population in developed countries, while in developing countries more than 80% of people with disabilities are estimated to be un- or underemployed”  

Major contributing factors include ignorance and failure to provide reasonable accommodations that would allow qualified individuals to perform the essential functions of their job. Persons with disabilities face stereotypes, marginalization and often patronizing responses from managers, colleagues and employers. An example discussed at the CEDAW Committee on Cape Verde was that if a woman with an intellectual disability is offered a job, many times the boss has the perspective that she must back him back with sexual favors because he has done her a favor by offering a job to a woman with a disability

It is widely believed in areas like Africa where stigmatization creates negative connotations that the employment of persons with disabilities would cause a less productive workplace, due to special needs and slower production rates. When in fact according to the ILO, countries are missing out on an additional 2-5% of GDP because they are not including persons with disabilities in employment sector. Governments fight this figure by arguing that it would take too much money to make business accessible and provide training for persons with disabilities that it is not worth it. The counterargument would be that the long term benefits would outweigh the immediate costs. Due to the limited job options, it is speculated that persons with disabilities are motivated to prove


26 IDA Secretariat Staff Member. International Disability Alliance. Personal Interview. (July 16, 2013).

27 Emeka Nwefoh Chinweuba. CBM. Personal Interview. (July 14, 2013).
themselves and work hard to keep their positions. Currently, there is not sufficient data to prove one way or another, so it is difficult to convince governments to mandate employment inclusion.

**Advocacy**

**Gaps Remaining**
A primary gap remaining between ratification of the CRPD and implementation of developmental inclusion programs for countries is the disconnect between international and national governments. It is difficult to organize national governments to all be on the same page about disability. There is a need for better on the ground coordination and monitoring in order for program mandates to be fulfilled. As well as governmental advocacy and activism, continued education to minimize stigmas regarding disabilities must be further maintained.

**Post 2015 Millennium Development Goals**
"People with disabilities asked for an end to discrimination and for equal opportunity. They are looking for guarantees of minimum basic living standards." It is for this reason that it is essential that the Post 2015 Millennium Development Goals include persons with disabilities as a target group.

The High-Level Panel of Eminent Persons on the Post-2015 Development Agenda has released the report "A New Global Partnership: Eradicate Poverty and Transform Economies through Sustainable Development". The report sets out a universal agenda to eradicate extreme poverty from the face of the earth by 2030. It includes a good number

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29 *A Vision and Framework for the post-2015 Development Agenda*. p 2, ch 1
of references to persons with disabilities insisting that targets should only be considered achieved if they are met for all relevant income and social groups. Progress has been made for the Post 2015 MDGs in bringing persons with disabilities out of invisibility and into inclusive living, but currently the goals are broad and do not specifically address development for persons with disabilities. Instead of holding a specified policy presence, persons with disabilities have more or less been clumped in with the existing Millennium Development Goals as a means of satisfying the growing voice based on the CRPD. Goal One: “Leave No Child Behind” states that no child can be denied their basic human rights and opportunities, but does not state how this will be ensured. It is a general concept with little direction. Goal Two is a little more specific and advocates for better understanding and knowledge spread regarding persons with disabilities to address the primary cause of stigmatization and exclusion. This goal states that “A new partnership should be based on a common understanding of our shared humanity, underpinning mutual respect and mutual benefit…” There is a mention of inclusive education and integrating children with disabilities in the goal of universal primary education, but there is no mention of numeracy and literacy programs for disabled children, just inclusion in schools. There is no mention of the funding needed for inclusive programs. At the moment, inclusion of persons with disabilities is more of a grouped mention rather than specific focus in the Post 2015 MDG Draft. For now they have to be that way because the mentality of the international community towards persons with disabilities is still shifting. After the High Level Meeting in September there will be a greater focus on aid specific goals.

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30 IDA Disability rights bulletin May 2013. Print.
32 IDA Secretariat Staff Member. International Disability Alliance. Personal Interview. (July 16, 2013).
Recommendations
One way to assess the status of inclusive programs within a country is to look at the country’s budget and how much is being spent to programs for persons with disabilities.\textsuperscript{33}

The problem lies in the fact that it is difficult to access budget information for many developing countries, and even more so if the country is corrupt. Many African countries fit within this limit. There is no way to obtain this information in order for coordinating organizations like IDA to review the budgets and make recommendations for change.

Disabilities lead to a lack of political influence because of the exclusion from institutions and organizations, propelling the government to overlook their needs because there is no voice and face to represent this group. One issue that has played a role in the continued marginalization of people with disabilities and specifically children with disabilities is the lack of representation and the lack of voice they have in advocacy work and program implementation. Persons with disabilities often lack political, legal and financial influence. There is a need for more a unified voice and stronger representation through organizations of persons with disabilities.\textsuperscript{34}

One example of how this can be accomplished is in the case of AbleChildAfrica, where children have a say in everything they do. The Board meets with the communities two to three times per year and consults with their local partners regularly. These partners work with children everyday so they see what works and what does not in terms of program implementation. The partner organizations also work with the families of the disabled children in order to move away from the idea of just leaving the child to be taken care of

\textsuperscript{33} IDA Secretariat Staff Member. International Disability Alliance. Personal Interview. (July 16, 2013).
\textsuperscript{34} UNICEF, Lieve Sabbe, and Vladamir Cuk International Disability Alliance, comps. *Global thematic consultation on addressing inequalities*. 2012. Print.
by someone else and not included. For the partnership AbleChildAfrica has in Tanzania with Child Support Tanzania (CST), each child’s needs are assessed and they are given individual work plans and specific learning objectives. The NGO also works with the families to help meet these needs and works with them on the added cost of having a child with a disability. This model has proved successful for AbleChildAfrica and should be used an example for other organizations to promote better cooperation and partnership with persons with disabilities in order to give them a stronger voice. The presence of persons with disabilities in the creation and implementation of development programs would help to bridge the gap between international and national governments and provide a more effective source of local advocacy for community acceptance and inclusion.

Finally, it is important to keep in mind that not everything can happen at once and flexibility is necessary, especially in countries with narrow civil society spaces. For many of the developing countries in East Africa it is difficult to assume marginalized people will stand up for themselves because it is outside of the cultural norms. For East Africa the hierarchical system hinders self-advocacy, especially for children who are expected to not stand up to adults or step outside of the boundaries of their role as a child. Western mentalities cannot be projected on African societies For many persons with disabilities, the stigmatization and discrimination they have faced has been ingrained within them since birth. To assume a mentality shift will occur overnight is a false hope, but with continued advocacy, community education and developmental progression, persons with disabilities will no longer be invisible, but can be a collective part of the population.

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Conclusion

Stigmatization for persons with disabilities and their families is a very real and very debilitating issue and causes particular hurt and limitation for those living in Africa with disabilities. The main cause of stigmatization in Africa is a lack of education about disabilities and the needs of persons with disabilities and in-exposure to the capabilities and belief in potential for persons and especially for children with disabilities. The unknown creates fear in society and exclusion for persons with disabilities, prohibiting them from obtaining decent education and later from having access to jobs and financial support. Since the Convention for the Rights of Disabled Persons (CRPD) in 2006 societal education has been supplemented by implementation of development programs as a means of inclusion to mitigate the stigmas and provide fulfillment of all human rights and opportunities for persons with disabilities. Even though many countries have ratified the CRPD, but there is still a ways to go. Those who are working for inclusion are primarily specialized organizations and NGOs. Issues faced by persons with disabilities need to be mainstreamed for true change to occur. This comes in the form of the Post 2015 Millennium Development Goals, which still do not fully acknowledge the marginalization of persons with disabilities. The focus needs to be on specific programs and assessments and better coordination between international and national governments. Persons with disabilities are no longer to be regarded simply as objects of need, but as able and productive members of societies if given the proper facilitation. If poverty alleviation is to truly be considered eradicated and the achievement of international development goals met, persons with disabilities cannot be ignored and overlooked any longer.
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