Editorial

Stigma in Disability, Rock-hard Beliefs and Religion

In my consultancy work over the past 5 years in a number of African countries, it increasingly became clear to me that organisations of persons with disabilities, local and international non-governmental organisations are expecting that laws and policies will have an important role in curtailing or preventing stigma due to disability. While acknowledging the importance of legislation which is of course needed, we need to be honest about the fact that the impact of legislation on the mindsets of people is limited.

Changing mindsets and subsequent behaviour will prove a useless exercise until we examine the roots of stigma and understand its very nature. Only then will we be able to build structures to support the understandings and mechanisms that reduce stigma.

The core questions we need to ask - in whatever society one lives in and whatever stigmatising condition one has – are: what causes people to behave in a stigmatising manner? What causes people not to challenge or change stigmatising behaviour, even when they have the right knowledge about the disabling condition? Why are people treating their loved ones, employees, friends, as well as religious brothers and sisters in such inhumane ways? Why is stigma so widespread, regardless of social, educational, or economic strata?

The answer is simple, at least conceptually: at the core of any behaviour you will find a (or a series of) belief(s) – usually rock-hard and difficult to change – that cause individuals or groups to behave in a specific manner. We need to strip those beliefs to their core before we can effectively counteract stigma. It appears that there are reasons why people might fear people with certain types of disabilities. Is it the fear that the condition is contagious? Is it the fear of dealing with someone who looks or behaves different from what we see, and think is ‘normal’? Is it the wrong doctrine that is being preached in religions where some religious leaders may be using selective scriptures from Holy Books to show that it is God who is punishing individuals with a disability? Is it witchcraft that raises intense fear because it destroys human life and results in serious violations of human rights including, beatings, banishment, cutting of body parts, and amputation of limbs, torture and murder?

As long as we don't have the courage to challenge people's core beliefs, stigma will not disappear. Confronting society as well as traditional and religious leadership, with the devastating causes of stigma is not a comfortable – nor a popular – process. All too often, we have all sorts of excuses because we are afraid to offend tradition and culture even though we know that there are harmful elements in that culture. Let us, however, be bold and start challenging these – wrong – beliefs albeit in respectful ways. If we do not do this, we will have failed in doing what needs to be done to serve those who are stigmatised and scorned.

What has intrigued me in the past years is if and how we can confront and involve religious leadership about their (likely unconscious) role in stigmatising their followers. In most religions, one notices forms of charity directed at those considered to be weak. Charity in itself is not wrong but at the moment that it becomes disempowering to those who are cared for, we must ring the alarm bell. However, in our work in a number of African countries we hoped to show that in working with religious leadership we could a spread a message of solidarity, justice and righteousness for those with stigmatising conditions such as leprosy, cerebral palsy, and albinism.

Working increasingly in the field of cerebral palsy, I observe that in many cultures – not only African ones – there is a widespread belief that: *If you get a child with Cerebral Palsy, it must have been a long-ago sin so loathsome that the parents believe it as the cause for giving birth to such a child. That belief may be even compounded by superstition or witchcraft*.

What does it mean in practice for the mother and her child with cerebral palsy? It often means that fathers are running away from their families or that mothers abandon their child with a disability. At worst, they leave the child to die in the forest and, at best, they find a grandmother willing to take care of the child. The child is seen as worthless and a burden; fathers put the blame on mothers for conceiving a child with a disability; and mothers are either able to stay strong, love and care for their child, or they run away fearing the opinions and looks of the community in which they live.

In my most recent assignment in Congo I met a 14-year-old girl with Albinism. She told me that she didn't feel safe at school where fellow students mocked her. Her home was the place where she felt safest and her faith in God helped her to be strong. When we departed, she asked me if I could not take her with me to Europe…

What is relevant is that the above reality in many cultures illustrates behaviour based upon a belief that is quite fundamental and widespread. Such beliefs are expressed in different ways by a wide range of people, including parents of children with a disability, religious people, politicians, and the public at large. This belief is based upon what has been told from generation to generation, that it must be the result of divine intervention, superstition or witchcraft.

How to counter this?

In my view, we should educate the right people; the ones who are listened to; the ones who influence or can influence beliefs because they have legitimate power to do so. Legitimate power is perhaps the most prevalent and ubiquitous form of power in society. It refers to the formal authority given to a person as a result of their position in a hierarchical system. Such systems include governments. However, increasingly, I became aware that it is in actual fact by far more the traditional- and religious leaders who can be key in changing mindsets in a massive way...

We started in various countries to engage with religious leaders and involve them in training programmes about disability inclusion. We also developed specific training trajectories whereby we raise awareness; have in-depth discussions and work together in the development of local training manuals. We will test this year a new toolkit for clergy in two countries. We use in the training participatory methods and offer direction on the exegesis of difficult and controversial scriptures. It is interesting to see the usual positive response of clergy - especially among those who lack a robust theological training. I realise that we are not the only ones who are targeting religious leaders in becoming agents of change first in their own congregation. However, we believe that an inclusive congregation becomes also a witness of acceptance, participation and belonging of all members and as such may contribute to similar developments in society. I personally strongly believe that this approach is by far more effective than the impact of conventional community awareness raising efforts.

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