Editorial

Dear readers,

This is a very challenging year for the Journal.

The year started on a promising note, in anticipation of the University of Gondar stepping in to host and take over responsibility for the Journal. Who would have thought that this script would be altered due to the events currently (August 2023) taking place in the country of Ethiopia? The nightmare of civil war has spread from the Tigray region to impact the lives of the staff of the University of Gondar, their relatives and so many people in the Amhara region.

One of the walls of my living room showcases a beautiful painting bought many years ago in Ethiopia. It portrays a number of priests attempting to resolve a community dispute. A rising sun in the background symbolises hope in times of trouble and despair. I hope and wish that the resilience, pride and power of the Ethiopian people will conquer the evil that is afflicting the country at this time. This wish holds true not only for Ethiopia, but also for all the places on our planet. Let goodness and respect for everyone prevail, most of all for those who are vulnerable.

On the subject of evil, it is increasingly apparent that in many societies there exist high levels of stigma towards certain groups of people with disabilities. I notice in my work that people in various countries are urgently calling for laws and policies to curtail or prevent stigma due to disability. It is a call for changes in systems and structures. While this is very important, I am however afraid that it 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 mechanisms that alleviate stigma.

Stigma towards people with disability is a behaviour that has very serious impact upon fair and equal opportunities in society. What causes people to stigmatise others? What causes people not to challenge or change stigmatising behaviour, even when information is widely available about the causes of disability? Why is stigma still so widespread in many societies? In many cultures where I work(ed) in Africa (and Asia) – for longer or shorter periods – there is still a widespread belief that *"If you get a child with disability, you must have done something wrong"*. A child born with a disability is often seen as worthless and a burden. Fathers blame the mothers for conceiving a child with a disability and often run away; and mothers

either decide to stay strong, love and care for their child, or run away fearing the opinions of the community in which they live. In the worst cases, mothers – in despair – leave their child to die in the forest; at best, they find a grandmother or grandfather willing to take care of the child. I noticed this in Kyrgyzstan and Bangladesh, as well as in Congo, Burundi and Ghana. The grandmother and, at times, the grandfather ask themselves the cruel question, *"What will happen to the child when I / when we die?"*. This is the reality in many cultures. These behaviours are based upon old traditional beliefs referring to divine punishment, including witchcraft, which are most often widespread in situations where resources are limited. I have heard this expressed in subtle or harsh ways by different people, including parents of children with disabilities, religious leaders, politicians, and the public at large.

How to fight such widespread beliefs that cause serious harm to so many people? While many would say that we simply need to inform people about the *actual* causes of disability, I increasingly believe that we need to consider whom to inform and how to inform them. For decades, parallel to the disability emancipation movement, we have informed – usually in a western way and with western methods – society at large and rehabilitation professionals, about disability and stigma. We train and educate; we motivate and get frustrated about people rejecting children (and adults) with disabilities on 'irrational' grounds. Is it not time to study the existing cultural methods of influencing ideas and practices in the countries we work in? The coffee ceremony in Ethiopia may be a more effective way to spread messages than by attending a workshop with a PowerPoint presentation at an expensive hotel.

I also think that we are reaching the wrong people. We should target the ones whom others listen to, those who are influential and those who have power. On the one hand there are people with formal – legitimate – authority in the countries' hierarchical systems (i.e., governments), and on the other hand there are traditional and religious leaders. It is the last groups that have captured my interest in the past decade or so, for the simple reason that we need to counter (traditional) beliefs that are often perpetuated by traditional or religious leaders. If the existing beliefs related to religious scriptures may give the(wrong) idea that it is God or the Gods who punish people with disabilities for sins committed (in a previous life), one cannot and *should not* ignore this.

In my current work I continuously question people about what they hold true in their cultures: something I ask(ed) myself as well about my own culture! It is

time that we challenge people's core beliefs because it is these very beliefs that are creating the problem. If this is done in a respectful way, we can then make a much bigger impact on stigma, discrimination, inequity, and a range of other social issues. We need to challenge religion to not only examine the emphasis on blame-shame-punishment (versus compassion), but also to do so actively and publicly. Religions and religious leaders have a fundamental and profound influence on the understanding of what causes 'bad' things to happen (read the almost classical publication on this issue from Harold Kushner, a Jewish rabbi) and how we should respond to this. It matters because people want to go to Heaven. For many people, peace, joy, and fulfilment are not potentially possible in their physical circumstances, so instead of 'here', they seek it in the future, in Heaven. And, in their minds, it is the religious/moral authorities who *control the keys to Heaven'*; the very same leaders who, at times, say disability is proof of sin.

In working towards a disability-inclusive society, we should concentrate on the root causes of stigma, namely fear (of being worthy enough to be accepted and loved). This applies not only to the relationship of people (with disabilities) with God or the Gods, but also to other people. We cannot ignore the reality that most people in the world (85%)[1] have strong religious value systems, whether this is Islam, Christianity, Hinduism, Buddhism or traditional animism. We also cannot ignore the fact that religion may have a very powerful influence on stigma, including self-stigma by those affected. We cannot therefore ignore an entry point to dealing with stigma, nor can we forget the widespread resource infrastructures in dealing with the consequences of disability, such as home-based care, community-based care, rehabilitation, caring for abandoned children (with a disability), prevention of infanticide, and numerous other issues. Protecting old negative ideas and/or practices will not lead to the necessary change with regard to the acceptance of people with disabilities and their families. It is high time we stop the simplistic methods of awareness-raising. Awareness does not come from statistics or posters. Awareness comes from a deep internalised consciousness that what we always believed is wrong. It requires more than a radio jingle or the celebration of World Disability Day.

Your Editor-in-Chief,

Huib Cornielje

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1 https://worldpopulationreview.com/country-rankings/religion-by-country