Editorial: Speak Less but Act More

“The best way to find yourself is to lose yourself in the service of others”- Mahatma Gandhi.

The disability world globally, together with many INGOs active in the field of disability, have – rightfully – been focussing their activities on lobby and advocacy for equalisation of opportunities and full inclusion of people with disabilities in all spheres of life. These efforts have indisputably and significantly contributed to the position of people with disabilities in many parts of the world. It resulted in – at times – new commitments to address the serious inequalities that exist in the world. However, it is also obvious that the euphoria of the past 20 years or so that culminated in the adoption of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007 and subsequent ratification of the UNCRPD of many national states, including those who are openly or less openly have a track record of gross violation of even the most basic human rights of its civilians, has often not resulted in any significant change in the lives of the poorest of the poor. Those who live in the slums and remote rural areas of many countries have not yet seen any change in their lives and that of their families. One can call me cynical, but this is the sheer reality for still hundreds of thousands of people in low- and middle-income countries. They live in a reality in which one cannot do anything but try to survive. Such people are not seen by corrupt or not so corrupt politicians (disabled or not), but rather are regarded as useless people who are not worthy to invest in.

I am now editor-in chief of this great journal for one year. But do all the articles that have been written in the past year truly contribute to a better life, better acceptance, better opportunities for those people who are often the subject of our writings? After one year of my editorship, I received a handful comments by readers and that is worrying me. Do we only have time to write more manuscripts but forget to read? And when we are reading, do we read about the real situation on ground? Do we read about successes in overcoming the political battles; the attitudinal barriers and the simple fact that so many people with disabilities have no access to even the most essential services they need? I am aware that providing services is not so sexy but in essence, is that not often what the poor mother of the child with microcephaly in a day care centre of a refugee camp on the coast needs? And is the fact that a smart, 12-year-old athetoid child with cerebral palsy who is just sitting in a day care centre, getting old-fashioned therapy in
the form of passive exercises for many without knowing what for, not being intellectually stimulated, not a missed opportunity for that child but also a sign a failure from the side of the government as well as the INGO sector? These are just a few examples of thousands of children in a country which I recently visited, and which was among the early ones that ratified the UNCRPD, has inclusive legislation and policies in place but fail to serve those who need to be served for the past decades.

During my recent and first assignment this year in that African country, I felt depressed with the fact that so many people talk about inclusion; that training of rehabilitation professionals seem to be especially based on western and international criteria and standards but is hardly contextualised and mainly theoretical and for many, a steppingstone for a decent personal life only. I am worried about the lack of access to services for the poor as well as the poor quality of services which seem to even be harmful at times. I am, however, even more concerned about the fact that those who are in power (politically and academically) seem not to be aware of this; may deny this or have no interest in changing this. And what about the international development community of whom many have been working in that part of the world? Did they play a role in the lip service paid which one literally notices?

I realise that I am asking many critical questions but who to blame? Or better what to do? Should we invest in just more awareness raising activities and just more lobby and advocacy? Or is it time to be genuine and realistic, look into the mirror and conclude that we are failing those who didn’t benefit from progressive legislation but also not from inclusive policies and programmes? Will all the new grand policies coming from the ivory towers of various origins and capitals of western societies bring the much-required changes? Or will it be the usual rhetoric with new terminology and strategies which have been tried in the past and keep us intellectuals to remain in power?

It is time for reflection and taking stock of what we do. Possibly, it is time that we start using all our senses and listen to those who so far were the ones that are least listened to; to talk with those we usually don’t talk with; to spend more time in the field and less time in the office; to look for contextualised developments instead of promoting standard approaches to situations that require non-conventional interventions. May I challenge you to submit papers that deal with the not so good practices; may I challenge you to write about your concerns but also about much needed suggestions in ensuring that this world become a bit a better place.
for all. This journal allows you to write letters to the editor and I am inviting you once again to share your ideas; innovative ones and not so innovative ones but ones that will add knowledge and which will inspire us as readers (academics and practitioners) to do our work better and ensure that there is impact in what we are doing.

Finally, during the aforementioned assignment, we came across a frontline worker who is running a day care centre for children with neuro-developmental disabilities without any salary. She learned while working with the caregivers of those children that rehabilitation is much more than giving therapy. She learned that one can be bothered about ways to feed a child with cerebral palsy but if the family is not having access to food, the provided adapted chair and instructions to the mother about handling and positioning of the child while feeding become easily futile. She thus made sure that the programme also focusses on socio-economic development. Such a person is a hero. Such people are the ones making a real difference in the lives of people. Such people don’t talk the politically correct language but instead do the work that needs to be done and are glimmers of hope.

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