

Editorial

Balancing between Rehabilitation and Inclusion and not ignoring the most valuable resource in Society

Community Based Rehabilitation (CBR) was formally initiated by the World Health Organisation (WHO) in the year 1978. Most people will remember this year as the one in which 122 National States committed themselves to foster Primary Health Care (PHC); addressing the main health problems in the community, as well as providing promotive, preventive, curative and rehabilitative services. As much as PHC - in fact - did already exist long before its formal launch by the World Health Organisation, so did CBR before its formal launch. In fact, it existed for centuries in the daily practice of people who had no access to rehabilitative services but who had to cope with their own disability or the disability of relatives and who had to find solutions to the challenges they experienced in daily life. It of course is true that CBR did evolve over the past few decades, from paying attention to improve and increase access to formal rehabilitation services into a more community-development approach. In such a model, increasingly attention is given to a much-needed transformation of society in which people with and without disabilities have equal rights and opportunities. As such, CBR became a model that is no longer directed solemnly on individuals with disabilities but now also has the community as its target in order to make sure that those with disabilities can claim their rights and entitlements. The unique focus on the individual needs of people with disabilities, as well as need to transform society is at the core of what CBR is all about. It seems, however, that this is still not well-understood by those who criticise this approach or maybe even more, this philosophy...

Nowadays this unique twin-track approach seems to be ripped apart in 2 relative new approaches: i.e.

- 1) the WHO increasingly focusses on access to rehabilitation within Universal Health Coverage (UHC) and it is hoped that with the Rehab2030 Action Plan, rehabilitation will indeed become accessible and available to everyone even to the so often unreached; the poorest of the poor living in the most remote and peripheral parts of societies; and
- 2) Community Based Inclusive Development (CBID), which in fact is not the equivalent of CBR but rather a fundamentally different approach that is

directed at systems development or in other words, an approach directed at the realisation of a just, more egalitarian society with equal opportunities for all.

Time will tell us what the impact of this division is and the disability world as well as the rehabilitation sector should take stock of this development within the coming years. It is sincerely hoped that both developments will lead to the so much needed changes so many people are longing for.

In the midst of all these developments we notice, however, that within both aforementioned approaches, those promoting them seem to have little attention for the most vulnerable groups in society: children with disabilities. They also hardly recognise the immense importance and value of caregivers within the family: usually women and mostly mothers, sisters or grandmothers of relatives with disabilities. Both groups are hardly represented within the (global) disability movement. Their voice is seldomly being heard and yet their needs are often the biggest. On the other hand, one sees in low- and middle-income countries that it is the group of children with serious neurodevelopmental disabilities who lack access to good quality rehabilitation services. In the basic training of rehabilitation personnel - all over the world - hardly any attention is given to childhood disability and rehabilitation. Curricula of training of therapists in many low- and middle-income countries are copied from those in high-income countries, and the relevance of the work done by graduates is in general marginal for children with neurodevelopmental disabilities.

A greater focus on the untapped and fundamental resources of informal - family - caregivers is sensible and so much needed. It is the women in most societies who care for their disabled relatives; it the mothers who endlessly try to help their disabled children to eat, to move, to develop. They are the ones offering 24-hour care; they support and encourage their relatives with disabilities to participate in family life and society.

Lessons from projects which, for instance, do consider the importance of informal - family - caregivers in providing rehabilitation to their children with neurodevelopmental disabilities show that one cannot do without them. The rehabilitation physician; the therapist; and even the rehabilitation field worker is never able to seriously contribute to the improvement of the child without a close involvement of mothers or other women in the family. As such their work consists largely about coaching, training and supporting families. It was the late disability

scholar Mike Miles who stated decades ago already that CBR was mostly about mothers and he pleaded on several occasions for CBR to be re-named into MBR: Mother Based Rehabilitation. And although that probably is a too small basis as it is often siblings and grandmothers that play a significant role in the parenting process as well, it is crucial and urgent for all those who work in the field of disability and development to recognise both in advocacy and lobby, but also in policy and planning, the enormous value of family members supporting a relative with a disability.

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