

Editorial

Parents, Teachers and Rehabilitation Professionals: Are all needed in enabling children with disabilities?

Recent discussions taking place in the early Childhood Development task force (ECDtf) for Global Partnership on Children with Disabilities centre around arguments in favour of de-medicalisation of early child and family support. Yet, it is almost a *déjà vu* of discussions held in the past and one wonders at times 'what is new?'. In fact, it was in the mid-eighties of the last century that one of the leading disability activists in Africa addressed 'the three enemies of the disabled child' in his presentation at a conference in Lesotho, apparently a discussion which is still relevant. This activist was trying to convince the audience that it was parents of children with disabilities, followed by teachers and finally social workers who were forming the biggest barriers towards equal opportunity and participation in society. When reading his paper again a short while ago, I thought he must have had a miserable youth. And at the same time, in spite of all those barriers, he became a prominent activist. Could it have been his parents and family who helped him get the right education, which ultimately made him able to obtain a master's degree? Was it the commitment of teachers and rehabilitation professionals which contributed to his career? Or was he right from the onset a charismatic leader whom, without any support, could achieve such a fantastic career?

I learned over the years of working in African and Asian contexts that parents – in spite of all shortcomings (and which parents anywhere in the world don't have shortcomings?) – are key to the development of their children. Yes, I am aware of some parents who are overprotecting. Yes, when reflecting upon bringing up my own children, I realise I made mistakes too. And yes, I know that unfortunately there are parents who neglect their children, who may even abuse them in several ways. I am however convinced that most parents – even those who have children with disabilities – do their utmost best to help their children become responsible and independent citizens of their communities.

Teaching staff – certainly on the African continent – are often faced with a bare minimum of resources and classes with far too many students. Further, the quality of their teaching, especially when faced with children with special needs, although not optimal is often unrelated to negative attitudes. Most likely, they

are not sufficiently equipped to work with children with disabilities; most likely, they work under miserable conditions with too many children in the classroom; too few chairs and tables, let alone having access to the necessary assistive technology that will benefit children with special needs.

Rehabilitation professionals including social workers are hard to find, certainly in rural communities and slums in most African and Asian countries, even today. If you find them working in such areas, one can be assured that these are the most committed professionals who with little means and support from government do their utmost best to offer their services to those who are in need. This journal has shown over the past 30 years many examples of people in African, Asian and South American countries, working within impoverished conditions, at time on the fringes of society.

Isn't it timely to make very clear that those who criticise parents, teachers and rehabilitation professionals living and working in low- and middle- income countries should first start recognising and appreciating the context in which they live and work? Isn't it also of great importance to realise that children with disability and their families require both medical and non-medical support as early as possible?

Many parents in low- and middle- income countries are struggling to come to terms with the challenges of having a child with a disability. In many of such countries, the only recourses for them to turn to are either traditional or faith healers. If they are lucky and living close to town where secondary health care services are available, they can ask for support from the health sector. However, even in those cases it is not assured that they and their children can access rehabilitation services or schools where teachers have been trained to work with children with special needs. The following example may give some insight into the reality of being a child with a disability and raising a child with a disability in a low-income country:

During a recent CBR programme evaluation in the capital city of an African country, our team was visiting a large regular secondary school, which proudly stated that out of the 1200 children they were serving, approximately 50 were children with various types of disabilities. There was some excitement in our evaluation team about visiting a disability-inclusive school without having that label of being disability-inclusive. When talking with the headmaster and some teachers, they informed us about children with visual impairment and hearing

difficulty. They had decided in both cases that it would be useful for those children to sit in the front row of the class; to write in large letters on the whiteboard and to pay attention to their own way of speaking i.e. speaking slower and articulating more. At first sight, we all were very positive about such interventions. However, when asking them if they had referred these children to the nearby primary health care centre for eye exams and audiometric (hearing) tests respectively by a nurse, the answer was no.

The above example shows us a glimpse of the challenges faced by the child with a disability and parents in a low-income country. In the above country, the national educational policy aims to ensure that all children and youth – including those with disabilities – have access to equitable, inclusive, and quality education. The reality is that the policy is fine, but practicing that policy is something else given a large number of eco-social factors. What we, however, can learn from the above example is that headmasters, teachers and parents are committed to the best of their knowledge and ability to support the child with a disability.

In view of the current discussions aforementioned in this editorial, it is important to stress how careful we should be in our debates about possible opposing fields; in this case the role of the education sector versus the role of the health sector. Such opposing views may all too easily exist between professionals and activists as well. In addition to this, there may be views presented and promoted by professionals and activists living in high-income countries. They should especially be careful in critiquing those who live and work in low-income countries and make sure that they very well understand the existing realities. And instead of criticising systems and structures, they should seek workable solutions that fit the child, the parents, the teachers and the scarce number of rehabilitation professionals. The child with a disability will only optimally develop if the parents, the teachers and health staff – including rehabilitation professionals – work together in a system that takes into consideration the needs of the child and of the parents, and look for culturally appropriate interventions and solutions.

While the needs of children with disabilities and their parents are well documented, the tragedy is that in low- and middle- income countries, resources (both human and material) in offering appropriate services/interventions to such children remain scarce. In practice, it means that there is a continued shortage of competent special needs teachers, rehabilitation professionals and field workers as well as a large unmet need for appropriate assistive technology. An article (Ghosh et al., 2021) in this issue refers to the importance of training and employing mid-level

rehabilitation workers in low-and middle-income countries and propose that they are a solution that may be more appropriate than copying training programmes and deploying highly specialised rehabilitation professionals. The latter being an old idea promoted in the early eighties by the World Health Organisation, but which never got the attention it deserved in spite of some successful pilots in some African, Asian and South American countries.

I hope that the large diversity of manuscripts presented in this issue is of interest to many of our readers. We wish you well, stay healthy and continue to play your role in making this world a better and more inclusive place for all.

Huib Cornielje
Editor-in-Chief