

The reality of cerebral palsy in Uganda

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This commentary is on the original article by Andrews et al. on pages 454–462 of this issue.

Cerebral palsy (CP), the most common motor disability of childhood, has a prevalence of approximately 2.1 per 1000 live births¹ and disproportionately affects children from low- and middle-income countries (LMICs).² Epidemiological studies have found that younger children from LMICs have a higher prevalence and are more severely affected than older children.² Also, a higher proportion of children in LMICs have post-neonatal CP compared to children with CP from high-income countries (HICs) (25% vs 5–6%).²

The epidemiological picture of CP in LMICs compared to HICs is no surprise to CP researchers and clinicians who provide services to the affected children. However, what do we know from a population perspective about impairments and functioning of these children and the healthcare-seeking behaviours of their families? As a concerned CP community, we often remind ourselves that the goal in identifying CP is to provide services and improve the quality of life for the children and their families. Updated information on tools for early identification and implementation of early intervention, such as the Precht Qualitative Assessment of General Movements and the Hammersmith Infant Neurological Examination, are based on more recent understanding of neuroplasticity of the brain and the goal of minimizing secondary impairments that can worsen functioning.³ Studies have shown that parents benefit from engagement in early intervention programs. These tools and approaches to early identification and intervention show promise, but are they available to all children?

Andrews et al.⁴ address the question of how we are improving the overall quality of life, as measured by func-

tioning, associated impairments, and participation, for children with CP in LMICs. Building on previously reported methods,² the authors collected extensive information on children with CP in rural Uganda and compared their findings to those from children with CP in Sweden and Australia. Although a paucity of services in LMICs is not surprising, the associated poverty was also noted. For Uganda and for many other LMICs, data that describe the state of rehabilitative services in these communities do not exist. The findings from this study help fill that void, but should not be generalized to all LMICs. The authors found that approximately 40% of the children with epilepsy were on antiepileptic medication; only 3 of 37 children had working wheelchairs (13 children who had no means of ambulation were carried by their parents); no children had assistive devices for hearing, vision, or communication; and only about one-third of children attended school. As expected, none of the children who were most impaired (Gross Motor Function Classification System levels IV and V) attended school. Interestingly, the authors noted a slowing of developmental trajectories, which supports the point that early intervention might have benefited these children.

The experiences of the parents indicate that there are attempts by some to find services for their children, but often to no avail because there are few if any services available. There is a statement in the paper that, ‘At the time of the study, no NGOs were providing regular services for children with disabilities in the area’.⁴ The sense of hopelessness and despair experienced by the parents is expressed using direct quotes from family members.

This paper highlights the immense need to help those who care about all children with CP. The United Nations Sustainable Development Goals hold promise for promoting equality in education and access to healthcare for all children, including those with developmental disabilities,⁵ but will they make a difference in the lives of children with CP in LMICs, such as in Uganda? One hopes.

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