A South African cerebral palsy registry is needed

Africa has undergone exponential population growth over the past decade, with children accounting for more than half of the entire population. Therefore, a potential outcome of the proposed National Health Insurance Bill may be the improvement of the public sector healthcare system to ensure adequate management of children suffering from CP. A CP registry in SA may enable the improved evaluation of current services that are being provided for children with CP, identify gaps in service provision (constrained resources for equipment and interventions, effects of the shortage of suitably trained and experienced staff, inequitable distribution of healthcare access across SA) and provide measures for the quality of life of children with CP and their families.

Children with CP are highly vulnerable, with few vocal advocates, and are frequently neglected in healthcare planning. This inevitably results in fewer resources allocated to children with disability by policymakers. It is, however, important that resource allocation by policymakers in all sectors, including health, should effectively even out the ethical criteria of cost effectiveness, equality and improved quality of life for all, regardless of one’s level of function.

There is therefore an urgent need for SA to learn from and adapt already-established CP registries to develop a context-relevant tool with reference values drawn from the epidemiological profile of the country. This is an essential requirement if valuable data are to be acquired. Linking existing administrative health data to a well-established, population-based CP registry would assist in providing evidence-based motivations for significant policy-making, planning and managing of healthcare resources and preventive strategies for children with CP.

CP registers are ideal for monitoring effectiveness of interventions and policy changes over time. The establishment of a multi-institution CP registry would further facilitate the relationships between sectors that are involved in the holistic management of children with CP, i.e. the healthcare sector, and educational, rehabilitation and community settings.

The information-rich CP database that can be created through the registry would also provide a source from which novel research can be done to inform strategies for the prevention of and management strategies for CP in SA.

This calls for the combined efforts of government and other stakeholders to leverage and expand the clinical expertise in the SA healthcare system, invest in high-quality data management and curation infrastructure. This is a critical step in equitable and effective care for children with CP. Establishing a CP register will be the information backbone for being able to implement such initiatives within a relevant evidence-based framework, which is currently being planned for Western Cape Province, SA.

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