

The Increasing Global Burden of Childhood Disability: A Call for Action

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Over the past 20 years, there have been tremendous reductions in early childhood mortality, largely stimulated by the United Nations Millennium Development Goals.¹ With improved survival, the sustainable development goals (SDGs) shift focus to “ensuring healthy lives and promoting well-being at all ages” and endeavor toward disability inclusiveness around the world, with equal access to health care and education.² Olusanya et al,³ in their article in this month’s issue of *Pediatrics*, offer a sobering look at the global burden of childhood disabilities, estimating that >1 in 10 (291.2 million) children and adolescents are affected by epilepsy, intellectual disability, vision loss, or hearing loss. This is notably higher than previous estimates and likely still underrepresents the true burden of childhood disability from other conditions not included in this analysis, such as developmental delay or cerebral palsy.

These data from the Global Burden of Disease Study 2017 are important for several reasons. First, the authors of the study provide an objective and carefully measured estimate of childhood disability, which is not often included among commonly reported global health metrics. Without recognition of the global burden of childhood disability, it is impossible to provide adequate resources to allow for these children to reach their full potential, as called for by the SDGs. The Convention on the Rights of Persons with Disabilities, adopted in 2006, mandated that persons with disabilities enjoy all

human rights and fundamental freedoms.⁴ Despite this, there is poor integration of services to detect and support children with disabilities, particularly in countries with the fewest resources, where these disabilities are the most common. The data from this study demonstrate that failure to recognize and address these disabilities provides a disservice to hundreds of millions of children around the world.

A second important conclusion is the geographic disparity of these specific disabilities: most (94.5%) children with the disabilities examined live in low- and middle-income countries. This suggests that many disabilities may be preventable with adequate health care resources. Examples include epilepsy as the result of severe central nervous system infections (neurocysticercosis or meningitis),⁵ intellectual disability from birth trauma due to poor access to high-quality perinatal care, visual impairment from infections such as onchocerciasis (river blindness) or trachoma,⁶ or hearing deficits resulting from chronic, untreated ear infections.⁷ Although the focus of global health statistics is on the mortality of certain conditions, the resultant long-term disability must also be recognized.

Through efforts such as the American Academy of Pediatrics’ Helping Babies Breathe and Helping Babies Survive programs,^{8,9} neonatal mortality rates are declining. As more infants survive, the prevalence of disability is likely to increase further because the number of children at risk will be greater.³ With a conservative estimate that 1 in 10

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children has a neurologic disability, medical systems must develop and implement programs to screen for and manage affected children. For example, screening for visual or hearing impairment must be universally available for all children starting at an early age to allow for the provision of corrective lenses, hearing aids, or other assistive technologies that may reduce the impact of the child's disability.

Arguably more important than diagnosing and recognizing the burden of these disabilities is ensuring adequate access to appropriate treatments or interventions for those affected. As an example, it is essential that children with epilepsy (estimated here as ~23 million children around the world) have access to safe and effective antiepileptic drugs (AEDs). There are 6 preventive and 3 abortive AEDs included on the World Health Organization's Model List of Essential Medicines,¹⁰ but in many low- and middle-income country settings, options may be limited to 1 to 2 AEDs at best, compared with an available selection of >20 for most neurologists in high-income countries. In addition to equitable access to appropriate medications, early intervention services, such as physical therapy, occupational therapy, speech-language therapy, and vision therapy, must also be established.

Finally, the adequate management of each of these 4 disabilities requires significant improvement in health care capacity, particularly pediatric subspecialty care, including pediatric neurologists, developmental pediatricians, ophthalmologists, audiologists, and speech therapists. In the United States and Canada, there are ~2000 child neurologists for

a population of ~330 million, a ratio of 1 per 110 000 (data from Child Neurology Society), compared with some lower-income countries, where there may be only 1 to 3 child neurologists for an entire country.¹¹ There has been some traction within the field of child neurology to address this issue,¹¹ but there is still a long way to go.

The data reported here bring into stark reality the magnitude of children living worldwide with a disability and should serve as a call to action to focus on collaboration and equality to achieve the SDGs. Now that the burden has been calculated, it is time to move to find a way to proactively identify and provide equitable care and opportunities for the millions of children living with disabilities throughout the world.

ABBREVIATIONS

AED: antiepileptic drug
SDG: sustainable development goal

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