Early childhood developmental disabilities—data still needed

Lancet Glob Health 2018
Published Online
August 29, 2018
http://dx.doi.org/10.1016/S2214-109X(18)30399-1
See Online/Articles
http://dx.doi.org/10.1016/S2214-109X(18)30309-7

The first 5 years of life form the building blocks for lifelong health and wellbeing, as shown by epidemiological risk and physiological, psychological, and neuroscientific evidence. Advances in research, policies, and programmes have resulted in increased attention on early childhood development, particularly in the Sustainable Development Goal (SDG) era.[1] Although attention on childhood developmental disabilities is also increasing, the pace has lagged, partly due to data gaps for the prevalence, epidemiology, and causes of disabilities in low-income and middle-income countries (LMICs).[2] Bolajoko Olusanya and colleagues' systematic analysis in *The Lancet Global Health* for the Global Burden of Diseases, Injuries, and Risk Factors Study 2016 (GBD 2016) begins to address these gaps by estimating the prevalence and years lived with disability (YLDs) for six developmental disabilities among children younger than 5 years: epilepsy, intellectual disability, vision loss, hearing loss, autism spectrum disorder, and attention deficit hyperactivity disorder (ADHD).[3]

GBD 2016 includes data from multiple sources (health surveys, systematic reviews, hospital and claims databases, case notification systems, and studies of specific disabilities, such as epilepsy or autism) and uses complex spatiotemporal modelling to produce prevalence estimates.[3] Although some of these sources might include data on children's medical disabilities, neurodevelopmental disabilities such as ADHD do not necessarily include medical comorbidities and are often undiagnosed before age 5 years. ADHD has traditionally been diagnosed during school age when the inattention, distractibility, and other behaviours indicative of ADHD come into conflict with the demands of primary school.[4] The ADHD diagnosis has been extended to preschool children (age 4 years), and screening checklists have been validated for use by parents and preschool teachers.[5] Prevalence estimates among young children might depend on parents' ability to recognise symptoms and to bring their concerns to the attention of health-care providers who must in turn recognise them as symptoms of ADHD.[4] Children without access to preschool or health-care services, such as those in rural areas, or with parents with limited education and economic means are the least likely to be identified; an example of the inverse data law whereby those most at risk are least likely to be counted. It is therefore not surprising that GBD 2016 reports the highest ADHD prevalence in high-income countries (HICs; specifically Sweden and Australia), with very low prevalence in LMICs.[3] Countries with incorrectly reported low prevalence of ADHD might not develop policies and programmes to diagnose and provide treatment for children with ADHD.

Vision and hearing are typically screened by health-care providers, and vision and hearing loss are the most prevalent GBD-reported disabilities.[3] Effective preventive and treatment interventions have been promoted by WHO and governmental and non-governmental organisations. For example, retinopathy of prematurity, a leading cause of childhood blindness, is eminently preventable.[6] As interventions are scaled up and become more broadly available, estimates of the burden of vision and hearing loss should include not only prevalence, but also the reduction in burden associated with the interventions.

Considering the diagnostic controversies associated with autism spectrum disorder, it is interesting that the condition is included in the GBD 2016 report, while the common neuromotor disorder cerebral palsy is not fully discussed. The GBD 2016 report incorporates cerebral palsy in the prevalence estimates of intellectual disabilities. However, 55% of children with cerebral palsy do not have intellectual disabilities. Children with cerebral palsy and intellectual disabilities have motor disabilities and might have an increased risk of medical comorbidities, such as epilepsy or autism.[7,8]

The prevention and management of disabilities depend not only on the prevalence of disabilities, but also on the underlying causes and epidemiology. Over the past 50 years in HICs, the epidemiology of childhood disabilities, and the understanding of the causal networks underlying them, have changed. Improvements in obstetric and neonatal care have reduced brain injuries from birth complications and neonatal jaundice (which classically resulted in choreoathetoid cerebral palsy). Thus, in HICs, child disability, including cerebral palsy, has shifted to include more extremely preterm infants (gestational age <26 weeks).[5] In LICs, as child survival improves, half of child deaths are in the neonatal period and, as intensive newborn care is scaled up and more children survive,

multiple causes of brain injury will be more common among survivors.

Disability weights underlying the YLDs in the study are invariant across geographical locations.[3] However, children's development and quality of life are affected not only by their disability, but also by family care, home resources, and community opportunities.[9] Children with disabilities in HICs benefit from access to high-quality health care and educational services, with fewer opportunities in LMICs.[10] Contextual differences affecting children and families are not considered in the YLDs.

In summary, the field of developmental disabilities is garnering attention and beginning to make major strides in research, interventions, and policies for young children with disabilities. The adoption of the UN Convention on the Rights of Persons with Disabilities in 2006 provided momentum for ensuring that countries have policies and programmes to support children with disabilities and their families. Although the prevalence estimates from GBD 2016 are a first step in recognising the burden of developmental disabilities, both improving and using the data are crucial next steps. Attention to the changing epidemiology of developmental disabilities, and to the context provided by countries and families, is fundamental to understanding these conditions and using evidence to improve opportunities and quality of life for young children with disabilities.

Maureen M Black, Joy E Lawn
University of Maryland School of Medicine, Baltimore, MD 21201, USA (MMB); RTI International, Research Triangle Park, NC, USA (MMB); and March Centre, London School of Hygiene and Tropical Medicine, London, UK (JEL)
mblack@som.umaryland.edu

We declare no competing interests.

1 Black MM, Walker SP, Fernald LC, et al. Early childhood development coming of age: science through the life course. *Lancet* 2017; **389:** 77–90.
2 Maulik PK, Darmstadt GL. Childhood disability in low- and middle-income countries: overview of screening, prevention, services, legislation, and epidemiology. *Pediatrics* 2007; **120** (suppl 1)**:** S1–55.
3 Global Research on Developmental Disabilities Collaborators. Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Glob Health* 2018; published online Aug 29. http://dx.doi.org/10.1016/S2214-109X(18)30309-7.
4 Bitta M, Kariuki SM, Abubakar A, Newton CRJC. Burden of neurodevelopmental disorders in low and middle-income countries: a systematic review and meta-analysis. *Wellcome Open Res* 2017; **2:** 121.
5 Wolraich M, Brown L, Brown RT, et al. ADHD: clinical practice guideline for the diagnosis, evaluation, and treatment of attention-deficit/hyperactivity disorder in children and adolescents. *Pediatrics* 2011; **128:** 1007–22.
6 Blencowe H, Lawn JE, Vazquez T, Fielder A, Gilbert C. Preterm-associated visual impairment and estimates of retinopathy of prematurity at regional and global levels for 2010. *Pediatr Res* 2013; **74** (suppl 1)**:** 35–49.
7 Reid SM, Meehan EM, Arnup SJ, Reddihough DS. Intellectual disability in cerebral palsy: a population-based retrospective study. *Dev Med Child Neurol* 2018; **60:** 687–94.
8 Burton K, Rogathe J, Whittaker RG, et al. Co-morbidity of epilepsy in Tanzanian children: a community-based case-control study. *Seizure* 2012; **21:** 169–74.
9 Bronfenbrenner U, Morris PA. The bioecological model of human development. In: Damon W, Lerner RM, eds. Handbook of child psychology. 6th edn. New York, NY: John Wiley & Sons, 2006: 793–828.
10 Lawn JE, Blencowe H, Darmstadt GL, Bhutta ZA. Beyond newborn survival: the world you are born into determines your risk of disability-free survival. *Pediatr Res* 2013; **74:** 1–3.