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### Disability in children

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# Disability in children: a global problem needing a well-coordinated global action

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In September 2015, 193 member states of the United Nations (UN) unanimously signed a social contract with their citizens to commit resources to realising a global agenda consisting of 17 development goals under the Sustainable Development Goals (SDGs).<sup>1</sup> Unlike the Millennium Development Goals, the SDG agenda makes explicit provisions for disability inclusiveness in policy interventions over the life course: childhood, adolescence, adulthood and old age. The UN agencies like the WHO, UNICEF, UNESCO and the World Bank Group are usually tasked with providing global leadership in implementing the SDGs within their respective core mandate.

The specific focus on early childhood development (ECD) for children under 5 years as one of the targets under the fourth SDG (SDG 4.2) is unprecedented and a clear recognition of the importance of the early years from birth as the foundation of optimal human capital development. SDG 4.2 is dedicated to the education sector, and it seeks to ensure that all girls and boys have access to quality ECD, care and preprimary education so that they are ready for primary education. Ordinarily, matters relating to the well-being of children under 5 years are more associated with the health sector because of the well-established global efforts to reduce under-5 mortality and childhood malnutrition. However, the architects of this SDG recognised the crucial and unique role of the health sector in preparing children from birth to age 5 years for effective enrolment in primary education. The SDG specifically acknowledged the importance of health and psychosocial well-being in assessing child development in early childhood.

Surprisingly, none of the targets and indicators for SDG 4, including ECD for children

under 5 years, are listed among the health-related SDGs by the WHO or the global health community in general.<sup>2</sup> As a result, a lacuna emerged that has been exploited by various ECD champions to promote discordant narratives that do not align with the extensive scientific evidence on the crucial role of the health sector in facilitating early detection and intervention services (EDIS) for all children at risk of poor development in early childhood.<sup>3</sup> This situation potentially impairs the opportunity for effective primary school enrolment among children under 5 years with disabilities as envisioned by SDGs. Moreover, the absence of an effective and universally accepted priority ECD framework for children under 5 years continues to undermine political support for appropriate policy and investment. For example, the flagship ECD programme by the WHO, UNICEF and the World Bank Group, titled Nurturing Care Framework (NCF), was premised on an estimated 250 million children under 5 years in low-income and middle-income countries (LMICs) who are suspected to be at risk of poor development or developmental delays due to stunting and poverty in 2015.<sup>4</sup> The recommended core interventions are home-based psychosocial stimulation and responsive caregiving among children younger than 3 years, which can be helpful but largely insufficient in addressing the special needs of children with disabilities. This ECD narrative was justified on the grounds that global estimates on children with disabilities, who are arguably at greater risk of poor development, especially in LMICs, were not available when the NCF was conceived in 2007.<sup>5</sup>

Meanwhile, estimates from the Global Burden of Disease database published in 2018 suggested that more than 53 million children

under 5 years were at risk of poor development due to developmental disabilities.<sup>6</sup> In addition, the prior and widely cited estimate of 93 million children under 15 years with moderate-to-severe disabilities first reported in 2014 was updated in 2020 to at least 291 million children under 20 years and includes mild-to-severe disabilities.<sup>7</sup> In November 2021, UNICEF published a special report for the first time in which almost 240 million children aged 2–17 years are estimated to be disabled based on parent-reported functional deficits.<sup>8</sup> The landmark report found that, compared with children without disabilities, children with disabilities are 34% more likely to be stunted, 25% more likely to be wasted, 24% less likely to receive early stimulation and responsive care, 25% less likely to attend early childhood education, 42% less likely to have foundational reading and numeracy skills, 49% more likely to have never attended school and 47% more likely to be out of primary school. In addition, a comparison of global estimates of under-5 mortality and under-5 disability suggests that globally, newborns are 10 times more likely to be disabled than to die before their fifth birthday.<sup>9</sup>

Taken together, available evidence from different sources, including the latest UNICEF report, clearly suggests the need for a complete overhaul of the NCF to reflect the required priority for ECD as envisaged under the SDGs. A major challenge is that global governance for child health and well-being is fragmented and disjointed.<sup>10</sup> The UN agencies often give the appearance of collaboration in their publications and reports, but in reality, the agencies tend to promote independent priorities that may inadvertently undermine the realisation of the commitments of UN member states to their citizens.<sup>11 12</sup> Mechanisms for accountability to the public are not clearly defined. Jurisdictional disputes and rivalry among units and professionals within and across these agencies are also not unusual, especially where roles and functions overlap.<sup>3</sup> These have contributed to the absence of an effective global governance for ECD policies and programmes. The evidence-based priorities for ECD are rarely embraced and matched with the core competences of the agencies. For example, whereas UNICEF is officially designated as the sole custodian agency for monitoring SDG 4.2.1 for ECD, the organisation would require a closer collaboration with the WHO, the World Bank Group and UNESCO in conceptualising - evidence-driven priority agenda. The WHO has a stronger leverage in the health sector among UN member states than any other agencies and is more resourced to guide and deliver health-related EDIS from birth to age 5 years. Without such an understanding and collaboration at the global level, the likelihood is that local officials in various government ministries will simply focus on sectoral programmes foisted on them by individual agencies without any consideration or sense of ownership for the outcomes among the target beneficiaries.

LMICs have a lot to benefit from time-tested approaches for children with disabilities in high-income

countries (HICs) where health sector-led ECD initiatives have proven to be a vital component of effective inclusive education policy. Countries without effective EDIS rooted in the health sector are likely to have poor enrolment, participation and retention of children with disabilities. These services are routinely offered in HICs but are yet to be considered a priority, in some contextually relevant form, in LMICs where the burden of disabilities in children under 5 years is substantial. The different approaches to ECD between HICs and LMICs only exacerbate the huge health, educational and social inequalities between the two regions and violate the spirit and letter of the SDGs that seek the well-being of all populations regardless of race, location and disability status.<sup>1</sup> It is important to emphasise that the scope of services required by children with disabilities in early childhood is multisectoral and extends beyond the health sector. However, the health sector provides the most reliable gateway to delivering and accessing the requisite services.

The case for investing in children under 5 years with disabilities to ensure meaningful progress by 2030 has been extensively discussed elsewhere.<sup>9</sup> Without effective partnership among the UN agencies and other key players in ECD, it is doubtful that the SDG vision for children under 5 years will be realised. The disabled persons organisations (DPOs) also need to be fully equipped and engaged to challenge and support these agencies. So far, this group of children is hardly included by the DPOs in their activities at the global and country levels. The synergistic benefits of this partnership for children with disabilities in LMICs are invaluable. For example, school readiness for inclusive education if appropriately conceptualised can serve as a key performance indicator for EDIS.<sup>13</sup> This would require that EDIS policy and programmes are geared towards addressing the poor statistics on school enrolment and drop-out rates in mainstream education among children with disabilities. This, in turn, would entail concerted efforts to address the well-documented social, cultural and economic barriers for effective EDIS, especially in LMICs.<sup>8 14 15</sup> Thus, UNESCO, as the lead agency for education globally, can provide the requisite long-term strategic vision for WHO–UNICEF-led ECD initiatives from birth to age 5 years as exemplified in some HICs.<sup>16</sup> Similarly, global investment in promoting inclusive education without complementary investment in EDIS for school readiness from birth is unlikely to yield optimal enrolment of children with disabilities. The health systems in LMICs will need to be adapted and strengthened to be functional and disability-friendly as it is currently the case in high-income countries. These recommendations are necessary and achievable to ensure an equitable ECD priority for children with disabilities and their families by 2030, especially in LMICs .

**Collaborators** Bolajoko O Olusanya, Ricardo Halpern, MKC Nair, Nem Yun Boo, Vivian G Cheung and Mijna Hadders-Algra, on behalf of the Global Research on Developmental Disabilities Collaborators (GRDDC).

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#### REFERENCES

- 1 United Nations. *Sustainable development goals*. New York, NY, USA: UN, 2015. <http://www.un.org/sustainabledevelopment/sustainable-development-goals>
- 2 GBD 2017 SDG Collaborators. Measuring progress from 1990 to 2017 and projecting attainment to 2030 of the health-related sustainable development goals for 195 countries and territories: a systematic analysis for the global burden of disease study 2017. *Lancet* 2018;392:2091–138.
- 3 Shawar YR, Shiffman J. Generation of global political priority for early childhood development: the challenges of framing and governance. *Lancet* 2017;389:119–24.
- 4 United Nations Children's Fund (UNICEF), World Health Organisation (WHO), the World Bank Group. *Nurturing care for early childhood development: a framework for helping children survive and thrive to transform health and human potential*. Geneva: World Health Organisation, 2018. <http://apps.who.int/iris/bitstream/handle/10665/272603/9789241514064-eng.pdf?ua=1>
- 5 Grantham-McGregor S, Cheung YB, Cueto S, *et al*. Developmental potential in the first 5 years for children in developing countries. *Lancet* 2007;369:60–70.
- 6 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;6:e1100–21.
- 7 Olusanya BO, Wright SM, Nair MKC, *et al*. Global burden of childhood epilepsy, intellectual disability, and sensory impairments. *Pediatrics* 2020;146:e20192623.
- 8 United Nations Children's Fund (UNICEF). *Seen, counted, included: using data to shed light on the well-being of children with disabilities*. New York: UNICEF, 2021. <https://data.unicef.org/resources/children-with-disabilities-report-2021/>
- 9 Global Research on Developmental Disabilities Collaborators. Accelerating progress on early childhood development for children under 5 years with disabilities by 2030. *Lancet Glob Health* 2022. doi:10.1016/S2214-109X(21)00488-5. [Epub ahead of print: 14 Jan 2022].
- 10 Clark H, Coll-Seck AM, Banerjee A, *et al*. A future for the world's children? A WHO-UNICEF-Lancet Commission. *Lancet* 2020;395:605–58.
- 11 Spicer N, Agyepong I, Ottersen T, *et al*. 'It's far too complicated': why fragmentation persists in global health. *Global Health* 2020;16:60.
- 12 Frenk J, Moon S. Governance challenges in global health. *N Engl J Med* 2013;368:936–42.
- 13 Peterson JW, Loeb S, Chamberlain LJ. The intersection of health and education to address school readiness of all children. *Pediatrics* 2018;142:e20181126.
- 14 George CE, Norman G, Benjamin TE, *et al*. Barriers to early diagnosis, intervention and social integration of children with developmental disabilities: a qualitative study from rural villages and a poor urban settlement of Bangalore, South India. *DCID* 2014;25:61–83.
- 15 Sapiets SJ, Totsika V, Hastings RP. Factors influencing access to early intervention for families of children with developmental disabilities: a narrative review. *J Appl Res Intellect Disabil* 2021;34:695–711.
- 16 U.S. Department of Education. 41st annual report to Congress on the implementation of the individuals with disabilities education act, parts B and C, 2019. Available: <https://sites.ed.gov/idea/files/41st-arc-for-idea.pdf> [Accessed 5 Feb 2022].