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EDITORIAL

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 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).[1] Unlike the Millennium Development Goals (MDGs), the SDGs 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 World Health Organisation (WHO), United Nations Children's Fund (UNICEF), United Nations Educational, Scientific and Cultural Organisation (UNESCO) and the World Bank Group are usually tasked with providing global leadership in implementing the SDGs within their 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 early childhood development, care, and pre-primary education so that they are ready for primary education by 2030. 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 through age 5 years for effective enrolment in primary education and 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 WHO or the global health community in general.[2] 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.[3] This action potentially impairs the chances of children under 5 years with disabilities for effective primary school enrolment 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 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- 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.[4] The recommended core interventions are home-based psychosocial stimulation and responsive caregiving among children younger than 3 years. 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.[5]

Meanwhile, estimates from the Global Burden of Disease (GBD) database suggest that more than 53 million children under 5 years were at risk of poor development due to developmental disabilities.[6] 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.[7] In November 2021, UNICEF, for the first time published a special report in which almost 240 million children aged 2-17 years are estimated to be disabled based on parent-reported functional deficits.[8] The landmark report found that, compared to children without disabilities, children with disabilities are 34 percent more likely to be stunted, 25 percent more likely to be wasted, 24 percent less likely to receive early stimulation and responsive care, 25 percent less likely to attend early childhood education, 42 percent less likely to have foundational reading and numeracy skills, 49 percent more likely to have never attended school and 47 per cent 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 ten times more likely to be disabled than to die before their fifth birthday.[9]

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. It is common knowledge that global governance for child health and wellbeing is fragmented and disjointed.[10] The UN agencies often give the appearance of collaboration both at international and local levels, especially in their publications and reports, but in reality, the agencies often

work in isolation, thereby undermining the realisation of the commitments of UN Member States to their citizens.[11,12] Mechanisms for accountability to the public are not clearly defined. Internal rivalry and power-play among units and professionals within these agencies is also not uncommon. This has resulted in 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 WHO, the World Bank Group and UNESCO in conceptualising an 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 learn 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 of children with disabilities. These services are routinely offered in HICs but are yet to be considered a priority 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 both regions and violates the spirit and letter of the SDGs that seek the well-being of all populations regardless of race, location, and disability status.[1] 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 accessing the requisite services.

The case for accelerating progress for children under 5 years with disabilities by 2030 has been extensively discussed elsewhere.[9] 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 are 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, inclusive education at school entry if appropriately conceptualised can serve as a key performance indicator for EDIS. This would require that EDIS policy and programmes are geared towards addressing the awful statistics on the low enrolment and drop-out rates in mainstream education among children with disabilities. This would entail concerted efforts to address the well-documented social, cultural, and economic barriers for effective EDIS, especially in LMICs.[8,13,14] 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 till age 5 years.

Similarly, global investment in promoting inclusive education without complementary investment in EDIS from birth is unlikely to yield optimal enrolment of children with disabilities. This would require a special attention to ensuring that health-systems in LMICs are functionally disability-inclusive as it is currently the case in high-income countries. These recommendations are achievable and necessary to ensure an equitable ECD priority for children with disabilities and their families, especially in LMICs.

Abbreviations

DPO: Disabled Persons Organisation; ECD: Early childhood development; EDIS: Early detection and intervention services; HIC: High income country; LMIC: Low- and middle-income country; NCF: Nurturing Care Framework; SDG: Sustainable Development Goal

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development, especially in LMICs, were not available when the NCF was launched in 2018.[5]

Meanwhile, estimates from the Global Burden of Disease (GBD) database published in 2018 suggested that more than 53 million children under 5 years were at risk of poor development due to developmental disabilities.[6] 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.[7] In November 2021, UNICEF, for the first time published a special report in which almost 240 million children aged 2-17 years are estimated to be disabled based on parent-reported functional deficits.[8] The landmark report found that, compared to children without disabilities, children with disabilities are 34 percent more likely to be stunted, 25 percent more likely to be wasted, 24 percent less likely to receive early stimulation and responsive care, 25 percent less likely to attend early childhood education, 42 percent less likely to have foundational reading and numeracy skills, 49 percent more likely to have never attended school and 47 per cent 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 ten times more likely to be disabled than to die before their fifth birthday.[9]

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. It is common knowledge that global governance for child health and wellbeing is fragmented and disjointed.[10] The

UN agencies often give the appearance of collaboration both at international and local levels, especially in their publications and reports, but in reality, the agencies often work in isolation, thereby undermining the realisation of the commitments of UN Member States to their citizens.[11,12] Mechanisms for accountability to the public are not clearly defined. Jurisdictional disputes and power-play among units and professionals within these agencies is also not uncommon especially where roles and functions overlap.[3] These have resulted in 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 WHO, the World Bank Group and UNESCO in conceptualising an 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 learn 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 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 both regions and violates the spirit and letter of the SDGs that seek the well-being of all populations regardless of race, location, and disability status.[1] 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 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.[9] 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 are 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.[13] 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 would entail concerted efforts to address the well-documented social, cultural, and economic barriers

for effective EDIS, especially in LMICs.[8,14,15] 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 till age 5 years as exemplified in some HICs.[16] 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 more functional and disability-friendly as it is currently the case in high-income countries. These recommendations are achievable and necessary to ensure an equitable ECD priority for children with disabilities and their families, especially in LMICs by 2030.

Abbreviations

DPO: Disabled Persons Organisation; ECD: Early childhood development; EDIS: Early detection and intervention services; HIC: High income country; LMIC: Low- and middle-income country; NCF: Nurturing Care Framework; SDG: Sustainable Development Goal

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