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

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EDITORIAL

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

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9 Surprisingly, none of the targets and indicators for SDG 4, including ECD for children
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11 community in general.² As a result, a lacuna emerged that has been exploited by various
12 ECD champions to promote discordant narratives that do not align with the extensive
13 scientific evidence on the crucial role of the health sector in facilitating early detection
14 and intervention services (EDIS) for all children at risk of poor development in early
15 childhood.³ This action potentially impairs the chances of children under 5 years with
16 disabilities for effective primary school enrolment as envisioned by SDGs. Moreover, the
17 absence of an effective and universally accepted priority ECD framework for children
18 under 5 years continues to undermine political support for appropriate policy and
19 investment. For example, the flagship ECD programme by WHO, UNICEF and the
20 World Bank Group, titled “Nurturing Care Framework” (NCF), was premised on an
21 estimated 250 million children under-5 years in low- and middle-income countries
22 (LMICs) who are suspected to be at risk of poor development or developmental delays
23 due to stunting and poverty in 2015.⁴ The recommended core interventions are home-
24 based psychosocial stimulation and responsive caregiving among children younger than
25 3 years. This ECD narrative was justified on the grounds that global estimates on
26 children with disabilities, who are arguably at greater risk of poor development,
27 especially in LMICs, were not available.⁵
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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

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2 work in isolation, thereby undermining the realisation of the commitments of UN
3
4 Member States to their citizens.^{11,12} Mechanisms for accountability to the public are not
5
6 clearly defined. Internal rivalry and power-play among units and professionals within
7
8 these agencies is also not uncommon. This has resulted in the absence of an effective
9
10 global governance for ECD policies and programmes. The evidence-based priorities for
11
12 ECD are rarely embraced and matched with the core competences of the agencies. For
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14 example, whereas UNICEF is officially designated as the sole custodian agency for
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16 monitoring SDG 4.2.1 for ECD, the organisation would require a closer collaboration
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18 with WHO, the World Bank Group and UNESCO in conceptualising an evidence-driven
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20 priority agenda. The WHO has a stronger leverage in the health sector among UN
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22 Member States than any other agencies and is more resourced to guide and deliver
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24 health related EDIS from birth to age 5 years. Without such an understanding and
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26 collaboration at the global level, the likelihood is that local officials in various
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28 government ministries will simply focus on sectoral programmes foisted on them by
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30 individual agencies without any consideration or sense of ownership for the outcomes
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32 among the target beneficiaries.
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43 LMICs have a lot to learn from time-tested approaches for children with disabilities in
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45 high-income countries (HICs) where health-sector led ECD initiatives have proven to be
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47 a vital component of effective inclusive education policy. Countries without effective
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49 EDIS rooted in the health-sector are likely to have poor enrolment of children with
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51 disabilities. These services are routinely offered in HICs but are yet to be considered a
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53 priority in LMICs where the burden of disabilities in children under 5 years is
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2 substantial. The different approaches to ECD between HICs and LMICs only exacerbate
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4 the huge health, educational and social inequalities between both regions and violates
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6 the spirit and letter of the SDGs that seek the well-being of all populations regardless
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8 of race, location, and disability status.¹ It is important to emphasise that the scope of
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10 services required by children with disabilities in early childhood is multisectoral and
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12 extends beyond the health sector. However, the health sector provides the most reliable
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14 gateway to accessing the requisite services.
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21 The case for accelerating progress for children under 5 years with disabilities by 2030
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23 has been extensively discussed elsewhere.⁹ Without effective partnership among the UN
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25 agencies and other key players in ECD it is doubtful that the SDG vision for children
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27 under 5 years will be realised. The disabled persons organisations (DPOs) also need to
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29 be fully equipped and engaged to challenge and support these agencies. So far this group
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31 of children are hardly included by the DPOs in their activities at the global and country
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33 levels. The synergistic benefits of this partnership for children with disabilities in
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35 LMICs are invaluable. For example, inclusive education at school entry if appropriately
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37 conceptualised can serve as a key performance indicator for EDIS. This would require
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39 that EDIS policy and programmes are geared towards addressing the awful statistics
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41 on the low enrolment and drop-out rates in mainstream education among children with
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43 disabilities. This would entail concerted efforts to address the well-documented social,
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45 cultural, and economic barriers for effective EDIS, especially in LMICs.^{8,13,14} Thus,
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47 UNESCO, as the lead agency for education globally can provide the requisite long-term
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49 strategic vision for WHO-UNICEF-led ECD initiatives from birth till age 5 years.
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2 Similarly, global investment in promoting inclusive education without complementary
3 investment in EDIS from birth is unlikely to yield optimal enrolment of children with
4 disabilities. This would require a special attention to ensuring that health-systems in
5 LMICs are functionally disability-inclusive as it is currently the case in high-income
6 countries. These recommendations are achievable and necessary to ensure an equitable
7 ECD priority for children with disabilities and their families, especially in LMICs.
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19 **Abbreviations**

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21 DPO: Disabled Persons Organisation; ECD: Early childhood development; EDIS: Early
22 detection and intervention services; HIC: High income country; LMIC: Low- and middle-
23 income country; NCF: Nurturing Care Framework; SDG: Sustainable Development
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17 Moreover, the absence of an effective and universally accepted priority ECD framework
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8 policies and programmes. The evidence-based priorities for ECD are rarely embraced
9 and matched with the core competences of the agencies. For example, whereas UNICEF
10 is officially designated as the sole custodian agency for monitoring SDG 4.2.1 for ECD,
11 the organisation would require a closer collaboration with WHO, the World Bank Group
12 and UNESCO in conceptualising an evidence-driven priority agenda. The WHO has a
13 stronger leverage in the health sector among UN Member States than any other
14 agencies and is more resourced to guide and deliver health related EDIS from birth to
15 age 5 years. Without such an understanding and collaboration at the global level, the
16 likelihood is that local officials in various government ministries will simply focus on
17 sectoral programmes foisted on them by individual agencies without any consideration
18 or sense of ownership for the outcomes among the target beneficiaries.

19 LMICs have a lot to learn from time-tested approaches for children with disabilities in
20 high-income countries (HICs) where health-sector led ECD initiatives have proven to be
21 a vital component of effective inclusive education policy. Countries without effective
22 EDIS rooted in the health-sector are likely to have poor enrolment of children with

1 disabilities. These services are routinely offered in HICs but are yet to be considered a
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4 priority, in some contextually relevant form, in LMICs where the burden of disabilities
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7 in children under 5 years is substantial. The different approaches to ECD between HICs
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10 and LMICs only exacerbate the huge health, educational and social inequalities
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12 between both regions and violates the spirit and letter of the SDGs that seek the well-
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14 being of all populations regardless of race, location, and disability status.¹ It is
15
16 important to emphasise that the scope of services required by children with disabilities
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18 in early childhood is multisectoral and extends beyond the health sector. However, the
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20 health sector provides the most reliable gateway to accessing the requisite services.
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26 The case for investing in children under 5 years with disabilities to ensure meaningful
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28 progress by 2030 has been extensively discussed elsewhere.⁹ Without effective
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30 partnership among the UN agencies and other key players in ECD it is doubtful that
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32 the SDG vision for children under 5 years will be realised. The disabled persons
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34 organisations (DPOs) also need to be fully equipped and engaged to challenge and
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36 support these agencies. So far this group of children are hardly included by the DPOs
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38 in their activities at the global and country levels. The synergistic benefits of this
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40 partnership for children with disabilities in LMICs are invaluable. For example, school
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42 readiness for inclusive education if appropriately conceptualised can serve as a key
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44 performance indicator for EDIS.¹³ This would require that EDIS policy and programmes
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46 are geared towards addressing the poor statistics on school enrolment and drop-out
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48 rates in mainstream education among children with disabilities. This would entail
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50 concerted efforts to address the well-documented social, cultural, and economic barriers
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2 for effective EDIS, especially in LMICs.^{8,14,15} Thus, UNESCO, as the lead agency for
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4 education globally can provide the requisite long-term strategic vision for WHO-
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6 UNICEF-led ECD initiatives from birth till age 5 years as exemplified in some HICs.¹⁶
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8 Similarly, global investment in promoting inclusive education without complementary
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10 investment in EDIS for school readiness from birth is unlikely to yield optimal
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12 enrolment of children with disabilities. The health-systems in LMICs will need to be
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14 adapted and strengthened to be more functional and disability-friendly as it is currently
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16 the case in high-income countries. These recommendations are achievable and
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18 necessary to ensure an equitable ECD priority for children with disabilities and their
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20 families, especially in LMICs by 2030.
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28 **Abbreviations**

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