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Global leadership to optimize early childhood development for children with disabilities

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In 2015, 193 world leaders, under the auspices of the United Nations, adopted as ‘a universal call to action’ 17 Sustainable Development Goals (SDGs), to be achieved by 2030 [1]. The fourth goal (SDG 4) included a commitment to take steps to ensure inclusive and equitable quality education and promote lifelong learning opportunities for all [1]. To achieve this goal, the leaders further agreed that “by 2030, all children should have access to quality early childhood development, care, and pre-primary education so that they are ready for primary education” (SDG 4.2). To assess the progress toward achieving this target globally, UNICEF is required to monitor the proportion of children under 5 years of age (revised subsequently to children 24-59 months of age) who are developmentally on track in health, learning and psychosocial well-being, (SDG 4.2.1), while UNESCO is charged with monitoring school readiness indexed by “the participation rate in organized learning, one year before the official primary entry age” (SDG 4.2.2). Thus, optimizing the readiness of children with disabilities for school, in order to facilitate their access to inclusive and equitable quality education, constitutes a fundamental aspect of the global pledge and commitment to early childhood development [2]. Given the urgency of the matter, there is a need to prioritize early childhood development and education for children with disabilities, in addition to implementing effective governance, monitoring, and accountability mechanisms, in order to realize the global commitment to inclusive education by 2030.

Prevalence and Consequences of Childhood Disabilities

When the SDGs were launched in 2015 there were limited data available on the global prevalence of disabilities in children and adolescents to guide purposeful policy intervention. In 2018, the Global Burden of Disease (GBD) Study used data from 195 countries and territories from 1990-2016 to estimate that 53 million children worldwide under 5 years had developmental disabilities [3]. Additional data from the 2019 GBD Study showed that, globally, the likelihood of a child having a disability before their fifth birthday was ten times higher than the likelihood of dying (377.2 vs 38.2 per 1000 livebirths) [4].

In November 2021, UNICEF published a special report showing that when compared to children without disabilities, children with disabilities experience substantively more discrimination and are likely to have substantially poorer foundational reading and numeracy skills [5]. Children with disabilities are also significantly more likely to have never attended school and less likely to complete primary education [5]. The report further showed that children with disabilities of almost every background (gender, family income level and residential status) have lower rates of primary school readiness than children without disabilities and that the disparities are largest among children in the poorest households.

To date, global funding programs for early childhood development do not reflect the substantial health, social, educational, and economic inequities faced by children with disabilities and their families; this is especially true in low- and middle-income countries (LMICs), where the prevalence is greatest [5-7]. For example, of the estimated US\$79.1 billion disbursed as development assistance for early childhood development by donor countries and private foundations between 2007 and 2016 only US\$0.5 billion (0.6%) was channeled to disability [7]. Whereas components of early childhood development such as good health, early learning, responsive care, as well as nutrition and growth recorded increased funding of between 6.5% and 24.5%, disability-specific funding declined by 11.4% over this period [7]. This funding pattern is iniquitous given the increase in the population of children surviving globally – including those with disabilities [3].

Progress Reports on SDGs

The latest Goalkeepers Report from the Bill & Melinda Gates Foundation has shown that seven years after the launch of the SDGs, the world is on track to achieve almost none of the goals, although under-5 mortality continues to decline globally since 1990 [8]. The UN’s primary and extended

progress reports on the SDGs for 2022 did not provide any data on the global status of early childhood development [9]. This is particularly concerning as school closures due to the COVID-19 pandemic have had worrisome consequences for children's learning and well-being, particularly for girls and those who are disadvantaged, such as children with disabilities. It is estimated that the current generation of children could lose a combined total of \$17 trillion in lifetime earnings (in current value) due to the pandemic [10]. Even among the disability community, the critical role of early childhood development is not always fully appreciated or emphasized. For example, early childhood development was not included in the agenda for inclusive education at the Global Disability Summit 2022, and as a result, received no funding commitments from donors [11]. It is not too late for action. UNICEF, as the leading global advocate for child health and well-being, as well as the joint-custodian of SDG 4.2, can reverse this trajectory for children with disabilities before 2030.

Matching Priorities with Pledges

In 2018, UNICEF in partnership with the World Health Organization (WHO) and the World Bank launched a global initiative for early childhood development termed the “Nurturing Care Framework” (NCF) [12]. The initiative has been presented as a roadmap for action to ensure that every baby gets the best start in life. However, at its conception, the NCF was based on children under 5 years old who were at an increased risk of poor development due to stunting and extreme poverty. It is, therefore, not surprising that the recommended package of interventions excluded services for children with disabilities [13]. An integrated framework for nurturing care has now been proposed for all children regardless of their disability status, [14] but there is no robust scientific or anecdotal evidence to support such a one-size-fits all approach to early childhood development, particularly for children with disabilities [15]. Moreover, efforts to portray existing policies as disability-inclusive often mask the priorities for the needs of children with disabilities. Thus, inclusion does not always assure prioritization.

In January 2022, UNICEF launched the Strategic Plan 2022-2025 aimed at accelerating progress toward the attainment of SDGs within its purview by 2030 [16]. The organization rightfully pledged to prioritize the most marginalized children and adolescents, including children with disabilities, children affected by humanitarian crises, children on the move, and children from the poorest households. This promise is consistent with UNICEF's mission statement since 1946, which committed to ensuring that the most disadvantaged children and the countries in greatest need will have priority literally “in everything it does” [17]. Strangely, there is scant mention of “children with disabilities” in Goal Areas 1 and 2, no mention of SDG 4.2, nor does this Strategic Plan reflect the evidence on the prevalence and impact of disabilities in children published by the organization since 2013 (Web Appendix) [5,18]. This exclusion has profound implications on the public perception of the priorities of this organization in the deployment of its resources till 2025, barely 5 years till end of the SDGs. Children with disabilities are likely to remain invisible to policy and decision makers in global health if appropriate and timely action is not taken by relevant stakeholders including families and care givers.

Translating Evidence into Action

Available evidence has now shown that children with disabilities deserve to be prioritized in any global program on early childhood development and care. In practical terms, this would entail first and tangible action for the needs of children with disabilities before the needs of other children in the allocation of resources for health and educational services. WHO has published a policy document for promoting health equity for persons with disabilities in consultation with representatives of the disability community [19], Early childhood development was clearly acknowledged as a fundamental factor for the meaningful participation of persons with disabilities in society and offers a critical

window of opportunity to shape the trajectory of a child's holistic development and build a foundation for their future life. Family-centered early detection and intervention from birth for children with or at risk of disabilities is vital in any global initiative for early childhood development [20,21].

An overview of actions needed to address the needs of children with disabilities and their families are summarized in Table 1. An effective strategy on early childhood development for children with disabilities must identify and address the barriers to service utilization. For instance, poor parental awareness of disability, unfavorable cultural and religious beliefs, social stigma, discrimination and exclusion, lack of services for routine detection and management of disabilities, unaffordability of services when available, are all common barriers to early detection and intervention for children with disabilities [5,22]. Transportation costs add to the financial burden on families as most children with disabilities reside in rural areas while the available health facilities for disabilities are concentrated in large urban towns [22]. Delayed diagnosis reduces the effectiveness of intervention services. Universal Health Coverage is acknowledged in the SDGs as a pathway for addressing most of these barriers across four domains: socio-cultural context and family experience; early detection and diagnosis; evidence-based early intervention; and social policy and legislation [23]. Universal Health Coverage provides an opportunity to recruit and train health workers, while also increasing their awareness of barriers to access for children with disabilities. A specialist workforce is also needed for the diverse range of childhood disabilities, as outlined in a recent report from the International Pediatric Association (IPA) [24].

Policy makers, relevant UN agencies and funding partners need to embrace the overarching vision of inclusive quality education as mandated by the SDGs [2]. The wide array of stakeholders in global child health and development can lead to a multiplicity of vested interests, priorities and approaches to early childhood care and development which require effective multi-sectoral coordination [25]. UNICEF has a critical role to play in providing global leadership to implement evidence-based priorities for early childhood development in LMICs. in line with the subsisting and unfilled global commitment for inclusive education [1]. It is important to acknowledge that UNICEF was not primarily established as a funding agency, and its role is not to fund programs. However, the organization possesses the political influence, capacity, and goodwill for mobilizing technical and financial resources to build requisite local capacity in LMICs, and thus accelerate progress in addressing the needs of children with disabilities and their families.

Accountability Nurtures Commitment

The lack of coordination between global pledges and priorities, plans, or programs on early childhood development for inclusive education is likely to evoke mistrust among the target beneficiaries, particularly when proven strategies that can be implemented in LMICs exist [2,3]. An independent accountability framework in global health is required that provides a mechanism for evaluating the appropriateness of planned programs and priorities for realizing the agreed pledges and commitments [21]. Such an accountability framework will include measurable performance indicators and targets for advancing health equity. For example, the SDGs requires the participation rate in organized learning (one year before the official primary entry age typically 5-6 years) to be monitored regardless of disability status. This performance indicator of early childhood development should be accompanied by specific targets at the country level to assess progress or the lack of it, similar to the country targets for reducing under-5 mortality by 2030 in the SDGs [1].

We acknowledge that the realization of optimal early childhood development and school readiness for inclusive education is a task that cannot be accomplished solely by UNICEF, considering the challenges in the health, social and educational systems in many LMICs [25]. Therefore, collaboration with other stakeholders such as the World Health Organization and UNESCO, regional-local governments, key civil ministries (health care, education, civil rights), funders and

NGOs is deemed essential. Representatives of families of children with disabilities are equally important in this collaborative process. The effectiveness of UNICEF's Strategic Plan (2022-2025) will ultimately be evaluated based on the degree to which its long-standing commitment to prioritize children with disabilities and other disadvantaged children is consistently reflected in all its actions, as a statutory, evidence-based, and ethical imperative. Effective and accountable leadership is crucial to realizing the unfilled commitments for the world's children with disabilities.

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Table 1. Recommendations for promoting early childhood development for children with disabilities in global health

Theme	Recommended Actions
Global Leadership and Governance	<p>UNICEF in consultation with WHO, UNESCO, World Bank and Relevant Disabled Persons Organizations should:</p> <ul style="list-style-type: none"> • Clarify and frame global policy and priorities for early childhood development for children under 5 years with disabilities in line with existing global health and educational agenda (SDG 4). • Ensure that the concept of disability-prioritization is not erroneously presented solely as disability inclusion or mentions in policy document. • Emphasize the three components of School Readiness for Inclusive Education - child readiness, family and community readiness, and school readiness – necessary for achieving SDG 4.2.
Global Early Childhood Development Framework	<p>UNICEF in consultation with WHO, UNESCO, World Bank and Relevant Disabled Persons Organizations should:</p> <ul style="list-style-type: none"> • Avoid an omnibus or “inclusive” early childhood development program for all children regardless of disability status and severity. • Develop a universal framework for promoting early childhood development for children under 5 years with disabilities. • Evaluate and coordinate existing strategies, plans, and programs developed by various global institutions to implement early childhood development for children under 5 years to optimize impact. • Emphasize the role of early detection and intervention from conception and its integration into the global initiative on Universal Health Coverage. • Develop evidence-based operational guidelines and provide technical support for country-level pilot programs to determine what works in different settings.
Model of Care	<p>Ministries of Health in collaboration with Ministries of Education and Social Welfare should:</p> <ul style="list-style-type: none"> • Integrate maternal education on early childhood development for children under 5 years with or at risk of disabilities into routine antenatal care. • Provide free, routine, and mandatory newborn screening for congenital disorders including hearing loss. • Introduce routine developmental screening and surveillance during health visits for immunization and other services using appropriate and well validated tests. • Establish referral systems for primary care providers to facilitate timely diagnosis and enrolment into intervention program. • Establish a two-channel system for early intervention by means of family coaching: one channel using lay community health workers and the other using the combination of lay community health workers and health professionals.

- Provide affordable and well-adapted assistive technologies (e.g. Augmentative Alternative Communication devices for non-speaking autistic children) where required, with appropriate and functioning supply chains.
- Establish early detection and intervention for mental health concerns among parents of children under 5 years with disabilities.
- Facilitate and strengthen multi-disciplinary co-ordination at all levels of service delivery: tertiary, secondary and primary/community.

Quality of Care

Ministries of Health in collaboration with Ministries of Education and Social Welfare should:

- Provide evidence-based local guidelines for service provision for children with disabilities to strengthen the quality-of-service provision.
- Introduce local legislation to protect families from financial exploitation and substandard service delivery especially by unregulated private sectors care providers.
- Deinstitutionalize mental care for children under 5 years with psychosocial disabilities.
- Institute community-based counselling and mental health services for parents of children under 5 years with disabilities.
- Develop quality standards for locally produced and imported assistive devices.

Physical Infrastructure and Health Workforce

Ministries of Health in collaboration with Ministries of Education and Social Welfare should:

- Implement a universal design-based approach to the development or refurbishment of health facilities and services.
- Designate and equip tertiary centers for advanced specialist care for severe and complex disabilities.
- Optimize telemedicine and mobile-based platforms for delivery of educational materials and disability services.
- Ensure the availability of a skilled health and care workforce.
- Provide training for all health service providers including community health workers on how to meet the needs of children under 5 years with disabilities directly or appropriate referral.
- Facilitate the recruitment of adults with lived experience of disability or parents of children with disabilities as community health care workers, primary care providers, early interventionists, and pre-school educators as part of the health and education workforce.

Social Barriers to Service Utilization

Ministries of Health in collaboration with Ministries of Education and Social Welfare should:

- Promote public campaign for greater awareness and positive attitude to children with disabilities.
- Provide emotional support services for parents and young children with disabilities, focused on acceptance, empowerment, and coping strategies to deal with daily stress.
- Implement public health strategies to address social stigma and discrimination especially with the use of assistive technologies.
- Introduce legislation against violence, abuse, and maltreatment of children with disabilities.

Financial Support for Families

Ministries of Health in collaboration with Ministries of Education and Social Welfare should:

- Introduce Child Disability Allowance for low-income families.

- Include disability care seeking as a component of National Social Safety Net Program typically supported by the World Bank.
- Introduce community-based health insurance schemes to cover expenses for specialist services and assistive technologies.
- Introduce a financial policy that ensures that access to professionally recommended services is not denied on account of affordability.
- Provide tax incentives to private organizations that invest in services for children with disabilities.

Global Funding

World Bank in partnership with Providers of Developmental Assistance for Health and International Donors should:

- Align funding programs for early childhood development with existing global commitments and the SDGs.
- Support countries to set up dedicated budget and financing mechanism for strengthening health systems, including the recruitment, and training of specialists and community health workers for disability services.
- Consider match-funding with countries and local organizations for disability focused projects.
- Ring-fence disability funding programs within the general developmental assistance for child health to LMICs.
- Institute routine country audits and independent monitoring mechanism for disability-focused expenditures.
- Ensure the on-going country funding is contingent on satisfactory performance review of disability services.
- Commission periodic independent review of global health financing for children with disabilities globally.

Performance Targets and Indicators

UNICEF in consultation with WHO, UNESCO, World Bank and Relevant Disabled Persons Organizations should:

- Determine valid, reliable, and timely targets and indicators to measure quality of services for children with disabilities.
- Report on and monitor service providers in national human resources information systems to inform workforce development and distribution.
- Determine measurable targets and indicators that reflect uptake of services by children with disabilities.
- Establish independent data collection team at the country level and encourage country ranking by performance on agreed indicators.

Monitoring and Accountability

UN Accredited Civil Society Organizations, Child Advocacy Groups, Human Rights Organization, and Independent Scientists should:

- Undertake periodic evaluation of global and national progress in implementing agreed policies.
- Identify challenges to service provision and possible mitigants.
- Monitor to ensure alignment of disability programs with agreed global commitments and priority.

Note: This table was developed by members of the Global Research on Developmental Disabilities Collaborators (GRDDC) based on published reports and contributions from a diversified group of professional caregivers with and without lived experience of disabilities, including parents of children with disabilities, from different world regions and cultures. The list is not exhaustive and can be modified as appropriate for different contexts.

