

Global leadership is needed to optimize early childhood development for children with disabilities

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UNICEF and other international bodies must produce a clear plan that prioritizes development and education for children with disabilities, especially in low- and middle-income settings, as required for achieving the United Nations Sustainable Development Goals.

In 2015, 193 world leaders, under the auspices of the United Nations (UN), adopted 17 Sustainable Development Goals (SDGs) as a universal call to action to be achieved by 2030 (ref. 1). The fourth goal (SDG 4) included a commitment to ensure inclusive and equitable quality education and promote lifelong learning opportunities for all¹. 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 made toward achieving this target globally, UNICEF is required to monitor the proportion of children under five 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 as indexed by “the participation rate in organized learning, one year before the official primary entry age” (SDG 4.2.2). Optimizing the readiness of children with disabilities for school, to facilitate their access to inclusive and equitable quality education, is the overarching purpose of the global pledge and the commitment to early childhood development. Given the 2030 deadline, 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, to realize the global commitment to inclusive education.



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Childhood disabilities

When the SDGs were launched in 2015, there were limited data available on the global prevalence of disabilities in children and adolescents that could be used to guide purposeful policy intervention. In 2018, the Global Burden of Disease (GBD) study used data from 195 countries and territories that were collected across 1990–2016 to estimate that 53 million children aged under five years had developmental disabilities worldwide². Additional data from a GBD study in 2019 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 versus 38.2 per 1,000 livebirths)³.

In November 2021, UNICEF published a special report showing that children with disabilities experience substantively more discrimination and are likely to have substantially poorer foundational reading and numeracy skills, compared to children without disabilities⁴. Children with disabilities are also significantly more likely to have never attended school and less likely to complete primary education⁴. The report further showed that children with disabilities of almost every background, regardless of gender, family income level and residential status, have lower rates of primary school readiness than children without disabilities; these disparities are greatest among children in the poorest households.

Existing global funding schemes 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 of children affected is greatest^{4,5}. 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 channelled for disability⁵. Components of early childhood development such as good health, early learning and responsive care, as well as nutrition and growth, recorded increased funding between 6.5% and 24.5% during this period, whereas disability-specific funding declined by 11.4% (ref. 5). This funding pattern is iniquitous given the increase in the population of children surviving globally – including those with disabilities^{2,3}.

Slow progress

The latest Goalkeepers Report from the Bill & Melinda Gates Foundation has shown that the world is on track to achieve almost none of the goals, although the mortality of children under five years of age has continued to decline globally since 1990 (ref. 6). 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 development⁷. This is particularly concerning as school closures due to the COVID-19 pandemic have had negative consequences for children's learning and wellbeing, 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 US\$17 trillion in lifetime earnings (in current value) due to the pandemic⁸. Even among the disability community, the critical role of early childhood development is not always fully appreciated or emphasized, as demonstrated by the lack of funding commitments from donors during the Global Disability Summit in 2022 (ref. 9). It is not too late for action. UNICEF, as the leading global advocate for child health and wellbeing, as well as the joint custodian of SDG 4.2, can reverse this trajectory for children with disabilities before 2030 by acting promptly and decisively on the recommendations in this article (Table 1).

Inclusion without prioritization

In 2018, UNICEF in partnership with the WHO (World Health Organization) and the World Bank launched a global initiative for early childhood development: the Nurturing Care Framework (NCF)¹⁰. 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 five years of age who were at an increased risk of poor development due to stunting and extreme poverty, and so excluded services for children with disabilities. An integrated framework for nurturing care has now been proposed for all children regardless of their disability status, 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 disabilities¹¹. Moreover, efforts to portray existing policies as disability-inclusive often mask the priorities for the needs of children with disabilities. Inclusion does not always assure prioritization.

In January 2022, UNICEF launched the Strategic Plan 2022–2025, aimed at achieving the SDGs within its purview by 2030 (ref. 12). 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 the UNICEF mission statement established in 1946, which committed to ensuring that the most disadvantaged children and the countries in greatest need will have priority “in everything it does”¹³. However, there is scant mention of “children with disabilities” in goal areas 1 and 2, no mention of SDG 4.2, and this strategic plan does not reflect the evidence on the prevalence and impact of disabilities in children that has been published by UNICEF since 2013 (ref. 4). Children with disabilities are likely to remain invisible to policy and decision makers in global health if appropriate, and timely actions are not taken by relevant bodies and stakeholders including families and care givers.

Evidence demands action

Children with disabilities deserve to be prioritized in any global program on early childhood development and care. In practical terms, this would entail 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. The national health-care system is the principle contact for children with disabilities to receive medical support, underscoring the need for collaboration with WHO. For example, WHO has published a policy document for promoting health equity for persons with disabilities in consultation with representatives of the disability community¹⁴. Early childhood development was 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.

An overview of actions needed to address the needs of children with disabilities and their families in ten key subject areas are summarized in Table 1. Policy makers, relevant UN agencies and funding partners need to embrace the overarching vision of inclusive quality education as mandated by the SDGs. The wide array of stakeholders in global child health and development comprises a multiplicity of vested interests, priorities and approaches to early childhood care and development that require effective multisectoral coordination.

Table 1 | Recommendations to promote early childhood development for children with disabilities under five years of age

Theme	Key actors	Recommended actions
Global leadership and governance	UNICEF in consultation with WHO, UNESCO, World Bank and relevant disabled-persons organizations	<ul style="list-style-type: none"> Clarify and frame global policy and priorities for early childhood development for children with disabilities under five years of age, in line with existing global health and educational agenda under the SDGs Ensure that the concept of disability inclusion is not erroneously presented as disability prioritization Emphasize the three components of school readiness for inclusive education necessary for achieving SDG 4.2: the child's readiness, family and community's readiness and school's readiness
Global Early Childhood Development Framework	UNICEF in consultation with WHO, UNESCO, World Bank and relevant disabled-persons organizations	<ul style="list-style-type: none"> Avoid any omnibus early childhood development program designed for all children regardless of disability status and severity Develop a universal and comprehensive framework for promoting early childhood development for children with disabilities under five years of age Evaluate and coordinate existing global and sectoral programs to implement early childhood development for children under five years of age to optimize impact Emphasize the role of early detection and intervention from conception and its integration into 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	Ministries of health, women and child development, in collaboration with ministries of education and social welfare	<ul style="list-style-type: none"> Integrate maternal education into routine antenatal care, highlighting the importance of early detection and intervention for children under five years of age with or at risk of disabilities Provide free, routine and mandatory newborn screening for metabolic and congenital disorders, including hearing loss Promote basic developmental screening and surveillance during routine 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 Introduce 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 (such as augmentative alternative communication devices for non-speaking autistic children) where required, with appropriate and functioning supply chains Emphasize the importance of early detection and intervention for mental health concerns among parents of children with disabilities under five years of age Facilitate and strengthen multidisciplinary coordination at all levels of service delivery: tertiary, secondary and primary/community
Quality of care	Ministries of health, women and child development, in collaboration with ministries of education and social welfare	<ul style="list-style-type: none"> Provide evidence-based and family-centered local guidelines for children with disabilities to ensure the best possible service quality Emphasize care delivery that focuses on activities and participation and is not restricted to body impairments Introduce local legislation to protect families from financial exploitation and substandard service delivery, especially by unregulated private-sector care providers Deinstitutionalize mental care for children under five years of age with psychosocial disabilities Institute community-based counselling and mental health services for parents of children under five years of age with disabilities Develop quality control standards for locally produced and imported assistive devices
Physical infrastructure and workforce	Ministries of health, women and child development, in collaboration with ministries of education, social welfare and public works	<ul style="list-style-type: none"> 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 Facilitate the use of telemedicine and mobile platforms for delivery of educational materials and disability services Ensure the availability of skilled health and pre-school workforce at all levels of service delivery Recruit, as far as practicable, adults with lived experience of disability or parents of children with disabilities as community healthcare workers, primary care providers, early interventionists and pre-school educators as part of the health and education workforce Provide entry-level and ongoing disability training for service providers, including the recognition of the importance of timely and appropriate referral
Social barriers to service utilization	Ministries of health, women and child development, in collaboration with ministries of education, social welfare and justice	<ul style="list-style-type: none"> Promote a 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 for users of assistive technologies Introduce and enforce legislation against violence, abuse and maltreatment of children with disabilities
Financial support for families	Ministries of health, women and child development, in collaboration with ministries of education, social welfare and finance	<ul style="list-style-type: none"> Introduce a child disability allowance for low-income families Promote 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 promote and invest in services for children with disabilities

Table 1 (continued) | Recommendations to promote early childhood development for children with disabilities under five years of age

Theme	Key actors	Recommended actions
Global funding	World Bank in partnership with providers of developmental assistance for health and international donors, and in consultation with relevant ministries	<ul style="list-style-type: none"> Align current and future funding programs for early childhood development with existing global commitments under the SDGs Support countries to set up a dedicated budget and financing mechanism to strengthen health and pre-school systems, including the recruitment and training of a specialist and community-based workforce 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 to LMICs for child health services Institute routine country audits and an independent monitoring mechanism for disability-focused expenditures Ensure that ongoing 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, ministries of health and education and relevant disabled-persons organizations	<ul style="list-style-type: none"> Introduce valid, reliable and timely targets and indicators to measure the quality and impact 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 organizations and independent experts	<ul style="list-style-type: none"> Undertake periodic evaluation of global, regional and national progress in implementing early childhood development and care for children with disabilities under five years of age Identify challenges to service provision and uptake and suggest possible mitigants Monitor and evaluate alignment of disability programs and funding with agreed global commitments and priorities Disseminate findings from periodic assessments to the general public, donors and relevant stakeholders

Recommendations were developed 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 and expanded as appropriate for different contexts.

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 global commitment for inclusive education¹. 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 accelerate progress in addressing the needs of children with disabilities and their families.

An effective strategy on early childhood development for children with disabilities must identify and address the barriers to service utilization. Common barriers to early detection and intervention for children with disabilities include: poor parental awareness of disability; cultural and religious beliefs; social stigma; discrimination and exclusion; lack of services for routine detection and management of disabilities; and unaffordability of services when available⁴. 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. Delayed diagnosis reduces the effectiveness of intervention services. The provision for universal health coverage in the SDGs offers a pathway to address most of these barriers across four domains: sociocultural context and family experience; early detection and diagnosis; evidence-based early intervention; and social policy and legislation¹⁵. Universal health coverage also provides an opportunity to recruit and train primary and community health workers, while also increasing their awareness of barriers to access for children with disabilities. A specialist workforce is also needed to handle referrals for the diverse range of childhood disabilities.

Accountability nurtures commitment

The lack of coordination between existing global pledges on inclusive education and the current programs on early childhood development is likely to evoke mistrust among the target beneficiaries, particularly when proven strategies that can be implemented in LMICs exist³. An independent accountability framework in global health that provides a mechanism to evaluate the appropriateness of planned programs and priorities so that the agreed pledges and commitments can be realized is required. Such an accountability framework will include measurable performance indicators and targets for advancing health equity. For example, the SDGs require the participation rate in organized learning (1 year before the official primary entry age, which is 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 SDG country targets for reducing mortality of children under five years of age by 2030 (ref. 1).

The realization of optimal early childhood development and school readiness for inclusive education is a task that cannot be accomplished solely by UNICEF, in part because of the challenges in the health, social and educational systems in many LMICs. Therefore, collaboration with other agencies and stakeholders, including WHO and UNESCO, regional-local governments, key civil ministries (such as healthcare, education and civil rights), funders and non-governmental organizations, is essential. Families of children with disabilities must also be included in this collaborative process. The effectiveness of UNICEF's Strategic Plan 2022–2025 will ultimately be evaluated by whether 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 unfulfilled commitments for the world's children with disabilities.

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Competing interests

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