The Nurturing Care Framework and Children with Developmental Disabilities in LMICs

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Abbreviations: ECD, Early childhood development; LMICs, Low- and middle-income countries; NCF, Nurturing care framework; SDGs, Sustainable Development Goals; UNICEF, United Nations Children's Fund; WHO, World Health Organization

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In 2018, the World Health Organization (WHO), the United Nations Children's Fund (UNICEF) and the World Bank jointly launched a global early childhood development (ECD) program termed the "Nurturing Care Framework" (NCF).[1] The NCF - seeks to support children's care and development in the first three years of life across five dimensions: responsive caregiving, early learning, safety and security, nutrition, and health. The recommended core intervention package consists of the training of parents and caregivers to promote good nutrition, and opportunities for early learning and psychosocial stimulation through play in the first three years of life.[1,2]

At its conception in 2007, the NCF was predicated on an estimated 200 million (later updated in 2016 to 250 million) children under 5 years in low- and middle-income countries (LMICs) at risk of not realizing their developmental potential due to stunting and poverty in 2010.[3] There was no consideration for children with developmental disabilities due to the dearth of population-based data. However, the global health agenda from 2015 to 2030 under the United Nations Sustainable Development Goals (SDGs) calls for a global ECD program specifically aimed at promoting school readiness toward inclusive education for children under 5 years with or at risk of developmental disabilities (SDG 4.2).[4] The principle and concept of inclusive education predominantly requires a dedicated focus on children with developmental disabilities.[5] The need for such a disability-focused ECD program has been reinforced by the emerging evidence on the high prevalence of developmental disabilities in children and adolescents in LMICs.[6,7]

In an attempt to respond to this call, there has been an on-going effort to broaden the scope of NCF as an integrated, all-inclusive ECD program for all children regardless of their disability status.[8] In this perspective paper, we examine the practicality of such an inclusive ECD strategy for all children and offer some suggestions on the way forward based on the available evidence on the special health and educational needs of children with developmental disabilities in

LMICs.

Prevalence and Consequences of Developmental Disabilities in Early Childhood

In 2018, some 53 million children under 5 years were estimated in the Global Burden of Disease (GBD) Study 2016 to have developmental disabilities, 95% of whom resided in LMICs.[6] A subsequent report by UNICEF suggests that children with developmental disabilities are 42% less likely to have foundational reading and numeracy skills, 49% more likely to have never attended school, 47% more likely to drop out of primary school, 32% more likely to experience severe physical punishment at home, and 20% less likely to have expectations of a better life.[7] Childhood disability also imposes a heavy economic burden on families, health systems, and societies in LMICs.[9] Available evidence would thus suggest that children with developmental disabilities deserve to be prioritized in any global initiative for ECD in LMICs if the aspiration and commitment of the 193 UN Member States for inclusive and equitable education under the SDGs is to be realized.

Barriers to ECD for Children with Developmental Disabilities in LMICs

Early detection and intervention of children with or at risk of developmental disabilities is perhaps the most critical component of any ECD policy. The need for routine newborn and developmental screening, developmental surveillance and timely intervention in the first five years of life in LMICs has been consistently reported in the literature before and after the introduction of the NCF.[6,10-12] However, these services are still not widely provided in LMICs.[13,14] For example, in a recent statement by the International Pediatric Association, only India was reported to have national guidelines on developmental monitoring for ECD.[14] More crucially, the health systems in many LMICs which are the first and primary contact for all children outside the home are presently ill-equipped, understaffed and poorly structured to support children with developmental disabilities and their families.[15] Where services are available, they are usually not optimized due to stigma and discrimination associated with developmental disabilities and the ability of families to afford the services.[7] Any global initiative on ECD aimed at children with developmental disabilities must recognize and address

these challenges.

Limitations of an Inclusive NCF for Children with Developmental Disabilities

Since inception, the NCF has stimulated unprecedented global attention towards a broader approach to child health beyond the exclusive child survival agenda for LMICs. However, it is unlikely that the package of interventions originally designed for typically developing children can effectively serve the unique needs of children with developmental disabilities in readiness for inclusive education as from age 5 years as envisioned by the SDGs for several reasons.

Whereas components of the NCF have been extensively implemented among typically developing children, the potential effectiveness of an all-inclusive NCF is yet to be demonstrated among children with developmental disabilities in LMICs, where most children with developmental disabilities reside.[16] Moreover, it is common practice in ECD intervention research to specifically exclude children with developmental disabilities which may be attributable to the complexity in measuring and evaluating developmental progress in this group of children compared to other children.[6,17,18] For instance, responsive parenting, which is a core component of NCF does not reflect the considerable emotional and psychological challenges faced by parents in caring for children with developmental disabilities, especially in cultural settings where societal stigma and discrimination are pervasive and social or welfare support systems are non-existent.[19] In fact, recent WHO-sponsored assessment of evidence on parenting interventions for ECD specifically excluded children with developmental disabilities,[17,18] which is an acknowledgment of the far more complex requirements for effective parenting of children with developmental disabilities.[7]

The primary focus of NCF on the first three years of life leaves a critical service gap in the preschool period (3-5 years) for children with developmental disabilities and makes transition to inclusive education difficult.[6,8] For lifelong impact, the gains from early intervention in the first three years need to be consolidated and strengthened in the preschool years.[20] This period

also provides a critical window of opportunity to identify and support children who would have been missed including those with progressive and late-onset developmental disabilities. Moreover, preschool or pre-primary education is also essential for school readiness as it provides children the learning opportunities to develop social interactions with peers outside the home and to acquire logical and reasoning skills and autonomy.[20] The fact that policies on childhood disability from birth to age 5 years are still not well-coordinated within and across relevant multilateral agencies due to overlaps in institutional roles and priorities limits the potential usefulness of NCF for children with developmental disabilities.[21]

Furthermore, an inclusive NCF is likely to leave children with developmental disabilities who often require specialist care to compete for resource allocation with children without developmental disabilities who require cheaper and less sophisticated intervention services. A review of disbursements for ECD between 2007 and 2016 found that only US$484 million or 2% of the estimated US$79·1 billion invested in various components of NCF and disability, was spent on developmental disabilities, compared to investment in responsive caregiving (US$2.3 billion), early learning (US$702 million), safety and security (US$3.5 billion), nutrition and growth (US$6.2 billion), and health (US$65.9 billion).[22] It is therefore, unlikely that services for children with developmental disabilities will be adequately funded to facilitate requisite support for parents and the provision of affordable services within the proposed integrated NCF.

The Way Forward

In our view, the disproportionate burden faced by children with developmental disabilities and the absence of any published evidence to support an aspirational all-inclusive ECD program in LMICs reinforces the need for an independent and proven pathway for children with developmental disabilities to optimize opportunities for inclusive education.[23,24] For example, WHO in partnership with the disability community has published a comprehensive roadmap for promoting health equity for children and adults with disabilities covering issues such as

governance, health systems, workforce and health financing.[24] While acknowledging the principles of NCF as essential for promoting ECD, the International Pediatric Association also emphasized the need for other strategies to address the special needs of children with developmental delays and developmental disabilities.[14] Many LMICs rely on the guidance and support offered by UN agencies and their developmental partners in strengthening their health systems to address public health challenges. The absence of a dedicated global ECD initiative for children with developmental disabilities as a public health necessity,[24] is likely to limit the capacity of these countries in mobilizing human and financial resources to implement early detection and intervention services for children with developmental disabilities from birth. An effective global initiative would require specific and significant allocation within the overall global funding for ECD and will also address the prevailing social and financial barriers to access.[7,25] A global performance indicator to monitor progress, identify unforeseen challenges and guide resource allocation in all countries will also be necessary. For example, it would be helpful to set targets for and monitor the number or proportion of children with developmental disabilities that receive early intervention services and those enrolled in inclusive education settings at school entry. These suggestions are consistent with the recommendations by UNICEF,[7] WHO,[24] and UNESCO,[5] and offer the best prospect for advancing the interests of children with developmental disabilities and their families. More crucially, the commitment of all UN Member States to inclusive education by 2030 under the SDGs is unlikely to be realized without urgent steps to prioritize services for all children under 5 years with developmental disabilities in LMICs. The exceptional opportunity provided by the SDGs should not be missed.

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