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Prioritising rehabilitation in early childhood for inclusive education: a call to action

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ABSTRACT

Purpose: This commentary examines the provisions for early childhood development (ECD) in the global action plan for rehabilitation published by the World Health Organisation (WHO) within the context of the United Nations' Sustainable Development Goal (SDG) for inclusive education.

Methods: The meeting reports of the WHO Rehabilitation 2030 for 2017 and 2019 and the related documents were reviewed along with ECD policy documents from WHO, UNICEF, UNESCO, and the World Bank.

Results: The importance of a life-course approach to rehabilitation for the health and wellbeing of persons with disabilities was highlighted in the Rehabilitation 2030. However, the critical and foundational role of rehabilitation in ECD for children with disabilities to facilitate inclusive education, especially in low- and middle-income countries as envisioned by the SDG 4.2, was not clearly addressed. Children under 5 years with developmental delays and disabilities who are not developmentally on track in health and psychosocial wellbeing require timely rehabilitation to ensure that they benefit from inclusive education.

Conclusions: The culture and practice of rehabilitation should be nurtured from infancy as an indispensable component of ECD to adequately prepare children with developmental disabilities for inclusive education and ensure effective rehabilitation services over the life course.

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► IMPLICATIONS FOR REHABILITATION

- Rehabilitation is an integral and critical component of early childhood development to optimise school readiness for children with developmental disabilities.
- Routine newborn screening, developmental assessment, and surveillance of children from birth are foundational to any effective rehabilitation in early childhood.
- Global investment to promote and support rehabilitation services from early childhood within the health systems and across all levels of service delivery including community settings is warranted to achieve the sustainable development goals for children with disabilities.

Introduction

The global epidemiological transition in the last decade marked by the emergence of non-communicable diseases as the leading determinants of morbidity and well-being, particularly in the most populous regions of the world, has resulted in a growing attention to life-course approach to rehabilitation within the framework of the United Nations' (UN) Sustainable Development Goals (SDGs) [1–5]. In 2017, the World Health Organisation (WHO) launched a global initiative tagged “Rehabilitation 2030: A Call for Action” to draw attention to the increasing need for rehabilitation, highlight the role of rehabilitation in achieving the SDGs and call for coordinated global action towards strengthening rehabilitation in health systems [3]. A life-course approach was recommended for integrating rehabilitation into the health systems at all levels of care: primary, secondary, and tertiary. This call was reinforced at the Second Rehabilitation 2030 meeting in July 2019 [4], along

with a comprehensive guide for action (the Rehabilitation 2030 Guide for Action) which is intended as a practical framework and implementation tool to support countries to identify priorities, develop a national strategic plan, and establish monitoring and evaluation mechanisms for rehabilitation in health systems [5].

The SDGs represent the global agenda and commitments of the 193 UN Member States till 2030 for the world's population. Concerted efforts by the disability community ensured that several of the 17 SDGs address the inclusion of persons with disabilities [6,7]. Two of these goals are most closely related to and cannot be achieved without rehabilitation services within the health care systems. The first goal (SDG 3) seeks to ensure healthy lives and well-being of all people regardless of age, race, gender, geographical location, and disability status. The second goal (SDG 4) addresses the need for inclusive and equitable education for children younger than 5 years with developmental delays and

Table 1. Barriers and recommendations for effective rehabilitation in early childhood.

Barriers	Recommendations
Individual level	
<i>Child and family</i>	
Parental denial, grief, guilt and fear of social isolation	Train caregivers to provide necessary psychological consultation as part of the rehabilitation services' package
Financial constraints	Advocate for social welfare scheme and provide information about financial resources to support families of children with disabilities
Unfavourable beliefs and attitudes towards intervention	Educate parents on disability issues and the importance of timely and on-going rehabilitation services to improve the quality of life for the child.
<i>Services</i>	
Lack of access to rehabilitation services	Include rehabilitation services for children with disabilities as a critical component of maternal and newborn care as well as the WHO's universal health care package of interventions.
Late presentation, assessment and confirmation	Improve public awareness and access to services; and provide continuing education for health professionals on the importance of early assessment and confirmation.
Lack of appropriate parental counselling	Train and empower caregivers to provide appropriate parental counselling services along with provision of requisite services for children with disabilities
<i>Community</i>	
Perceived/Real Discrimination and Stigma	Improve public awareness on achievers with disabilities in all walks of life who have received appropriate community-support to contribute to the society.
Lack of accessibility to physical and virtual environments	Address accessibility issues through developmental plans at countries level including the provision of accessible transportation, medical equipment, and facilities for children with disabilities. Consider universal design in buildings for inclusiveness.
Health system level	
Low priority for child disability services	Engage policy makers for maternal and child health on the importance of disability issues as envisioned by the disability-inclusive provisions of the SDGs.
Lack of rehabilitation facilities, equipment, and assistive technology	Advocate for improved funding for rehabilitation services and access to affordable assistive technologies by developmental partners and donor organisations.
Inadequate workforce	Develop national plans to recruit and train rehabilitation workforce within the health systems as part of UHC policy.
Budget constraints	Educate policy makers on the opportunities for optimal developmental outcomes from early rehabilitation and the consequences of late intervention.

disabilities and calls for actions to facilitate access to early childhood development in readiness for primary education. While SDG 3 largely relates to health-related rehabilitation services, SDG 4 additionally entails early childhood and school-based rehabilitation services before the children transition into adolescence and adulthood.

In this commentary, we examined the extent to which early childhood development (ECD) for children with developmental disabilities as envisioned under the SDGs has been considered in the various global policy documents about rehabilitation. To achieve this, we reviewed the WHO Rehabilitation 2030 reports for 2017 and 2019 and the Rehabilitation 2030 Guide for Action [2–5]. We also examined the ECD policy documents by WHO, UNICEF, UNESCO, and the World Bank published after 2015 when the SDGs agenda was launched [8,9]. The term “early childhood” in this paper covers the period from birth to age 5 years approximately (59 months).

Timely rehabilitation for children with developmental disabilities

Globally, about 162 million children younger than 15 years are estimated by WHO to require rehabilitation services due largely to sensory impairments, mental disorders, neurological disorders, and musculoskeletal disorders [2]. Children younger than 5 years account for 20% or 33 million and are associated largely with developmental intellectual disability, cerebral palsy, sensory impairments, and autism spectrum disorders. The vast majority, about 31 million (93%), of children who require rehabilitation from early childhood, reside in low- and middle-income countries (LMICs). This population is expected to continue to rise due to rapid population growth particularly in sub-Saharan Africa and South-East Asia, as well as the substantial global investment toward reductions in neonatal and child mortality by 2030. We

used the term “rehabilitation” broadly to embrace the services provided to foster acquisition of functional skills in early infancy by children with congenital disabilities, usually termed “habilitation,” as well as the systematic efforts to restore, or maintain previously developed functional skills subsequently impaired by a disability or disorder. The goal for both “interventions” is to optimise functioning for the health and well-being of individuals with disabling health conditions throughout the life course. While health systems-related rehabilitation is a form of intervention, the broader term “early intervention” commonly used in the literature does not necessarily include rehabilitation services and is often multi-sectoral.

The two Rehabilitation 2030 meeting reports did not address ECD [3,4]. Early detection and intervention for children with developmental disabilities were mentioned in the Rehabilitation 2030 Guide to Action. However, the critical role of rehabilitation in optimising school readiness towards inclusive education was not emphasised or clarified [5]. Neither was any reference made to the main global ECD policy document (tagged as the “Nurturing Care Framework”) jointly promoted by WHO, UNICEF, and the World Bank [9]. This suggests the lack of coordination and proper governance for promoting and ensuring effective rehabilitation for children with disabilities in early childhood. This is a serious and avoidable oversight as the scientific evidence on the developmental plasticity of basic functional skills in humans and the foundational role of optimal early childhood development for healthy living and wellbeing throughout the life course are well documented [10]. Children with disabilities who are not detected and supported early and appropriately are unlikely to benefit optimally from rehabilitation services in later years of their lives as they transition into adolescence and adulthood [11]. The timing of intervention, especially for those with congenital and early-onset sensory impairments is critical for these children. Meanwhile, the lack of rehabilitation and family-centred support

services for children with disabilities in LMICs account for a high risk of premature death including infanticide [12]. For others who survive, opportunities for school attendance, active participation in school, and completion of primary or secondary education are highly limited. Recent data from UNICEF, for example, suggests that compared to children without disabilities, children with disabilities are 42% less likely to have foundational reading and numeracy skills, 49% more likely to have never attended school, 47% more likely to be out of primary school, 33% more likely to be out of lower-secondary school, 27% more likely to be out of upper-secondary school, and 20% less likely to have expectations of a better life [13]. The integration of rehabilitation into early childhood development must therefore begin from infancy with the active involvement of families and other caregivers [10,11,14]. This integration is also foundational and essential for effective transitioning as well as optimal health and wellbeing of adults with childhood-onset disabilities [15,16].

Barriers to effective rehabilitation in early childhood

Several socio-cultural, infrastructural, institutional, and economic barriers to effective rehabilitation of children with disabilities, particularly in LMICs have been highlighted by WHO and others [3,5,13,17–19]. These factors are grouped under personal and health systems levels as shown in Table 1. They include but are not limited to discrimination and stigma on the grounds of disability, lack of accessibility to physical and virtual environments, lack of access to assistive technology, poverty, as well as ill-equipped and beleaguered health systems. Recommendations for addressing these barriers have been proposed. Overall, these recommendations would require effective leadership, governance, planning, and coordination by national governments in partnership with developmental partners including WHO, UNICEF, UNESCO, and the World Bank. Perhaps, more crucially, a significant portion of the global investment for child health must be allocated and deployed for supporting rehabilitation services for children with developmental disabilities as extensively discussed elsewhere [20]. Moreso, the recommended package of interventions for ECD presented to global leaders for funding at the G20 meeting in 2019 did not include early detection and rehabilitation services for children with disabilities [21]. There is no evidence that this omission has been addressed by the relevant UN organisations which remains a major barrier in attracting funding support for rehabilitation in global health. Without a globally coordinated funding programme as exemplified by successful global health initiatives for child immunisation and survival [20,22], it is unlikely that many donor-dependent LMICs will be in a position to take the required actions.

A recent UNICEF report provides valuable and authoritative insights into the future that awaits children with disabilities without timely rehabilitation [13]. Unfavourable cultural beliefs, societal stigma, and discrimination against children with disabilities may predispose them to prolonged parental grief, infanticide, and various forms of child abuse [23,24]. Caring for children with disabilities places a significant financial burden on families besides the round-the-clock attention. This is compounded by the general lack of social welfare schemes for vulnerable children and their parents commonly available in high-income countries. The poorer prospects for foundational learning and primary education without early rehabilitation in LMICs may foster a sense of despair, frustration, and hopelessness especially when the health systems are ill-equipped to offer the requisite support. It is, therefore, not uncommon for parents to resort to a traditional ethnomedicine

system and faith-based interventions. More crucially, the lack of rehabilitation services will not provide an incentive or impetus for the development of early detection of children with sensory and other hidden time-sensitive disabilities in early childhood.

Call to action

The WHO Rehabilitation 2030 Guide to Action includes a plan to develop a package of evidence-based rehabilitation interventions to facilitate the integration of rehabilitation interventions in all service delivery platforms [5]. The life-course approach necessitates a global initiative for the early detection of children requiring rehabilitation. This would entail investment in the health systems to provide routine newborn screening, complemented by systematic developmental screening and surveillance in early childhood. This is the standard and best practice in high-income countries (HICs) that can be equitably adapted for LMICs. Effective framework and process for implementing cultural adaptations of proven interventions have been reported [25,26]. A comprehensive report on the range of assistive technologies to support the requisite rehabilitation services has been published by WHO [27]. The WHO Rehabilitation 2030 Guide for Action provides an evidence-based framework for delivering different rehabilitation services organised across tertiary, secondary, and primary health care or community settings [5]. The framework covers specialised (dedicated), high-intensity rehabilitation that is commonly delivered through longer-stay facilities; rehabilitation that is highly integrated across a wide range of medical specialties in tertiary and secondary health care; rehabilitation integrated into primary health care; community-delivered rehabilitation that may be dedicated or integrated into a range of community-delivered health programmes and the informal and self-directed care that occurs in community settings. It is also important to recognise that many children with developmental disabilities encounter challenges in transitioning from early childhood through adolescence to adulthood in the provision of rehabilitation services which must be carefully managed [15,16,28].

It is now time to explicitly prioritise ECD for children with disabilities for global health investment. The vision and promise of inclusive education, healthy lives, and well-being by 2030 as stated in the SDGs will remain elusive without an early childhood development framework that fully and explicitly incorporates rehabilitation services from infancy. The opportunities for greater and effective participation in education, employment, and community life for children with disabilities globally must be fully harnessed. Indicators for measuring progress must be clearly defined and monitored. For example, in 2021, a measure for tracking progress in early childhood development adopted by UNICEF excluded children younger than 24 months due to a controversial claim that it is impracticable to assess functioning in this age group through household surveys. However, because early detection of disabilities in this age group is essential for effective rehabilitation, steps should be taken as quickly as possible to adopt a measure that covers all children under 5 years as originally agreed by the Member States for SDG 4 in 2015 [1].

In conclusion, we applaud the on-going and dedicated efforts by WHO to highlight the critical role of rehabilitation for the SDGs. However, there is an urgent need to address the stark health, educational, social, and economic inequalities between children with and without disabilities within LMICs and between HICs and LMICs [13]. While the WHO Rehabilitation 2030 focuses on the health systems, it is necessary to recognise that the educational system also has a critical and complementary role to play in promoting healthy lives and well-being for children with

disabilities [29]. Access to timely and appropriate rehabilitation services is essential for optimal developmental outcomes in early childhood and facilitates access to inclusive education and development [30]. We, therefore, submit that any global action plan for rehabilitation must adequately and explicitly prioritise the time-sensitive needs of children with developmental disabilities to optimise their functioning and well-being over the life course, including equitable access to inclusive education, as envisioned by the SDGs.

Author contributions

This manuscript was conceived by members of GRDDC. All authors contributed equally to drafting of this manuscript and approved the final version for submission.

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