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The role of caregivers in mental health and child development policy and practice

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As the health community reflect on World Caring Day and the UK's National Carers Week in June, 2024, it is important to recognise the contribution of families caring for the 240 million children with disabilities worldwide.[1] These caregivers, including parents, grandparents, siblings, and extended family members, have a crucial role in supporting some of the world's most marginalised children. However, caregivers face considerable challenges, including psychological stress,[2] mental health conditions,[3] financial burdens, stigma, and discrimination,[4] which impact their wellbeing and ability to provide care effectively.[5] Moreover, the responsibilities of caregivers often conflict with other social roles, such as partnerships, parenting, education, and employment.[2] The difficulties that caregivers face are generally pronounced in low-income and middle-income countries (LMICs), given the constrained role of statutory services in providing support, and that children are ten times more likely to be disabled than to die before their fifth birthday.[6] A fundamental shift is needed in how caregiver support is approached globally, one that acknowledges caregivers' contributions to society, addresses their rights, and recognises their own support needs.

Fortunately, there are contextually appropriate interventions to help address these challenges. Peer support groups and networks offer effective approaches to health promotion and improved short-term psychosocial functioning for caregivers.[7] Additionally, in many settings these programmes are adopted by caregivers after implementation, providing further opportunities for social connectedness and resource mobilisation, as has been seen in Ghana[8] and Kenya.[9] Despite providing vital support to caregivers, peer interventions are not routinely available because of factors such as fragmented mental health and child development services.[10,11] Insufficient accessible, formal early childhood intervention services and social support for caregivers in LMICs leaves many caregivers without adequate support as their expectations for their child's future are altered.[12] Moreover, there is limited inclusion of caregivers' voices in policies and programmes that are designed to impact their lives. Barriers to implementation and scale include limited evaluation of long-term effectiveness and cost-effectiveness. Implementation research should be prioritised to understand the factors needed for effective and sustainable impact at scale, with clear theories of change, standardised outcome measures, long-term follow-up, and cost-effectiveness analyses. Where programmes are in place in LMICs, missing or dysfunctional referral pathways can restrict access to care and support for caregivers. Additionally, some groups may be sidelined from programmes. For example, programmes are not usually tailored to the preferences of fathers and male caregivers, and their circumstances, reflecting societal expectations and stereotypes regarding paternal roles in caregiving. It is crucial to progress beyond treating fathers as mere companions to mothers by developing father-inclusive caregiver interventions that actively support men as co-beneficiaries.[13]

To scale up peer support groups and networks, health policies and systems must adapt to address the needs of caregivers of children with disabilities. One promising approach involves implementing policy provisions that endorse community-based interventions. For instance, an inclusive early child development programme in Addis Ababa prioritises marginalised families and shows how policy provisions can bolster caregiver support within the broader health-care system in Ethiopia.[14] This programme includes comprehensive home visits by community members known as coaching mothers who also facilitate access to essential services for all children younger than 6 years in Addis Ababa.[14] Public–private partnerships, as well as collaborations with the third sector and public entities, can contribute to the provision of comprehensive support for caregivers.

Crucially, programmes are best designed and most sustainable, when caregivers and people with disabilities co-develop and facilitate these groups and networks. This collaborative, user-led approach fosters inclusivity, empowers participants, and leverages first-hand experiences, leading to tailored solutions to address their challenges.[15] Initiatives that are largely community or civil society organisation led, such as those provided by Shonaquip Social Enterprise in South Africa,[16] Baby Ubuntu peer support programmes in Uganda,[17] and Carers UK in the UK, have potential for long-term positive impact on caregivers' lives if adequately funded and prioritised.

Low spending on mental health and social care services in LMICs by governments and non-governmental organisations constrains caregiver support programme development,[18] especially in poorer, rural areas where needs are also higher.[19] Looking ahead, priority actions for governments to incorporate caregivers of children with disabilities in national systems must include developing and financing of national action plans for early detection of children with disabilities that also provides support for their caregivers, and establishing measurable targets. These key performance indicators are required to monitor and improve policies, financing, advocacy, and services. For instance, in 2007, Chile implemented a successful national early childhood development programme, supported by effective developmental household surveys for children younger than 5 years.[20] In 2019, data gathered as part of the programme indicated that the programme was not effectively reaching children with developmental disabilities. The programme has since adjusted to ensure improved access to assistive technology and communication services for caregivers and children.[20] Expanding and developing a community workforce with the appropriate skills to provide support groups and networks can bridge accessibility gaps. To overcome scaling up or integration barriers, strategic involvement of all stakeholders, including decision makers and service users, is crucial for sustainability. Services to support caregivers must be evidence-based, locally relevant, and systematically assessed to disseminate practical recommendations.

Governments need policies and action plans to support caregivers, which should be translated into budget allocations necessary to implement the support effectively. Thus, it is crucial for international organisations such as WHO, the World Bank, and UNICEF to strengthen normative guidance to integrate peer support groups and networks within national health strategies, and facilitate system restructuring to bolster national governments and civil society organisations in their endeavours to support caregivers. These organisations can have a catalytic role in providing overarching leadership, coordination, and accountability mechanisms to ensure the equitable provision of support for caregivers worldwide.

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For more on **Carers UK** see https://www.carersuk.org/

1 UNICEF. Seen, counted, included: using data to shed light on the well-being of children with disabilities. 2022. https://data.unicef.org/resources/children-with-disabilities-report-2021/ (accessed May 30, 2024).

2 Haley WE, Elayoubi J. Family caregiving as a global and lifespan public health issue. *Lancet Public Health* 2024; **9:** e2–3.

3 Scherer N, Verhey I, Kuper H. Depression and anxiety in parents of children with intellectual and developmental disabilities: A systematic review and meta-analysis. *PLoS One* 2019; **14:** e0219888.

4 Mkabile S, Garrun KL, Shelton M, Swartz L. African families' and caregivers' experiences of raising a child with intellectual disability: a narrative synthesis of qualitative studies. *Afr J Disabil* 2021; **10:** 827.

5 Loucaides EM, Zuurmond M, Nemerimana M, et al. Livelihood support for caregivers of children with developmental disabilities: findings from a scoping review and stakeholder survey. *Disabil Rehabil* 2024; **46:** 293–308.

6 Global Research on Developmental Disabilities Collaborators. Accelerating progress on early childhood development for children under 5 years with disabilities by 2030. *Lancet Glob Health* 2022; **10:** e438–44.

7 Barlow J, Coren E. The effectiveness of parenting programs:a review of Campbell Reviews. *Res Soc Work Pract* 2018; **28:** 99–102.

8 Zuurmond M, Seeley J, Shakespeare T, Nyante GG, Bernays S. Illuminating the empowerment journey of caregivers of children with disabilities: understanding lessons learnt from Ghana. *Afr J Disabil* 2020; **9:** 705.

9 Bunning K, Gona JK, Newton CR, et al. Empowering self-help groups for caregivers of children with disabilities in Kilifi, Kenya: impacts and their underlying mechanisms. *PLoS One* 2020; **15:** e0229851.

10 Black MM, Walker SP, Fernald LCH, et al. Early childhood development coming of age: science through the life course. *Lancet* 2017; **389:** 77–90.

11 Bolton P, West J, Whitney C, et al. Expanding mental health services in low- and middle-income countries: a task-shifting framework for delivery of comprehensive, collaborative, and community-based care. *Glob Ment Health (Camb)* 2023; **10:** e16.

12 He C, Evans N, Graham H, Milner K. Group-based caregiver support interventions for children living with disabilities in low-and-middle-income countries: narrative review and analysis of content, outcomes, and implementation factors. *J Glob Health* 2024; **14:** 04055.

13 Jeong J. Redesigning and delivering inclusive parenting interventions for fathers. *Lancet Glob Health* 2021; **9:** e596.

14 Office of the Mayor of Addis Ababa. Initiative Detail: Early Childhood Development (ECD). 2024. https://www.addismayor.gov.et/index.php/initiatives/early-childhood-development-ecd (accessed May 23, 2024).

15 Bird M, McGillion M, Chambers EM, et al. A generative co-design framework for healthcare innovation: development and application of an end-user engagement framework. *Res Involv Engagem* 2021; **7:** 12.

16 Trafford Z, van der Westhuizen E, McDonald S, Linegar M, Swartz L. More than just assistive devices: how a South African social enterprise supports an environment of inclusion. *Int J Environ Res Public Health* 2021; **18:** 2655.

17 Nanyunja C, Sadoo S, Kohli-Lynch M, et al. Early care and support for young children with developmental disabilities and their caregivers in Uganda: The Baby Ubuntu feasibility trial. *Front Pediatr* 2022; **10:** 981976.

18 Freeman M. Investing for population mental health in low and middle income countries—where and why? *Int J Ment Health Syst* 2022; **16:** 38.

19 Kakuma R, Minas H, van Ginneken N, et al. Human resources for mental health care: current situation and strategies for action. *Lancet* 2011; **378:** 1654–63.

20 Breinbauer C, Vidal V, Molina P, Trabucco C, Gutierrez L, Cordero M. Early childhood development policy in Chile: progress and pitfalls supporting children with developmental disabilities toward school readiness. *Front Public Health* 2022; **10:** 983513.