

Family-based care and support: the role of male caregivers

Nathan Grills PhD¹, Nicole Bishop¹, and Vivian Yao PhD²

2024

This 'Disability equity and rights: Challenges, opportunities, and ways forward for inclusive development' publication was prepared under the DFAT – CBM Inclusion Advisory Group Disability Inclusion Technical Partnership, an Australian aid initiative implemented by CBM Inclusion Advisory Group and the Nossal Institute for Global Health at the University of Melbourne.

This publication has been funded by the Australian Government through the Department of Foreign Affairs and Trade. The views expressed in this publication are the author's alone and are not necessarily the views of the Australian Government.

Background

Caregivers can be an important resource in enabling people with disabilities to access services and community resources and to promote inclusion more widely. It is accepted, and supported by evidence, that caregivers play an important role in maximising the wellbeing of many people with disabilities.³ This is especially the case for children with disabilities. Where a child has a profound intellectual disability, such as the child of one of the authors, the caregiver can in effect be the 'communication aid', equivalent to a sign interpreter, through which the person communicates their needs, desires, and preferences.

Globally, primary caregivers are predominantly women and girls. Caregiving by family members is informal, unpaid, and performed in addition to other roles that caregivers have, such as paid employment. Providing informal care over prolonged periods can result in caregivers experiencing burden and stress.^{4,5} If the caregiver is stressed or isolated, or has poor mental health and minimal resources, the person with disabilities being cared for is less likely to maximise their potential and wellbeing. While recognising that women and girls provide the majority of informal caregiving in the family, this essay focuses on the under-researched area of male caregivers.

Opportunities and challenges

The stress that caregivers experience has been well documented in both low- and high-income settings. Caregivers experience high levels of negative mental health and social isolation; financial strain; the physical burden of caregiving; feelings of pessimism, exhaustion, and anxiety; cognitive and memory difficulties; and, consequently, reduced quality of life. These negative impacts are

¹ Nossal Institute for Global Health, University of Melbourne. Lead/corresponding author: Nathan Grills, ngrills@unimelb.edu.au

² Melbourne Disability Institute, University of Melbourne.

³ World Health Organization. 2004. The importance of caregiver-child interactions for the survival and healthy development of young children: A review. <https://iris.who.int/bitstream/handle/10665/42878/924159134X.pdf?sequence=1>

⁴ Joling K J, O'Dwyer S T, Hertogh C M, and van Hout H P. 2018. The occurrence and persistence of thoughts of suicide, self-harm and death in family caregivers of people with dementia: a longitudinal data analysis over 2 years. *International journal of geriatric psychiatry*, 33(2), pp.263-270. <https://doi.org/10.1002/gps.4708>

⁵ Murthy R S. 2016. Caregiving and caregivers: Challenges and opportunities in India. *Indian Journal of Social Psychiatry*, 32(1), pp.10-18. DOI: [10.4103/0971-9962.176761](https://doi.org/10.4103/0971-9962.176761)

compounded by a lack of internal resources, such as information, skills and coping behaviours, and limited external resources, including finances, help from extended family, and formal supports.⁶

The economic impact of the additional expenditure and decreased income of caregivers is well known. These impacts provided justification for the National Disability Insurance Scheme (NDIS) in Australia whereby supports provided to people with disabilities and their families enable caregivers to engage in the workforce. In most countries, caregiving is unpaid and the economic contribution of caregiving is uncounted. Informal caregiving enables a person with disabilities to live at home rather than in institutional- or state-based care. Home-based care generally costs less and is often preferred by people with disabilities. The UN Convention on the Rights of Persons with Disabilities emphasises the right of people with disabilities to live in the community (Article 19) and the right of children with disabilities to family life (Article 23).

The role of caregivers is often overlooked in global development cooperation. Failing to engage with caregivers can further disadvantage people with disabilities, especially for those with severe intellectual disabilities. The Committee on the Rights of Persons with Disabilities General Comment Number 7 highlights the importance of including caregivers and family members in consultations. Including caregivers is important where there is a risk of losing access to the voice of some people with disabilities, for example, where the caregiver may play a critical role in supporting communication.⁷

Without assuring appropriate representation of caregivers within the disability movement and related dialogue there is a risk of excluding people with disabilities who rely on supported communication through their caregivers. A recent study noted that people with intellectual or profound disabilities are underrepresented in organisations of people with disabilities (OPDs).⁸ Reasons for this include limited mechanisms for supported decision-making or communication, a role commonly provided by caregivers for some people with disabilities.

Research has shown that female caregivers of children with disabilities are often marginalised and disempowered socially and financially.⁹ This marginalisation has been associated with poorer wellbeing, health, and education outcomes for the child. Male involvement in the day-to-day care of a child with disabilities is often limited due to various factors such as paid labour, absence due to migration for work, societal norms and gendered domestic role allocations associated with caregiving. In some contexts, men may not be welcome to engage in personal caregiving due to cultural and traditional norms around gender roles in the family.¹⁰ There has been limited engagement with the role of male caregivers in the literature and practice. The role of male caregivers in contributing to childhood development and wellbeing has been shown to be important; for example, male caregivers' participation in parenting programs in Japan was associated with positive outcomes on their child's behavioural problems and communication skills.¹¹

⁶ Joling K J, O'Dwyer S T, Hertogh C M, and van Hout H P. 2018. The occurrence and persistence of thoughts of suicide, self-harm and death in family caregivers of people with dementia: a longitudinal data analysis over 2 years. *International journal of geriatric psychiatry*, 33(2), pp.263-270. <https://doi.org/10.1002/gps.4708>

⁷ Committee on the Rights of Persons with Disabilities. 2018. General comment No. 7 on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention. <https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no7-article-43-and-333-participation>

⁸ Banks L M, Eide A H, Hunt X, Abu Algaib O, and Shakespeare T. 2023. How representative are organisations of persons with disabilities? Data from nine population-based surveys in low- and middle-income countries. *Disability & Society*, pp.1-17. <https://doi.org/10.1080/09687599.2023.2215397>

⁹ Fisher P, and Goodley D. 2007. The linear medical model of disability: Mothers of disabled babies resist with counter-narratives. *Sociology of Health & Illness*, 29(1), pp.66-81. <https://doi.org/10.1111/j.1467-9566.2007.00518.x>

¹⁰ Shorey S, and Pereira T L B. 2023. Experiences of fathers caring for children with neurodevelopmental disorders: A meta-synthesis. *Family process*, 62(2), pp.754-774. <https://doi.org/10.1111/famp.12817>

¹¹ Sato N and Araki A. 2022. Fathers' involvement in rearing children with profound intellectual and multiple disabilities. *Journal of Family Nursing*, 28(1), pp.57-68. <https://doi.org/10.1177/10748407211037345>

Understanding the role and function of male caregiving in providing disability support in the family is essential for furthering women's empowerment. For example, the sharing of domestic loads, which are typically greater in the context of disability, increases opportunities for women to engage in paid employment outside the home. Studies also demonstrate more equitable caregiving for children with disabilities in a household can reduce potentially negative impacts on female caregivers, such as depressive symptoms and exposure to stress.¹²

Often it is the lack or absence of caregiving by men that is the focus of research and intervention with little attention paid to the positive aspects of caregiving by men to a child with disabilities' welfare. A negative portrayal with a focus on the shirking of responsibilities by men can perpetuate gendered inequalities. There is appreciable scope to better understand and address the constraints to male engagement in caregiving for family members with disabilities in development research and programming.

Looking ahead to 2030

An important question that remains unanswered in low- and middle-income countries is: does the absence or exclusion of male or female caregivers hinder the child's development? Also, what additional impact does the absence of a male or female caregiver have when caring for a child with disability? In order to recognise this key component of childhood development and disability, new efforts need to be made to foster understandings and engagement of caregivers, including their own wellbeing.

It is critical to develop strategies for both male and female caregiver engagement, such that they have a comprehensive understanding of the care needs of children. Notably, engaging male caregivers in appropriate allocation of resources and creating a supportive social and family arrangement affords critical support to women and the family.

Ensuring gender equality and the social and financial empowerment of women in households with people with disabilities who require support or care requires us to work with men. We should take a strengths-based and co-design approach to understanding this dynamic and designing appropriate interventions for men. Such initiatives would involve looking at the whole family unit and dynamics in the care of children, including a focus on better supporting and promoting care by men, given male caregivers are often excluded from research and interventions.

We recommend the following to better ensure more equitable provision of care and support for people with disabilities by 2030:

1. Work with partner countries to generate co-designed, evidence-informed research and develop policies and programs to understand and support the role of male and female caregivers respectively in promoting the wellbeing and positive development of people with disabilities.
2. Encourage OPDs and community self-help groups to be actively inclusive of male caregivers, or to develop structures that facilitate the inclusion of men in caregiving roles in line with the principles of supported decision making.

¹² Laxman D J, McBride B A, Jeans L M, Dyer W J, Santos R M, Kern J L, et al. 2015. Father involvement and maternal depressive symptoms in families of children with disabilities or delays. *Maternal and child health journal*, 19, pp.1078-1086. <https://doi.org/10.1007/s10995-014-1608-7>

3. Develop targeted, sustainable interventions to improve the health and wellbeing of male caregivers to optimise the potential of those for whom they care.
4. Invest in developing and delivering evidence-based positive parenting programs, such as those being co-designed in rural India,¹³ and specifically tailored to meet the needs and challenges faced by male caregivers while promoting gender equality in caregiving roles.

¹³ Mathias K, Nayak P, Singh P, Pillai P, and Goicolea I. 2022. Is the Parwarish parenting intervention feasible and relevant for young people and parents in diverse settings in India? A mixed methods process evaluation. *BMJ open*, 12(2). <https://doi.org/10.1136/bmjopen-2021-054553>