

**Call for Input: Human Rights Council resolution 54/6 on the centrality of care and support from a human rights perspective**

Carers Worldwide is the only organisation working exclusively and strategically with unpaid family carers in the Global South. We act as a catalyst by promoting recognition of unpaid family carers and drawing attention to their needs. We do this at all levels with families, communities, local, national, and international NGOs, service providers, academics, the corporate sector and local and national Governments across India, Nepal and Bangladesh. We also interact with other carer organisations on a global scale to promote a global change for carers.

These inputs are written in the context of the situation in India, Nepal and Bangladesh – the three countries where Carers Worldwide operates and of which we have the greatest knowledge.

1. *In your country, regional or at the global level, how are the following****rights recognized and protected under national, regional and/or international law****? Please provide concrete examples, such as legal provisions, jurisprudence of courts and/or human rights mechanisms:*
	* ***Human rights of unpaid and paid caregivers****, including those who are women, persons with disabilities, children and older persons;*
	* ***Human rights of recipients of care and support****, including those who are women, persons with disabilities, children and older persons;*
	* ***Human right relevant to self-care of caregivers and recipients of care and support****, including those who are women, persons with disabilities, children and older persons*

*Such recognition and protection may be made in relation to, but not limited to, the rights to work, social security, adequate housing, health, education, enjoyment of scientific advancement, legal capacity, equality in marriage, independent life in the community, rest and leisure, and the rights relevant to participation. It may include the recognition of care and/or support as human right(s) under the law.*

INDIA:

1. Human rights of unpaid and paid carers:
* National level: The Constitution of India guarantees equality before the law (Article 14) and prohibits discrimination on grounds of sec (Article 15). The Maternity Benefit Act 1961 provides for maternity leave and other benefits to women employees, recognising their caregiving role. The Rights of Persons with Disabilities Act 2016 ensures protection and promotion of the rights of persons with disabilities, including limited provisions for their carers (including a carers allowance for those caring for a person with a high level of support needs). In practice though, implementation of these acts varies from State to State and even more as provisions move down to the level of practical implementation. Extended advocacy by Carers Worldwide has resulted in increasingly effective implementation of the carers allowance provision, particularly in Karnataka state where the 2024/2025 budget now includes a carers allowance for unpaid family carers of people with cerebral palsy, multiple sclerosis, Parkinson’s disease and muscular dystrophy. Other provision such as the provision of respite care services to unpaid family carers to allow them temporary relief from their caregiving responsibilities, promote their wellbeing and prevent burnout are virtually non-existent and those that do exist are provided by civil society, for example the Community Caring Centres set up by Carers Worldwide and its network of local NGOs.
1. Human rights of recipients of care and support:
* National level: The Maintenance and Welfare of Parents and Senior Citizens Act 2007 provides for the maintenance and welfare of parents and senior citizens, ensuring their right to care and support from their families. The National Policy for Older Persons 1999 outlines the rights and entitlements of older persons including access to healthcare and social security. Similarly, the Rights of Persons with Disabilities Act 2016 does the same for people with disabilities and the Mental Healthcare Act 2017 enshrines provision for people with a range of mental illnesses. The Mental Healthcare Act 2017 also recognises the rights of persons with mental illness to self care and autonomy in treatment decisions. Again though, challenges remain in ensuring effective implementation and enforcement of these rights, particularly for the most marginalised groups such as women, people with disabilities, children and older persons.

NEPAL:

1. Human rights of unpaid and paid carers:
* National level: Nepal’s latest Constitution (2015) guarantees equality and non-discrimination (Article 18) and prohibits gender-based discrimination (Article 20). The Elderly Rights Act 2006 acknowledges the rights of senior citizens, including their right to care and support. The Disability Rights Act 2017 ensures the protection and promotion of the rights of persons with disabilities, and also includes provisions for their carers. These include: recognition of the vital role played by carers; the importance of empowering carers; protection from discrimination in all spheres of life including employment, education and healthcare; training and capacity building of carers to enhance their skills in providing care and support to persons with disabilities; access to information and services necessary for providing care and support; and legal recognition and support. Again though, there are real issues around implementation of these provisions since the bureaucratic hurdles to receiving, for example, recognition of a disability to receive the necessary ID card are huge. Rights for unpaid carers remain far from reaching the carers themselves who remain largely unrecognised and unsupported.
1. Human rights of recipients of care and support:
* National level: The Senior Citizens Act of 2006 safeguards the rights of elderly citizens, ensuring their access to care and support. The Child Rights Act of 2006 protects the rights of children in relation to their right to care and support and the recently updated Child Rights Act further strengthens these rights and provisions. The Mental Health Act 2018 enshrines the rights of persons with mental health issues. However, implementation of all of these legislations is variable across the country, especially in the context of the federal system, with discrimination and exclusion persisting especially in remote areas and for the most vulnerable. Much more needs to be done by government and civil society to address these challenges.

BANGLADESH:

1. Human rights of unpaid and paid carers:
* National level: Bangladesh’s Constitution guarantees equality before the law (Article 27) and prohibits discrimination on grounds of sex (Article 28). The National Policy for Persons with Disabilities 2013 outlines the rights of persons with disabilities. Carers are only indirectly mentioned though, and those mentions related purely to how the care they provide supports the disabled person, rather than acknowledging the rights and needs of carers themselves. There is much to be done to improve implementation at grass roots level of the rights of persons with disabilities and an urgent need for further development and implementation of specific measures to support and empower unpaid carers in Bangladesh.
1. Human rights of recipients of care and support:
* National level: The National Security Strategy of Bangladesh aims to ensure social protection for vulnerable groups, including recipients of care and support. Much more needs to be done though to ensure awareness of and access to these various schemes.

INTERNATIONAL:

All three countries are signatories to international conventions such as the Convention of the Rights of Persons with Disabilities (CRPD) and the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) which stress the rights of unpaid carers and the need to prevent discrimination against them.

In addition to legislations which directly mention and apply to unpaid carers, it is possible to interrogate more general policies and schemes to look at ways unpaid carers can be highlighted as a vulnerable group entitled to access those provisions and entitlements. An example is the Mahatma Gandhi Rural Employment Guarantee Scheme in India which guarantees 100 days of paid work to vulnerable groups living in rural areas of the country. Advocating for recognition of unpaid carers as a vulnerable group enables them access to this scheme, which is highly beneficial for economic wellbeing. Carers Worldwide has conducted thorough reviews of applicable policies in India, Nepal and Bangladesh and these are being used by a number of in-country NGOs to advocate locally. The India Policy Review paper is available here: [Policy-Review-India.pdf (carersworldwide.org)](https://carersworldwide.org/images/publications/Policy-Review-India.pdf) and copies of the Nepal and Bangladesh reviews are available on request.

1. Concrete **policy or programmatic** **measures taken to promote and ensure the rights of caregivers and recipients of care and support**in national care and support systems,mentioned under Question 1 above. If possible, please indicate the impacts of such measures.

Such measures may include, but not limited to, social security/protection, working conditions, human support, childcare, long-term care and support, health services, education, transportation, housing, water and sanitation, assistive devices, digital technology, [**deinstitutionalization**](https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpdc5-guidelines-deinstitutionalization-including), access to justice, governance, financing, monitoring and evaluation, and awareness raising.

So few measures have been put in place for unpaid family carers in India, Nepal and Bangladesh at a systematic level that this question is challenging to answer. Others are better placed to answer regarding recipients of care and support.

1. **Main challenges faced at the national level** in creating robust, resilient and gender-responsive, disability-inclusive and age-sensitive care and support systems with full respect for human rights.

As outlined above, implementation of legislation is challenging and at best patchy in all three countries. Key challenges in relation to unpaid family carers include:

* Lack of awareness regarding the existence of unpaid family carers, including amongst carers themselves
* Stigma relating to the status of being an unpaid family carer, including ‘stigma by association’ which perpetuates the lack of awareness and prevents carer from coming forward and advocating for their rights
* Lack of a strategic approach to a) achieving recognition of carers, b) systematic identification of carers as carers and c) provision of support
* Lack of evidence and data in relation to the number of unpaid family carers and their demography resulting in a ‘not counted, not included’ scenario and a lack of political will to uphold their rights

Only once these fundamental challenges are faced will it be possible to start to address the challenges associated with rolling out any significant level of support in a comprehensive way that is accessible to all.

1. As much as possible, we would appreciate receiving the following information in relation to your responses to points 1 and 2 above:
	* **Data disaggregated by sex/gender, age, disability**, and if possible also by other grounds, including income, race/ethnicity, geographic location, migratory status and other characteristics;
	* **Information on people** **who are in vulnerable situations and/or who face intersecting forms of discrimination**, such as single parents, widows/widowers, children deprived of family environment; persons with disabilities and older persons in care institutions; as well as those who are affected by humanitarian crises, armed conflicts, disasters; living in poverty; living in rural areas; migrants, refugees, asylum seekers; belonging to minorities or indigenous communities; and those who are deprived liberty.

Since its inception in 2012, Carers Worldwide has systematically collected data on unpaid family carers which is disaggregated by gender, age, education level, employment and income levels and which provides information on carers’ health and wellbeing and the level of their caring responsibilities. As an example, a number of these studies can be found here: [Reports and Publications | Carers Worldwide](https://carersworldwide.org/about-us/reports-and-publications) Studies relating to Bangladesh are available on request and we would be very happy to discuss our data further as a means of informing this enquiry.

A broad summary shows that approximately 84% of unpaid family carers are women, though this can increase to 96% when looking at carers of disabled children. Typically, the majority of unpaid carers are of working age with the average amongst groups studied by Carers Worldwide being 60% and as high as 96.4% amongst mothers of disabled children in Nepal. In the predominantly rural areas that we have studied, at least 50% of unpaid carers have not completed secondary education. 92% of unpaid family carers studies in Bangladesh were not in employment, with their level of caring responsibilities being the reason for that in 85% of cases.