**OHCHR LFTW response**

**List of references, relevant documents:**

1. UNCRPD
2. UNCRC
3. The Universal Declaration of Human Rights (UDHR)
4. Mozambique, Estratégia Nacional de segurança Social Básica 2016 – 2024
5. Mozambique Politica da Acção Social Estratégia de Implementação
6. Mozambique Política da Pessoa Idosa Moçambicana
7. Mozambique Politica de Genero e Estrategia da sua Implementacao
8. Mozambique National strategy on inclusive education 2020 - 2029
9. Mozambique Accesibility law and policy
10. My Body My Right
11. The lives of children with disabilities in Africa, a glimpse into a hidden world (2012)
12. IDAI report
13. Inclusive Sofala Project Endline 2022
14. The right to disability inclusive health, LFTW brief 2021
15. The International Covenant on Economic, Social, and Cultural Rights (ICESCR)
16. India National Social Assistance Programme (NSAP)
17. India Employees' Provident Fund (EPF)
18. India The Right to Education Act, 2009
19. India Rights of Persons with Disabilities Act, 2016
20. India Protection of Children from Sexual Offence Act 2012
21. India Protection of Women from Domestic Violence Act, 2005
22. Ethiopia [Child Protection Matters for Children with Disabilities — A Case Story](https://www.licht-fuer-die-welt.at/app/uploads/sites/8/2021/09/childprotection_web_accessible.pdf)
23. Roads to Inclusion

**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:**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.

LFTW response:

The rights of people with disabilities are recognised in international conventions like the UNCRPD, or UNCRC which 163 countries are signatory to, for example in Article 19 the right to live independently and be included in the community is mentioned (1,2). The International Covenant on Economic, Social, and Cultural Rights (ICESCR) in Article 6 recognizes the right to work as a fundamental human right and in Article 11 the right to adequate housing (15). The Universal Declaration of Human Rights (UDHR) (3) in Article 22 recognizes the right to social security and in Article 26 the right to education. In our focus countries (Burkina Faso, Ethiopia, Mozambique, South Sudan, Uganda, Kenya, and India) there is a provision for social protection and basic social support for people with disabilities in the form of financial subsidy or food support, or subsidised healthcare.

In our focus countries people with disabilities still struggle to have their right to health, education, work, leisure, social security, adequate housing, Assistive Technology (AT) met and to be able to develop their potential to participate in the home and community with adequate support, either formal or informal, to become empowered and contributing citizens. This is especially true for children with disabilities and woman with disabilities.

Many children with disabilities are abandoned by the father and live in single parent households, often a single mother, or are living with grandparents or aunts and not the biological parents. This might not be the best care that the child deserves. There is no formal recognition of the right to decide where to live, with who, or independently in the community.

In many of our focus countries access to epilepsy medication is difficult which creates a burden for families having to buy expensive medication from private pharmacies, or medication is stopped, leading to further disability and lack of participation. National policies on provision of essential drugs are often not inclusive of epilepsy medication or this medication is not prioritised, leading to shortage in the community. The needs for epilepsy medication is often not sufficient documented, which means that less medication is provided then is needed.

For example, in Mozambique Disability Inclusion in Community Development (DICD) partners and LFTW work together with Human Rights organisations, like PNHD, or MULEIDE, to address human rights violations, and support people with disabilities to have their rights recognised and address human rights abuses, if needed with support in court. A practical example is the support for children with disabilities to have a registration card, needed to be able to be enrolled in school.

For example, in South Sudan we have supported the Ministry of Education in the development of their inclusive education policy to improve the access of learners with disability into the education system and practice their right to learn.

For example, in Ethiopia the My body My right project supported girls with intellectual disabilities to learn about their menstruation periods and how they can handle the monthly menstruations. Girls tended to stall their education during this time and stay home. They also learned about protecting themselves from unwanted sex.

In India the right to work is embedded in Article 41 of the Constitution, which directs the State to secure the right to work, education, and public assistance in case of unemployment, as well as the right to rest and leisure and the right to housing is recognized under Article 21 of the Indian Constitution as part of the right to life and personal liberty. The Right to Education Act (18) mandates free and compulsory education for all children aged 6 to 14 years, including children with disabilities. India has various laws and policies promoting inclusion and participation of persons with disabilities in the community.

**Human rights of unpaid and paid caregivers**, including those who are women, persons with disabilities, children and older persons;

LFTW response:

Many countries have a National Human Rights Commission (NHRC) which monitors and addresses human rights violations also related to caregivers of people with disabilities. The Universal Declaration of Human Rights (UDHR) (3) in Article 25 recognizes the right to a standard of living adequate for health and well-being, indirectly encompassing the rights of caregivers.
Decisions and recommendations from international human rights bodies such as the UN Human Rights Council and the Committee on the Rights of Persons with Disabilities contribute to establishing jurisprudence on the rights of caregivers globally.

Paid caregivers in our focus countries are often health care workers, or primary care workers, there are some institutions like orphanages and old people’s homes, run by government social services. Other institutions, like rehabilitation centres for people with disabilities are often run by NGOs, like the Cheshire Foundation.

There is limited recognition and support for the role of unpaid caregivers, and especially caregivers of children with disabilities or elderly people are expected to carry out care giving duties without adequate support. DICD or CBR programmes in the community support informal care givers with skills in home based rehabilitation and activities and knowledge about rights and access to services. Support is often organised informally and carried out by community workers, or volunteers, for example through the church or local community support groups.

In India the rights of caregivers of persons with disabilities are recognized in The Rights of Persons with Disabilities Act (19) which mandates provisions for their support and assistance. For example, in the case of Olga Tellis vs. Bombay Municipal Corporation, the Indian Courts have affirmed the rights of caregivers, particularly in cases related to persons with disabilities and older persons.

**Human rights of recipients of care and support**, including those who are women, persons with disabilities, children and older persons;

LFTW response:

Rights are recognised through national and international mentioned documents and legislation. Many government institutions have detailed policies and operational manuals for the implementation of support services or care. However, most of these policies focus on the implementation and provision of the service and not on the rights of the recipients of these services.

Safeguarding policies should be in place for the mentioned institutions to protect the human rights of people with disabilities, especially of children and vulnerable people. Government institutions, NGOs and key players in the field of disability should have a comprehensive child protection policy to ensure that rights of the child with disabilities are met and not violated. It is important that these policies are clearly displayed and communicated so that recipients of care or services are aware of their rights and where to go if their rights are violated.

Even though policies and legislation are in place in many countries, there is often lack of knowledge and implementation of these laws or policies. To fight for human rights to be recognised and acknowledged is a difficult process and often hampered by lack of resources, such as financial, transport or mobility, as well as understanding the legal system. Lack of monitoring and discrimination still prevent people with disabilities to enjoy the same rights as people without disabilities.

For example, in Ethiopia a learning publication was developed; Child protection matters for children with disabilities (22). This case study was based on the experiences of partners who developed projects to improve the protection of children with disabilities from harm. The main finding from the stories collected was that both children, their parents and the communities often did not realise that children with disabilities had the right to be protected from harm.

In India the human rights of recipients of care and support, including women, persons with disabilities, children, and older persons, are protected under laws such as the Rights of Persons with Disabilities Act (19), Protection of Children from Sexual Offence Act 2012, and the Protection of Women from Domestic Violence Act, 2005,

**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

LFTW response:

The right to self-care of caregivers and recipients of care and support is indirectly safeguarded in many countries under constitutional provisions guaranteeing the right to life and personal liberty and international conventions such as the CRPD (1). Additionally, national healthcare schemes often aim to promote access to healthcare services for all individuals, including caregivers and recipients of care.

There is little provision for psychosocial support which would recognise the need for self-care for caregivers or recipients of care. Emotional support is available from informal support systems in the community such as, DICD or CBR programmes, CBO, OPDs, or churches. Decision making power of children with disabilities is limited in relation to self-care, or for example with whom they would live, they are dependent on the family, many children cannot influence how they are cared for, for example what to eat or wear, the more severe the disability and therefore dependency on caregivers, the less able children with disabilities are able to influence their right to self-care. (10)

Many countries have an informal community support system, for example a community committee, with volunteers that address social protection, child protection and support children and other people in vulnerable situations. The role of these committees is to identify violation of rights, the need for support, as well as improve the care and address violation of basic human rights.

**2. 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, access to justice, governance, financing, monitoring and evaluation, and awareness raising.

LFTW response:

Measures in place in our focus countries include provision of health care, rehabilitation, education, and social services, including social protection, these services are often free of charge, or with a minimal fee, but many of these services are not sufficient to meet the needs of people with disabilities. Most services are only based in regional centres, therefore not accessible for people living in remote areas, most service providers require additional payments to attend to the needs of people with disabilities. Accessible healthcare for all, including caregivers, leads to improved healthcare access, leading to more participation and better outcomes in education, livelihood, employment or leisure.

Social protection strategies should include caregiver support and assistance and provide for example disability benefits, support for vulnerable people with food, or the provision of AT, to promote the rights, dignity, and inclusion of persons with disabilities in society and ensure that they have the necessary support to meet their basic needs and to live fulfilling and independent lives (3,4,5,6, 8,11,16, 9,20,21). Many of the social protection strategies still do not cover or reach all the people that need support.

LFTW supports local partners that implement community programmes, DICD and CBR which are vital to support both care givers and recipients of care. These activities include home based rehabilitation, inclusive play, transfer of skills to families, provision of AT, support groups, for example parent support group, community saving groups and programme for Economic Empowerment. LFTW supports mainstreaming disability which improves participation and supports creating opportunities for participation.

OPDs play an important role in awareness raising, lobby for inclusion and recognition of rights, the UNCRPD, or national action plans for disability inclusion (1). OPDs have a role in monitoring the implementation of national policies and legislation, ensuring access of people with disabilities to services and in creating opportunities for participation and capacity building for people with disabilities and families. (1,12,13, 19) Accessibility of public places, or transport, are one example of impact of legislation and recognition of rights of people with disabilities.

Impact of LFTW supported programmes and implementation can be measured through baseline/endline studies, CBR indicators, Roads to Inclusion, increase in children with disabilities enrolled in school, access to EE and more employment, participation of people with disabilities. For example, the research study of disability inclusion after IDAI. (11)

The Enable-me platform established in Kenya supports people with disabilities to access information about their rights, services and connect and link up with others locally for support and having their rights met.

In collaboration with WHO we have supported the Rehab 2030 assessments and development of strategies for Rehabilitation into the health system in Mozambique, Burkina Faso and Ethiopia. In these three countries rehabilitation was not included into the health system yet and most of the rehabilitation services provided were NGO supported or implemented. While there are still steps to take in the implementation of the strategy the realisation of the needs of providing rehabilitation services for people with disabilities and the population at large.

**3. 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.**

LFTW response:

Main challenges are human resources, financial resources, capacity building, lack of knowledge and skills, attitude, implementation of laws and regulations, discrimination, lack of collaboration with key stakeholders, especially in the field of disability and lack of mainstreaming disability.

For example, absence of comprehensive policies specifically addressing the needs of caregivers and recipients of care and support, leading to gaps in support mechanisms. Challenges in effectively implementing existing laws and policies related to disability rights, gender equality, and social welfare at the grassroots level. Inadequate accessibility to healthcare, social services, and support facilities for caregivers and recipients, especially in rural and remote areas. Persistent stigma and discrimination against persons with disabilities, older persons, and women caregivers, hindering their access to rights and services. Limited financial resources and infrastructure for implementing inclusive care and support systems, resulting in unequal access and quality of services. Lack of awareness among caregivers, recipients, and the community, about rights, available support services, and the importance of inclusive care, leading to underutilization of existing resources.

**4. 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;

LFTW response:

The following LFTW documents support data about people with disabilities, including rights, participation and accessibility. For example: Inclusive Sofala Endline study, the REHAB 2030 STAR assessments, gender intersectionality report, information from APOM/MERLA.

**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.

LFTW response:

LFTW takes a holistic and inclusive approach in programme development and implementation as is seen in various strategic framework and consortiums, ensuring disability mainstreaming and inclusion in programme development and implementation in Eye Health, Inclusive Education, Economic Empowerment, Advocacy and Humanitarian Action.

In many countries there is an increase in humanitarian crises which has shaped responses by NGOs and other key actors in the field of disability and human rights. It is important that government, NGOs and civil society work together to ensure that basic rights for food, shelter and care, as well as access to services that provide for the basic needs of people with disabilities, especially children and women with disabilities are met. This requires a comprehensive and inclusive approach to humanitarian action and other programmes.

Some examples of this approach are CONNECT programme in Cabo Delgado, Mozambique, Education in Emergency Project in Ethiopia, INPOWER in Mozambique.