

Disability Inclusion Helpdesk Report No: 106

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Contents

1. Key facts on disability inclusion in Timor-Leste
2. Methodology
3. Definition of disability
4. Disability prevalence in Timor-Leste
5. Policy and legislative context of disability inclusion in Timor-Leste
6. Disability inclusion and governance in Timor-Leste
7. Disability inclusion and climate change in Timor-Leste
8. Disability inclusion and health in Timor-Leste
9. Disability inclusion and social protection in Timor-Leste
10. Key stakeholders on disability inclusion in Timor-Leste
11. Expert contributors
12. References

Disability Inclusion Helpdesk Report No: 106

Key facts on disability inclusion in Timor-Leste

- > Estimates on disability prevalence vary. The most detailed recent data indicates **21% of the population aged 15 and older have some level of difficulty, and 2.4% have a significant disability** (DHS, 2016). At the household level, the prevalence of any functional difficulty is at 46.6%.¹
- > The Government of Timor-Leste **ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2022** along with the Optional Protocol that allows for individual complaints to be submitted to the UN Committee on the Rights of Persons with Disabilities for any violations.
- > There is an **active disability rights movement** in Timor-Leste led by the national organisation for people with disabilities (OPD) Ra'es Hadomi Timor Oan (RHTO) and the disability umbrella organisation Association for Disability Timor-Leste (ADTL), who have been instrumental in securing growing government commitment to disability inclusion. However, OPDs have been reliant on international donors to fund programming and advocacy efforts.
- > The government's **Disability National Action Plan 2021-2030** developed by the Ministry of Social Solidarity and Inclusion (MSSI) with support from OPDs sets out targets for each government ministry to promote disability inclusive services. However, resource allocation to deliver on these commitments is not clearly outlined.
- > **People with disabilities are significantly more likely to face deprivation in health, education, work and living standards.** People with a lot of functional difficulty have a multidimensional poverty headcount of 94% compared to 82% for people with some functional difficulty and 71% for people with no difficulty (DDI 2016).
- > **Almost half of children with disabilities between 3 and 18 years are not attending school due to systemic barriers to education (UN, 2021).** Only 15% of people with disabilities can read and write in any of the country's four working languages. The 2017 Inclusive Education Policy recognised the need for interventions to ensure equitable access and participation. Inclusive education resource centres have been established in three municipalities and some teachers have received training inclusive education.
- > **The unemployment rate for people with disabilities is 19.6%**, four times the rate for the overall population (GoTL VNR, 2023).
- > **Women with disabilities are significantly more likely to experience physical, sexual and/or emotional intimate partner violence in their lifetime than women without disabilities** (Gupta et al., 2023). Timorese OPDs have raised concerns that the police and judiciary are slow to respond to such incidents (US State Dept, 2022). Facilities are often physically inaccessible and service providers and justice institutions are not always trained to adequately support women and girls with disabilities who have experienced violence (RHTO, 2015).
- > **Discriminatory and stigmatising attitudes towards disability have contributed to high**

¹ The survey used the DHS Programme's Disability Module, a series of questions based on the Washington Group on Disability Statistics (WG) questions. The questions address six core functional domains: seeing, hearing, communication, cognition, walking, and self-care.

Disability Inclusion Helpdesk Report No: 106

levels of socioeconomic exclusion. This is especially the case for people with mental health conditions and psychosocial disabilities, who frequently experience discrimination and violence (Hall et al., 2019) and are denied the right to vote in Presidential elections in violation of the International Covenant on Civil and Political Rights, which Timor-Leste has ratified (UN, 2021).

- > **People with disabilities rate their economic situation less positively** and are less likely to agree that Timor-Leste is generally progressing in the right direction compared to people without disabilities (Asia Foundation, 2022).
- > **Whilst Timor Leste offers a disability pension only 21% of those eligible are estimated to be receiving the entitlement** (World Bank, 2022).

Methodology

An extensive literature review was conducted for the report and supplemented by key informant interviews with representatives from OPDs and disability inclusion experts in Timor-Leste (details are provided in the expert contributor section).

Definition of Disability

Article 1 of the UN Convention on the Rights of Persons with Disabilities defines people with disabilities as: ‘...those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.’

Physical, cognitive or sensory impairments become disabling when they interact with prevailing discriminatory attitudes, behaviours and policies or physical spaces to effectively bar the individual(s) from participating fully and on an equal basis in society. For example, inaccessible signage or a lack of ramps and handrails are environmental barriers that deny access to schools or health facilities for individuals with visual or physical impairments. Other types of barriers include attitudinal barriers such as stigma and discrimination, and institutional barriers such as discriminatory laws and policies. Impairments can also combine with other key factors and characteristics to compound the level of marginalisation, for example characteristics based on age, gender, ethnicity, socio-economic background, rural versus urban locations. People may also experience different levels of discrimination based on whether their impairments are visible or not. The experience of disability varies widely, with at least as much variation amongst people with disabilities as there is amongst those without disabilities.

The Government of Timor-Leste affirms this social model of disability in the 2012 National Policy on the Inclusion and Promotion of the Rights of People with Disabilities and the National Action Plan for People with Disabilities 2021-2030 (GoTL, 2021). However, disability rights advocates have flagged that discriminatory or pitying attitudes towards people with disabilities persist and more advocacy is needed on rights-based approaches to inclusion (Kills with OPDs).

Data on disability in Timor-Leste

Estimates on the prevalence of disability in Timor-Leste vary due to different survey methodologies used. For example, the 2015 census ascertained how much difficulty an

Disability Inclusion Helpdesk Report No: 106

individual had in carrying out specific functions and classified people with *some difficulty*, *a lot of difficulty* and *cannot do at all* in at least one of the domains. The 2022 census used the Washington Group short set and only included those with ‘a lot of difficulty’ or ‘cannot do at all’ as people with disabilities in the analysis. For context, the WHO estimates that 16% of the global population has a disability, a figure that is likely to be higher in low- and middle-income countries and contexts that have experienced conflict. Moreover, **stigma and sensitivities associated with having a disability might prevent people from disclosing information in national surveys**. A lack of national data disaggregated by disability is also cited as a key barrier to measuring and advancing the country’s progress against the Sustainable Development Goals (GoTL VNR, 2023).

Prevalence

- > The 2015 census reported 3.2% of the population have a disability (just over 38,000 people out of a population of 1.18 million, representing 3.4% of the male population and 3.1% of the female population).
- > The 2016 DHS found 15% of people aged 5+ and 21% of people aged 15+ have some level of difficulty in at least one domain of functioning. 1.8% aged 5+ and 2.4% aged 15+ have either a lot of difficulty or cannot function at all in at least one domain.
- > The 2022 census used the Washington Group of questions on functional difficulties to measure the prevalence and characteristics of disability across six domains. The results showed 1.4% of the population (17,061 people) have one or more significant disabilities (a lot of difficulty or cannot do at all), of which 45.5% have multiple disabilities.
- > Approximately the same proportion of men and women live with disabilities. However, the report cautions that the census underrepresents the actual disability prevalence in households due to the sensitivity of the question (Census, 2022).

Functional domains

- > Difficulties with seeing was the most prevalent functional difficulty recorded in the 2015 census (affecting 2.1% of males and 2.0% of females), following by walking (1.4% of males and females), hearing (1.2%) and intellectual/mental disability (0.9%).
- > The 2016 DHS found 10% of the population have at least some difficulty seeing, and 1% have a lot of difficulty seeing or cannot see at all.
- > The 2022 census found that walking was the most common limitation (affecting 44.3% of those with a disability), followed by seeing (39.1%) and hearing (37.3%).

Age and gender

- > 11% of widowed women have either a lot of difficulty or cannot do at all at least one of the functions asked about, more than any other marital status (GDS DHS, 2016).
- > The prevalence of functional difficulties increases with age, starting at 3.4% for ages 15 to 29, increasing to 12.2% for ages 30 to 44, 40.6% for ages 45 to 64, and 67.6% for ages 65 and over.
- > There is a notable gap in knowledge on disabilities among children under 5.

Disability Inclusion Helpdesk Report No: 106

Education

- > People with disabilities have considerably lower literacy rates than people with no disabilities. Women (aged 15 and above) with severe disabilities have a literacy rate of 9.5% compared to 60.2% of women overall; 20.1% of men with severe disabilities are literate compared to 68.7% of the adult male population (2015 census).
- > Women and men with no education are more likely to have at least some difficulty of function than women and men with any education (GDS DHS, 2016; DDI, 2016).
- > 29% of women and 30% of men with no education have at least some difficulty seeing, twice the national average (GDS DHS, 2016; DDI, 2016).

Urban/Rural

- > 86% of people with disabilities live in rural areas compared to 70% of the total population who live in rural areas (2015 census; DNAP, 2021).
- > Rural residents are more likely to have some functioning difficulties than are urban residents. For rural and urban areas, respectively, the prevalence rates are 23.5% compared to 14.9% among adults and 48.6% compared to 40.3% among households (GDS DHS, 2016; DDI, 2016).

Policy and legislative context of disability inclusion in Timor-Leste

Timor-Leste's **constitution (2002) guarantees equal rights for all people** and forbids discrimination based on a “mental or physical condition”.

Timor-Leste is signatory to the **Incheon Strategy (2013-2022)** in 2012, a regional set of 10 disability inclusive development goals that build on the UNCRPD to catalyse action towards an inclusive society that ensures, promotes and upholds the rights of all persons with disabilities in Asia and the Pacific. The goals include promoting participation in political processes and in decision-making, strengthening social protection, and ensuring disability inclusive disaster risk reduction and management (UN ESCAP, 2012).

In 2012, the Government approved a **National Policy for Inclusion and Promotion of the Rights of People with Disabilities**. The policy mandates that each government department and agency include activities that promote the rights of people with disabilities in their plans and annual budgets (GoTL DNAP, 2021).

There was limited progress in implementing the policy until 2019, when the MSSSI led a participatory and inclusive process with OPDs to develop the **National Action Plan for People with Disabilities 2021-2030** (DNAP). The plan mainstreams disability inclusion across 11 government ministries, setting targets and guiding annual budgeting to deliver inclusive services (ADTL UPR 2021, GoTL 2021), in line with the government's commitment to the Sustainable Development Goals (SDGs). The Ministry of Finance is developing a disability marker to ensure that budgets and plans measure allocation and achievements compared to obligations and commitments on disability (MOF, 2022). Each ministry has a designated disability ambassador to support implementation. Targets in the DNAP include reviewing and amending all policies and laws to be aligned with the UNCRPD by the end of 2025.

The priority of the MSSSI's National Directorate for the Promotion of People with Disabilities (DNPDPD) is to establish the long-planned **National Council on Disability** to coordinate

Disability Inclusion Helpdesk Report No: 106

implementation and monitoring of the National Disability Policy, the Incheon strategy and UNCRPD (KII).

Disability inclusion and governance in Timor-Leste

The new coalition government, formed on 1 July 2023, has stated their commitment for further implementation of the UNCRPD and the DNAP, including the importance of creating a system to monitor the implementation of the convention. They will launch a 5-year plan after 100 days of governing and it is highly anticipated it will include plans to develop programmes and services for people with disabilities such as improving the National Rehabilitation Centre in Dili and expanding rehabilitation services to other municipalities. However, the change in leadership will require OPDs to form new relationships and intensify advocacy efforts to ensure recent gains are not lost, advance a human rights approach to disability inclusion and secure adequate funding for DNAP implementation (KIIs with OPDs). The MSSI has pledged to continue raising awareness with all ministries to allocate the necessary budget (KII).

Civil society groups in Timor-Leste have historically tended to overlook the needs of people with disabilities. However, this is beginning to change with greater global commitment to the Sustainable Development Goals' leave no one behind agenda, the specific requirement from donors to collect disability data and increasing recognition of the value of collaboration and solidarity across marginalised groups. OPDs have partnered and shared resources with youth organisations, women's organisations, LGBTQI+ groups and human rights advocates on cross-cutting issues. Actors working to tackle violence against women and girls, for example, have improved service delivery through partnering with OPDs and strengthening referral networks (KIIs with OPDs).

Disability inclusion and climate change in Timor-Leste

Timor-Leste is extremely vulnerable to climate shocks including floods, landslides, sea-level rise and higher temperatures. About 80% of the population is dependent on climate-sensitive livelihoods (IFRC, 2021). Globally people with disabilities are estimated to be two to four times more likely to die in a disaster due to barriers such as inaccessible physical environments and communication channels, lower socioeconomic resilience to shock and a failure by disaster management and response to account for their needs (IFRC, 2021; Baker, 2021).

Climate change is also expected to intensify food insecurity in a country where malnutrition is a major contributor to premature death and disability. Forty-six percent of children under five years old are stunted (a sign of chronic malnutrition); and one in four children under five years old are wasted (a sign of acute malnutrition caused by insufficient food and nutrient intake, infectious diseases, or a combination of both) (DHS, 2016; IFRC, 2021).

People with disabilities are not being included in national climate change policy. Timor-Leste's first National Adaptation Plan to address climate risks and build climate resilience drafted in 2020 contains just one reference to people with disabilities (Secretariat of State for Environment, 2020).

However, OPDs have begun to be actively involved in local and national disaster

Disability Inclusion Helpdesk Report No: 106

management and response through donor funded programming. National OPD RHTO has partnered with the Australian Humanitarian Partnership's **Disaster READY** project (2018-2021) to mainstream disability inclusive disaster risk reduction, strengthening community and government capacity, and ensuring almost half of supported municipal disaster management committees include people with disabilities. (Dibley et al., 2021; Baker, 2021).

Severe flooding in Dili in March 2020 marked the first involvement of an OPD with a government-led disaster response, with RHTO supporting identification, assessments and response work, for example, amending government rapid assessment forms to identify the specific needs of people with disabilities and providing targeted assistance such as rebuilding homes in an accessible way. This collaboration was an important first step to mainstream disability inclusive practices into government disaster response work (Dibley et al., 2021; Baker, 2021).

Widespread damage caused by Tropical Cyclone Seroja in April 2021 further raised awareness of the need to integrate disability considerations into emergency preparedness and response plans given the disproportionate impact of disasters on socially excluded groups (World Bank, 2022). An estimated 6.7% of flood-affected residents were people with disabilities. (Dibley et al., 2021)

Disability inclusion and health in Timor-Leste

Health services, including mental health services, are provided by the government for free. However, the health system in Timor-Leste is under-resourced in terms of staff, infrastructure and medicine, and due to the challenging terrain geographic coverage is uneven (GoTL VNR, 2023). Wealthier patients access hospital services at nearly twice the rate of poorer patients due to poor transport infrastructure, out-of-pocket expenses such as accommodation and food, and stigmatising attitudes of hospital staff (Price et al., 2016). A public perception survey of 2022 found that people with disabilities report having to pay for health services and being unable to access medicines more frequently than people without disabilities (Asia Foundation, 2022). Additional barriers, including a lack of specialist care, poor access to health information, inaccessibility of services, lack of early detection centres, affordability of costs and insensitive or unskilled treatment by health care workers exist for people with disabilities.

A lack of disability inclusive training leads to varying quality of care for people with disabilities. Pre-service medical training does not include modules on how to support people with disabilities (GoTL VNR, 2023; USAID, 2021). A study on maternal and newborn health provision found some women with disabilities were subjected to discriminatory practices such as forced sterilisation and the use of physical restraint during labour, while others recounted very positive experiences of treatment including outreach services in the home to enable accessible care (Ledger, 2016).

Access to health and rehabilitation services, including access to wheelchairs, speech therapy and physiotherapy, outside of Dili is particularly challenging (DNAP, 2021; Ledger, 2016). Results from a 2022 survey of public perceptions illustrate dissatisfaction with both health services and transport infrastructure: while people with disabilities in Dili feel health should be the government's top priority (chosen by 74% of Dili residents with disabilities compared to 59% of Dili residents overall), those living outside Dili feel roads should be the government's top priority (chosen by 73% and 74% of non-Dili residents with

Disability Inclusion Helpdesk Report No: 106

disabilities and non-Dili residents overall) (Asia Foundation, 2022). Inaccessible transport infrastructure creates a barrier to accessing key services including health and education.

Improvements have been made in recent years, for example, people with disabilities received targeted health information and vaccination services during the COVID-19 pandemic (GoTL VNR, 2023). National OPD RHTO has partnered the Ministry of Health to deliver training on disability inclusion to medical personnel through a three-year Inclusive Health project (Tatoli, 2021) and mental health capacity building has been delivered by PRADET (GoTL DNAP, 2021). Through the DNAP the Ministry of Health has committed that by 2025 all health facilities provide inclusive health services including diagnostics and referrals. However, the lack of reliable and regular data disaggregated by key characteristics including disability is a barrier to understanding needs and appropriately allocating limited investment (ADTL, 2021; USAID, 2021). The Australian Government is working with the Ministry of Health on the development of a disability assessment tool for children (KII).

Mental health services are severely under-prioritised and under-resourced. The Ministry of Health's Mental Health Section, responsible for developing, implementing and monitoring mental health programmes and policies, is staffed by one medical doctor and two mental health programme officers. The government developed a National Mental Health Strategic Plan (2018-2022), which emphasised both a primary care approach to mental health services and partnerships with non-government service providers, but it was not fully implemented due to lack of capacity and the Covid-19 pandemic. There is currently no mental health policy or mental health legislation (WHO, 2022). There are no recent studies with reliable data on the prevalence of people with mental health conditions in Timor-Leste (WHO, 2022). However, the 2016 Global Burden of Disease study estimated 11.6% of people in the country have mental health conditions and/or psychosocial disabilities or use substances. High prevalence rates of post-traumatic stress disorder and severe distress have been found associated with the country's tumultuous history of conflict, violence and forced migration (Silove et al., 2014).

There are only three mental health professionals per 100,000 people in Timor-Leste (Hall et al. 2019). Mental health services are mostly delivered through primary health centres and posts, and hospitals in each municipality. Community-based mental health services are provided by mental health nurses (Hall et al., 2019). There is one tertiary mental health treatment facility at the Guido Valadares National Hospital in Dili, which has 12 beds for acute cases and employs the country's only two psychiatrists and the only clinical psychologist. Patients are sometimes referred to the NGO PRADET for psychosocial, rehabilitation and reintegration support. There is also an inpatient mental health facility at Laclubar in Manatuto municipality run by NGO São João de Deus; however, the quality and approach of service provision need strengthening (WHO, 2022).

Disability inclusion and social protection in Timor-Leste

Timor-Leste offers a disability pension, referred to in language that reflects discriminatory attitudes as the "Allowance for the Support of the Invalid" (SAII), for adults with disabilities who are deemed unable to work. Under the new National Strategy for Social Protection (NSSP) 2021-2030, developed with support from the International Labour Organization (ILO), the pension was increased from US\$30 to US\$50 per month, and indexed to update in line with inflation. This equates to 43% of the national minimum wage or 9% of the average wage (World Bank, 2022).

Disability Inclusion Helpdesk Report No: 106

However, a World Bank study of 2022 demonstrates that the disability allowance is not reaching those most in need. While the number of beneficiaries has more than doubled since it was introduced, only 21% of those eligible are estimated to be receiving the entitlement. Furthermore, despite people with disabilities being overrepresented in the poorer segment of Timor-Leste's society, less than half of the disability pension beneficiaries are in the two poorest quantiles (World Bank, 2022). Service delivery challenges include beneficiary identification, registration processes, payment systems and monitoring mechanisms (GoTL VNR, 2023). Families must navigate a complex bureaucratic process only available in municipality capitals and larger towns to access the pension, requiring several identity documents from multiple sources, including health and social assessments by two government ministries (Hall et al., 2019).

In July 2022, the government began phased roll out of the first social assistance programme for children with a disability through an expansion to the Bolsa da Mãe subsidy, a long-established social protection programme targeting vulnerable households with children. Developed with support from the Australian government's Partnership for Human Development (PHD), the Bolsa da Mãe-Jerasaun Foun programme aims to reduce poverty and early childhood malnutrition with monthly cash transfers of US\$15 for all pregnant women and US\$20 for children up to their sixth birthday. An additional payment of US\$10 is provided to children with disabilities. The programme estimates reaching over 4,000 children with a disability by 2029. PHD are now providing technical support to MSSSI on policy reform formulation for social assistance for children with a disability aged 6-17 years (GoTL BdM-JF, 2021; KII with PHD).

Ensuring timely disbursements has proven challenging due to poor financial and transport infrastructure particularly impacting rural communities. Payments for Bolsa da Mãe occur once a year and for SAII twice a year, with no fixed schedule (GoTL NSSP, 2021). A new digital registration and payment system is being rolled out to increase efficiency and coverage of the expanded Bolsa da Mãe-Jerasaun Foun programme (Catalpa). An additional barrier to coverage is that families may hide relatives with disabilities from social workers and survey collectors due to the stigma associated with disability, thereby preventing eligible citizens from registering for the entitlement (ILO, 2016). OPDs have also flagged concerns that people with severe disabilities are at risk of exploitation by family members who hold decision-making power over how the subsidy is spent.

Key stakeholders on disability inclusion in Timor-Leste

The **Ministry of Social Solidarity and Inclusion (MSSSI)** is the main government body responsible for designing, executing and coordinating activities in the area of disability across all government ministries. Mental health falls primarily under the purview of the **Ministry of Health**. The MSSSI and MoH have standard operating procedures to coordinate referrals and services for people with disabilities (KII). The MSSSI's National Directorate for the Promotion of People with Disabilities (DNPDPD) is tasked with guiding planning and budgeting for the implementation, monitoring and evaluation of the DNAP, ongoing cooperation with the disability sector, and overseeing a medium-term evaluation of the DNAP in 2024 or 2025 (GoTL DNAP, 2021). The MSSSI funds several OPDs which implement services for people with disabilities (KII).

There is an active disability rights movement in Timor-Leste. Key organisations include:

Disability Inclusion Helpdesk Report No: 106

- > **ADTL, the Association for Disability Timor-Leste**, is the umbrella body for organisations working for disability rights in Timor-Leste. Founded in 2006, ADTL now represents 22 member organisations. Their programming covers 1) Education and capacity building; 2) Membership empowerment; 3) Advocacy and Social inclusion and 4) Economic empowerment.
- > **Ra'es Hadomi Timor Oan (RHTO)** is the largest national OPD with a presence across all 13 municipalities. RHTO was established in 2006 to represent and advocate for the rights of people with disabilities to fully participate in all levels of society in Timor-Leste. In addition to advocacy work, RHTO provides technical assistance to government ministries to promote accessible and inclusive services, such as training health workers, making public buildings accessible, facilitating inclusive access to justice and elections.
- > **PRADET (Psychosocial Recovery & Development in East Timor)** was started in 2002 and provides rehabilitation services for people with mental health conditions and psychosocial disabilities, those experiencing trauma and grief, and survivors of sexual assault and domestic violence. PRADET works with government to provide support to vulnerable people through education, counselling, social support, rehabilitation, referrals and medical services.
- > Other key OPDs in Timor-Leste include the women-led Community Rehabilitation Network, which provides specialised services for attending rehabilitation to people with physical disabilities, the Leprosy Mission and Asosiasaun Halibur Defisiensia Matan (AHDMTL) providing services for people who are blind or with low vision.

Donor programmes

The 10-year (2016-2026) **Partnership for Human Development (PHD)**, the Australian government's \$120 million multi-sectoral social development programme, has supported OPDs to advocate for disability inclusion and advised the Timor-Leste government on policy development and implementation, including on the Disability National Action Plan. The programme's independent midterm review found that "PHD has successfully driven a transformative disability agenda through both mainstreaming and disability-specific programming, [resulting] in tangible positive outcomes for people with disabilities" (Olliver et al., 2022).

Expert contributors

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Disability Inclusion Helpdesk Report No: 106

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