



**Submission from Member Organisations of the
Association for Disability Timor-Leste
to the
26th Session of the Human Rights Council Universal Periodic Review Working Group
Recommendations for Timor-Leste**

INTRODUCTION

1. In 2011, the Government of Timor-Leste underwent its first Universal Periodic Review. During this review, the members of the Human Rights Council made a total of 125 recommendations for future improvements to ensure that the human rights of all citizens of Timor-Leste would be protected and upheld. Of these recommendations, 10 stipulated that the Government of Timor-Leste should ratify the UN Convention on the Rights of Persons with Disabilities (CRPD). The Human Rights Council members recognised that the discrimination faced by people with disabilities in Timor-Leste was significant, and concrete action was needed to change this situation. Unfortunately, as at March 2016, the Government of Timor-Leste has not yet ratified the CRPD, despite making repeated promises that they would do so. Although the Government has made good progress, for example finalising a National Policy for disability inclusion, the Government still wants to take a number of extra steps prior to signing and ratifying, including establishing a national council for disability. However, this delay goes against the principle of "progressive realisation" embedded in the CRPD.

2. This joint submission from the member organisations of the Asosiasaun Defisiensia Timor-Leste (the Association for Disability Timor-Leste) provides information on the current human rights situation of people with disabilities, and what future action is needed. Recommendations for the Government of Timor-Leste are included, which can be incorporated into the Universal Periodic Review Working Group's final report. This is an important opportunity to ensure the Government is prompted to take action to uphold the rights of all citizens, particularly people with disabilities, who continue to struggle to claim their equal rights.

THE SITUATION OF PEOPLE WITH DISABILITIES IN TIMOR-LESTE

Discrimination, prejudice and stereotypes **(Universal Declaration of Human Rights Article 2)**

3. Timor-Leste's Constitution explicitly provides for non-discrimination and equal treatment for all people, regardless of their gender or because of mental or physical disabilities.¹ Despite this, stigma and discrimination against people with disabilities remains common. A study undertaken in 2010 found that children and adults with disability may be "shunned, ignored, driven from their communities, imprisoned in rooms or chained to objects to keep them out of sight".²

¹ Sections 6 and 21 of the Constitution of the Democratic Republic of Timor-Leste (2002).

² BESIK. 2010. "Disability and Rural Water, Sanitation and Hygiene (RWASH) in Timor-Leste".

4. The **Government of Timor-Leste has not taken sufficient action to uphold the rights of people with disability**. A National Policy for the Inclusion and Promotion of the Rights of People with Disabilities exists, but implementation of the policy's commitments is weak. A National Action Plan for People with Disabilities has been in draft status for two years, and has not yet been debated or formally approved by the Council of Ministers. The Government has plans to establish a National Disability Council, which will facilitate inter-ministerial coordination, and link people with disabilities to Government representatives. However, the Council has not yet been created due to delays in the consultation and legalisation processes, and there are concerns that if the Council is located within the Ministry of Social Solidarity it will lack influence and decision-making abilities. Furthermore, disability inclusion is not only a social welfare issue, but should be a priority action for all government agencies. Therefore, ADTL Member Organisations recommend the Council secretariat should be housed in the Prime Minister's Office. Most problematic, the Government of Timor-Leste has not yet signed or ratified the Convention on the Rights of People with Disabilities, despite a large number of recommendations from the first cycle of the UPR (in October 2011).

5. There is also **a lack of statistical data concerning women and girls with disabilities** in Timor-Leste. The 2010 Census reports that just 4.6 per cent of the population, or 48,243 people, are persons with disabilities. However, this prevalence data varies considerably from international experience and is likely to be an under-representation of the true prevalence of disability in the country. The Census data collection process used a limited definition of disability, which only captures certain types of impairments. Applying the World Health Organisation and World Bank 2011 - that estimates a percentage of 15 per cent of the world's population being comprised by persons with disability³ - the population in Timor-Leste would be around 175,000 of persons with disability.⁴ The Government of Timor-Leste is therefore making programming and budget decisions that do not take into account all people with disabilities including women and girls with disabilities in the country. Furthermore, administrative data collected through education or health management information systems do not adequately disaggregate data by disability. Thus, data exposing the real situation for people with disabilities is not being adequately collected or utilised to inform appropriate policies and programs, including budget allocation.

Recommendations:

1. Ratify the Convention on the Rights of People with Disabilities (CRPD) without further delay.
2. Review and update the draft National Action Plan for Disability and ensure the Plan is finalised and approved by the Council of Ministers by December 2017 at the latest.
3. Adopt the internationally agreed Washington Group Short Set of Six questions related to disability - developed by the Washington City Group of the United Nations Statistics Division - in all future census and demographic and health survey processes.

Violence, Inhuman and Degrading Treatment of People with Disabilities (Universal Declaration of Human Rights Article 5)

6. International evidence shows that women with disabilities are twice as likely to experience violence compared to women without disability.⁵ They are likely to experience domestic violence over a longer period of time, and to suffer more injuries as a result of the

³ http://www.who.int/disabilities/world_report/2011/report.pdf

⁴ Based on a population of 1.167 million (from 2015 Census data).

⁵ United Nations Special Rapporteur. 2012. *Report of the UN Special Rapporteur on Violence Against Women, Its Causes and Consequences: Report on Violence Against Women with Disabilities*. Available: http://www.wda.org.au/wp-content/uploads/2013/12/UN_SR_Report_2012.pdf

violence. Women with disabilities, particularly women with sensory impairments or impairments which make communication difficult, face significant barriers accessing support and justice. The Government has taken no action to address risks of violence against women with disabilities, and is not taking sufficient action to ensure effective response in terms of ensuring inclusive and accessible support services, safe houses and access to police and justice for women and girls with disabilities who are victims of violence.

7. There is evidence that **violence and neglect of children with disabilities is widespread** in Timor-Leste. Due to the shame and stigma associated with disability, many families hide children inside the house, or limit the child's exposure to society. **There is evidence of shackling and restraining of children with disability, particularly children with psychosocial impairments.** A report from the United Nations in 2011 reported that there had been a number of cases in which children with psychosocial disabilities were held in long-term restraints.⁶ Field staff of the national organisation of persons with disabilities (Ra'es Hadomi Timor Oan, RHTO) are also aware of situations in which children with disabilities have been left in the family house all day without supervision, food, water, or means of communication. Although child protection officers, mobilised and managed by the Ministry of Social Solidarity, are present in all municipalities, have not yet been trained on disability awareness, and there are not clear referral pathways between services to persons with disabilities and child protection services.

8. The 2010 Census concluded that there are more than 10,000 people with psychosocial disabilities in Timor-Leste. However, **there are only two non-governmental organisations that provide services to person with psychosocial disabilities:** Psychosocial Recovery and Development in East Timor (PRADET), and Centro São João de Deus. Both these organisations are struggling with limited resources, and are only able to support 20 people in their in-patient facilities. The two organisations are concerned that people with psychosocial disabilities and intellectual impairments are at high risk of experiencing violence and degrading treatment. In many cases, people are left unattended due to the inadequate national protection system and lack of psychological and physical recovery facilities in Timor-Leste. The Ministry of Health has drafted a national policy on mental health, which has been presented for discussion and consultation with key stakeholders in 2015. The policy proposed strategies for strengthening effective leadership and governance for mental health, provide comprehensive inter-sectoral responsive to mental health and social care services, and sets out required infrastructure, equipment and financial resources. This policy has not yet been approved or implemented.

Recommendations:

1. Provide adequate support and resources, such as provision of interpretation services, assistive devices and accessible transport, to enable women with disabilities to access victim assistance support, and support from police and the justice system.
2. Ensure victim assistance services, such as refuges and safe houses for women who have experienced violence, are physically accessible for women with disabilities, and that staff are trained in disability awareness and are able to meet the specific needs of women and girls with disabilities who have experienced violence.
3. Train all Child Protection Officers on the rights of persons with disabilities, and establish clear referral guidelines of protection of children with disabilities who are at risk of violence.

⁶ United Nations Integrated Mission in Timor-Leste (UNMIT). 2011. "Of Course We Can: Report on the Human Rights of Persons with Disabilities in Timor-Leste".

4. Increase the availability of support services for persons with disabilities, including through training of psychologists, physical therapists, occupational therapists, and support workers, and opening facilities for psychological, physical and occupational therapy.

Recognition and Equal Protection Before the Law & Access to Justice (Universal Declaration of Human Rights Article 6 and 8)

9. When people with disabilities are required to access the justice system they face many barriers. For example, RHTO and the Agape School for the Deaf recently supported a woman with disability who had experienced violence. She had an impairment that impacted her ability to communicate and she struggled providing evidence to police, lawyers and judges about the crime perpetrated against her. RHTO worked with a women's legal assistance organisation, Asistencia Legal ba Feto no Labarik (ALFeLa), to help her make connections with the police. In addition, staff from the Agape School provided sign language interpretation to ensure she would be able to participate in tribunal proceedings and submit her testimony. Without this support, she would have had no access to the formal justice system and her experiences would not have been heard.

Recommendation:

1. Reform Witness Protection Law to include provisions for assistants and sign language interpreters to enable persons with disabilities, in particular people with sensory impairments (for example hearing impairments) to provide testimony in the court.

Freedom of Expression (Universal Declaration of Human Rights Article 19)

10. People with hearing impairments and who are Deaf in Timor-Leste have limited freedom of expression, as **there is no official sign language in Timor-Leste developed or recognized by the State**. At present, the AGAPE School for the Deaf located in Dili has established a 1000+ word vocabulary using a combination of local signs, Filipino sign language, and American sign language. However, outside of the AGAPE School, sign language is not utilized in Timorese society. Notably, in the report from the National Languages of Timor-Leste Conference 2010, in their Guiding Principles of the Language in Education Policy for Timor-Leste, linguists recommend that sign language in Timor-Leste be officially recognized and that an official Timorese sign language be developed.⁷ However, these ideas were never written into law. As a result, children with disabilities (especially those living outside of Dili due to their lack of proximity to Agape School) do not have methods of communication in their communities, often do not attend school, and lack the ability to express themselves due to lack of access to a recognised sign language.

11. Furthermore, participation in community activities is restricted for many people with disabilities. One member of RHTO, a woman with a vision impairment living in Manufahi District, said that she is not really able to participate in meetings occurring in her *aldeia* (hamlet). She is often not invited and the meetings are not accessible for her. Indeed, of 49 women with disabilities recently interviewed, **67 per cent said they are not able to participate in community meetings** due to lack of accessibility.

Recommendations:

1. Commit resources and support to enable the Timor-Leste Deaf community to develop a recognised sign language, ensuring that children and young people who are Deaf and who

⁷ Report of the First Conference on the National Languages of Timor-Leste: Many Languages, One People. 2010.

have hearing impairments to have the opportunity to be taught in their national sign language.

2. Train local leaders, including hamlet and village chiefs (*Chefe de Aldeia* and *Chefe de Suco*) on disability and gender awareness, to help them be aware of the role they can play in supporting people with disabilities to participate in local-level public life and decision-making processes, including community meetings and *suco* elections.

Social Security and Protection **(Universal Declaration of Human Rights Article 22)**

12. International evidence shows pervasive links between poverty and disability. People with disability and their families are more likely to be poor because they face additional social exclusion and costs, such as paying for assistive devices or regular rehabilitation and health care, as well as indirect costs such as loss of productivity due to lack of access in schooling and employment opportunities.

13. Despite these extra costs and vulnerabilities, persons with disability are not adequately supported by the current social protection system in Timor-Leste. The Government of Timor-Leste does provide a disability pension. However, only people over the age of 18 who have “a mental or physical condition, from any source, that determines an absolute and definitive inability to perform a work activity” are eligible⁸, which means that families with children or youth persons with disabilities under of 18 cannot access such support. A 2011 survey found that **86 per cent of people with disability do not receive the disability pension.**⁹

14. The process to apply for the benefit is complicated, difficult and inaccessible for people to undertake. RHTO has heard testimonies of many women with disabilities who have been unable to access the disability pension because of lack of support from family or community leaders (the village chief must provide a declaration confirming that the citizen in their village is a person with disability), difficulty getting the official paperwork required, and lack of transportation to travel to government offices. One female member of RHTO said:

“I cannot get help from the government through the subsidy because our *Chefe de Suco* (village chief) does not place attention on people with disabilities. Sometimes, I go intending to talk to him, but he always says he doesn’t have time.”

15. The lack of a specific carer’s allowance to support those who look after children with disability under the age of 18 is creating problems for families who struggle to support their children with disability. The Government’s Bolsa Da Mae (“mother’s purse”) stipend is aimed at supporting “vulnerable” families, including female-headed households. However, the eligibility criteria and application process are not well understood, and there is limited information provided by the Government about this program. It remains unclear whether a family that includes a disabled member would be prioritised or even eligible to receive the Bolsa Da Mae stipend. There is also anecdotal evidence that people with disabilities believe that if a family receives the Bolsa Da Mae payment, any member of that family would be ineligible to receive the Disability Pension, as a family can only receive one payment. It is unclear whether this is true or not, as official information about these programs is difficult to access.

⁸ The “Allowance for the Elderly and Deficient” (known as the “disability subsidy”) was approved by Decree-Law No. 19/2008, dated June 19, defines and regulates a pecuniary periodic lump sum intended to Timorese citizens living in the country, aged 18 years or more, that have “a mental or physical condition, from any source, that determines an absolute and definitive inability to perform a work activity” (Articles 1, 4 and 6).

⁹ Referenced in: Magdalena Sepúlveda Carmona. 2012. “Report of the Special Rapporteur on Extreme Poverty and Human Rights, Mission to Timor-Leste.”

Recommendations:

1. Reform Decree Law Number 19/2008 on the Subsidy to the Elderly and Disabled People to make the subsidy easier to access, and reform Decree Law Number 18/2012 on Bolsa da Mae to revise the criteria to prioritise families that include a member with disability to receive the Bolsa Da Mae, and ensure citizens are aware of this eligibility.
2. Implement a specific carer's stipend to support people (parents or carers) who look after children with disability under the age of 18, including those who are children and youth with intellectual, sensory, physical and psychosocial disabilities, until the children with disability reach the age of 18 and are able to independently apply for the disability stipend, if needed.

Work and Employment**(Universal Declaration of Human Rights Article 23)**

16. People with disabilities face particular barriers and struggle to enter employment. This is despite the legislative protection provided by the Labour Law of Timor-Leste, which prevents discrimination against people with disabilities when they apply for or are in employment.¹⁰ **People with disabilities face barriers in accessing education (as discussed below) and vocational training, thus hindering their ability to enter into employment.**

17. Of 49 women with disabilities recently interviewed by RHTO, 86 per cent said they had never accessed vocational training, and 65 per cent do not work or engage in livelihood activities. A survey of 300 people with disabilities undertaken by ADTL in 2014 showed that 47 per cent were self-employed through self-help groups established by organisations working in the disability sector.

18. One RHTO member, "Maria", a woman with a physical impairment, shared her story about the challenges she faces because she cannot find work:

 Maria is a person with physical impairment, and cannot manage hard work. Due to lack of accessibility and reasonable accommodation, she is not allowed to access employment, which results in a serious financial restriction to her and her children, including huge restriction to access the minimum to live, such as rice and basic food. Every day the neighbours help them to get goods and food, such as rice or petrol.

Recommendations:

1. Improve access to employment by creating a quota that requires 1 per cent of all positions in public service and private sector must be for persons with disabilities.
2. Develop vocational and employment programs and training targeted to persons with disabilities to boost their opportunities for entry and advancement in the workforce. Ensure people with disabilities are able to access mainstream vocational training opportunities.
3. Ensure that reasonable accommodation is provided to persons with disabilities in the workplace.

Standard of Living Adequate for Health**(Universal Declaration of Human Rights Article 25)**

¹⁰ The Labour Law was adopted by Law No. 4/2012 of February 21, provides in paragraphs 2 and 4 of Article 6 that "No employee or applicant for employment shall be...discriminated...because...of physical or mental condition" and "are not considered to be discriminatory measures of a temporary nature...of a legislative nature that benefit certain disadvantaged groups, particularly in the light of...disability."

19. People with disability have the same needs for health services, including primary health care and health screening services, as people without disability. Furthermore, people with disability may also have specific health care needs related to their disability (for example, physiotherapy or assistive devices), and require additional support.

20. Despite this, **persons with disability in Timor-Leste are often not able to access health care on an equal basis with others**, due to (1) discriminatory or stereotyped attitudes of health care workers, (2) health facilities that are inaccessible and (3) lack of awareness raising targeting persons with disabilities on available services.¹¹ People with disabilities in rural areas face extra challenges due to the distance to health posts, and lack of accessible transport.

21. Early and appropriate access to health care and rehabilitation support is crucial. If children with disability are not supported, their physical, cognitive and emotional development may be reduced, leading to long-term and even additional health issues and impairments.

22. Indeed, staff from RHTO has reported intervening in situations where children who had mild physical impairments when young have gone years without receiving rehabilitation and health support, and their physical condition has deteriorated as a result, leaving them with aggravated impairments requiring greater levels of support.

23. The development of children with and without disabilities is affected by stunting and chronic undernourishment. According to the 2013 report from UNICEF, 58 per cent of children under 5 in Timor-Leste are stunted, ranking Timor-Leste among the top countries with the highest percentage of stunting of children under five across the globe.¹² **Chronic under-nutrition can cause developmental and learning impairments in children, but also affects children that are already children with disabilities.**

24. RHTO's field officers state that the Ministry of Social Solidarity holds sessions on the importance of nutrition and impairments in rural areas, but rural farmers often do not understand the concept of vitamins and the connection with impairments. Poor water and sanitation practices also affect people with and without disabilities, and is often not considered in nutrition programs.

25. Attitudinal barriers in particular are likely to play a big role in **preventing women with disabilities from accessing sexual and reproductive health care**. Frequently, health care providers and the broader community make assumptions that persons with disability are not sexually active and therefore do not require information about reproductive health. This means that women and youth with disabilities are not targeted to receive such information, and reproductive health services are often not accessible for them.

Recommendations:

1. Ensure the obligatory training of all health care workers, including nurses, doctors and midwives, in awareness regarding persons with disabilities and their rights as an integral part of their training, including respect for the right to free and informed consent of women and youth with disabilities.

2. Allocate adequate budget and resources to enable the Centre for National Rehabilitation (Centro Nasionál Rehabilitasaun, CNR) to undertake regular outreach visits to the Municipalities, through which they can provide rehabilitation therapy and assistive devices

¹¹ Megan McCoy, Cornelio De Deus Gomes, Joel Alex Morais and Jonio Soares. 2013. "Access to Mainstream Health and Rehabilitation Services for People with Disability in Timor-Leste".

¹² UNICEF. 2013. "Improving Child Nutrition: The Achievable Imperative for Global Progress".

to people with disabilities who require them but cannot access them due to lack of accessible and affordable travel to Dili (where CNR is located).

3. Adopt measures to ensure that all education, information, healthcare and services related to sexual and reproductive health, including physical treatment and psychological counselling, HIV and STIs, are made accessible to women, youth and girls with disabilities in age-appropriate formats and in rural regions.

Education

(Universal Declaration of Human Rights Article 26)

26. Children with disabilities in Timor-Leste, particularly girls, face significant challenges attending and completing schooling. **The 2010 Census reports that 72 per cent of people with disability in Timor-Leste had never attended school**, and a National Survey of Disability in Timor-Leste's Primary Schools conducted by the Ministry of Education, Plan International, and the ASSERT rehabilitation centre (now the Centro Nasionál Rehabilitasaun) found that, **of the children with disability identified who were attending school, 64 per cent were boys and only 36 per cent were girls.**¹³

27. A 2011 report on access to education for children with disability, which involved interviews with people with disabilities and their families as well as teachers and education officials, identified a number of barriers for this lack of access, including: inaccessible infrastructure, distance, cost, community and family attitudes, lack of access to assistive devices and rehabilitation, and lack of training on disability for teachers.¹⁴

28. Children with intellectual impairments and sensorial impairments, such as children who are blind or Deaf, face particularly significant challenges in attending school and accessing learning material. Regular schools throughout the country are not equipped to provide Braille materials or sign language interpretation, and they are not able to teach in these formats. The only option for children who are Deaf is the Agape School for the Deaf in Dili. Some children move away from their families in the municipalities to attend this school in Dili, however this deprive them from their right to a family environment (CRC Article 20) and does not immediately facilitate their right to education through the mainstream schooling system.

Recommendations:

1. Take concerted steps towards inclusive education, prioritising the training of all teachers in inclusive education as an integral part of core teacher training curricula and in continued in-service teacher training. Allocate budget for the availability of assistive devices and accessible materials, equipment and environments in schools as well as the provision of support in classrooms to children with disabilities.

¹³ Plan Timor-Leste, Ministry of Education and ASSERT. 2008. "The First National Survey of Disability in Timor-Leste's Primary Schools".

¹⁴ Megan McCoy, Elizabeth Morgan, Joazito Dos Santos and Natalie Smith. 2011. Timor-Leste Disability Inclusive Education Situational Analysis Report".

CONTRIBUTORS TO THIS JOINT SUBMISSION

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- Ra'es Hadomi Timor Oan (the national disabled person's organisation; RHTO)
- East Timor Blind Union (ETBU)
- Halibur Defisiénsia Matan Timor-Leste (HDMTL)
- AGAPE School for the Deaf
- Ahisaun Disability Foundation
- Psychosocial Recovery and Development East Timor (PRADET)
- Alma Sisters
- Centro Joao de Deus (Saint John of God)
- Klibur Domin
- Klinika Uma Ita Nian
- Klibur Aleizador Timor-Lorosa'e (KATILOSA)
- Fuan Nabilan
- Centro Nasionál Rehabilitasaun (CNR)
- The Leprosy Mission Timor-Leste (TLMTL).