Access to Mainstream Health and Rehabilitation Services for People with Disability in Timor-Leste

Situational Analysis

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Megan McCoy – AusAID Regional Specialist, Disability Inclusive Development (Asia)
Cornelio de deus Gomes – AusAID Dili Post
Joel Alex Morais – Ra'es Hadomi Timor Oan
Jonio Soares – Disability Working Group Secretariat

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Acronym List

AusAID	Australian Agency for International Development
ATLASS I	Australia – Timor-Leste Assistance for Specialist Health Services (Phase One)
ATLASS II	Australia – Timor-Leste Assistance for Specialist Health Services (Phase Two)
BESIK II	Bee, Saneamentu No Igene Iha Komunidade (or the Australia-East Timor Rural Water Supply and Sanitation Program) Phase Two
BSP	Basic Service Package
CBR	Community-Based Rehabilitation
CHC	Community Health Centre
CNR	Centre for National Rehabilitation
CRPD	Convention on the Rights of Persons with Disabilities
DHC	District Health Centres
DHS	District Health Services
DPO	Disabled People's Organisation
DWG	Disability Working Group
ETBU	East Timor Blind Union
GoTL	Government of Timor-Leste
HMIS	Health Management Information System
HP	Health Post
HSSP-SP	Health Sector Strategic Support Program
ICF	International Classification of Functioning, Disability and Health
MOH	Ministry of Health
MSS	Ministry of Social Solidarity
NCD	Non-Communicable Disease
NGO	Non-Government Organisation
PRADET	Psychosocial Recovery and Development in East Timor
RACS	Royal Australasian College of Surgeons
RHTO	Ra'es Hadomi Timor Oan
SISCa	Servisu Integradu Saude Communitaria (Integrated Community Health Services)
SHDC	Sub-District Health Centres
USD	United States Dollar (currency)
UNTL	University Timor-Leste
WHO	World Health Organisation

Executive Summary

AusAID's Timor-Leste Country Program is currently in the design phase of its new Health Program, which will focus on maternal and child health and nutrition. To ensure that women, children and people with disability are included in and benefit from this support on an equal basis with others, AusAID's Timor-Leste health team commissioned this specific analysis on access to health for people with disability. This analysis provides information on disability-inclusiveness in the health sector and identifies practical solutions to addressing current barriers, which can be drawn on to inform the design of the new program.

The analysis has found a number of strengths and opportunities within and unique to Timor-Leste which the new Health Program can leverage off. For example: there is strong commitment by the national Disabled People's Organisation; the existence of a Disability Working Group facilitates coordination and information-sharing; the Ministry of Social Solidarity and Ministry of Health are working together towards implementation of the National Disability Policy; and partnerships at local levels between the Ministry of Health and NGO service providers.

However, there are a number of challenges which impact on the ability of women, children and people with disability to access health services. There is a lack of knowledge among mainstream health care workers about how to make health services inclusive. People with disability are often missed in community mobilisation efforts. Barriers such as distance, cost of transport, stigma and discrimination mean people with disability do not access health services. Rehabilitation is another critical enabler which is required to support people with disability to be able to access other health services. However, there are limited human resources for rehabilitation, both in terms of the overall number of professionals and the types of professionals. Furthermore, rehabilitation service provision is currently divided between parallel systems of health service provision and more specific disability and rehabilitation service provision. These parallel systems are not coordinated, with roles and responsibilities of the multiple service providers and government ministries involved unclear. Systematic referral pathways between the parallel systems do not exist, meaning people with disability do not always receive the services and support they require.

To address these barriers, this analysis recommends that the new Health Program design should include explicit short and long-term strategies to improve access to quality rehabilitation services for people with disability, particularly women and children. The new Health Program should also facilitate collaboration between the Ministries of Health and the Ministry of Social Solidarity, in order to address emerging issues with parallel rehabilitation service delivery.

The analysis also makes recommendations to ensure health services are accessible, for example through incorporating universal design into construction and by training health care workers, and to increase the awareness of people with disability. Detailed recommendations are provided in the final section of this report.

1. Introduction

Support to the health sector is one of the key pillars of AusAID's *Timor-Leste Country Strategy 2009-2014* and the *Strategic Planning Agreement for Development* which outlines the joint commitments and priorities of the Government of Timor-Leste (GoTL) and Australia. The *Australia – Timor-Leste Health Delivery Strategy 2013 – 2020* outlines that the specific focus of AusAID's work in the health sector aims to ensure that 'households, especially the most vulnerable, increasingly practice behaviours that are conducive to better maternal and child health and nutrition, and use reproductive, maternal, newborn and child health services'. To achieve this outcome, future AusAID support to the heath sector will focus on two key programs:

1. **Timor-Leste Health Program (2013 – 2020)**: This is a new program, focused on maternal and child health and nutrition, and is expected to support interventions in service delivery, medicines and supplies, health workforce, health financing, health information, leadership and governance and community mobilisation. As this is an ambitious range of possible interventions, the program will include: a) accelerated access to basic health care services (working in line with Ministry of Health (MOH) standards, but likely through other organisations); and b) sustainable support for institutional development (i.e. working to strengthen the systems which will enable MOH to implement reforms and develop new processes at a feasible pace). The new program will incorporate some elements of support to date, including the Health Sector Strategic Support Program (HSSP-SP). The new program is currently being designed in partnership with MOH.

2. **Australia–Timor-Leste Assistance for Specialist Health Services (ATLASS) II**: Through this program, the Royal Australasian College of Surgeons (RACS) provides long-term advisors (including in general surgery, anaesthetics, orthopaedic surgery and emergency medicine) to work with Timorese counterparts. Short-term clinical visits are also conducted by Australian specialists who undertake surgery in areas such as paediatrics, urology and ear, nose and throat. ATLASS II covers the period 2012 to 2016, and follows a previous five year program (ATLASS I)[1].

AusAID will take a multi-sectoral approach to its health sector support, by ensuring links with other programs including in water, sanitation and hygiene (through BESIK II).

AusAID is strongly committed to promoting the rights of people with disability. This commitment is demonstrated by the ratification of the Convention on the Rights of Persons with Disabilities (CRPD) in 2008. Under Article 32 of the CRPD, concerning international cooperation, Australia is obligated to ensure that people with disability benefit from the aid program on an equal basis with others. Implementation of this obligation is supported at a policy level by AusAID's *Development for All* strategy and the *Comprehensive Aid Policy Framework*, which includes 'enhancing the lives of people with disability' as one of the ten development objectives for the aid program. Timor-Leste is a focus country for AusAID's disability-inclusive development efforts.

[1] Refer RACS, *ATLASS II Six Monthly Progress Report* (July – December 2012).

This situational analysis was commissioned to ensure that the new Timor-Leste Health Program includes and benefits women, men and children with disability on an equal basis with others. The aim of this analysis is to provide basic information on the barriers people with disability face in accessing mainstream and specialised health services in Timor. It is important to note that this analysis was not intended to undertake primary research nor review activities to date; rather the main purpose is to provide an overview of key barriers that prevent people with disability from accessing quality health services in Timor-Leste. The analysis provides recommendations of practical actions that can be integrated into the new Health Program. While the proposed new program will focus on maternal and child health and nutrition, this analysis examined barriers for people with disability in accessing broader mainstream health services, in order to assist with more comprehensive understanding of the challenges.

The situational analysis was undertaken by a team comprising representatives from AusAID, Ra'es Hadomi Timor Oan (RHTO, the national Disabled People's Organisation (DPO)), MOH and the Disability Working Group (DWG) Secretariat. An important aspect of the methodology was the focus on a predominantly Timorese team, and the involvement of people with disability in the analysis team, in recognition that people with disability are experts in their own lives and their meaningful involvement is critical in ensuring good quality information and recommendations. For more detail on the analysis methodology, refer to Annex 1 for the Terms of Reference and Annex 2 for the analysis schedule.

As disability is often a misunderstood term, and the issue of people with disability and health is sometimes complex, further background on these areas is provided in the next two sections. The report then outlines the key analysis findings, including existing strengths and challenges impacting on the access to health services for people with disability. Section 4 provides the key recommendations of interventions that could be integrated into the new Health Program.

2. What is disability?

AusAID utilises the understanding of disability as outlined in the CRPD: '*persons with disabilities include 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*'[2].

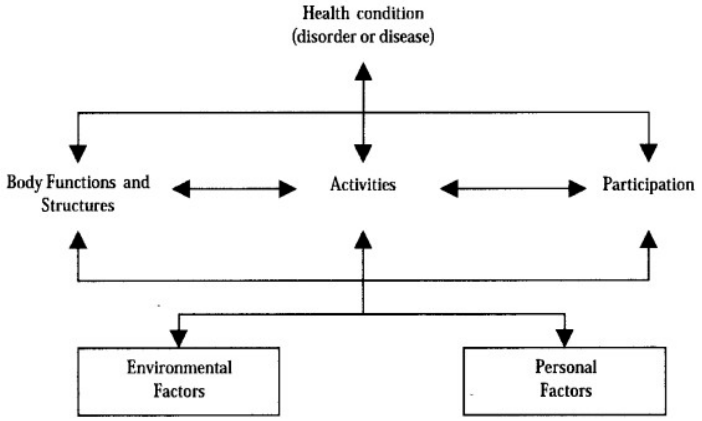
This understanding recognises that people with disability do not face exclusion and discrimination only because of impairment, but also because of physical, attitudinal, institutional, communication or other socially created barriers. Importantly, this approach sees people with disability as citizens with equal rights to participate and benefit from development initiatives, including health programs.

Disability has previously been viewed within a medical or charitable model, where people with disability had health conditions that needed to be 'fixed' through medical interventions or were considered passive recipients of welfare. This ignored societal and environmental barriers, and

[2] UN Convention on the Rights of Persons with Disabilities, Article 1: Purpose. http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx.

failed to recognise that society needs to actively facilitate the inclusion of people with disability. In order to properly understand disability, it is necessary to go beyond these narrow medical or charitable approaches to recognise the interrelationship between a health condition, impairment, functional limitations (i.e. difficulties in daily life)[3], and external factors (such as environmental accessibility). This approach is known as the 'bio-psycho-social model' and is the basis of the International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organisation (WHO, refer Diagram 1). The ICF demonstrates that 'disability' is a dynamic concept and that the causes of exclusion do not rest with the individual and their impairment, but rather with physical, attitudinal, institutional and communication and other barriers within society.

Diagram 1 – The WHO's International Classification of Functioning, Disability and Health 'bio-psycho-social model'



While this may appear to be complicated, it is in fact vitally important, particularly in the context of health programs, to appreciate this complexity, as it helps us to understand that people with disability are not all the same. Two people with exactly the same impairment, for example two people with total blindness, can have completely different lives depending upon where they live, what access they have to services, and how their communities perceive them. This approach to understanding disability is also important because it helps us understand the need for both mainstream and specialised services for people with disability.

To put it simply:

Impairment + Barriers = Disability (and a lack of participation)

3. People with Disability and Health and Rehabilitation Services

People with disability need the same mainstream health services as everyone else. For example, children with disability need access to immunisation programs, and women with disability need sexual and reproductive health services just like all other women. However, due to barriers such as

[3] But note that functional limitations can be impacted by the provision of services and supports. For example, a properly fitted wheelchair can enable a person with mobility impairment to move freely and participate in regular daily life activities, such as going to school or work.

the attitude of health care workers and health care facilities that are inaccessible, people with disability have unmet health care needs and poorer health outcomes when compared to people without disability[4].

People with disability may also require additional services, including access to rehabilitation services and specialised health services, to assist with improving functioning so they can undertake regular daily activities like cooking, looking after themselves and going to school or work. This could include medical and surgical services, for example treatment of epilepsy or reconstructive surgery for club foot. It can also include rehabilitation services like physiotherapy. People with disability may also require specialised and support services in the areas of education and employment, however, for the purpose of this report, the term 'rehabilitation' will be used to cover those aspects of specialised health services and rehabilitation relating only to the health sector.

It is important to note that rehabilitation services are not just used by people with disability. Such services are also used by people who may have a temporary impairment or injury. For example, a person recovering from an accident might require short-term physiotherapy, and a person facing a one-off stressful situation might need access to psychological counselling. In situations where people with a temporary impairment do not receive the rehabilitation services they require, it can sometimes lead to permanent disability. Because rehabilitation services are not just used by people with disability, it is important to see such services as part of the broader health system, rather than only a disability-specific service.

Depending upon the type of impairment, rehabilitation can be carried out by different health specialists and allied health professionals, such as psychiatrists, orthopaedic surgeons, audiologists, ophthalmologists and nurses with specialities in these areas. Rehabilitation can also be carried out by physiotherapists, occupational therapists and speech therapists through centre-based and outreach services. People working at a community level, sometimes known as Community-Based Rehabilitation (CBR) workers, also play an important role in rehabilitation: they are often the link between people with disability and health and rehabilitation services. CBR is an approach which aims to reduce the barriers people with disability face at the community level and improve their inclusion in social, economic, political and cultural activities; it covers activities in the health, education, livelihoods, social (such as justice) sectors and empowerment of people with disability[5].

Assistive devices are another important part of rehabilitation. These are devices that help people with disability perform the regular tasks of daily activities. This includes items such as wheelchairs, tricycles and prosthetic limbs for people with mobility impairments, hearing aids for people with hearing impairments, and white canes or glasses for people with vision impairment.

While there are ways to address barriers within health services to make sure that people with disability are able to access them – for example, we can make sure health care workers do not discriminate against people with disability – this does not necessarily mean that people with disability will automatically be able to access health services. Assistive devices and rehabilitation might be needed. For example, a woman with mobility impairment might require a wheelchair in order to get from her home to a health facility for advice on contraception. In this respect,

[4] WHO, World Bank, *World Report on Disability* (2011), pp. 57 – 65
[5] WHO, ILO, UNESCO, *Community-Based Rehabilitation Guidelines* (2010)

rehabilitation should be seen as a critical 'enabler' for people with disability to access other health services.

4. Situational Analysis Findings

Strengths

In addition to examining the challenges and barriers facing people with disability in Timor-Leste, during this analysis the team identified several strengths and opportunities within and unique to Timor-Leste. These opportunities are important to reflect upon and leverage off.

- In 2012, GoTL endorsed the *National Policy for the Inclusion and Promotion of the Rights of People with Disability*[6]. This policy includes 11 specific strategies aimed at ensuring people with disability have equal access to health services, including measures for early identification and intervention and increasing specialised human resources for rehabilitation.
- The Ministry of Social Solidarity (MSS) is committed to supporting the implementation of the National Policy, including by coordinating with other Ministries. This includes providing funding (from regular resources) for workshops with line Ministries (including MOH) to prioritise actions for inclusion in the 2014 work plans and budgets of line ministries. This work is assisted by a Handicap International technical advisor.
- There is a good level of commitment by MOH to taking forward this work. This includes the MOH Partnership Department (which may be able to facilitate connections between MOH and civil society, in particular the DWG), and the Non-Communicable Disease (NCD) section within the Public Health Department, which is the focal point within MOH on disability. It also appears the recent workshop between MSS, MOH, other Ministries and civil society representatives, including people with disability, led to an improved understanding by the MOH NCD Section focal point on a broader range of issues relating to disability.
- At the national level, the existence of the DWG and establishment of the DWG Secretariat provides an opportunity to support coordination and sharing of lessons learned between civil society and with Government (including MOH).
- At the sub-national level, in certain areas such as Viqueque Sub-District, there is good cooperation between MOH staff and non-government organisations (NGOs) focused on people with disability. This is often as a result of basic disability awareness training for health care workers provided by NGOs (for example the work being done by Katilosa) and relationships established over many years. This engagement and cooperation results in appropriate referral of people with disability to NGO-provided rehabilitation services.
- Over the last year or so RHTO have established district officer positions in each of the 13 districts. These staff are working hard to find people with disability and provide support, including by providing information on available health and rehabilitation services to people with disability.
- There is a strong commitment to CBR which, as noted above, is important in linking people with disability to health and rehabilitation services. This commitment is demonstrated by

[6] Refer *Government Resolution No. 14/2012 of May 9 Approving the National Policy for Inclusion and Promotion of the Rights of People with Disabilities*

the existence of the *National CBR Strategic Framework* (2010) and the commencement of the country's first ever one-year CBR Diploma, offered by the University of Timor-Leste (UNTL) in partnership with NGOs and RHTO. This will have UNTL lecturers and RHTO staff as Co-Facilitators.

- AusAID is strongly committed to ensuring that people with disability have access to health services in Timor-Leste. This is an important opportunity, particularly as AusAID is the largest donor to the health sector.

Challenges

The barriers that prevent people with disability from accessing quality health and rehabilitation services are many, complex and inter-linked. This analysis has found that these barriers fall into four broad areas:

1. Lack of understanding and action on disability within the health sector.
2. Low levels of access to a range of quality rehabilitation services.
3. Lack of understanding by families/communities about disability.
4. Parallel systems of rehabilitation service delivery (which are insufficiently integrated and which do not have effective referral pathways to ensure appropriate service delivery).

Further detailed information on the barriers identified through this analysis will be provided below under headings related to the areas of possible intervention for the new Timor-Leste Health Program, in order to enable possible recommendations and interventions to be easily identified[7]. But the barrier of parallel systems of rehabilitation service delivery in particular was found to affect each of the Timor-Leste Health Program's possible intervention areas. As such, further explanation of this particular barrier is provided here and illustrated in Diagram 2.

Barriers related to parallel systems of rehab service delivery

Through this analysis a common picture has emerged as to how people with disability in Timor interact with mainstream health and rehabilitation services: most people with disability enter the mainstream health system only when they are very sick and for issues often unrelated to their disability. Depending upon where they go, and what information the health care provider has, will determine whether or not they are referred to appropriate rehabilitation services, most of which are provided outside the mainstream health system. Furthermore, because rehabilitation services are provided in a parallel system with ineffective linkages with the mainstream health system, very few people with disability have their impairment diagnosed or receive rehabilitation and support services early in life (which can lead to greater challenges later on). Often people with disability are taken to a traditional healer, and when this does not 'cure' the impairment families either give up or (due to barriers to be discussed below) are unable to access other health and rehabilitation services. And when it comes to making decisions regarding scare resources, families will often invest in good

[7] Note: these areas of possible intervention in the new Health Program are based on the WHO's six building blocks of a health system (service delivery, health workforce, information, medical products, vaccines and technologies, financing and leadership/governance) plus a seventh area of 'community mobilisation' reflecting the importance of demand-side elements.

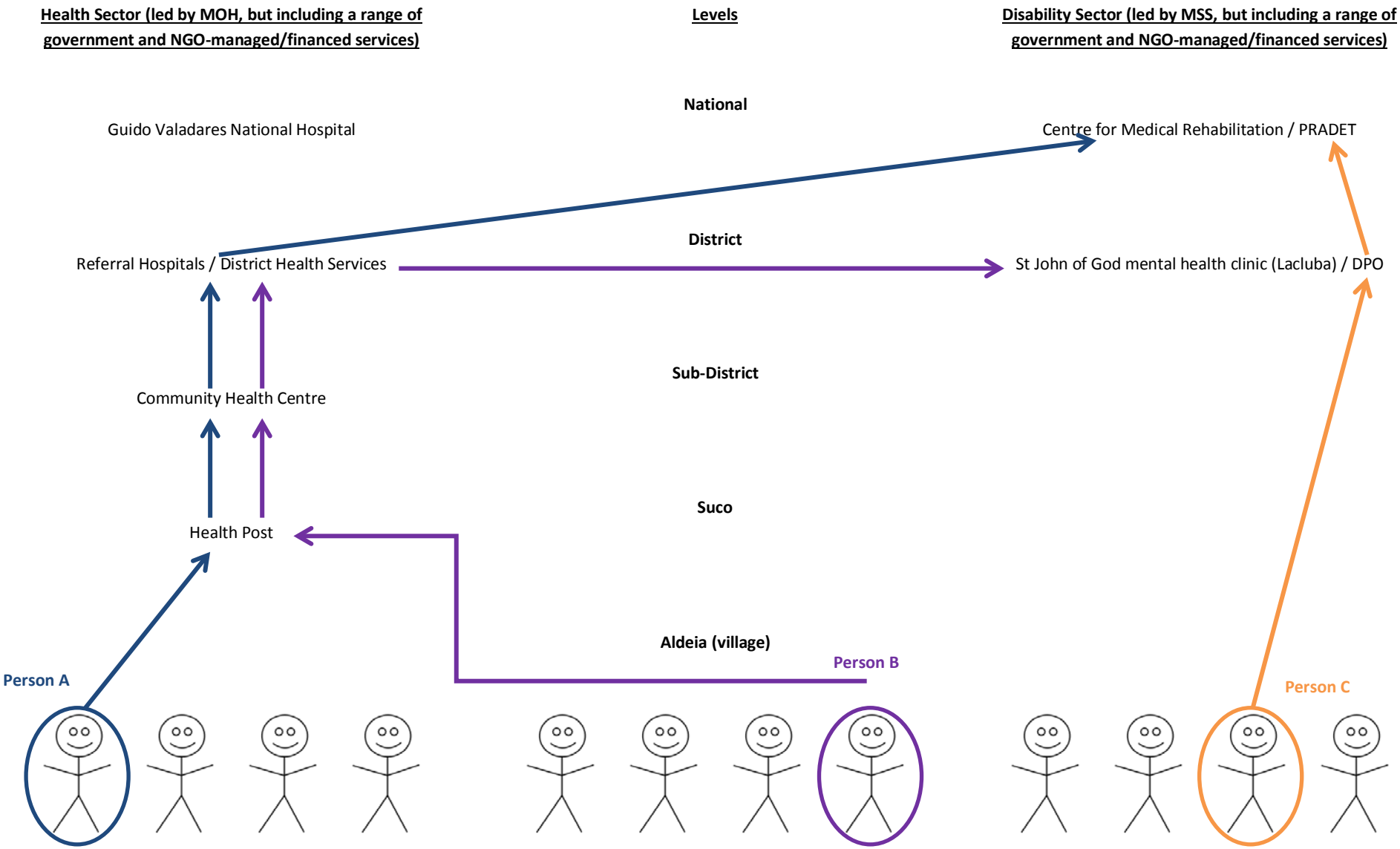
health for the members of their family they consider to be most likely to make a contribution later on, which often means people with disability miss out.

The problem of the parallel systems of rehabilitation service delivery and the lack of standardised referral between the systems and service providers is demonstrated by the following illustrative examples, developed based on common issues identified in this analysis. These examples demonstrate how the lack of a standardised referral pathway affects how people with disability enter and transition through the health and disability service delivery sectors:

- Person A is a 22 year old woman with mobility impairment. She gets sick from dengue fever and her family takes her to the local health post. The nurse at the health post provides treatment for dengue but also notices her mobility impairment and is not sure what to do about it, so refers her to the Community Health Centre (CHC). Once at the CHC, Person A is seen by a Doctor who notes that her mobility impairment is most likely a result of polio, and then refers her to the referral hospital. However, the referral hospital only has limited physiotherapy services available, so they then provide a referral to the Centre for National Rehabilitation (CNR). At CNR the woman is fitted with an orthotic and provided with a crutch.
- Person B is a 32 year old man whose unpredictable behaviour has become increasingly difficult for his family to manage. After several attempts by the local traditional healer to treat him, the family takes him to the local health post. The nurse at the health post is not sure what to do, so refers Person B to the CHC. The Doctor at the CHC notes the man probably has some psychosocial impairment but does not have the training nor the medicine to provide support. A request is put to the District Health Services (DHS) who then recommends a referral to the St John of God mental health clinic in Lacluba Sub-District. There the man is formally diagnosed with schizophrenia and is provided the right treatment and support.
- Person C is a 50 year old man who lost his job and hasn't left the house in many months. The local DPO leader comes to his village to find people with disability and is referred to his house because neighbours noted that Person C's wife walked with a limp. Upon meeting Person C, the DPO leader thought he might have depression and so arranged for the man to be referred to PRADET (Psychosocial Recovery and Development in East Timor) in Dili. Person C eventually made it to Dili where PRADET diagnosed depression and arranged for counselling. (His wife was also went to CNR at the same time).

These examples, which are illustrated in Diagram 2 below, demonstrate the lack of standardised training and information on appropriate and regular referral pathways. The service provided to people with disability currently relies on the point of entry and what information that health care provider has. Services, regardless of whether they are provided by the government health sector, health-related NGOs or disability-focused NGOs, need to be integrated as part of an overall strategic plan.

Diagram 2 – Parallel systems of rehabilitation service delivery



Barriers in the area of Service Delivery

According to the WHO, good quality service delivery requires a package of integrated services (based on the health needs of the population), organisation of the provider network (including public and private providers, such as NGOs), management and infrastructure and logistics[8]. Service delivery also includes raising demand for services; however this is covered in the section below on community mobilisation according to the scope of the proposed AusAID health program concept note.

There are four key service delivery challenges for people with disability in Timor-Leste:

- There is limited reference to rehabilitation services in GoTL *Basic Service Package for Primary Health Care and Hospitals (BSP)*[9]. The BSP outlines the priorities for basic and complementary health services at different levels: Guido Valadares National Hospital, provincial referral hospitals, District Health Services (DHS), District Health Centres (DHC, which are situated in those areas without provincial referral hospitals), Sub-District Health Centres (SHDC), and Health Posts (HPs). Rehabilitation services relevant to people with disability in the package include the provision of mental health patient follow-up at HPs and 'treatment for mental health patients and the disabled' and 'disability services (with NGOs)' at DHCs[10]. There is no elaboration of concepts of 'treatment' and 'disability services', and as such there is no acknowledgement of the range of rehabilitation services required by people with disability. The analysis team understands that the draft MOH *Non-Communicable Disease National Plan* includes disability considerations, but further information was not available at the time of writing.
- This lack of focus on provision of disability services in the mainstream health system is compounded by the issue of parallel systems of rehabilitation and disability service provision. Because the mainstream health system does not adequately provide the rehabilitation or specialised health services people with disability might require, these services are largely provided by NGOs. However, as described above and outlined in Diagram 2, there is insufficient coordination and referral pathways between these parallel systems, meaning that people with disability are not able to efficiently access the range of health and rehabilitation services they might need.
- The BSP also does not acknowledge the issues people with disability may face in accessing mainstream health services. This has a flow-on effect, and opportunities to adapt service provision to be more accessible to people with disability are being missed, for example within the *Integrated Community Health Services* (SISCa). One of the common barriers to accessing health services for all people in Timor-Leste is geographic, with services not located close to homes or communities. But people with disability are less able to overcome this barrier. People with mobility and sensory impairments are unable to walk to the service point. But other modes of transport are expensive, and families are also unable to cover the cost of a carer travelling with the person with disability[11]. Although SISCa aims to reach the local community (aldeia) level, which in theory should make the services more accessible for

[8] WHO, *Everybody's Business: strengthening health systems to improve health outcomes: WHO's framework for action* (2007), pp. 14-15. Available at http://www.who.int/healthsystems/strategy/everybodys_business.pdf
[9] Ministry of Health, May 2007
[10] WHO, 2007, pp. 26, 28
[11] This includes indirect costs, such as time away from income generation activities.

all people, including people with disability, there does not appear to have been any practical action to adapt they way SISCa is delivered to ensure people with disability are able to be included. During this analysis, the team heard conflicting views regarding the inclusion of people with disability. Those with positive views regarding inclusion seemed to base this on the (often incorrect) assumption that people with disability are always automatically included in community processes. People with disability, their families and representative organisations consulted during the analysis seemed to present a different picture, with more examples of people with disability missed out rather than being included.

- Most health infrastructure (HPs and DHCs etc) is physically inaccessible to people with disability. This means that even if people with disability are able to overcome the geographic, distance and cost barriers to reach a health service, they will be unable to get inside the building (for example health facilities often have stairs) or be unable to use the facilities safely and with dignity (for example toilets if they are available are unlikely to be accessible). This challenge also extends to SISCa, with many of the community sites noted as being inaccessible. It is important to understand that the accessibility of infrastructure is not just relevant to people with mobility impairments; it is also an issue for example for people who are blind or who have low vision (they might require tactile surfaces to differentiate between different rooms or Braille signs). In addition, easily accessible health infrastructure is not just important for people with disability; it is also important for people who have a temporary impairment or injury, pregnant women and older persons. This means that ensuring infrastructure is accessible can benefit a significant portion of the population.

Barriers in the area of Health Workforce

According to WHO, health workforce issues cover all people working in the health sector, including service providers and management, and includes pre-service and in-service training and workforce planning[12]*.*

There are two key challenges relating to Timor's health workforce which impact the ability of people with disability to access health and rehabilitation services:

- A lack of basic knowledge and skills on how to support people with disability amongst all health care workers. This results from the absence of a basic and mandatory module on disability in healthcare worker pre-service training. While some NGOs have provided in-service training to health care workers, this is relatively ad hoc and not recognised within formal MOH human resource systems (e.g. professional development recognition, remuneration, career pathways etc). During the analysis, one doctor noted that, until exposure to physiotherapy during in-service training in Australia, he had no understanding of the concept of rehabilitation, its importance regarding functioning, and how he should refer patients. There is also a lack of training for healthcare workers regarding a range of sensitive issues that may arise relating to the health of people with disability (see Box 1 below).

[12] WHO, 2007, pp. 16-17

- Low numbers of the appropriate range of rehabilitation professionals. At present there are just:
    - MOH: 3 Timorese physiotherapists across five referral hospitals (trained in Australia, in future they will be trained at the Fiji School of Medicine);[13] 1 orthopaedic surgeon; 2 psychiatrists (one Timorese who trained in Papua New Guinea, and one from Cuba) at the National Hospital; approximately 20 psychologists (from Cuba); 13 ophthalmologist technicians (in the 13 Districts); and 4 eye health nurses.
    - Centre for National Rehabilitation: 1 ortho-prosthesist (trained in Cambodia in 2006); 1 prosthetic technician; and 3 bench technicians.
    - Klibur Domin: 2 physiotherapists; and 1 occupational therapist (both trained in Solo, Indonesia)
    - PRADET: 60 staff in total across three areas (Dili, Suai, Malaia). Most are nurses, mid-wives or have non-health related university qualifications. Of this total staff, 8 work on the organisation's mental health program: 6 mental health staff; and 2 staff focused on the promotion of psychosocial activities. Training is on-the-job provided by visiting international specialists.
    - Katilosa: 2 Timorese physiotherapists (no formal qualification, have received on-the-job training).
    - Other NGOs which employ staff include St John of God in Lacluba (which employs an unknown number of psychiatrists, psychologists and mental health/psychiatric nurses); Alma Sisters (unknown number of physiotherapists and prosthetic and orthotic technicians); and Fred Hollows Foundation New Zealand (unknown number of ophthalmologists and eye health nurses).
    - And there are no psychiatric nurses (although some are currently training at the Fiji School of Medicine) and no speech therapists in the country.

In relation to the challenge of low workforce numbers, at the recent meeting between MSS and MOH to agree on actions to implement the National Disability Policy, the DWG advocated for an increase in the number of rehabilitation professionals. At this stage it appears that MOH has agreed to some increase, but it remains unclear how this will actually be implemented. However, given the lack of coordination between government and NGO service providers (as well as the lack of coordination between mainstream health sector providers and those who are seen to be disability service providers) it is unclear exactly what the current number of available personnel in each category is. Furthermore, given the lack of information about disability in Timor, there is also uncertainty about the required need and the appropriate level of personnel numbers across the rehabilitation workforce categories. If not addressed, this lack of information and coordination between the parallel systems of service delivery could lead to inefficient and ineffective human resource planning, deployment and retention of rehabilitation health and allied health professions.

Furthermore, both the challenges highlighted above are situated within broader and significant issues facing health workforce in Timor, including: a lack of basic information about the existing workforce and the likely required workforce levels; a lack of a workforce data system; lack of capacity to manage such a system; shortage and inequitable distribution of skilled healthcare

[13] Ideally there should be one MOH physiotherapist at each referral hospital.

workers and managers; poor living and working conditions for health workforce staff[14]. The analysis team understands that WHO is providing support[15] to MOH to develop a human resource development plan, with the first step being a basic human resource profile. This will apparently build on the previous 2007 MOH human resource plan[16]. It is unclear to what degree the human resource profiling and the new human resource plan will include rehabilitation professionals.

Box 1: Sensitive and difficult issues require capacity development and support for health workers

While there are many relatively simple things that can be done to improve the ability of healthcare workers to appropriately care for people with disability, it is also important not to underestimate some of the sensitive and difficult issues that can arise. For example, the analysis team heard of a woman with mild intellectual disability who had 13 children, none of whom she was able to care for. The health care workers responsible for her care felt she was not capable of making informed decisions regarding her fertility. However they also felt very uncomfortable and unsure about how to secure her informed consent for what they considered to be the most appropriate method, a long term contraceptive implant.

Barriers in the area of Information

Information is a broad area and covers the production, analysis and use of information by decision makers on: health determinants (for example issues such as poverty that can determine an individual's health), health system performance, and health status[17].

There key challenges relating to information in Timor's health sector are:

- A lack of rigorous data on disability in Timor-Leste, both generally and specific to the health sector. The 2010 Census reports that just 4.6 per cent of the population have a disability. However, this varies from international experience and data from the WHO and World Bank which finds that 15 per cent of the world's population have some form of disability[18]. For Timor-Leste, this would equate to 176,400 people with disability[19]. There is no information collected on people with disability either in the Demographic Health Survey (DHS, the latest of which was in 2010), nor within regular administrative data collected through the Health Management Information System (HMIS). There is no data that indicates the extent to which people with disability are accessing mainstream services offered by SISCa.
- The lack of information on the number of people with disability, their quality of life, and their access to services, makes it difficult for GoTL to gauge the need for mainstream and

[14] Refer AusAID's *Timor-Leste Health Program (2013 – 2021) Concept Note*, dated 31 January 2013, p. 10
[15] HSSP-SP is also providing support to MOH human resource planning.
[16] Although stakeholders are unclear which plan is referred to here.
[17] WHO, 2007, pp. 18-19
[18] The discrepancy in prevalence rates between official government statistics and the World Report on Disability can be attributed to several factors including variance in disability definitions used in Timorese legislation and Census reporting, and the lack of visibility of people with disability in the community related to stigma and shame.
[19] Based on a population of 1.176 million from 2011 World Bank data (http://data.worldbank.org/country/timor-leste).

rehabilitation services, whether or not that need is being met, and to assist them to make informed and prioritised plans to address the gap. There is some information available from rehabilitation service providers – including referral hospitals and NGOs. For example, the Baucau Referral Hospital physiotherapy department sees approximately 10 patients per day and this number triples when the Orthopaedic Doctor is on rotation. RHTO District staff also collect information on people with disability. They work with local leaders, including Xefe de Suco and Xefe de Aldeia, to find people with disability in each household in specific areas. For example, in just three months the RHTO District staff member in Viqueque found 61 people with disability in two sub-districts. This is considerably higher than information held by the CHC for the same sub-districts on people with disability receiving the disability pension from MSS. However, it is unclear to what extent the information and data collected by rehabilitation service providers is used by the broader health system.

- The MOH does not use an appropriate approach or definition of disability to inform data collection. One of the most important issues in determining what and how information is collected and the reliability of it, is the understanding or definition of disability that is used to inform classification systems. The WHO's ICF is the best available tool to help understand disability and inform classification systems. During stakeholder consultation, the analysis team was urged to recommend MOH adopt the ICF.

Barriers in the area of Medical Products, Vaccines and Technologies

The availability of appropriate medical products, vaccines and technologies is an important part of a well-functioning health system. Issues relevant to this area include policies, standards, manufacturing, distribution, and procurement[20]*.*

'Assistive devices' is a broad term that encompasses any devices that are made or adapted to help someone perform a particular task[21]. For the purpose of this report, the term is used to refer to those devices normally delivered by health and allied health professionals (including through both government and NGO service providers), including prostheses, orthoses, wheelchairs, crutches, hearing aids, spectacles, white canes, etc.

The timeframe for this analysis did not allow for a comprehensive assessment of the availability and quality of current assistive device service provision. However, several key issues were noted, such as reliance on NGO procurement (which has its own set of challenges), the insufficient provision of particular devices (such as those related to hearing and vision impairments), and the absence of common standards and approaches (compounded by the parallel rehabilitation service delivery as per Diagram 2). Box 2 also outlines how assistive device provision must consider the perspectives of the individual person with disability. A few illustrative examples of the status of current device provision are:

- Assistive devices for mobility impairments have commonly been provided through NGO service providers. For example, ASSERT has provided a range of affordable wheelchairs through local manufacture or importation. However challenges have been faced in managing this procurement, including the lack of information on possible suppliers, a lack of

[20] WHO, 2007, p. 20
[21] WHO, World Bank, 2011, p. 301

clear procurement processes, and a reliance on overseas donations for materials such as foam (without which wheelchairs can lead to postural degradation, pressure sores and pain). Motivation Australia has provided significant support to ASSERT to date[22].

- Hearing aids (provided by Rotary Australia) are sometimes provided at provincial referral hospitals during visits from audiologists.
- East Timor Blind Union (ETBU) provides rehabilitation and support services to approximately 15 people with low vision or who are blind per year. This includes mobility training with white cane provision.

In addition to assistive devices, people with disability may also require medicines, for example psychotherapeutic drugs for mental health problems, or medication for epilepsy. With stockouts of all drugs common in Timor, the provision of such medicines is currently inadequate.

Box 2: Assistive Device Provision

Providing assistive devices is not just about the device and whether or not it fits someone properly; it is also about understanding the lifestyle of people and what will work for them, given their own unique lifestyle and perspectives. While it was relatively rare, the analysis team heard a few stories about poor quality assistive device provision. In Viequeque, a 66 year old male veteran who had a mobility impairment as a result of shrapnel injury was given a wheelchair and crutches by a prominent politician as a way of saying thank-you for his service in the resistance. However he does not use the crutches because they are they too big for him. And he does not use the wheelchair because he does not like feeling like a 'lazy man' and thinks he should walk if he can. This demonstrates that personal and community attitudes towards assistive devices need to be considered.

Barriers in the area of Financing

A good health financing system means that people can use the services they need without having to make themselves very poor by having to pay for them. Issues related to financing includes improving the efficiency of services, but also relates to issues that are broader than the health sector, such as the availability and coverage of social protection programs which can help to ensure the poorest and most vulnerable have access)[23].

There are two areas relevant to health sector financing and people with disability: the cost borne by service providers to ensure people with disability are able to access mainstream health services, and the cost of rehabilitation services. The cost of these services is currently provided through three types of institutions/mechanisms: (1) MOH; (2) MSS; and (3) local and international NGOs. The challenges faced are:

- There is a lack of consolidated information on the current level of financing being directed to ensuring mainstream health services are accessible for people with disability, as well as the provision of rehabilitation services. Again this is partly a reflection of the issue of parallel

[22] Motivation Australia, *ASSERT/Motivation Australia: Technical Support Visit* report, November 2012
[23] Ibid, p. 21

systems with a lack of coordination amongst the three key players. MOH and local and international NGOs receive support, including financial support, from development partners (both multilateral and bilateral), but it is unclear how much of their resources are focused on ensuring accessibility or providing rehabilitation or disability-specific services. Even though MSS does not currently receive direct financial support from development partners, it provides direct funding from its regular budget to 11 NGOs which provide services to people with disability. In 2013, MSS funding to these NGOs is supporting activities such as provision of physical rehabilitation, mental health rehabilitation, and training for health care workers[24].

- As outlined above in relation to information building block, the lack of information about people with disability reduces the ability of GoTL to understand the additional barriers they face in accessing mainstream health and rehabilitation services, and reduces their ability to make informed resource allocation decisions. These challenges also reflect broader financing challenges facing the health sector. This includes the absence of multi-year plans, instead relying on annual plans and budgets that predict increases based on a flat percentage (as opposed to need); as well as the challenge that the costings of the BSP have not yet been agreed[25].

It is also important to understand the costs borne by people with disability and their families in accessing mainstream and rehabilitation services (the demand-side costs and financing). One of the most common challenges regarding demand-side financing was the prohibitive cost of transport to access services. While this is an issue for most Timorese, it can be more challenging for people with disability and their families. This is because people with disability may often require a family member to accompany them to the service, which can result in a more significant direct cost (i.e. paying for two people instead of one) as well as increased indirect costs (such as the time away from income generating activity for the accompanying family member). Some people with disability may also be unable to use common modes of transport, such as motorbikes, necessitating more expensive options, such as a car. Box 3 outlines a particular example of these challenges.

Box 3: Transport Challenges

The analysis team met with a 12 year old girl with intellectual disability and epilepsy and her family in Viqueque. Her family had tried to take her to SISCa once, but she had a seizure while riding on the motorbike with her father. He was so scared that it would happen again and she would fall off and badly injure herself, and the family hasn't tried to take her since. The family said they would like to take her to SISCa in future, but can't afford the cost associated with hiring a taxi.

[24] The 11 NGOs receiving funding in 2013 are: Katilosa ($84,490 to deliver basic training for midwives and nurses on disability-inclusion, and to provide physical rehabilitation); Klibur Domin ($88,598 to provide physical rehabilitation and services for referral); HDMTL ($20,796); PRADET ($28.900 to provide mental health rehabilitation); ASSERT/CNR ($182,253.50 for physical rehabilitation service provision); Sao Joao de Deus ($48,481 for mental health rehabilitation; STRELA + (Esperansa) ($16,500 to provide support services for HIV/AIDS positive people); Alma Sisters ($19,979); AGAPE ($66,000.90 for provision of impairment course); AHISAUN ($10,983.25); and SOTL ($75,289).

[25] AusAID Health Resource Facility (Diane Northway), *East Timor 2013 Health Budget Analysis*, 4 March 2013.

MSS provides a pension (of USD30 per month) for people with disability who met certain eligibility criteria. Despite several attempts, the analysis team was unable to locate a copy of the assessment criteria for disability pension eligibility nor information on people currently receiving the pension payments. Nevertheless, the amount of money is unlikely to sufficiently cover the additional cost associated with accessing mainstream health and rehabilitation services. All people with disability and their families were consulted by the analysis team were asked about the disability pension. A diverse picture emerged: some people consulted were receiving the pension, others had tried to but were not eligible (and many were unsure why), and others did not know of the pension scheme at all.

Barriers in the area of Leadership and Governance

This area concerns the role of the government, its relationship with other stakeholders, and how decisions are made in ways that balance demand for services against limited resources[26].

As noted in the strengths section, GoTL (both MOH and MSS) demonstrate relatively good leadership and commitment to increasing access to mainstream and rehabilitation services for people with disability, including via collaboration with DPOs and NGOs. This is also demonstrated by the 2012 Decree that made ASSERT a department within MSS (the Centre for National Rehabilitation, CNR). CNR is currently developing a five-year plan and new regulations to enact the Decree.

However, an emerging issue is the lack of clarity regarding roles and responsibilities for rehabilitation services delivery between ministries (with the current parallel systems and lack of coordination contributing). The MSS has proposed the establishment of a new Disability Council (envisaged as an inter-ministerial, multi-stakeholder governance and coordination body), which is intended to support implementation of the National Disability Policy. This may provide opportunities to bring the MSS and MOH together, along with key central ministries such as Finance and other stakeholders. Other coordination mechanisms, such as the Timor-Leste Development Partners Meeting, may also help to resolve these issues.

Two key factors will influence the success of GoTL leadership and governance related to people with disability and their access to mainstream health and rehabilitation services:

- The degree to which people with disability, through their representative organisations, are involved in decision-making. People with disability are experts in their own lives and can assist GoTL in making informed decisions regarding priorities within constraints of limited resources.
- The extent of MOH (and other ministries) commitment in wanting to better understand and address the barriers faced by people with disability. This will be in part informed by the level of support (both financial and technical) and encouragement from development partners, as well as increased demand from citizens and civil society.

Barriers in the area of Community Mobilisation

[26] WHO, 2007, p. 23

For AusAID, this area focuses on communities determining priorities, in particular in maternal and child health, and then taking action to achieve them.

The ability of people with disability to participate in and benefit from community mobilisation is constrained by a number of challenges:

- Stigma and discrimination often prevents people with disability and their families from participating in community events and decision-making forums. Due to the stigma they experience, they feel too ashamed or embarrassed to come out of their homes. There can also be physical, communication and logistical barriers to their participation in community events. For example, the community mobilisation event may have been advertised on the community notice board, which people with disability and their families may not be able to see.
- In relation to community mobilisation that aims at increasing the knowledge of the community of existing services, because people with disability are likely to not be involved in community mobilisation activities, they will continue to not have access to the same information as others, or information about services relevant to them and that they have the right to access. For example, the analysis team met many people with disability who thought that SISCa only catered to pregnant women, not realising that it provides a much wider range of primary health services directly relevant to them. In part this may be because many people with disability have lower levels of literacy compared to people without disability, so cannot understand written information. In addition, people with vision, hearing or intellectual impairments often require adapted information and communication methods, which for the most part are not provided.
- In relation to community mobilisation activities that aim at increasing the demand for services or demanding better quality of services, because people with disability are unlikely to be involved, the demand for services to be accessible for people with disability and the demand for services that people with disability might require such as rehabilitation and provision of assistive devices, is unlikely to be raised and lead to changes.
- In relation to community mobilisation focused on changing the health-related behaviours of individuals, households and communities, the barriers outlined above such as discrimination, stigma, lack of accessible information, distance etc, will mean that people with disability will miss out and they will not make changes to their health-seeking behaviours.
- Related to the above point about health-seeking behaviour, another challenge is that people with disability have a lack of confidence in seeking mainstream health and rehabilitation services. The analysis team found that this lack of confidence particularly affects several women with disability. Women with disability consulted by the team noted that a challenge they themselves (and other women with disability they knew) faced was a lack of confidence to seek mainstream health and rehabilitation services. Further information would be required to investigate the causes of the lack of confidence to inform program response (for example is it lack of confidence in the services, or lack of self-confidence to leave their houses and access services). International experience shows that low confidence in accessing maternal child health services can be related to the expectation of being discriminated against due to perceptions that women with disability should not have

children[27]. And stigma related to beliefs around causes of mental illness (eg that it is caused by sorcery or wrongdoing in a past life) can reduce confidence in attending health services for treatment[28].

5. Recommendations

The proposed AusAID *Timor-Leste Health Program (2013 – 2020)* will not be able to address all of the significant number of actions required to improve access to quality mainstream health and rehabilitation services for people with disability. As such, the recommendations below represent a considered and select number of issues for AusAID to consider during the Health Program design process. Some of the recommendations relate to actions for other stakeholders, but have been included here to ensure a broad picture of what is required.

Recommendations are structured in relation to the seven proposed intervention areas for the new Health Program (WHO's six building blocks plus 'community mobilisation'), and are differentiated depending upon those that might fit with a 'fast-track support package' (short to medium term) and those are best dealt with over the longer-term (for example those that relate to institutional development support), as per the scope of the proposed new AusAID program.

Overarching Recommendations

1) The new program design should include explicit short and long-term strategies (as per the recommendations below) to improve access to quality rehabilitation services for people with disability, particularly women and children. Rehabilitation is a critical enabler for many people with disability to access other services, including mainstream health services. Without it, AusAID's investment to improve the inclusiveness and accessibility of mainstream health services will, for many people with disability, be redundant.

2) AusAID's new Health Program should facilitate collaboration between MOH and MSS to address emerging issues with parallel rehabilitation service delivery. This should be aimed at: (a) ensuring a common understanding of the challenges with the current model of parallel service delivery, and (b) working towards an agreed vision for rehabilitation service delivery over the long-term that offers the GoTL the most efficient and effective delivery options. The *National Community-Based Rehabilitation Strategy* provides a useful common framework for this collaboration.

Recommendations relating to Service Delivery

Short-term actions

3) Ensure all infrastructure supported by the program utilises universal design principles. This should draw on AusAID's Accessibility Design Guidelines.

Long-term actions

[27] WHO/UNFPA (2009). *Promoting sexual and reproductive health for persons with disabilities: WHO/UNFPA guidance note*.
[28] WHO (2010). *Mental health and development: Targeting people with mental health conditions as a vulnerable group*.

4) Integrate universal design principles into all MOH infrastructure standards.

Recommendations relating to Health Workforce

Short-term actions

5) Investigate options for establishing and/or slowly increasing numbers of rehabilitation (health and allied) health professionals for under-served areas, such as speech therapists. This would involve recruitment of international professionals and training overseas for nationals. This should draw on additional examination (see Recommendation #10) of the existing rehabilitation workforce and likely need and gaps. In the longer-term, efforts to increase numbers of rehabilitation health professionals should emerge out of a joint MOH-MSS human resource plan (see Recommendation #7).

6) Assess options for increasing provision of in-service training of health care workers on basic disability identification and support through experienced NGOs. In the longer-term, options to establish pre-service training modules on disability could draw on the cadre of CBR Co-Facilitators at UNTL. While the Co-Facilitators will no doubt need to focus the next few years on delivering the CBR Diploma, they are likely to become experienced CBR professionals with appropriate skills and experience to support in-service disability training.

Long-term actions

7) Support development of a long-term joint MOH and MSS human resource plan for rehabilitation professionals, which should be linked to the Human Resources for Health program. This would be based on identification of service gaps through short and long-term actions under Information as below (see Recommendations #9-12). Should appropriate mechanisms not be available under the proposed new program, Dili Post (with support from the AusAID Disability Policy Section) could investigate options for an appropriate institution in Australia to submit a proposal to the AusAID's Government Partnerships for Development Program, thereby enabling a long-term twinning partnership that could support GoTL gradually over time at an appropriate pace.

8) Ensure employment of healthcare workers does not discriminate against people with disability. This will likely require reasonable accommodation provisions, which may need to be stipulated via Decree, which should cover all sectors and thus would be beyond the scope of the health program (although AusAID's health, governance and other sectoral teams could work together to undertake policy dialogue on this issue). Positive steps towards this could involve including people with disability as community health care workers, or involving them within SISCa.

Recommendations relating to Information

Short-term actions

9) Assess whether a disability module could be included in the next Demographic Health Survey[29]. There is work happening at an international level currently to improve modules

[29] Although there isn't a specific Measure (the organisation that implements DHSs) module for disability, there is the Washington Group questions which have been internationally tested and are able to be integrated into census or survey instruments. To date AusAID is unaware of any country that has included the Washington

related to children with disability, in addition to existing modules appropriate for adults. This should draw on expertise from the World Health Organisation (Geneva) and the Washington Group on Disability Statistics. AusAID's Disability Policy Section in Canberra has close connections to individuals in both, and could assist in facilitating connections.

10) Under-take a short-term research project to gather and analyse all information from current rehabilitation service providers. This would provide a valuable picture of the type of services currently being provided (including assistive device provision), more detail on the existing rehabilitation workforce as well as likely need and gaps, as well as some broader demographic information of the users[30] of these services, including their health status.

11) Work with MOH to determine whether and how the ICF could be used as the framework for disability classification. The WHO Geneva (via the country office and/or the South East Asia Regional Office) could be called on to provide technical support.

Long-term actions

12) Integrate disability-disaggregated data into Health Management Information Systems for mainstream health services. This could draw on emerging experience and expertise in Australia through the Australian Institute of Health and Welfare in collaboration with the Australian Bureau of Statistics. Once appropriate indicators are developed and trialled, a plan for gradual rollout should be developed; the criteria for rollout could be based on a number of factors, including focusing on those services most relevant to the majority of people with disability, those with the most robust data collection processes or where local DPOs could be involved. (*Note: there are other data collection processes that sit outside the health sector, such as the census, which could usefully have disability modules included and would then be able to provide demographic information, including health status, for people with disability. These could be utilised while HMIS is streamlined and appropriate indicators for inclusion in HMIS are developed and trialled).*

Recommendations relating to Medical Products, Vaccines and Technologies

Short-term actions

13) Ensure research undertaken (see recommendation #10) includes investigation into assistive device provision and access to medications required by people with disability.

Long-term actions

14) Aim to clarify roles and responsibilities regarding procurement for assistive devices within facilitating collaboration between MSS and MOH. This should be linked to reform of SAMES (Timor-Leste's drug procurement body). It is too early to provide more detailed recommendations at this stage.

Group questions in a DHS, but a number of countries have used the questions in Census or other surveys. AusAID's Cambodia Country Program is considering whether the Washington Group questions can be integrated into the 2015 Cambodia DHS.

[30] It is recognised that collecting information only on the current users of these services is unlikely to be representative of the wider population of people with disability. However, the information gathered from service providers could be referenced against other information on people with disability such as that collected through DHS/Census etc.

Recommendations relating to Financing

Short-term actions

15) Ensure research undertaken (see recommendation #10) includes investigation into financial aspects of access to health and rehabilitation services, including costs of the services and costs to access the services, covering both cost to service provides and GoTL, as well as costs for people with disability and their families.

Long-term actions

16) Depending upon outcomes of collaboration between MSS and MOH, investigate options to increase commence financing of rehabilitation service delivery through core MOH (and hence health sector development partner) resources.

Recommendations relating to Leadership/Governance

17) N/A - refer overarching recommendations.

Recommendations relating to Community Mobilisation

Short-term actions

18) Where feasible, ensure involvement of RHTO and their District Officers in community mobilisation activities[31]. The District Officers in particular will be able to either represent people with disability or be able to locate and support them to participate in community events/decision-making processes.

19) Encourage NGOs focused on women and NGOs focused on access to health to include women with disabilities in their work. This could be as simple as facilitating connections between RHTO and/or DWG with the women- and health-focused NGOs AusAID already works with.

20) AusAID should consider the engagement of RHTO in the new Health Program alongside other country program initiatives. Issues in particular of whether RHTO are resourced appropriately to engage effectively (should they so choose) need to be considered.

[31] Although it is noted that there is only one RHTO District Officers per district, meaning that they may not have the capacity to take part in all community mobilisation activities occurring generally at suco level. Nevertheless, the Health Program should endeavour to engage with the District Officers when designing mobilisation activities to draw on the District Officers' knowledge of where people with disability live and what strategies would be useful to support and facilitate the involvement of people with disability.

Annex 1

Terms of Reference

Background

AusAID's Timor-Leste Country Program is currently in the design phase of its new Health Program. This new program will be the next 4-8 years of support to the health sector in Timor-Leste. It is expected that the new program will focus on maternal and child health and nutrition. Improvements in Timor-Leste's maternal and child health outcomes require better functioning in all elements of the health system to provide, and promote use of, a high-quality continuum of reproductive, maternal, neonatal and child health (RMNCH) care.

AusAID wants to make sure that women, children and people with disability are included in and benefit from support to the health sector on an equal basis with others. To make sure this happens, the new health program design needs to include good quality information on disability-inclusiveness in the health sector in Timor-Leste, and practical solutions to addressing barriers. This Disability-inclusive health sector situational analysis will inform the design to make sure the new health program is disability-inclusive.

This Terms of Reference document briefly outlines how the Disability-Inclusive Health Sector Situational Analysis will be undertaken.

Objective of the Disability-Inclusive Health Sector Situational Analysis

The objective is to inform AusAID's Health program design by assessing access to quality health services for women, men, children and young people in Timor-Leste.

Key Questions

a. What is the **experience** of children and people with disability in accessing mainstream and specialised health services throughout their lives?
b. What factors impact (positively and negatively) the **quality** of mainstream and specialised health service delivery for women, children and people with disability?
c. What factors impact (positively and negatively) **access** to mainstream and specialised health services for women, children and people with disability?
d. What **information** is available to inform a disability-inclusive health sector in Timor-Leste?
e. What are the ways in which AusAID's new Health Program can address these issues?

Approach

AusAID recognises that people with disability are experts in their own lives and their meaningful involvement is critical in ensuring good quality information and recommendations. The wealth of experience of other individuals and organisations in disability-inclusive health in Timor-Leste is also acknowledged.

The process to develop the Disability-Inclusive Health Sector Situational Analysis will therefore be undertaken in a way that draws on these existing strengths. It will also aim to enhance the mutually beneficial relationship between AusAID and these stakeholders so that:

a) AusAID's future support to the health sector continues to be informed by existing expertise, including in particular of people with disability; and,
b) Stakeholders are better able to provide advice on disability-inclusion in the future through increased understanding of how AusAID operates as well as the broader health sector in Timor-Leste.

This analytical process will therefore prioritise the participation of people with disability through their representative organisations (Disabled People's Organisations, DPO) and other key stakeholders. To ensure this happens in a meaningful way, the detailed methodology (and report format[32]) will be discussed and agreed with key stakeholders in-country. AusAID's Regional Specialist, Disability Inclusive Development (Asia) and Inclusive Development Program Officer (East Asia) will be responsible for facilitating this process (along with AusAID Dili) and writing up the final situational analysis report.

The Regional Specialist and Inclusive Development Program Officer will work with a small team throughout this process which will include a number of individuals/organisations who already have significant experience of disability-inclusive health in East Timor and/or are likely to have a key role in providing ongoing advice to AusAID. It is recommended this include:

1. Disability Working Group representative
2. RHTO representative
3. Ministry of Health Disability focal point
4. Ministry of Social Solidarity Disability focal point
5. AusAID Disability focal Point.

AusAID's Timor-Leste Country Program will invite the organisations to nominate one staff member with experience in disability-inclusive health to participate in the team. Ideally, team members must be available full-time over the two week period that the Disability-Inclusive Health Sector Situational Analysis is taking place, as well as one day (full-time) afterwards to comment on the draft report. The detail of roles and responsibilities of team members will be discussed and agreed at the introductory team meeting.

Timeframes

Date	**Milestone/Outputs**
Week of 2 May	AusAID to invite nominations for the team
Week of 13 May (one day meeting)	Initial team meeting • Introductory team meeting • Briefing with AusAID Dili • Discussion and agreement on methodology of the Disability-Inclusive Health Sector Situational Analysis • *Output – detailed methodology*[33]
Week of 14 May	Disability-Inclusive Health Sector Situational Analysis commences (week 2 of 3) • Stakeholder consultation workshops and meetings (based on the detailed methodology agreed through the initial team meeting) • Field trips and visits to community health centres, health posts, service providers, communities and family with people with disability (based on the detailed methodology agreed through the initial team meeting) • Ongoing team feedback and meetings to discuss initial findings
Week of 24 May	Disability-Inclusive Health Sector Situational Analysis continues (week 4 of 4) • Stakeholder feedback workshop to discuss findings • Presentation of findings and recommendations to AusAID Dili (24 May) • *Output – stakeholder feedback workshop* • *Output – presentation of findings to AusAID Dili*
10 June	Final Disability-Inclusive Health Sector Situational Analysis report due

[32] The report format will be informed by AusAID's Tool – Situational Analysis Format, and discussion with the AusAID East Timor Country Program Health Team.

[33] Detailed methodology to include methods, work plan and roles and responsibilities of team members.

Annex 2

Analysis Schedule and Consultations

Date	Meeting/Activity
21 May 2013	Meeting with AusAID management (Minister-Counsellor and Counsellor Health and Education)
22 May 2013	Consultation meeting with National Director of Social Affairs (MSS)
	Consultation meeting with Head of NCD Dep (MoH)
	Consultation meeting with Pradet
	Consultation meeting with Fred Hollows
23 May 2013	Consultation meeting with MSITL
	Consultation meeting with WHO
	Consultation meeting with Agape
	Consultation meeting with ETBU
	Consultation meeting with Ahisaun
24 May 2013	Consultation meeting with DPO (RHTO & TLMTL)
	Consultation meeting with ASSERT / CNR
	Consultation meeting with HAI
	Consultation meeting with Klibur Domin
	Plan International Timor-Leste / world vision
27 May 2013	Consultation meeting with Director of Hospital Referral Baucau
	Consultation meeting with DPO Viqueque
28 May 2013	Consultation meeting with community and people with disability and their families in Viqueque Sub-district
	Consultation Meeting with Director of CHC Viqueque Observe clinic facility
29 May 2013	Consultation meeting with community and people with disability and their families in other Sub-district
	Consultation Meeting with Director of CHC Ossu and observe clinic facility
30 May 2013	Consultation meeting with DPO Baucau
3 June 2013	Stakeholder feedback workshop to discuss findings (see attendance list below)
	Presentation of finding and recommendation to AusAID

Stakeholder Consultation Attendance List	
Name	**Intuition**
Dr Herculano Seixas dos Santos	Head of Non Comunicable Disease, MoH
Sr. Amandio Freitas Amaral	National Director for Social Affairs, MSS
Sr. Mateus Oliveira	Chefe Departementu Asistensia Idoso no Defisiencia, MSS
Joazito dos Santos	RHTO
AGAPE	
Elisabeth Elson	HAI Country Director
Almarindo Cardoso	MSITL reproductive health officer
Dr Jorge Mario Luna	WHO – Country Director
Leonito	WHO
Dr. Domingas	WHO
Amanda Crookes	Handicap International – Technical Adviser
Martion	East Timor Blain Union (ETBU) – Director
Ms Nona Lisnahan	TLMTL – Country Leader
Natalie Smith	TLMTL – Technical Adviser