Access to maternal and newborn health services for women with disabilities in Timor-Leste

August 2016
CBM-Nossal Partnership for Disability Inclusive Development &
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ACRONYMS

ANC	Antenatal care
CHC	Community Health Centre
CRPD	Convention on the Rights of Persons with Disabilities
DPHO-MCH	District Public Health Officer - Maternal and Child Health
DPO	Disabled People's Organisation
EVAW	Ending Violence Against Women
MCH	Maternal and Child Health
MNH	Maternal and Newborn Health
MoH	Ministry of Health
NGO	Non-Government Organisation
PNC	Postnatal care
PRADET	Psychosocial Recovery and Development East Timor
RHTO	Ra'es Hadomi Timor Oan
RMNCAH	Reproductive, maternal, newborn, child and adolescent health
SISCa	Sistema Integradu Saude Communitaria (integrated community health services)
SRH	Sexual and reproductive health
TBA	Traditional Birth Attendant
UNFPA	United Nations Population Fund
WHO	World Health Organization

EXECUTIVE SUMMARY

Background

In many contexts, women with disabilities experience more barriers to health information and services, including maternal and newborn health (MNH) services, when compared to women without disabilities[1]. The United Nations Population Fund (UNFPA) has argued that people with disabilities are a "significant constituency with neglected needs" in relation to sexual and reproductive health[2] (SRH) care. Furthermore, various studies have reported current maternity services present women with disabilities "with structural barriers, poor labour and birth facilities and lack of access to appropriate services"[3] and that this "appears to be widespread throughout current maternity services across different countries"[4].

In Timor-Leste, disabled people's organisations have highlighted some of the specific challenges that women and girls with disabilities face in accessing health care, and SRH services in particular, such as "[mistaken] assumptions that people with disability are not sexually active"[5]. Civil society organisations in Timor-Leste have also argued that current frameworks relating to the rights of women require increased attention to "the specific multiple and intersectional discrimination women with disabilities face"[6]. Additionally, the Ministry of Health's Reproductive, Maternal, Newborn, Child and Adolescent Health Strategy 2015 - 2019 highlights the need for research in various aspects of MNH to support "strategic decision making for improving services"[7]. It is hoped the present study will contribute to more informed and strategic decision making by improving understanding of the factors which influence access to MNH services for women with disabilities.

In this context, to support disability inclusion within the health systems of Timor-Leste, the Australian Government's Department of Foreign Affairs and Trade commissioned research to better understand the access of women with disabilities to family planning and maternal and newborn health (MNH) services, including antenatal care (ANC), delivery and postnatal care (PNC). The research was also commissioned to explore the experience of service providers in delivering services to newborns with impairments. Newborns were considered as those within the post-natal phase, zero to six weeks old.

This report explores the perspectives of midwives and doctors (service providers) and women with disabilities in terms of access to services. Research participants' understanding of disability and the MNH needs and rights of women with disability are presented as well as the reported access to different services in the continuum of care. The influence of barriers and enabling factors on the access of women with disabilities to family planning and MNH services is discussed. Additionally, the experience of service providers in providing services to newborns identified as having impairments during the postnatal period[i] is documented. Importantly, this report provides recommendations developed from the findings to promote disability inclusion within family planning and MNH programs in Timor-Leste.

Methodology

This research was carried out by the CBM-Nossal Partnership for Disability Inclusive Development, in partnership with Ra'es Hadomi Timor Oan (RHTO), a national Timorese Disabled People's Organisation (DPO). Fieldwork was conducted in Timor-Leste in September 2015 and included collection of qualitative information using key informant interviews, in-depth interviews and two focus group discussions. There were a total of 29 participants, including 10 service providers, 14 women with disabilities and 5 key informants. Participants were selected through the Timor-Leste Ministry of Health and the networks of RHTO. Participants from both rural and urban areas were included, selected from Dili and Ermera. Wherever possible, efforts were made to ensure the sample of women with disabilities was representative of participants with different types of impairments. Interview and

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[i] The postnatal period for newborns is defined from immediately post-birth up until 6 weeks after birth (see: The Global Strategy for Women's, Children's and Adolescents' Health (2016-2030) http://www.who.int/pmnch/media/events/2015/gs_2016_30.pdf?ua=1)

focus group discussion transcripts were coded and analysed to develop an iterative thematic analysis. Ethics approval was gained in Australia through the Human Research Ethics Committee at Melbourne University and in Timor-Leste through the Research Technical Committee of the National Institute of Health. The research was funded by the Australian Department of Foreign Affairs and Trade in Timor-Leste.

Key Findings

Findings highlighted a range of factors, both supportive and inhibitive, which influenced access to MNH services for women with disabilities in Timor-Leste. These factors suggest that there is a need to improve the inclusion of women with disabilities in mainstream family planning and MNH services in Timor-Leste by building on the many positive enabling factors also found in this research. Furthermore, the findings indicate identification and intervention services for newborns with impairments appear to require strengthening, as well as supports for parents of newborns with impairments.

Perceptions and understanding of disability and the MNH needs and rights of women with disabilities

Many service providers recognised that women with disabilities have the same right to health as women without disability. Women with disabilities also expressed their right to have children, but only a small number of service providers explicitly expressed a similar view.

However, the majority of service providers had a limited understanding of the range of impairments related to disability and a human rights based approach to disability. Service providers most commonly reported physical impairment, and to a lesser extent, vision impairment as being related to disability. Language used by some service providers to describe disability was reflective of non-rights based approaches towards disability. For example, service providers often differentiated between women with and without disability as a dichotomy between normal and abnormal, rather than recognising diversity as a normal part of humankind. Language used by some service providers in relation to psychosocial disability was particularly negative.

Women with disabilities reported that community members sometimes held negative misperceptions about their sexual activity and parental capacity. This included misperceptions that women with disabilities do not practice sexual behaviour, a misperception also reflected by one service provider. Similarly, some women with disabilities reported that community members at times questioned their parenting capacity and some reported that service providers actively discouraged them from having more children. There were also examples whereby the right of women with psychosocial disability to have and parent children may have been undermined.

Several service providers perceived women with disabilities to be particularly vulnerable to sexual harassment and abuse. Service providers associated pregnancy from sexual abuse more frequently with women with psychosocial disabilities than women with other types of disability, though whether this is based on misperception or fact could not be ascertained in this research.

Experience providing services to women with disabilities

There were rural/urban differences in service providers' exposure to women with disabilities in health settings. All service providers in Dili reported providing services to women with disabilities and most were able to recall multiple experiences. In contrast, service providers in Ermera reported less experiences of directly providing services to women with disabilities and some were not able to recall a single case.

Of those service providers providing MNH services to women with disabilities, most of these were women with physical impairments, but a diverse range of impairments was noted. Most service providers reported identifying disability by means of visual observation (although many impairments are not visible). Data on disability at the clinical level that could be used to measure access to health services may not be consistently available, as a small number of service providers reported they do not record disability status of women presenting for family planning and MNH services whilst others reported that they did record disability status of female patients in general medical notes. No service providers reported that disability data was collected for monitoring and evaluation purposes.

Service providers reported being more likely to refer upwards from the primary health care system towards secondary and tertiary health services for women with disabilities, and sometimes based this on the presence of impairment alone (including hearing and communication impairments). Service providers' generally had a low knowledge of disability services to refer women with disabilities for additional support and no service providers were aware of any DPOs.

Access to services across the continuum of care

Most women with disabilities who received information from service providers about family planning, received this after the birth of their first child. Several women with disabilities highlighted they had no access to "modern" family planning information and methods, but conversely many women with disabilities had awareness of family planning practice (i.e. the need to space children). Women with disabilities received information on family planning from family, community members as well as health service providers. Of concern, was that sterilisation was reported by some research participants (including a service provider and several women with disabilities) as some service providers' preferred method of family planning for women with disabilities rather than less invasive and non-permanent approaches. It is possible in at least one of the cases reported in this research that informed consent for sterilisation may not have been obtained.

Differences in access to services between the rural and urban settings were apparent in the findings. Not surprisingly, women with disabilities reported greater access to antenatal (ANC) services, skilled care at birth, and post-natal care (PNC) for their newborns in Dili than in Ermera. However, disability-specific barriers and enablers were reported. Notably, some service providers assumed incapacity of women with disabilities to have a vaginal delivery and suggested a generalised approach to requesting caesarean surgery that appeared not necessarily bound in clinical necessity. Additionally one service provider indicated that the practice of physically restraining some women with psychosocial disability during childbirth may be used.

Barriers to accessing MNH services for women with disabilities

The results of interviews and discussions with both service providers and women with disabilities suggest that a range of physical, communication, attitudinal and institutional barriers negatively impact the access of women with disabilities to quality and respectful MNH services.

Physical barriers related to geography, distance to health facilities and limited accessible and affordable transportation were key issues impacting women with disabilities' service access. While these may also create barriers for women without disabilities, they are compounded for many women with disabilities, particularly in rural areas, by the interaction of their particular impairments with these environmental barriers. Other physical barriers preventing women with disabilities from obtaining a quality service included inappropriate equipment such as hospital beds ill-suited to the functional abilities of some women with disabilities.

Verbal and visual communication barriers were frequently noted by both service providers and women with disabilities. These barriers indicated low resourcing and limited skills of some service providers to adapt their messages for people with impairments impacting communication including vision, hearing and psychosocial disabilities.

A range of institutional level factors such as limited visible prioritisation of disability in health policies, centralised decision making in the Ministry of Health, lack of data on disability, limited knowledge and training of service providers regarding disability and the number and distribution of health staff were all reported as barriers.

Women with disabilities living in rural areas faced more economic barriers to accessing services, which aligns with the well documented link between poverty and disability[8]. The high cost of transport to reach secondary or tertiary health facilities to which women with disabilities were often referred was also attributed to creating barriers to service access.

Negative attitudes, including presumptions about women with disabilities, created barriers to women accessing quality family planning and MNH services. Presumptions about the capacity of women with disabilities were evident in practises such as possible forced sterilisation[ii], use of physical restraint during labour and use of derogatory terms to describe disability. In addition, the attitudes of families towards their female relative with disabilities could also form barriers to accessing health services if families felt 'shame' and sought to hide family members with disabilities and did not provide them practical support. Women with disabilities were also perceived in some cases to have internalised negative views about themselves to the extent they felt too ashamed to venture outside to seek health care.

Enablers for women with disabilities to access MNH services

Despite the barriers to service access described above, this research found that most women with disabilities reported previously accessing at least one MNH service, whether it was family planning, single or multiple ANC visits, skilled birth assistance or PNC, and for a few women - all of these services. Much encouragement can be taken from the supportive practices exhibited by some service providers that enable women with disabilities to access these services.

Service providers described a range of strategies they undertook to assist women with disabilities whilst accessing MNH services. These demonstrate consideration by midwives of the various support needs of women with disabilities despite not having formal training in disability. Strategies included provision of respectful physical assistance and adapting communication modalities. A dominant theme emerging from the findings with service providers was the role of outreach services in the home to provide accessible MNH care to women with disabilities. Importantly, several women with disabilities highlighted very positive experiences of treatment from service providers, and one linked this with providing motivation for her to return to the health facility.

Participants also proposed resourceful solutions to improve access of women with disabilities to MNH services. These included introducing a non-emergency patient transport system and liaising with Chefe de Sucos[iii] to locate women with disabilities.

Additionally family support and connection with DPOs were significant factors enabling access of women with disabilities to family planning and MNH services. The research suggests that the attitude of a woman's family may be a key determinant of whether a woman with disability can access health services. Research participants reported that family support enabled women with disabilities to navigate the health system, improve communication with health professionals, access home-based services and travel to health facilities. Connection with DPOs was also found to potentially relate to a woman with disability's capacity to assert her rights to MNH services.

Newborns with impairments

Younger service providers, who reported they had limited years of work experience, explained that they had no experience of supporting delivery of a newborn with impairment, however most other service providers recalled cases of supporting delivery of newborns with impairments. The birth of a newborn with an impairment was reportedly often received negatively by family members and sometimes the associated shame was reported to lead families to avoid health services.

Capacities of primary and secondary health services to respond to identified impairments appear low, though further investigation would be required to substantiate exactly what capacities currently exist at the secondary level. Most service providers reported being able to identify significant newborn impairments in the postnatal period, though practices for doing so varied and there were some instances when impairments that could impact on a newborn were not followed up possibly due to a lack of knowledge of the potential impact, for example - the impact of cleft palate on feeding.

[ii] Forced sterilisation refers to sterilisation that occurs in the absence of free, full and informed consent. For further information about forced sterilisation, please see the World Health Organisation's Interagency Statement on 'Eliminating forced, coercive and otherwise involuntary sterilization', 2014, available from: http://www.who.int/reproductivehealth/publications/gender_rights/eliminating-forced-sterilization/en/

[iii] Suco is the level of governance in Timor-Leste equivalent to sub-district level. The chefe is the leader of this area.

Additionally service providers were generally unable to offer options for support to mothers of newborns with impairments, possibly because few support options exist. Some service providers agreed that training about newborn impairment would be useful.

Recommendations

The findings of this research suggest that a number of different strategies are required in order for women with disabilities to equitably access family planning and MNH services and to maximise the quality of life of newborns with impairments. Recommendations presented in this report have been developed with a view to support alignment of policy and practice with the CRPD. As these recommendations are informed by a human rights based approach, there are key principles, including participation and reasonable accommodation, that are applicable across many recommendations. These principles are explained in more detail in text boxes 1 and 2 in section 5 of this report. It is essential to highlight that the principle of participation requires that people with disabilities are actively included in the planning and implementation of responses to these recommendations.

It is understood that these recommendations are made in a context where many women without disabilities also experience significant challenges to access family planning and MNH care and so plans to improve the access of women with disabilities may need to be considered in light of overarching plans to improve access for all women in Timor-Leste to MNH services. It is anticipated that an implementation plan would be developed to support progressing the recommendations in this report. Such a plan would need to include: identification of the relevant duty-bearers, realistic prioritisation and timeframes, appropriate budgeting and further specification of implementation activities.

1 Accessibility of health services

1.1 Make transport available to health facilities for women with disabilities

1.2 Consider how social protection schemes could support family members who facilitate women with disabilities' access to health services

1.3 Provide family planning and MNH outreach services for women with disabilities

1.4 Develop and include universal accessibility into standards for new and existing health facilities (see Annex A for suggested physical and communication accessibility items to be included in standards)

2 Health system processes and systems

2.1 Collect information and data on disability to inform equitable health service delivery

2.2 Review clinical guidelines/processes for identifying high-risk pregnancies and development of birthing plans

2.3 Develop a brief directory of existing disability services in Timor-Leste for use by health professionals

2.4 Strengthen disability awareness, collaboration and referrals between health services, ending violence against women programs and disability stakeholders

3 Training

Disability related training for health professionals should be undertaken. This will require the selection of the most strategic entry points for such training, as well as prioritising health professionals’ roles for training which could include delivery of training systematically through training of trainers. Training content areas should include: awareness of the human rights based approach to disability, informed consent, communication skills, disability identification and the interaction of pregnancy and impairment.

4 Policy

4.1 Review MNH related legislative, policy and strategic frameworks from a disability and human rights perspective

4.2 Designate inclusive MNH as a policy priority

4.3 Continue initiatives for the formal development of a national Timorese sign language, and in the future when trained sign language interpreters are available, allocate funding in the health system for professional sign language interpretation.

5 Advocacy and awareness

5.1 Include people with disabilities in mainstream family planning and MNH community mobilization campaigns

5.2 Support DPOs to target attitudinal barriers among families and communities and build confidence of women with disabilities

6 Newborns with impairment

6.1 Identify and document expectations of what newborn impairments should be typically dealt with at which specified levels of the health system

6.2 Improve timely identification and treatment of newborn impairment during the postnatal period

6.3 Develop support mechanisms for parents of newborns identified as having an impairment

6.4 Further investigate how identification and intervention of disability during early childhood currently operates in Timor-Leste

1. BACKGROUND

> *"You could say that [for] women without disabilities there may be challenges too with their families or in the hospital...but for women with disabilities there are more challenges" (Key Informant, Dili)*

In many contexts, women with disabilities experience more barriers to health information and services, including maternal and newborn health (MNH) services, when compared to women without disabilities[9]. This is despite the factors impacting access to health services often being situated in broader health systems constraints which affect access for all women. It is important to understand context specific factors which impact on access to services for women with disabilities in order to inform appropriate responses to improve disability inclusion within these services.

In recognition of this and as part of a larger program to support disability inclusion within the health systems of Timor-Leste the Australian Government's Department of Foreign Affairs and Trade commissioned research to better understand the access of women with disabilities to family planning and MNH services, including antenatal care (ANC), delivery and postnatal care (PNC).

In Timor-Leste these services are governed by the Maternal and Child Health Department (MCH) which sits within the Timor-Leste Ministry of Health (MoH). Services are delivered by health professionals through facilities in the primary health care system including health posts and community health centres, or community based services such as SISCa[iv] and the newer domiciliary home visiting program[v]. Secondary and tertiary level health services are delivered through district referral hospitals and the National Hospital in Dili.

The aim of this qualitative research was to explore the knowledge, attitudes and practices of MNH service providers in the provision of services for women with disabilities in Timor-Leste. The objectives were to understand the perspectives of services providers and women with disability in terms of access to services; as well as to explore the experience of service providers in providing services to newborns identified as having impairments during the postnatal period[vi].

This report aims to contribute to understanding the factors which influence access to services for women with disabilities and to inform recommendations to promote disability inclusion within MNH programming in Timor-Leste.

1.1 What is disability?

The framework for this research draws on the conceptualization of disability as outlined in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in Article 1:

> *"Persons with disabilities include those who have long-term physical, mental[vii], 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"[10].*

Defining disability as an interaction means that disability is not merely an attribute of the person[11]. Rather, impairment refers to a difference in body structure or physiology and disability results from

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[iv] SISCa, or Sistema Integradu Saude Communitaria (integrated community health services), are mobile health services that periodically visit rural and remote communities.

[v] The domiciliary visiting program comprises staff from Health Post Services Teams who visit the households in their catchment area to assess and provide treatment in the home setting.

[vi] The postnatal period for newborns is defined from immediately post-birth up until 6 weeks after birth (see: The Global Strategy for Women's, Children's and Adolescents' Health (2016-2030) http://www.who.int/pmnch/media/events/2015/gs_2016_30.pdf?ua=1

[vii] Psychosocial disability is the preferred term used by the international organisation representing people with mental impairments (World Network of Users and Survivors of Psychiatry WNUSP) and describes the interaction of mental impairments with barriers. Psychosocial disability will be the term used in this document when describing disability.

the interaction of this with "the structural restriction or barriers caused by society"[12]. This is the essence of the social model approach to disability which has informed this research project.

1.2 Global context of access to services for women with disability

In many contexts, women with disabilities are often excluded from accessing health care[13]. The United Nations Population Fund (UNFPA) argues that people with disabilities are a "significant constituency with neglected needs" particularly in relation to sexual and reproductive health[14] (SRH) care. UNFPA and others have also highlighted that in some cases, SRH programs tend to focus on preventing women with disabilities getting pregnant, rather than acknowledging women with disabilities have the right to choose to have children[15].

The difficulty experienced accessing MNH services by many women in low-resourced settings is acknowledged by Smith et al in their Zambian study. The authors also highlighted that "it is likely that women with disabilities may experience a double burden; encountering additional barriers specific to having an impairment"[16]. Further, the maternal health component of SRH services, have been identified in the literature to be failing women with disabilities[17].

Other studies have reported current maternity services present women with disabilities "with structural barriers, poor labour and birth facilities and lack of access to appropriate services"[18] and that "this experience appears to be widespread throughout current maternity services across different countries"[19].

These findings represent violations of a number of rights of women with disabilities[viii] with efforts to uphold these rights being hampered by the lack of context specific information about the experience of women with disabilities in accessing MNH services. Studies exploring the perspective of women with disabilities about their access to these services, are particularly lacking[20]. Without context specific information, international development programs focusing on improving access to SRH programming for women "may inadvertently exclude women with disabilities"[21].

1.3 Timor-Leste context

Disability and institutional frameworks in Timor-Leste

An estimated 15 per cent of the world's population have disabilities[22]. The estimated prevalence of disability in Timor-Leste has been reported to be 4.6 per cent[23]. As in many contexts, this may be an underestimation of actual prevalence due to the inherent challenges of measuring disability[24]. Whilst Timor-Leste has not yet ratified the CRPD, a guarantee that people with disabilities have the same rights as all other citizens has been enshrined in Article 21 of the Constitution of the Democratic Republic of Timor-Leste. The National Policy for the Inclusion and Promotion of the Rights of People with Disabilities, approved in 2012, outlines a number of focus areas to support the realization of rights of people with disabilities in the country, including health which is highlighted as a specific pillar of action. Further, a cross-ministerial National Action Plan for People with Disabilities (2014-2018) has been developed to progress implementation of this Policy, however it is yet to be approved[25]. In the domain of health, the National Action Plan identifies actions for the Ministry of Health to further the National Policy strategy to "ensure that people with disabilities may obtain the services provided by health professionals...in an equitable manner"[26].

Women with disabilities and MNH services

A study was conducted in 2013 which investigated the access to mainstream and disability specific health services for people with disabilities in Timor-Leste[27]. The study highlighted a number of strengths which provided the potential to leverage off for improving access, including the Government's endorsement of the National Policy in 2012, commitment by the MoH to progress

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[viii] The CRPD compels states to provide equal access to gender sensitive health care and related services for people with disabilities (Article 25), to ensure the rights and empowerment of women (Article 6), including the rights to bodily integrity (Article 17) and to family (Article 23)

disability inclusion and the existence of Ra'es Hadomi Timor Oan's (RHTO)[ix] network of district based field officers. However, overall, people with disabilities were found to experience a number of barriers to healthcare such as attitudes of health care workers and inaccessible health facilities. Additionally, Timor-Leste disabled people's organisations have highlighted some of the specific challenges that women and girls with disabilities face in accessing health care, and SRH services in particular, such as "[mistaken] assumptions that people with disability are not sexually active"[28].

In relation to MNH services, consideration of disability is included in the National Strategy on Reproductive, Maternal, Newborn, Child and Adolescent Health (RMNCAH) 2015-2019[29] which incorporates concerns to address the health needs of marginalised groups, including people with disabilities[x]. However civil society organisations have argued that governmental frameworks relating to the rights of women require increased attention to "the specific multiple and intersectional discrimination women with disabilities face"[30]. In this regard, the RMNCAH Strategy highlights the need for research in various aspects of MNH to support "strategic decision making for improving services"[31] and it is hoped the present study will contribute to this.

1.4 Methodology

This research was developed and implemented by the CBM-Nossal Partnership for Disability Inclusive Development, together with Ra'es Hadomi Timor Oan (RHTO), a national Disabled People's Organisation (DPO) in Timor-Leste. Fieldwork was implemented in Timor-Leste in September 2015. Qualitative data were collected using key informant interviews, in-depth interviews and focus group discussions. A total of 29 participants were purposively selected through the networks of RHTO and the Timor-Leste Ministry of Health (MoH). Participants included MNH service providers (midwives and doctors) and women with disabilities.

Aims and objectives

The aim of this research was to explore the knowledge, attitudes and practices of MNH service providers in providing services to women with disabilities in Timor-Leste. The specific objectives were:

1. To investigate MNH service providers’ knowledge, attitudes and practices in provision of services for women with disabilities.
2. To explore the experiences of women with disabilities in accessing MNH services.
3. To investigate barriers and enablers to accessing MNH services by women with disabilities.
4. To explore MNH service providers experience in providing care to newborns identified as having an impairment.

Study Design

The study design was primarily qualitative: a flexible approach useful for exploratory research, involving a range of stakeholders and utilising semi-structured question guides to explore objectives relevant to each respondent. This approach permitted an in-depth examination of current levels of disability inclusion in MNH care, explanations for barriers and enablers, and discussions on potential ways to strengthen disability inclusion within these services.

[ix] RHTO is the national disabled people's organisation in Timor-Leste. RHTO represents and advocates for the rights of people with disability. RHTO works with government, partners in the disability sector, public and private organisations, civil society, and the broader development sector, in order to support and improve the inclusion of and access to human rights of People with Disability. For more information about RHTO please visit their website: http://dpo-rhto.wixsite.com/timor

[x] The RMNCAH Strategy references disability as follows:
- "Address special needs of marginalized children, e.g. children with different ability" (p. 32)
- "Expand access to quality family planning services to reach the unreached and to address special needs of various segments of communities. The key activities are...vii) address special needs for family planning services for special groups...[including] those with different abilities" (p. 55)
- "Reproductive health needs of adolescents, men and people with different abilities require special attention" (p. 62)

Location
The study was conducted in the districts of Dili, which contains the urbanised capital of the country (Dili) and Ermera, situated approximately 60 kilometres from Dili in a rural mountainous region. These locations were chosen to capture the variation of factors relating to access to MNH services across urban and rural settings.

Interview structure
All participants were asked to participate in an in-depth interview or group discussion which took approximately 60-90 minutes. Interview guides were developed by the CBM-Nossal research team, in consultation with RHTO. Guides were then translated into Tetun, the local language, and reviewed by RHTO. Guides covered a range of considerations regarding participant's perceptions of the intersection of disability and MNH services and systems. Interviews were conducted face-to-face by a CBM-Nossal staff member with the support of a Tetun interpreter. Focus group discussions were facilitated by an RHTO staff member in Tetun. All were digitally recorded, transcribed and translated into English for thematic analysis.

Participants and their recruitment
Participants were recruited purposively in consultation with the MoH and RHTO (Table 1). Key informants participated in in-depth interviews and comprised representatives from the Ministry of Health (n=2), health professional associations (n=1), disability organisations (n=1) and disabled peoples organisations (n=1). In-depth interviews were conducted with ten MNH service providers whose ages ranged from 29 to 47 years old (median=38) and included midwives (n=8) and doctors (n=2) in Dili and Ermera based in either community health centres or the National Hospital. Amongst key informants and service providers there was one male, with the remainder (n=14) being female.

Women with disabilities, who had been pregnant in the last five years, participated in either an in-depth interview or focus group discussion. Their ages ranged from 25 to 45 years old (median=31). As identified through self-report, of these women, two were blind, one had a psychosocial disability, one had multiple disabilities and ten had physical disabilities. In-depth interviews were conducted with five women with disabilities and two focus group discussions; one in Dili with four women and one in Ermera with five women (Table 1).

Table 1. Interview sample

Location	Method	Participants		
		Women with disabilities	Key Informants	Service Providers
Dili	In-depth interviews	3	4*	6
Dili	Focus group discussions	1 (4 participants)	-	-
Ermera	In-depth interviews	2	1	4
Ermera	Focus group discussions	1 (5 participants)	-	-

*One key informant was a woman with disability.

Analysis
Interview and focus group discussion transcripts were coded and analysed to develop an iterative thematic analysis developed collaboratively by the CBM-Nossal staff member who conducted the interviews and the Principal Investigator. A workshop was conducted by CBM-Nossal staff members in Dili in February 2016 to review draft findings with disability and MNH stakeholders and feedback received during the workshop has been incorporated.

Ethics

Ethics approval was obtained from The University of Melbourne Human Research Ethics Committee in Australia. Approval in Timor-Leste was received through the Research Technical Committee of the National Institute of Health.

Limitations

The research was conducted in a short timeframe and with limited resources, leading to a small sample size. As such, despite efforts made to ensure people with different types of impairments were included in the sample, it was difficult to ensure adequate representation of all groups. In particular, women with intellectual disabilities and women who are deaf or hard of hearing were not directly interviewed. Furthermore, women without disabilities were not interviewed to provide a basis for comparison about the experience of MNH services. Finally, the families of children with congenital[xi] impairments were not interviewed about their experience of accessing PNC services. Future research could aim to address these limitations.

[xi] 'Congenital' refers to a condition that a person is born with

2. FINDINGS

Findings highlight a range of factors influencing the access to MNH services for women with disabilities in Timor-Leste. The understanding of service providers in relation to disability is first outlined, followed by their perceptions on the MNH needs of women with disabilities, as well as findings relating to women with disabilities' reported access to MNH services across the continuum of care. Specific barriers and enablers to women with disabilities accessing MNH services are then described.

2.1 PERCEPTIONS AND UNDERSTANDING OF DISABILITY

It is useful to understand how service providers perceive and understand disability and the MNH needs and rights of women with disabilities as this impacts service provision practices[32]. Service providers' understanding of disability are explored in this section. How this may have influenced the provision of services for women with disabilities is discussed throughout this report.

2.1.1 Language associated with disability

Language used by service providers in both Dili and Ermera to describe disability was reflective of the medical and charitable approaches towards disability[xii]. For example, service providers often differentiated between women with and without disability as a dichotomy between normal and abnormal.

> *"In the health context I think disability people are people who have incomplete body parts or are abnormal"* (Service Provider, Ermera)

Language was variously evocative of sympathy, notions of dependency and vulnerability with one service provider in Ermera reflecting that people with disabilities *"are the one who cannot do anything without other people helping"*. Language used by some service providers in relation to psychosocial disability was particularly negative, with a small number of service providers referring to women with psychosocial disability as "crazy".

2.1.2 Service provider perceptions of relationships between impairments, barriers and disability

The majority of service providers perceived disability to be primarily related to physical impairment, and to a lesser extent, visual impairment. When asked to recall experiences of providing services to women with disabilities, service providers most frequently recalled examples of interactions with women with physical or visual impairment. This was also evident in their perceptions of what is meant by disability which tended to emphasise impairment related issues.

> *"When we talk about disability it means...some part of their body is not functioning well for example eyes [or] hands"* (Service Provider, Ermera)

Specific prompting on experiences of providing services to women with other types of impairment (such as Deaf or hard of hearing, intellectual or psychosocial), occasionally led to service providers highlighting examples of interacting with women with other types of impairment.

A few service providers conceptualised the 'barriers' to accessing service provision as being a product of the woman's impairment, rather than the result of the interaction of impairments with environmental barriers as per the rights based approach to disability described in section 1.1.

> *"Because of these disabled people's... conditions, it's hard for them to get access to it [health services]"* (Key Informant, Dili)

[xii] From a social and rights based perspective (see section 1.1 "what is disability?"), charitable and medical approaches are disempowering because they view the person with disability as an object of pity and consider that the person needs to be "fixed" before being part of society.

One service provider thus implied the onus was on women with disabilities to "fit in" with the health system.

> *"It's better when they [women with disabilities] are transferred here [to the health facility] along with their own bed, wheel chair and other facilities...so when they arrive here we only support them to push and on how to deliver"* (Service Provider, Dili)

2.2 PERCEPTION OF THE MNH NEEDS AND RIGHTS OF WOMEN WITH DISABILITIES

2.2.1 Non-discrimination

Many service providers recognised that women with disabilities have the same right to health as women without disability. Whilst there was some recognition that women with disability may have greater health needs that require more attention to achieve equitable outcomes, most service providers did not want to discriminate between women with and without disabilities in terms of service delivery.

> *"We don't forget to attend all the people, we don't see whether these people have disability or not. Everyone gets the same treatment"* (Service Provider, Ermera)

Some linked the imperative for non-discriminatory treatment back to the Constitution and to professional codes of ethics that enshrine the need to treat everyone equally.

> *"As health professionals...after studying we have to take an oath saying we have to take good care of every patient"* (Key Informant, Dili)

One service provider felt providing additional assistance to women with disabilities to access services, represented 'favourable treatment', which was perceived to be discriminatory as opposed to being a means for equalising opportunities to accessing health services.

2.2.2 Sexuality of women with disabilities

The misperception that women with disabilities are asexual was evident among some of the service providers and community members. In one example a service provider described her disbelief during her first interaction with a women with a vision impairment who was pregnant.

> *"We had a patient, two of them - both of them are blind. So, in their [staff's] mind maybe they are thinking how they did it, the sex. Of course the first time we [staff] think like that, how?... how they [people with disabilities] did it we don't know"* (Service Provider, Dili)

This was triangulated by reports from women with disabilities interviewed in both Dili and Ermera, who described the assumptions that many service providers, families and community members have about the sexuality of women with disabilities, with examples shared that highlighted community surprise when a woman with disability identified as being pregnant.

> *"The community feel surprised [and] they might wonder why disability people are pregnant or have their own family"* (Woman with disabilities, Dili)

2.2.3 The right to have children

Women with disabilities expressed their right to have children, and this view was supported by a small number of service providers.

> *"People who have disability...I don't think they are different with people who don't have disability, they have [a] right to...have children"* (Woman with disabilities, Dili)

> *"If they [women with disabilities]...want to have a baby, it's their own right to do that"* (Service Provider, Dili)

Several women with disabilities reflected that they themselves, or their families, viewed their capacity to bear children as not only a source of pride, but as an important part of being a woman in Timor-Leste.

> *"Some family members, will be feeling proud [about their relative with a disability bearing children]"* (Woman with disability, Dili)

This is consistent with literature reflecting that for women with disabilities, pregnancy affirms their identity as a woman and confers agency on a person "otherwise viewed only as a dependent"[33].

Having children was also highlighted by some women with disabilities as a 'necessity'. It was difficult to know if this is similar to all women, or particular to women with disabilities to ensure they had someone who could support them if they experienced functional limitations arising from their impairment or barriers in the environment.

> *"This is what I want, why I want to have so many children - so that they could help me. I don't want to have one or two children, I want many children to help me"* (Woman with disabilities, Dili)

Some service providers and women with disabilities did reflect that some women may need assistance with child care related duties.

2.2.4 Perception of capacity to care for children

Similar to reactions recalled regarding surprise at women with disabilities becoming pregnant, women with disabilities recalled community concern regarding their parenting capacity.

> *"The community's attitudes [are] that they wonder about us as blind people...post birth on how we could take a bath for the baby, dress and all. On how we are being responsible or not. These become questions from the community to disabled people"* (Woman with disabilities, Dili)

These misperceptions of community members appeared to have a very negative impact on one woman with disability's belief in her capacity to look after her children. When compounded by a fear that she would pass on her disability to her unborn children, or that her impairment would negatively impact on her delivery, she expressed a desire to abort her pregnancies. This woman did not have access to family planning information or services, or support to help her understand that women with many types of disabilities are able to safely deliver and parent children.

> *"So, when I get pregnant...I start [to] stress out because of my legs. So I have bad thoughts to kill the child...I have so many concerns like how to raise the baby, how to deliver the baby with my condition...so when I'm pregnant I'd like to do abortion to the baby"* (Woman with disabilities, Ermera)

Whilst service providers interviewed in this study did not express these views, they may be influenced by broader community perceptions, which in turn may influence their practice.

Some women with disabilities reported that service providers actively discouraged them from having more children.

> *"After delivering the baby [the service provider said] 'with this condition you just have two children. That's enough don't have more'"* (Woman with disabilities, Dili)

MNH stakeholders suggested[xiii] such a directive by service providers to restrict the number of children was rare in Timor-Leste and thus may just be the unwarranted perception expressed to women with disabilities.

[xiii] A half-day workshop was held with several MNH stakeholders in February 2016 to present and seek feedback on draft research findings.

In the face of these comments from service providers, some women with disabilities found they needed to defend their right to have children.

> *"But I responded to them [service providers] I carried them [children] in my body not theirs. This is what I want"* (Woman with disabilities, Dili)

There were also examples whereby the right of women with psychosocial disability to have and parent children, was undermined. A small number of service providers described instances whereby the children of women with psychosocial disabilities were removed from their mothers.

> *"After [the woman with psychosocial disabilities] delivered the baby, the family or some other people will take the baby"* (Service Provider, Dili)

One woman with psychosocial disability recounted the experience of having one of her own children taken from her. She linked this to the perception that community members believed she was "mad".

> *"Some of the families they saw me taking my baby to hospital many times [for health treatment] so they thought maybe I am mad because I'm...taking my kid every time to the hospital...so they took my baby away from me. They took the baby to [district name] and then I went to police to report and then when the police went there, they hid the kid away from the police and now they just separate me and my kid"* (Woman with disabilities, Dili)

2.2.5 Perceptions of vulnerability to sexual abuse

Service providers perceived women with disabilities to be vulnerable to sexual harassment and abuse, particularly women who are Deaf or hard of hearing, women with communication difficulties and women with psychosocial disabilities.

> *"You know women with disabilities - many men would like to do sexual harassment to them"* (Service Provider, Dili)

Several service providers also described examples of providing services to women with disabilities whose pregnancies they suspected to be the result of sexual abuse. Reasons why service providers presumed pregnancies among women with disabilities were the result of sexual abuse were not specified or evidenced.

Service providers associated pregnancy from sexual abuse more frequently with women with psychosocial disabilities. Again whether this is based on evidence or perception is not able to be determined from the findings.

> *"And you know one who is like that [woman with psychosocial disabilities] she had five babies. But this all is sexual abuse...they are all because of sexual abuse"* (Service Provider, Dili)

One service provider felt that the impact of pregnancy as a result of sexual abuse may make women with disabilities more embarrassed to seek health services, and that this could mean they were missing out on information and support for family planning, pregnancy, childbirth and parenting.

2.3 EXPERIENCE PROVIDING SERVICES TO WOMEN WITH DISABILITIES

Service providers described a broad array of experiences, in providing services for women with disabilities across the continuum of care, including antenatal care, childbirth and postnatal care.

2.3.1 Provision of services to women with disabilities

Service providers in Dili did report providing services to women with disabilities and most were able to recall multiple experiences, with one midwife estimating she may see up to three women with disabilities per month.

Service providers in Ermera reported experiences of directly providing services to women with disabilities less frequently, with some not being able to recall a single case. This may be related to years practising, as service providers with less experience were less likely to report having provided services to women with disabilities.

Some service providers speculated that the low number of women with disabilities they have seen might be related to shift roster patterns and that the overall number of women with disabilities seen at a given clinic may be higher than what just they have seen on their particular roster.

Of the service providers in supervisory or senior roles interviewed, one reported she had no experience with women with disabilities, while the other reported having experience some time ago when she was directly providing services, but no recent experience to draw on. Linked to this, a junior service provider reported that one strategy she felt would improve understanding of how to provide 'treatment' for women with disabilities, would be to seek advice from her superiors, yet these were the same superiors who themselves reported limited experience.

2.3.2 Experience providing services to women with different types of impairment

Service providers reported providing MNH services to women with a diverse range of impairments, though most commonly to women with physical disabilities. When further prompted, some service providers went on to describe providing services for women with other types of impairments or health conditions such as women with epilepsy, psychosocial disabilities, women of small stature, women with speech impairments, women who are Deaf or hard of hearing, women with intellectual impairments, vision impairments, and women with fistulas.

Some service providers in Dili reflected that they have only seen women who they perceived as having "mild" disabilities at the clinic, possibly indicating that those with more significant impairments may not access facility-based health services.

> *"We haven't faced people who couldn't walk at all, we just met people who can walk but only one of their feet was disabled"* (Service Provider, Dili)

Perceptions of women with psychosocial disabilities focussed on the perception that people with psychosocial disabilities may be more likely to exhibit aggressive behaviour, and be less compliant in following the advice of service providers.

> *"So women who have mental illness, it is hard for the midwives to help them because they are scared because of her condition. It's scary - maybe when they want to help her...she will throw stones to them"* (Key Informant, Dili)

Service providers and key informants in Dili also perceived women with psychosocial disabilities were less likely to be living within the family home, with less access to appropriate and supportive MNH services.

> *"There's one mentally ill woman who is...just sleeping on the road, and she was pregnant, about to deliver the baby, and the police guys just came and took her to the hospital to deliver the baby"* (Key Informant, Dili)

2.3.3 Including women with disabilities in mainstream services

Some service providers interviewed felt that women with disabilities could not be appropriately supported within mainstream health services and required 'special programs'. In some interviews, this seemed to be related to the perception that responding to the MNH needs of women with disabilities required additional skills which service providers did not have, or should not be responsible for.

> *"So like this kind of thing [fistula] we can do referral because it is part of our job to look after the mother and child health but for people with disability...maybe some other department will look after that"* (Key Informant, Ermera)
>
> *"For me it's important to have [disability] training for us [service providers] from Ministry of Health but it's better if Ministry of Health arranges [a] special place for women with disability who*

> *are pregnant to check up. They cannot be treated the same with normal pregnant women"* (Service Provider, Dili)

Another service provider reported pregnant women with disabilities should receive priority care within mainstream MNH services.

> *"So we will...put them in priority or make them more special"* (Service Provider, Ermera)

2.3.4 Practices to support disability inclusion

Identification of women's disability status

When service providers were asked how they knew whether a female patient had a disability, some reported that they undertook a thorough examination process; with some also indicating there is a form they use to identify the type of disability, though what form this is was not verified during the research. However, many reported they relied on visual observation only (as opposed to asking) and one service provider reported health personnel might not know if women visiting health services have a disability.

> *"Women with disability, I just see their physical condition, there is no other way to tell if she is disabled"* (Service Provider, Dili)
>
> *"Maybe the women come here but we don't identify this woman as a disabled woman"* (Service Provider, Dili)

A small number of service providers reported they do not record disability status of women presenting for family planning and MNH services. However, several other service providers reported that they did record disability status of female patients in general medical notes, including more specifically in forms pertaining to what kinds of allergies the woman has, as well as in referral letters. One service provider explained how she recorded this to ensure information about disability status was consistently used by other service providers.

> *"We put in notes this woman has a disability...and when we handover to a different shift...then we pass on verbally the information about how to treat and the type of disability"* (Service Provider, Dili)

Further investigation would be needed to understand how disability status information recorded by service providers is used by them to direct responding to any specific MNH needs of women with disabilities. Additionally, no service providers reported that disability data was collected for monitoring and evaluation purposes.

Referral practices

Consistent throughout most service providers' responses was a tendency to refer upwards from the primary health care system towards secondary and tertiary health services. This may be consistent with practices pertaining to all women, regardless of disability[xiv]. However, service providers gave reasons for these referral practices which were frequently linked to the presence of impairment (including hearing and communication impairments) suggesting service providers perceive there are reasons specifically related to disability status for referral out of the primary health care system.

One service provider at a community health centre (CHC) recalled a case where health post staff referred a Deaf woman who was pregnant to the CHC as the health post staff did not know how to communicate with her. A similar story was reported by a key informant when she described interactions with women who are Deaf or hard of hearing and women with psychosocial disabilities and stated:

> *"If it is hard to communicate with them then we will just [do] referral to the National Hospital or referral hospital in the district"* (Key Informant, Dili)

[xiv] MNH stakeholders provided feedback to this effect during a half-day workshop with several MNH stakeholders conducted in February 2016 to present and seek feedback on draft research findings.

These referral practices highlighted the assumption that staff at the National Hospital have more expertise in communicating with women who are Deaf or hard of hearing. However, National Hospital service providers interviewed described they also did not always have the skills to adequately communicate with women with communication impairments.

One service provider in Ermera linked the referral of women with disabilities to Dili with the perception that women with disabilities would require a caesarean delivery, which is more readily available in Dili. Other reasons service providers gave for why they may refer women with disabilities included concern for safe delivery.

> *"Because some women are dwarf so it is hard for them to deliver the baby at the CHC so they [service providers] do referral to referral hospital"* (Key Informant, Dili)

The implications of referral of women with disabilities to Dili from rural areas was an issue identified by a couple of service providers in Ermera. One noted that referral to Dili results in a disruption of the continuum of care. Another argued that women with disabilities might be reluctant to travel to Dili for childbirth due to limited finances, transport options, fear of bad treatment at the National Hospital and a lack of social support in Dili. It should be noted that these reasons were highlighted as barriers for women without disabilities as well.

Service providers' knowledge of disability services to refer women with disabilities for additional support, if required, was generally low, though a couple of service providers were aware of PRADET[xv] mental health programming and the National Rehabilitation Centre. No service providers were aware of any DPOs.

2.4 ACCESS ACROSS THE CONTINUUM OF CARE

Except for one woman with disabilities from Ermera who had not heard of the term "maternal and child health", all other women with disabilities interviewed generally demonstrated knowledge of the concept of MCH services and the importance of accessing them. However this knowledge manifested in varying levels of access to services across the continuum of care which are examined in this section.

2.4.1 Family Planning

Family planning entry points, knowledge and methods

A couple of service providers and most women with disabilities who received information from service providers about family planning noted this occurred after the birth of a woman's first child. One service provider noted this was similar for women without disabilities.

Barriers to accessing facility based health services (see Section 2.5) indicate family planning programs relying on women coming to health centres may be ineffective for some women with disabilities. Several women with disabilities highlighted they had no access to "modern" family planning information and methods.

> *"To stop having baby...I used many traditional medicines but I couldn't stop having children"* (Woman with disabilities, Ermera)

One woman with disabilities who did regularly present at a health centre, described how she was not provided with any information on family planning, however the reasons for this were not explored.

> *"Because at the hospital [after birth] they just explained to us if we wanted to get family planning. But if we just go [and] get medical treatment regularly, then they wouldn't tell me [information about family planning]"* (Woman with disabilities, Dili)

Nevertheless, many women with disabilities did reflect that they were aware of the need to space children. Responses indicated information related to family planning came variously from family or

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[xv] PRADET (Psychosocial Recovery and Development East Timor) is an NGO psychosocial service for people who are experiencing trauma, mental illness and other psychosocial problems in East Timor.

community members as well as health service providers. One key informant, a woman with disabilities, noted a rural/urban disparity in ease of access to family planning information for women with disabilities.

> *"In Dili it is easy to get [family planning] information because people are telling around the other people, so it's easy for people with disabilities here. But in rural areas or in the districts it's hard for them to get this information"* (Key Informant, Dili)

A couple of women with disabilities described their families were very supportive of them availing of family planning information and services. However some women with disabilities described how family members influenced or pressured their decision to cease family planning which is not uncommon amongst women generally in Timor-Leste given evidence indicates "that the high prevalence of marital control in Timor-Leste could undermine family planning"[34].

> *"My first daughter died so my husband's family prevent me to do this [family planning] program"* (Woman with disabilities, Dili)

Methods of family planning offered to women with disabilities were not specifically explored with service providers. However various methods were mentioned by women with disabilities including injection, implant, intra-uterine devices and the rhythm method. Use of condoms and the contraceptive pill were not mentioned.

Sterilisation

Sterilisation was reported by some research participants as some service providers' preferred method of family planning for women with some types of disabilities rather than less invasive and non-permanent approaches. It was reported by a service provider that family members of women with some types of disabilities request medical staff to perform a tubal ligation on their family member although this service provider also reported proactively offering this as an option to the family of a woman with psychosocial disabilities. In a case recalled by this service provider, when asked about the role of the woman with disabilities in the decision making process she noted:

> *"No, they [women with disabilities] just keep quiet, they didn't say any word, they only follow what the family say...because with her condition like that, why not do the bilateral tubal ligation so as to not continue to have more pregnancies"* (Service Provider, Dili)

This indicates in some situations sterilisation is the first method for family planning considered, and given reported acceptance of the family decision for sterilisation as a proxy for the woman's own consent, it is possible that informed consent for sterilisation may not have been obtained. Sterilisations performed in the absence of informed consent are considered as forced sterilisation[xvi].

Two women with disabilities in Dili and Ermera also tearfully reflected on their own sterilisations and described their reluctance to be sterilised.

> *"They [service providers] just talk about the delivery [by caesarean surgery] and whether I could still have children. They ask me to do sterilisation but I still feel that I can have more children that's why I don't want it...the doctor explained to me rudely"(Woman with disability, Dili)*

Women explained that the recommendation for sterilisation was tied in each case to the perceived risk posed to their health of having more caesarean surgeries. This suggests that sterilisation may be more necessary in the view of some service providers for women with disabilities to avoid undergoing numerous caesarean deliveries which were viewed as necessary because they had a disability (see section 2.5.3 of this report).

[xvi] For further information about forced sterilisation, please see the World Health Organisation's Interagency Statement on 'Eliminating forced, coercive and otherwise involuntary sterilization', 2014, available from: http://www.who.int/reproductivehealth/publications/gender_rights/eliminating-forced-sterilization/en/

2.4.2 Antenatal Care

Regular access to antenatal care (ANC) was more commonly reported amongst Dili based women with disabilities. Women with disabilities in Ermera reported a number of barriers to accessing MNH services which are reported in greater detail in section 2.5 of this report.

One woman said she felt it was very important to seek ANC due to her disability in order to establish if the childbirth process would be impacted by her impairment. Others reported that they had received ANC that was of good quality.

> *"For my last child I went to [the] health centre to get the treatment. I feel that the midwife gave me very good treatment starting first month to the eighth month until the baby was born"* (Woman with disabilities, Dili)

Another woman with psychosocial disabilities described the confusion she was confronted with whilst pregnant, when trying to obtain advice about whether she could continue her psychiatric medication during pregnancy. She expressed a belief that because she did not receive timely advice about potential contraindications of psychiatric medication with pregnancy and continued to take the medication during pregnancy, that it may have contributed to her child's congenital disability. Another couple of women with disabilities reflected that their motivation to access ANC did not relate to concerns linked to their disability, but was situated in a range of concerns that many women may have about first-time pregnancies.

2.4.3 Childbirth

Access to skilled care at birth

One key informant reported that 30 per cent of Timorese women access skilled care at birth. National statistics regarding skilled care at birth are not currently disaggregated by disability so it is not possible to quantify if and how women with disabilities access skilled care at birth. Whilst this key informant felt most women with disabilities would utilise traditional birth attendants (TBAs), many of the service providers interviewed for this study, especially in Dili, did provide examples of providing assistance to women with disabilities during childbirth indicating some women with disabilities do have access to skilled care at birth in Dili.

Women with disabilities interviewed in this study also reported that they felt facility based birth with skilled assistance was important. This was more evident amongst Dili based women, but also reported by some women in Ermera. Most Dili based women with disabilities reported accessing skilled care at birth for at least some of their pregnancies. However, women with disabilities from Ermera predominantly reported delivering at home, many with assistance from their husbands and in the case of one woman with disabilities, delivering alone.

> *"Eight of them delivered at home...at the time of labor, just my husband and I were at home to deliver the baby...but maybe with God's help because I don't go to hospital and I don't take any medicine"* (Woman with disabilities, Ermera, describing delivering her eight children)
>
> *"No [help from family] at the time of delivery, I just delivered myself and alone"* (Woman with disabilities, Ermera)

Two women with disabilities from Dili and Ermera recalled experiences of their newborns passing away shortly after delivery. For a woman with disabilities in Dili this provided strong motivation to seek skilled care at birth for her subsequent childbirths. However for one woman with disability in Ermera who had lost her newborn shortly after delivery, she felt the barriers to accessing skilled care at birth were still insurmountable and did not access skilled care for her subsequent deliveries.

This seemed to be reflective of the situation more broadly in Timor-Leste where coverage of skilled care at birth overwhelmingly favours Dili, with disparities across much of the country outside of Dili[35].

In a subsequent workshop with MNH stakeholders, Ermera was highlighted to have a particularly low number of skilled birth assistants compared to other districts[36].

One service provider described using physical restraint on a woman with psychosocial disabilities during and after childbirth, as she was perceived to want to kill her newborn baby. While this specific situation was not clearly described in the interview, the service provider indicated the practice of restraining women with psychosocial disability may be more widespread than the example shared:

> *"This is the method [tying feet and hands] that we use here for women who have mental illness or are very crazy in the time of delivery because here there is not a mental illness hospital"* (Service Provider, Dili)

Modality of birth

Service provider comments sometimes assumed incapacity of women with disabilities to have a vaginal delivery and suggested a generalised approach to requesting caesarean surgery not necessarily bound in clinical necessity.

> *"When the doctor sees this congenital [disability] condition, the only option that we take is caesarean operation because they are not able to deliver normally"* (Service Provider, Dili)

This generalisation was mentioned largely in relation to women with physical disabilities, with several service providers commenting that women with vision impairments would be able to deliver naturally as they still have *"complete hands and feet"* (Service Provider, Dili). However several service providers indicated undertaking full examinations of women during ANC visits to ascertain the safest birth modality.

Two out of 15 research participants with disabilities reported they gave birth via caesarean section, with several others reflecting that service providers strongly encouraged them to give birth via caesarean-section whilst they argued to deliver naturally.

> *"What they [service providers] have in mind is how to do surgery for me to deliver the baby...The reason was because I'm with disabilities so they thought I couldn't have much energy to deliver the baby. That was the reason...but in my own willing I want to give birth naturally [and] at the end I did it"* (Key Informant, Dili)

2.4.4 Postnatal Care

Many women with disabilities in Dili described accessing PNC for their newborns, either independently or with family support.

> *"Every month I got a vaccination for the baby until she is getting nine months old and if there is a...malaria campaign, then I took the baby to the health facility to get it"* (Woman with disabilities, Dili)

This was in contrast to some women in Ermera, who generally described not accessing PNC for their newborn or that access was delayed. Some women described being embarrassed to access PNC due to having disabilities and difficulties in carrying their children due to their impairment.

> *"I have difficulties walking with the youngest one so I don't go [to the health centre]"* (Woman with disability, Ermera)

In the absence of family support, this meant the newborns of some women did not access PNC. This is reflective of national statistics which note the greater likelihood of newborns in urban areas receiving PNC[37].

2.5 BARRIERS TO ACCESSING MNH SERVICES FOR WOMEN WITH DISABILITIES

'Access' considers not only the ability to reach a health service, but also the quality and disability inclusiveness of the service for those who have been able to reach it. Interviews with most service providers demonstrated they were cognizant of many issues that might prevent women with disabilities from accessing quality MNH services. Many of these correspond with barriers identified by women with disabilities themselves and hence demonstrate the capacity of some service providers to identify with the situation experienced by many women with disabilities.

2.5.1 Physical Barriers

Geography, distance and transportation

Several service providers identified that geography, distance to health facilities and limited transportation were key issues impacting women with disabilities' service access.

> *"If they cannot walk to health posts, then they will go to SISCa...but they don't go [there] either because of the geographic condition of Timor-Leste"* (Key Informant, Dili)

This was also a common finding amongst participants with disabilities who highlighted the mountainous terrain, monsoonal rains and distance to health facilities as considerable barriers to accessing health services. While these may also create barriers for women without disabilities, they are compounded for many women with disabilities, particularly in rural areas, by the interaction of their particular impairments with these environmental barriers, as reflected by this service provider:

> *"Maybe sometimes it [health centre] is far [and] sometimes with their condition [disability]...it is hard for them to walk"* (Service Provider, Ermera)

This difficulty could impact women with a variety of impairments that impact mobility and way-finding, including physical, visual, intellectual and mental impairments. Mobility difficulties led to greater reliance on transport, and due to very limited, accessible and affordable transport options, particularly in rural areas, women with disabilities' difficulties in accessing MNH services were compounded. Some women with disabilities in both Dili and Ermera reflected on difficulties accessing transport including ambulances in situations of planned delivery or in the event of an emergency.

> *"We think that there is no ambulance. They [ambulance service] tell us to find another vehicle by ourselves to go to Dili. Patiently, we have to find [transport] on our own"* (Woman with disabilities, Ermera)

The financial burden that this was reported to place on women with disabilities is explored further in section 2.5.3 of this report.

Health facilities and equipment

Other physical barriers preventing women with disabilities from obtaining a quality service included inappropriate equipment. Service providers and women with disabilities both commented on the use of beds ill-suited to the functional abilities of some women with disabilities.

> *"In hospital, the bed is high so we have to take a chair to climb and it's slippery...I think they [midwives] were rude because they say "you know how to make a baby, you know how to be pregnant so you have to know how to get up on the bed"...I was sad"* (Woman with disabilities, Dili)

The comments of this woman with disabilities also speak to the negative attitudes of some service providers towards women with disabilities. These are explored further in section 2.6.4 of this report. Other physical barriers described by women with disabilities included the number of stairs in facilities and the lack of ramps, lack of way-finding indicators for women with vision impairments, narrow door widths and limited circulation spaces in health facilities.

> *"There is a challenge when we enter the door to do the consultation...it's so hard to move the wheelchair inside because the room is small"* (Woman with disabilities, Dili)

Finally, a couple of women with disabilities specifically reflected on how lack of wheelchairs in health facilities or service provider reluctance to provide available wheelchairs reduced the quality of MNH services.

> *"It's a big problem for us women with disability to walk by our self when we're pregnant because you know it's kind of heavy and when we get to the hospital there is no wheelchairs to carry us to the room for delivery"* (Woman with disabilities, Dili)

2.5.2 Communication Barriers

Verbal and visual communication barriers were frequently noted by both service providers and women with disabilities. These barriers indicated low resourcing and limited skills of some service providers to adapt their messages for people with communication impairments. Particular difficulty in communicating with women who are Deaf or hard of hearing was noted by several service providers and a key informant.

> *"There are a lot of people who don't understand their language [of people who are Deaf or hard of hearing], that is number one, language barrier...so if there is [sign] language barrier, then there is difficulty of giving services, or the success of giving services"* (Key Informant, Dili)

Service providers further reported barriers to provision of information about MNH through visual modalities.

> *"For ANC they need the explanations for the babies or their health, and the midwife wants to show the pictures but it's hard because they [women with vision impairment] cannot see...it's hard for them to show the flipcharts and pictures and many other things"* (Key Informant, Ermera)

In addition to noting challenges communicating with and providing information to women who are Deaf or hard of hearing or blind or vision impaired, some service providers perceived difficulties in communicating with women with psychosocial disabilities.

> *"See if the midwife is talking [to] the women with disability who is mentally sick...then it is hard to communicate with them"* (Key Informant, Dili)

These findings are in line with those of similar studies that have noted service providers' difficulties in adapting their communication modalities to suit the needs of women with disabilities[38].

2.5.3 Institutional barriers

A range of institutional level factors that impact on equitable access to MNH services for women with disabilities were discussed by service providers and women with disabilities. These included policies, centralised decision making in the Ministry of Health, lack of data on disability, knowledge and training of service providers, the number and distribution of health staff, and resource constraints.

Knowledge and Awareness of Policy

Some key informants reflected that they did not think there was any particular consideration of women with disabilities within reproductive and MNH policies and programs, with one admitting:

> *"I want to say frankly there's no attention for this"* (Key Informant, Ermera)

A couple of service providers indicated existence of top down approaches to development and implementation of MNH policy. Related comments reflected the centralised nature of health system decision making and the low level of power or influence primary health care professionals felt they had to accommodate different needs of patients.

> *"We are at the base [of the health system]. We cannot...do things by ourselves. So if there is a form to give medical assistance for women with disability then we would do [it]"* (Service Provider, Ermera)

At present, the RMNCAH Strategy 2015 - 2019 does identify inclusion of people with disabilities within concerns for addressing marginalised groups[39]. However it appears centralised processes reflected above may not have facilitated dissemination of this information. This is supported by a primary health care service provider who noted:

> *"Maybe there is something that's already done [about disability] but we don't know it yet"* (Service Provider, Ermera)

Data on disability

Several service providers and key informants regarded that current disability related data, particularly relating to numbers of women with disability, was inadequate and perceived this as a barrier to planning for disability inclusive MNH services.

> *"There is no specific research on disability people. So when the Ministry of Health want to run their program for MCH, they are going to do it in general, so not specific for disabled women, because there is no clear number of women and children with disability"* (Key Informant, Dili)

Further investigation is required to determine why service providers perceive prevalence of disability is important to planning. Lack of these statistics need not be a barrier to commencing development of more disability inclusive policy nor prevent frontline service providers from implementing simple reasonable accommodation[xvii] measures to ensure equity of access for women with disabilities.

Knowledge and training of service providers about disability

The low level of knowledge and training of service providers regarding disability was a significant barrier that emerged from interviews with service providers across both urban and rural areas. Several service providers described that they were confused about how to provide MNH services to women with disabilities and felt unprepared to address their needs.

> *"We have been only giving the treatment to [women who are] normal physically, as sometimes we don't know the techniques to use for them [women with disabilities]"* (Service Provider, Dili)

A key informant representing women with disabilities corroborated the views of service providers:

> *"I want to repeat it, health people are not really knowledgeable about how to treat women with disabilities, especially their type of disabilities"* (Key Informant, Dili)

This lack of knowledge and confidence to provide services can be correlated with the almost unanimous agreement across service providers that they had not received any information or training about disability more broadly, let alone MNH needs of women with disabilities. It was also reported by one key informant that limited support from the MoH meant that disability was not adequately addressed in pre-service midwifery education. One doctor did report that some training was received in the pre-service medical training in Cuba about rehabilitation for people with disabilities. This was not a view reflected by midwives regarding their pre-service training, though a small number reported that NGOs had provided them with some information about disability issues.

A couple of service providers with a greater length of midwifery experience noted that though they haven't had formal training regarding disability, the length of their experience supplemented this, as they have had the opportunity to work with patients with disabilities and learn from these experiences. However, even these long serving midwives indicated the positive contribution formal training would have in building their confidence to better meet the needs of women with disabilities.

Financial barriers

A couple of service providers reflected that the economic circumstances of women with disabilities might make it difficult for them to access health services. This was also mentioned by women with disabilities, though almost exclusively by those in Ermera. Some of these women's stories highlighted the extreme financial difficulties experienced by some families with members with disabilities which aligns with the well documented link between poverty and disability[40]. Women with disabilities in Ermera noted costs incurred when accessing MNH services further compounded financial difficulties due to lost earnings by taking time out from livelihood activities to seek health care. Another woman

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[xvii] Reasonable accommodation means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights (Article 2, CRPD).

noted the opportunity-cost of spending money on transport for a facility-based childbirth versus purchasing essential items such as food for her other children.

The high cost of transport to reach secondary or tertiary health facilities to which women with disabilities were often referred was also attributed to creating barriers to services.

> *"Family is the one to pay the transport. When we are pregnant for one or two months we have prepared some money until the baby is nine months, little by little. When we delivered at hospital, we paid transportation by our own...one way is $5 so for two ways it is $10 (USD)"* (Woman with disabilities, Ermera)

Availability of services

Several service providers commented that there was an inadequate number of health professionals and their geographic distribution may lead to inadequate time to provide quality care to women with disabilities who may visit health facilities.

> *"I don't want to say that people [service providers] are not patient enough to take care of these women [with disability] but that maybe they are just too busy"* (Key Informant, Dili)

This is consistent with findings of the 2015 Health Worker Survey in Timor-Leste which found despite an unclear correlation between workload and feelings of overload, almost half of the respondents agreed they had 'too much work to do'[41]. While this may impact all women, in situations where women with disabilities require additional assistance, perceived high workload burdens reported by service providers may prevent them from providing sufficient time to meet the needs of women with disabilities, potentially resulting in reduced quality of service.

Additionally, one key informant noted that while doctors can visit patients in their homes, which is a useful strategy to reach pregnant women with disabilities, due to the current distribution of health professionals this does not always occur. This may further decrease the likelihood that women will access skilled care at birth.

From women with disabilities' perspective, human resource constraints were highlighted with examples of long waiting times and limited contact with health professionals. Whilst this could be the experience of all women, it appeared to exacerbate difficulties in accessing services for women with impairments that impacted their mobility.

> *"In...the health centre, it's so difficult for us to register our names, we have to wait for so long until our hips turn bad. We [are] already sick with the illness then we have to suffer again with our hips because we have to wait too long. We should [get to] register our name faster to get the medical treatment"* (Woman with disabilities, Dili)

2.5.4 Attitudinal Barriers

Interviews with service providers and women with disabilities revealed various negative attitudes and presumptions about women with disabilities. This was situated in descriptions of broader family and community attitudes, including the internalisation of these by some women with disabilities themselves.

Service provider attitudes

Evidence of generally negative attitudes towards women with disabilities by service providers was provided by many participants, with one key informant noting:

> *"Sometimes they [service providers] see these disabled people [and] they don't want to take care of them, or they don't even want to treat them"* (Key Informant, Dili)

Similarly a woman with disabilities in Dili stated:

> *"Some midwives will yell at them [women who are blind], say something bad to them, they may do something bad that the women with disabilities don't see. With a lot of these health people they don't have enough conscience."*

Some service provider's negative attitudes related to women with disabilities are also implied through practises highlighted in the findings such as forced sterilisation, use of physical restraint during labour and use of derogatory terms such as 'crazy' to describe women with psychosocial disability.

Family and community attitudes

Service providers reported that the attitudes of families towards their female relatives with disabilities could also form barriers to accessing health services. This was particularly so if families felt 'shame' and sought to hide family members with disabilities within the home.

> *"Women with disabilities if they're getting pregnant they just stay at home. You know in Timorese culture, actually they [family] are ashamed to bring the woman to Dili for hospital...so they hide them "* (Service Provider, Dili)

One service provider situated this in broader family disregard for relatives with disabilities.

> *"So many times in Timor Leste, the families, the member[s] of family, they don't really support the disabled persons"* (Service Provider, Dili)

Several women with disabilities concurred with this view and indicated how negative family attitudes could also manifest in a lack of practical support for their female relative with disabilities. Conversely, as presented later in this report in section 2.6.4, many women with disabilities also highlighted positive family support was a crucial factor in enabling their access to MNH services.

Women with disabilities' internalised beliefs

Negative social attitudes towards disability can in turn contribute to low self-esteem amongst women with disabilities and "avoidance of potentially difficult situations"[42], including as evidenced in this study, avoiding accessing facility-based health services.

Several service providers believed women with disabilities may have internalised negative views about themselves to the extent they feel too ashamed to venture outside to seek health care.

> *"They cannot come [to the health facility] because some of them are shy with their [disability] condition...[so they] avoid to come to us health personnel "* (Service Provider, Dili)

A couple of women with disabilities in Ermera also noted the impact of internalised negative feelings towards their own disability leading to reluctance to engage with MNH services.

> *"I was shy for myself because I use walking stick. That's why I don't want to go [to health facility]"* (Woman with disabilities, Ermera)

This was also reflected in the distressing story of a woman with disabilities in Ermera, recounted in section 2.3.3, who internalised extremely negative views about her capacity to parent as a woman with disabilities and thus considered abortions for all her pregnancies.

2.6 ENABLERS FOR WOMEN WITH DISABILITIES TO ACCESS MNH SERVICES

Despite the barriers presented in the previous section, most women with disabilities in this study reported previously accessing at least one MNH service, whether it was family planning, ANC, skilled birth assistance or PNC, and for a few women - all of these services were accessed. It is important to examine what factors enabled women to successfully access services. Both women with disabilities and service providers identified practices that supported access and enabling strategies that were already in place within some services, while other strategies were thought to have the potential to improve disability inclusion if implemented.

2.6.1 Enabling strategies to address physical barriers

Providing physical assistance and accessible equipment

Service providers described a range of strategies they undertook to assist women with disabilities whilst accessing MNH services. These demonstrate consideration by midwives of the various support needs of women with disabilities despite not having formal training in disability. A couple of service providers gave examples of providing physical assistance to women with disabilities (potentially at their own physical risk) which supported their access to services.

> *"When they come with [a physical] disability...then we try to lift them up to put them on [the] bed"* (Service Provider, Dili)

Several other service providers described supporting family members of women with disabilities and health professionals to provide women with appropriate physical assistance during childbirth.

> *"Because the left leg was shorter it was difficult for her to place her legs so we needed the husband to help position her legs"* (Service Provider, Dili)

Once at health facilities, difficulty in moving around facilities was discussed by a few service providers. They suggested that having wheelchairs available at health facilities may be useful to help women with disabilities that have mobility difficulties move about the health facility, or to help transfer women from the facility entrance to consultation areas. A couple of women with disabilities also explained that wheelchair availability could support women with mobility difficulties as well as installing way-finding indicators to support the mobility of women with vision impairments.

Outreach services

A dominant theme emerging from the findings with service providers was the role of outreach services to provide MNH care in the home to women with disabilities. One key informant noted the MoH's domiciliary home visiting process (launched in 2015) may assist reaching women with disabilities. Several service providers supported this approach and one reported how staff at a CHC went to great lengths to support a woman with disabilities in this manner.

> *"When she was 4 to 5 months pregnant, they went there one time in one month [to her home], but when the pregnancy got more like 9 months they went there every week until they took her to the hospital. And after she delivered her baby...the midwives still went to her house...to give follow up and immunisations to her kids"* (Service Provider, Dili)

This service provider noted that such an approach was possible because the Director of the CHC scheduled these home visits in staff time. Another service provider from Ermera noted that home visits to women with disabilities would be particularly useful to enhance continuity of care when undertaken by staff from the woman's nearest CHC on her return from delivery in Dili or elsewhere. A woman with disabilities from Ermera suggested that increasing the frequency of SISCa mobile health clinics could also support more timely and continuous health care.

Other outreach strategies, including distribution of informative brochures and use of mobile phone technology were mentioned by some service providers as potential means of overcoming the difficulties women with disabilities may face in coming to health facilities.

Transport arrangements

Several Dili based women with disabilities described how they managed to access microlets[xviii] and taxis to enable timely presentation to health facilities for childbirth. This is reflective of their relative increased agency to access skilled birth assistance compared to women in Ermera.

In Ermera, while a couple of service providers reported use of ambulances to transport women with disabilities to the National Hospital, one Dili based service provider suggested that a patient transport system not reliant on the ambulance service could more efficiently enable timely access to services.

[xviii] Microlets are small vans that make up an informal public transport network

> *"When we meet the patients who have this condition [disability], there should be an arranged car for them so that if something happens to them there is no need to wait for ambulance to pick them up"* (Service Provider, Dili)

This recommendation is given in the context that the ambulance service's main purpose is for medical emergencies, and alternative health transport options for non-emergency planned admissions are absent.

2.6.2 Personal characteristics of the service provider

Characteristics of respect and desire to provide good quality service were described as equipping service providers to better meet the MNH needs of women with disabilities. A couple of service providers noted that a respectful bedside manner towards all women, including women with disabilities was an important factor in enabling quality service provision. One service provider felt it was particularly necessary to have patience and remain calm when working with women with psychosocial disabilities who may require additional support during periods of distress.

> *"What we have to do is not to get emotionally tense...sometimes, they pinch our hand until our hands [are] sore...but we have to be patient because this is our job"* (Service Provider, Dili)

The notion of empathy in enabling service providers to provide quality MNH services to women with disabilities was emphasised by one key informant:

> *"It's not in the book. It's in the heart, the common sense. You know, you put yourself in their [women with disabilities] shoe, you feel how they feel, think how they think and then you will be able to deliver service properly"* (Key Informant, Dili)

Importantly, several women with disabilities highlighted very positive experiences of treatment from service providers, and one linked this with providing motivation for her to return to the health facility.

> *"These positive attitudes [of service providers]...make me want to go always to health centre...they never talked to me rudely and they gave great service"* (Woman with disabilities, Dili)

2.6.3 Communication strategies

Service providers identified clear communication between themselves and women with disabilities as critical to enabling access to MNH services and information. A range of non-verbal communication strategies were noted by service providers to improve the ability to share information with women with disabilities. Some of these included use of body language and gesture and use of written language through mobile phone or writing on paper in a clinic. One service provider stated:

> *"There was one Deaf woman, it was hard to communicate with each other...[but] as she went to school she can write, so then we used this to communicate"* (Service Provider, Dili)

This demonstrates the service provider's initiative in overcoming communication barriers and that in this case, access to education enabled this Deaf woman to develop adequate literacy skills to communicate in writing. A range of other communication-enabling strategies to use with women who are Deaf or hard of hearing were also described by a key informant.

> *"When it comes to Deaf people, they [service providers] must always bring pictures and samples. We are teaching them [people who are Deaf] a condom – what is that? You can just finger spell condom. Granting that the person doesn't know how to do spelling...then you show – this is a condom...this is the IUD, you show them the example"* (Key Informant, Dili)

Other service providers also suggested use of text messages with MNH related information and reminders, as in the Liga Inan[xix] program, could assist overcoming communication barriers with women who are Deaf or hard of hearing. Notably, the very limited mention of the usefulness of

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[xix] Liga Inan is an MCH project using mobile phones to connect expectant mothers with health providers to improve the likelihood of a healthy pregnancy and birth.

professional sign language interpreters may reflect the absence of an official national sign language and thus lack of professional sign language interpreters.

Regarding communication enabling strategies for women with vision impairment, provision of Braille signage at health facilities to enable way-finding (for those able to read Braille) and provision of very clear verbal explanations about MNH issues were identified. Service providers also recalled practical support for communication provided by family members of women with disabilities as very helpful in making communication easier, reflected in the following section 2.7.4.

2.6.4 Family and community support

Support provided by families to women with disabilities was described as an essential and mediating factor in women with disabilities' access to MNH services in both Dili and Ermera. Participants described how family support enabled women with disabilities to navigate the health system, support service providers to visit women with disabilities in the home environment, and enable women to access transport to a health facility. Family support through physical assistance during childbirth and taking newborns to access PNC was also highlighted. One woman with disabilities in Dili stated:

> *"My family and my husband's family really support me. My father and my mother including my sisters, they gave good attention for me and my baby [because of] my condition... As we live in the hill, my younger sisters and mother always be there to support me to take my baby to hospital...They never said no. So, I have no difficulties to do the treatment"*

Family support was considered essential by service providers to enable them to communicate with women with disabilities if the woman's impairment affected her communication.

> *"Some women with disability it is kind of hard to talk to them...then the family will talk really slow or explain it slowly so that women will understand...When we [service providers] don't know what they said, we also ask their family for clear information"* (Service Provider, Dili)

2.6.5 Awareness of women with disabilities

To provide MNH services for women with disabilities, service providers must first know or be aware of their existence. Service providers described examples of potential strategies that could be used to locate women with disabilities, including approaching Chefe de Sucos or Aldeias[xx] who may know of women with disabilities in the community.

> *"It is good if you go to Chefe de Sucos or Aldeias because there could be...a couple of women with disabilities in one Suco"* (Service Provider, Dili)

Other strategies mentioned by service providers included speaking with colleagues who may be aware of, or had contact with, women with disabilities; creating a list of women with disabilities in the local area so that they can be proactively contacted to ensure they access ANC and establishing a mechanism by which families can alert service providers of women with disabilities that require support.

2.6.6 Training and awareness raising programs

Most service providers would value the opportunity for disability related training and many noted how this would enable them to provide better services to women with disabilities. Preferred training content included information about how to communicate with women with disabilities, how to provide physical assistance to women with different types of impairments and what type of MNH information they should provide to women with disabilities.

[xx] Sucos and Aldeias refer to different levels of governance in Timor-Leste, with Aldeia being the closest to village level, and Suco being the governance unit above Aldeias.

This information included how women with disabilities can take care of themselves during pregnancy, after delivering the baby and what they need to do to take care of their newborn. One service provider indicated it would also be useful to understand how to provide information to women with disabilities on self-protection skills.

> *"So the type of information that [would be] good...is how to give information to women with disability about how to take care of themselves, [about] not getting sexual abuse from men"* (Service Provider, Dili)

Training entry points in both pre- and in-service training were identified by both doctors and midwives as relevant to improving inclusion. One service provider spoke of needing training specifically about pregnant women with disabilities, indicating that general disability training may not be enough to adequately support MNH service providers to develop confidence to provide services to women with disabilities.

Raising awareness of disability amongst community and family members was also a strategy discussed by several service providers. Awareness raising can create an enabling environment for women with disabilities to access health services by fostering more positive attitudes towards disability and one key informant spoke of the role of political institutions in facilitating this.

> *"It's not only the government's responsibility but also the other stakeholders and the parliament... to raise community awareness of the way they...see disabled people"* (Key Informant, Dili)

2.6.7 Strength of women with disabilities and association with DPOs

Several women with disabilities provided examples of how their own tenacity and persistence enabled them to assert their reproductive rights or assure their access to the MNH assistance they required in the face of negative attitudes of service providers and community members. This is evident in examples recounted earlier in this report where women with disabilities successfully argued for having a natural birth, and defended their right to have children in the face of service provider judgement. Another woman with disabilities recounted how she did receive the reasonable accommodation she required, but that this required significant persistence on her part in requesting a midwife allow her to use a vacant wheelchair in a health facility.

In each of these cases where women with disabilities advocated for their rights, the women were members of DPOs. Thus while there are many factors supporting access of women with disabilities to MNH services, it is possible that improved confidence and knowledge of rights brought on by association with DPOs, may also contribute to women with disabilities' capacity to negotiate access to MNH services. This is supported by the call of a service provider in Ermera for disability organisations operating in Dili to:

> *"Work in sub-districts too...so that they can give advice or training to these people [with disabilities] so that they...reduce the feeling of being disabled so they could access health facilities"* (Service Provider, Ermera)

3. FINDINGS - NEWBORNS WITH IMPAIRMENTS

A smaller component of this research explored service provider experiences in working with newborns with congenital impairments born to mothers with or without disabilities. These findings were limited by the comparatively small amount of data gathered from service providers and not having the ability to triangulate this data with the experience of families. Notwithstanding this, these findings revealed a range of attitudes and beliefs about newborn disability as well as service provider practices in relation to identification of impairments, treatment and referral.

3.1 Attitudes and beliefs about impairment of newborns

Service providers from Dili and Ermera both noted how the birth of a newborn with an impairment can be received negatively by family members of the newborn, including mothers.

> *"We put the baby on the [mother's] chest but when the mother held the babies hand, she was in shock and stress because the baby doesn't have a hand"* (Service Provider, Dili)

Other service providers described how families of newborns with impairments may feel ashamed of having a newborn with impairment and how this can lead to avoidance of health services.

> *"For example a mother with a child [with disabilities], she could not come to do the treatment because she is shy"* (Service Provider, Ermera)

A couple of service providers attributed disability to being determined by God.

> *"It is not that we want them to be disabled but it is given from God"* (Key Informant, Ermera)

This could not only potentially inhibit service providers understanding and knowledge about the biological causes of impairment and indeed causes related to safety during delivery, but also create barriers in seeking appropriate treatment and support for newborns and their mothers that could improve the quality of life for a child. One key informant counteracted this concern, stating:

> *"They [service providers] do take care of these kids with disabilities...because they are just human beings, so we have to take care of them too, it's not [like] they are going to abandon the baby"* (Key Informant, Dili)

3.2 Service provision for newborns with impairments and their mothers

3.2.1 Level of reported experience in caring for newborns with impairments

Younger service providers reported that they had no experience of supporting delivery of a newborn with impairment, however most other more experienced service providers in Dili and Ermera recalled cases of supporting delivery of newborns with impairments. Service providers recalled children born with cleft palate, club feet, genital anomalies, missing or incomplete hands and feet, flaccid limbs, additional digits, hydrocephalus and spina bifida.

3.2.2 Identifying and recording newborn impairments

Service provider practices for identifying newborn impairments are situated in a context where "only 32 per cent of postpartum mothers and their newborns received postnatal care"[43]. Hence it is possible that many newborn impairments that are capable of being detected in the postnatal period are not identified[xxi]. Even when newborns with impairments are born at a facility or present soon thereafter, service provider reports in this research indicate some inconsistency in how impairment would be identified and recorded.

[xxi] Note: only a select number of impairments are capable of being identified in the postnatal period, for example hip dysplasia, clubfoot, neural tube defects, cleft lip and palate and paralysis of the plexus brachialis. See Handicap International, (2014) 'Inclusion of disability issues in mother and child health projects'. Retrieved from: http://www.hiproweb.org/uploads/tx_hidrtdocs/Sd_PG06MCH.pdf

One service provider noted that some impairments can be detected in utero by ultrasound, however most described that impairment was more likely to be identified post-birth. Some service providers described that some newborn impairment was immediately apparent through observation, particularly if the impairment was significant. Others explained that they undertake a full assessment. These service providers explained how newborns with impairments would be triaged depending on severity, noting that children with more life-threatening conditions, such as being born without an anus, would be prioritised over children born with a condition perceived as being less immediately life threatening, such as cleft palate. One midwife in Ermera stated:

> *"It depends on the cases whether they are emergency or not. When the babies are delivered with hydrocephalus...it's [an] emergency and we must refer to the hospital so that they can give treatment"*

Similarly, a couple of service providers reported that for newborns with 'less concerning' impairments such as additional digits, or cleft palate, they will delay action, or take no action at all. This may indicate limited service availability to address such conditions, or a lack of service provider understanding that conditions like cleft palate should be addressed to support child survival and quality of life.

> *"If the baby [has] cleft palate or 12 fingers then...they [service providers] are going to write on their notes but there's no more actions taken or done"* (Key Informant, Ermera)

Service providers reported they would note newborn impairment in general medical notes or in the section of medical treatment forms that have provision to note 'birth defects'. Consistent with evidence that only 17 per cent of people with disabilities are born with an impairment[44] and in recognition that disability is the interaction between impairment and a person's environment, one service provider highlighted that disability may only become evident as the child grows older.

> *"As the baby is growing up...we can find the illness [disability]"* (Service Provider, Ermera)

This highlights that any approach to identifying disability in newborns and children must consider multiple entry points for identification across early childhood.

3.2.3 Referral practices

Service providers' responses favoured referral of newborns with impairments out of the primary health care system. Perceptions of service provider capacity to provide services to newborns with impairments within the primary health care system differed between a supervisor and practicing service providers, with the supervisor indicating:

> *"I think they [service providers] are prepared to take care of this type of baby because as I mentioned already that is one of the programs that I run - taking care [of] the newborn babies"* (Key Informant, Ermera)

This was contradicted by the view of several primary health care service providers with the most frequently cited response to dealing with newborn impairment being referral out of the primary health care system.

> *"Here [at the CHC] everything is just general. We don't really know about it [newborns with impairments]...so we have to refer to the National Hospital"* (Service Provider, Ermera)

This was more frequently mentioned by service providers in Ermera and some noted that referral would be made on the basis of the seriousness of the impairment.

> *"In general, if we look at the type of disabilities that the kid might have, or things that he might need...if it is too serious then we will do referral"* (Service Provider, Ermera)

However a key informant highlighted that referrals of newborns with impairments living in rural areas such as Ermera would be slower compared to those born in Dili.

> *"In Dili it is okay because it is going to be fast to do referral for the medical doctors. But how about in remote areas? So it is important to give information for them (service providers) about what to do before referral"* (Key Informant, Dili)

This raises the need to consider how the capacity of the health system outside of Dili to provide identification and intervention services for newborn impairment could be strengthened. Meanwhile, tertiary level services providers at the National Hospital noted their approach to newborn impairment is referral to a paediatrician.

Finally, whilst a couple of service providers noted the names of health and rehabilitation NGOs (Tibar[xxii], Global Medic[xxiii], ASSERT[xxiv]) that they might refer to, this was mentioned in relation to children beyond the newborn period. One service provider did note that if a newborn was born with club feet they would make a referral to the National Rehabilitation Centre. This was at a CHC where posters explaining club foot diagnosis and treatment were prominently displayed, indicating the benefit of awareness raising material.

3.2.4 Support to mothers of newborns with impairments

Service providers had generally limited awareness of what support options existed for mothers of newborns with impairments, likely indicating that limited support options exist. One service provider described the immediate impact of a lack of support to mothers of newborns with impairments:

> *"So maybe there is no attention for women after delivering the kid with disability. So they will ask us what are we going to do with this kid? And the midwife will tell them, 'oh we're going to send her to a specialist', and they [midwives] don't really do or say something to make them [mothers] feel better, so they [mothers] just feel that they get abandoned"* (Service Provider, Dili)

A limited range of informal strategies to support the mother and family of newborns with impairment were described by several service providers including provision of information on the newborn's condition and counselling to families.

> *"They [service providers] will let the mother know your kid is getting this and this and we are going to refer her to this doctor and then they would...give counselling to the mother to accept the reality"* (Key Informant, Dili)

3.3 Training

Similarly to service providers' preference for further training about women with disabilities, some service providers also agreed that training about congenital impairments and those which are acquired in the postnatal period, would be useful. One key informant noted that training about newborn pathology cases, including disability, ran from 2003 to 2009 at the National Health Institute and included information about how to treat and refer newborns. This key informant suggested re-introduction of this course. Additionally, as mentioned earlier, another key informant suggested it was imperative that rural primary health care professionals had training providing them greater knowledge about approaching newborn impairments given delays in rurally based newborns accessing specialist services.

[xxii] Klibur Domin, based in Tibar, is a Timorese NGO that provides community based rehabilitation services amongst other services.

[xxiii] Global Medic is an international NGO that was reported by a service provider to provide cleft palate surgeries during periodic medical missions to Timor.

[xxiv] ASSERT or Assosiasaun Hi'it Ema Ra'es Timor Loro sa'e was an NGO operated rehabiliation service based in Dili. It was renamed Centro Nacional Rehabilitacao in 2014 when the Ministry of Social Solidarity assumed responsibility for the service.

4.0 DISCUSSION

The findings of this study suggest that there is a need to improve the inclusion of women with disabilities in mainstream family planning and MNH services in Timor-Leste. The results of interviews and discussions with both service providers and women with disabilities suggest that a range of issues including physical, communication, attitudinal and institutional barriers negatively impact the access of women with disabilities to quality and respectful MNH services. However, encouragement can be taken from the fact that service providers and women with disabilities reflected on multiple factors enabling access to these services, including practices of service providers themselves as well as social factors.

While it is recognised that many women may face difficulties accessing family planning and MNH services in Timor-Leste, in line with findings of similar studies "it is likely that women with disabilities may experience a double burden; encountering additional barriers specific to having an impairment"[45]. In this study misperceptions and negative attitudes of some service providers, as well as an institutional environment with limited visible prioritisation of disability inclusion and no systematic program of disability awareness raising and training are some of the most significant barriers.

Some of these attitudes and misperceptions were reflected in negative language used by service providers, assumptions of asexuality and negative perceptions of women with psychosocial disability. Presumptions of asexuality of women with disabilities amongst community and service providers are aligned with the results of many other studies[46] and run the risk that low priority is given to meeting the SRH needs of women with disabilities[47]. Given all women with disabilities interviewed in this study had multiple pregnancies these views on asexuality are evidently misinformed. This is supported by literature which shows that rates of sexual activity and childbirth are comparable between women with and without disabilities[48].

The particularly negative perceptions of women with psychosocial disability evident in this study appear to be based on a number of assumptions including those of dangerousness and incapacity to make independent or supported decisions. It was concerning that research participants identified several examples whereby the right of women with psychosocial disability to have and parent children may have been undermined through reported removal of their children. Though the circumstances around the removal of children in all these cases are unknown, on the face of it these removals are denials of the right of women with disabilities to have children or to be supported in doing so as per Article 23 of the CRPD[xxv].

Negative attitudes, misperceptions and limited knowledge about disability were also reflected in a number of practices including application of physical restraint, forced sterilization and the potential routine over referral of women with disabilities to tertiary maternity facilities. The three sterilization cases reported in this research come in the context of only 0.5 per cent of all women in Timor-Leste having ever used female sterilization as a contraceptive method[49]. Though further investigation would be required to establish the precise circumstances around these cases, some appeared to possibly fall short of the UN Interagency Standard for "free, full and informed consent"[50] required to avoid characterisations of sterilisations as coerced or forced. Sterilization that occurs in the absence of these conditions has been described by international and regional human rights bodies as:

> "an involuntary, coercive and/or forced practice, and as a violation of fundamental human rights, including the right to health, the right to information, the right to privacy, the right to decide on the number and spacing of children, the right to found a family and...the right to be free from torture and other cruel, inhuman or degrading treatment or punishment...[and] as a form of discrimination and violence against women"[51]

Furthermore, relying on third party consent for sterilization, as in one of the cases reported by a service provider, denies women with disability their right to equal recognition as persons before the

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[xxv] Article 23 of the CRPD relates to 'Respect for home and the family'.

law as per Article 12 of the CRPD[xxvi]. This requires that persons with disabilities have access to the support they may require in exercising their legal capacity. This means that when a woman with disability is making a decision for or against sterilization, she "must not be induced by incentives or forced by anyone, regardless of whether that person is a spouse, parent, other family member, legal guardian, health-care provider or public officer"[52]. As argued by the WHO and UNFPA, when service providers extend negative attitudes, such as some of those reflected above, towards women with disabilities, this may repel them from seeking health services in the future[53]. The importance of addressing these barriers and practices are reflected in recommendations in Section 5.

In this study, service providers' limited knowledge and training about disability was also reflected in the reported tendency towards referral of women with disabilities to the National Hospital and for birth by caesarean section. Two of fifteen women with disabilities in this study reported giving birth by caesarean section while in Timor-Leste less than 1.7 per cent of births are delivered by caesarean section[54]. This aligns with the findings of other studies which highlighted that low disability awareness and limited education of health-care providers led them to perceive women with disabilities as having 'high-risk' pregnancies and consequently not offering the same opportunities for an "optimum birthing experience"[55]. The World Health Organization (WHO) and UNFPA argue that it is not necessary that the birthing process for women with disabilities requires specialist care or a caesarean section[56]. Additionally, in Timor-Leste, birth by caesarean section is thought to occur mostly amongst "highly educated mothers who are also from wealthy households, most commonly in Dili"[57]. Such a demographic does not align with the situation of women with disabilities, who are more likely to be poor and have lower educational attainment[58]. This indicates that in Timor-Leste there is an under explored dynamic between disability and caesarean section which requires further investigation.

Many service providers in this study stated they would value further training, and several of the issues identified in the report, including those highlighted above, indicate that training of service providers related to disability will be a critical means of addressing many of the barriers identified in this research.

As indicated in the findings, no service providers appeared aware of the mention of disability in the RMNCAH Strategy 2015-2019. While the findings proposed this could be related to issues with dissemination of policy, other explanations are feasible. Although not explored further in this study, it is possible that lack of knowledge about the mention of disability within the RMNCAH Strategy is due to the fact that the very brief mention of disability in a lengthy strategy does not provide a strong enough impetus to encourage action towards disability inclusive RMNCAH services.

The findings also reflected a tendency of service providers to not directly engage with women about whether they have difficulties (arising from impairment) that may affect their pregnancy or access to MNH services. Additionally, many service providers held a narrow understanding of what type of impairments may lead to disability, focussing largely on physical and visual impairments. Because service providers relied more on visual observation to identify disability and tended to not directly engage with women to find out if they have impairments which may impact their pregnancy or lead to issues accessing MNH services, this means service providers will not be able to accommodate impairment specific needs. The implication of this is that women with disabilities may continue to experience difficulties accessing MNH services that may have been resolved through collaboratively working out strategies with a midwife to ensure they receive all necessary MNH services.

In addition to these issues were difficulties related to women with disabilities' access to services and accessibility within these services. Primarily these related to very limited affordable and accessible transport options, combined with limitations faced by existing outreach services which particularly affected rural women with disabilities, similar to the situation for many women in the country. However, as other studies have also found, this was exacerbated by the tendency for referral of women with disabilities to hospital level care which creates significant difficulties by increasing travel

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[xxvi] Article 12 of the CRPD relates to 'Equal recognition before the law'

costs beyond the means of many[59]. The difficulty is also exacerbated for women with disabilities "given the high rates of poverty found in this population"[60] and for whom, due to mobility impairments, walking to a service is sometimes not feasible.

Difficulties communicating was repeatedly raised by service providers as a concern impacting their capacity to deliver a quality service to women with disabilities. Despite having limited to no training about disability, some service providers overcame these issues through making adjustments, but others described continuing difficulties. This evidenced limited knowledge about how to make communication accessible such as service providers adapting how they deliver information to women with a variety of impairments, including women with vision, hearing and mental impairments. Issues of physical accessibility within health facilities were also raised by a number of research participants. These included the number of stairs in facilities and the lack of ramps, lack of way-finding indicators for women with vision impairments, narrow door widths, limited circulation spaces in health facilities, inappropriate beds and a lack of wheelchairs.

While it is the responsibility of MNH services to provide MNH-specific services to women with disabilities, disability services can indirectly support addressing both MNH and non-MNH needs. Disability specific needs of women, such as provision of assistive devices could improve mobility and enhance access to MNH and other services. In this study service providers had limited knowledge of disability-specific services and no knowledge of disabled people's organisations that they could refer women with disabilities to if needed.

Perceptions of women with disabilities being vulnerable to sexual abuse also arose in this study, as well as a service provider's suggestion that women with disabilities need training to protect themselves from harassment by men. These concerns reflect findings of the Nabilan Baseline Study on 'Understanding Violence against Women and Children in Timor-Leste' which found a linkage between potential disability status and the experience of physical and/or sexual intimate partner violence[61]. This indicates an important need to ensure a multisectoral approach, in particular that health, ending violence against women (EVAW) and disability stakeholders collaborate to ensure women with disabilities are included in EVAW initiatives and that any risk factors unique to being a woman with disability are reflected in programming.

Despite the barriers to service access described in this discussion, this research found that most women with disabilities reported previously accessing at least one MNH service, whether it was family planning, single or multiple ANC visits, skilled birth assistance or PNC, and for a few women - all of these services. Much encouragement can be taken from the supportive practices exhibited by some service providers that enable some women with disabilities to access MNH services. These practices, such as providing respectful physical assistance, adapting communication modalities and conducting regular outreach visits, as well as resourceful solutions proposed by participants, including liaising with Chefe Sucos to locate women with disabilities, have informed recommendations in section 5. The fact that some women with disabilities reported positive experiences when they interacted with service providers should also provide service providers and the MoH with the encouragement to implement actions for disability inclusion more systematically.

Additionally family support and connection with DPOs were significant factors enabling access of women with disabilities to family planning and MNH services. The research suggests that the attitude of a woman’s family may be a key determinant of whether a woman with disability can access health services. Less supportive families may hide a woman away in the home out of shame or fail to provide her with practical support, while research participants also reported that family support enabled women with disabilities to navigate the health system, access home-based services and travel to health facilities. Connection with DPOs was also found to potentially improve a woman with disability's capacity to assert her rights to MNH services. Actions to enhance the influence of these factors will be important to promote women with disabilities' access to services.

In relation to newborns with impairments, findings highlighted that consistent identification of newborn impairment in the postnatal period needs to be improved. Capacity of primary and secondary health services to respond to identified impairments appears low based on the common response of primary health care providers to refer newborns to the tertiary level; though further investigation would be required to substantiate exactly what capacities currently exist at the secondary level. Other research has found that children with feeding difficulties are significantly more likely to be malnourished than those without difficulties[62]. When service providers in this study were able to identify impairments, a couple considered certain impairments, most notably cleft palate, to be 'less concerning' reportedly resulting in delayed or no action. Yet, cleft palate is a condition that can significantly affect child survival and quality of life[63] and lack of knowledge of service providers in this regard is concerning. During the post-natal period, it is possible for a specific range of impairments to be identified[xxvii] and early action taken to ensure a greater chance of survival and improved quality of life. At the primary health care level, more consistent postnatal detection of significant impairments could be possible with appropriate capacity development of health staff; though for more advanced screening and treatment for newborn impairments this would require referral[64]. However, it is important to recognise that identification of impairment during the postnatal phase only captures a small amount of impairments that may develop later during childhood. This highlights the need to further study how early identification and intervention of disability during childhood currently operates in Timor-Leste.

Additionally this research showed that there appears to be limited support options available to parents of newborns identified as having impairments. Service providers were generally unable to offer options for support to mothers of newborns with impairments, possibly because few support options exist. This will be important to explore further as the need for appropriate support of women who give birth to a newborn with an impairment is crucial, especially during initial bonding stages.

The findings of this research suggest that a number of different strategies are required in order for women with disabilities to equitably access family planning and MNH services and to maximise the quality of life of newborns with impairments. The Timor-Leste Government has a vision of "universal access to key RMNCAH services"[65] and there are reasons to be optimistic that health professionals and the disability community support this goal. However universal access will only be achieved with intentional inclusion of women with disabilities and implementation of measures to improve their access to family planning and MNH services. Hence recommendations in the next section have been designed to support such efforts.

[xxvii] Note: only a select number of impairments are capable of being identified in the postnatal period, for example hip dysplasia, clubfoot, neural tube defects, cleft lip and palate and paralysis of the plexus brachialis. See Handicap International, (2014) 'Inclusion of disability issues in mother and child health projects'. Retrieved from: http://www.hiproweb.org/uploads/tx_hidrtdocs/Sd_PG06MCH.pdf

5.0 RECOMMENDATIONS

These recommendations are responsive to the findings of this research and developed with a view to support alignment of policy and practice with the CRPD, in light of the Timor-Leste Government's consideration of CRPD ratification[66]. It is important to understand that though some recommendations would require little resource allocation, some may require significant resource allocation. While it is understood that resource constraints exist in contexts like Timor-Leste, such recommendations were included to provide a complete picture of what steps are required to reach a future where women with disabilities can achieve their right to health on an equal basis with women without disabilities.

It is understood that these recommendations are made in a context where many women without disabilities also experience significant challenges to access family planning and MNH care and so plans to improve the access of women with disabilities need to be considered in light of overarching plans to improve access for all women in Timor-Leste to MNH services. It is anticipated that an implementation plan would need to be developed by concerned stakeholders to support progressing the recommendations in this report. Concerned stakeholders could include government and non-government organisations, people with disabilities, their representatives organisations and donors. An implementation plan would need to consider: identification of the relevant duty-bearers, realistic prioritisation and timeframes, appropriate budgeting and further specification of implementation activities.

As these recommendations are informed by a human rights based approach, there are a couple of principles that should be kept in mind while reading them. These principles are explained in text boxes 1 and 2.

Text Box 1: Reasonable Accommodation

According to CRPD Article 2, "reasonable accommodation" means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure persons with disabilities enjoy and exercise their human rights on an equal basis with others. "Accommodation" refers to "the adjustment of a rule, practice, condition or requirement to take into account the specific needs of an individual with disabilities, with the aim of enabling this person to participate fully and equally"[1].

Reasonable accommodation is sometimes necessary because general accessibility might not be enough to meet the needs of people with particular impairments, or there might be delays in implementing accessibility standards. In these cases, service providers need to be equipped to provide reasonable accommodation. In health services, this means providing respectful, individualised assistance or adjustments to a service for a woman with disability to ensure she can still access quality MNH services to the same extent as women without disability. This does not represent discrimination, but necessary differentiation of strategies to ensure women with disabilities can achieve the same health outcomes as women without disabilities.

Strategies to accommodate the needs of women with disabilities are reflected throughout these recommendations. It is important to note that there will be women with disabilities who may not require any specific accommodations. In all cases, the preferences of the woman herself should direct the provision of reasonable accommodation.

[1] Office of the High Commissioner for Human Rights. (2010). *Monitoring the Convention on the Rights of Persons with Disabilities: Guidance for human rights monitors.* Geneva: OHCHR, p. 21. Retrieved from http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/2&Lang=en

Text Box 2: Participation

‘Nothing about us without us’ has been a slogan and integral message from the disability-rights movement for decades. Participation is fundamentally about people with a disability participating in decisions that relate to them so that actions affecting people with a disability are not planned or performed without their input. This highlights the need for people with a disability to be brought into processes in such a way that they can directly influence decisions. This results in improved inclusion of people with a disability and also brings with it lasting change[1].

In relation to the recommendations in this report, people with disabilities and their representative organisations, DPOs, must be centrally involved in designing implementation of recommendations as well as in implementation of recommendations themselves. For example, people with disabilities must be involved in review of MNH policies to ensure a disability perspective (see recommendation 5.4.2) and in training initiatives for health professionals (see recommendation 5.3).

[1] CBM. (2012). *Inclusion Made Easy: A quick program guide to disability in development,* p. 21. Retrieved from: http://www.cbm.org/article/downloads/78851/CBM_Inclusion_Made_Easy_-_complete_guide.pdf

5.1 Accessibility of health services

5.1.1 Make transport available to health facilities

It is recommended that affordable and accessible transport options be provided. There are two potential mechanisms for achieving this:

(i) Non-emergency transport could be provided directly. This could take the form of a trial service where patients are picked up in the morning and dropped to health facilities, with an afternoon return service.

(ii) Transport subsidy schemes could be introduced to cover the cost of transport. Given that Timor-Leste’s government payment system is still evolving, the most feasible approach to delivering the subsidy would be to reimburse patients at health facilities. This would require patients to have access to enough cash to cover the costs upfront and facilities to have the system to provide the cash to patients. To make it more affordable, a subsidy could be targeted to people with disability or mobility impairments. Given the challenges of identifying people with disability, such a measure would require close consultation with disability stakeholders, as well as consideration in the broader context of existing social protection schemes in Timor-Leste.

Given these challenges, the feasibility of a subsidy would need to be carefully studied and the direct provision of transport may well prove to be more cost-effective.

If implemented in conjunction with outreach-based services (see recommendation 5.1.3), transport vouchers could be provided during home visits where referrals or in-facility treatment were identified as necessary. However, patients should not have to rely on home visits to obtain transport vouchers.

5.1.2 Consider how social protection schemes could support family members who facilitate women with disabilities' access to health services

Given how important the role of family support was in enabling some women with disabilities' access to health services, it is recommended consideration is given to how, in certain circumstances, this non-remunerated care and support provided by family members could be potentially compensated through expansion of criteria of existing financial social protection schemes.

5.1.3 Provide outreach services for women with disabilities

It is recommended that outreach services be incorporated into delivery of family planning and MNH services. This would consist of:

(i) Strategies to actively locate women with disabilities in communities. This could include approaching Chefe de Sucos or Aldeias, people with disabilities in the community, drawing on information collected through the domiciliary home visiting process, linking with DPOs and establishing a mechanism by which families can alert service providers of women with disabilities that require support.
(ii) The delivery of services via outreach. Service providers interviewed during the research identified home-based service delivery as an effective way of providing MNH care to women with disabilities. Entry points include, amongst others, the MoH's domiciliary home visiting program, SISCa mobile health clinics, Liga Inan and Marie Stopes International Timor-Leste's National youth hotline Liña Foin-Sa'e[xxviii]. However flexibility should be retained for outreach to women with disabilities to occur outside these entry points and in consultation with DPOs. Additionally, the accessibility of Liga Inan technology for women with hearing and vision impairments and telephone hotlines for people with hearing impairments would need to be determined by working with DPOs.

Outreach would complement the above recommendation to provide transportation, and/or serve as an interim measure while an approach to transportation is designed.

5.1.4 Develop and include universal accessibility into standards for new and existing health facilities

It is recommended that accessibility standards for health facilities be developed encompassing dimensions of both physical and communication accessibility. This should include respective standards for new and existing facilities, with mitigating strategies where it will not be possible in the short-term to make accessibility adjustments (for example provision of assistance by staff and outreach strategies). This recommendation could take the form of development of a stand-alone standard on physical and communication accessibility and, where relevant standards currently exist, such as lists of essential equipment for health facilities and other public health standards, accessibility measures could be included in these when they are reviewed. Development of standards will need to be accompanied by planning and budgeting for their implementation.

Annex 1 includes a list of items that should be considered in development of these standards. The annex includes items related to both physical and communication accessibility incorporating physical infrastructure, availability of equipment and alternative formats for providing health information as well as service provider practices to enhance communication accessibility. Given some elements of the standard may be behavioural in nature, systematic dissemination of the standard would need to occur.

5.2 Health system processes and systems

5.2.1 Collect information and data on disability to inform equitable health service delivery

Information on disability is relevant at the clinical level, health administration level, and health information systems level to support equitable health service delivery.

(i) Service providers should engage with women with disabilities to identify any difficulties they might have in accessing MNH services: At the health facility level, and during outreach services including SISCa, domiciliary home visiting and Liga Inan, service providers should be equipped with strategies for identifying if a person is likely to have a disability. This does not mean service providers must always undertake a formal assessment (unless this is deemed necessary), but that they should engage directly with the woman to ask if she has difficulties that might make accessing MNH services challenging[i]. The purpose of this should be to ensure that the service provider can discuss with the woman what practical strategies would support her improved access to MNH care. Equipping service providers with these skills should form part of a disability training program for health staff (see recommendation 5.3.3).

[xxviii] Liña Foin-Sa'e is a telephone based service that offers information about health relationships and reproductive health and can provide information and service referrals.

(ii) *Record disability data to inform health service monitoring and evaluation*: The disability status of all patients should be recorded in a consistent manner at facility level and during outreach visits. This will enable disaggregation of health data by disability, enabling comparison of health outcomes between people with and without disability. Training requirements to support this measure are elaborated further in recommendation 5.3.3.

5.2.2 Review clinical guidelines/processes for identifying high-risk pregnancies and development of birthing plans

Given a possible tendency to refer women with disabilities to tertiary care for birth and to recommend caesarean section, it is recommended that processes to identify what criteria are used to determine high-risk pregnancies, and development of birth plans are reviewed from a disability perspective. Assessment on a case-by-case basis in consultation with individual women with disabilities is recommended, rather than generalising that all women with disabilities' pregnancies are high-risk. This would be complemented by training, as discussed in recommendation 5.3.3.

5.2.3 Development of a brief directory of existing disability services in Timor-Leste

This could be distributed to health services to promote knowledge of disability services and support linkage between services in different government and non-government organisations. This would require information inputs from the Ministry of Social Solidarity, Ministry of Health, ADTL and DPOs in Timor-Leste. However it is important to recognise that effective referral to disability services for assistive devices, rehabilitation and other services, and to DPOs for the range of supports they can offer their members with disabilities, could result in increased demand for these services. Given at present many of these services currently face geographical, financial, human resourcing and other constraints, strategies would need to be developed to cope with increased demand for services via referral from health professionals.

5.2.4 Strengthen disability awareness, collaboration and referrals between health services, ending violence against women (EVAW) programs and disability stakeholders

This report echoes the recommendations of the Nabilan Study on 'Understanding Violence against Women and Children in Timor' to 'strengthen the role of the health sector in preventing and responding to violence against women'[67] and to ensure such efforts are inclusive of women with disabilities by recognising and addressing the risks they face of violence. As referral networks between health and EVAW services are developed, DPOs should be consulted to determine what roles they wish to play in such networks. Furthermore, as suggested by a service provider in the present study, where EVAW programs include efforts to support women's development of self-protection strategies, these efforts should ensure engagement with women with disabilities as well. Equally, EVAW measures targeted at men should include reference to women with disability to support the understanding that women with and without disabilities are entitled to a life free from violence and abuse.

5.3 Training

Recommendations are provided here for training entry points, priority health professional roles and training content areas. However, it will be important for priority health professional roles and content areas for training to be considered in the context of the training needs of the broader health workforce regarding disability.

5.3.1 Entry points for training

It is recommended that the most strategic entry points for introducing disability content are selected when planning for implementation of these recommendations. The following entry points exist for including disability content in training:

(i) Pre-service training of midwives, doctors and nurses at universities. Adding disability inclusion content to the curriculum for these professions would ensure all new health personnel were trained in disability inclusion and understood disability inclusion to be a core part of their work.

(ii) In-service training of midwives, doctors and nurses through the National Institute of Health. At a minimum, disability should be mainstreamed across family planning and maternal and newborn health related training. A stand-alone course on disability should also be considered.

Relevant competency checklists and position descriptions for health professional roles could also be reviewed and skills included to ensure staff are able to address the needs of people with disabilities. This may include checklists such as the DPHO-MCH[xxix] supportive supervision checklist. Note that all staff affected would need to receive training in disability related competency areas prior to this recommendation being implemented.

5.3.2 Priority groups for in-service training

It is recommended that groups of health personnel are prioritised for in-service training given that it will not be feasible to provide in-service training for all nurses, doctors and midwives in the short term. Prioritisation of particular roles for training could capitalise on findings that indicated that disability sensitisation of midwife supervisors and senior staff at CHCs and health posts is important in increasing the chance that disability inclusive practices are adopted by more staff in the primary health care system. Thus it is recommended that in-service training takes a training of trainers approach which engages personnel in these senior roles to be able to govern inclusive approaches and teach subordinates basic disability related skills. Suggested priority groups for training include maternity ward staff in the National Hospital and District Referral Hospitals, midwife supervisors (DPHO-MCH) in each district, and Directors of CHCs and health posts.

5.3.3 Training content areas

High priority training content areas have been recommended below, noting that many of these areas are relevant for health professionals beyond those in MNH specific roles. Development of training content should build on existing resources and should actively include women with disabilities who can share challenges and successes in accessing services.

(i) *General disability sensitisation:* Attitude-level training is an essential foundation for more technical content. Training should improve awareness of the human rights based approach to disability and address attitudinal barriers and misconceptions about women with disability.

(ii) *Informed consent:* This research noted some potential instances where medical procedures (such as sterilization) were carried out on women with disabilities without their free, full and informed consent. It is critical that health personnel understand and seek informed consent. Training on informed consent from women with disabilities may be most usefully incorporated into existing training on informed consent, if this exists, rather than in a specific training module on informed consent by women with disabilities.

(iii) *Communication skills:* Training should include content on how to interact and communicate with people with disabilities. This could be incorporated into any existing training curricula on interpersonal skills and interaction with patients, and form part of a stand-alone disability training module. This content area could include appropriate language about disability, adjusting communication styles to work with people who have hearing, vision, intellectual or psychosocial impairments, and the ability to collaborate with patients with disabilities to identify their preferences for support. The principle of informed consent should be strongly reflected in training in this area.

[xxix] District Public Health Officer of Maternal and Child Health.

(iv) *Disability identification:* Service providers need training on how to elicit information on disability to guide clinical care, and how to record information on disability in health information systems for effective monitoring and evaluation of equitable health services.

(v) *Pregnancy and impairment:* Service providers, particularly midwife supervisors, should be provided with training on the relationship between pregnancy and impairment to prevent the generalization that women with disabilities' pregnancies are automatically high-risk. Understanding how, if at all, different impairments impact pregnancy, could help inform clinical reasoning that impacts birth planning and also position service providers to meet women with disabilities' information needs. This could include understanding if and how psychotropic medications may impact on pregnancy and foetal development, given the delayed access to such information evidenced in the experience of a woman with psychosocial disability in this study.

5.4 Policy

5.4.1 Review legislative, policy and strategic frameworks from a human rights perspective

This research identified practices such as the application of physical restraint, possible forced sterilization and the removal of children from their parents. While the particulars of each of the instances of these practices are not fully known, some instances may well be inconsistent with international human rights standards. Related Timor-Leste legal frameworks were not examined in this research and so it is recommended that relevant legislation is reviewed to ensure consistency with international human rights law, including the CRPD. Any subordinate regulations, policies or procedures, particularly those related to use of restraint in healthcare settings, female sterilization and removal of at-risk children, should also be reviewed to ensure a rights based approach to disability is appropriately incorporated. This review would provide a basis for reforms to the relevant legislative and policy frameworks.

5.4.2 Designate inclusive MNH as a policy priority

Some service providers expressed that there was little attention to disability in current MNH policy and that due to the hierarchical nature of the health system it was important for health professionals to believe disability inclusion was a high-level priority in the MoH. Given the next scheduled review of the RMNCAH Strategy 2015-2019 may be some years away, consideration should be given in the meantime to development of a high-level directive that would signal it is a priority for the MoH to address the family planning and MNH needs of women with disabilities. Any disability inclusion measures incorporated in official policy and strategic frameworks should be budgeted realistically to ensure disability inclusion can be actioned.

Non-government organisations, such as the Midwives Association of Timor-Leste, or sector wide initiatives, such as the National MCH Working Group, could also develop position statements on the inclusion of women with disabilities to influence MNH care to address disability inclusion.

5.4.3 Initiatives are required for the formal development of a national Timorese sign language

Several disability stakeholders have expressed the intention to support development of a national sign language in Timor-Leste. Such an initiative is vital to ensure that women who are Deaf or hard of hearing are able to engage in confidential discussions about their family planning and MNH needs with service providers through a professional sign language interpreter. When development of an official Timorese sign language has occurred, funding within the health system will need to be allocated to ensure that women who use sign language are able to access a professional interpreter free of charge. Because this may take some time, training on alternative ways to communicate with women who are Deaf or hard of hearing has been included in recommendation 5.3.3.

5.5 Advocacy and awareness

5.5.1 Include people with disabilities in mainstream family planning and MNH community mobilization campaigns

While attitudes of service providers have already been recommended to be targeted through training recommendations, this current recommendation targets mainstream family planning and MNH community mobilization efforts to ensure inclusion of women with disabilities in these efforts. It is recommended that information and education materials as well as behaviour change communication materials, such as posters, pamphlets or community gatherings, incorporate references to women with disability. This will support normalising that women with disabilities are equally entitled to participate in such programs and support improving community attitudes as well as women with disabilities' own perception that they are entitled to access such programs. DPOs should be consulted to support how these messages can be mobilized in ways that will reach women with disabilities.

5.5.2 Target attitudinal barriers among families and communities and build confidence of women with disabilities

Support is required to continue and expand existing initiatives that aim to resolve family and community level attitudinal barriers. In Timor-Leste much of this work is currently undertaken by DPOs who work with a range of stakeholders, including their individual members with disabilities and often their families, to support family understanding of needs and rights of people with disabilities and support their access to a range of services. Stakeholders supporting such vital programs should not only support these current efforts which help address negative attitudes of families and community members, but also support efforts of DPOs in the area of inclusive health. If prioritized by DPOs, donors should extend support for staff, including female DPO staff, to strengthen understanding of family planning and MNH so they can support women with disabilities and their families to link with mainstream MNH services.

5.6 Newborns with impairment

These recommendations are situated in the knowledge that newborn impairment capable of being identified in the postnatal period represents a small percentage of total impairment. Thus efforts to address management of impairment during this phase of life should be considered in the context of broader early childhood disability identification, treatment and parental support processes. Nevertheless, in the postnatal period there are a range of particular impairments that can be identified[xxx], and quality of life for the newborn and family enhanced through improved early identification and intervention.

5.6.1 Identify and document expectations of what newborn impairments should be typically dealt with at which specified levels of the health system

This should be done in order to identify the need for training at particular levels of the health system (see recommendation 5.6.2 (i)) and to support formalising referral processes between these levels in the case of newborn impairment.

5.6.2 Improve timely identification and treatment of newborn impairment during the postnatal period

(i) In line with a training of trainers approach, training should be developed for selected service providers in the primary health care system on identifying newborn impairment during the postnatal period and how to treat these impairments as well as triage and refer when treatment is beyond the capacity of primary health care services. This should be included in existing training programs focused on essential newborn care and consideration given to the possibility of re-commencing the training course reported to be previously facilitated at the National Institute of Health on newborn pathology[xxxi].

[xxx] Note: only a select number of impairments are capable of being identified in the postnatal period, for example hip dysplasia, clubfoot, neural tube defects, cleft lip and palate and paralysis of the plexus brachialis. See Handicap International, (2014) 'Inclusion of disability issues in mother and child health projects'. Retrieved from: http://www.hiproweb.org/uploads/tx_hidrtdocs/Sd_PG06MCH.pdf

[xxxi] One key informant noted that training about newborn pathology cases, including disability, ran from 2003 to 2009 at the National Institute of Health and included information about how to treat and refer newborns.

(ii) Consideration should be given to development of advanced screening and treatment capacities in the secondary health system at referral hospitals and in the primary health care system at District CHCs given the reported delays in rural families accessing referral services in Dili. Alternatively, or as an adjunct to this, consideration could be given to potential periodic paediatric outreach clinics from Dili to secondary health services.

(iii) Development and display of newborn impairment related information, education and communication materials, such as posters, in health facilities to remind service providers about identification, treatment and referral protocols for newborn impairment.

5.6.3 Support mechanisms are developed for parents of newborns identified as having an impairment

This would require further investigation with parents of newborns with impairment and linkage with DPOs who support parents of children with disabilities to understand what parents feel would be useful to support them in adjusting to parenting a newborn with an impairment.

5.6.4 Further investigate how identification and intervention of disability during early childhood currently operates in Timor-Leste

During such an investigation, consideration should be given to how early identification and intervention could be incorporated in a broad range of existing processes, such as vaccination clinics, the Livrado Saúde Inanfante hoet Onan (Mother and Child Health Book), Integrated Management of Childhood Illness protocols or education system related processes.

Annex A: Suggested items for health facility accessibility standards

The following items are items arising from the research to consider during development of accessibility standards. Please note this does not constitute a draft standard, but ideas, amongst others, that could be considered in developing such a standard.

Physical standards:

- Way-finding in health facilities: tactile ground surface indicators, braille signage or handrails around a health facility building so that people who are blind or have low vision can find their way around safely.
- Health facility waiting areas and thoroughfares should have obstacles removed so as to not obstruct movement of wheelchairs and other mobility devices.
- Seating should be available for those unable to stand for extended periods
- Doorways should be wide enough to accommodate movement of mobility devices
- Accessible entry and exit points from health facilities should be assured by installing ramps
- Bathroom facilities in health facilities should be accessible
- Adequate lighting should be available day and night
- A minimum number of height adjustable beds/examination tables to enable women with physical and mobility difficulties ease of access.
- Depending on facility size, a wheelchair/minimum number of wheelchairs should be available at a facility to assist people with mobility difficulties to mobilise.
- Guidance for health professionals on the provision of respectful physical assistance

As some of the recommended accessibility measures involve the provision of accessible equipment, a simple protocol would assist health professionals to decide who is to receive preference to use the equipment, for example wheelchairs or height adjustable beds..

Communication standards:

- All women with disabilities should be consulted on their preferred means of communication (for example, using written explanations, pictures/photographs, visual demonstration, verbal explanations). After establishing the woman's communication preference, service providers can make appropriate adjustments.
- Provision of information materials in alternative formats
  - Further consultation with DPOs representing women with visual impairment is recommended to understand how widespread use of Braille of is to inform health information accessibility standards.
  - Formalised sign-language interpretation is currently not available in Timor-Leste. Thus in the future accessibility standards would need to be revised to incorporate access to trained sign language interpreters .
- Where it is their preference, women with disability should have the opportunity to have an individual of their choosing present to facilitate communication with health workers.

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