

### Exploring Access to Health-Related Rehabilitation Services for Persons with Disabilities in the Maldives

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Candidate's Declaration

I, Timothy O'Fallon, confirm the work presented in this thesis is my own. Where

data and information has been derived from other sources, I confirm that this has

been indicated in the thesis.

Signature:

Date: June 18, 2024

Nihil de nobis, sine nobis

### Abstract

# Exploring Access to Health-Related Rehabilitation Services for Persons with Disabilities in the Maldives

Introduction: Rehabilitation is an important component of health systems, yet it has not received the attention it requires. Many persons with disabilities could benefit from health-related rehabilitation services and evidence suggests there is a high unmet need for rehabilitation services, especially in lower and middle-income countries including the Maldives. However, limited knowledge is available on the issues impacting provision of, and access to, rehabilitation in different settings. The aim of this research, using quantitative and qualitative methods, was to explore access to rehabilitation services in the Maldives from supply and demand perspectives.

**Methods:** Secondary quantitative analysis of data from a 2016 National Disability Survey in the Maldives was conducted to estimate use of and unmet need for rehabilitation services among persons with disabilities. Qualitative interviews were conducted with 21 persons with disabilities and 14 rehabilitation service providers and government representatives. A thematic analysis of supply and demand side dimensions of access was undertaken guided by frameworks of Levesque and Allin.

**Results:** At the health systems level, findings suggest that a lack of governance and political commitment, coupled with poor coordination of rehabilitation services at the ministry level, resulted in inadequate rehabilitation provision, especially on the smaller and more remote islands. This in turn impacted service providers who reported financial and human resources challenges in providing rehabilitation programmes. For persons with disabilities, availability and affordability were identified as significant systems-level barriers to accessing services. The

quantitative data suggest unmet need for rehabilitation was highest among people in lower socioeconomic position and older adults.

**Conclusion:** Persons with disabilities, service providers and government representatives provided unique perspectives on access to rehabilitation services in the Maldives. The results from this study can be used to inform planning of policies and programmes to strengthen rehabilitation in this setting as well as contribute to global data.

## **DrPH Integrating Statement**

LSHTM's Doctor of Public Health (DrPH) programme aims to develop the analytical and practical skills of its graduates so they can understand and adapt scientific knowledge in order to achieve public health gains. In particular, the programme focuses on developing the student's expertise in conducting and evaluating research projects and enhancing, to a doctoral level, the analytical and practical skills required for leadership in the public health field. As a physiotherapist with 15 years of clinical experience working in a variety of clinical and nonclinical settings, as well as teaching at the undergraduate and graduate level, I felt this programme would help expand and improve my skills as a researcher and a leader in the fields of disability and rehabilitation. More importantly, I hoped that this DrPH programme would help provide me with the necessary skills and knowledge to link research, policy and clinical practice that is needed for rehabilitation and disability.

The first components of the DrPH programme were the two taught modules:

- 1) Evidence Based Public Health Policy (EBPHP)
- 2) Understanding Leadership, Management, and Organisation (ULMO).

The EBPHP module was key in developing my skills to evaluate and synthesize evidence and how it could be used to inform public health policy and practice. It helped me understand the policy process and appropriate influencing activities at each stage of policy development. I appreciated the insights and experiences of the guest speakers who were involved in research and policy at a global level. The assignments also piqued my interest in local, national and international policy. Specifically, I found the influencing strategy and systematic review assignments were key in applying the skills and knowledge I learned from this course. The ULMO module was also an important component of the DrPH programme. In this, I learned about the different leadership, management and organisational theories, and it increased my understanding and awareness of the challenges and opportunities organisations face when trying to develop and implement policies and programmes. The course assignment was a useful opportunity to apply the

various organisational theories and frameworks to a healthcare organisation I was previously employed with in Toronto, Canada.

I also had the opportunity to participate in the DrPH's three-day residential professional development workshop. Not only did this allow me to meet my DrPH classmates on a personal level, but the workshop activities also provided me with good insight into my own leadership skills and gave me a chance to revisit both my personal and professional goals.

The Organisational and/or Policy Analysis (OPA) was the next component of the DrPH programmes. Its purpose was to explore firsthand how a public health organisation shapes public health policy, using the knowledge and skills learned from the taught modules. Since I spent my entire physiotherapy career in the clinical field, I purposely chose a topic I was unfamiliar with and had no experience in. Thus, I sought out an opportunity to analyse an INGO in Kathmandu, Nepal. I felt it was important for both my personal and professional learning that I explore how INGOs and NGOs in low income countries function in low-resource settings influence government policies on disability and rehabilitation. This was my first time organising a research project and completing the fieldwork on my own. It was also my first foray into qualitative research and first time working in a low-income country. I experienced several challenges in this research which also strengthened my ability to solve problems quickly and to adapt to change. I was fortunate to have my thesis supervisors available to help me work through these challenges and, despite these challenges, my time in Nepal was exciting and rewarding. I met a number of amazing individuals who were dedicated to improving the lives of persons with disabilities and saw how resourceful they were in providing rehabilitation services in an under-resourced environment.

The DrPH thesis was the final opportunity to integrate and use the knowledge and skills learned from the taught modules, professional development workshop, and the OPA. For my thesis, I wanted to focus on a topic that was related to a field I was

most familiar with – physiotherapy and rehabilitation. In particular, I wanted to explore the experiences of persons with disabilities as they try to access rehabilitation services in low-and-middle income countries and under-resourced environments. After my time researching disability and rehabilitation in Nepal, an opportunity presented itself where I could investigate these areas in-depth in the Maldives, alongside one of my thesis supervisors, who is an experienced qualitative researcher doing disability research in the area. My OPA experience in Nepal had greatly influenced my views and thoughts on rehabilitation and disability. My greater awareness of these issues in Nepal had given me a new way to approach access to rehabilitation in the Maldives. During my fieldwork in the Maldives, I had the opportunity to listen to the experiences of persons with disabilities as they tried to access rehabilitation and to the service providers and government officials who worked hard to deliver these services in a country with over 180 inhabited islands. My time in the Maldives gave me better insight into the complexity of accessing rehabilitation and how multiple factors (e.g., structural, personal, environmental) can influence a person with a disability to access services or not. I found it interesting how motivated and dedicated rehabilitation service providers were in providing quality rehabilitation to persons with disabilities in a fragmented and environment with few resources available to them.

Overall, this DrPH journey has greatly influenced my thoughts and views on rehabilitation and disability. It challenged me to take a step back from the clinical realm I have been so involved in over the past 15 years and to consider a new perspective on disability and rehabilitation in both research and clinical practice. In conclusion, I hope this thesis will reflect my theoretical understanding of access, rehabilitation and disability.

# Acknowledgement

I would like to acknowledge and thank the many individuals who supported me and contributed to my DrPH journey.

Firstly, I would like to thank my supervisors Drs. Sarah Polack, Nicki Thorogood, and Shaffa Hameed for their ongoing support and guidance during my DrPH programme. I am grateful for your wisdom, time, and patience since I started the DrPH programme in 2016. You all challenged me to think and write about disability and rehabilitation in a different way. It has been an honour and a privilege to learn from you. I would also like to thank my advisory committee members Drs. Allen Foster and Morgon Banks for their knowledge and expertise on global health issues and statistics. Thank you to my colleagues in the Disability group and DrPH programme for their friendships. In particular, I would like to thank PS and DB for their support and guidance. I enjoyed our weekly chats where we would talk about everything but school!

I would like to thank my partner Graham, family, friends and my four legged friends who provided me with ongoing encouragement and laughs. In memory of my mom who always instilled in me the value and importance of learning and education. She was always my biggest supporter. And finally, this DrPH thesis would not be possible without the persons with disabilities, service providers, policy makers, and those involved in the disability and rehabilitation fields who took time out of their daily schedules to share their stories and experiences about accessing rehabilitation. It has been an honour to have met and spent time with you.

### **Abbreviations**

AP Assistive products

AT Assistive technology

CHW Community health workers

DPO Disabled Persons Organisation

GP General practitioner

HIC High income country

ICF International Classification of Function, Disability and Health

INGO International non-governmental organisation

LMIC Lower- and middle-income country

NGO Non-governmental organisation

NHS National Health Service (UK)

NSPA National Social Protection Agency

PHC Primary health care

rATA Rapid Assistive Technology Assessment

SIDS Small Island and Developing States

UN United Nations

UNCRP United Nations Convention on the Rights of Persons with Disabilities

WHO World Health Organization

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### Overview of Thesis

The aim of this research is to explore access to rehabilitation services for persons with disabilities in the Maldives from supply and demand perspectives. The thesis has been organised into seven chapters. Chapter One provides an introduction to the topics of disability, rehabilitation, and access as well as background information on the Maldives. This is followed by the study rationale and the research aims and objectives. Chapter Two provides information on the quantitative and qualitative methods used for this research. Chapter Three describes the quantitative findings of a secondary data analysis on persons with disabilities seeking rehabilitation services in the Maldives. Chapters Four and Five present the qualitative findings and analyses from government and rehabilitation service providers, followed by those of persons with disabilities. Chapter Six discusses the findings in relation to the current literature. Chapter Seven concludes this thesis.

## Chapter One: Background

#### 1.1 Introduction

Rehabilitation is an important component of health systems, especially so in lower and middle-income countries (LMIC) where 80% of people with disabilities live. Many of these people could benefit from rehabilitation, yet there has been little focus on this issue (World Health Organization, 2011, World Health Organization, 2017a). At a global level, recent estimates suggest one out of three people are living with a health condition or injury that could benefit from rehabilitation (Cieza et al., 2020). Similarly, over 2.5 billion people could benefit from assistive products (AP), such as hearing aids, prostheses, or wheelchairs (World Health Organization and United Nations Children's Fund, 2022a). However, access to rehabilitation and assistive products is often limited, especially for people living in LMIC, leading to high unmet need, especially for persons with disabilities. As universal healthcare has been identified as a target for Sustainable Development Goal #3 (ensure healthy lives and promotion of well-being for all at all ages), countries are encouraged to ensure equitable and timely access to quality and affordable health services, including rehabilitation (World Health Organization, 2017a). It is therefore important to identify how best to strengthen and scale up rehabilitation services in different settings, and to understand the different health system components and the supply and demand factors which may influence access for persons with disabilities.

The aim of this DrPH research thesis is to explore access to health-related rehabilitation services among persons with disabilities in the Maldives. This was accomplished through i) a secondary analysis of data from a survey to estimate unmet need for rehabilitation services among persons with disabilities in the Maldives and ii) in-depth semi-structured interviews with persons with disabilities and key informants.

#### 1.2 Global Scene

#### 1.2.1 Rehabilitation

#### Defining Rehabilitation

The World Health Organization (WHO) defines rehabilitation as "a set of measures that assist individuals, who experience or are likely to experience disability, to achieve and maintain optimal functioning in interaction with their environment" (World Health Organization, 2011). It encompasses a set of interventions to address impairments, activity limitations, and participation restrictions, including personal and environmental factors that may impact a person with disabilities' overall function (World Health Organization, 2011). Rehabilitation is an important resource for persons with disabilities and their families and it can contribute to their wellbeing as well as the social and economic development of a community (Skempes et al., 2022)There is an array of rehabilitation services across multiple sectors which may be appropriate to address the needs of persons with disabilities ranging from health care interventions, psychosocial supports, vocational training, return to work programmes, and environmental adaptations and modifications (Skempes et al., 2015).

Health related rehabilitation aims to optimise an individual's functionality and minimise the experience of disability of people with health conditions (Stucki et al., 2007). It goes beyond the medical approach to health care to embrace the lived experiences of people with disabilities (Skempes et al., 2015). Health related rehabilitation is delivered along the continuum of care ranging from primary care, hospital settings, inpatient and outpatient rehabilitation centres, and community environments. It includes a broad range of rehabilitation measures to improve health and well-being outcomes for a wide range of disabling conditions (Skempes et al., 2015). Table 1 shows the different types of health rehabilitation services, interventions, and professionals available depending on the health condition of the individual. Rehabilitation programmes range from cardiac, pulmonary, geriatrics, orthopedic, or neurological (e.g., stroke, head injury, spinal cord) and involve a

number of different rehabilitation professionals. For example, a stroke patient with right hemiplegia could benefit from working with a physical therapist to improve their functional mobility. This may include regaining the ability to walk independently with a cane outdoors to facilitate independence; for example, being able to go grocery shopping. A person with a visual impairment who attends vision rehabilitation could work with an occupational therapist to learn how to read braille or use assistive products such as speech or magnification software to facilitate their participation in school (World Health Organization, 2017b).

Assistive technology (AT) is an umbrella term covering the systems and services related to the delivery of assistive products (e.g., wheelchairs, hearing aids) and services (Orji et al., 2020). The primary purpose of assistive products (AP) is to maintain or improve an individual's functioning and independence in order to facilitate the inclusion, participation, and engagement of persons with disabilities, ageing population, and individuals living with chronic diseases in all areas of society, including family and community (World Health Organization, 2011, World Health Organization and United Nations Children's Fund, 2022a). AP can enhance performance in the different functional domains, including hearing, vision, cognition, communication, mobility, and self-care. For example, physical products include wheelchairs, hearing aids and prosthetic limbs while digital APs can come in the form of software or apps which support verbal and visual communication or time management (World Health Organization and United Nations Children's Fund, 2022a). AT is important across the lifespan. For children with disabilities, for example, access to AT can be fundamental as part of childhood development, access to education, and participation in sports and community activities (World Health Organization and United Nations Children's Fund, 2022a). With aging, many experience a decline in various functional domains (e.g., loss of hearing or vision) and require AT to allow them to continue to participate in family, employment, and social settings.

Rehabilitation and AP play an important role in the lives of some persons with disabilities. While rehabilitation focuses on improvements in an individual's

function, use of AT can help increase their independence (World Health Organization, 2011). Either on their own or together, rehabilitation and AP can facilitate the inclusion and independence of persons with disabilities.

Table 1: Example of Interventions and Rehabilitation Service Providers by Impairment

Disability	Interventions*	Rehabilitation Service Provider*
Hearing	<ul><li>Hearing aids</li><li>Cochlear implants</li><li>Sign Language</li></ul>	<ul><li>Audiologist</li><li>Ear Nose &amp; Throat Physician</li></ul>
Vision	<ul> <li>Optical aids (e.g., eyeglasses)</li> <li>Guide canes</li> <li>Life skills training</li> <li>Braille training</li> </ul>	<ul><li>Optometrists</li><li>Ophthalmologist</li><li>Occupational Therapist</li></ul>
Physical	<ul> <li>Exercise programmes</li> <li>Gait/ambulation training</li> <li>Speech/swallowing training</li> <li>Activities of daily living</li> <li>Life skills training</li> <li>Assistive technology</li> <li>Pain reduction</li> <li>Prosthetics and orthoses</li> </ul>	<ul> <li>Physical Therapy</li> <li>Occupational Therapy</li> <li>Speech Language         <ul> <li>Pathology</li> </ul> </li> <li>Prosthetics and Orthotists</li> <li>Physical         <ul> <li>Medicine/Rehabilitation</li> <li>Physician</li> </ul> </li> <li>Nursing</li> </ul>
Learning/ Cognitive	<ul> <li>Education/learning modifications</li> <li>Cognitive (re)training</li> <li>Life skills training</li> <li>Assistive Technology</li> </ul>	<ul> <li>Occupational Therapist</li> <li>Speech Language         <ul> <li>Pathology</li> </ul> </li> <li>Behavioural Therapist</li> <li>Psychologist</li> <li>Special Education Teacher</li> <li>Physical therapy</li> </ul>
Mental Health	<ul><li>Counselling</li><li>Life Skills Training</li></ul>	<ul> <li>Occupational Therapist</li> <li>Psychologist</li> <li>Psychiatrist</li> <li>Behavioural Therapist</li> <li>Mental Health Counsellor</li> <li>Rehabilitation Therapist</li> <li>Social Worker</li> </ul>

<sup>\*</sup> This list is not exhaustive. Types of interventions and rehabilitation service providers will vary depending on severity and type of disability.

The research for this thesis focuses on health-related rehabilitation (e.g., physical, intellectual, visual) rather than broader rehabilitation services for people with

disabilities such as vocational training or personal assistance. Health-related rehabilitation is not just for persons with disabilities, but a service that should be available for everyone. For example, someone may require physical therapy to recover from an ankle sprain or see an orthotist for foot orthotics to reduce low back pain. However, this research will focus primarily on persons with disabilities. AT is considered a part of this, given the important role it can play in the rehabilitation process and the independence and participation of persons with disabilities. The learning gained from this can be used to inform strengthening of health-related rehabilitation services, which will also ultimately benefit the wider population. For simplicity, health-related rehabilitation will be referred to as 'rehabilitation' in the remainder of this document and will also include AP.

#### Needs and Unmet Needs for Rehabilitation Services

There is a significant and growing need for rehabilitation services around the world, especially in LMIC (World Health Organization, 2011). At a global level, an estimated 2.4 billion people are living with health conditions that could benefit from rehabilitation and/or AT (World Health Organization, 2019b, World Health Organization and United Nations Children's Fund, 2022a). Based on data from the Global Burden of Disease report, 92% of the burden of disease in the world is related to causes that could benefit from rehabilitation services, including AT (World Health Organization, 2004a).

With population growth, an ageing population, and the increased prevalence of chronic diseases globally, the number of people experiencing functional limitations is increasing (World Health Organization, 2017b). Data from the WHO suggests that by 2050, 3.5 billion people will require the need for rehabilitation and/or AT (World Health Organization and United Nations Children's Fund, 2022a). The demand for rehabilitation services and AT already exceeds availability, leaving a large unmet need that is expected to increase (World Health Organization, 2017b).

In 2018, the WHO (2022a) developed the rapid Assistive Technology Assessment (rATA), which collects data on self-reported access to AT, to address the global data gap on AT access. Based on rATA surveys from 29 countries, including those from high and low-middle income countries, 10% to 69% of people reported a need for an AP while 3% to 90% reported they had access to APs. The need for spectacles was highest followed by hearing aids and access to APs was lower in LMIC compared to HIC (World Health Organization and United Nations Children's Fund, 2022a). Overall, the report estimates that 2.5 billion people would benefit from AT and that there are substantial inequities in access, within and between countries.

Global estimates of rehabilitation need are derived from extrapolations that are based on limited quality data. Reliable population estimates at national and subnational levels are generally lacking and when available are incomplete, inconsistent, and fragmented; comparability is often hindered by differing methodological approaches (World Health Organization, 2011). A scoping review by Kamenov et al. (2018) also found an absence of comprehensive and systematic evidence on rehabilitation needs.

#### Rehabilitation in Health Systems

The WHO defines a health system as all activities whose primary purpose is to i) promote, restore and/or maintain health; and ii) the people, institutions and resources, arranged together in accordance with established policies, to improve the health of the population they serve (World Health Organization, 2017a). A health system consists of all organisations, institutions, resources and people who deliver preventive, promotive, curative, rehabilitative, and palliative interventions through a combination of public health activities and healthcare facilities that deliver health services (World Health Organization, 2010a).

The WHO has developed the "Health Systems Building Blocks", a health systems framework which describes a health system in terms of six components and include:

1.	Leadership	and Governance
	LCGGCISIIID	and dovernance

- 3. Health Workforce
- 5. Medicines and technology
- 2. Financing
- 4. Service Delivery
- 6. Health Information Systems

(World Health Organization, 2010a)

These building blocks work together to help strengthen a health system in different ways. For example, leadership/governance and health information systems provide the basis for overall policy and regulation of all other health systems blocks. Financing and health workforce provide key input to health systems, while medical products and technology and service delivery reflect key outputs of a health system (World Health Organization, 2010a). However, for the purpose of this thesis, I will primarily focus on leadership and governance, and the rehabilitation workforce and where it intersects with the delivery of rehabilitation services in the Maldives.

Rehabilitation is often not effectively prioritized or invested in, and has been a low priority for many governments, especially in LMIC where health investments are limited (World Health Organization, 2011, World Health Organization, 2017a). This has resulted in underdeveloped and poorly coordinated services (World Health Organization, 2017a). The significant unmet need for rehabilitation negatively impacts the social and economic outcomes of healthcare, so rehabilitation within national health systems needs strengthening at all levels of care (e.g., primary, secondary, tertiary) (World Health Organization, 2017a, World Health Organization, 2018b). This is important to ensure that high quality and affordable services are available to all that need them (World Health Organization, 2017a), and is especially important in low resource settings where capacity and resources are often more limited.

There are also social and economic benefits to investing in rehabilitation as part of a health system. As a key recommendation, the WHO suggests that investment in rehabilitation can increase human capacity by allowing people with health

conditions to achieve and maintain optimal functioning, and provide them the opportunity to participate in life activities, such as employment, education or community activities (World Health Organization, 2017a). For example, Lambeek et al., (2010) found that individuals suffering from lower back pain who received comprehensive rehabilitation interventions (e.g., physical therapy, occupational therapy, medical doctor, psychology) had better social and economic outcomes in terms of improved work productivity, less work absenteeism, and improved quality of life compared to those who received information sheets only.

As an economic investment, rehabilitation programmes have been shown to decrease healthcare costs by reducing hospitalizations, decreasing length of hospital stays, and preventing further readmissions (O'Connor, 2020). For example, a systematic review by Shields et al. (2018) found that cardiac rehabilitation programmes were more cost effective (compared to no cardiac rehabilitation) in terms of reducing subsequent cardiac events (e.g., heart attack), and the costs related to hospitalization and medical interventions (e.g., cardiac bypass surgery). This in turn resulted in financial savings for health care systems.

Though there is limited reliable data on the availability of rehabilitation services and how they are implemented into health systems, studies conducted in Lesotho and South Africa found governments paid limited attention to the need for rehabilitation services (Kamaleri and Eide, 2011, Smythe et al., 2022, World Health Organization, 2004c). The WHO recognized this issue and in 2017 launched the "Rehabilitation 2030 Initiative" where it developed a series of recommendations to guide governments in developing rehabilitation services and delivering them at all levels of health systems and on all service delivery platforms (World Health Organization, 2022b). Please refer to Table 2 for a list of the recommendations.

The purpose of these recommendations was to strengthen the quality of rehabilitation by a) establishing sustainable funding mechanisms to support and maintain rehabilitation service delivery and b) advocating for a multi-disciplinary workforce (World Health Organization, 2022b). However, it is unclear to what

extent any of these recommendations are being implemented, especially in LMIC. The WHO's "Call for Action" identifies a need to fill this gap in a lack of knowledge and evidence in this area of rehabilitation.

Table 2: WHO Rehabilitation 2030 Initiative Recommendations

- 1. Creating strong leadership and political support for rehabilitation at subnational, national, and global levels.
- 2. Strengthening rehabilitation planning and implementation at sub-national, national, and global levels.
- 3. Improving integration of rehabilitation into the health sector and strengthening intersectoral links to effectively and efficiently meet population needs.
- 4. Incorporating rehabilitation in Universal Health Coverage.
- 5. Building comprehensive rehabilitation service delivery models to progressively achieve equitable access to quality services, including AP, for all populations, including those in rural and remote areas.
- 6. Developing a strong multidisciplinary rehabilitation workforce that is suitable for country context and promoting rehabilitation concepts across all health workforce education.
- 7. Expanding financing for rehabilitation through appropriate mechanisms.
- 8. Collecting information relevant to rehabilitation to enhance health information systems including system level rehabilitation data and information on functioning utilizing the International Classification of Function, Disability and Health (ICF).
- 9. Building research capacity and expanding the availability of robust evidence for rehabilitation.
- 10. Establishing and strengthening networks and partnerships in rehabilitation, particularly between low-middle- and high-income countries.

(World Health Organization, 2022b)

Some countries face significant challenges when trying to integrate rehabilitation into their existing health systems. In 2017, the WHO developed the "Rehabilitation in Health Systems: Guide for Action" to aid governments in the planning and implementation of this process (World Health Organization, 2019d). This resource guides governments through health system strengthening with a focus on

rehabilitation, facilitating leadership and planning for rehabilitation through an assessment and strategic planning process. It builds rehabilitation data and evidence through the integration of rehabilitation monitoring and evaluation in the health information system. The WHO has supported over 20 countries in strengthening their health systems to improve rehabilitation services (World Health Organization, 2022b). For example, Myanmar launched its national rehabilitation strategic plan in 2019, focusing on key areas such as increasing access to rehabilitation services, improving the rehabilitation workforce, and expanding access to AP (World Health Organization, 2019c).

#### Rehabilitation Workforce

Improving access to rehabilitation services requires addressing the key constraints related to human resources (Gupta et al., 2011). However, this is often a neglected component of health systems development (Gupta et al., 2011). Information about the rehabilitation workforce is generally lacking at both global and national level, but evidence suggests there is a major shortage of skilled rehabilitation professionals, especially in LMIC (Gupta et al., 2011, World Health Organization, 2011). Clearly, this will have a significant impact on the extent to which rehabilitation needs can be met (Gupta et al., 2011, World Health Organization, 2011).

A proxy indicator for the level of rehabilitation provision is the number of health professionals available to deliver these services (World Health Organization, 2017b). Please refer to Table 1 for a list of key rehabilitation service provider types. Although those listed are the most usual types of providers, rehabilitation can include other professions who deliver rehabilitation services in low resource settings, such as family physicians or nurses.

The WHO has found that in LMIC's skilled rehabilitation practitioner density is often below 10 per 1 million population and the number of other health professionals who can deliver rehabilitation services is also low (World Health Organization,

2017b). Figure 1 shows the significant difference in rehabilitation human resources from LMIC to high income countries (HIC).

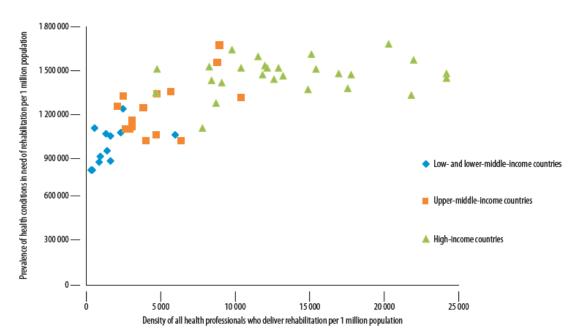


Figure 1: Density of Rehabilitation Health Professions to Prevalence of Health Conditions in Need of Rehabilitation

(World Health Organization, 2017b)

Bernhardt et al., (2020) reviewed data on rehabilitation practitioners and found a significant difference between HIC and LMIC. In Sub-Saharan Africa, for example, there are 2.5 physical therapists per 100,000 and 0.6 occupational therapists per 100,000 (Alochi, 2018, Bernhardt et al., 2020). In comparison, there are 95 physical therapists and 25 occupational therapists per 100,000 in the USA (American Physical Therapy Association, 2020, DATA USA, 2022).

The Global Atlas of Health Workforce provides information on the general health workforce; however, there is limited, if any, data available on the rehabilitation workforce (World Health Organization, 2017b). According to the WHO, data in this Atlas is generally based on sources from government or regulatory agencies and is usually incomplete or fragmented (World Health Organization, 2017b). The lack of consistent reliable data makes it difficult to develop rehabilitation human resources

guidelines or policies and can negatively impact the coordination of rehabilitation services (World Health Organization, 2017b).

#### 1.2.2 Disability

Of the many groups who may need rehabilitation, one of the largest is of those people who identify as, or can be categorised as, people with disabilities. The concept of disability is complex, multifaceted, and evolving. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) identifies persons with disabilities as:

"[people with] long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

(United Nations: Department of Economic and Social Affairs (Disability), 2006)

Perspectives of the 'Global North' tend to dominate commonly accepted conceptualizations of disability. For example, disability studies have typically been dominated by scholars from the Global North who use language based on international normative frameworks, such as the UNCRPD or the International Classification of Function, Disability, and Health (ICF) (Mbazzi et al., 2020). These frameworks are often used to discuss disability in the Global South without considering the cultural context of disabled people living there (Mbazzi et al., 2020). While understanding the conceptualization of disability in the Maldives was not an aim of this study, using these commonly accepted conceptualisations will have influenced the research process and interpretation of the data. As such, it is important to bring a critical lens to these approaches before undertaking reporting and analysing the study findings.

#### Models of Disability

There are different models of disability which align with how disability has been perceived over time (Hammell, 2006). Five models discussed frequently in the

literature will be described below, including consideration of the impact they have had on disabled persons and the rehabilitation field.

#### The Charity Model

The charity model is one of the oldest and most widespread frameworks for understanding disability (Hammell, 2006). It dates back to the Middle Ages and still exists today in many cultures and societies throughout the world (Griffo, 2014). This model is based on the notion that a person with a disability has problem that requires fixing; it suggests that disabled people are dependent, inferior and in need of help (Tsai and Ho, 2010). This idea of providing help or charity to the "less fortunate" uses the emotional power of fear, pity and guilt to raise resources for people with a disability (Tsai and Ho, 2010). As such, this model led to the establishment of charitable organisations to provide of service delivery (Griffo, 2014, Tsai and Ho, 2010).

Critics suggest that this model reinforces the idea that disability is an individual problem rather than a social issue (Tsai and Ho, 2010). It has led to segregating practices, social exclusion and the institutionalisation of disabled people (Hammell, 2006). It has strongly stigmatised individuals with a disability and made them socially undesirable (Griffo, 2014). The model does not try to change the circumstances of persons with disabilities by addressing the social, political or environmental barriers they face on a daily basis. Hammel (2006) suggests the model reinforces the relationships of superiority and inferiority and perpetuates inequality. Some also feel this this model has enabled widespread discrimination against persons with disabilities (Hammell, 2006).

From a rehabilitation perspective, charitable organisations do play an important role in providing rehabilitation services where there is a lack of services available. Tsai and Ho (2010) suggest that the involvement of rehabilitation workforce has 'professionalised' the charity model and reinforces the core assumption of the

charity model by offering services that only consider the individual attributes of a person's disability.

#### The Biomedical Model

The biomedical model views disability as a 'problem' of the individual and the consequence of an impairment in body structure or function. This implies the need for a medical or rehabilitation intervention from a specialised healthcare professional, such as a physiotherapist, to 'improve, fix or cure' the 'problem' and return the individual back to as near 'normal' function and independence as possible (Haegele and Hodge, 2016, Mitra, 2006). Taking an individualistic approach to rehabilitation, it is this model which has heavily influenced the conceptualisation of disability in the rehabilitation field (Gibson, 2016).

A key criticism of this model is that it sees the problem as one of the individual. There is an emphasis on the need for the individual to adapt to the environment rather than recognising the impact society and environment have on creating the disability. Another criticism of this model is its focus on normalization at an individual level. Hammel (2006) suggests that the goal of 'normality' reflects the dominant standards and values of ableist societies which may not be in the best interest of persons with disabilities. It confers power to the medical/rehabilitation professionals who impose their own valuative norms on disabled persons in order to make them appear 'normal' in society regardless of the consequences.

#### Social Model

Unlike the biomedical model, the social model sees disability as a social construct (Palmer and Harely, 2012). In this view, an individual's impairment is not the problem, but rather the 'disability' is created by the social environment that does not accommodate the individual; this in turn prevents the disabled person from functioning in their society (Haegele and Hodge, 2016, Palmer and Harely, 2012). This model is socially and politically positioned in the disabled persons' movement

and activism for change, and it situates disability as a form of social oppression. It puts the disabled person in control of their own lives (Berghs et al., 2016). For many in the disability field, this model is seen as a positive move forward and provides a new perspective of the lived experience of those whom society labels 'disabled'.

However, critics suggest this model fails to address the significance of having an impairment as a visible feature of an individual that is an important facet of their lived experience (Hammell, 2006, Palmer and Harely, 2012). They argue the social model artificially separates impairment from disability and does not consider, for example the pain and fatigue some persons with disabilities experience which can limit their ability to participate in society (Hammell, 2006). The social model also suggests that the impairment is not the problem – that people are disabled by society – where Shakespeare (2014) notes that rather than opposing medicalisation, the model can be interpreted as rejecting medical prevention, rehabilitation, or cure of impairment.

The social model is also based on the belief that it is possible to remove the barriers (e.g., physical, social, economic) which negatively impact the lives of persons with disabilities. Shakespeare (2010) suggests that the concept of a world in which people with disabilities live free of environmental barriers is difficult to operationalise. While the aim of removing barriers is to facilitate participation and improve the quality of lives of persons with disabilities, it is not always practical or feasible where resource constraints can make it difficult to overcome these barriers (Shakespeare, 2014). For example, a public library may not be able to offer all books in different formats (e.g., Braille, large print) visually impaired individuals may require due to high costs. The London Underground system, initially built in the 19th century, would require a huge financial investment to make all eleven lines and over 270 tube stations accessible for wheelchair user (Shakespeare, 2014). Though certain accommodations can be made (e.g., some books are available in Braille upon request or wheelchair accessible buses), not all barriers can be removed and persons with disabilities will continue to experience barriers in their lives (Shakespeare, 2014).

From a Global South perspective, Grech (2009) suggests the social model is based on the concerns of western, white, urban, educated disabled academics in industrialised settings and it runs the risk of being contextually and culturally inappropriate. The model makes inferences from the western context about the presumed situation of persons with disabilities in LMIC and does not consider where these individuals live, their concerns, or the political environment they live in (Grech, 2009). It misses out on the context-specific issues, such as the role and influence of community and culture, dependence on natural resources, vulnerability to environmental stresses, chronic poverty, household disadvantages, and geographical distribution when the model is viewed through the industrialist and individualised lens of the west (Grech, 2009).

However, it is important to understand that more than one "social model" of disability currently exists in the disability literature. Though I have used the UK social model of disability for the basis of this DrPH thesis, I will briefly describe the three predominant models, which include the United Kingdom (UK), North American, and Nordic, each with different origins and orientations.

As previously discussed above, the UK social model sees disability as a social construct and suggests that all persons with disabilities experience oppression (Owens, 2015, Shakespeare, 2014). It originated in the 1970s through an association of the Union of Physically Impaired Against Segregation (UPIAS) and the Disability Alliance where their aim was to consider how persons with disabilities could become active members of society (Shakespeare, 2014).

The North American social model defines disability as the failure of a structured social environment to adapt to the needs of persons with disabilities rather than from the inability of disabled persons (Owens, 2015). This model is linked to the disability rights movement, coinciding with the Civil Rights Movement of the 1960s against racial segregation and discrimination (Owens, 2015). It uses a minority group rights-based approach with political action being based on the

individualisation of disabilities and omits the UK model of oppression (Owens, 2015).

There are slight differences between the UK and North American models. While the North American model explores the social, cultural and political dimensions of disability, it does not distinguish between impairment and disability – which the UK model does (Owens, 2015). The UK literature focuses on issues of equality in political and material participation while the American literature focuses on more issues of "psychology, identity, personal affirmation and moral development" (Owens, 2015).

Finally, the Nordic Social Relative Model evolved from the 1960s as a result of the welfare state which evolved by focusing on the entry of women into the labour market and family policies (Owens, 2015). It conceptualises disability as a relation between an individual and the environment, encompassing both social and material factors (Lid, 2013). It looks at a person-environment mismatch, where a gap is created (Lid, 2013). Thus, the relational model theorises disability as a gap (Lid, 2013). The model suggests that disability exists on a continuum shifting between the individual and their environment (Owens, 2015). It focuses on the individual's capacities and abilities rather than being the defining characteristics of the individuals (Owens, 2015).

The development of these different models originated from similar time frames but from diverse historical, intellectual, and political positions, creating contrasting interpretations (Owens, 2015). However, a key aspect of all forms of these social models is the role of the environment in creating barriers to participation — whether in persons with disabilities' everyday lives, healthcare, or policy (Owens, 2015).

Returning to a rehabilitation perspective, some critics have suggested that rehabilitation professionals are more aligned with the biomedical model, typically ignoring the social, economic, and political environments of the disabled person

and addressing only the individual impairment. Persons with disabilities have reported feeling undervalued, pressured to fit a specific 'norm', or treated as if they were globally incapacitated when interacting with rehabilitation professionals with a biomedical understanding of disability (Goering, 2015). However, Gibson (2016) argues that health-related rehabilitation providers do consider the social and physical barriers a disabled person lives with (although they generally omit issues at a political level). Gibson acknowledges that the social and physical barriers are addressed at the individual level but does not consider the barriers at the structural or institutional level. For example, as Hammel (2006) suggests, physical rehabilitation professionals generally focus only on teaching new mobility skills, depending on impairment, to enable functioning in an able-bodied environment. The onus is on the disabled persons to learn to adapt to the environment, rather than the environment adapting to the disabled person (Hammell, 2006). As teaching new mobility skills is a significant component of rehabilitation, there is a need for greater awareness of social and rights-based models of disability to improve rehabilitation practice.

#### Human Rights Model

Article 25 of the UNCRPD states that persons with disabilities have the right to access good quality and appropriate health services, including rehabilitation, without discrimination on an equal basis to nondisabled persons (United Nations: Department of Economic and Social Affairs (Disability), 2006). This legally binding international rights treaty provides the framework which should govern access to healthcare for persons with disabilities (Shakespeare et al., 2018). Although the UNCRPD has been ratified by 185 countries, evidence indicates that persons with disabilities continue to experience a number of barriers when accessing healthcare services, especially those with lower socio-economic status living in the global south (Nowrouzi-Kia and Yazdani, 2016). Lack of government disability laws and policies and negative societal attitudes leads to or increase barriers to inclusion of, and representation of, persons with disabilities (Meekosha and Soldatic, 2011).

Similar to the social model of disability, a human rights model also recognises disability as a social construct. The approach to rehabilitation looks beyond a person's impairment and towards societal norms, practices, and structures (Nowrouzi-Kia and Yazdani, 2016). It emphasises that persons with disabilities should be able to participate equally in decision-making activities which involve them (Katsui, 2008). To fully realise a human rights approach to rehabilitation requires the development and implementation of policies, legislation, regulations, and practice in health and rehabilitation to ensure the principles of the UNCRPD are upheld (Tompa et al., 2022). According to the WHO, understanding health and rehabilitation as a human right places states under a legal obligation to ensure all people have access to appropriate healthcare and to address the underlying determinants of health, such as safe water, food, housing, and gender equality: factors which can have a significant impact on the experience of disability (World Health Organization, 2017c).

However, critics suggest there is a downside to the human rights model for disability. For example, the term 'human rights', is vague and therefore difficult to operationalise. Furthermore, a human-rights approach is generally "one-size-fits-all" and does not consider the social, political, and historical conditions of a situation (Katsui, 2008, Kennedy and Mayhew, 2004). In some settings, the stigma around disability can complicate the operationalization of the human rights process (Katsui, 2008).

#### The International Classification of Functioning, Disability and Health (ICF)

In an attempt to integrate the biomedical and sociopolitical factors of disability, the WHO adopted the ICF in 2001 (Gibson, 2016). This framework conceptualises function and disability as a dynamic interaction between health conditions and contextual factors, both personal and environmental (World Health Organization, 2011). It views disability as an umbrella term for impairment, activity limitations and participation restriction, referring to the negative interaction between an individual (with a health condition) and their contextual factors (environmental and

personal) (World Health Organization, 2011). (See Figure 2) For example, a person with right hemiplegia due to a stroke (health condition) may have difficulties walking (activity) because of leg weakness (body function). They may not be able to attend their place of employment (participation) because of environmental issues (e.g., workplace not accessible) or personal factors (e.g., self-esteem issues; stigma).

Body Functions and Structures

Activities Participation

Environmental Personal Factors

Figure 2: International Classification of Functioning, Disability, and Health

Source: https://www.cdc.gov/nchs/data/icd/icfoverview\_finalforwho10sept.pdf

From a rehabilitation perspective, the ICF shifts from a biomedical perspective to a person's lived experience (Stucki, 2021). It standardises terminology and definitions in the rehabilitation and disability fields which can help guide research and data collection, as well as making them comparable. It also provides scientific standards to inform local, national, and international policies (Berghs et al., 2016, Hammell, 2006, Madden and Bundy, 2019, Palmer and Harely, 2012).

However, the ICF is a classification system, and as such, relies on statistical norms to define a human dysfunction and disability where these norms are based on the experiences of people without specific disabilities or health conditions (Gibson, 2016). Critics argue that the ICF does not consider the role of the environment in the creation of impairments (Hammell, 2006). According to Hammell (2006), the ICF sees the environment as impacting the individual but not the disease or disorder even though many of these diseases, illnesses or injuries are caused by the

environment, such as wars, violence, poverty or pollution. There is also no capacity to examine the broader social, political, legal or economic impact or the impact of the environment on the social disadvantage, oppression and marginalisation experienced by persons with disabilities (Hammell, 2006).

#### Exploring the Implications of Critical Disability Studies and Rehabilitation Science

Critical Disability Studies and Rehabilitation Science occupy opposite ends of the continuum. While Critical Disability Studies takes a critical view towards the 'production' of disability, Rehabilitation Science takes a medical approach, seeing disability as a problem requiring an intervention (Molesh, 2019 Nov, Ned et al., 2021). Those involved in academic research or service provision would acknowledge a tension exists between the epistemological positions of both Critical Disabilities Studies and Rehabilitation Studies. It is this tension that needs to be acknowledged in order for the needs of persons with disabilities to be effectively addressed.

Briefly, Critical Disability Studies (i.e., UK social model) views disability as a social construct. It considers the cultural representations and the policies and practices of societies to understand the social, economic, and political elements of disability (Gibson, 2016). Although Critical Disability Studies acknowledges that persons with disabilities may require some intervention for their individual impairment, this approach challenges the idea that persons labelled as disabled are socially and economically marginalised as a result of their impairment. So, from this perspective, 'disability' is a social construct not simply an individual experience (Goodley, 2014).

I am deeply rooted in the biomedical model of disability (due to my physical therapy training). Based on a positivist epistemology, I have typically focused on a disabled person's impairment and determined an appropriate intervention to 'fix' the problem (Gibson, 2016). The aim is to restore the individual to a state that is as close to 'normal' as possible (Hammell, 2006). This view is seen by some critics as

strongly normative suggesting people are considered disabled since they are unable to function as 'normal' people do (Haegele and Hodge, 2016, Mitra, 2006). Gibson (2016) suggests that 'normality' is socially ingrained and affects rehabilitation practice. Though rehabilitation science focuses on disability, it generally does so at the individual level without acknowledging the larger physical, social, political and economic themes that create the disabling environment (Gibson, 2016).

#### 1.2.3 Access to Health Services

The concept of access in health services is complex. The literature contains varying interpretations of this concept and there is no universally accepted definition for it (Aday and Andersen, 1974, Jacobs et al., 2012, Levesque et al., 2013, O'Donnel, 2007, Oliver and Mossialos, 2004, Penchansky and Thomas, 1981, Peters et al., 2008). For example, Aday and Andersen (1974) define access as entry into the health system. This definition appears to only look at the individual's attempt to access the health system without considering the impact on access of the health system as a whole. Penchansky and Thomas (1981) define access as a degree of 'fit' between the clients and the system. This definition suggests that access is more complex than just an individual's attempt to access the health system, but it is instead the result of an interaction between the individual user and the health system. Building on this, Peters et al. (2008) view access linked to the timely use of services according to need. Peters' definition adds another level of complexity to the definition of access by adding a time element from supply and demand perspectives. Levesque et al., (2013) defines access as the interface between the characteristics of persons, households, physical and social environments and that of the service provider, organisation, and health system. Developed from previous research, this definition identifies the complex factors of access during a person's journey along the healthcare access continuum. It also includes factors from the health system which may impact access for the individual.

There are also a number of different access frameworks in the literature. However, none specifically for access to health-related rehabilitation services. Therefore, I will draw on current access to health services frameworks for the purpose of this thesis.

In terms of different access frameworks, Margolis et al., (1995) created a model of access to health services for socially disadvantaged children using three dimensions: structural, financial, and personal. While this model focused on a specific population group, it only considered three access dimensions. Also, factors within each dimension were broad, covering many areas of access. For example, the structural dimension included physical availability, national health insurance provision, continuity of care and transport.

Peters et al.'s (2008) conceptual framework is based on the works of Aday and Andersen (Aday and Andersen, 1974), Penchansky (1981) and the WHO (1978). It identified four dimensions: geographic, availability, financial, and acceptability of services from both users and suppler sides. Quality of care is at the centre of the dimensions as Peters argues that quality is related to the technical ability of the health services to affect an individual's health. A key strength of this framework is that it more explicitly considers the capacities of the user of the health service. It also recognises the wider influences of policy and the macroenvironment (e.g., political, economic, etc.) as well as individual and household characteristics (e.g., poverty) which are not always considered in other access frameworks. However, critics suggest this framework is missing certain elements of access. For example, Jacobs et al. (2012), felt that healthcare workers' attitudes and interpersonal skills, referral systems and task restrictions were vital aspects of access to care and were missing in Peters' framework.

The concept of access has evolved over time, but without a consensus on definitions and frameworks, measuring access is challenging. However, an increasingly recognized conceptual access framework used in the literature today is by Levesque et al. (2013). In this framework, access is seen as the opportunity to reach and obtain appropriate health services when there is a perceived need for

care. This framework highlights the complex and interacting factors from both supply and demand sides that can influence access to healthcare services in order to meet someone's health needs. The framework consists of five supply dimensions and the associated abilities of individuals when they interact with the health service. See Figure 3 below for details of framework. This framework highlights the complexity and interactions of factors from both the supply and demand sides, that can influence access to healthcare services to meet the health needs of an individual. Refer to Appendix 1 for definitions of Levesque's (2013) access dimensions and abilities of persons to interact with access dimensions.

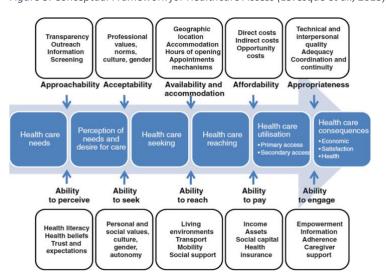


Figure 3: Conceptual Framework for Healthcare Access (Levesque et al., 2013)

Because of its comprehensive nature, the framework can be helpful in identifying facilitators and barriers to access from both the health system/healthcare provider and user perspectives. This can help policymakers, health organisations and service providers to identify and improve access and support within the health system for those who require healthcare.

A scoping review by Cu et al. (2021) on Levesque's framework's use in the literature identified some challenges. While the framework's multifaceted and comprehensive approach to access can be considered a strength, its complexity of it can also create a challenge in the context of quantitative data collection. For example, some researchers found it difficult to categorise health access questions

or data into one dimension or ability to access. A question or data may cover two or more dimensions. For example, an individual cannot access healthcare because the facility is located too far away. Is the identified barrier due to geographical distance (e.g., availability) or due to the cost required to travel (e.g. affordability)? However, this may reflect the fluid and complex nature of access to health services from both the health system or user perspectives and perhaps lends itself well to qualitative research. Another challenge of the framework is its inability to consider time factors related to access. For example, patient waiting time or travel time is not necessarily a consequence of distance. Therefore, it is difficult to determine how to classify dimension or ability time factors (Cu et al., 2021).

The framework has been previously used in a variety of settings, ranging from access to antibiotic treatment, perinatal care, or primary care for different population groups (e.g., maternal, indigenous, and migrant) (Cu et al., 2021). However, it appears to have received limited use in research on disability or rehabilitation. For example, one study looked at caregivers' experience accessing oral care for children with cerebral palsy (Abduludin et al., 2019). A few studies have looked at access to mental health services for persons with different mental health conditions (e.g., anxiety, depression) (Corscadden et al., 2018, Packness et al., 2019). A study by Kurpas et al. (2018) looked at access to health and social care, which also included rehabilitation services, for the elderly. The majority of studies were carried out in high income countries (HIC), with few in low and middle income countries (LMIC).

Because of its comprehensive approach to access and its consideration of both supply and demand perspectives on access, Levesque et al's., (2013) definition and conceptual framework will be used to underpin this research, including their access terminology (e.g. abilities of persons). Since there is limited use of the framework in disability and rehabilitation research, this research can add to the repertoire of literature in these fields.

#### 1.2.4 Access to Rehabilitation Services for Persons with Disabilities

In addition to higher general healthcare needs, some people with disabilities may also require specialist health services related to their impairment, including rehabilitation. As previously discussed at the start of this chapter, access to rehabilitation is often limited for persons with disabilities in LMIC. This has resulted in a high unmet rehabilitation need for this population group. Though research is available to show the benefits of rehabilitation for persons with disabilities (e.g., stroke, cardiovascular disease), there is limited research in the area of access to and influencing factors on rehabilitation services for persons with disabilities in different settings, including LMIC. The following section will review the current literature in terms of access to rehabilitation, factors influencing access to rehabilitation services, and unmet rehabilitation need for persons with disabilities.

A recent systematic review by Bright et al., (2018) highlighted limited and inconsistent research on access to rehabilitation for people with disabilities in LMIC. Their review defined 'access' as use and coverage of services and included only quantitative studies. The evidence suggested coverage among those needing services was generally low and varied across countries. For example, access to visual rehabilitation ranged from 0% to 82%, while access to hearing specific services ranged from 0% to 66%. The authors highlighted that the outcomes to measure access to rehabilitation, including measures of impairment/disability, varied considerably, making comparison and generalisability difficult. Similarly, another systematic review of coverage (e.g., effectiveness, accessibility, availability) of mental health programmes by De Silva et al., (2014) found a lack of empirical evidence, with no studies from LMIC, and highlighted the methodological difficulties of estimating coverage. Finally, Danemayer's et al.'s (2022) systematic review estimating need and coverage of AP for five assistive products found that there is a high unmet need (>60%) for hearing aids, limb protheses, wheelchairs, eyeglasses and personal digital assistants. However, the authors noted methodological and reporting variations among the studies in their review, as well

as discrepancies in how key terms related to AP access were defined. As such, this, too, led to variations when estimating need for AP, especially in LMIC.

#### Factors influencing access to Rehabilitation for People with Disabilities

Barriers to access are those factors that contribute to preventing an individual from utilizing a health service when required (Scheer et al., 2003). They are likely to be multi-factorial and influenced by contextual factors. Barriers can impact different population groups as well as different impairments and/or diseases. Current research suggests that people in LMIC more often experience substantial barriers to health services than those from HIC (Peters et al., 2008). While there is growing evidence on barriers to access to general health services for persons with disabilities, there is limited research on factors that influence access to rehabilitation for people with disabilities in LMIC (Baart and Taaka, 2018, Bright et al., 2017a, Jacobs et al., 2012, O'Donnel, 2007, Scheer et al., 2003, Waterworth et al., 2022, World Health Organization, 2011).

As one of the most marginalized groups in society, persons with disabilities can face additional complexities and range of barriers, such as physical, financial, or institutional, which can impact their ability to access rehabilitation services (Shakespeare et al., 2018, World Health Organization, 2011). For example, physical barriers may include stairs without a ramp, narrow pavements, or dim room lighting. Users fees for health services or childcare fees are examples of financial barriers, while government legislation or polices that discriminate against people with disabilities are examples of institutional barriers. While people with disabilities are a diverse group and comprise individuals with different impairment types and other characteristics, they may be particularly vulnerable to certain types of barriers to accessing services (Shakespeare et al., 2018). For example, cost barriers are likely to disproportionately affect persons with disabilities considering they are, on average, poorer and more marginalized and often incur additional costs associated with living with a disability (Banks et al., 2020). These

compounding issues can make it significantly more difficult for persons with disabilities to access rehabilitation they require.

Bright et al.'s (2018) systematic review of 77 quantitative studies on access to rehabilitation for persons with disabilities in LMIC found only 22 evaluated what the barriers to access were, as secondary outcomes. Commonly reported barriers included geographical accessibility (e.g., distance to service, lack or cost of transport), financial (cost of services, lack of health insurance), and acceptability (e.g., lack of awareness of service). The authors pointed out that many of the identified barriers were not unique to the disabled population; however, they found particular acceptability barriers were disability related, including discrimination from health provider, provider's lack of skills, and communication barriers (e.g., lack of sign language interpreter). However, this systematic review did not explore the 'lived experiences' and perspectives of the respondents and their attempts to access rehabilitation (Raham, 2016b).

Other research suggests a range of interacting factors that are likely to influence access to rehabilitation services for people with disabilities. For example, a qualitative study in Malawi explored reasons for low uptake of referrals to hearing services (e.g., hearing aids) among children and identified the interplay of multiple challenges including transport difficulties, financial costs, and lack of information regarding the referral (Bright et al., 2017b). However, generally there is limited research exploring in-depth the barriers and facilitators to access, or experience of using, rehabilitation services for people with disabilities in different LMIC settings. It is important to understand these in their specific contexts in order to develop locally appropriate strategies and maximise access.

Limited research is available on factors which facilitate access to rehabilitation for persons with disabilities. A recent scoping review by van Biljon et al., (2022) on access to public healthcare rehabilitation in South Africa identified a number of factors which facilitated access for persons with disabilities. Family and community support was a key factor, followed by government financial support in the form of a

disability or childcare grant (persons with disabilities could use this to cover the cost of transportation, childcare, and rehabilitation services).

#### Disability, Gender and Poverty and its Impact on Access

According to Banks et al., (2016), disability and poverty are interrelated and can operate in a cycle where one reinforces the other. For example, conditions linked to poverty, such as unsafe housing conditions, lack of access to clean water, sanitation or healthcare, can increase the risk of being born with or acquiring a disability (Banks et al., 2016). In turn, people with disabilities are at a higher risk of exclusion from education, employment, or healthcare, or can incur higher healthcare cost and other disability-related expenses. This can further exacerbate economic and other multidimensional forms of poverty (Banks et al., 2016).

Recently, the Global Burden of Disease Report (2019) identified that women accounted for over 50% of the estimated 2.4 billion people who live with a health condition where rehabilitation could benefit them (Cieza et al., 2020). The World Health Survey suggests there is a higher disability rate among women compared to men in LMIC (World Health Organization, 2011).

Research on the intersection of gender, disability and access to health services is limited. There is a dearth of evidence available on the different challenges women with disabilities face when trying to access impairment-specific rehabilitation services. However, current evidence suggests that, compared to men, women with disabilities living in poverty face unique access barriers to health services. As such, women with disabilities are more likely to have higher unmet healthcare needs (Matin et al., 2021).

Matin et al., (2021) completed a systematic review on access barriers to health services for women with disabilities and identified several barriers unique to this population group. They found that women with physical, sensory, or cognitive impairments felt their ability to seek and understand the information they needed

for their health was limited. Several encountered healthcare professionals who were discriminatory or disrespectful towards them, and also lacked awareness and knowledge about their disability. Most of the healthcare workers did not have appropriate communication skills, which limited disabled women's ability to effectively interact with these individuals. A lack of adaptable equipment or insufficient time with healthcare providers was also highlighted as a barrier for women with a disability. However, financial dependency was considered one of the most significant access barriers for disabled women. Many were unemployed and did not have an income, and therefore, had to rely on household income to pay for services. Since many lived in low-income households, they could not afford to access these health services and would go without. Some noted they had to spend more on specialised transport services because they were unable to use public transportation (e.g., bus, train).

Further research in this area is needed in order to understand the specific barriers encountered by women with disabilities when accessing rehabilitation services.

## 1.2.5 Unmet Need for Rehabilitation for Persons with Disabilities

As previously discussed, the need for rehabilitation services is expected to increase due to an aging population and increased prevalence of chronic diseases at a global level (Kamenov et al., 2018, World Health Organization, 2019b). However, there is very limited global data on need for rehabilitation services or estimates of unmet need (World Health Organization, 2011). Understanding this 'need' is important to ensure appropriate and timely rehabilitation services are available to persons with disabilities in a timely manner.

'Need' has been interpreted in the literature as the capacity to benefit from healthcare (Allin et al., 2010, Smith and Connolly, 2020). Levesque et al., (2013) identified the perception of need as a part of the access journey and suggests that the ability to perceive need is important and determined by factors such as health literacy and knowledge and beliefs about health and sickness.

However, defining 'unmet need' in healthcare has been difficult (Allin et al., 2010, Smith and Connolly, 2020, World Health Organization, 2011). It is a complex concept, and without a universally agreed upon definition, measuring unmet need has been a challenge in rehabilitation and other health services research (Allin et al., 2010, Boggs et al., 2021b, Cavalieri, 2013, Pryor et al., 2018, Smith and Connolly, 2020). Definitions that exist in the literature view unmet need as the difference between the health services judged necessary to deal appropriately with a defined health problem and the actual services received (Carr and Wolfe, 1976, Smith and Connolly, 2020). Using a clinical assessment, unmet need was determined by a medical professional (Carr and Wolfe, 1976, Cavalieri, 2013, Smith and Connolly, 2020).

Research on unmet need links it to barriers to access (e.g., availability, acceptability) (Chen and Hou, 2002, Pryor et al., 2018, Tan, 2015). However, most research does not disaggregate the data into different categories of unmet need. Without this differentiation, it is difficult to understand why individuals may not seek out services for personal reasons (e.g., job restrictions) vs. structural issues (e.g., long wait times) and where specific interventions (e.g., health policy) should be implemented (Allin et al., 2010, Smith and Connolly, 2020).

To understand the issues creating unmet need, Allin et al., (2010) conceptualised unmet need into five different categories. (See Figure 4) They defined it as when an individual does not receive an available and effective treatment that could have improved their health. To determine unmet need, a subjective assessment was created. Allin et al., (2010) felt that individuals are better able to estimate their health status and identify any shortcomings they experience in the health system.

Figure 4: Classification of Unmet Need (Allin et al., 2010)

Category	Туре	Definition
1	Unperceived unmet need	An individual does not perceive they need health care. For example, they have hypertension without symptoms but would require a clinical intervention for detection.
2	Subjective, chosen unmet need	An individual perceives themselves as in need of a health intervention but choose not to demand the health services available. For example, an individual seeks alternative complementary medicine approaches (e.g., homeopathy)
3	Subjective, not- chosen unmet need	An individual perceives themselves as in need of a health intervention but does not because of access barriers. For example, individual lives in a remote area and cannot afford to travel to health facility.
4	Subjective, clinician- validated unmet need	An individual perceives a need for health intervention, accesses health care but does not receive treatment a clinician would judge appropriate. For example, individual without a family doctor may not be effectively treated in a walk-in clinic or emergency department.
5	Subjective unmet expectations	An individual perceives themselves as in need of health intervention, accesses care but perceives care as not suitable. For example, an individual experiences poor quality services in search of appropriate diagnosis or treatment for ailment/disease.

These five categories reflect different mechanisms (e.g., awareness, individual choice) where unmet need can arise and help to differentiate problems creating unmet need. Allin's (2010) definition and conceptualization of unmet need is used to guide this research in the context of unmet rehabilitation needs.

# 1.2.6 Disability and Access to Rehabilitation in Small Island and Developing States

Small island and developing states (SIDS) are a distinct group of 39 states and 18 associate members of the United Nations regional commissions. They are located in three geographical regions in the world: 1) Caribbean, 2) Pacific, and 3) Atlantic, Indian Ocean, and South China Seas (AIS) (United Nations, 2024a, United Nations, 2024b). Please refer to figure 5 for a map of SIDS. The Maldives is a part of the AIS. While the aggregate population of SIDS is approximately 65 million (less than 1% of the world's population), these nations are far from similar.

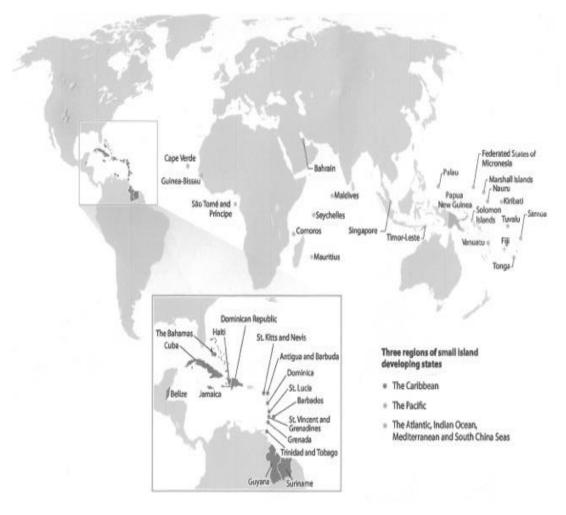


Figure 5: Map of Small Island and Developing States

(Thomas et al., 2020)

There are significant differences in territorial area, governance systems, economic development, and geographical characteristics (Thomas et al, 2020). However, SIDS each face social, economic, environmental vulnerabilities (United Nations, 2024a). These countries are characterised by their narrow economic base, high production costs, shortage of skilled labour, and heavy dependence on foreign trade (Suzana et al., 2018). Most SIDS economies rely on tourism, fisheries, and agriculture. For example, coastal-based tourism makes up more than 20% of national gross domestic product for more than half of SIDS. As such, these SIDS are particularly vulnerable to changes in the environment (Thomas et al., 2020). Other factors such as small population size, remoteness from international markets, high transport costs, and fragile lands and marine ecosystems make SIDS vulnerable to biodiversity

loss and climate change because they lack economic alternatives (United Nations, 2024a).

Healthcare access in SIDS vary and are dependent on a number of different factors including geography, population size, and how each country or territory's healthcare system is developed and resourced. Because of their smaller economies of scale, many SIDS experience shortage of medicines, healthcare workers, and health facilities (Suzana et al., 2018). Not only does this impacts their ability to establish UHC programmes, but it also impacts the availability and access to these services for people requiring them. For example, Singapore has a population of five million. It has a well-resourced health system, along with a UHC programme, where its citizens can access primary, secondary, and tertiary in both the public and private sectors, and with minimal, if any, out of pocket payments (Legido-Quigley and Asgari-Jirhandeh, 2018, Tan et al., 2021). Conversely, Tokelau is a small island in the Pacific region and a dependent territory of New Zealand. It has with a population of 1500. While the country has UHC, its health system relies heavily on international aid, including grant money from New Zealand, to fund it (Somani, 2020). Currently, the territory has 3 small health centres which only provide primary care services and some basic secondary services (e.g., blood tests, x-rays). Anyone requiring secondary or tertiary care must go abroad with limited financial assistance from the government. Since there is no airport in Tokelau, individuals must take a 24 hour boat ride to Samoa to seek healthcare services (Malfie'o et al., 2019, Somani, 2020).

This comparison highlights the significant differences in SIDS health systems and demonstrates the type of healthcare services provided. Like the Tokelau example above, some SIDS are so small, it is difficult for governments to justify the cost (including equipment and healthcare workers) of providing some healthcare services (e.g. oncology) (Sarfati et al., 2019). Since a majority of SIDS receive high levels of overseas development assistance and have established bilateral/multilateral trade agreements with other countries, this has been a

strategy smaller SIDS have used to overcome the domestic healthcare shortages (Suzana et al., 2018).

There is limited research on accessing rehabilitation services for persons with disabilities living in SIDS. However, many SIDS, regardless of population size, face similar issues to other LMICs when it comes to providing rehabilitation services for persons with disabilities. This includes limited government support and funding, disability and rehabilitation laws and policies, and rehabilitation workforce. In 2017, the WHO did a review of disability and rehabilitation/AT in the Western Pacific including the Pacific Region SIDS (World Health Organization, 2017d). The purpose was to look at each country's capacity to deliver rehabilitation for persons with disabilities. Overall findings suggested that few rehabilitation services were available in the low and middle income SIDS compared to HIC SIDS. Physiotherapy was the most predominant rehabilitation service across all SIDS compared to other rehabilitation services (e.g., OT, SLP, audiology, prosthetics and orthotics). Few rehabilitation polices or national rehabilitation, limited rehabilitation workforce and a lack of government priority and financial commitment were identified as factors limiting access to rehabilitation for persons with disabilities. The study also suggested that smaller economies of scale and small populations were factors impacting the availability of both health and rehabilitation services for persons with disabilities.

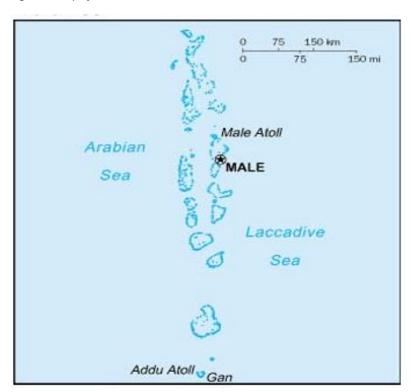
Walker et al. (2022) found similar findings with access to mental health services in SIDS in the Caribbean Region. While mental health services were available in these SIDS, those countries with smaller populations and economies were underresourced; this, in turn, impacted the availability of mental health personnel and facilities. Mental health was not considered a priority by governments as reflected in the limited number of mental health policies or national strategies being implemented and lack of government funding for mental health programmes within the health systems. The lack of service availability and the stigma associated with mental health in the Caribbean region, resulted in a high treatment gap, with many individuals in need of mental health services unable to access them.

## 1.3 The Maldives

## 1.3.1 Background

The Republic of Maldives is located in an archipelago of approximately 1,190 low-lying coral islands located in the Indian Ocean, located 600 kilometres southwest of India. The islands are grouped into 26 atolls spread across 289 square kilometres. Refer to Figure 5 for a map of the country. The current population is 391,000 (2021); approximately one third live in Malé, the county's capital city and 10% in Addu City, while the remainder of the population is spread over the 180 populated islands (U.S. Federal Government, 2022). The country's main industries include tourism and fishing (U.S. Federal Government, 2022). The country's Gross National Income per capita is \$15,130 (USD) (2017) and it is classified as an Upper Middle - Income Country by the World Bank (U.S. Federal Government, 2022). Ninety percent of the population is under the age of 55 years (U.S. Federal Government, 2022).

Figure 6: Map of The Maldives



#### 1.3.2 Disability in The Maldives

A recent survey found the prevalence of disability is 6.8% (Banks et al., 2020). In 2010, the Maldivian government passed the "Law on Protection of the Rights of Persons with Disabilities and Provision of Financial Assistance". It was designed to prohibit any form of discrimination based on disability and to protect the rights of persons with disabilities. In that same year, the country also ratified the UNCRPD (World Health Organization, 2010b). Since then, the Maldivian government has made progress to ensure the rights of persons with disabilities are protected. The National Social Protection Agency (NSPA) administers the national social health insurance scheme, Aasandha, and social protection programmes. It also oversees seven financial assistance programmes, of which three address persons with disabilities (National Social Protection Agency, 2019). Specifically, the Disability Allowance provides financial assistance to persons with disabilities while the Aasandha and Medical Welfare programmes are intended to ensure free medical assistance and some financial assistance for medical equipment (National Social Protection Agency, 2019). See section 1.3.4 below for a description of these social protection programmes for persons with disabilities.

## 1.3.3 The Maldives Healthcare System

The description of the health system that follows is informed by document review as well as observations and informal conversations with key informants that took place during the data collection period.

The Maldives health system is organised into a three-tier system based on the following: i) island level primary care centres; ii) higher level health centres providing secondary care at the atoll level (each atoll serves up to 10 islands); and iii) tertiary care at a central/regional level (each region services 3-4 atolls). The country is divided into six regions, each with a number of atolls (Maldives Ministry of Health, 2021). The distribution of secondary and tertiary health facilities is based on population, patient load, and distance to hospital. However, there are primary

health posts on every island, regardless of population (Maldives Ministry of Health, 2021, Maldives Ministry of Health, 2014).

The private sector and health-related non-governmental organisations (NGOs) also play an important role in the delivery of health services in the country. This includes hospitals and clinics providing health services, including rehabilitation, that may not be available in the public health system. For example, based on informal conversations with key informants, while the public health system includes medical assessment for individuals with autism spectrum disorder, longer term rehabilitation services are only available in the private or NGO sectors. Individuals requiring these services cover the cost of these programmes themselves.

A grading criterion for primary care centres and public and private hospitals determines the level of specialised health services offered. Regional and atoll hospitals act as the main coordinating body in providing general and specialised health services for that atoll. Each atoll health centre covers a population from 5,000 - 15,000 people (Maldives Ministry of Health, 2021).

Below is a brief description of each level of care (Maldives Ministry of Health, 2021, Sri Balakrishnan and Caffrey, 2022, Suzana et al., 2015):

1. Primary care - there are 164 publicly funded primary care health posts in the country, one centre located on each island. The services provided include medical exams and investigations, immunisations, antenatal care, and medication. In terms of rehabilitation services, healthcare professionals (general practitioners, nurses, pharmacists, lab technician, community health workers, family health workers) provide basic physical, vision, hearing, cognitive and mental health basic screening assessments and refer individuals to other clinics/hospitals which can provide more advanced assessments and interventions.

- 2. Secondary care there are three hospitals based in Malé, six regional hospitals and 13 atoll hospitals that provide secondary care. In addition, two private clinics, one based in Malé, and another located in the southern part of the country (Addu City) also provide secondary care. Services provided at the secondary level include maternal and childcare and specialty care, such as orthopedics, ophthalmology, or emergency care. In terms of rehabilitation services, most secondary level hospitals provide physical therapy services along with vision, hearing, cognitive and mental health interventions. However, individuals requiring more advanced rehabilitation assessments and interventions not available at the secondary care level would be referred to tertiary level hospitals.
- 3. Tertiary care there are three tertiary level hospitals in the country. The national referral hospital is based in Malé while the north and south regions of the country each have one regional hospital which also provides tertiary level care. The country's National Thalassemia Centre is also considered a tertiary level hospital and is based in Malé. There are two private hospitals in Malé which also provide tertiary level care. Physical, vision, hearing and cognitive assessments are available at tertiary level hospitals. Ongoing physical therapy, occupational therapy, and vision interventions are available at these hospitals while individuals requiring hearing cognitive therapies would be referred to the private sector. These hospitals provide acute care services for mental health disabilities, but those requiring ongoing intervention would have to seek out private services in Malé.

#### Rehabilitation Services in the Maldives

The following information on rehabilitation services in the Maldives is based on observations, internet search, and information obtained from key informants and participants at the time of data collection (2019). Table 3 provides a brief summary of the rehabilitation services available in the country.

Table 3: Summary of Rehabilitation Services Available in Public and Private/NGO Sectors

Rehabilitation Service	Public Sector	NGO/Private Sector
	<ul> <li>Physical therapy available at secondary/tertiary level care</li> </ul>	<ul> <li>Physical therapy available at private clinics and comprehensive rehabilitation programmes (e.g., autism,)</li> </ul>
Physical	<ul> <li>Occupational therapy/speech language therapy available at tertiary level care</li> </ul>	<ul> <li>Occupational and speech language therapies available at comprehensive rehabilitation programmes (e.g., autism)</li> </ul>
Hearing	Assessment available at tertiary level care	<ul> <li>Assessments for hearing aids available in private sector but cost is covered by national health insurance.</li> </ul>
		<ul> <li>Sign language courses available through NGO</li> </ul>
Vision	Basic vision assessments/ interventions available at primary, secondary and tertiary level care	Basic vision     assessments/interventions     available at optician clinics
	<ul> <li>Complex vision         assessments/interventions         available at tertiary level         care</li> </ul>	
Mental Health	<ul> <li>Acute mental health services available at tertiary level only</li> </ul>	Long term mental health / behavioural counselling
Cognitive	Assessments available at tertiary level care	Assessments/     interventions available     through comprehensive     rehabilitation programmes     (e.g., autism, brain injury)

Rehabilitation services are limited. Most services are based in Malé, with few available on some of the larger islands. No publicly funded specialised (e.g., stroke, cardiac, cognitive) rehabilitation centres exist. Physical therapy is available at tertiary, regional and some atoll hospitals. It is also available in the private sector,

but individuals have to pay out of pocket to utilise this service. Occupational and speech therapy are available at the tertiary level, but user fees are charged. Some private clinics do provide occupational and speech services, but these are generally a part of a comprehensive rehabilitation programme (e.g., autism spectrum disorder, long term behavioural counselling). Basic vision assessments and treatments are available at the primary, secondary, and tertiary level health centres as well as in the private sector (e.g., optician clinics). However, for complex vision conditions (e.g., glaucoma), services are available at tertiary hospitals or abroad. Hearing assessments are available at tertiary hospitals. Assessments for hearing aids are only through a Malé based private clinic but the service is covered through Aasandha. One NGO for the hearing impaired offers sign language programmes once or twice a year at a nominal fee.

Acute mental health services are available at tertiary hospitals only, while long term counselling services are only available in the private sector (based in Malé). For cognitive impairments (e.g., autism spectrum disorder, cerebral palsy, acquired or traumatic brain injuries), initial assessments requiring medical specialties (e.g., neurology, psychiatry) or equipment (e.g., MRI, CT scan) are only available at tertiary hospitals or abroad. Children with learning disabilities can access some special education programmes at public schools until the age of 18. Private rehabilitation programmes which provide physical therapy, occupational therapy, speech therapy and behavioural therapies, as well as school teachers who specialise in education for children and young adults (under 24 years of age) with disabilities, are available only in Malé. Otherwise, there are no long-term rehabilitation programmes for adults with learning disabilities.

While there are over 700 registered NGOs in the Maldives, the NGO sector in health is small but developing. Most are based in Male' but their capacity is limited due to few resources (e.g., finance, staff, equipment) (Maldives Ministry of Health, 2014).

Delivery of healthcare services at the rural island level is difficult due to the geographical isolation of the islands (Maldives Ministry of Health, 2014). Limited

healthcare staff and the logistical challenge of delivering medicines and medical equipment to the remote islands negatively impacts the quality of care received by individuals living on these islands (Maldives Ministry of Health, 2014). People requiring specialised medical services, including rehabilitation, must travel to Male' or abroad. This may be particularly challenging for persons with disabilities, who are more likely to require specialised services, and are therefore disproportionately affected by costs as well as facing additional barriers such as lack of accessible transportation (Hameed et al., 2019, Hameed et al., 2022a).

When healthcare services are not available in the Maldives, individuals can access services in India or Sri Lanka through a public sector physician referral. The government has established contracts with health service providers in these countries (Suzana et al., 2018). Aasandha will cover airfare and medical costs for the patient and one caregiver (Suzana et al., 2018). However, the individual is expected to cover additional expenses such as transport, lodging, or food in the destination, either out of pocket or through private insurance, which can be a financial burden for many (Suzana et al., 2015). Others, if they have the financial resources available, opt to self-fund their medical treatment abroad, allowing them greater flexibility in choice of health service providers and cost of treatment (Suzana et al., 2015).

#### Maldives Rehabilitation Workforce

Information on the Maldives rehabilitation workforce is limited. The most recent data from the Maldives Health Statistics 2020 (Maldives Ministry of Health, 2021) only provides information on "Allied Health Professionals", "Clinical and Physical Therapy", and "Professionals of Behavioural Sciences". No data on the breakdown of specific rehabilitation professionals (e.g., occupational therapy, audiology, speech language pathology) was available.

However, based on the 2020 Health Statistics data, there are 51 clinical and physical therapists in the country. Most of these therapists are expatriate (64%)

while the remaining minority are from the Maldives (36%). Few clinical/physical therapists work on the Atolls (35%) while most work in Malé (65%). Only 35% of the therapists are female. There are 20 individuals classified as professionals of behavioural sciences. The majority of these professionals are local (75%), female (90%), and work in Malé (90%).

#### 1.3.4 Maldives Social Protection Programmes

The National Social Protection Agency (NSPA), formed under the National Social Health Insurance Act (2008) administers the country's six social protection programmes which include:

- 1. Aasandha National Social Health Insurance
- 2. Medical Welfare
- 3. Disability Allowance
- 4. Single Parent Program
- 5. Foster Parent Program
- 6. Food Program

Persons with disabilities in the Maldives can access all programmes as long as they meet the eligibility criteria. However, Aasandha, Medical Welfare, and the Disability Allowance are the three most relevant programmes for persons with disabilities in the Maldives and are described below.

1. Aasandha - this is the country's social health insurance programme or universal health scheme, established in 2014. It covers inpatient and outpatient care, medications, and transportation in emergency cases with no limits on spending for eligible services (Banks et al., 2022a). Health services and treatments from all public sector healthcare providers and government-approved private health facilities are available free to beneficiaries (Aasandha Company Ltd, 2023). However, fees may be charged at some private hospitals or clinics covered under the scheme, or if accessed without an appropriate doctor's referral. The scheme provides coverage for some public sector rehabilitation services, including physical therapy, basic

vision and hearing assessments and treatments, but does not cover the cost of AP (e.g. spectacles). For physical therapy offered in private clinics in the country, Aasandha may cover up to 50% of the assessment/treatment fees (National Social Protection Agency, 2019).

- 2. Medical Welfare this programme is available to people with and without disabilities. It provides financial assistance for medical services, medications, or assistive technology not covered by Aasandha. For example, it will cover the cost of travel (e.g., airline tickets) for an individual and companion when medical care is required abroad. It will also cover the cost or provide AP, such as oxygen tanks or wheelchairs (National Social Protection Agency, 2019). The applicant needs to submit documentation from a medical doctor verifying the need for medication or equipment as well as three price quotations from different vendors if the item is not stocked by NSPA or the State Trading Organization (STO), a business organisation responsible for procurement of goods for the country. If approved, NSPA or the STO will either provide the AP/medication or money to purchase the item (Hameed et al., 2022b).
- 3. **Disability Allowance** this social protection programme specifically targets persons with disabilities. It was introduced under the country's Disability Act (2008) to provide financial assistance on a monthly basis for persons living with a disability in the Maldives. Its purpose is to afford those living with a disability the same rights and opportunities as non-disabled citizens of the country. Beneficiaries can use the monthly cash transfer to defray the costs of living with a disability. This may include therapeutic fees or medical/AP. A medical certificate and application must be submitted to NSPA for approval (National Social Protection Agency, 2019). A benefit of this programme is that any beneficiary can currently enroll in other social protection programmes (e.g., Old Age Security) and is available to all with a disability regardless of poverty level or capacity to work (Hameed et al., 2022b).

However, the high costs related to obtaining the medical certificate or travel to Malé to obtain the documentation prevent some from applying for the programme (Hameed et al., 2022b).

## 1.3.5 Maldives Disability and Rehabilitation Laws and Policies

Based on an online search, I could only locate a limited number of disability and rehabilitation laws or policies available in the English language. As noted above, the country's Disability Act (Law on Protecting the Rights of Persons with Disabilities and Provision of Financial Assistance) was passed in 2010, at the same time the country ratified the UNCRPD. The Health Care Professional Act (2015) provides regulatory direction for healthcare professionals, including those providing rehabilitation services (e.g., physical therapy). The country's Health Master Plan 2015-2025 provides the strategic approach of the government would like to address the needs of its population, including key health indicators it would like to achieve. The document does reference rehabilitation and disability in terms of expanding rehabilitation programmes for persons with disabilities.

I could only locate two impairment-specific policies online and available in the English language. The "Maldives Vision 2020 Action Plan" (Maldives Ministry of Health and Family, N.D.). laid out its approach to improving eye care services across the country through primary, secondary and tertiary level care. Similarly, the government developed the Maldives National Mental Health Policy (2015-2025). The policy includes a strategic plan to improve mental health services across the country (Maldives Ministry of Health, 2014). Please refer to Appendix 2 for a summary of the country's Disability Act, Health Care Professional Act, Health Master Plan, and Mental Health Policy.

## 1.4 Study Rationale

This research built upon an existing research project led by the International Centre for Evidence in Disability: "Impact Evaluation of The Disability Allowance in the Maldives" (Hameed et al., 2019). This evaluation explored the impact of the Disability Allowance social protection scheme on poverty, quality of life, and participation of persons with disabilities in the Maldives. The study involved a baseline population-based survey of disability in 2017, with a nested case control study comparing people with disabilities ('cases') and those without disabilities ('controls') in terms of poverty, quality of life and participation. In 2019, cases and controls were followed up and re-interviewed to assess the impact of the Disability Allowance. Qualitative data was also collected from both recipients and non-recipients at baseline and endline, to provide in-depth information about their experiences.

This research has provided important evidence on disability in the Maldives (Banks et al., 2020, Hameed et al., 2019, Hameed et al., 2022b, Hameed et al., 2022a). However, an identified gap was the lack of evidence regarding health-related rehabilitation and factors influencing access to these services for persons with disabilities. The country ratified the UNCRPD which includes the right to health and rehabilitation services. However, it remains unclear the extent to which these policy commitments are being implemented, the met and unmet need for rehabilitation services for persons with disabilities, and the factors that influence access to rehabilitation services from both the supply and demand perspectives.

This project aims to address this gap by exploring factors influencing access to rehabilitation for people with disabilities in the Maldives from both the user and service provision perspectives in the Maldives. Building this understanding is crucial in order to promote evidence-informed planning and decision making to strengthen rehabilitation services in the country. Furthermore, it will contribute to the scarce global data on access to health-related rehabilitation.

# 1.5 Research Aim and Objectives

## <u>Aim</u>

 To explore access to rehabilitation services for persons with disabilities in the Maldives.

## **Objectives**

- To estimate use of, and unmet need for, rehabilitation services among persons with disabilities living in the Maldives.
- 2. To explore the strengths and weaknesses of the Maldives health systems' delivery of rehabilitation services in the Maldives (e.g., government, rehabilitation workforce, NGOs, disabled persons organisations (DPOs))
- 3. To explore the facilitators and barriers to accessing rehabilitation services for persons with disabilities in the Maldives.

# Chapter Two: Methods

## 2.1 Positionality

As a research student, I assumed the role of a non-participant observer and an 'outsider' to the interviewees of this research project. I was aware of my lack of familiarity with Maldivian culture, the Dhivehi language, and the delivery of rehabilitation services in this country. However, since this research was a part of a wider research study, I was able to work alongside the lead investigator, of the Impact Evaluation study (who is also one of my DrPH supervisors) during my field work. She is Maldivian, speaks the local language and has insights into Maldivian culture. She was present and acted as a translator for most of the interviews and provided me with background information on the Maldives and its health system.

Initially, I felt I was entering into this research project with a good understanding of the concepts of rehabilitation and disability owing to my 15 years of physical therapy practice working with marginalised populations in the Canadian health system. Arguably, though, this may have provided what I came to appreciate was a medical model of understanding of disability and the delivery of rehabilitation services. As such, this positivist viewpoint influenced how I approached this research project through the study design, development of the topic guides, the interviews, and the interpretation of the findings. Please refer to Chapter 1 on models of disability and the relationship of the medical model to rehabilitation. However, working closely with my supervisors, I became acutely aware of the potential issues with my positivist interpretation of the data, and through discussions with them, I learnt to take a more constructivist view.

I also came to a deeper understanding and appreciation of other models of disability, in particular the ICF framework and the social and human rights models. This helped me to analyse my data through a different lens, rather than simply assuming the medical model of disability was 'the truth'.

I was also influenced by my own assumptions about my role as an interviewer. On reflection, I realised that I may have taken a clinical approach to the interviews, focusing on an individual's impairment, and thinking about appropriate treatment plans for them. However, for this research study, the interviewer's role was to listen to the participants' stories and be receptive to their situation as it related to disability and their attempts to access rehabilitation. As a doctoral student, I needed to realise that this was an opportunity to learn and grow as a researcher and not as a clinician. As my fieldwork progressed and through discussions with my fieldwork supervisor, I began to understand my role as a researcher and to ask questions to support my research.

Finally, I was aware that my presence, gender, and physicality (white male) may have caused reticence for some participants as they did not know who I was. Upon reflection, it is possible that some of them may have altered their responses because of my presence, impacting the findings of this study. Also, my lack of familiarity with the Maldives and my discomfort at seeing the reality of the living or working conditions of some of the interviewees might also have been apparent to the interviewees. They may have felt negatively judged and altered their responses accordingly. It certainly took me a bit of time to 'settle in', and whilst it was uncomfortable being a naïve stranger, it did have the benefit of observing this environment with 'beginner eyes'.

# 2.2 Rationale for Mixed-Method Approach

A mixed methods approach includes both qualitative and quantitative viewpoints on a particular topic. I chose this approach for my DrPH because I felt it would enable a more comprehensive understanding of access to rehabilitation for persons with disabilities in the Maldives. There are different approaches to mixed methods research, each with advantages and limitations. This study used a triangulation design, convergence model whereby qualitative and quantitative methods were conducted, analysed and presented separately (results), then compared and interpreted together (discussion). The quantitative methods aimed to provide

statistical insight into the level of need/unmet need as well as the socioeconomic and demographic characteristics influencing access to rehabilitation (e.g. who in the population is most at risk of unmet need). The qualitative approach aimed to provide in-depth insight through the subjective interpretation of persons with disabilities' experiences on accessing rehabilitation (Jogulu and Pansiri, 2011) and understanding of the facilitators and barriers from both supply and demand perspectives. A mixed method approach is useful in the data analysis as it allows for a comparison of the two data sources. It also allows for a more comprehensive understanding and triangulation of findings and enhances the credibility and reliability. Triangulation not only strengthens the research findings, but it also supports the overall conclusions made because multiple techniques were used within a single research problem (Jogulu and Pansiri, 2011). In terms of the approach to the integration of the quantitative and qualitative data, the data collection for the secondary quantitative analysis was completed in April 2017 (for the Impact Evaluation of the Disability Allowance in the Maldives (2018)) while the qualitative data collection was completed in May 2019. The analysis of both the quantitative and qualitative data took place concurrently, though I completed the quantitative data analysis prior to the completion of the qualitative data.

## 2.3 Study overview

This study used both quantitative and qualitative methods to explore access to rehabilitation services from both supply and demand sides for persons with disabilities in the Maldives. This included:

- a secondary quantitative data analysis to estimate use of and unmet need for rehabilitation among people with disabilities.
- qualitative interviews with rehabilitation service providers to explore their perspectives on the strengths and weaknesses of rehabilitation service delivery.

iii. qualitative interviews with persons with disabilities to explore their experiences in accessing rehabilitation services and on barriers and facilitators to access.

## 2.4 Quantitative - Objective 1

 To estimate use of, and unmet need for, rehabilitation services among persons with disabilities living in the Maldives.

## Sub-Objectives:

- To estimate the use of rehabilitation services related to specific functional domains.
- To estimate unmet need for rehabilitation services related to specific functional domains.
- To assess any association between rehabilitation need and sociodemographic and economic characteristics.

In order to achieve objective 1, I performed a secondary analysis of the quantitative data collected from the "Impact Evaluation of Disability Allowance in the Maldives" (Kuper et al., 2018). I used this data to analyse the estimated use and unmet need for rehabilitation services and AT related to different functional difficulty/impairment types. Moving forward this will be referred to as rehabilitation services.

The original research project explored the impact of the Disability Allowance on poverty, quality of life and social participation for persons with disabilities and their families in the Maldives. The study took place from January 2017 to May 2019. A baseline assessment included two main components:

 a population-based survey to estimate the prevalence of disability and coverage of the Disability Allowance and ii. a nested case-control study to compare people with and without disabilities in terms of their economic situation and other key life areas (e.g., education, work, well-being).

The Washington Group questions (2011) on functioning were used to screen enumerated individuals aged 2 years or older for a disability. I was not involved in the design or data collection for either component of this original study, but detailed description of the original study methods is provided in Appendix 3 for understanding.

I was as responsible for conducting the secondary data analysis that is included in this thesis. The results from this analysis were also included in a paper about access to health services in the Maldives, which I co-authored (Banks et al., 2022a). See Appendix 4 for a copy of this paper.

#### Data analysis

For this secondary analysis of the data that Objective 1 is based on, people with disabilities were grouped by functional domains: vision, hearing, mental health (anxiety and depression), cognitive (remembering), communication, and physical (walking and lifting). Disability was assessed through the self-reporting of difficulties, using the Washington Group of questions. Please refer to Appendix 3 for more details.

Data were analysed using STATA 16. The self-reported indicators of use, awareness, need and unmet need for assistance were calculated separately for each of the following functioning domains: vision, hearing, physical (walking/fine motor skills), cognitive, communication, and mental health (anxiety/depression).

The access indicators and definition used for this objective have been derived from the quantitative data collected for the Impact Evaluation and reflect the various components of access. It is important to note that access indicators are not static and are defined and measured differently across the research literature. The questions used in Table 4 below were grouped into six broad themes which are related to this study objective.

Table 4: Questions Asked About Health and Rehabilitation/Devices for People Reporting Some Difficulties in Different Areas of Functioning

## Questions: Have you ever gone to see a doctor/health professional about the difficulties<sup>1</sup> you have in this area? (Yes or No) Did you see: 1) Specialist; 2) General doctor (hospital/clinic); 3) Other healthcare professional (RN, healthcare worker); 4) Traditional/alternative medicine Was the advice you received useful? (Yes/No) • Why have you never been to a doctor/professional about this area of difficulty? 1) Don't need/not useful; 2) Too expensive; 3) Not available; 4) Don't know where to go; 5) No time; 6) Other Have you ever heard of devices/services for helping people who have difficulties in this area (e.g., specific to disability – e.g., glasses, Braille (vision); hearing aid (hearing); walker, cane (walking))? (Yes/No) Would one of these services/devices be helpful for you? (Yes/No) Have you ever used one of these devices? (Yes/No) Are you currently using one of these services/devices? (Yes/No)

Table 5 below provides a definition of each access indicator using the vision domain as an example.

Table 5: Self-Reported Indicators of Access: Questions, Definitions, and Calculations

Indicator	Question(s)	Population level definition	Calculation
indicator		using vision as an example	
	Have you ever gone to	Proportion of people with a	No. people who have
	see a doctor/	difficulty seeing who have	seen health professionals
Health	healthcare	sought related health	for their difficulties
Services Use	professional about the	service.	seeing/
Services Use	difficulties you have in		No. people reporting
	this area (e.g., vision)?		difficulties seeing

<sup>&</sup>lt;sup>1</sup> "Difficulties" refers to participant's reporting "a lot of difficulty/cannot do" on a specific functional activity (e.g., hearing)

	Have you ever heard	Proportion of people with a	No. people who are
Awareness	of service/device for helping people who have difficulties in this area (e.g., vision)?	difficulty seeing who report being aware of service/device to help people with vision difficulties.	aware of service/device for vision difficulties/ No. people reporting difficulties seeing
Need	Would one of these services/devices (e.g., for vision) be helpful for you?	Proportion of people with difficulties seeing who report that service/device for vision would be useful.	No. people who feel they would benefit from service/device for vision difficulties/ No. people reporting difficulties seeing
Use	Have you ever used one of these services/devices (e.g., for vision)?	Proportion of people with difficulties seeing who report ever using a service/device for vision.	No. people who have ever used service/device for their vision difficulties/ No. people reporting difficulties seeing
Coverage	1. Have you ever used one of these service/device (e.g., for vision)? (numerator) - answered "YES"  2. Would one of these services/devices be helpful (e.g., for vision)? (denominator) - answered "YES"	Proportion of people who have used a service/device and feel they need a service/device for their vision difficulties.	No. people with vision difficulties who report using device/service/ No. people with vision difficulties who report needing a device/service
Unmet Need	1. Have you ever used one of these services/devices (e.g., for vision)? (numerator) - answered "NO"  2. Would one of these devices/services be helpful (e.g., for vision)? (denominator) - answered "YES"	Proportion of people who feel they need but <u>have</u> <u>not</u> used a service/device for their vision difficulties.	No. people with vision difficulties who report needing it but not having the device/service / No. people reporting difficulties seeing and reporting a service/device helpful

Logistic regression was then used to assess the association between sociodemographic and economic characteristics (rural/urban, marital status, education, household income, asset index and per capita household expenditure) and i) reporting a need for assistance in at least one functional domain (Table 12) and ii) reporting needing, but not using (i.e., an unmet need) assistance in at least one domain (Table 13). Regression analysis included adjustments for age and sex as potential confounders.

# 2.5 Qualitative - Objectives 2 and 3

While Objective 1 provided quantitative estimates of access in terms of use and need for rehabilitation, Objectives 2 and 3 explore in-depth the factors influencing access, using qualitative methods:

Objective 2: To explore the strengths and weaknesses of the delivery of rehabilitation services in the Maldives from the workforce perspective (e.g., government, rehabilitation service providers, NGOs, DPOs)

Objective 3: To explore the facilitators and barriers to accessing rehabilitation services for persons with disabilities in the Maldives.

## 2.5.1. Study Participants

Key Informants - Rehabilitation Service Providers (Supply-side)

I interviewed fourteen key informants involved in the delivery and support of rehabilitation services. This group included government representatives, rehabilitation service providers, and individuals from non-government organisations and disabled persons organisations. Initially, key informants were identified through discussion with the lead researcher from the "Impact Evaluation of the Disability Allowance in the Maldives" who was from the Maldives and familiar with government agencies, service providers, NGOs, and DPOs involved in disability and rehabilitation in the country (Kuper et al., 2018). Care was taken to ensure the key informants represented different areas of rehabilitation service

delivery: policy makers, 'front-line' service providers across impairments involved in this study, and representatives of organisations who were advocates for disability and rehabilitation (Hameed et al., 2022a). A snowballing technique, where key informants suggested additional individuals to interview, was also incorporated to ensure a broad range of individuals involved in disability and rehabilitation services were covered. However, time and scheduling conflicts meant that it was not possible to include some relevant stakeholders who may have provided additional insight. For example, I could not interview people from services specific to every impairment type (e.g. no-one from vision services were interviewed) or rehabilitation profession (e.g. no Occupational Therapists or Speech Language Therapists were interviewed) and not all government entities were represented in the sample (e.g., Disability Council). Limitation of this are considered in the interpretation and discussion of the findings.

Refer to Appendix 5 for background information on key informants, including information on types of services they provided.

#### Participants - People with Disabilities (Demand-side)

Twenty-one participants with disabilities were sampled from among participants included in the "Impact Evaluation of Disability Allowance in the Maldives" (2018) study. People with disabilities are a diverse group. Participants were purposively sampled to ensure representation across age groups, gender, location, impairment type (e.g., vision, hearing, physical, cognitive, mental health) as well as those who were using or used rehabilitation and those who had not to try and capture some of the diversity of experiences. I chose purposive sampling because I wanted to explicitly select individuals who would likely provide insightful information on access to rehabilitation as well as provide sufficient data to answer my research question (Green and Thorogood, 2014). I felt that by identifying themes and patterns across people with different impairments would generate findings applicable to the broader population of persons with disabilities in the Maldives.

However, persons with disabilities are a diverse group and this approach likely prevented a deeper understanding of the specific experiences faced by people with different impairment types and risked oversimplifying, or missing important insights into, the unique experiences of individuals with different impairment types.

Though attempts were made to ensure fairly equal representation of the different impairment types, this was not always possible. For example, only one participant with mental health difficulties was willing to participate in my research study. Other individuals who were contacted either declined or were not available due to other commitments (e.g., family, work). This likely limited understanding of the unique challenges faced in accessing mental health services. Purposive, iterative sampling would have been the ideal approach to ensure better coverage of different subgroups and this should be used in future similar studies. However, it was not possible within the time and logistical constraints (e.g. length of time and distance to travel to different islands) of my study which was embedded into the wider "Impact Evaluation of Disability Allowance in the Maldives" (2018) project.

A sample size of 15-20 people with disabilities and 15-20 service providers was selected in consultation with my thesis supervisors, taking into account the research question, and time, financial and logistical constraints of this study. This is in line with other studies and supported in the literature where Green and Thorogood (2014) suggest that if addressing a fairly specific research question, little new information comes out of the transcripts after 15 or so with a similar group of participants. With the appropriate sample size of persons with disabilities and key informants, data saturation was achieved after the completion of all interviews.

Data adequacy was attained through the various methods and sources of data I collected for this study. For example, I used purposive sampling of persons with disabilities and snowballing of government representatives, rehabilitation service providers, and individuals from OPDs to seek out a diverse group of individuals who I felt could provide me with information rich data relevant to my study. The interview questions were open ended, flexible, and short in order to garner long

responses, and I took every opportunity to summarise and seek clarification during the interviewees' responses (Morrow, 2005). This helped to elicit stories and deeper meanings from participants' and key informants' experiences with accessing and/or delivering rehabilitation services (Levitt et al., 2017, Morrow, 2005). Additional information from participant observations, field notes, journal articles, and grey literature on the Maldives health system and rehabilitation services also helped to obtain rich data with breadth and depth (Morrow, 2005).

Please refer to Tables 6 and 7 for breakdown of participant information.

For children younger than 10 years and adults who had difficulties with communication, the individual's caregiver or guardian were interviewed. Children between 10-17 years were interviewed directly in the presence of their caregiver. The caregiver assisted the child during the interview if required. All children under 10 years or adults who could not communicate were present in the interviews except for one participant, who was attending school at the time of interview. The participant's parents answered questions on the child's behalf.

Table 6: Participants' Location and Gender

#### **Location and Gender**

	Female	Male	Total
Island	5	6	11
Male'	5	5	10
Total	10	11	21

Table 7: Participants' Age and Functional Limitations

## Age and Functional Limitations

	Hearing	Vision	Cognitive	Physical	Mental Health	Multiple	Total
0-17 years	1	-	4	-	-	1*	6
18-39 years	1	4	1	2	1	-	9
40-59 years	1	-	1	1	-	1**	4

60+	_	_	_	2	_	_	2
years	_	_	_	2	-	_	2
Total	3	4	6	5	1	2	21

<sup>\*</sup> hearing/cognitive impairments

## Benefits and Limitations of Including Participants with Different Disability Types

There are benefits and limitation of including people with different types of impairments rather than focussing only on one type. A benefit is that it can provide a more comprehensive understanding of facilitators and barriers to accessing rehabilitation by people with different impairments from both supply and demand perspectives. By examining the common themes and patterns across different impairment types, I aimed to draw conclusions applicable to the broader population of persons with disabilities in the Maldives.

However, there are also limitations to this approach. For example, it may have limited deeper exploration and insight into the unique experiences faced by persons with different impairment types. For example, only including three people with hearing impairments likely limited the breadth and depth of understanding the specific issues related to accessing hearing rehabilitation services. This approach may have risked oversimplifying and normalising the unique experiences of individuals within each impairment group.

#### Data Collection - Qualitative Interviews

Data collection for qualitative interviews was conducted between April and May 2019. Topic guides for participants and key informants were developed with input from my thesis supervisors. The first few interviews served as pilot tests, after which the questions were refined and adjusted for the remaining interviews. These interviews were included as part of the final dataset.

<sup>\*\*</sup> vision/hearing/physical impairments

For the participants' (persons with disabilities) topic guide, key areas covered included:

- awareness of services/devices,
- referral process,
- geographic access (e.g., location, distance, transport),
- financial access (e.g., cost),
- acceptability (e.g., quality of service/device)
- availability (e.g., service/device availability)

For those individuals who had not accessed rehabilitation services, the topic guide explored their awareness of services, potential benefits of rehabilitation and reasons why they had not accessed such services. The topic guide questions used for access to rehabilitation were added at the end of the topic guide used in the "Impact Evaluation". See Appendix 6 for an example of the topic guides.

Interviews with these study participants were undertaken in person at their home, in private, and audio-recorded with their consent. Interviews were conducted in Dhivehi using the assistance of a translator, the lead investigator of the "Impact Evaluation", a Maldivian herself, and one of my thesis supervisors. She would ask the question in the local language and then would translate the participants' response back to me in English where I would ask a follow up question if required. I was present for 13 participant interviews as I was only in the Maldives for approximately four weeks. The remaining eight participant interviews were completed by her. As one of my thesis supervisors, she provided oversight to the development of the access to rehabilitation topic guides, and therefore, she was familiar with the questions and to ask follow-up questions if needed.

To maintain consistency, the lead investigator acted as a translator for all interviews with participants. Interviews were then transcribed in Dhivehi and then translated into English for data analysis by two research assistants (Maldivian university students) who were fluent in both Dhivehi and English. The lead investigator

reviewed five randomly chosen English transcripts to ensure accuracy. Detailed notes were taken during the interviews which supplemented the interview data.

Key informant topic guides explored their perception of the strengths and weaknesses of the rehabilitation delivery system in the Maldives, the impact these had on service delivery for persons with disabilities and possible strategies to strengthen the system. Topic guides were tailored to the type of organisation the key informant belonged to (e.g., government, service provider, NGO, DPO) and their individual role. See Appendix 7 for a topic guide example.

For the key informants, all interviews except two were undertaken in person at the key informant's workplace and audio-recorded with their consent. Due to their remote location on other islands, the other two interviews were conducted by telephone. I conducted all interviews in English since all key informants were fluent in English. Interviews were then transcribed by me for data analysis. Detailed notes were taken during the interviews which supplemented the interview data.

## **Document Review**

Relevant documents related to health, rehabilitation, and disability (e.g., policies, government acts) were found on the Maldives government websites (e.g., Ministry of Health, Ministry of Gender). Only documents in English were included in the review. Since I did not understand the local language, documents in Dhivehi were not included, and it is unknown whether they could be relevant to this research project or not. This is a recognized limitation of this DrPH thesis. Please refer to Appendix 2 for a list of documents reviewed.

#### Non-participant Observation and Reflective Journal

The interview process included informal observation of all participants' and key informants' general demeanour, interaction with their family members or work colleagues as well as their living or working environment. These observations provided helpful insight into how these individuals functioned in their home or

work environment (Kawulich, 2005). A reflective journal was used to record observations, activities, and informal conversations with participants and key informants. I also used the notebook to reflect on my day-to-day experiences of interacting with participants, key informant, and general thoughts related to the research project itself.

### Data Analysis

Braun and Clark's (2006) six phases of thematic analysis were followed during the data analysis process. Table 8 outlines these six phases and a description of each process:

Table 8: Braun and Clarke's (2006) Six Phases of Thematic Analysis

Phase	Description of process
1. Familiarising Yourself	Transcribe data; read and reread data, writing down initial
with Your Data	codes
2. Generating Initial	Code interesting aspects of the data in a systematic process
Codes	across the entire data set, collate data relevant to each code
3. Searching for Themes	Collate codes into possible themes; collect relevant data to
	each possible theme
4. Reviewing Potential	Developing themes are reviewed in relation to the coded data
Themes	and entire data set; thus, creating a thematic map of the
	analysis
5. Defining and Naming	Identifying what is unique and specific about each theme;
Themes	ensuring each of them addresses your research questions
6. Producing the Report	Purpose is to produce a compelling, clear yet complex story
	about your data based on the analysis; it needs to go beyond
	the description of the data to make an argument that answers
	your research questions

To familiarize myself with the data, I reviewed my interview notes and interview transcripts multiple times. Key themes, reoccurring issues and patterns were identified. A coding scheme was developed and modified iteratively as appropriate. Codes were collated into themes and reviewed by the thesis supervisors. I used both Levesque et al.'s (2013) conceptual framework of access to healthcare and Allin et al.'s (2010) categorization of unmet healthcare needs within the context of persons with disabilities and service providers to organize the codes and themes that emerged. Whilst these frameworks were helpful for consolidating most of the

study findings, there were some additional areas or themes which fell outside of these categories, and these may suggest areas in which these frameworks might be enhanced or developed.

## 2.6 Application of Theoretical Frameworks to the Qualitative Section

As previously discussed, Levesque's (2013) access framework and Allin's (2010) unmet need categories are used to underpin the qualitative section of this study. Initially, I used Peter's (2008) access framework as a guide at the early stages of this research project (e.g. DrPH Review). This framework highlighted general access areas which was helpful in understanding the various components of access and developing the initial topic guides for participants and key informants.

However, prior to analysis of the qualitative data, I did further research on access frameworks where I became familiar with, and decided to use Levesque's (2013) framework. I chose to use this framework to inform my analysis and discussion because it comprehensively considers both the supply and demand aspects of access to health services. While the quantitative component assessed factors associated with unmet need, I also wanted to include a framework that captured different aspects of unmet need for my qualitative analysis. I found Allin's (2010) unmet need categories appropriate for my study and adapted it for my qualitative section.

Both Levesque's (2013) framework and Allin's (2010) unmet categories were used for coding and identifying key themes in the qualitative data. For example, Levesque's (2013) access dimensions identified access barriers and facilitators to rehabilitation from participant and key informant perspectives, while Allin's (2010) unmet categories identified specific unmet needs within the context of rehabilitation services in the Maldives.

In order to add more depth to my analysis, I combined both Levesque's (2013) framework and Allin's (2010) categories. This combination allowed for a detailed

examination of the types of barriers and facilitators leading to unmet and met needs and was key in guiding both the analysis and the presentation of the qualitative findings.

## 2.7 Ethical Consideration

Ethical approval was obtained from the LSHTM Ethics Committee (Ref 12071-2, via amendment to the original ethics application "Impact Evaluation of the Disability Allowance in the Maldives") and the Maldives National Health Research Committee at the Ministry of Health. See Appendix 8 for copies of the ethics approval letters.

For participants, verbal or written informed consent was obtained at the start of each interview. For children under 18 years and participants with a disability that severely impacted their ability to understand or communicate, a caregiver provided consent and answered questions on their behalf. These children or adults provided assent and their input was still sought when possible. Participants were provided an information sheet describing the study objectives and their rights to participate. Details were reviewed verbally and were given the opportunity to ask questions.

Similarly, verbal and/or written consent was obtained from all key informants before the start of each interview. They were provided with written information describing the study objectives and their rights to participate. These details were reviewed verbally and KIs were provided the opportunity to ask questions.

## Chapter Three: Results for Objective One

 To estimate use of, and unmet need for, rehabilitation services among persons with disabilities living in the Maldives.

## 3.1 Participant Characteristics

In the original survey (Banks et al., 2020) 5363 people were screened for a disability (response rate 83%) and 403 people were identified as having a disability based on the study criteria (Banks et al., 2020). Please refer to Appendix 3 (original study methods) for a detailed description of the methods of the original study and how individuals were screened for a disability. The overall prevalence of disability was estimated at 6.8% (95% CI: 6.1–7.5%). In total, 385 people with disabilities were asked about their use of health/rehabilitation services, and their responses included in the analysis in this chapter. Table 9 presents the participants' characteristics including age, location, sex and types of functional limitations. The majority of the 385 people with disabilities (60%) were over the age of 40. Females with disabilities accounted for approximately 60% of the study sample. The majority (60%) of participants with a disability lived on other islands and 40% lived in Male'. The most common functional limitation among study participants was physical (49%) followed by vision (23%) and mental health (22%). Nearly a third (30%) reported limitations in more than one domain.

Table 9: Participant Characteristics

Participant Characteristics								
		n	%					
	0 - 17 yrs	62	16					
Λσο	18 - 39 yrs	96	25					
Age	40 - 64 yrs	125	33					
	65+ yrs	101	26					
Location	Outer Islands	231	60					
Location	Malé	154	40					
Sex	Female	219	57					
Sex	Male	165	43					
	Vision	88	23					
	Hearing	35	10					
Functional	Physical	190	49					
Limitations	Cognitive	75	19					
LIIIIILALIOIIS	Communication	56	15					
	Mental Health	86	22					
	Multiple Limitations*	116	30					

<sup>\*</sup>Participants identified as having multiple limitations were counted twice. That is, an individual with vision and hearing impairments would be counted in both vision and hearing, as well as in the multiple limitations category.

# 3.2 Seeking Help, Type of Service Provider Seen and Advice Given

During the disability screening process, individuals who self-reported they had a disability (according to the Washington Group questions) were asked about their experience of seeking a healthcare professional related to for their specific reported functional limitation(s), who they saw, and whether the advice they received was helpful or not. Table 10 below provides a breakdown of this information.

Among individuals who self-reported a functional limitation, on average more than three quarters had sought out a healthcare professional. This was highest for people with physical (92%), vision (90%), hearing (77%) and communication (75%) limitations, while lower for those with mental health (51%) and cognitive (53%) limitations.

Table 10 (Seeking Help table below) also shows the reasons given for not seeking a healthcare professional. For example, among those not seeking mental health advice, 30% said they did not need it, or that it would not be helpful, 28% said other issues (e.g., lack of childcare), 5% said high costs, and 5% noted a lack of available services. Other responses included a lack of time, no knowledge of service availability, too far and no transport or a combination of the above responses. However, these data should be interpreted with caution since the numbers for not seeking care were relatively small for most functional domains.

Of those who saw a healthcare professional, the majority (>85%) saw a specialist doctor for their disability. For example, 95% of persons with a visual limitation saw a doctor specialising in eye care, such as an ophthalmologist or optometrist, while 5% saw general practitioner (GP). Likewise, 100% of those with hearing impairments saw a specialist doctor, such as an ear/nose/throat doctor.

The proportion of individuals who reported that the advice they received from their healthcare professional was helpful was generally high (>75%), particularly for mental health (90%), cognitive (90%), physical (88%) and communication (88%).

Table 10: Seeking Help, Type of Service Provider Seen, and Advice Given

Seeking Help, Type of Service Provider Seen and Advice Given										
		Vision	Hearing	Physical	Mental Health	Cognitive	Communication			
		(n=88)	(n=35)	(n=190)	(n=81)	(n=75)	(n=56)			
Question	Response Choices									
Did you see a	No	9 (10%)	8 (23%)	16 (8%)	40 (49%)	35 (47%)	14 (25%)			
HCP for your	Yes	79 (90%)	27 (77%)	174 (92%)	41 (51%)	40 (53%)	42 (75%)			
issue?	Total	88	35	190	81	75	56			
	Specialists*	75 (95%)	27 (100%)	159 (91%)	35 (85%)	37 (93%)	38 (90%)			
Who did you	General Practitioner	4 (5%)	0	13 (8%)	6 (15%)	3 (7%)	4 (10%)			
see?	Traditional	0	0	2 (1%)	0	0	0			
	Total	79	27	174	41	40	42			
Wastha	No	20 (25%)	5 (19%)	23 (13%)	5 (12%)	4 (10%)	4 (10%)			
Was the advice helpful?	Yes	59 (75%)	22 (79%)	151 (87%)	36 (88%)	36 (90%)	38 (90%)			
auvice neipiui:	Total	79	27	174	41	40	42			
	Don't need or not useful	1 (11%)	1 (13%)	10 (63%)	13 (33%)	8 (23%)	5 (36%)			
For those who	Too expensive	3 (33%)	2 (25%)	0	6 (15%)	7 (20%)	2 (14%)			
didn't seek	Not available	1 (11%)	1 (13%)	1 (6%)	4 (10%)	3 (9%)	0			
professional	Too far & no transport	1 (11%)	0	0	1 (2%)	2 (6%)	1 (7%)			
help. Why	No time	2 (22%)	0	1 (6%)	3 (7%)	2 (6%)	1 (7%)			
not?	Other	1 (11%)	4 (50%)	4 (25%)	11 (28%)	12 (34%)	5 (36%)			
	Total	9	8	16	40	35	14			

<sup>\*</sup> Specialists includes physical therapists, occupational therapists, speech-language therapists, medical doctors specialising in ophthalmology, neurology, orthopedics, ENT, psychology, psychiatry, audiology.

## 3.3 Access Indicators for Rehabilitation Services/Device

In the second set of questions, participants were asked specifically about the use of rehabilitation services/devices for their functional limitations (with examples provided, e.g., rehabilitation services or AT). Table 11 below provides a breakdown of information pertaining to each indicator of access, disaggregated by functional domain. Please refer to Table 2 for more details on indicator definitions and calculations.

In terms of Awareness, across all domains a reasonably high proportion of participants had heard of any specific service/AT related to the corresponding functional domain (>80%) except for cognition which was lower at 61%. In terms of self-reported need (reporting that a service/device would be helpful) for their functional limitation, this was moderately high for physical (71%), vision (67%) and communication (59%) domains and lower for hearing, mental health and cognitive (<50%). However, reported use (current or ever) of a service/device for their functional limitations was generally low across all domains. Only 53% of participants with a physical limitation had used a service/device while it was only 40% for those with a vision limitation. It was considerably lower for those with limitations in the mental health (35%), communication (23%), cognitive (20%) and hearing (11%) domains.

Reported unmet need was moderate (5-36%) across most functional limitations. However, among those individuals who identified as having physical and mental health limitations, unmet need was low (18% and 5% respectively). Reported unmet need was moderate for vision (27%), hearing (34%), cognitive (28%) and communication (36%).

Table 11 Access Indicators - Health Services, Awareness, Need, Use, Unmet Need, and Coverage

Access Indicators - Health Services Use, Awareness, Need, Use and Unmet Need												
	Vis	ion	Hea	ring	Phys	sical		ntal alth	Cogr	itive	Commm	unication
ACCESS INDICATOR	N=88	%	N=35	%	N=190	%	N=81	%	N=75	%	N=56	%
Health Services Use	79	90%	27	77%	174	92%	41	50%	40	53%	42	75%
Awareness	81	92%	28	80%	175	92%	65	80%	46	61%	49	88%
Need	59	67%	16	46%	135	71%	32	40%	36	48%	33	59%
Use	35	40%	4	11%	101	53%	28	35%	15	20%	13	23%
Unmet Need	24	27%	12	34%	34	18%	4	5%	21	28%	20	36%
Coverage	35	59%	4	25%	101	75%	28	88%	15	42%	13	39%

<sup>\*</sup> Note: Health Services Use, Awareness, Need, Use & Unmet Need - the denominator is total number of people reporting any limitation in the functional domain

<sup>\*\*</sup> Note: Coverage - calculation is Use/Need

## 3.4 Factors Associated with Reporting a Need for Assistance in at Least One Functional Domain

Overall, 60% of people with functional limitations reported need for at least one service/device. Table 12 below presents analysis of the association between sociodemographic and economic factors with identifying a need for a service/device in at least one functional domain. There was no association observed between reporting a need for a service/device and most variables apart from age. Reported need for at least one service/device was significantly higher among adults aged 40-59 (aOR OR 2.16, 95% CI 1.13 – 4.11) and 60+ years (aOR 2.60, 95% CI 1.41-4.80) compared to children/adolescents (2-18 years). Please note that all ORs in Table 12 are adjusted for age and sex except for the analyses of Age and Sex.

Table 12: Factors for REPORTING A NEED for Assistance in at Least One Domain

		Total N	REPORTING a Need for Service/Device	Age and Sex Adjusted Odds Ratio (95% CI)	P-Value
Overall Total		386	229 (60%)		
Variables					
	2-17 yrs	62	28 (45%)	Reference	
<b>A</b>	18-39 yrs	96	49 (51%)	1.26 (0.66 - 2.4)	0.471
Age	40-64 yrs	125	82 (65%)	2.32 (1.24 - 4.31)	0.008
	65 yrs+	101	70 (69%)	2.74 (1.42 - 5.28)	0.003
Carr	Male	165	94 (57%	Reference	
Sex	Female	219	135 (62%)	1.21 (0.80 - 1.83)	0.92
1	Other Atoll	231	135 (58%)	Reference	
Location	Male'	154	94 (61%)	1.08 (0.71 - 1.66)	0.716
Marile Chin	Working	87	47 (55%)	Reference	
Work Status	Not Working	234	152 (65%)	1.44 (0.86 - 2.43)	0.168
Marital Status	Married	178	109 (61%)	Reference	
	Not Married	142	90 (63%)	1.34 (0.82 - 2.19)	0.241
Completed	No	284	176 (62%)	Reference	
Primary Education	Yes	101	53 (53%)	0.74 (0.42 - 1.25)	0.257
	0 - 9300	96	58 (60%)	Reference	
Household Income	9301 - 15000	85	51 (60%)	0.85 (0.46 - 1.58)	0.609
(MVR)	15001 - 27000	97	59 (61%)	0.92 (0.51 - 1.67)	0.782
(IVIVIV)	27001 - 49000	103	57 (55%)	0.74 (0.42 - 1.33)	0.321
Asset Index	No	295	174 (59%)	Reference	
(Bottom 25th Percentile)	Yes	89	54 (61%)	0.98 (0.61 - 1.62)	0.962
	0 - 1670	105	61 (58%)	Reference	
Income Per	1671 - 2835	105	66 (63%)	1.13 (0.64 - 2.02)	0.669
Capita (MVR)	2836 - 4800	89	49 (55%)	0.75 (0.41 - 1.36)	0.346
	4801 - 62000	82	49 (60%)	1.00 ( 0.55 - 1.84)	0.992
Per Capita	0 - 1925	108	64 (59%)	Reference	
Expenditure	1926 - 3125	93	51 (55%)	0.88 (0.49 - 1.56)	0.655
(excluding HC costs and	3126 - 6260	104	62 (60%	1.15 (0.66 - 2.02)	0.623
Rent)	6261 - 46000	80	52 (65%)	1.49 (0.75 - 2.58)	0.29
	Below Average	109	67 (61%)	Reference	
Wealth	Average	201	111 (55%)	0.71 (0.43 - 1.16)	0.174
	Wealthier	73	49 (67%)	1.15 (0.60 - 2.21)	0.668

## 3.5 Factors Associated with Reporting an Unmet Need

Table 13 below shows the association between socio-demographic and economic factors and reporting an *unmet* need for a service/device in at least one functional domain. Overall, 94 (24%) of participants reported that they could benefit from, but did not use, at least one service/device. In terms of age, participants in the age group 40-59 years were more likely to report an unmet need compared to those aged 2-18 years, though this was of borderline significance (aOR 2.05, 95% CI (0.95 – 4.42)). In terms of per capita expenditure (excluding health care costs and rent), participants in poorest quartile (quartile 4; 0 – 1925 MVR; aOR 1.99, 95% CI 1.0 – 4.05) and second quartile (3126 – 6260 MVR; aOR 2.12, 95% CI 1.05 – 4.27) were twice as likely to report an unmet need compared to the wealthiest quartile (quartile 1). Those in the third quartile (1926 – 3125 MVR) were also likely to report an unmet need, although this was not statistically significant. No statistically significant associations with any of the other socio-demographic and economic variables were identified.

Table 13: Factors of Reporting an Unmet Need

	Facto	rs of Repo	orting an U	Jnmet Ne	ed	
Predictors	. 4615	Unmet Need NO Reported (1) (Did not use service)			Age and Gender Adjusted Odds Ratio (95% CI)	P-Value
	2.40	N	%	Total	5.6	
	2-18 yrs	12	18%	68	Reference	
Age	19-39 yrs	20	22%	90	1.32 (0.59 - 2.96)	0.494
(Years)	40-59 yrs	32	31%	104	2.05 (0.95 - 4.42)	0.067
	60+ yrs Total	30 94	25%	122 384	1.51 (0.72 - 3.21)	0.278
	TOLAT	94		384		
_	Male	38	23%	165	Reference	
Sex	Female	56	26%	219	1.03 (0.63 - 1.69)	0.894
	Total	94		384		
	Malé	36	23%	154	Reference	
Location	Atoll	58	25%	231	1.14 (0.70-1.84)	0.593
	Total	94		385		
	Working	20	23%	87	Reference	
Work Status	Not Working	60	26%	234	1.17 (0.64 - 2.13)	0.607
	Total	80		321		
	Married	46	26%	178	Refence	
	Not Married					
Marital	(e.g. single,					
Status	divorced,	34	24%	142	1.04 (0.61 - 1.78)	0.874
	widowed)					
	Total	80		320		
			240/		D -f	
Completed	Yes	21	21%	101	Reference	0.300
Primary	No	73	26%	284	1.39 (0.75 - 2.58)	0.300
Education*	Total	94		385		
* restricted to	PWD aged 13 yrs	& older				
	27001 - 49000	18	17%	103	Reference	
Household	15001 - 27000	28	29%	97	1.36 (0.58 - 3.18)	0.477
Income	9301 - 15000	19	22%	85	1.26 (0.53 - 2.98)	0.593
(MVR)*	0 - 9300	27	28%	96	1.22 (0.50 - 2.98)	0.655
	Total	92		381		
*MVR = Maldivia	n Rufiyaa					
Asset Index	No	74	25%	295	Reference	
(Bottom 25th	Yes	19	21%	89	0.77 (0.43 - 1.37)	0.375
Percentile)	Total	93		384	, ,	
-	10141			JJ 1		
_	4801- 62000	15	18%	82	Reference	
Income Per	2836 - 4800	22	25%	89	0.68 (0.34 - 1.36)	0.282
Capita	1671 - 2835	23	22%	105	0.93 (0.47 - 1.82)	0.831
(MVR)*	0 - 1670	32	30%	105	1.38 (0.72 - 2.65)	0.331
	Total	92		381		
Per Capita	6261 - 46000	13	16%	80	Reference	
Expenditure	3126 - 6260	28	27%	104	2.12 (1.05 - 4.27)	0.034
(excl Health	1926 - 3125	21	23%	93	1.86 (0.91 - 3.81)	0.088
Care Costs &	0 - 1925	32	30%	108	1.99 (1.0 - 4.05)	0.05
Rent)	Total	94		385		
(MVR)*						
	Above Average	16	22%	109	Reference	
Wealth	Average	46	23%	201	1.03 (0.53 - 1.98)	0.928
(2)	Below Average	31	28%	73	1.40 (0.68 - 2.87)	0.36
	Total	93		383		

<sup>(1)</sup> Unmet Need - reported they could benefit from BUT DID NOT use service/device

<sup>(2)</sup> Self-report of wealth compared to other households

## Chapter Four: Findings for Objective Two

 To explore the strengths and weaknesses of the Maldives health systems' delivery of rehabilitation services from the workforce perspective (e.g., government, rehabilitation service providers, NGOs, DPOs)

The first part of this chapter looks at rehabilitation service delivery, focusing on the perspectives of government officials involved in the delivery of rehabilitation in the Maldives health system. The second part of this chapter considers the perspectives of the rehabilitation service providers: those who provide 'front line' rehabilitation services and support to persons with disabilities. Information from relevant health, rehabilitation and disability documents and policies are also included in this chapter as a data source.

## 4.1 Government Perspective

This section considers 1) how rehabilitation is prioritised in the Maldives health system, 2) the government entities involved in disability and rehabilitation, and 3) the policies related to disability and rehabilitation. Conceptualisation of disability and rehabilitation were not specifically explored during the key informant interviews; however, comments made by key informants provided insight into the prevailing attitudes and where disability and rehabilitation were situated in the Maldives health system. The findings have been organised using the relevant WHO's Health Systems Building Blocks discussed in Chapter 1.

## 4.1.1 Leadership and Governance

#### Prioritising Rehabilitation

Government respondents described how healthcare was prioritised and where disability and rehabilitation were situated within the country's health system.

According to these key informants, the government's main priority was addressing

the overall health needs of a population and ensuring all Maldivians, regardless of where they lived, had equitable access to basic health services, for example:

"We ensure that certain services are available ... maternal and child health is a very important program, so this is one of the priority programs. We think it's one of the basic programs that should be available, like, on all the islands. Whatever level of care we have, whatever the level or the grading of the healthcare, maternal and child healthcare should be there.

*Key Informant #4 – government* 

Government key informants also said they felt that the government has a responsibility to work closely with key international agencies, such as the WHO and other UN agencies, to address global health issues. These might include the Sustainable Development Goals, tuberculosis, or malaria, and there was often also accompanying financial support from these agencies. However, rehabilitation and disability did not appear to be identified as a priority by the government. For example, one government key informant said:

"Frankly speaking, [rehabilitation] — this is not an area that was given ... much thought..."

*Key Informant #3 – Government* 

One exception was mental health. While there was no mention of addressing the overall need for rehabilitation in the country, all government key informants noted that the "President's 100-Day Pledge" did include political support and government funds to address mental health services throughout the country and to ensure persons with disabilities could access mental health services at no charge.

## Multiple Government Agencies Involved in Disability and Rehabilitation

Different ministries or agencies are responsible for providing oversight of disability and rehabilitation services in the Maldivian government. The Ministry of Gender, Family and Social Services provided oversight for disability, while another

government agency, situated within the Ministry of Gender, the National Social Protection Agency (NSPA) managed the social protection programmes, including those for persons with disabilities. The Ministry of Health was responsible for rehabilitation services, although there was no specific department or persons with responsibility for rehabilitation within this ministry or any other. For many of the key informants, the involvement of these different ministries or agencies in disability and rehabilitation created challenges and confusion. Some suggested these government entities worked within their own separate silos with minimal communications. Not only could this limit their accountability and responsibility to plan and support rehabilitation services in the country, but it could limit advocacy for NGOs and DPOs. These organisations may not know where to go or with whom to speak with in the government to address the rehabilitation needs for persons with disabilities.

The Ministries of Health and Gender each had their own separate priorities. There appeared to be a lack of clarity regarding roles and responsibilities when it came to addressing the rehabilitation needs for persons for disabilities. As one government key informant noted:

"Ok, so mental health is a mandate of Ministry of Health and disability is a mandate of [the] Gender Ministry. Now, who's going to do what...? Two different [ministries] given two different mandates, given equal power... what are [they] going to do? So, we need to come up with...better policies..."

*Key Informant #3 - government* 

## Government Policies on Disability and Rehabilitation

Government key informant interviews and a review of government documents (those available in English language), suggested disability and rehabilitation did not appear to be feature in existing policies. No national rehabilitation framework was located and only two impairment-specific action plans (mental health and vision) were located. The UNCRPD (2008) and the country's Disability Act (2008) both acknowledge that persons with disabilities should have access to rehabilitation

services, but the extent to which these policies/Act have been implemented remains unknown.

The government key informants identified the country's Health Master Plan (2016-2025) as a key document which provides strategic direction on the delivery of health services for the government. However, while some government key informants felt rehabilitation was addressed appropriately in this strategy, others felt it did not directly address the rehabilitation situation in the country. As noted by one government key informant:

"The master plan doesn't have one policy or one area which focuses on rehabilitation."

Key Informant #4 – Government

Though not specifically defined, the term "rehabilitation" is referenced throughout the Health Master Plan, particularly in the strategic inputs on public health protection and healthcare delivery. For example, rehabilitation services are to be provided for cancer, mental health and substance abuse/drug users. The document also suggests that rehabilitation programmes or therapy are to be expanded for older people, people with long term illnesses and disabilities using the country's existing disability laws and regulations.

There appeared to be no national level data on rehabilitation. As rehabilitation is highlighted as a strategic output indicator for improving quality of life for older people, people with long term illness and disabilities, it seems data is to be collected in terms of the percentage of those with access to rehabilitation services and AP as well as the prevalence of impairments (e.g., hearing, visual, etc.). Overall, there does not appear to be a strategic, joined-up approach to rehabilitation. Without a rehabilitation strategic plan, including a formal national level rehabilitation database, implementation of rehabilitation services could be negatively affected. This could result in appropriate services not available to meet

the needs of persons with disabilities, especially those living on islands outside of Malé.

## 4.2 Rehabilitation Service Providers

This section explores rehabilitation service providers' views on the delivery of rehabilitation services in the country. Firstly, this section reviews rehabilitation service availability in the country, and then considers the financial challenges experienced by these key informants and how they mitigate these challenges as they attempt to deliver services. Next, I explore how the service providers influence rehabilitation and disability policies and programmes through interactions with policy makers. This is followed by the service providers' perspectives on the government's actions and attitudes towards rehabilitation and disability. Finally, I conclude this section with an exploration of the tensions both government and service providers experience in their attempts to provide rehabilitation service in the country. The findings have been organised using the relevant WHO Health Systems Building Blocks discussed in Chapter 1.

## 4.2.1 Service Delivery

## Rehabilitation Service Availability

Most public and private rehabilitation services were based in Malé. Most key informants, especially those who provided rehabilitation programmes for persons with disabilities, expressed that rehabilitation services were not well established across the country and that this was particularly an issue for those living on the other islands. Some services, such as physical therapy or basic diagnostic services for vision, were only available at the larger atoll regional hospitals, with limited to no services on smaller or more rural islands. Hearing services were only available in Malé. A few key informants expressed concern that there were no specialised rehabilitation centres available for people with specific types of injury such as head injury or spinal cord injury in the country. Without specialised rehabilitation services, individuals may not receive the specific type of rehabilitation needed to

function as independently as possible in their home and community. As one key informant noted:

"There are no proper rehabilitation facilities for persons with disabilities in the country. There has to be a national disabilities centre where ... a rehabilitation system can be [established especially] for the rural areas. It's not happening."

Key Informant #1 - DPO

Programmes for children and young adults with cognitive impairments (e.g., autism spectrum disorder or developmental delays) were limited to two private rehabilitation services based in Malé. These offered a comprehensive multidisciplinary approach to working with children and young adults with learning disabilities. Similarly, mental health services (e.g., behavioural counselling) were limited and available only at the tertiary level hospital and a few private clinics in Malé. Concerned about the lack of mental health services in the country, one key informant working in this field stated:

"... [there are] very few clinics are available here [in Malé] as well [and]...no clinical services are available in any – like, I'm not aware of any clinic that is specifically providing mental health services in any of the islands..."

Key Informant #9 – NGO

Given the limited rehabilitation available on the islands, some Malé based service providers in both the public and private sectors found ways to improve access for those travelling from the islands and requiring their services. For example, those who provided physical therapy, mental health and cognitive rehabilitation said they would move services users from the Islands to the top of the waitlist or alter their appointment times in order to accommodate their travel from the islands and the indirect costs (e.g., transport, lodging) of having to stay in Malé.

For specific rehabilitation services not available on the islands, some service providers organised outreach programmes for these remote areas. This included

community-based rehabilitation or medical/rehabilitation camps, which offered different rehabilitation services (e.g., physical therapy, SLP). These programmes would be advertised through social media or at island health posts or local schools. Service providers would travel to these islands for 1-2 days to provide the programmes and between 10-30 persons with disabilities would participate.

One NGO that provided rehabilitation services also offered telephone consultations for island-based parents/caregivers of children with cognitive impairments, providing assessment and intervention information. It would also offer outreach training programmes for schoolteachers who taught children with learning/cognitive impairments. One key informant noted:

"Lately, we found a gap [in knowledge on teaching children with autism] and what we did was we opened up a training session for all the teachers. ... we train them on educational – individual educational planning, and behavior modification therapies, some of the speech activities we do, some of the occupational activities we do..."

Key Informant #8 – NGO

## Financial Challenges

The financial aspect of providing rehabilitation was another contributing factor impacting the delivery and access to rehabilitation services. NGOs, private sector rehabilitation services and DPOs are categorised as non-governmental organisations by the government and do not qualify for any government funding. Key informants working in the public sector all noted that government funding for rehabilitation in the public sector is limited.

Key informants in NGO, private and public sectors noted that their clients have had to make varying out-of-pocket payments in order to utilise their services.

Depending on the type of rehabilitation services used, clients are charged a user fee on top of what is covered by the country's national health insurance programme,

Aasandha. Providers need this additional payment in order to subsidise services

because there is insufficient government funding to cover, for example, additional therapy fees, the use of rehabilitation equipment (e.g., ultrasound machine, spinal traction) or the cost of maintenance and repairs of the machines. As one key informant from the public sector noted:

"...for some services, [patients] have to pay around...ten, fifteen Rufiyaa (\$1 USD). So, the patient is coming, and we [use] the traction [machine]; the Aasandha is paying around 50 Rufiya (\$3.50 USD). So, the patient has to pay 15 Rufiyaa ..."

Key Informant #12 – Public Sector

Key informants working in the private sector acknowledged that the high costs of assessments and therapies could be a challenge for those seeking their services. Since most NGO and private rehabilitation assessment and therapy fees were not covered by the national health insurance programme, these additional costs could be a financial burden for persons with disabilities and/or their families, and deter them from seeking treatment. While rehabilitation organisations providing services for children with disabilities often work with the parents to develop a payment plan, one key informant noted parents sometimes just cannot pay:

"... 200 dollars (USD) [for therapy fees] for a parent with even one child is a bit of a difficult thing ... most of them they don't pay... we don't pressurize them ... they bring in what they can but then ... So, we are out of pocket ... not a little bit, a huge amount most of the time.

Key Informant #8 – NGO

However, as this quote illustrates, key informants in both the private and NGO sectors interviewed for this research were committed to ensuring that their clients had access to their services, regardless of whether they could pay. As such, they found various ways to improve access to such services such as lowering assessment and treatment fees or finding a business to sponsor the person or child with a disability. As noted by one key informant:

"... when there are parents who cannot pay for three or four months ... we make a phone call and tell them look there is a company who'd like the sponsor the child ..."

*Key Informant #8 – NGO* 

Many key informants in the private or NGO sector noted that one consequence of keeping programme fees low, was that it was challenging to cover overhead expenses, including staff salaries or expansion of services, and the ongoing struggle to keep their businesses open was a concern. Despite this, many of the private and NGO sectors key informants seemed very dedicated to the work they do to ensure adults and children with disabilities receive the therapy they need. One key informant noted:

"... one of our biggest challenges is finances, right? So, we have a very dedicated group of teachers and therapists here, where ...if we aren't able to pay the salary for a month, they would still show up..."

*Key Informant #2- NGO* 

With limited financial resources, key informants in this sector said they must find innovative ways to ensure their businesses can stay afloat. For example, one respondent said his organisation rented out a floor in their building to another organisation in hopes of generating more revenue to expand their services; a few other key informants noted that they try to seek donations from the business community. Other respondents sought out individuals or businesses to sponsor the adult or child with a disability to cover some of their rehabilitation fees or donate money or equipment/materials to their organisation. According to one key informant:

"...we've a project where [the young adults with disabilities] will be sewing all uniforms of all the staffs [for a local] centre. We'll be splitting the profit where [the young adults with disabilities] will be getting 60% of the profit and then 40% of the profit will be retained [by the organisation] to maintain the programme."

*Key Informant #2 – NGO* 

#### Rehabilitation Human Resources

Many key informants identified the challenges related to health human resources as another factor impacting the delivery of rehabilitation services. At the time of the data collection, rehabilitation training/education programmes in areas such as physical therapy, occupational therapy, or behavioural counselling were not available in the country. Some key informants who had received training in a rehabilitation field (e.g., physical therapy), noted they obtained their training abroad. As one key informant noted:

"Physical therapy training programmes do not exist in the Maldives [so] I had to move to India to study physical therapy."

Key Informant #12 - Public Sector

The key informants noted there was a high demand for rehabilitation services in the country, but there was a limited supply of qualified and skilled therapists available to fill this demand. Key informants whose rehabilitation programmes required specially trained therapists, such as speech, occupational or behavioural therapists, described their struggles in finding these therapists:

"a person of high caliber and experience – you wouldn't be able to find in Maldives. Some of these therapists – occupational therapy is very difficult finding one ... speech therapists ... we cannot get..."

*Key Informant #8- NGO* 

To address the lack of highly qualified and skilled therapists (e.g., speech language therapists, behavioural therapists), therapists from other countries are recruited. However, some key informants felt there were challenges with this approach, due to language and cultural barriers. For example, one key informant whose organisation provides mental health services noted:

"It's very difficult to recruit qualified individuals and sometimes there is a language barrier... our existing two therapists [are] from India [and do not

speak the local language] ... we've been trying, but it's very hard to actually get qualified individuals from – local individuals."

Key Informant #9 - NGO

One public sector key informant, who is Maldivian, felt that being a local who understands the Maldivian culture and language was beneficial in building rapport with their clients:

"Here in the Maldives, as a local physical therapist ... the main thing is people like us because we are locals... we speak the language and know the culture ... so people feel comfortable with us..."

Key Informant #12 – Public Sector

Another reported challenge of recruiting therapists from other countries was that it is a time-consuming and costly process. A key informant stated it took her organisation over a year to bring in an occupational therapist from India and they had to cover other expenses in addition to the therapist's salary. For many rehabilitation services in the country, this additional cost is another financial burden they must deal with on a regular basis:

"When we bring [in] the ... therapist, the accommodation and food might be covered by us. But you know like, that's a tough thing for us to do [financially], so there are challenges like that..."

*Key Informant #2 – NGO* 

Government key informants were aware of the high demand for and limited supply of rehabilitation professionals and education/training programmes. They also acknowledged other challenges to service providers' experiences when hiring a foreign-trained rehabilitation therapist, such as the qualifications of the therapist, language barriers and cost. A government key informant noted that, in general, a therapist's education/training (e.g., masters vs. a doctorate in physical therapy), skill set, and proficiency level will determine their scope of practice or the

therapeutic techniques they are able to perform within their standards of practice. Recruiting highly skilled and specialised rehabilitation service providers to the Maldives has been difficult for the government. This has implications for the type and quality of rehabilitation service that are offered. As noted by one government key informant:

"... we have an [allied health] regulatory college where [rehabilitation therapists] can register and their scope [of practice] is identified...a PhD in physical therapy or ... a master's in physical therapy, they are given certain independent work; but then most of the physiotherapists that we have [only have a] diploma rather than a degree. So then again it becomes difficult in what should we [allow] them to do independently..."

*Key Informant #3 - Government* 

In this context of limited rehabilitation expertise and service availability in the Maldives, key informants from the private, NGO, and public sectors stated their concern about the well-being, health and safety of their therapists and other support staff, which in turn impacted on the services they were able to offer. This was especially the case among people working in cognitive and mental health services, related to the intensive nature of providing therapeutic interventions to vulnerable clients. For example, one key informant who provided therapy for children with autism commented:

"We cannot take any child who is about 14 years. We had some 14 and above, but then we made a policy of not taking that age because they become slightly destructive, and sometimes when they get aggravated, they can be very aggressive, and then hurt the teachers and damage the facility."

*Key Informant #8 – NGO* 

Other key concerns highlighted by key informants included heavy caseloads, long workdays, significant time restraints (e.g., length of client sessions), repetitive/overuse injuries, and burnout. This led, in turn, to ill-health and negatively impacted staff retention. The issues described by the key informants

suggest that if they were better resourced (e.g., finance, staff training, quality and skill of staff, etc.), this could lessen the chances of burnout, workplace injuries, or illness and lead to improved staff retention. Retaining staff is important in a country that already suffers from a shortage of rehabilitation expertise, and where there is a high unmet rehabilitation need for persons with disabilities.

## Influencing Rehabilitation and Disability Policies and Programmes

Most key informants attempted to influence government policies and programmes to improve the delivery of rehabilitation services, since many felt it was not a priority for the government. Key informants from NGOs and DPOs seemed to have a more direct role in influencing policy makers through lobbying and advocacy, whereas key informants in the public sector influenced through indirect activities such as education and advocacy programmes at the community level.

Many of the NGOs and DPOs have been established in the country for many years. Key informants noted that they had sought out government officials or policy makers to provide feedback on disability or rehabilitation policies, such as those on mental health services, or to lobby or advocate for new government supported rehabilitation programmes for persons with disabilities. However, some found their attempts to establish a working relationship with the government challenging. As noted by one key informant:

R: We've had meetings with the [government]; we haven't seen any [progress]

*I:* What is the government aiming towards? Do they want a partnership?

R: That's what we always try to advocate with them. We are an NGO, we're not your competitors. Let's try to work together...but it doesn't [seem] to work.

Some key informants described other activities, including developing public awareness and education programmes on disability, organising a network of disability rights campaigners on different islands, or collaborating with local community and business groups and other disability NGOs to advocate for the rights of persons with disabilities. Though key informants working in the public sector had felt they had limited opportunities to interact with the government, some said they participated in community events to increase awareness on the role of rehabilitation.

Another approach to influencing disability and rehabilitation policies and programmes was the use of different media platforms such as radio, television, and social media to raise awareness of and access to rehabilitation programmes for persons with disabilities. Key informants from the NGO sector noted their organisations had sent out emails on a regular basis to educators, health centres or regional hospitals on all islands with the goal of increasing awareness of their education programmes or screening services. However, one key informant highlighted the importance of using different media platforms to increase awareness:

"Because on the islands [people] don't really use social media ...we attend to radio programs, tv programs ... sometimes we get calls from the islands when they are visiting Malé, they would call us..."

*Key Informant #2 – NGO* 

# 4.3 Perspectives on Government's Actions and Attitudes on Disability and Rehabilitation

Non-government key informants expressed concerns that the government was not addressing the needs of persons with disabilities, including access to rehabilitation services, across the country. Many felt that the government's lack of attention to

disability and rehabilitation policies and programmes reflected a limited understanding in these areas.

Many felt the government had adopted a medical or charity model approach to disability and rehabilitation. For example, it was noted that medical doctors acted like gatekeepers and determined who could access publicly funded rehabilitation services. A few key informants noted that, in some cases, doctors would also determine the type and course of therapy their client should receive. Some felt this undermined their professional independence and limited their scope to use their own clinical judgement to determine what intervention would be best for their clients:

"...depending on the condition...the doctor decides whether the patient should do therapy or not..."

Key Informant #13 – Public Sector

Non-government key informants felt the government did not recognise the value of persons with disabilities, or their capacity to contribute to society, and the role of rehabilitation could play in supporting social inclusion for this vulnerable group. As one key informant noted:

"... [the government] need[s] to change their mentality towards people with disabilities...they need to see them as functional people who can be useful to the community instead...they just follow the whole charity model over and over again."

Key Informant #2 – NGO

At a global level, there has been a shift away from the medical and charity models to a rights-based model where persons with disabilities are recognised as being entitled to the same rights as everyone else in society. However, some key informants noted a rights-based approach to disability had not been adopted in the Maldives, and that government policy on the delivery of health-related therapies

remained underpinned by the previously mentioned medical or charity models. According to one key informant, whose organisation works closely with the government:

"[Disability] is an issue we've never had a discussion [on] at a [the] national level. We've never talked about the rights of a person with disability."

Key Informant #10 – Intergovernmental Organisation

From a policy perspective, most respondents were aware of the legislature, and of international commitments on disability (e.g., the Disability Act (2010), UNCRPD) that were put in place to make sure the government promoted, protected, and ensured the rights of persons with disabilities. The government did create a Disability Council in 2010 to uphold these efforts and to ensure that the needs of persons with disabilities were addressed. However, many key informants expressed their disappointment about the ineffectiveness of the Disability Council, noting that the government had not implemented these legal instruments to their full potential. As one respondent noted:

"Even the Convention of the Rights of Person with Disabilities was signed by the Maldives, ... but nobody really tries to implement it or try to talk about it."

Key Informant #10 – Intergovernmental Organisation

At the time of data collection, the government was in the process of developing and implementing a mental health policy to address the limited service availability around the country. However, some key informants indicated a lack of government policies or guidelines for other impairments/conditions, such as autism, which could have negative implications for funding and service delivery for service providers in all sectors. These key informants also felt the government had limited involvement in rehabilitation programmes, especially on the islands. Some indicated they had interacted with government officials on several occasions to discuss the

opportunity to collaborate on programme development but experienced limited to no progress. According to one key informant:

"I suggested to the [government] we have mobility [rehabilitation] teams to travel to the islands ... I [also] suggested we start a community-based rehabilitation system ... it is difficult to convince the government how important it is to create these rehabilitation programmes in the rural areas."

Key Informant #1 - DPO

Acknowledging the lack of access to rehabilitation programmes on the islands, many key informants felt the need to address the gap in services on their own. These service providers took the initiative to organise and implement a variety of programmes and activities, such as outreach/educational programmes or medical/rehabilitation camps on islands where rehabilitation services were lacking or where access to Malé was difficult (e.g., high cost of travel and accommodation). These examples demonstrate key informants' perception that the lack of government action in disability and rehabilitation policy and programme arenas, reflects the low importance attached to these areas, meaning rehabilitation services will remain limited.

# 4.4 Tensions among the Key Stakeholders in the Delivery of Rehabilitation Services

It appeared that all key informants who provide and support rehabilitation services had experienced frustration when trying to provide high quality services for persons with disabilities. Many felt they functioned in a policy environment which offered little support in terms of general policies or funding for specific impairment-based programmes. Many operated in a physical environment with limited physical space for therapy, minimal equipment to treat their clients, or few qualified therapists to provide quality rehabilitation services. This ongoing tension was difficult and frustrating for these key informants to navigate, as they had to operate in uncertain circumstances, as key informant quote below suggests:

"... rehabilitation equipment is lacking here [at the government hospital]. There is a lack of machines ... there is no proper equipment for paraplegic patients or stroke patients. I just do what I can ..."

Key Informant #13 - Public Sector

There was a clear sense of battling a lack of prioritisation at the policy level, but key informants also experienced this challenge at the individual client level. Many noted it was difficult to ensure their clients understood the benefits of rehabilitation. They also felt their clients did not appreciate that these benefits could only be realised if the clients regularly attended their therapy appointments, actively participated in their programme, and understood that rehabilitation extends beyond the four walls of the therapy environment (where completing a prescribed home exercise programme is imperative to clients achieving their rehabilitation goals). One key informant who provides physical therapy services expressed their frustration:

"[My clients] don't do exercises also. We give every patient to do exercises at home. They don't follow those exercises [and] that's a big problem!"

Key Informant #12 – Public Sector

For key informants working in the NGO and private sectors, there was the ongoing struggle of trying to maintain and manage their businesses. At times, their clients would not be able to pay for the services they received, which placed an added burden on service providers and their businesses. Many continued to treat these clients despite knowing their business's finances could be negatively impacted: unable to pay staff, delay in paying rent, unable to expand services or purchase new equipment. They chose to do this as they knew, given the limited availability of rehabilitation programmes, that there would be negative consequences for their clients, their families, and society. Key informants employed in the public sector noted the ongoing struggle of working within the confines of government restrictions. They commented on an overburdened public rehabilitation sector, a

lack of rehabilitation policies, high caseloads, limited funding to purchase new equipment, and small treatment spaces. Yet, they too wanted to provide their clients with the best quality of care.

The government itself was not immune to the tensions experienced by service providers, albeit expressed somewhat differently. The Ministry of Health must deal with challenges and stresses in delivering and financing quality healthcare services to a dispersed island population while ensuring that all Maldivians, regardless of where they live and the island population, have access to essential healthcare services. This also includes considering the specific health needs, such as maternal health, and prioritising such programmes for each island. One government key informant noted:

"...we identify what should be the services that has to be in that particular healthcare facility depending on the population and also depending on the needs of that particular population and numbers..."

*Key Informant #3 – Government* 

In the political environment, another cause of tension is the government's ability to manage its competing priorities. When the current government was elected in 2018, the President's "100 Day Agenda," which included new policies and programmes, was given priority and legislation was pushed through. The current government was also in the process of developing and implementing its own policies to reflect its new health priorities. As one key informant from the government noted:

"Governments...come in with their own manifestos. The manifestos would have policies [and would lay] down policies. So, the current government would also have health policies and the current government's policies includes providing the necessary healthcare for like developmental and other disabilities [and] disorders."

As a Member State of the United Nations, the Maldives government must ensure the Sustainable Development Goals have been addressed and certain targets have been met to receive funding from the UN. Conversely, the UN not only has to work closely with the government but other key players, including civil society organisations, to ensure the Sustainable Development Goals can be achieved.

## 4.5 Summary

In summary, this chapter reflects the perspectives of key informants (government and rehabilitation service providers) on the delivery of rehabilitation in the Maldives. Government key informants reflected on the challenges they face in the delivery of rehabilitation. These included: competing healthcare service priorities for a diverse and dispersed population in an island country; a bureaucratic system where multiple ministries which are involved in disability and rehabilitation each working in their own silos; and limited implementation of existing disability and rehabilitation laws and policies. Rehabilitation service providers acknowledged the resource challenges (e.g., human resources, finance, space/equipment etc.) in delivering high quality rehabilitation but also highlighted ways to mitigate these challenges in order to improve access to their programmes. They felt that the challenges they experience trying to deliver rehabilitation reflects the government attitudes to, and understanding of, the role rehabilitation plays in the lives of persons with disabilities. Finally, the challenges faced by both government and service providers created tensions as they struggle to deliver rehabilitation services. Overall, there was a general sense from all key informants that rehabilitation for persons with disabilities was not well delivered in the Maldives.

# Chapter Five: Findings for Objective 3

 To explore the barriers and facilitators of accessing rehabilitation services for persons with disabilities in the Maldives

This section explores the access barriers and facilitators which have influenced unmet and met rehabilitation needs for persons with disabilities. Based on the findings of this study, I have adapted both Levesque's (2013) access framework and Allin's (2010) classification of unmet need to the rehabilitation context. Please refer back to Appendix 1 for definitions used in Levesque's framework (2013) and Chapter 1, for Allin's (2010) classification.

Barriers to access to rehabilitation have been categorised under Levesque's Access Dimensions. These dimensions relate to the supply-side aspects of a health system and organisation. They reflect the constraints within the health system/organisation, and the challenges persons with disabilities encounter when trying to access rehabilitation (Levesque et al., 2013). Facilitators to access have been organised using the 'abilities' of person accessing rehabilitation. These abilities reflect the demand side, including characteristics of the user of the health system/organisation (e.g., person with a disability) and the process factors which describe how access is realised (Levesque et al., 2013). Figure 6 below provides a brief summary of the barriers and facilitators influencing unmet and met rehabilitation needs of persons with disabilities in the Maldives.

During the interviews, participants' experiences accessing rehabilitation were often discussed together rather than as separate issues. The barriers and facilitators participants identified were interwoven into their narrative. While I have tried to clearly differentiate the various barriers and facilitators participants experienced, in reality, there are many different and overlapping factors, operating at the personal, psychological, societal and structural levels, which can impact an individual's decision to access rehabilitation (Zuurmond et al., 2019).

Figure 7: Brief Summary of Access Barriers and Facilitators Influencing Unmet/Met Need Categorised Under Access Dimensions/Abilities of Person

Access Dimension/ Abilities of Person	Identified Barriers and Facilitators	Unmet / Met Need Category
<ul> <li>Approachability</li> </ul>	<ul> <li>Lack of awareness of need for</li> <li>Lack of available rehabilitation services</li> </ul>	<ul> <li>Unperceived</li> <li>Unmet Need</li> </ul>
Ability to Perceive	<ul> <li>Health literacy/ knowledge</li> <li>Awareness of services</li> <li>Advocacy</li> </ul>	<ul> <li>Met Rehabilitation Need</li> </ul>
Acceptability	Gender roles	Initial     rehabilitation     needs met but no     follow up
<ul> <li>Availability</li> </ul>	<ul> <li>Lack of rehabilitation services on islands and Malé</li> <li>Limited access to AT and medications</li> <li>Lengthy waitlists</li> </ul>	<ul> <li>Initial rehabilitation needs met but no follow up</li> </ul>
Ability to Reach	<ul><li>Family/friend support</li><li>Relocate to Malé</li></ul>	Met Rehabilitation Need
<ul> <li>Affordability</li> </ul>	<ul> <li>Direct cost (e.g., high fees)</li> <li>Indirect costs (e.g., travel)</li> </ul>	<ul> <li>Initial rehabilitation needs met but no follow up</li> </ul>
Ability to Pay	<ul> <li>Family/friend financial support</li> <li>Personal savings/bank loans</li> <li>Private health insurance</li> </ul>	<ul> <li>Met Rehabilitation Need</li> </ul>

<ul> <li>Appropriateness</li> </ul>	<ul> <li>Technical/quality of services</li> </ul>	Initial Unmet Need

# 5.1 Approachability and the Ability to Perceive

### Unperceived Unmet Need

Some participants with physical disabilities were not aware of the capacity to benefit from rehabilitation. Limited awareness of the availability and potential benefit of rehabilitation was a barrier to utilising services. The participants in this category were all elderly and living with chronic illnesses. They may not have perceived of any benefit from rehabilitation due to their age, health status or disease process. Since these participants also lived on small remote islands, the limited availability of rehabilitation services on the islands could have impacted their awareness of services available to them. I will further discuss aging and rehabilitation in Chapter 6 - Discussion section.

Additionally, these participants and caregivers commented that they were never informed by their healthcare providers or government health agencies of the potential benefits of rehabilitation for their impairments, or where to access such services. Below is a quote from a caregiver whose 79-year-old housebound mother lives with a physical impairment, describing an interaction they had with healthcare professionals on the island:

*I:* Has the doctor ever said anything about doing ... physical therapy [for your mother]?

R: [They] didn't say anything.

*I:* Did they tell you to do any extra thing?

R: [The doctor] didn't say do any extra thing. [They] did say for her to go out but no physical therapy

*I:* Did they tell her to use anything like something like a wheelchair outside?

R: No

Caregiver of 79 year old female with physical impairment living in the islands

### Facilitators Influencing Met Need

Health literacy was a key facilitator. A common characteristic among participants with 'met need' was that they either had knowledge of rehabilitation needs and services, or they had the capacity and motivation to seek out information on accessing rehabilitation services. This included word-of-mouth sources, using family/friend connections in the rehabilitation field, or (in the case of parents or carers) advocating on behalf of disabled family members to find the most appropriate services available to ensure their rehabilitation needs were met. For example, parents of a child with autism identified early in the child's life that "something was different about their child", sought out medical help right away and asked questions regarding appropriate medical treatment which led to this child receiving the appropriate treatment:

"When [our son] son was five months old, we knew something was different about him, so we moved back to Malé [to seek treatment for him]."

Caregiver of 4-year-old male with cognitive impairment

However, it must be noted that not everyone would have family/friend connections to rely on, or the educational background to seek more information.

# 5.2 Acceptability

### Initial Rehabilitation Needs Met but No Follow Up

The intersection between gender and disability appeared to have an impact on access to rehabilitation. While female participants in this category were able to access rehabilitation services for an initial assessment for their disability, many encountered challenges when attempting to access ongoing interventions. For example, whether they lived in Malé or on another island, some female participants

indicated they were dependent on a male relative to accompany them for rehabilitation services. In the Maldives, a woman will typically travel with a man for safety reasons (e.g., they feel they will experience less harassment if travelling with another man). Also, there is the ease of travel for them as men are more likely to drive, and men are more likely to oversee household money or bank accounts. Other female participants noted that they delayed seeking further rehabilitation interventions for their disability because of their caregiving and household responsibilities. Below is a quote from a female participant who prioritised the caring of her children over her own disability needs:

"I have ear problems. [The doctors] wanted to do the surgery, but because the children were small, I decided to wait. I have a lot of kids, 5 kids, so [I need to] care for them."

54-year-old female with multiple impairments living in Malé

### 5.3 Availability and the Ability to Reach

Initial Rehabilitation Needs Met but No Follow Up

### i) Availability of Rehabilitation Services

Participants felt that the limited availability of rehabilitation services was a significant barrier to receiving ongoing interventions. While some island-based assessments were possible for those with visual and physical impairments, those with hearing or cognitive impairments had to travel to Malé where healthcare professionals specialising in these areas were based. However, for more advanced assessments and testing requiring specialised healthcare professionals and equipment (e.g., MRI), all participants, regardless of impairment, had to travel to Malé. This was particularly problematic for those living on other islands with complex rehabilitation needs.

Notably, these island-based participants had the ability to cover the initial out-of-pocket expenses associated with travel (e.g., transport, accommodation, food) to Malé as well as family support (e.g., family member to accompany them to Malé).

However, because of the lack of rehabilitation services on smaller or more rural islands, these participants reported it was not feasible for them to travel to Malé on a regular basis for ongoing rehabilitation interventions. Reasons included lengthy travel times, high travel costs, employment commitments, or family responsibilities. As such, these participants would forgo any further interventions which could have improved the quality of their lives. Below is a quote from a caregiver living on a small rural island who expressed her frustrations with the lack of cognitive therapy programmes for her 6-year-old learning disabled son:

"There are no doctors here on the island [to treat my son's condition]. No one at the regional hospital and there are no special classes [at the school] for him..."

Caregiver of a 6-year-old male with a cognitive impairment living in the islands

Malé-based participants with vision, hearing and physical disabilities were able to access rehabilitation services at the publicly funded hospital in Malé with minimal additional out-of-pocket expenses. This also meant they were more likely attend ongoing interventions. While participants with cognitive impairments were able to access some services in the public sector (e.g., psychiatry or neurology at the tertiary level hospital), those who required specific diagnostic assessments for autism or learning impairment, were required to seek out and pay out of pocket fees for these services in the private sector.

### ii) Availability of Assistive Devices Repair

Some island and Malé-based participants who required assistive devices such as wheelchairs, hearing aids or prescription spectacles, reported they had to purchase these devices either in Malé or abroad. Devices requiring any basic repairs, such as wheelchairs or hearing aids, had to be taken to repair shops, all based in Malé. Some participants noted that any complex repairs, such as for hearing aids, would require the devices to be sent abroad for a few months and at the participant's own expense.

Some participants living on other islands reported frustration at the lack of island-based repair services, as it required them to travel to Malé and this was not always feasible. For example, one participant, a 40-year-old female with a physical impairment, noted she was unable to find a repair shop on the island to fix her electric wheelchair. Because of its large size and weight, it was not feasible to transport the wheelchair to Malé to be repaired. As such, as she was housebound, there was an increased dependence on her family, her ability to participate in her community was limited, and my informal observation revealed a sense that she had lost her dignity.

"... there's a problem with [the wheelchair] now. I don't know what's happened to the wheel. There isn't anyone on this island that can fix it right...I can't walk, [so] every time I have to use the toilet, my kids have to [help] me to the toilet..."

40-year-old female with a physical impairment living in the islands

### iii) Availability of Specific Medications

Regardless of the type of impairment, Malé-based participants requiring medications noted they could obtain them at local pharmacies. However, for some other island-based participants, it meant a dedicated trip to Malé, as some island pharmacies did not carry the medicines they required. This highlights the large disparity of access to medication between Malé and the other islands, and the inconvenience for persons with a disability trying to access such services. A few participants indicated that medications prescribed to them abroad were not available in the Maldives, and they would either try to travel back to the country where the medication was prescribed, or rely on the goodwill of someone travelling to that country to pick up the medication. Those who could not renew their prescriptions would go without, negatively affecting their health, their disability, and impacting their ability to participate with family and their community. The quote below reflects the frustrations of a 31-year-old male participant living on an island who experienced difficulties getting medication for his vision impairment:

"... the most recent medicine that the doctor gave, it's an eye drop [for my glaucoma]. I couldn't get it in Malé, ... so, I still haven't got it. Things like this are really difficult."

31- year-old male with vision impairment living in the island

### iv) Waitlists

Long waitlists to access public sector rehabilitation services (such as occupational therapy, speech language therapy or mental health services) based in Malé were another barrier preventing participants from receiving ongoing interventions. The exception was physical rehabilitation services (e.g., physical therapy, orthopedic doctors) at regional atoll hospitals, which participants noted they could access immediately.

However, most participants who sought rehabilitation services at the government hospital in Malé for their hearing, vision, physical or cognitive impairments, faced variable wait times to access ongoing interventions. As a result, some sought out these services in the private sector if available and if they could afford it, while others had no choice but to wait or go without. Those who experienced a delay or no ongoing interventions potentially faced a worsening of their impairment and the emotional impact for individuals and their caregivers of not receiving the required rehabilitation. The quote below describes the frustration a caregiver experienced when making an appointment for her young adult daughter with a cognitive impairment at a government hospital:

"Actually, it's really difficult to get an appointment at [government hospital]... it's difficult for me. Because when you put your name down for an appointment with the nerve doctor [neurologist]... you get an appointment about 2-3 months later. "

Caregiver of 24 year old female with cognitive impairment living in Malé

The public sector did not offer any cognitive rehabilitation programmes (e.g., autism) for children or adults, though a few programmes for children were available in the private sector, all based in Malé. Caregivers of children with cognitive impairments noted waitlists to these private sector programmes were not an issue and participants could access these programmes for ongoing interventions in a timely manner.

#### Facilitators Influencing Met Need

Another common finding among participants with met needs was that they felt they were supported by those around them, such as family or friends, which helped them meet their rehabilitation needs. For some participants, it was family or friends who assisted them regularly with their activities of daily living, such as dressing or cooking meals. For others, it was accompanying the participant to their rehabilitation appointments, whether travelling to Malé or abroad, or providing childcare services for participants so they could attend rehabilitation. Some participants, parents or caregivers relocated permanently from the islands to Malé so they or their family member with a disability could access rehabilitation services not available on the islands. Below is a quote from a man who moved to Malé in order to access the ongoing rehabilitation services he need for his cognitive disability:

I: Why did you move [to Malé] after living on the island?

R: I moved here [because] I can consult the neurology doctor more quickly... there are no neurology doctors on the island I was from...

47-year-old male with a cognitive disability living in Malé

## 5.4 Affordability and the Ability to Pay

### Initial Rehabilitation Needs Met but No Follow Up

For many participants, financial difficulty was perceived as another challenge in addressing ongoing unmet rehabilitation needs. This varied by type and severity of

the participant's impairment, and where they lived. Despite access to social protection programmes, such as the Disability Allowance, some participants noted they still had difficulties covering the cost of rehabilitation services, including AT and medication, which were not covered by Aasandha.

Limited rehabilitation services or lengthy waitlists directly impacted the financial capacity of some participants who were seeking ongoing rehabilitation services for their impairment. As previously discussed, the additional expense of travel to Malé or abroad prevented some participants, especially those living on the islands, from receiving the ongoing rehabilitation they needed for their disability.

When public sector hospital waitlists for rehabilitation services were too long, participants would seek these services in the private sector if they could afford the fees. Some participants noted they could not afford the out-of-pocket expense charged by the private clinics and had gone without any rehabilitation interventions for their condition:

"[The doctors] tell me to go for physio, ... but it doesn't happen [because of the long waitlist]. I'd have to go somewhere else which would be very expensive. We can't afford that."

54-year-old female with a physical impairment living in Malé

Caregivers of participants with cognitive impairments noted significant financial challenges in trying to access cognitive rehabilitation programmes. As previously noted, all cognitive rehabilitation programmes were based in Malé and in the private sector only. For many caregivers, especially those from smaller or more rural islands, the high cost of accessing rehabilitation along with transport and accommodation costs was such a financial strain it was not feasible for them to travel to Malé on a regular basis. This essentially meant that those living on the islands could not afford to send their child to the programme:

"We would like to [have our child attend therapy] but we can't rent and stay [in Malé] for a long time. Going there and staying fifteen days or ten days becomes very expensive... So, it's like financial difficulties in staying in Malé, and it's also very difficult here [on the island], so we can't just go ... we face a lot of difficulties."

Caregiver of 5-year-old boy with a cognitive impairment living on an island

Additional costs for assistive devices and medications were another source of strain for some participants. Some participants were able to access government funding to obtain hearing aids or wheelchairs, while others had purchased AP with their own money because they either were not aware of the government funding programme, or they had purchased the item abroad. A few participants also expressed their concerns that certain items, such as hearing aid batteries or prescription eyewear, were not covered by government funding programmes. Therefore, they would be required to pay out of pocket which was costly for them.

Similarly, some participants noted that some medications prescribed by doctors abroad were not available in the Maldives. Thus, they would be responsible for purchasing the medications and for accessing these medications abroad. This proved to be challenging for some, and they reported they would just go without the medication.

### Facilitators Influencing Met Need

All participants who were able to meet their rehabilitation needs had the capacity to access additional funds to cover any rehabilitation expenses, such as assessment or therapeutic fees in private clinics, AP not covered by NSPA, or costs related to travel to Malé or abroad. While these participants were able to obtain some government funding to cover travel and healthcare costs abroad (through social protection programmes such as Aasandha and Medical Welfare), additional funds came from personal savings, family, friends, or banks loans; others had access to work-related private health insurance.

For these participants, having this financial security meant they had the ability to travel to Malé, if living on other islands, or abroad to another country (e.g., India, Sri Lanka) on a regular basis for therapy or treatment, or to purchase medication not available in the Maldives. For some participants, whether they lived on other islands or Malé, having access to additional funds meant they could afford to seek rehabilitation services in the private sector faster, especially if the waitlist in the public system was too long. Below, a participant explains how he covers the cost to see rehabilitation professionals abroad for his vision impairment:

R: Once a year I have to go to Colombo, to see the doctor ... to check the [eye] lens.

*I:* How do you cover [the cost]?

R: My older brother... I [also] have access to private health insurance from work. It covers the costs of my surgeries abroad.

32-year-old male with a vision impairment living in Malé

## 5.5 Appropriateness

#### Initial Need Unmet

### i) Perceived Appropriateness

A few participants with hearing and physical impairments questioned whether the rehabilitation service providers had provided them with an appropriate diagnosis or intervention. These participants sought out assessments in Malé only to be referred abroad to India or Sri Lanka, where assessment and treatments techniques were expected to be more advanced than those currently available in Malé.

However, lack of a definitive diagnosis or perceived inappropriate intervention for their impairment seemed to lead to mistrust and decreased confidence in the local healthcare system. A participant living on a smaller island felt their physical function (e.g., walking without pain, lower limb strength) had not improved from the physical therapy intervention they had received at a regional atoll hospital, and felt they did not receive appropriate intervention due to the complexity of their

disability. Another participant living in Malé perceived no benefit to wearing the hearing aids offered to him both in Malé and India. The hearing aids did not support his hearing loss and further added to his frustrations. Below is a quote from this participant's primary caregiver:

R: Because [my brother] couldn't hear, we went to [India again] where the doctors gave him hearing aids.

*I: Ok, the [doctors] gave him hearing aids. What happens when he uses them?* 

R: ...he didn't want to wear them because he couldn't hear and because they were a big annoyance to keep wearing them...sometimes the hearing aids would fall off and it wasn't easy to find the battery that was used for them.

Caregiver of 44-year-old man with a hearing impairment living in Malé

## 5.6 Summary

Most disabled participants encountered several access barriers which resulted in unmet rehabilitation needs. Affordability and availability were the predominant barriers to accessing rehabilitation services. However, it appears that various interacting personal level factors (including health literacy, financial, and family support) were important in enabling participants to meet their rehabilitation needs.

# **Chapter Six: Discussion**

This chapter is divided into eight parts. For part one, I begin with a review of the key findings from Objectives 1, 2 and 3 respectively. Part two provides a discussion on the quantitative findings of Objective 1 (use of and unmet rehabilitation need). Part three discusses the qualitative findings from Objective 2. This includes a discussion of governance and leadership (from the perspective of government), followed by a consideration of service delivery in the context of rehabilitation (from the perspective of rehabilitation service providers). Part four discusses the qualitative findings from Objective 3, interviews with persons with disabilities. Part five provides a summary of the discussion, while part six is a reflection piece on the frameworks used in this thesis. Part seven and eight conclude this chapter with a discussion of the strengths and limitations of this research and dissemination of this research for key stakeholders involved in rehabilitation services in the Maldives.

## 6.1 Summary of Key Findings

### Objective 1:

 To estimate use of, and unmet need for, rehabilitation services among persons with disabilities living in the Maldives.

Among people with disabilities, reported awareness of at least one rehabilitation service/device they could benefit from was reasonably high. However, use of services was relatively low, especially for hearing (11%), cognitive (20%) and communication (23%) difficulties. Self-reported need varied by functional domain from 40% to 71%. Overall, nearly a quarter of people with disabilities reported they needed, but had not accessed, at least one service/device. However, there was variation by sub-group; unmet need was highest for people with communication (36%) and hearing difficulties (34%) and among people living in the lower per capita expenditure (excluding health care costs and rent) quartiles. People with mental health difficulties reported the lowest unmet need.

### Objective 2:

 To explore the strength and weaknesses of the Maldives health systems' delivery of rehabilitation services in the Maldives (e.g., government, rehabilitation workforce, NGOs, DPOs).

The country has established a number of social protection programmes (e.g., Aasandha, Medical Welfare, Disability Allowance) to facilitate access to healthcare services for persons with disabilities. Aasandha provides universal health coverage to all Maldivians regardless of location, while Medical Welfare covers the cost of most assistive devices and travel/hospital costs abroad. The Disability Allowance is relatively high compared to other social protection programmes and does help to alleviate some disability-related costs. However, key informants noted that these programmes did not appear to be sufficient to meet the rehabilitation needs for this population group. The findings also highlighted competing government priorities, such as trying to provide equitable health services to a dispersed population, the lack of a national rehabilitation framework, and (at the bureaucratic level) a lack of clarity of roles, responsibilities or leadership relating to rehabilitation. This in turn contributed to fragmented rehabilitation service provision throughout the country.

Service providers' perspectives indicated rehabilitation was not well supported in the country. There was a sense that rehabilitation was not prioritised by the government and, as such, many reported they found it difficult to engage with the government. For example, the importance of some specific rehabilitation services (e.g., autism spectrum disorder) was not recognised at the policy level. Many service providers also felt they lacked autonomy, identifying gatekeepers (e.g., medical doctors) at the primary care level as controlling access to rehabilitation services. Service providers also highlighted several challenges (e.g., high overhead costs, difficulties hiring qualified personnel) which made it difficult for them to offer quality and affordable programmes. To overcome these challenges, key informants, in particular private, NGOs, and DPOs, made efforts to meet these service gaps by

offering alternative service delivery options (e.g., telephone consultations, outreach programmes, bypass waitlists) and financial options (e.g., business sponsors) to accommodate their clients. Many also took on advocacy roles to try to ensure policies and programmes for disability and rehabilitation were addressed.

### Objective 3

 To explore the barriers and facilitators to accessing rehabilitation services for persons with disabilities in the Maldives.

Access barriers related to affordability and appropriateness of services led to initial unmet rehabilitation needs. For example, direct and indirect costs of rehabilitation, along with limited financial resources as well as inappropriate or ineffective interventions were cited as access barriers. Initial rehabilitation needs were met but access barriers prevented further follow up interventions. In particular, a lack of services (especially on smaller and more remote islands) and high direct and indirect financial costs were found to be major barriers to receiving ongoing intervention. Household and/or childcare responsibilities were also identified as access barriers. Perceiving the need for and benefit of rehabilitation, and the capacity and motivation to seek out information on accessing services, were key facilitators influencing met need. Family and social support to reach services, and the financial capacity to pay for such, were also important facilitators to accessing rehabilitation.

### 6.2 Use of and Unmet Rehabilitation Need

The results from Objective 1 found that most people reported seeing a healthcare professional, most commonly a specialist rather than a general practitioner, and considered it beneficial. However, this varied by functional domain. For example, approximately 50% of persons sought out a healthcare professional for mental health and cognitive limitations compared to 90% for those with vision or physical limitations. This variation could reflect the availability and location of services in the

Maldives. For example, while rehabilitation services for physical and visual impairments are available at most atoll regional and Malé based health centres, hearing services are very limited and only available in Malé. This variation may also reflect a person's awareness and attitudes. For example, Walker et al., (2022) found that there was a lack of mental health supports in the community as well as low mental health literacy rates in the Caribbean islands. Furthermore, research suggests that the stigma related to mental health may prevent people from recognising the need for, or seeking treatment (Chen, 2018, Patel and Prince, 2001, Wong and Li, 2014).

In terms of rehabilitation services/devices, awareness was reasonably high across all functional domains. There is limited research in other SIDS to compare to; however, this contrasts with research in Vanuatu, a small island state in the Pacific Islands, which found that individuals requiring mental health services had relatively low awareness of type of and where to access mental health services (Dawes et al., 2019). While persons with disabilities, in general, may be in greater contact with health services due to their impairments (Mactaggart et al., 2015), perhaps disabled persons in the Maldives have better access to health services compared to those in Vanuatu. This may explain the higher awareness of rehabilitation services/devices available to persons with disabilities in the Maldives.

Overall, 1 out of 4 persons with disabilities in the Maldives reported an unmet need for at least one rehabilitation service/AP. This is lower than other studies looking at met and unmet need. For example, a study in Bangladesh found an overall unmet need of 70% for AP, such as wheelchairs, hearing aids or communication products among people with disabilities (Pryor et al., 2018). There could be a number of explanations for these different findings. For example, the social protection programmes in the Maldives may cover some costs related to rehabilitation services/AP which may explain lower unmet need. The Medical Welfare programme provides financial assistance for some rehabilitation services/AP not covered by Aasandha, while the Disability Allowance can be used to cover some direct and indirect costs (e.g., transport, lodging, childcare) related to accessing these

services/AP (National Social Protection Agency, 2019). However, the variation in unmet need could also reflect methodological differences in the research studies. For example, in the Bangladesh study, and other studies which use the WHO's rapid Assistive Technology Assessment (rATA) questionnaire, participants were shown pictures of specific APs and asked about need/unmet need for them, rather than the more general questions about service use/need asked in the current study (Boggs et al., 2022, World Health Organization and United Nations Children's Fund, 2022a). This may have resulted in a higher reported need for AP.

There were variations in access by functional type and access indicator. Of those who perceived a need for a rehabilitation service/AP for their functional limitation, the majority sought it. Reported need was lowest for mental health services, perhaps due to the reasons noted above. This is in contrast to other studies where reported need was lower. For example, Fuhr et al., (2019) found that of Syrian refugees living in Istanbul who screened positive for mental health difficulties, only 9% sought treatment. For those who did not, structural (e.g., cost, opportunity costs) or attitudinal (e.g., stigma) barriers were identified. However, definition on need and use for health services vary in the literature and make it difficult to provide comparison.

In terms of socioeconomic and demographic factors, as expected, older people were more likely to report a need for rehabilitation services/AT. This finding is likely to be due to an increase in the number and severity of health problems individuals experience related to the senescence process. People with disabilities in the lower per capita expenditure groups were more likely to report an unmet need than those in the wealthier group. This finding is in line with other studies were old age, low economic status, and lower standard of living were main reasons for unmet health needs (Asuman et al., 2021, Banks et al., 2022b, Herr et al., 2014). Cost (e.g., direct and indirect) is a commonly reported barrier to accessing health and rehabilitation services for persons for disabilities. Although there are social protection schemes in place in the Maldives, indirect costs (e.g., transportation, child care, loss of wages) may still act as a barrier to accessing care.

The quantitative findings on met/unmet need do not show a difference between settings in Malé and other islands. This is surprising given the geographical setting and distribution of rehabilitation services in the country, and the qualitative findings in this study. This deserves further attention. However, it may reflect that the analysis used a combined 'any unmet need' (for reasons of sample size) estimate and masked some of the variation in access by type of functional domain (Boggs et al., 2021a). For example, if one looked separately at hearing impairment, there is a difference, but the sample size is insufficient for such a sub-group analysis in this study. These data limitations are important to consider in understanding the disconnect between the quantitative and qualitative findings in this study relating to Malé/other island comparisons.

A number of key limitations should be considered when interpreting these findings. Evidence suggests that self-reported need of rehabilitation/AP is not very reliable (Boggs et al., 2021b). While self-reporting assessments are seen as less expensive, faster and require fewer human resources compared to clinical assessments, a limitation is that they may over and/or under-estimate need (Boggs et al., 2022). For example, assessing the need for AP is complex and is dependent on several factors including understanding the clinical diagnosis and prognosis of the functional impairment (Boggs et al., 2022). AP assessments require a functional assessment by a trained rehabilitation professional to determine needs, based on the individual's functional goals and their personal and environmental factors (e.g., home environment) (Boggs et al., 2021b). When clinical information is not available and awareness of the role and function of AP or rehabilitation is limited, it is difficult for people to understand what type of AP or rehabilitation may be appropriate for them (Boggs et al., 2021a, Boggs et al., 2022).

Secondly, the questions used for the self-reported indicators of access in this study asked about rehabilitation/AT in general terms with few examples. The questions may therefore have been interpreted differently by participants, depending on their overall awareness and understanding of the different types of rehabilitation/AP

available. For example, some participants may have considered hearing services/AP to include healthcare professionals/audiology services, while others may have considered hearing aids only. To address this issue, the rATA approach of asking about specific rehabilitation services/APs (with pictures) may be a more standardised approach to consider. Also, the question about seeking a healthcare professional did not include anything about follow up, continuity of care or referrals. Therefore, there is no information available on the extent to which participants were able to take up any recommended rehabilitation interventions or AP. Finally, there were no questions about quality of care, which can be seen as a barrier to rehabilitation services.

### 6.3 Government and Rehabilitation Service Providers

## 6.3.1 Perspective of Government

The factors that influence successful health systems include good governance and political commitment, effective bureaucracies and institutions, ability to innovate, and health systems resilience (Balabanova et al., 2013). Kuiper (2014) used these factors and applied them to disability and rehabilitation services to show how LMIC health systems could be improved with limited financial resources. Based on Kuiper's (2014) paper, I will use some of the headings provided by Balabanova to shape this section and will focus on the components of governance and political commitment and bureaucracies and institutions within the context of rehabilitation in the Maldivian health system. I have added a third section on "Social Protection Schemes" which are available to assist persons with disabilities to access health and rehabilitation services in the country.

#### Governance and Political Commitment

Good governance and leadership are key in creating the foundation for successful integration of rehabilitation services into the health system (World Health Organization, 2007). However, findings from this study suggest that within the

Maldives there is limited leadership or political commitment to support this. With competing priorities, the government does not appear to consider rehabilitation a key priority. This situation was also seen in Ireland where Burke et al., (2020) discovered that a lack of political leadership and commitment by the Irish government prevented the implementation of the country's national neurorehabilitation framework (Skempes et al., 2022). It appeared that neurorehabilitation was a low priority for the government, and as a consequence, services were found to be insufficient and fragmented across the country, negatively impacting those who required these specialised neurological services (Burke et al., 2020).

In 2015, the Maldivian government implemented its mental health strategy as a part of the "President's 100-Day Agenda". This strategy involved the creation of a mental health leadership/advisory board, appropriate legislation and policies, funding, human resources and training, and service delivery plan at the primary, secondary and tertiary level of healthcare (Government of Maldives, 2017). The implementation of this strategy demonstrates the government's political will to address the mental health needs of Maldivians and provides an example that government commitment can positively influence the country's health system. As Skempes et al., (2022), Kuiper (2014), and Balabanova, et al., (2013) suggest, if a health system is to include rehabilitation services, effective governance, strong leadership and a long-term vision is required.

While few disability and rehabilitation specific policies were available in the Maldives (in English), none appeared to include any specific outline or strategic framework to assess the overall rehabilitation needs and service availability in the country. A framework is a useful tool to help identify key priorities and objectives. In rehabilitation, when developing appropriate policies and programs, it would be useful to address service availability, funding mechanisms, and rehabilitation human resources, including workforce regulation (Ahmadzadeh et al., 2020). As described in Chapter 1, the WHO created the "Rehabilitation in Health Systems: Guide for Action" to assist governments in strengthening rehabilitation services in health

systems, and it has been used successfully in many LMICs where rehabilitation services were not well established. For example, Jordan used this guide to create a comprehensive rehabilitation strategic plan (Ministry of Health (Jordan) and World Health Organization, 2020). Using a participatory approach, key rehabilitation stakeholders, including persons with disabilities, identified key objectives for improvement which reflect the six components of WHO's Health Systems Building Blocks.

The Maldives government has demonstrated its capacity to develop and implement its mental health strategic plan. Lessons could be learned from this strategic process, as well as from existing strategic planning resources used by other countries, to develop and implement a comprehensive rehabilitation strategy integrated into the health system. In doing this, the country will continue to progress to developing a comprehensive universal health coverage for all Maldivians and achieve Sustainable Development Goal 3.8 (achieve universal health coverage).

#### Bureaucracy and Institutions

Another key factor in a successful health system is the presence of well-functioning bureaucracies and institutions (Balabanova et al., 2013). At the bureaucratic level in the Maldives, multiple players were involved in the disability and health sectors, with no specific rehabilitation section within the health ministry. The findings from this study suggest each ministry worked in its own silo, with their own separate priorities for disability or rehabilitation. For example, key informants from government and rehabilitation service providers highlighted the limited communication/collaboration among the key stakeholders involved in disability and rehabilitation. This gap has likely contributed to a fragmented system of rehabilitation services across the country, which in turn contributes to some of the access barriers discussed below. A recent study by Neill et al., (2023) found that a lack of intersectoral coordination across government ministries, including unclear programming, accountability structures, and poor communication, were key factors

which impeded prioritisation of rehabilitation in LMIC health systems. Similarly, Marias and Petersen (2015) found that poor communication and lack of collaboration among key stakeholders (e.g., government ministries, service providers and service users) were barriers to integrating mental health care into primary care services in South Africa.

For rehabilitation services to be successfully integrated into the Maldives' health system, greater collaboration and coordination is needed between government and other key stakeholders (e.g., NGO, rehabilitation workforce, private/public sector, DPOs, civil society organisations, persons with disabilities)(Balabanova et al., 2013, Marais and Petersen, 2015, McVeigh et al., 2016, Neill et al., 2023).

#### Social Protection Schemes

It is well established that persons with disabilities are at higher risk of living in poverty and can face extra costs associated with their disability; thus, there is a need for governments to provide social protection schemes (Banks et al., 2022b, Banks et al., 2018a, World Health Organization, 2011). This study found evidence of some disability inclusive and rights-based policies, including social protection schemes, which may help persons with disabilities avoid excessive financial hardship due to high healthcare costs, including rehabilitation. For example, the country's universal health coverage programme, Aasandha, covered the cost of some rehabilitation services, such as physical therapy hearing, and vision, while the Medical Welfare programme covered some health expenses, including medical services and AT, not covered by Aasandha. Funds from the Disability Allowance could be used towards the cost of accessing rehabilitation services. Please refer to section 1.3.4 for a description of the social protection programmes available in the Maldives.

However, the findings from this study suggest that these social protection programmes do not provide sufficient coverage for rehabilitation services for persons with disabilities. While a majority of participants had accessed the

Disability Allowance and/or Medical Welfare, many felt these programmes were inadequate and financial barriers remained in terms of accessing rehabilitation. Service providers and some government key informants also felt that these social protection programmes were not sufficient to cover the cost of rehabilitation services. Recognising this issue, service providers in the NGO and private sectors would work with their clients to find alternative funding sources (e.g., business sponsor) rather than ask them to use the Disability Allowance to pay for rehabilitation. This is in line with findings from the broader research study "The Impact Evaluation of the Disability Allowance" where most participants felt the Disability Allowance was not enough to cover costs for disability specific goods and services, including rehabilitation (Banks et al., 2023). In both this study and the Impact Evaluation study (2018) few participants indicated the Disability Allowance was used to cover the cost of rehabilitation services. Most felt it was not enough to cover costs for disability specific goods and services, including rehabilitation. Many reported the money was allocated to more urgent items such as food, clothing, or other living costs (Banks et al., 2023, Hameed et al., 2022b). Research on the use of disability-specific social protection programmes for rehabilitation is limited. However, findings from regional districts in Vietnam and Nepal are in line with the findings from the Maldives. Most beneficiaries used their disability cash transfers for basic food/clothing needs or for access to general health services, with very few using it to pay for rehabilitation (Banks et al., 2018b, Banks et al., 2018c).

# 6.3.2 Perspectives of Rehabilitation Service Providers

Without the appropriate political support, rehabilitation services may not be fully embedded in the Maldives health system, and services not fully provided. This will have an impact on the rehabilitation workforce and how they deliver their services. This research identified four key areas that challenged the provision of rehabilitation services for persons with disabilities: 1) service availability, 2) finance, 3) health human resources, and 4) doctors as gatekeepers. Finally, because of these challenges, many service providers actively participated in activities to

increase awareness of disability and rehabilitation and to influence government on disability and rehabilitation policies and programmes. Each of these key factors will be discussed below.

### Rehabilitation Service Availability

This study found that service providers felt rehabilitation services were not well established in the Maldives health system and that there was an inadequate and unequal distribution of services across the country. Most public, NGO, and private sector rehabilitation services (e.g., physical therapy, audiology, ophthalmology) were centralised in Malé, with limited availability on islands. Based on data collected, no specialised rehabilitation services (e.g., stroke, pulmonary) appeared to exist in the public sector, though some impairment specific services (e.g., autism, behavioural counselling) were available in the NGO or private sectors, again most based in Malé. These findings are consistent with other research in LMICs, where rehabilitation services were found to be lacking or not well organised in the health system (Gutenbrunner et al., 2018, Khan et al., 2015) and more likely to be centralised in urban areas. For example, most physical rehabilitation services (e.g., physical therapy, occupational therapy) were not well integrated into mainstream public health services in Bangladesh (Al Imam et al., 2022). Most services were based in large urban areas with limited availability in rural areas. Furthermore, few services were offered at the secondary or tertiary care level, those that were mainly available in the private sector. One potential consequence of the disparities between urban/rural and public/private services and resources is a further exacerbation of inequalities in the unmet rehabilitation need for persons with disabilities.

In order to address this lack of services on remote islands, many service providers personally took on the additional responsibility to provide tele-rehabilitation or outreach programmes in these under-resourced areas. Limited funds or human resources prevented service providers from providing these programmes on an ongoing basis. However, a possible strategy to improve access to rehabilitation,

especially in rural areas, is to integrate rehabilitation into primary healthcare (PHC), an approach strongly recommended by the WHO. PHC goes beyond the traditional care provided by primary care physicians. It emphasises disease prevention, identifying health conditions at an early stage, and promoting health and wellness through community-based health and social programmes, which would include rehabilitation (Shahabi et al., 2022).

Access to rehabilitation services, such as audiology or occupational therapy, available at PHC level can minimise the disabling effects of chronic conditions and facilitate continuity of care that promotes full recovery (e.g., from surgery) (World Health Organization, 2018c). There are many different approaches to this, including training existing staff and community health workers (CHWs), adding rehabilitation professionals into PHC teams, as an example in Brazil, or strengthening referral systems (da Silva et al., 2021). For example, Chinchai and Khamwong (2017) studied local village health volunteers, who received rehabilitation education and training and provided community-based rehabilitation to stroke survivors in their homes. They found that the volunteers were instrumental in improving their patients' walking and upper extremity function, especially for those who lived in remote rural areas of Thailand who might otherwise have received no treatment. The study also found that family members/caregivers could be trained to provide rehabilitation. There was a positive effect on stroke survivor's functional activities (e.g., bathing, toileting, dressing) when their caregiver received formal post stroke care training from rehabilitation professionals (Raham and Salek, 2016a). In Malawi, training was also effective in improving the knowledge of CHW in ear and hearing care (M'ulwafu et al., 2017). The CHWs were able to identify individuals with ear and hearing disorders and refer them to ENTs (Ear, Nose and Throat) doctors for further assessments and interventions.

Strengthening rehabilitation at the PHC level would be beneficial for the Maldives and would address the lack of service availability throughout the country. Since a PHC infrastructure already exists on each island, there are opportunities for rehabilitation services to be implemented in a way that improves coverage. There

is also scope to leverage existing staff. CHWs based at island health centres provide preventative and curative services in both the health centre and community settings (Sri Balakrishnan and Caffrey, 2022). Since there is only a limited rehabilitation workforce, CHWs could play an important role in increasing the availability of services in the country, particularly in remote rural areas. With education and training, CHWs can identify and refer individuals that require advanced assessments and interventions by a rehabilitation professional, but they could also provide rehabilitation interventions for individuals who have been previously assessed by a rehabilitation professional. They could also assist in training caregivers to provide rehabilitation to family members.

Using alternative approaches (such as CHWs or caregivers) for the delivery of rehabilitation may be appropriate in under resourced areas. However, there can be challenges associated with engaging family or local community members when delivering these services. Gupta et al. (2017) found that members of a community located in northern India did not share the view of the importance of hearing screening and refused to train as community health workers to address this. Also, community members did not share the bio-medical model of the disease process of hearing loss, did not see this issue as life threatening, and therefore did not afford much importance to the need for individuals to attend follow up appointments.

Further, the feasibility from the perspective of CHWs must be considered. Heavy workload has been identified as significant challenge for CHWs in different settings (Astale et al., 2023, Johnson et al., 2022, Musoke et al., 2022). For example, Johnson et al., (2022) found that CHWs are burdened with heavy workloads and unclear job expectations. This in turn creates a difficult work environment and can lead to negative impacts on their health. Astale et al., (2023) suggests that CHWs are often overwhelmed by the high number of broad ranging activities they are asked to do, and this limits their capacity to deliver on all required tasks. Astale et al., (2023) also found that CHWs were expected to perform tasks without appropriate training. Not only does this create additional stress for CHWs, but it can also compromise the quality and success of the CHW programmes.

A lack of renumeration for their services is also an issue for CHWs. While some are paid for their services, a majority of CHWs volunteer their time (Musoke et al., 2022). Volunteer CHWs typically spend more time working with clients in the community and often face challenges with competing time demands, such as family responsibilities and limited capacity to participate in income generating activities for the household (Astale et al., 2023). They may even face additional expenses related to CHW activities; for example, in Rwanda, volunteer CHWs had to cover the out of pocket expenses for work related activities (e.g., transport) which led them to becoming poorer after joining the volunteer work (Schurer et al., 2020).

A limited or lack of recognition, including payment or non-financial incentives, can also negatively impact on CHWs and contribute to retention issues. For example, Glenn et al.,(2021) found a lack of incentives negatively impacted a group of Bangladeshi CHWs' desire to work without compensation resulting in decreased quality of care they provided in a food programme for children. This also contributed to a high attrition rate as CHWs needed to find paid work to support their families. Conversely, Oladeji et al., (2022) found that non-financial incentives, such as continuing education programmes, supportive leadership, and access to amenities (e.g., running water, electricity, internet) were key for retaining CHWs working in health centres in rural Ethiopia. With this in mind, the introduction of additional activities related to rehabilitation for CHWs in the Maldives would require careful consideration, planning, and adequate resourcing to ensure sustained capacity, skills, and motivation.

Finally, an additional potential issue is the increased pressure on caregivers if they are also responsible for providing rehabilitation to their families/local community. For example in a study in South Africa, caregivers reported the challenges of managing employment, home and family duties as well as providing personal and rehabilitation care for the stroke survivor, which led to caregiver burnout (Hassan et al., 2011).

The development and implementation of Community-Based Rehabilitation (CBR) programmes is another alternative to support health related rehabilitation for persons with disabilities in the Maldives, especially those who live in remote areas with limited access to rehabilitation services. Briefly, CBR is a development strategy that aims to enhance the quality of life for persons with disabilities and their families and ensures their inclusion and participation in the community (World Health Organization, 2017d). It mobilises local capacity (e.g., persons with disabilities, DPOs, NGOs, etc.) and resources and uses community strengths and structures, and it often fills community service gaps (World Health Organization, 2017d). Not only does CBR address the health/rehabilitation needs of persons with disabilities, but it also supports education, livelihood, social, and empowerment programmes for this population group (Mannan et al., 2012).

Research suggests that CBR programmes have had a positive impact on the quality of life at the individual, family, and community levels for persons with disabilities (Cayetano and Elkins, 2016). For example, studies suggest that persons with disabilities who participated in CBR programmes experienced improved access to health services which promoted better health and functional independence (Iemmi et al., 2015, Mauro et al., 2015). Mol et al., (2014) found there were positive changes in the lives of children with disabilities and their families related to physical health, social participation and independence. CBR was also seen to improve the well-being of individuals and communities by modifying attitudes, addressing prejudices and exclusions, improving knowledge and skills, and supporting disability inclusion (Mauro et al., 2015). This in turn improved access to assistive technology, education, paid employment and pensions improving persons with disabilities personal autonomy (Mauro et al., 2015, Trani et al., 2021).

However, Cayetano and Elkin's (2016) literature review of CBR programmes in Asia Pacific region also identified challenges with establishing and running these programmes. For example, lack of teamwork and cooperation along with limited understanding about the purpose and role of CBR by professionals and CBR workers, and limited awareness of CBR in the community lead to poor

implementation of CBR programmes in rural regions of Japan and Korea. Batura et al., (2024) also found that limited financial and human resources were key challenges in providing effective CBR for persons with psychosocial disabilities in LMIC. Not only was it difficult to recruit and train CBR workers, logistical challenges such as inadequate social infrastructure (e.g., roads, electricity), added to the burden and cost of travel for CBR workers to provide psychosocial support (Butura et al., 2024). Butura et al., (2024) suggested that political instability at the local and national level was another issue for establishing mental health CBR programmes in LMIC. For example, local mental health organisations in Nigeria faced difficulties engaging with government entities to design and implement effective mental health policies (Mental Health Innovation Network, 2024).

mHealth and tele-rehabilitation technologies are additional resources that could be used to address the lack of available rehabilitation services in rural areas, for example as a useful tool to provide additional education and training to local CHWs and caregivers (Kumurenzi et al., 2022). For example, mobile technology was useful in providing additional training and resources for community health nurses in the early identification of depression, and of individuals at risk of suicide living in Pacific Island countries (Chang et al., 2021). However, there are also potential challenges that need consideration in relation to technology. For example, a lack of technical skills by service providers or users as well as poor mobile phone signal or internet connection can make the use of technology challenging and risk exacerbating inequalities in access (Nizeyimana et al., 2022).

Effective integration of rehabilitation services into PHC or creation of CBR programmes would require a coordinated effort by all key stakeholders involved in rehabilitation and disability in the Maldives. This would include all levels of government involved in providing health services in the country (e.g., island, Atoll, federal), health and rehabilitation service providers, NGOs, DPOs and persons with disabilities. Issues such as adequate funding, health human resources, education and training, health information systems, including the use of technology, as well as

CHWs' workload, renumeration and recognition would need to be addressed for successful integration of rehabilitation into PHC.

### Financial Challenges Delivering Rehabilitation

The findings from this study suggest that service providers in the Maldives experienced financial challenges in providing rehabilitation programmes. While current research acknowledges that rehabilitation is underfunded and under resourced at a global level, most studies on financial barriers to rehabilitation are focused on persons with disabilities (Shahabi et al., 2022, Skempes et al., 2022). There is little research on the financial challenges in relation to service providers, making it difficult to get a comprehensive understanding of the wider financial issues impacting access to rehabilitation. In order to address these barriers, both user and provider perspectives are needed to develop effective strategies to mitigate financial barriers to access.

Service providers in the public sector felt that limited government funds negatively impacted their ability to provide rehabilitation services. Rehabilitation services are covered under Aasandha and should be free to access, but the amount allocated does not always cover service provider costs (of repairs, replacement of equipment) and some service providers nevertheless charged user fees to cover those costs. A lack of government funding for public sector rehabilitation services has been found to be an issue in other LMICs, too. For example, the limited financial support from the Bangladeshi government negatively impacted the productivity of public sector rehabilitation and disability service providers in the country (Nuri et al., 2022). For example, minimal logistical support, such as the lack of office supplies, disability forms, or computers, hampered the quality of the Bangladeshi service providers' work in providing services to children with disabilities (Nuri et al., 2022). Nuri et al, (2022) also found that limited travel funds available for out-patient services resulted in service providers having to cover their own travel costs, which could be a significant financial burden for many of them. This also negatively impacted the

service providers' ability to reach remote or under-serviced areas, further exacerbating health and rehabilitation disparities for persons with disabilities.

Service providers in the NGO and private sectors also faced significant financial challenges due to high overhead and operating costs, limited revenues, and minimal, if any, government financial support. Since the rehabilitation therapies they offered were not available in the public sector, clients were expected to pay out of pocket to access these services. Service providers acknowledged that the fees they charged for their programmes could be a financial burden for some of their clients. Many took steps to address this issue by offering payment plans or finding business sponsorships to cover their clients' rehabilitation fees. However, delays in receiving payments made it difficult for some to pay utility bills, rent, and employee salaries on time. Where service providers experience financial difficulties, they struggle to provide affordable and effective rehabilitation for persons with disabilities. In other countries, financial challenges also impact service providers' ability to deliver rehabilitation. For example, a study from the Minas Gerais region of Brazil examined barriers to cardiac rehabilitation in public and private settings from the perspectives of healthcare administrators and rehabilitation providers. It found that the lack of government or private funding sources were reasons why cardiac rehabilitation programmes were either limited or unavailable in the region (Sérvio et al., 2019). Though the study did not consider the consequences of financial challenges as experienced in the Maldives, it does highlight that insufficient funding can negatively impact the availability and reach of rehabilitation services. Thus, it is essential that government and other stakeholders involved in the delivery of rehabilitation find solutions to fund and support sustainable services. This will help to ensure individuals living with a disability have access to the right rehabilitation treatments.

There is limited integration of rehabilitation into health financing schemes in many countries (World Health Organization, 2023). This has generally resulted in reduced budget allocation, which in turn, has impacted quality and created a mismatch between population need and the rehabilitation services which are actually

financed and made available (World Health Organization, 2023). The Maldives government has made certain impairment-specific services (e.g., physical therapy, hearing, vision) available at no or low costs for persons with disabilities, and more recently, invested in creating a mental health strategy across the country. However, there is a need for further investment for other rehabilitation services, such as cognitive, speech, or occupational therapy. These services are generally provided by NGOs or the private sector at a cost and can be expensive for persons with disabilities, which means such services can become unaffordable to those who need them. Such services can also be quite costly for the service providers who offer them, in terms of high rent, overhead costs and staff salaries and training (World Health Organization, 2023).

To ensure rehabilitation services are adequately financed, service providers need opportunities work with policy makers and share their experiences of the facilitators and challenges they face in delivering rehabilitation services in the Maldives. Moreover, this is an opportunity for all key stakeholders, including persons with disabilities, to collaborate on designing funding strategies in order to improve availability of programmes across the country.

### Rehabilitation Human Resources

The insufficient number of qualified rehabilitation service providers was identified as a significant barrier to providing rehabilitation services in the Maldives. This is a challenge experienced by other LMICs where there is a shortage of appropriately skilled and qualified rehabilitation workforce (Gupta et al., 2011, Nuri et al., 2022, Raham, 2019). For example, 78% of African countries have less than one audiologist per one million people, while over 50% of European countries have 10 audiologists per one million people (Kamenov et al., 2021).

To address the shortage of rehabilitation professionals in the Maldives, this study found that service providers often rely on rehabilitation professionals from other countries. However, key informants indicated this presented some challenges, including language and cultural barriers, as well as the lengthy recruitment process and the additional cost of covering housing and travel of non-Maldivian professionals. According to Scott (2016), any breakdown between non-local service providers and their clients due to language and cultural differences can adversely impact an individual's health outcomes. A number of studies have demonstrated that language and cultural training, as well as skill set support, can improve patient care and safety among foreign-trained healthcare professionals (Shen et al., 2010, Viken et al., 2018). This suggests that Maldivian service providers should prioritise language and cultural training for non-Maldivian rehabilitation professionals. This would enable persons with disabilities to access high-quality rehabilitation services that are culturally sensitive and appropriate for their needs and so improve rehabilitation outcomes.

Furthermore, driven by funding constraints and limited service availability, existing rehabilitation staff often experienced long work hours, high caseloads, complex client issues and burnout. Thus, the health and well-being of rehabilitation staff in the Maldives was another concern for service providers in the public, NGO and private sectors. Key informants highlighted that these challenging work environments would often negatively impact staff morale.

Staff morale in healthcare is a significant issue impacting healthcare services, particularly in low resource settings. Without adequate government health human resource polices or guidelines, service providers in the Maldives and elsewhere have been left to address the health and safety concerns of their staff on their own. For example, in a tertiary hospital in Lilongwe, Malawi, several de-motivating factors were identified which led to high frustration levels, burnout, and low morale amongst nurses and doctors. Similar to rehabilitation workers in the Maldives, high caseloads, inadequate resources (e.g., healthcare and management staff, equipment) and lack of human resource policies (e.g., performance management, compensations, training) were factors which created a challenging work environment for staff (Chipeta, 2014).

These examples above highlight some of the challenges healthcare workers experience while working in the context of low resources and workforce shortages. Research by Rowe et al., (2005) found that a multi-pronged approach, such as effective supervision, appropriate feedback and in-service training, are effective ways to improving morale and performance in under-resourced environments. In the Maldives, rehabilitation service managers need to acknowledge the importance of employing workplace interventions, such as human resource polices and health and well-being programmes, to address the health and safety needs of their staff. By recognising the value of their staff and investing in their well-being, these rehabilitation service providers can create a supportive work environment that will benefit both staff and persons with disabilities.

The results from this study also suggest that the limited number of rehabilitation educational programmes in the Maldives may have contributed to the shortage of rehabilitation professionals. At the time of fieldwork, medicine and nursing educational programmes were the only courses delivered for health care professionals in the Maldives. Education programmes, such as speech language therapy or behavioural counselling training, were not available. This is not unique to the Maldives: rehabilitation educational programmes are limited in other LMICs. For example, there are only 27 occupational therapy educational programmes available in nine out of 21 Anglophone Sub-Saharan African countries (Agho and John, 2017), in contrast to the 115 occupational therapy educational programmes in the United Kingdom (UK) (UK Health & Care Professions Council, 2023). These findings underscore the need for the Maldives government to develop rehabilitation educational programmes, thereby addressing the shortage of rehabilitation professionals within the country and reducing reliance on recruiting from abroad.

#### Doctors as Gatekeepers

In the Maldives, a referral by a medical doctor is required in order to access public sector rehabilitation services, and for the country's national health insurance

scheme, Aasandha, to cover the cost of treatment. In some cases, the referral would also determine the type and duration of the intervention. In their interviews for this study, rehabilitation service providers highlighted this issue as a possible constraint to rehabilitation access. They also suggested this reflected, and reinforced, the government and medical community's medical model approach to rehabilitation and disability. This may be the reason service providers noted that doctors act as "gatekeepers" - that is, the role a doctor plays in authorising access to public sector health services (Greenfield et al., 2016). Historically, this gatekeeper approach has been introduced in a number of health systems as a response to a shortage of medical specialists (e.g., neurology, oncology) and as a way of controlling healthcare costs (Sripa et al., 2019). However, the literature is mixed on its usefulness and its effectiveness in controlling healthcare costs is unclear. As Greenfield (2016) states, delayed diagnosis and adverse health outcomes have both been attributed to this approach. It is difficult to draw conclusions on the impact of gatekeeping on health systems and healthcare users. In most cases, research is from HIC, each with different health systems, and focuses on referral or direct access to medical specialists, rather than on access to rehabilitation services.

The literature on gatekeeping in relation to accessing rehabilitation is limited and again, mostly from HICs (e.g., US, UK), each with different health systems. However, some studies have demonstrated that there are significant benefits for health systems and patients when self-referral or direct access to rehabilitation is available. For example, Holdsworth et al., (2007) compared the cost between direct access and general practitioner referral to physical therapy in primary care in Scotland. Using data from over 3000 patients, the average cost of direct access to physical therapy was £66 compared to £90 for those referred by general practitioners. Those who self-referred to a physical therapist required fewer doctor visits, drug prescriptions, x-rays and referrals to secondary care (e.g., medical speciality) resulting in lower spending by the National Health Service (NHS). The authors concluded that direct access could save NHS Scotland up to £2 million per year. Savings have also been found when patients have had direct access to other

healthcare professionals. Furthermore, similar cost-savings were found when individuals' first point of contact were nurse practitioners (compared to family doctors) in Dutch primary care settings (Dierick-van Daele et al., 2010). Nurse practitioners' direct costs (e.g., resource use, consultation length, salaries) were significantly less than the family doctors.

Although these studies were conducted in HICs, they do suggest potential economic benefits to direct access to rehabilitation. These cost savings may be of interest to Maldivian policy makers and could be reinvested in rehabilitation, permitting expansion of services to remote areas, hiring service providers, or purchasing rehabilitation equipment. For persons with disabilities, it could save the indirect costs associated with travel, accommodation, or opportunity costs when required to see a general practitioner for a referral. All of which may have presented as barriers to access for service users.

Other studies have found additional health benefits for those who access a rehabilitation professional directly or self-refer in the public sector. For example, individuals in the Netherlands who accessed physical therapy directly experienced fewer physical therapy visits and better health outcomes (e.g., return to work faster, reduction in pain) than those who were referred by a doctor (Leemrijse et al., 2008). A comparison could also be made by looking at self-referral to other rehabilitation services, such as mental health, where it was found that parents, children or youths in England who self-referred had better outcomes, including greater satisfaction as they were able to access mental health programmes faster and avoid lengthy waiting lists (Rocks et al., 2020). It has been suggested that direct access to rehabilitation can improve quality of care and clinical outcomes by decreasing waiting times, meaning rehabilitation interventions can be initiated closer to time of injury or onset of symptoms, reducing chances of complications and before chronicity begins (Moore et al., 2005a, Pendergast et al., 2012). However, a recent systematic review by Babatunde et al. (2020) found no difference in health outcomes between individuals who had direct access to physical therapy compared to those who were general practitioner referred. The

study suggested it was difficult to ascertain the most effective mode of delivery due to the paucity of robust quality evidence.

Potential limitations of direct access should be considered. Some medical doctors have identified concerns with direct access to physical therapy. For example, they argue that this model of delivery could cost the health system more money due to overuse and/or inappropriate use of physical therapy (Pendergast et al., 2012). Others feel serious pathologies might be missed due to physical therapist's limited diagnostic skills, and therefore, a doctor's examination would be required to correctly diagnose and assess the patient's condition and refer to appropriate health service (Moore et al., 2005b, Pendergast et al., 2012). However, Babatunde et al., (2020) found no evidence of adverse effects or misdiagnoses for individuals who accessed physical therapy initially. Others contend that physiotherapists are appropriately educated and trained to diagnose and treat conditions within their scope of practice, and to screen for other medical conditions requiring a doctor's assessment (Moore et al., 2005b, Piscitelli et al., 2018). A study by Moore et al., (2005a), found there was no difference between physical therapists' and orthopaedic surgeons' abilities to accurately diagnose patients with musculoskeletal injuries (e.g., fractures, ligament tears) and suggest appropriate interventions. This suggests that physical therapists are not only capable of making good clinical judgements and ordering appropriate diagnostic tests but can make clinical decisions independent of a general practitioner's referral (Moore et al., 2005a). Holdsworth, Webster and McFadyen (2008) also found that general practitioners in Scotland viewed patient self-referral to physical therapy in a positive manner. They recognised physical therapists as competent practitioners who can accurately diagnose and manage health conditions within their scope of practice. Rehabilitation professionals in the Maldives are highly educated and trained in their fields; they go through a rigorous registration process to ensure they meet the government standards to work in the Maldives (Maldives Allied Health Council, 2022); they are accountable to the Allied Health Council and must adhere to the rules and regulations set out in the country's Health Care Professional Act (2015), all of which might suggest they would be appropriately placed to handle

direct access or self-referral of those patients that might benefit from rehabilitation.

As with the majority of the population, persons with disabilities will always need to see a family doctor for a variety of health reasons. However, having the ability to directly access rehabilitation professionals in the public sector could not only have a positive impact on health outcomes for persons with disabilities, but also for the Maldives health system.

#### Capacity of Rehabilitation Service Providers to Influence Government

The key informants involved in providing or supporting rehabilitation noted that working in a resource limited environment with minimal government support has been challenging for them and their organisations. Most felt that little progress had been made in advancing disability and rehabilitation policies and programmes in the country. Key informants suggested this lack of change reflected the government's attitude towards these areas, as well as its limited understanding of the role and value of rehabilitation for persons with disabilities. Recognising the need for change, many key informants from the public, private, NGOs and DPO sectors took on the additional responsibility to organise and participate in activities designed to influence disability and rehabilitation policies and programmes in the country.

Civil society organisations, which can include NGOs and DPOs, have recognised the need to influence policy and the decision-making process more effectively in order to represent the needs of their interest groups or to ensure new and existing policies are evidence-based (Court et al., 2006). However, policy change is not a linear process - it is complex, dynamic, and time consuming for those involved (Court et al., 2006, Jones, 2011). There are many approaches to influencing policy. For example, Start and Hovland's (2004) typology of policy influencing activities include advising, lobbing, advocacy and activism. Using this model, several key informants participated in advocacy activities by organising disability and

rehabilitation awareness programmes or participating at local or national conferences. Others lobbied government officials directly to establish disability-specific guidelines or policies or to improve access to disability specific rehabilitation programmes. Most tried to collaborate with government on disability/rehabilitation projects with limited success. Key informants commented that they found the policy influencing process to be frustrating and challenging but necessary.

Research has identified several factors that can impact the ability of civil society organisations to influence policy and practice, including understanding the policy process or using evidence to support policy change. Meanwhile, limited collaboration or partnerships with others, including government entities, can be detrimental to the process (Boumans and Ferry, 2019, Court et al., 2006). This study's findings suggest that key informants working in the NGO, DPO and private sectors often worked independently of each other, and this may have limited their ability, efficiency, and power to effect policy change.

Gómez and Harris (2016) found that a lack of collaboration between NGOs and the Chinese government during the AIDS crisis in the mid-1980s resulted in a poorly coordinated national response to introduce prevention and treatment policies. Chinese health officials were unwilling to seek out and proactively work with AIDS NGOs due to a lack of trust, especially with those affiliated with western countries. This delayed response to this epidemic resulted in a significant increase in HIV/AIDS cases in the country (Gómez and Harris, 2016).

Conversely, a number of mental health NGOs working in low-resource settings in Africa joined together to create a regional body. This allowed the NGOs to share knowledge and provide technical and economic support for each other. It also enabled them to coordinate when advocating and lobbying local and national governments on developing and implementing mental health policies and increased funding for mental health programmes (Kleintjes et al., 2013). This example highlights the potential benefits of Maldivian NGOs and civil society organisation

partnerships in improving public health outcomes, and underscores the importance of partnerships and collaboration (with each other and the government) to improve access to rehabilitation for persons with disabilities in the country.

#### 6.4 Persons with Disabilities

From a systems level perspective, findings in this research suggest rehabilitation services in the Maldives are fragmented. Low government priority, few disability and rehabilitation policies and laws, along with an uncoordinated bureaucratic system, were highlighted as barriers to the delivery of rehabilitation services throughout the country. These system level factors can influence factors at the individual level and impact a disabled person's decision and ability to access rehabilitation services.

The next part of this chapter uses Levesque's conceptual framework (2013) as a guide to discussing the key factors that affect people's ability to access rehabilitation services in the Maldives. These include:

- 1) approachability and the ability to perceive need
- 2) availability/accommodation and the ability to reach services
- 3) affordability and the ability to pay
- 4) appropriateness and the ability to engage

Please refer to Appendix 1 for definitions of Levesque's (2013) access dimensions and abilities of persons to interact with the access dimensions.

#### Approachability and Ability to Perceive

The 'ability to perceive' the need for rehabilitation was identified as a factor impacting met and unmet rehabilitation needs in the Maldives. For some participants, their understanding of the underlying health issues related to their impairment, the need for rehabilitation, and where to find services, allowed them

to seek out rehabilitation services to meet their needs. However, some participants were unaware of, or did not perceive there to be, potential benefits from rehabilitation in terms of improving their functionality and quality of life. This led to an unperceived unmet need, a finding which was observed primarily among older people living in rural areas. It is not possible to generalise, given the small numbers of people included, but this aligns with other evidence that older persons' higher healthcare needs do not necessarily translate into health service demand or use, especially in LMIC (World Health Organization, 2015b). Research suggests that older people's views on the aging process can influence their health seeking behaviours. Negative self-perceptions of aging may lead to beliefs that conditions associated with aging (e.g., mobility difficulties) cannot be treated and are seen as unimportant or untreatable, reducing the likelihood of seeking healthcare services (Sun and Smith, 2017). Further research should examine healthcare providers' knowledge and experience of identification of rehabilitation needs and referral pathways, as well as attitudes towards aging and disability.

Participants also reported a lack of information from healthcare providers on the potential benefits of rehabilitation or where to access services. This is consistent with findings from other LMICs, where awareness and understanding of disabilityspecific rehabilitation services (e.g., vision, hearing) have been shown to impact individuals' decisions to seek out services for their impairments (Lee et al., 2013, Zuurmond et al., 2019). Awareness raising strategies may be important and these should be tailored to local needs. For example, in response to poor awareness and uptake of ear and hearing services in a rural area of Malawi, one study successfully developed and tested an educational intervention which included an information leaflet detailing where and how to access services, what to expect, and potential benefits and counselling (Baum et al., 2019). This DrPH study did not specifically explore determinants (e.g., social, economic, cultural) of the 'ability to perceive' rehabilitation needs. However, previous literature suggests factors such as education levels and motivation levels may play a role. Ensor and Cooper's (2004) review of the literature found that education levels were correlated with demand for health services. They suggested that higher literacy rates and knowledge of

health, associated with higher education levels, increased desired and actual use of health services.

#### Availability and the Ability to Reach

The availability of rehabilitation services in the Maldives and the ability to reach these services were identified as factors impacting a participant's rehabilitation needs. As an island nation, the geography of the Maldives affected the ability of some participants to access rehabilitation services, particularly those who reside on the smaller or more remote islands. While hospitals on larger islands provide certain services, such as vision and/or physical therapy, most other services (e.g., mental health, cognitive) are available only in Malé. As a result, many outer islandbased participants were required to travel long distances to Male', at their own expense, to obtain rehabilitation. Some participants travelled abroad to access services but would be required to cover some or all the travel and rehabilitation service expenses themselves if they had not been referred by a Maldivian medical doctor or applied through one of the government financial assistance schemes. Those who could not afford it, would forgo any rehabilitation. This challenge is also seen in other LMIC island states where rehabilitation services are limited and centralised in large urban cities. For example, low vision services and devices were extremely limited in Papua New Guinea with most services based in large urban centres (Marella et al., 2017). Due to the remoteness of the villages in the country, individuals would be required to cover travel costs (e.g., airfares and lodgings) themselves or walk long distances to access these services. A consequence of limited service availability, especially in rural areas, is that people with disabilities may not be able to access services in a timely manner or at all, resulting in unmet rehabilitation needs which negatively impact health and/or functional outcomes.

The availability of family and social support networks impacted some participants' ability to access rehabilitation services. For example, family members who assisted with childcare responsibilities, or who accompanied participants to Malé or abroad, were key factors in ensuring the rehabilitation needs of some of these individuals

were met. This is supported in the literature: Zuurmond et al., (2019) found that household members in Cameroon played a vital role in accompanying person with disabilities to health services. Conversely, some female participants in this study felt that the lack of childcare support or persons to accompany them to their appointments limited their ability to access rehabilitation services. From a gender perspective, this finding reflects that women with disabilities and with caregiver responsibilities were disproportionately affected by the lack of available support. These findings are in line with a study by Melese et al., (2004) who looked at the indirect costs associated with accessing low-vision services in the Gurage Zone in Ethiopia. Female participants in that study highlighted the lack of childcare or someone to accompany them to their appointments as significant barriers to accessing these services. The authors suggested "bridging" strategies where eye specialists or surgical units travel to the communities to provide services, thus improving access. Addressing access barriers need to be context specific. This bridging strategy could be a potential option to improve access to rehabilitation services in rural regions of the Maldives. For example, "travelling rehabilitation teams", which are based at Atoll hospitals, could travel monthly to remote islands to provide services. However, government and service providers would need to address the barriers such as providing daycare or chaperone services which were identified by participants in this study.

Lengthy waiting lists for public sector services were also an issue for some participants. Consequently, those who could afford more timely private sector services did so; those who could not either waited for services or went without. Several studies have identified that long wait times were a barrier to receiving rehabilitation care, resulting in unmet needs (Andersson et al., 2013, Borker et al., 2012). For example, a study by Sakellariou and Rotaru (2017) found that persons with severe disabilities were three times more likely to experience unmet health needs because of lengthy wait times to health services in the UK compared to persons without disabilities. Since persons with disabilities often have greater health care needs and access health services more frequently, the authors argue that long wait times can be a deterrent from using these services. Not only can this

lead to poorer health outcomes, but the inability to access services can further exacerbate the inequalities and poverty-disability cycle persons with disabilities may experience.

Ansell et al., (2017) did a systematic review of interventions to reduce wait times to primary care, and found same day or open access scheduling to be an effective method to reducing wait times for primary care clinics in Canada, U.S., and U.K. For example, Bundy et al., (2005) used this approach at four primary care practices in North Carolina, U.S.A., and reduced wait times, as measured by the third available appointment, from 36 days to 4 days over a one year period. Non-attendance at appointments also reduced by one third during the same period. Salisbury et al., (2007) found that patients preferred same day scheduling as it allowed them faster access to a healthcare professional as well the ability and control to book an appointment on a day they choose.

Most studies on reducing wait times for health care services are based in HICs, and there is a need for research on this in different LMICs. However, same day scheduling could be considered as one way of enabling improved access to rehabilitation for persons with disabilities in the Maldives. It could offer this population group and their families the flexibility to organise their trips (e.g., to Malé) accordingly to receive rehabilitation, especially for those living on the islands. In addition to this approach, I have highlighted other possible solutions in this chapter (e.g., integrating rehabilitation into PHC; self-referral, etc.) to address access barriers encountered by person with disabilities in the Maldives. While some of these strategies are already used by some rehabilitation service providers (e.g., tele-rehabilitation), consistent use will require commitment and funding from policy makers and service providers. It is also important that persons with disabilities and other users of rehabilitation services are consulted in the development of these strategies, and with consideration of how to ensure parity in outcomes for women.

#### Affordability and the Ability to Pay

Participants' ability to pay and the affordability of services also impacted their access to rehabilitation. The cost of rehabilitation, which includes direct costs, indirect costs, and the availability of financial supports, also affected participants' choice and autonomy over services available to them. Participants felt that direct costs (e.g., out-of-pocket payments for rehabilitation fees in private/public sectors) and indirect costs (e.g., transport fees, accommodation/lodging) were significant barriers to accessing rehabilitation services. Financial supports from family, friends or use of social support programmes (e.g., Disability Allowance) also influenced participants' ability to access such services.

Several studies that examined unmet health and rehabilitation needs found that affordability and the ability to pay for rehabilitation services had a significant impact on disabled persons' ability to access rehabilitation services (Bedford et al., 2013, Kamenov et al., 2018, Ravi et al., 2019). For example, Magnusson et al., (2022) found that the high cost of rehabilitation fees and medication, along with transport costs, were significant barriers preventing individuals from accessing health care and rehabilitation services in Sierra Leone. Pryor et al. (2018) carried out an analysis of unmet need and use of AP in Bangladesh, finding that 45% of participants citied affordability as a significant reason for not accessing AP. Participants in this DrPH study who had the ability to pay for services identified factors such as family financial support, employment income, private health insurance and access to government social protection programmes (e.g., Disability Allowance, Medical Welfare,) that facilitated their access to rehabilitation services. This aligns with the quantitative findings from this study which found that individuals with higher socioeconomic status (e.g., income, income per capita, and per capita expenditure) were less likely to report an unmet need. These findings are also in line with studies in other settings where higher socioeconomic status and access to health insurance were linked to greater use of rehabilitation services for persons with disabilities (Bernabe-Ortiz et al., 2015, Medeiros et al., 2021). Specifically, Bernabe-Ortiz et al. (2015) identified that persons with disabilities with

a higher socioeconomic status had 2.21 times more access to rehabilitation services in Peru compared to people of the lowest socioeconomic status.

These findings are contrary to the principles of universal health coverage, where individuals should be able to access the full continuum of health services (e.g., prevention, treatment, rehabilitation) during the course of their lifetime without experiencing any financial hardship (World Health Organization, 2022c). While the Maldives government has made progress with establishing a UHC programme (e.g., Aasandha) and addressing Sustainable Development Goals 3.8, this study's findings suggest that not all rehabilitation services, such as mental health or cognitive services, are covered. This has created inequitable and unequal access for some persons with disabilities, especially for women and those living on the smaller, more remote islands. While existing social protection programmes (e.g., Disability Allowance, Medical Welfare) were available to those who were aware of and qualified for these schemes, the direct and indirect costs of accessing rehabilitation services remained a challenge. As a result, some were unable to access these services because of financial constraints.

Policy makers need to address the direct and indirect costs people with disabilities face when accessing rehabilitation. Ensuring all rehabilitation services are covered under the country's universal health coverage can help reduce the direct costs associated with using rehabilitation services. Improving service availability in remote areas of the country (through telerehabilitation, engaging community health workers, or mobile rehabilitation teams) can help reduce indirect costs. Please refer to section 6.3.2 for further discussion on the potential to introduce these service delivery methods. However, other strategies are also necessary to address indirect costs such as travelling, lodging, or childcare, which can be costly for persons with disabilities and their families, especially those living in rural areas of the country. The social protection programmes (e.g., Disability Allowance, Medical Welfare) available could be tailored to cover indirect costs. For instance, the Medical Welfare programme, which provides airfare for travel abroad, could be tailored to cover boat or airplane costs for those travelling from remote islands to

Malé for rehabilitation. Likewise, the Disability Allowance could include additional funds to cover lodging or childcare costs. There are no restrictions on how the Disability Allowance may be used. However, most of the funds are used to cover the costs of basic items (clothes, food) and are therefore not available for the intended expenditures such as accessing rehabilitation, AP, and medications. Further research is required to identify and evaluate appropriate strategies to reduce indirect costs associated with accessing rehabilitation for persons with disabilities in island nations.

While the qualitative component of this research did not directly assess poverty levels, I cannot say that this was a factor that affected the participants. These additional, sometimes prohibitive rehabilitation costs are likely contributors to the increased risk of poverty for some persons with disabilities. The link between disability and poverty is well recognised, where one can reinforce the other (Banks et al., 2018a, Mitra et al., 2017). For example, the costs associated with rehabilitation contribute to the extra costs faced by persons with disabilities, which, where people are able to pay, can contribute to poverty (Banks et al., 2022b). Where costs are completely unaffordable, this may lead people to delay or abandon seeking out rehabilitation. This in turn contributes to reduced functionality and independence, which may limit income generating activities. This can also contribute to an increased likelihood of individuals with a disability living in poverty.

#### Appropriateness and the Ability to Engage

Participants' ability to engage in their rehabilitation in interaction with the appropriateness of services received were identified as factors impacting their ability to access rehabilitation services and meet their rehabilitation needs. For some participants, their perception that services were of poor quality led to a mistrust in the Maldives health system. For others, having to see multiple doctors or other rehabilitation service providers, or not receiving a definitive diagnosis for their health condition, led to their mistrust in healthcare workers.

Trust is a vital component of a successful clinician - patient relationship (Gopichandran and Chetlapalli, 2013). Research suggests that greater trust in clinicians and the healthcare system is associated with better health outcomes, while poor trust can negatively impact on health seeking behaviours and contribute to poorer health status (Mohseni and Lindstrom, 2007, Trachtenberg et al., 2005). Chandra and Mohammednezhad (2020) explored factors which influenced patients' level of trust in physicians in low resource settings in Fiji. They interviewed 20 participants who were seeking healthcare services at three outpatient health centre settings in Suva, Fiji. Key factors influencing patient trust included doctors' interpersonal and communication skills, attitude and approach, clinical competency and patient centred care. Patients had greater trust in physicians who completed a physical exam, effectively communicated the prognosis and involved them in the discussion about their health. However, long wait times to see the physician, lack of a physical exam or the feeling that their questions about their health were not satisfactorily answered resulted in patients losing trust in their physician. This DrPH study did not explicitly explore the user-provider relationship or clinician communication and interpersonal skills. However, it is an area that deserves further attention because strengthening trusting relationship has the potential to result in better adherence to treatment, improved patient satisfaction and quality of care, supporting the overall goal of better health outcomes (Chandra et al., 2018).

Having the capacity and the ability to seek and gather information about their impairment, and the confidence to engage with healthcare professionals, appear to be factors in having rehabilitation needs met. Alsem et al., (2017) found that in the course of seeking out healthcare information on their child's disability, parents became increasingly confident and engaged; more empowered to find information themselves; to correctly direct questions; and to take a more directing role in consultation with healthcare professionals, in order to meet their child's health needs. To achieve better health and rehabilitation outcomes, persons with disabilities and their families must be empowered to engage with their rehabilitation service providers. Effective rehabilitation requires active participation by the client, thus a client-centred care approach is preferred. There

should be an emphasis on service providers to take a holistic approach and interact with their disabled clients and families with empathy, dignity and respect (Jesus et al., 2016, Mlenzana et al., 2013). More importantly, the service providers needs to acknowledge persons with disabilities as individuals and not focus solely on their impairments in order to fully engage them during the rehabilitation process (Jesus et al., 2016, Mlenzana et al., 2013)

It is important to note that many of issues around availability (location, waitlists) or the affordability (direct/indirect costs) are likely experienced by non-disabled persons with seeking rehabilitation or other health services. However, these issues become magnified for persons with disabilities because they have greater needs for seeking these services for their impairments. Even in the context of a country with social protection programmes, these issues, along with the extra costs and financial challenges of living with a disability, put persons with disabilities at a greater risk of poverty and exclusion.

#### 6.5 Reflection on Use of Frameworks

A theoretical framework can act as a blueprint for research (Grant and Osanloo, 2014). Not only does it help to build and support the research study, but it also guides the research process (Adom et al., 2018, Grant and Osanloo, 2014). This DrPH thesis explored access to rehabilitation services for persons with disabilities in the Maldives from both supply and demand perspectives. Two frameworks, Levesque's (2013) Conceptual Framework on Access and Allin's (2010) Classification of Unmet Need, were used to guide this research study. They were key in developing the research problem, guiding the literature review and research design as well as the data analysis, discussion of the findings and its overall conclusions (Adom et al., 2018).

These frameworks were chosen because of their complex approaches to conceptualising access and unmet need. Levesque's access framework takes a more comprehensive approach to the supply and demand aspects of access to health

services, compared to other access frameworks in the literature (e.g., Penchansky and Thomas (1981), Peters et al., (2008)). As noted by Cu et al, (2021), Levesque's (2013) framework for conceptualising access is particularly nuanced, incorporating the parallel elements of the supplier and users of health services. This makes it useful for identifying specific supply and demand barriers, and facilitators, along the access continuum for rehabilitation for disabled people (Cu et al., 2021).

However, there were some challenges in using this framework as the research found that some access barriers overlapped and so could fit into more than one of Levesque's (2013) dimensions. For example, long journeys to a rehabilitation service could fit into either availability/ability to reach dimension (e.g., lack of service availability in area) or affordability/ability to pay dimension (e.g., high cost of travel). Also, I felt that this access framework did not take into consideration the impact government health legislation or policies (or the lack of) had on access to rehabilitation services for both service providers and persons with disabilities.

Although it can be argued that the Levesque's (2013) access framework does incorporate elements of government legislation, it is a matter of how the framework is interpreted that allows this to be considered. For this research, it was felt that this 'dual coding' made it challenging to understand the impact of barriers and facilitator along the access continuum. A second framework found helpful in making sense of the data from this research is Allin's (2010) Classification of Unmet Need. This also takes a comprehensive approach to unmet need by conceptualising it as falling into five categories. This classification helped me gain a better understanding and appreciation of the complex and nuanced nature of unmet need and its relationship to access barriers and facilitators. In particular, this classification underpins the conceptualisation of unmet need developed from the findings of this study and used in conjunction with Levesque's (2013) access framework. It was useful in identifying which access barriers influenced the different classifications of unmet needs

#### 6.6 Contribution to the Theoretical Frameworks

With the socio-economic and geographical setting of the Maldives, my study makes a new contribution to the research literature by combining the theoretical frameworks of Levesque et al., (2013) and Allin et al., (2010) to guide and analyse access barriers and facilitators with met and unmet needs within the context of rehabilitation in a small island state.

While the Levesque framework (2013) has been increasingly applied to explore access to health services for people with disabilities (e.g. Reichenberger et al., (2024), Smythe et al., (2022)) few studies have used it specifically for rehabilitation, especially in LMICs or SIDS, and those studies have typically explored either supply or demand side or focussed on a specific rehabilitation domain (e.g., Aenishanslin et al., (2022), McIntyre et al., (2021)). Similarly, Allin's et al., (2010) categorisation of unmet need has been cited in the literature in a variety of different healthcare settings and population groups (e.g., Cavalieri (2013), Smith and Connolly (2020)); however, there continues to be a paucity of research, including the use of Allin's et al., unmet categories in rehabilitation settings in SIDS and LMICs.

I believe this is the first study to combine these frameworks to carefully examine access to rehabilitation from government, service providers, and persons with disabilities' perspectives. For example, limited government support and poor coordination of rehabilitation services created a challenging environment for service providers to offer rehabilitation services. The lack of available services and high direct and indirect costs to access these services led to unmet rehabilitation needs, especially for those in lower socioeconomic positions and older people. In combination, these frameworks allowed for this in-depth analysis to identify the unique access barriers and facilitators to rehabilitation services for persons with disabilities in the Maldives. Not only does this study contribute new knowledge to the fields of disability, rehabilitation, and SIDS, it also suggests that these two frameworks can be used together to develop a comprehensive understanding of complex phenomena in health services research (Hiebert et al., 2023).

### 6.7 Strengths and Limitations

A strength of this study is the mixed-method approach used to explore the barriers and facilitators to accessing rehabilitation from both supply and demand perspectives. This approach allowed for a robust and in-depth understanding of the issues faced by persons with disabilities, government entities, and service providers in their attempts to access or deliver rehabilitation services in the Maldives.

Another strength of this study is that took a nationwide approach to explore access facilitators and barriers. It utilised quantitative data from a population based, nationally representative survey which used standardised sampling approaches, reducing sampling bias and increasing generalisability. The qualitative data was obtained from participants living on different islands around the country. While the quantitative research provides data that can be generalised to the wider population, the qualitative research provides rich and detailed insight into key informants' and participants' personal thoughts and opinions on access (Verhoef and Casebeer, 1997).

The findings from this study can contribute to the field of rehabilitation as it highlights the complexities around the concepts of access, disability and rehabilitation. It can be useful for policy makers and service providers to understand the key issues impacting access for persons with disabilities, and to develop strategies address these. It also highlights the challenges both government and service providers face in their attempts to deliver services. This study also provides evidence which persons with disabilities, DPOs and service providers can use to lobby and advocate policy makers to improve access for rehabilitation services in health systems.

There are a number of limitations with the quantitative data which should be taken into consideration when interpreting the findings. Please refer to Section 6.2 (Section One - Objective 1 Discussion) for a review of some of the limitations already described. However, there are other limitations that should be considered. Firstly, people with disabilities in the original study were identified through self-

reported functional difficulties. Evidence suggests that this may miss some people with impairments, who may benefit from rehabilitation (Mactaggart et al., 2016). Secondly, for the "Coverage" calculation, assumptions were made that the service/AP participants felt they needed was the same as the one they have used to meet a need. However, the questions asked about groups of services/AP by functional domain rather than specific individual services/AP, and therefore, this may not always be accurate. Related, because the questions group together services for healthcare and APs, it is unclear as to what the specific needs are and access to different types of services/AP is likely to be different (Boggs et al., 2021). Finally, the study was not originally powered to conduct this analysis and the sample size used is relatively small. Therefore, caution must be used in the interpretation of the results (Hackshaw, 2008). Despite these limitations, in the absence of other data available, they can provide an indication of the extent to which people with disabilities perceive that their needs for rehabilitation services are being met.

Limitations with the qualitative data should also be taken into consideration when interpreting the findings of this study. In keeping with a qualitative approach, only a few participants were interviewed from each subgroup (e.g., gender, location, impairment type, age group) and only key informants interviewed from the different aspects of the service delivery (e.g., government, rehabilitation specialists, NGOs, DPOs, and private/public sectors), so I may not have heard other, dissenting views.

Participants with a disability were identified from the baseline survey data; however, some may have accessed services since the baseline, so this had to be taken into consideration during the sampling process. While care was taken to choose participants with different impairment types from the demand side and key informants from different areas of the supply side, it was not always possible to do so. The Maldives is an island state and identified as a middle-income country. The results from this study may not be generalisable to other LMICs as the contextual factors in the Maldives may be different compared to other countries. For example,

the Maldives has a UHC programme, Aasandha, which does include access to some rehabilitation services (e.g., physical therapy, vision), and so it might it difficult to understand access barriers in comparison to other LMICs without UHC. Finally, findings from this research highlighted how access is shaped by personal factors (e.g., gender, family support, etc.) and health systems and structural factors (e.g., availability, cost of services). It did not explore in-depth the role of societal level factors (e.g., cultural, values and attitudes around disability) and environmental factors (e.g., physical environment, accessible communication) which may impact access to rehabilitation for persons with disabilities in the Maldives. This deserves further attention in future research.

## 6.8 Reflections on Study Approach

My research study was embedded in a wider study on the "Impact Evaluation of the Disability Allowance" (Kuper et al., 2018). This had both advantages and disadvantages in terms of the approaches used. For example, a benefit was that it made the study logistically possible within my DrPH. It enabled me access to data for the secondary analysis to generate statistics, and to people with disabilities and key stakeholders for in-depth interviews, for a more comprehensive understanding of the context, situation, and experiences of persons with disabilities and rehabilitation services providers in the use and delivery of rehabilitation services in the Maldives. I was also able to learn about Maldivian culture from working closely with one of my supervisors, a Maldivian researcher, during data collection.

There are many advantages for using in-depth interviews in qualitative research. For example, it allows for a deeper understanding of participants' perspectives, experiences, and emotions on a particular topic, and it encourages them to share more detailed and nuanced information they may not want to share in a group setting, such as focus group (DeJonckheere and Vaughn, 2019). As such, this approach allows for the collection of rich data where participants can elaborate on their answers providing context and detail that can help understand complex behaviours and attitudes (Busetto et al., 2020, DeJonckheere and Vaughn, 2019).

In-depth interviews also allow the researcher to be flexible with their questions and explore unexpected topics that may emerge during the interview (Barrett and Twycross, 2018).

However, to some extent, working within an existing project also limited flexibility and constrained the methodological approach. For logistical and resource reasons, my research needed to align conceptually and methodologically with the wider study. Although the wider study was developed in collaboration with local stakeholders, my specific research focus on rehabilitation was not. The research could have been strengthened by greater involvement of people with disabilities from the Maldives throughout the research process. For example, project advisory groups could be beneficial to shape and guide the research questions and approaches, and as co-researchers, working together on data collection, analysis, and dissemination. Following the 'nothing about us without us' mantra, these approaches are important to ensure that research is relevant to and informs action for the people it intends to support, as well as contributing to shared learning and capacity development of all involved.

Future research on this topic should consider other data collection approaches that enable more in-depth understanding of lived experience and active participation of persons with disabilities; for example observation, ethnographic approaches, arts based approaches, photo-voice, or community mapping. These approaches help ensure research is relevant, supporting persons with disabilities, and capturing what is important to people who are the focus of the research (Felner, 2020, Jagosh et al., 2012). Nathan et al., (2023) suggests that drawing on narrative, visual, audio, and experiential forms of art making, art-based research can reveal hidden knowledge as participants give meaning to their experiences in forms beyond spoken or written word. These approaches can also elicit great insight on a topic and are more likely to contribute to appropriate and effective community led solutions (Felner, 2020). For example, photo-voice methodology was key in identifying the enablers and barriers to social inclusion, including access to rehabilitation, and to family and community for people with psychosocial

disabilities living in rural India and Nepal (Fernandes et al., 2018). Thus, researchers should consider other approaches, such as art-based methodologies, that not only benefit the research literature, but also the participants themselves.

#### 6.9 Dissemination

Working with one of my thesis supervisors, who is Maldivian, I will engage with key stakeholders to organise a participatory workshop where I will share the findings and reflections from this research. These findings can be used to inform discussions on potential strategies related to access to and delivery of rehabilitation services for persons with disabilities in the Maldives.

## **Chapter 7: Conclusion**

In this conclusion, I will discuss how I have answered the research objectives. I will then discuss the recommendations based on the results/findings of this research.

This is followed by a brief discussion of the scope for further research.

This DrPH study aimed to answer the following research objectives:

- 1. To estimate use of, and unmet need for, rehabilitation services among persons with disabilities living in the Maldives.
- 2. To explore the strength and weaknesses of the Maldives health systems' delivery of rehabilitation services in the Maldives (e.g., government, rehabilitation workforce, NGOs, DPOs).
- 3. To explore the facilitators and barriers to accessing rehabilitation services for persons with disabilities in the Maldives.

Findings from Objective 1 suggest high unmet need across all impairments (functional limitations). Though awareness of rehabilitation services or devices was high across all impairment groups, use of such services was low. Age was identified as a factor for reporting a need for assistance and reporting an unmet need, especially among those 40 years and older. However, those in the wealthiest per capita expenditure quartile were less likely to report an unmet need.

For Objective 2, in-depth qualitative interviews sought different perspectives on the delivery of rehabilitation services from the supply side (e.g., government and rehabilitation service providers). From the government perspective, there appeared to be little political support for rehabilitation in the Maldives health system. Key informants from both government and rehabilitation service providers agreed that rehabilitation and disability were not a government priority. This was reflected in

the few disability and rehabilitation laws, policies and programmes, and in the limited service delivery throughout the country, especially on the smaller or more rural islands. Many felt that the social protection programmes (e.g., Disability Allowance) targeted at persons with disabilities were insufficient for their rehabilitation needs. This not only impacted persons with disabilities, but also rehabilitation service providers, who noted the high cost of delivering services and hiring qualified rehabilitation staff as barriers to service delivery.

Objective 3 considered the demand side (e.g., persons with disabilities), focusing on the barriers and facilitators to accessing services for their impairment. The findings suggest a variety of access barriers impacting the different levels of unmet need. Approachability (unaware services available) was identified as an access barrier for those participants who had an unperceived unmet need. Affordability (e.g., high cost of services, travel, and lodging) and accommodation (e.g., a lack of family/social support) were common factors for those who were unable to meet their initial rehabilitation needs as well and for those who were able to meet their initial need but unable to access follow-up rehabilitation. Appropriateness of services (e.g., inability to obtain disability-specific rehabilitation services) was another key factor impacting participants' initial unmet needs. Availability of services (e.g., therapy, AT repairs, medication), especially for those living on the islands, and acceptability (e.g., personal beliefs, gender) were factors impacting those seeking follow up services for their disability, after their initial need was met. The ability to perceive the need for rehabilitation services and the ability to reach and pay for services were identified as key access facilitators for those persons with disabilities who were able to meet their rehabilitation needs.

Overall, persons with disabilities, service providers and government representatives provided unique perspectives on access to rehabilitation services in the Maldives. The results from this study can be used to inform planning of policies and programmes to strengthen rehabilitation in this setting as well as contribute to the lack of global data on access to rehabilitation for persons with disabilities in the Maldives.

## 7.1 Research Implications and Recommendations

In this section, I discuss research implications and recommendations for policy makers and rehabilitation service providers. The recommendations are based on the findings from this research.

#### 7.1.1. Policy Makers

Despite the presence of schemes aimed at achieving UHC, not all rehabilitation services are available to all, especially not to those living on smaller or more rural islands. To ensure equitable access to all impairment-specific rehabilitation services, policy makers should include rehabilitation services within the existing health system infrastructure. In doing so, policy makers should consider the following:

- 1) Integrate Rehabilitation into the Health System:
  - Develop a plan to include all impairment-specific rehabilitation services into the Maldives health system. Use the WHO's "Rehabilitation in Health Systems - A Guide for Action" (2019d) as a guide and follow the four phases for development and implementation:
    - Phase 1: Assess the situation; the findings from this research could also be included in this situational analysis as a part of this process;
    - ii. Phase 2: Develop a national rehabilitation strategic plan which includes strategies to address the WHO's Six Building Blocks of a Health System (see p. 22 for details);
    - iii. Phase 3: Establish monitoring, evaluation, and review processes;
    - iv. Phase 4: Implement the strategic plan.
  - II. Integrating rehabilitation into the health system aligns well with the WHO's Rehabilitation Initiative. As previously discussed in Chapter 1, this Initiative

has identified 10 priority areas. Some of these priority areas have been highlighted throughout this thesis (e.g., creating leadership and political support, integrating rehabilitation in primary care, addressing service delivery and rehabilitation workforce issues) while other areas, such as financing, data collection, building research capacity and emergency preparedness, still need to be explored.

#### 2) National Rehabilitation Strategic Plan

- I. Develop a national rehabilitation strategic plan and ensure it aligns with the country's Master Health Plan, other existing disability and rehabilitation laws, policies or frameworks, and current social protection programmes, to ensure equal and equitable access to rehabilitation services for all who need it. Ensure key stakeholders involved in rehabilitation and disability, including government ministries, agencies, services providers (public/private/NGO/DPO sectors) and persons with disabilities and their families, are involved in the planning process.
- II. Create a national level database on rehabilitation using the data that is to be collected for the Master Health Plan's Monitoring and Evaluation of Outcome Measure 2 (Reduced disease and disability among population). This data can be useful for determining disease burden and unmet need for rehabilitation services for persons with disabilities. It can also be an effective tool to ensure improved outcomes are due to rehabilitation services (Neill et al., 2023).
- III. Support collaboration between government ministries and agencies involved in rehabilitation and disability and the Disability Council to improve coordination and deliver cohesive rehabilitation services for persons with disabilities.

#### 3) Impairment Specific Policies and Programmes

 Use the lessons learned from the Mental Health Strategy to explore whether impairment-specific policies and programmes, which address the health promotion, prevention, assessment, and treatment across the continuum of care, can be developed and implemented.

#### 4) Service Availability

- I. Import of Rehabilitation Services
  - The Maldives has established a government-funded medical travel programme for health services not available in the country. This programme requires a referral by a public sector physician and covers the cost of treatment and airfare for the individual and one caregiver. Currently, the Maldives does not have a rehabilitation centre which provides specialised inpatient and outpatient services for complex cases (e.g., neurology, cardiac, pulmonary, etc). Research suggests that patients with complex cases who received rehabilitation with a comprehensive multidisciplinary healthcare team with specialised training (e.g., stroke, spinal cord injury) fared better in functional outcomes compared to those who did not receive specialised rehabilitation (Cheng et al., 2017). It is recommended that the government-funding medical travel programme for health services be extended to include complex rehabilitation cases where specialised services are not available in the Maldives.
- II. Address rehabilitation service coverage at primary, secondary, and tertiary levels of care, as well as the service differential between rural and urban locations. Policy makers, service providers from the NGO, private and public sectors, persons with disabilities and their families, should collaborate to develop and implement new impairment-specific service delivery approaches. This should include appropriate funding schemes and professional training, especially in remote areas where rehabilitation services are limited or non-existent. Different delivery approaches, such as

travelling rehabilitation teams, telerehabilitation, or outreach programmes, could be useful in addressing the service gap. For example, task shifting strategies, such as training CHWs at the primary care level, could address the country's insufficient rehabilitation workforce and service delivery to remote areas. Using non-rehabilitation specialists (e.g., CHWs) could be an effective way to support the delivery of rehabilitation services to persons with disabilities in the smaller and more rural island settings.

#### 5) Alternative Referral Methods

I. This study highlighted doctors' gatekeeping role, by determining who could receive rehabilitation services. Service providers perceived this as an access barrier. Policy makers, Maldivian medical community, and rehabilitation service providers should work together to explore alternative rehabilitation referral methods, such as direct access or self-referral. The evidence suggests these methods do not increase service provider workloads and do not result in inappropriate referrals. In fact, as previously discussed, medicals doctors from the UK are supportive of this approach as they understand rehabilitation service providers are highly trained and will refer back to the doctor if the client has a health condition that is not appropriate for rehabilitation. Direct access may also assist in decreasing the long waiting lists some persons with disabilities had to endure while attempting to access rehabilitation services.

#### 6) Rehabilitation Workforce

I. Support and increase rehabilitation workforce development and training opportunities to expand the workforce at the individual, institutional, services and system levels, using the WHO's Rehabilitation Competency Framework as a guide (World Health Organization, 2020). The framework is designed to provide direction on the expected performance of rehabilitation professions (e.g., physical therapy, psychology, medicine, nursing, etc.) in order to provide quality care and service delivery. It consists of five domains

(rehabilitation practice, professionalism, research, management/leadership, learning/development) which are centred around core values and beliefs. It can be used at the ministry level, for accreditation/regulatory bodies, education institutions, and impairment-specific rehabilitation services.

#### 7.1.2. Rehabilitation Service Providers

Rehabilitation service providers in the Maldives feel it is a challenge to provide quality and affordable rehabilitation for persons with disabilities. The high cost of delivering services, workforce challenges, limited government support and interaction, and few disability, rehabilitation, and impairment specific policies and programmes, have together created a difficult environment for many rehabilitation service providers to operate in. In order to address these challenges, service providers from DPOs, NGOs, private and public sectors should consider:

#### 7) Networking and Collaboration

I. Create disability and rehabilitation networks across the country and collaborate with others, including academia, disability, and rehabilitation INGOs, rehabilitation-specific workforce organisations (e.g., Maldives Physical Therapy Association, World Rehabilitation Alliance) and persons with disabilities. Developing relationships with other disability and rehabilitation organisations and persons with disabilities could be an effective means to drive change in the Maldives health system.

#### 8) Influencing Strategy

I. To influence policy makers more effectively, service providers (public/private/NGO sectors), DPOs, and persons with disabilities and their families should work together to develop comprehensive influencing strategies that consider each phase of the policy process. A variety of activities, such as advising or advocacy approaches, should be considered in the strategy. While some service providers and those from DPOs have experience in influencing activities, they should take this opportunity to support local disability or rehabilitation organisations with less experience to understand the policy process and how to influence policies and programmes in the country;

- II. Incorporate global and local evidence into the influencing strategy as a way of legitimising and substantiating the influencing process;
- III. Develop a communications strategy which includes social media, television, radio, and newspapers. This could also assist service providers, DPOs, and persons with disabilities to develop a relationship with local media as another way of influencing policy;
- IV. Work with local policy experts who understand the nuanced aspects of influencing policies and programmes in the Maldives.

# 7.2 Health Impact of Climate Change on Persons with Disabilities

While it is not within the scope of this thesis, it is important to acknowledge that the impact of climate change will have a disproportionate impact on the lives of persons with disabilities around the world (International Disability Alliance, 2021). This is especially important for those living in the Maldives and other SIDS as these countries are at the forefront of climate change. An increase in sea level rises, heatwaves, droughts, and tropical storms have had a negative impact on these countries (Thomas et al., 2020). For example, hurricanes have destroyed communication, energy, transport, health facilities, and homes, having a devastating impact on peoples' lives (Thomas et al., 2020). Climate change also impacts how health systems function as a result in changes to the demands for services, the effects of climate variability on health infrastructure, and the cost to

provide services – though these effects will vary locally as the impact of climate change is not uniform (Sellers and Ebi, 2017). It is therefore likely to have a significant impact on people with disabilities and their attempts to access rehabilitation, particularly in remote areas where services are often limited (United Nations High Commissioner for Human Rights, 2020).

The health impacts of climate change may be experienced more severely by persons with disabilities owing to the harmful effects of climate change (United Nations High Commissioner for Human Rights, 2020). For example, extreme heat waves and high humidity can negatively impact individuals living with multiple sclerosis who have difficulties regulating their internal body temperature resulting in difficulties breathing, increased pain, and muscle weakness and possibly leading to hospitalisation (United Nations High Commissioner for Human Rights, 2020). During a severe weather event (e.g. hurricane), individuals with cognitive impairments may have difficulties understanding what is going on around them hampering preparation, evacuation, and recovery process impacting their safety (Gaskin et al., 2017). Persons with disabilities are more adversely affected during emergency weather events sustaining higher rates of morbidity and mortality since they are least able to access emergency support (United Nations High Commissioner for Human Rights, 2020).

The Maldives has felt the effects of climate change for many years. The 2004 tsunami had a devastating impact on the country where many islands experienced considerable damage where houses, businesses, and hospitals were destroyed, uprooting the lives of many people (World Bank et al., 2005). Some health clinics and hospitals, including rehabilitation services, on some islands lost all their medical equipment including x-rays and generators due to water damage and were unable to medical services to people (Carballo et al., 2005). This put additional stress on the health system; people requiring health and rehabilitation services were transferred to Malé for these services which experienced significant flooding itself (Carballo et al., 2005, World Bank et al., 2005).

Currently, an increase in ocean temperatures has had a devastating effects on the coral reefs, negatively impacting tourism and fishing, both critical to the livelihood of most Maldivians (UNDP, 2024). Rising sea levels and extreme weather events has resulted in many islands experiencing land loss due to flooding. This has resulted in significant challenges for those living on these islands, especially persons with disabilities, in terms of accessing housing, education, employment and health (Sakamoto et al., 2022, World Bank Group, 2021).

Given the acceleration of climate change, policy makers and rehabilitation service providers must understand the effects of climate change on persons with disabilities. They need to develop mitigation strategies that not only address these challenges to ensure access to rehabilitation services but are disability inclusive.

However, little is known on how and why people with disabilities are affected by climate change, and the contextual factors which shape their exposure, sensitivity, and adaptive capacity, and the solutions needed to ensure their resiliency (Jodoin et al., 2023). This lack in knowledge has led to the development and implementation of climate solutions that are inequitable and ineffective for persons with disabilities (Jodoin et al., 2023). Therefore, research must be conducted in collaboration with people with disabilities in order to produce climate research, policies, and programmes that promote solutions that are disability-inclusive (Jodoin et al., 2023, Kosanic et al., 2022).

Below I have included recommendations for policy makers and rehabilitation service providers with regards to climate change and persons with disabilities.

#### 9) Policy Change

- I. "Maldives Climate Change Policy Framework" (2015)
  - Revisit this policy document to ensure it is disability inclusive. Adopt a disability human rights approach to this framework which will reflect an

- understanding of how climate change affects persons with disabilities compared to non-disabled people (Stein et al., 2024).
- ii. Bring together persons with disabilities and their families, DPOs, health and rehabilitation service providers, policy makers, local island community council members, and climate change and disaster relief experts to address the impact climate change has on persons with disabilities across all impairment groups and incorporate their needs and challenges into the framework.
- iii. Increase awareness on the stresses of climate change on persons with disabilities among all islands using social media, radio, and television.

#### 10. Education and Training

- II. Climate change impact on health of persons with disabilities:
  - iv. Provide education and training for rehabilitation professionals to identify the health effects of climate change on persons with disabilities and provide support as required. For example, identify persons with disabilities who may require psychosocial support during an adverse weather event; identify vector-borne diseases (e.g., Dengue) and refer to the appropriate health care professionals (e.g. medical doctor) for medical care.
  - v. Educate and train rehabilitation professionals on the role and use of AT which can support persons with disabilities during climate change events. For example, suggest the use of a wheelchair to families who care for older adults with chronic respiratory issues during high temperatures so not to compromise the older adults' respiratory status.
  - vi. Rehabilitation professionals and organisations should consider developing their own disability inclusive climate change plan. This

should include the health impacts climate change may have on their clients as well potential barriers which may impact access to their services. They should develop solutions to ensure persons with disabilities can safely access their services during a climate change event.

## 7.3 Capacity for Further Research

This study has identified areas for further research into access to rehabilitation programmes from both supply and demand side perspectives.

- 1) Role of Social Protection Programmes and Rehabilitation
  - I. As previously discussed, there is limited evidence on the impact of social protection programmes on access to rehabilitation, including AT. In the Maldives, the Disability Allowance and Medical Welfare are available to assist persons with disabilities to access rehabilitation. However, recent evidence, including this study, suggests the Disability Allowance is not sufficient to financially support persons with disabilities to access these services nor is it being used for its intended purpose (to access rehabilitation) (Hameed et al., 2022b). There is an opportunity for further research into how these financial schemes are impacting access to rehabilitation from both the supply and demand perspectives.

- Factors Impacting Service Delivery from Rehabilitation Service Providers'
   Perspectives
  - I. Similarly, there is very little research available on the factors impacting the delivery of rehabilitation services in low resource settings, from the perspective of rehabilitation service providers. This study highlighted a few factors impacting service providers in their attempts to deliver quality and affordable rehabilitation to their clients. However, further research is needed to understand the issues in more detail, such as business operations, funding sources, human resources, and government policies. The results of this research will help guide service providers and policy makers to address key areas to improve access to services.
- 3) Evaluation on the Role of CHWs in the Delivery of Rehabilitation
  - I. As previously highlighted, CHWs can play a valuable role in enhancing service availability and supporting the delivery of rehabilitation for persons with disabilities, especially in smaller and remote islands. While some current literature exists on the role of CHWs in providing rehabilitation in other settings, more research is required to inform the evidence-based development, implementation, and evaluation of training programmes of rehabilitation interventions performed by CHWs on improving functional outcomes, especially in LMICs (Magnusson et al., 2019, O'Donovan et al., 2018). An opportunity exists in the Maldives to develop and evaluate the impact the training of CHWs provide for persons with disabilities across the different impairment groups. This information would be useful to policy makers and services providers to improve service delivery in remote and under-resourced areas.

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# **Appendices**

# Appendix 1

Definitions of Levesque's (2013) Access Dimensions (supply side) and corresponding abilities of persons to interact with the dimensions of accessibility (demand side)

		Associated Ability	
Access		of Persons to	
Dimension	Definition	interact with	Definition
(Supply Side)		Access Dimension	
		(Demand Side)	
Approachability	Individuals who need rehabilitation can actually identify some form of health services exist, can be reached, and can have an impact on their health needs. Elements such as transparency, and information on rehabilitation services and interventions, have an impact on whether the service is more or less approachable.	Ability to perceive	The notion of the ability to perceive rehabilitation services is determined by health literacy, knowledge and beliefs.
Acceptability	Social and cultural factors that can determine the possibility for individuals to accept aspects of services (e.g., gender of service providers.	Ability to seek	The concept of personal autonomy and the capacity to choose to seek care, knowledge about health services options, and individual rights that determine one's intention to obtain services.
Availability and Accommodation	Physical existence of health resources with the capacity to produce services which can be accessed in a timely manner. It also reflects the extent to which provider's operation is organised to meet the constraints and preferences of the user (e.g., hours of operation) <sup>2</sup>	Ability to reach	The notion of personal mobility and availability of transportation, occupational flexibility and knowledge about health services that would enable an individual to physically reach service providers.
Affordability	Reflects the financial capacity of an individual to spend resources and time to use appropriate services. It includes direct prices of services and related expenses (e.g.,	Ability to pay	The capacity of an individual to generate financial resources (e.g., income, savings, loans) to pay for health services without catastrophic expense of resources needed for basic life necessities.

 $<sup>^2</sup>$  McLaughlin, C. G., & Wyszewianski, L. (2002). Access to care: remembering old lessons. Health services research, 37(6), 1441–1443. https://doi.org/10.1111/1475-6773.12171

	opportunity costs related to loss of income).		
Appropriateness	The fit between services and the individual's health needs, its timeliness, amount of care spent assessing health problems, determining appropriate interventions and the technical/interpersonal quality of services provided.	Ability to engage	The participation and involvement of the individual in decision making and intervention decisions; this is strongly determined by capacity and motivation of the individual to participate in care and commit to its completion.

# Appendix 2

# **Document Review**

Title	Summary	Information Analysed
Master Health Plan 2016-2025	This document outlines the principles and health goals of the country; it describes the strategy to implement the plan in order to improve the health of the population and to develop the country's health system.	This document provided background information on the country's health system (e.g., primary, secondary, tertiary care levels); it also provided information on the country's health goals and outcomes as well as its future areas of focus.  Rehabilitation and disability was included as a strategic direction; in terms of expanding rehabilitation programmes in order to improve quality of life for persons with disabilities, older persons and those living with chronic diseases.
Health Care Professionals Act (13/2015)	This document provides guidelines for healthcare professionals to practice in the Maldives. It provides guidelines for standards of practice for each health discipline; it establishes and determines the mandate of governing bodies for each health discipline.	This document provided background knowledge and insight into the standards of practice, including registration requirements and workplace standards for all healthcare professionals. Focus was mainly on rehabilitation professionals.
Law on Protecting the Rights of Persons with Disabilities and Provision of Financial Assistance Law (Law 8/2010)	This disability law was created to ensure the provision and protection of basic rights and independence of persons with disabilities in the Maldives. This also includes financial assistance, equal opportunities, special protections, and the creation of national disability policies.	This document was instrumental in providing background knowledge and insight into the rights of persons with disabilities in the Maldives in all facets of life (e.g., health, education, employment, etc.). In particular, it provided information about the Disability Council which was created to manage and oversee all national disability policies.
Maldives Disability Report 2010	Commissioned by the Human Rights Commission of the Maldives, this report provided an evaluation of the current status of persons with disabilities in the Maldives.	Background information on the status of persons with disabilities in the Maldives in 2009. The report highlighted several issues, such as lack of access to assistive technology, limited financial support, and the need for better data collection on disability. This information was useful in terms of comparing how some services have improved over the past 10 years (e.g., financial assistance available)

National Mental Health Policy (2015 - 2025)	This policy document describes the country's strategic plan to improve mental health services across the country.	This document provided valuable detailed information and insight into the government's attempt to implement mental health services across the country. In particular, key priorities including leadership, financial support, service delivery, and human resources were described.
		If successful, this strategic template could be used to implement other national health programmes, such as autism spectrum disorder support programmes, across the country.
Vision 2020 Action Plan (2010-2020)	This document describes the country's strategic plan to improve vision services across the country.	Similar to the national mental health policy, this document is a strategic plan to improve access to vision services in the health system. Though limited in detail, this action plan did reveal key priorities to improving vision services in the country's health system.
Maldives Health Statistics 2020	This document provides current information on various aspects of the country's health system, including key health indicators (e.g., natality, morbidity rates)	This document provided useful information on the various components of the country's health system, included information on service delivery, workforce, health information systems, finance and governance.

# Appendix 3

Study Methods for Impact Evaluation of the Disability Allowance in the Maldives Below is a detailed description of the study methods used in the Impact Evaluation of the Disability Allowance in the Maldives (Banks et al., 2020). This data was used for the secondary analysis used to achieve Objective 1 of this study.

# **Population-Based Survey**

A two-stage sampling strategy was used. For the first stage, 52 clusters (island enumeration areas) were selected through probability proportionate to size sampling, using the Maldives 2014 National Censuses as the sampling frame. For the second stage, modified compact segment sampling was used. Using maps, each cluster was divided into segments, each including approximately 125 people. One segment was randomly selected and households in that segment were visited door-to-door until 125 Maldivian citizens aged 2+ were enumerated. If the segment did not include 125 people, then another segment was chosen at random, and sampling continued until 125 was reached. Where household members who were not available, three visit attempts were made in order to maximize response rate.

20 data collectors from the Maldives were involved in the collection of quantitative data for the disability screening. All participated in a six-day training period where they received information on the use of survey instruments and methodology, informed consent and other ethical considerations, the Disability Allowance, and interview techniques including impairment-specific considerations for interviewing people with disabilities. Data collectors were divided into five teams of four to cover the 52 selected clusters. All interviews took place in the participants' homes.

# **Disability screening**

Enumerated individuals aged 2+ were screened for disability using the Washington Group (WG) questions on functioning. Those aged 18 years and older were asked questions from the WG Extended Set (Washington Group on Disability Statistics, 2011). Children aged 2-4 years and 5-17 years were asked age-specific modules

using the UNICEF-Washington Group Child Functioning (Washington Group on Disability Statistics and UNICEF., 2016). The question sets include 9 to 11 questions, depending on the age of the respondent.

Disability is multifaceted and complex to define and measure. Direct report (e.g., asking people 'do you have a disability') may under-estimate prevalence, as people may not want to declare a disability (e.g., due to stigma) or do not consider themselves disabled. The WG questions were developed to address these issues and are widely used internationally for censuses and in surveys of disability. They were designed to capture self-reported activity limitation in functional domain as described in the ICF (Mactaggart et al., 2021). See Table 1 below for functional domains covered by the WG-ES for adults and the UNICEF-Washington Group Child Functioning for youths and children (Washington Group on Disability Statistics, 2011, Washington Group on Disability Statistics and UNICEF., 2016).

Table 1: Functional domain covered by the Washington Group Questions

#### Functional Domains Covered by Washington Group Questions: Adults and Youth/Children Youth and Children (ages 2-17) **Adults** Vision Vision Hearing Hearing Mobility Mobility Communication Cognitive Self-care Affect (anxiety/depression) Communication Upper body function Affect (anxiety/depression) Pain Upper body function **Fatigue** Pain Additional Domains Covered for Children (ages Fatigue 2-4) Dexterity Playing Additional Domains Covered for Youth (ages 5-17) Self-care Remembering **Focus Attention** Coping with Change **Relationships and Emotions**

The questions ask participants about their level of difficulties (e.g., none, some, a lot, cannot do) in the functional domains. For anxiety and depression two questions are asked pertaining to i) frequency and ii) intensity of symptoms.

Following previous research in this area, people who answered "a lot of difficulty" or "cannot do at all" for at least one functional domain, or who reported anxiety or depression "daily" and 'a lot' (for children only frequency question is asked) were categorized as having a disability (Banks et al., 2020). Children aged 5 years+ also received questions on depression and anxiety though only frequency was used to measure disability (Banks et al., 2020). People were also classified as having a disability if they i) had a self-reported health condition that was not captured on the WG-ES (e.g., autism, schizophrenia) and would make then eligible for the Disability Allowance in the Maldives; and ii) currently received the Disability Allowance (Kuper et al., 2018).

Table 2 below provides an example of the WG-ES questions used to classify functional domains, using vision as an example. The same question format was used for the other functional domains (e.g., hearing, physical, cognitive, communication, mental health).

Table 2: Example of WG-ES questions for vision

VIS_1. [Do/Does] [you/he/she] wear glasses?  1. Yes 2. No 7. Refused 9. Don't know	<ul> <li>VIS_2. [Do/Does] [you/he/she] have difficulty seeing, [If VIS_1 = 1: even when wearing [your/his/her] glasses]? Would you say</li> <li>1. No difficulty</li> <li>2. Some difficulty</li> <li>3. A lot of difficulty</li> <li>4. Cannot do at all</li> <li>7. Refused</li> <li>9. Don't know</li> </ul>		
VIS_3. [Do/Does] [you/he/she] have difficulty clearly seeing someone's face across a room [If VIS_1 = 1: even when wearing [your/his/her] glasses]? Would you say	Vis_4. [Do/does] [you/he/she] have difficulty clearly seeing the picture on a coin [If VIS_1 = 1: even when wearing [your/his/her] glasses]? Would you say  1. No difficulty		
<ol> <li>No difficulty</li> <li>Some difficulty</li> <li>A lot of difficulty</li> <li>Cannot do at all</li> </ol>	2. Some difficulty 3. A lot of difficulty 4. Cannot do at all 7. Refused		

7. Refused	9. Don't know
9. Don't know	

# **Nested-Case-Control Study**

Individuals identified as having a disability in the population-based survey were invited to take part in a case-control study as 'cases' (Banks et al., 2020). (For each case, one control without a disability was selected as comparison. Controls were drawn from the population-based survey and were the same gender, similar age (+/- 5 years) and living in the same cluster (or close to it) as the case. Case control study participants were interviewed using standardised questionnaires which collected information on socio-demographic and economic characteristics (e.g., age, sex, marital status, education, employment) and household poverty indicators. Socioeconomic status was calculated using Principal Component Analysis (PCA) and used data from household income, durable assets, and wealth. Data were also collected on Household Expenditure. The household member with the most knowledge about the household expenditures was asked these questions. The purpose of the Household Expenditure questionnaire was to collect data on household spending - overall and type (e.g., healthcare, food, education, transport, leisure activities etc.). For example, participants were asked about their monthly expenditures on key food (e.g., bread, milk, meat, etc.) and non-key food items (e.g., education fees, transport costs, personal sundry items, etc.) (Kuper et al., 2018).

# **PLOS ONE**

#### RESEARCH ARTICLE

# Disability and the achievement of Universal Health Coverage in the Maldives

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#### Abstract

#### Objective

To assess access to general and disability-related health care among people with disabilities in the Maldives.

#### Methods

This study uses data from a case-control study (n = 711) nested within a population-based, nationally representative survey to compare health status and access to general healthcare amongst people with and without disabilities. Cases and controls were matched by gender, location and age. Unmet need for disability-related healthcare is also assessed. Multivariate regression was used for comparisons between people with and without disabilities.

#### Results

People with disabilities had poorer levels of health compared to people without disabilities, including poorer self-rated health, increased likelihood of having a chronic condition and of having had a serious health event in the previous 12 months. Although most people with and without disabilities sought care when needed, people with disabilities were much more likely to report difficulties when routinely accessing healthcare services compared to people without disabilities. Additionally, 24% of people with disabilities reported an unmet need for disability-related healthcare, which was highest amongst people with hearing, communication and cognitive difficulties, as well as amongst older adults and people living in the lowest income per capita quartile. Median healthcare spending in the past month was modest for people with and without disabilities. However, people with disabilities appear to have high episodic healthcare costs, such as for disability-related healthcare and when experiencing a serious health event.

## Conclusions

This study found evidence that people with disabilities experience unmet needs for both disability-related and general healthcare. There is therefore evidence that people with

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disabilities in the Maldives are falling behind in core components relevant to UHC: availability of all services needed, and quality and affordability of healthcare.

#### Introduction

Strengthening health systems and addressing inequalities in access to healthcare to ensure healthy lives for all is a core Sustainable Development Goal (Goal 3) [1]. This goal includes a target to achieve Universal Health Coverage (UHC), meaning that there is access to quality healthcare for all, including the full range of services needed, with financial protection. Here too there is a focus on left behind groups, including people with disabilities. However, few studies have considered UHC from a disability perspective [2].

There is a strong rationale for a focus on people with disabilities in the journey towards UHC. They are a large group, making up one billion people, or one in seven people globally [3]. Furthermore, on average, people with disabilities have worse health than their peers without disabilities resulting from their underlying health condition/impairment and a higher prevalence of both proximal (e.g. obesity, lack of exercise, poor diet) and distal (e.g. poverty, discrimination, poor living conditions) risk factors [2, 3]. People with disabilities will therefore have greater general healthcare needs, on average. They also often require disability-related healthcare, including rehabilitation and assistive devices [4].

Evidence suggests, however, that people with disabilities are being left behind by health systems despite their greater need. They often experience greater challenges in accessing healthcare services, due to informational, financial, physical and attitudinal barriers [2]. They are also affected by large service gaps, particularly for rehabilitation [5]. Poor availability, quality and affordability of services can lead to unmet needs for many people with disabilities, resulting in worsening health and functioning [2]. These gaps may be particularly pronounced for people with disabilities living in rural areas, or with certain types of impairments [4, 6, 7]. They may also incur higher healthcare costs, as they may need to seek care more often and incur additional costs in doing so (e.g. paying for a companion to travel with them, accessible transport), yet have a lower capacity to pay due to their overrepresentation amongst people living in poverty [8]. In many settings, people with disabilities are more likely to experience catastrophic health expenditures compared to people without disabilities [3, 9, 10]. For example, the World Report on Disability found that across 51 countries, half of people with disabilities could not afford needed health services and people with disabilities were more than 50% more likely to report catastrophic health expenditures compared to people without disabilities [3].

Inclusive health systems are therefore important in the attainment of UHC. The right to health and healthcare for people with disabilities is also supported by international law, including the United Nations' Convention on the Rights of Persons with Disabilities, and the laws of most countries [11]. However, policies and programmes supporting these rights are often lacking or not put into practice or enforced. This neglect is reinforced by gaps in evidence documenting whether and how people with disabilities are deprived of health and healthcare, particularly in low- and middle-income countries (LMICs). Consequently, this study aims to explore access to general and disability-related health care among people with disabilities in the Maldives. This will be assessed using data from a nationally-representative, population-based survey with a nested case-control study [12]. It will cover health needs and access to both general and disability-related health services.

#### Study context

The Maldives is an upper-middle income country in South Asia that has made impressive development and public health gains in the past decades [13, 14]. A third of the population lives in the capital Malé, with the remainder dispersed across 186 inhabited islands [13]. Approximately 7% of Maldivian citizens have a disability [12].

In 2018, the Government of the Maldives spent 9% of gross domestic product (GDP) on health, far higher than other countries in the region (regional average is 3.5% of GDP) [15]. \*Husnuvaa aasandha ("Aasandha") is the national social health insurance scheme, which covers all Maldivian citizens and is financed through the national budget [16]. It was enacted in 2011 through the National Social Health Insurance Act and is run by the National Social Protection Agency (NSPA) operating under the Ministry of Health [17]. \*Aasandha\* covers inpatient and outpatient care, costs for medications and for transport in emergency cases, with no caps on spending for eligible services [16]. Services are free at point of use, although contributions are required if accessing services in the private sector, or without appropriate referrals [18]. The Maldives also runs Medical Welfare that can provide coverage of services, devices and treatments not covered through \*Aasandha\* (e.g. care in private hospitals, medical devices such as oxygen machines) [19]. Applications are made on an ad hoc basis and require an application to NSPA.

The Maldives has a four-tier healthcare system. Each inhabited island has a health centre from which patients can be referred to higher levels facilities in the atolls, region and central (Malé) level [20]. Given the geographic dispersion of the population, travel can be a significant cost in accessing healthcare particularly for people living outside Malé [21]. Further, travel abroad for healthcare is common in the Maldives, as some services are not available or perceived to be of inferior quality [21, 22]. *Aasandha* covers the travel and direct medical costs for some overseas medical healthcare from contracted providers in India and Sri Lanka, if the services are not available in the Maldives (e.g. certain types of cancer treatment), and the individual receives a referral from a public sector specialist doctor [22, 23]. Still, one study estimated that Maldivians spent on average US\$204 per capita in 2013 on overseas medical travel [23].

The Disability Act (2010) codifies the rights of people with disabilities to equal access to healthcare. Aasandha covers most disability-related health services (e.g. rehabilitation, psychiatry, ophthalmology), although many services are heavily centralised or not available in the country, necessitating domestic and overseas travel. Assistive devices, and their repair and replacement, are not covered through Aasandha, but can be provided through Medical Welfare [19].

#### Methods

This paper uses data from a nationally-representative population-based survey of disability and a nested case-control study comparing age-sex-location matched people with and without disabilities.

#### Sample selection

Data collection took place between July to August 2017. Participants were identified through a nationally-representative population-based survey and nested case-control study, the methods for which has been described in detail elsewhere [12]. In brief, a target sample size of 6,500 people aged 2+ was set and participants were selected through a two-stage sampling strategy (probability proportionate to size, followed by compact segment sampling).

All enumerated individuals were screened for disability using the Washington Group Short Set Enhanced for adults (18+) and the UNICEF-Washington Group Child Functioning

Modules (sets for children 2–4, 5–17) [24–26]. These questions focus on difficulties with every-day activities (e.g. seeing, hearing, walking, remembering) and most have four response options on level of difficulty experienced in performing each activity (none, some, a lot, cannot do). People were defined as having a disability if they reported "a lot of difficulty" or "cannot do at all" for at least one question or experienced "daily" symptoms of anxiety or depression at an intensity described as "a lot" (adults 18+; "daily" symptoms for children 5–17). People were also defined as having a disability if they received the Disability Allowance or reported a health condition that made them eligible for the Disability Allowance (e.g. psychosocial impairments such as schizophrenia, bipolar disorder; autism spectrum disorder) [27].

All people identified as having a disability were invited to participate in the nested case-control study. Each "case" with a disability was matched to a "control" without a disability, who was also drawn from the same population-based survey. Matching variables were age (+/- 5 years), gender and location (same survey cluster, or else same administrative island/atoll). Controls could not be from households with other members with a disability. Controls were selected at random if multiple eligible controls were available for a case. All participants were Maldivian citizens and thus eligible for *Aasandha* and Medical Welfare.

#### Selection of health indicators

Data was collected from both cases and controls on their health status and access to general healthcare. This included questions on: diagnosis of and treatment for chronic conditions; EQ-5D self-reported rating of current health on a scale from 0 to 100 (with 0 being worst imaginable state of health and 100 the best imaginable state of health) [28]; occurrence of a serious health event in the last 12 months and experience accessing care; frequency of experiencing different challenges when accessing healthcare (tool from Demographic and Health Surveys [29]); if they had private health insurance outside of *Aasandha* or had ever received Medical Welfare; and household healthcare spending in the last month. Healthcare expenditures were captured for the following: 1) household healthcare expenditures in the last month—which covered direct costs for general and disability-related healthcare services and products—and were presented as total per capita, as a percentage of household income and if they qualified as catastrophic (25% or more of household income) [30]; 2) costs associated with seeking care amongst people who had a serious health problem in the last 12 months, including direct (i.e. costs for services) and indirect (i.e. costs for accommodations, travel) expenditures; 3) lifetime spending on disability-related healthcare services and products.

People with disabilities were asked about their access to disability-related healthcare (e.g. rehabilitation, assistive devices) during the population-based survey. This included questions on: if they had ever been to health professional about the difficulties they faced for each functional domain; their awareness of impairment-relevant services/devices (e.g. glasses/ophthalmology for people with difficulty seeing); their perceived need and use of a service/device. Reporting needing, but not using a service/device, was categorised as self-reported 'unmet need'. Coverage was calculated as the proportion who reported using a service out of those who reported a need (i.e. use/need). If people experienced multiple functional limitations, they were asked about each limitation separately. Respondents were also asked about their total spending on disability-related healthcare.

#### Data analysis

Data was analysed using STATA 16. Indicators on general health and healthcare access were compared between cases and controls. For each variable on general health and healthcare access (e.g. health-related quality of life, having private health insurance), a multivariate

regression was run, which included variables for age, gender and location (Malé vs other atolls) as well as disability status and the outcome of interest. Met and unmet needs for disability-related services were compared amongst people with disabilities by functional domain. Further, sociodemographic and economic predictors of unmet need for disability-related services were assessed through logistic regression, adjusting for the individual's age, gender, and location.

For healthcare costs, medians and interquartile ranges (IQR) were compared using a Mann-Whitney test.

#### **Ethical considerations**

Ethical approval was granted by the ethics board at the London School of Hygiene & Tropical Medicine in the United Kingdom, the Maldives National Bureau of Statistics and the Ministry of Health's National Health Research Council. All study protocols, including for consent, were approved by these bodies.

Written or audio recorded consent was obtained for all study participants. Audio consent was used for interviews conducted by phone (e.g. household members temporarily working on other islands, fishing). In these instances, the full consent process was audio recorded and saved. Cases and controls were interviewed directly where possible, with healthcare expenditures answered by the household member who was most knowledgeable of household finances. Carer consent was sought for minors (<18 years) and people with impairments that severely limited their ability to communicate/understand, and assent received from the individual if they were able to self-report on any of the questions.

#### Results

Overall, 5,363 people aged 2+ were screened for disability (response rate: 82%) in the population-based survey, of whom 403 were identified as having a disability.

The case-control study included 380 cases and 331 controls (response rate: 90.1%). Cases and controls were similar in age and gender, although cases were more likely to live in Malé compared to controls and were in households with lower per capita incomes (Table 1).

### Access to general healthcare

Overall, people with disabilities had poorer health status than people without disabilities (Table 2). People with disabilities were more likely to have experienced a health problem in the last 12 months (19% vs 8% for controls, aOR = 2.5, 95%CI: 1.5, 4.0), and to have been diagnosed with at least one chronic condition (46% vs 33% for people without disabilities, p=0.001). People with disabilities reported significantly lower health ratings using the WHO-QOL-BREF tool (average score 55.5 vs 72.6 for people without disabilities,  $p\!<\!0.001$ ).

Healthcare coverage was similar amongst people with and without disabilities, whether measured in terms of seeking treatment for a health problem or for a specific chronic condition (Table 3). However, people with disabilities were more likely to report difficulties when accessing health services compared to people without disabilities. When asked about their typical experience accessing health services, people with disabilities were significantly more likely to report experiencing difficulties "often" for almost all questions, with the exception of lacking female service providers among women. For example, in comparison to people without disabilities, people with disabilities were about twice as likely to report often having difficulties with negative attitudes from staff and the distance and transport to facilities compared to people without disabilities and almost three times as likely to have difficulties paying for services and in getting someone to accompany them when seeking services. People with disabilities

 $Table\ 1.\ Description\ of\ the\ study\ sample\ (case-control).$ 

	Cases (n = 380)	Controls (n = 331)	OR (95% CI)*
Gender			
Male	163 (43%)	135 (41%)	Reference
Female	217 (57%)	196 (59%)	0.9 (0.7, 1.2)
Age group			
2–17	61 (16%)	48 (15%)	Reference
18-39	94 (25%)	87 (26%)	0.9 (0.5, 1.4)
40-64	123 (32%)	125 (38%)	0.8 (0.5, 1.2)
65+	102 (27%)	71 (22%)	1.1 (0.7, 1.8)
Location			
Malé	151 (40%)	85 (26%)	Reference
Other atolls	229 (60%)	246 (74%)	1.9 (1.4, 2.6)
Functional domain <sup>†</sup>			
Vision	88 (23%)		
Hearing	35 (9%)		
Physical	190 (49%)		
Mental health	81 (21%)		
Cognitive	75 (20%)		
Communication	56 (15%)		
Median annual per capita household income (SD)	\$2,625 (\$4,384)	\$3045 (\$5,361)	p = 0.004

 $<sup>{}^*{\</sup>it Bivariate}$  analysis

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were less likely to report being satisfied with the services they received compared to people without disabilities, although this difference was not statistically significant.

## Access to disability-related healthcare

Overall, 76% of people with disabilities reported seeing a healthcare professional for their functional difficulties (Table 4). By functional domain, health seeking was lowest for cognition (53%) and mental health (50%), and highest for physical (92%) and vision (90%) impairments. Most cases had heard of a specific service/device across each functional domain (>80%), while this was lower for cognition (61%). Self-reported need (reporting that a service/device would

 $Table\ 2.\ Health\ status\ amongst\ people\ with\ and\ without\ disabilities.$ 

	Disability (n, %)	No disability (n, %)	aOR (95% CI)
Experienced a health problem in last 12 months	71 (19%)	27 (8%)	2.5 (1.5, 4.0)***
Diagnosed with a chronic condition <sup>1</sup>			
• Diabetes	53 (17%)	33 (12%)	1.4 (0.9, 2.3)
Hypertension	108 (34%)	59 (21%)	2.0 (1.3, 3.1)**
• Asthma	36 (11%)	23 (8%)	1.4 (0.8, 2.4)
Any of above	147 (46%)	88 (31%)	1.9 (1.3-2.7)**
	Mean (SD)	Mean (SD)	
Health rating (0–100) <sup>1</sup>	51.5 (29.0)	72.9 (22.0)	p<0.001***

<sup>\*</sup> p < .05

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 $<sup>^{\</sup>dagger}\text{Categories}$  are not mutually exclusive as some participants reported multiple disabilities.

 $<sup>^{\</sup>ast\ast}$  p < .01 (adjusted for age, gender, location)

<sup>&</sup>lt;sup>1</sup> Amongst people aged 18+

Table 3. Access to general health services amongst people with and without disabilities.

	Disability (n, %)	No disability (n, %)	aOR (95% CI)
Current treatment for chronic conditions <sup>§</sup>			
Diabetes	43 (81%)	29 (88%)	0.6 (0.1, 3.1)
Hypertension	95 (88%)	52 (88%)	1.4 (0.5, 4.1)
Asthma	22 (61%)	10 (43%)	2.2 (0.7, 7.4)
Any of above <sup>‡</sup>	113 (77%)	66 (75%)	1.3 (0.7-2.4)
Health seeking amongst people experiencing a health pro	blem in last 12 months <sup>ß</sup>		
Sought treatment for health problem	68 (96%)	27 (100%)	n/a
Where went for services <sup>β</sup>			
Same island	25 (37%)	8 (30%)	Reference
Another island	32 (47%)	13 (48%)	1.1 (0.3, 3.8)
Abroad	11 (16%)	6 (22%)	0.7 (0.2, 2.8)
At least somewhat satisfied with services received <sup>β</sup>	54 (79%)	25 (93%)	0.3 (0.1, 1.5)
Reported difficulties when typically using health services			
Paying for services	119 (31.5%)	39 (11.8%)	3.7 (2.4, 5.5)***
Distance to facility	148 (39.4%)	66 (20.1%)	2.9 (2.1, 4.2)***
Transport to facility	165 (43.9%)	79 (24.0%)	2.7 (1.9, 3.8)***
Having someone accompany	91 (24.2%)	28 (8.5%)	3.7 (2.3, 5.8)***
(Women only) Lack of female service providers	43 (20.0%)	51 (26.2%)	0.8 (0.5, 1.2)
Staff availability	156 (41.3%)	110 (33.5%)	1.6 (1.1, 2.2)**
Lack of medications	166 (43.9%)	106 (32.1%)	1.8 (1.3, 2.5)***
Negative attitudes from staff	55 (14.6%)	27 (8.2%)	2.0 (1.2, 3.4)**

 $<sup>{}^{\</sup>S}\mathrm{Amongst}$  people reporting being diagnosed with a chronic condition

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be helpful) was higher for physical (71%), vision (67%) and communication (59%) domains and lower for hearing, mental health and cognitive (<50%). However, reported use (current or ever) of a service/device for their self-perceived functional limitations was generally low across all domains; 53% of participants reporting physical difficulties had used a service/device

Table~4.~~Met~and~unmet~needs~for~disability-related~health care~among~people~with~disabilities~by~functional~domain.

	Vision	Hearing	Physical	Mental Health	Cognitive	Communication	Overall
	N = 88	N = 35	N = 190	N = 81	N = 75	N = 56	N = 385
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N(%)
Ever been to a doctor about difficulties*	79 (90%)	27 (77%)	174 (92%)	41 (50%)	40 (53%)	42 (75%)	293 (76%)
Aware of service/device for difficulties*	81 (92%)	28 (80%)	175 (92%)	65 (80%)	46 (61%)	49 (88%)	307 (80%)
Expressed need for service/ device*	59 (67%)	16 (46%)	135 (71%)	32 (40%)	36 (48%)	33 (59%)	229 (60%)
Use of service/ device*	35 (40%)	4 (11%)	101 (53%)	28 (35%)	15 (20%)	13 (23%)	161 (42%)
Unmet need for service/device**	24 (27%)	12 (34%)	34 (18%)	4 (5%)	21 (28%)	20 (36%)	94 (24%)
Coverage**	59%	25%	75%	88%	42%	39%	79%

<sup>\*</sup>Denominator is the total number of people reporting any limitation in that functional domain and thus categories are not mutually exclusive; \*\*Coverage is calculated as use/need

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 $<sup>^{\</sup>ddagger}$  If reported multiple chronic conditions, treatment coverage defined as having received treatment for all conditions

β Amongst those who experienced a health problem in the last 12 months and sought treatment

 $<sup>^{*}</sup>$  p < .05

<sup>\*\*</sup> p < .01, p < 0.001 (adjusted for age, gender, location)

 $<sup>^\</sup>dagger Reported$  experiencing difficulties 'often' compared to 'never'/'sometimes'

Table 5. Healthcare spending.

Healthcare spending when seeking care for a serious health problem, previous year²         S93.85 (\$970.87)         \$194.17 (\$2543.69) $p = 0.80$ Direct costs (median, IQR)         \$177.99 (\$811.42)         \$388.35 (\$1035.60) $p = 0.17$ Overall costs (median, IQR)         \$501.62 (\$2297.74)         \$828.48 (\$3216.83) $p = 0.25$ Use of social health protection products           Has private health insurance (n, %)         21 (6%)         26 (8%)         aOR = 0.6 (95%CI: 0.3, 10.25)		Disability	No disability	Measure of association
Total as a proportion of household income (median, IQR) $0.4\%$ (5%) $0.2\%$ (4%) $p = 0.24$ Catastrophic healthcare expenditures¹ (n, %) $45$ (13%) $38$ (10%) $aOR = 0.8$ (95%CI: 0.5, 408)         Healthcare spending when seeking care for a serious health problem, previous year²         Direct costs (median, IQR)       \$93.85 (\$970.87)       \$194.17 (\$2543.69) $p = 0.80$ Indirect costs (median, IQR)       \$177.99 (\$811.42)       \$388.35 (\$1035.60) $p = 0.17$ Overall costs (median, IQR)       \$501.62 (\$2297.74)       \$828.48 (\$3216.83) $p = 0.25$ Use of social health protection products         Has private health insurance (n, %)       21 (6%)       26 (8%) $aOR = 0.6$ (95%CI: 0.3, 10.2)	Household spending on healthcare, previous month			
Catastrophic healthcare expenditures $^1$ (n, %)       45 (13%)       38 (10%)       aOR = 0.8 (95%CI: 0.5, Mealthcare expenditures $^1$ (n, %)         Healthcare spending when seeking care for a serious health problem, previous year?         Direct costs (median, IQR)       \$93.85 (8970.87)       \$194.17 (\$2543.69)       p = 0.80         Indirect costs (median, IQR)       \$177.99 (\$811.42)       \$388.35 (\$1035.60)       p = 0.17         Overall costs (median, IQR)       \$501.62 (\$2297.74)       \$828.48 (\$3216.83)       p = 0.25         Use of social health protection products         Has private health insurance (n, %)       21 (6%)       26 (8%)       aOR = 0.6 (95%CI: 0.3, Meaning of the control of the con	Total (median, IQR)	\$0.65 (\$8.70)	\$0.34 (\$9.32)	p = 0.51
Healthcare spending when seeking care for a serious health problem, previous year²         Direct costs (median, IQR)       \$93.85 (\$970.87)       \$194.17 (\$2543.69) $p = 0.80$ Indirect costs (median, IQR)       \$177.99 (\$811.42)       \$388.35 (\$1035.60) $p = 0.17$ Overall costs (median, IQR)       \$501.62 (\$2297.74)       \$828.48 (\$3216.83) $p = 0.25$ Use of social health protection products         Has private health insurance (n, %)       21 (6%)       26 (8%)       aOR = 0.6 (95%CI: 0.3, 10.25)	Total as a proportion of household income (median, IQR)	0.4% (5%)	0.2% (4%)	p = 0.24
$ \begin{array}{llllllllllllllllllllllllllllllllllll$	Catastrophic healthcare expenditures (n, %)	45 (13%)	38 (10%)	aOR = 0.8 (95%CI: 0.5, 1.3)
$ \begin{array}{llllllllllllllllllllllllllllllllllll$	Healthcare spending when seeking care for a serious health pr	roblem, previous year <sup>2</sup>		
Overall costs (median, IQR)         \$501.62 (\$2297.74)         \$828.48 (\$3216.83) $p = 0.25$ Use of social health protection products           Has private health insurance (n, %)         21 (6%)         26 (8%)         aOR = 0.6 (95%CI: 0.3, aOR)	Direct costs (median, IQR)	\$93.85 (\$970.87)	\$194.17 (\$2543.69)	p = 0.80
Use of social health protection products  Has private health insurance $(n, \%)$ 21 $(6\%)$ 26 $(8\%)$ aOR = 0.6 $(95\%$ CI: 0.3,	Indirect costs (median, IQR)	\$177.99 (\$811.42)	\$388.35 (\$1035.60)	p = 0.17
Has private health insurance (n, %) 21 (6%) 26 (8%) aOR = 0.6 (95%CI: 0.3,	Overall costs (median, IQR)	\$501.62 (\$2297.74)	\$828.48 (\$3216.83)	p = 0.25
	Use of social health protection products			
Has ever received Medical Welfare (n. %) 18 (5%) 3 (1%) aOR - 68 (95% CI-1.9.7)	Has private health insurance (n, %)	21 (6%)	26 (8%)	aOR = 0.6 (95%CI: 0.3, 1.2)
11a5 ever received intended in vehicle (ii, 70) 10 (570) 5 (170)	Has ever received Medical Welfare (n, %)	18 (5%)	3 (1%)	aOR = 6.8 (95%CI: 1.9, 23.5)**
Spending on disability-related healthcare (lifetime)	Spending on disability-related healthcare (lifetime)			
Total (median, IQR) \$1,100.32 (\$3,883.50) n/a n/a	Total (median, IQR)	\$1,100.32 (\$3,883.50)	n/a	n/a

 $<sup>^{\</sup>rm 1}$  Health care spending 25% or more of household income

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and 40% for those with a vision limitation. This was even lower for the domains of mental health (35%), communication (23%), cognition (20%) and hearing (11%). Self-reported unmet need for services/device was highest for the domains of communication (36%) and hearing (34%) and lowest for mental health (5%). Overall, coverage (use/perceived need) was high for the mental health (88%) and physical domains (75%) and lowest for communication (39%) and hearing (34%). Reported need increased significantly with age (S1 Table). Unmet need increased significantly with age and was more common among people living in the lowest, compared to the highest, income per capita quartile (S2 Table). No other demographic or economic variables were significantly associated with reported need or unmet need.

#### Healthcare financing

Median per capita expenditure in the last month was generally low, at \$0.65 (IQR = \$8.70) for people with disabilities and \$0.34 (IQR = \$9.32) for people without disabilities, which equated to a median of 0.4% and 0.2% of household income (Table 5). However, there was high variability in healthcare spending, with 13.4% of people with disabilities and 10.2% of people without disabilities living in household experiencing catastrophic health expenditures in the last month (greater than 25% of household income). Health spending was high when seeking services for a serious health problem in the past year; people with and without disabilities reported spending a median of \$502 and \$828 respectively (p = ns). Few people had private health insurance or had received Medical Welfare, although people with disabilities were significantly more likely to have received Medical Welfare compared to people without disabilities (4.8% vs 0.9%, aOR = 6.8, 95% CI: 1.9, 23.5).

People with disabilities reported high and variable costs for disability-related healthcare, with a median total spending of \$1,100.32 (IQR: \$3,883.50).

# Discussion

This study found evidence that people with disabilities experience unmet needs for both disability-related and general healthcare. For general health, people with disabilities had poorer

<sup>\*</sup> p < .0

<sup>\*\*</sup> p < .01 (adjusted for age, gender, location); Amongst people experiencing a health problem in the last 12 months, n = 68 for cases, n = 27 controls; Rate of exchange used: 1 USD = 14.45 MVR

levels of health compared to people without disabilities, including poorer self-rated health, increased likelihood of having a chronic condition and of having had a serious health event in the previous 12 months. Although most people with and without disabilities sought care when needed, people with disabilities were much more likely to report difficulties when routinely accessing healthcare services compared to people without disabilities. Additionally, 24% of people with disabilities reported an unmet need for disability-related healthcare, which was highest amongst people with hearing, communication and cognitive difficulties, as well as amongst older adults and people living in the lowest income per capita quartile. Median healthcare spending in the past month was modest for people with and without disabilities. However, people with disabilities appear to have high episodic healthcare costs, such as for disability-related healthcare and when experiencing a serious health event. There is therefore evidence that people with disabilities in the Maldives are falling behind in core components relevant to UHC: availability of all services needed, and quality and affordability of healthcare.

Our finding that people with disabilities have poorer health status, on average, is consistent with the wider literature. For example, as in this study, people with disabilities were more likely to report a serious health event in the last months compared to people with disabilities in studies in India, Cameroon, Vietnam and Nepal [31, 32]. The more frequent reporting of specific chronic health conditions among people with disabilities, including diabetes, is also mirrored in other studies [33], including in LMICs such as Guatemala [34], Malawi [35], and South Africa [36].

In contrast, there was little difference in treatment coverage-for chronic conditions or when seeking urgent care-between people with and without disabilities in the Maldives. This finding is in contrast to other literature from LMICs [37]. Potentially, the availability of Aasandha in the Maldives, which covers most healthcare services, contributed to good healthcare coverage among people with disabilities. Furthermore, knowledge of and access to disability-related health services were generally higher than in other studies in LMICs such as Bangladesh, India, Cameroon and Haiti (Danquah et al., 2015; Mactaggart et al., 2015; Pryor et al., 2018). For example, a study in Bangladesh found 70% of people with disabilities had an unmet need for an assistive product [38]. Again, the availability of Aasandha as well as Medical Welfare (which cover other services not included in Aasandha, such as assistive devices) may have supported the high coverage. Still, only 5% of people with disabilities had ever accessed Medical Welfare (for any reason) and spending on disability-related healthcare was high (median: \$1,100.32, IQR: \$3,883.50). Further research is required to understand the low use of Medical Welfare amongst people with disabilities, particularly as it is the main source of provision for assistive devices. Interventions such awareness campaigns, providing support with applications, or refining eligibility criteria/the application process should be explored to increase use of this programme amongst people with disabilities.

People with disabilities in the Maldives reported difficulties in accessing healthcare services and with quality of care, which is consistent with the available literature, particularly from LMICs [37, 39]. Other studies have reported much higher out-of-pocket healthcare spending than this study amongst people with disabilities, and greater unmet needs compared to people without disabilities [40, 41]. For example, in Vietnam 30% of people with disabilities covered through social health insurance still faced catastrophic health expenditure spending, which was significantly more compared to other insured groups [42]. The relatively low spending on healthcare in the Maldives may reflect the strengths of the national health insurance programme Aasandha, which does not have individual spending caps and covers many disability-related health services—which is in contrast to many other health financing schemes in LMICs [43, 44]. Alternatively, healthcare expenditures may have been high but infrequent, and so not adequately captured in the one month recall period. There is evidence to support this theory,

as people with disabilities had high lifetime costs for disability-related healthcare (median: \$1,100.32, IQR: \$3,883.50). Further, costs for seeking treatment amongst the 19% of people with disabilities who had a health problem in the previous year were high (median \$501, IQR: \$2,297). Indirect costs (e.g. for travel) were a significant source of spending, and were not captured in the monthly recall period for household healthcare spending. High indirect and opportunity costs associated with seeking healthcare have been found in other studies [45–47]. These costs are particularly high in the Maldives—and other low population density and/or island nations—due to the lack of economies of scale needed to support the provision of tertiary care (e.g. many disability-related services) [22]. Consequently, many people must travel from remote islands to the capital Malé or abroad to receive needed care [22, 23]. Further research is needed in the Maldives and other settings on the role of health insurance and other programmes in improving access to healthcare and reducing out-of-pocket direct and indirect costs for people with disabilities.

The generally good coverage of disability-related services conceals variation by sub-group, as low household wealth, age and functional domain were predictors of unmet need for disability-related services. Other research has found cost to be a key factor in poor access to disability-related services, along with poor availability and centralisation of services [38, 48-50], which may explain higher unmet need amongst people living in poverty. Similarly, difference in coverage by functional domain may be linked to the geographic spread of services. For example, coverage for mental health, physical and vision were relatively high (88%, 59% and 75%, respectively), while coverage for people with hearing and communication limitations was low (25% and 39% respectively). This variation could reflect the availability and location of services in the Maldives. While healthcare services for physical and visual impairments are available at most atoll regional health centres, hearing services are very limited and only available in Malé. Alternatively, people may not be aware of what services would be beneficial to them. For example, mental health coverage was high (88%), mainly because few (40%) reported needing services. Studies from other settings have found that people may not recognise mental health conditions as treatable health conditions, be aware of services that could improve their symptoms or that self-stigmatisation may inhibit individuals from recognising the need for services [51-53].

#### Limitations

In interpreting the results of this study, several considerations should be taken into account. Assessments of household healthcare only included direct costs and spending within the last month. Some healthcare expenditures, such as for disability-related services, may be high but infrequent and thus not captured fully within this recall period for a study of this size. Additionally, some unmet health needs for both disability-related and general healthcare may not have been captured as they were based on self-report. Capturing unmet health needs is methodologically challenging, as individuals may not know about products and services that could improve their functioning, particularly if awareness of these items is limited or requires specialist assessment [54]. Further, the survey only captured if an individual who reported needing disability-related health services/products was using it, but did not measure whether they were sufficient to meet the individual's needs. Consequently, assessments of unmet need are likely underestimated. Another concern is that this study focused on Maldivian citizens (84% of the population [55]). However, non-citizens, such as migrant workers—who are not entitled to Aasandha but must purchase health insurance as a condition of their work visaslikely have different experiences accessing healthcare. Further research is also required to explore in greater detail differences in access to general health services by characteristics such as gender, impairment type and location. In terms of strengths, the study was relatively large, nationally representative, and included comprehensive measures of disability and healthcare access.

#### Conclusion

Health discrepancies for people with disabilities may be less pronounced in the Maldives than in other LMICs, potentially because of the existence of a comprehensive national health insurance programme. Such initiatives may therefore not only support progression to UHC, but also ensure that people with disabilities are not left behind. The health system in the Maldives has several elements of good practice that could guide other countries in developing disability-inclusive UHC. Importantly, Aasandha provides wide coverage for most general and disability-related health services, is free at the point of use and does not have spending caps for eligible services. Medical Welfare is also available for services not covered on Aasandha, such as assistive devices.

Still, there are areas for improvement to ensure the Maldives is better able to meet its commitments to UHC for people with disabilities, which also carry implications for other settings. Importantly, centralisation of services and travel are major barriers to accessing required services, particularly for disability-related services as most are located in the capital Malé. Further, episodic costs appear high for both urgent care and disability-related service. Additional social protection programmes, or wider uptake of Medical Welfare, may help to offset some of the indirect costs of seeking required care. Similarly, decentralising services such as through community-based or outreach programmes could improve affordability and availability.

#### Supporting information

S1 Table. Predictors of reporting a need for an assistive device among people with disabilities.

(DOCX)

S2 Table. Predictors of reporting an unmet need for an assistive device or specialist service among people with disabilities.

(DOCX)

S1 File. (DOCX)

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# **Background Information on Key Informants (KI)**

KI#	Organisation Type	Impairment Focus / Role	Description
1	DPO	Physical	<ul> <li>Maldives Association for the Physically Disabled</li> <li>Primary role is to protect the rights of persons with disabilities and advocate for equal opportunities (e.g., human rights and equality).</li> <li>Advocates for persons with disabilities through the use of media (e.g., television, radio, social media), develops relationships with all levels of government, donors (e.g., local businesses) and other disability organisations.</li> <li>Organises awareness campaigns on the issues related to disability with parents, community members and local government councils.</li> <li>It also works with local businesses and organisations to offer medical camps on islands, especially where disability services are limited.</li> </ul>
2	NGO	Cognitive	<ul> <li>Care Society</li> <li>Provides education programmes, motor skills learning development, psychosocial support and life skills programme for developmentally delayed children and young adults (e.g., autism, Down Syndrome, hearing impaired).</li> <li>Offers CBR programmes to remote islands which lack access to these programmes.</li> <li>Participates in advocacy and awareness programmes for persons with disabilities and is involved in lobbying the government and other key stakeholders in the field of disability.</li> </ul>
3	Government	Ministry of Health	<ul> <li>Quality Assurance &amp; Regional Atoll Health</li> <li>Identifies what healthcare services should be available on each of the 183 health facilities located outside of Male' as well as medical supplies and staffing.</li> <li>Ensures quality standards are adhered to in these 183 health facilities.</li> <li>The type of services available at each island health centre or atoll health facilities depends on the size and healthcare needs of the population.</li> </ul>
4	Government	Ministry of Health	<ul> <li>Policy, Planning &amp; International Health</li> <li>Responsible for defining, implementing, and evaluating the current government's healthcare agenda, which is based on the government's 10-year health master plan and its manifesto.</li> <li>Provides oversight of the operational planning of the government healthcare policies.</li> </ul>
5	Government	Ministry of Gender - National Social Protection	Medical Welfare Department  NSPA provides financial oversight to the Maldives' healthcare financing schemes (e.g., Aasandha (national healthcare insurance programme),

		Agency (NSPA)	Medical Welfare), Disability Allowance and other social protection programmes;  Provides financial assistance for persons travelling abroad for healthcare not offered in the public sector hospital in Male';  Financial assistance for medicines and medical equipment/assistive devices not covered by Aasandha;
6	Government	Ministry of Gender - NSPA -	<ul> <li>As above - responsible for implementing and providing oversight of the government's social protection programmes (e.g., Aasandha, Medical Welfare, Disability Allowance, etc.) as well as address, implement and monitor the country's social protection policies.</li> <li>Provides financial oversight of the budget for assistive products and medical devices, and ensures access to these social programmes, including assistive products, is available for people who need them.</li> </ul>

KI#	Organisation Type	Impairment Focus / Role	Description
7	Regional Atoll Hospital	Acute Care Hospital: Hospital Manager	<ul> <li>GN Atoll Hospital (Fuvamulah Island)</li> <li>Main responsibility is running the day-to-day operations of the Atoll hospital.</li> <li>Organises the doctor's schedule, oversees the hospital administration and human resources and ensures upkeep and maintenance of the hospital.</li> <li>Key informant was a political appointee to this position and has no experience running a hospital. (Previously worked in marketing)</li> </ul>
8	Private	Autism	<ul> <li>Provides education and therapeutic programmes for children with autism, ages 2 - 13.</li> <li>Offers comprehensive services, including screening, assessment, therapies, and education programmes, as well as psychosocial and behavioural therapies.</li> <li>Provides outreach programmes such as parent support and education programmes and teacher training programmes for schoolteachers educating children with autism.</li> <li>Staff are involved in advocacy and awareness activities well as lobbying the government for programme/policy and funding for autism.</li> <li>Involved in fundraising activities, not only for the organisation itself, but for those parents who cannot afford to pay their children's therapy fees.</li> </ul>
9	Private	Mental Health	Institute for Counselling and Psychotherapy

10			<ul> <li>Provides psychological services for children and adults. Services include consultations, assessments, and treatment.</li> <li>The behavioural and rehabilitation therapists work with children with special learning disabilities (e.g., autism, learning disabilities, developmental delay, attention deficit hyperactive disorder), behavioural modification, psychological profiling, and parent counselling.</li> <li>For adults, the therapists provide treatment in the mental health areas of schizophrenia, bipolar, psychosis, and emotional disorders.</li> <li>Staff are involved in advocacy and awareness programmes for mental health, participate in lobbying activities with the government and offer mental health education and training programmes in the community.</li> </ul>
10	Intergovern- mental	United Nations -	<ul> <li>Political Affairs and Social Cohesion Officer</li> <li>RCO role in the Maldives is to coordinates the</li> </ul>
	Organisation	Resident Coordinators Office (RCO) -	<ul> <li>work of the UN system of specialised agencies and related organisations, which include the UNDP, WHO, UNFRA and UNICEF.</li> <li>Involves itself in the political affairs of the country and developing social cohesion. It plays a neutral role in that it focuses on developing relationships through promoting dialogue among different groups (including the different political parties which exist in the country), undertaking analysis to understand the country's political context.</li> <li>It looks into conflicts (e.g., political groups) and security within the Maldives as well.</li> <li>While disability and rehabilitation are not a priority for the UN in the Maldives, the RCO recognises there is an apparent need to address the needs of persons with disabilities. It works with DPOs and NGOs to increase awareness of disability issues with the government.</li> </ul>

KI #	Organisation Type	Impairment Focus /	Description	
	Турс	Role		
11	NGO	Hearing	<ul> <li>Maldives Association for the Deaf and Hearing Impaired</li> <li>This organisation is involved in advocacy work for the hearing impaired in the Maldives.</li> <li>Activities include awareness programmes on human rights, health, and protection (e.g., safety);</li> <li>It tries to liaise with government officials but has had difficulties establishing contacts.</li> <li>It organises courses in sign language and first aid, as well as job skills development. It also organises outreach programmes to remote islands.</li> <li>It also tries to establish relationships with community businesses in order to fundraise for</li> </ul>	

			financial support for its members, purchasing of laptops for courses, etc.	
12	Public	Physical	<ul> <li>Senahiya Military Hospital - Physical Therapy</li> <li>Provides general physical therapy services to children and adults in both inpatient and outpatient settings.</li> <li>Treats all musculoskeletal, neurological, and cardiorespiratory conditions.</li> <li>Based in Male', this military hospital does allow access to civilians.</li> </ul>	
13	Public	Physical	<ul> <li>GN Atoll Hospital - Physical Therapy</li> <li>Provides physical therapy treatment to children and adults with musculoskeletal and neurological conditions in an outpatient setting.</li> <li>The physical therapy treatment area is located off site from the main hospital</li> </ul>	
14	Private	Physical	<ul> <li>AIMS Medical and Diagnostic Centre - Physical Therapy (Addu City, Addu Atoll)</li> <li>A private multidisciplinary healthcare clinic which offers access to medical doctors (e.g., family, neurology, orthopaedic, psychiatry), nurses, and physical therapy, x-rays, lab work (e.g., blood, urine)</li> <li>Clinic offers outpatient physical therapy services to children and adults for musculoskeletal injuries.</li> <li>Individuals accessing physical therapy must pay out of pocket for treatment. If they show their national identity card, they will only have to pay 50% of the treatment fee while Aasandha covers the remaining 50%.</li> </ul>	

# Qualitative Interview Guidelines for Caregivers of Children with Disabilities Accessing Rehabilitation Services

Objective: To find out about the experiences of children with disabilities and their families in accessing rehabilitation services. In particular:

- Awareness of services
- Referral process
- Access of services
- Cost of Services
- Quality of Services

These questions should be used to guide discussion but do not have to be used in the sequence listed below. The interviewer should follow up on any additional issues that may arise and seem important in relation to the issues above.

# Introduction

Good morning and thank you for your time. I am (Interviewer's name) from......

Remind them of the issue of confidentiality and anonymity which is fully explained in the information and consent form that they completed. Check if they have any questions from the information and consent form about the research. Remind them that they are free to decline to answer any of the questions or stop the interview at any time.

Code	
Interview Date and time	
Interview venue and location	
Interviewer	
Interviewee	
Gender of child with	
disability	
Age of child with disability	
Child in school or not?	
Type of school and grade	
Nature of impairment(s)	
When was impairment	
acquired?	
General observations	
(anything which might impact	
how the interview is	
conducted)	

I am going to ask you some questions about a time when you had to access rehabilitation services\* for your child's disability. For example, a child with cerebral palsy may see a physiotherapist to improve her/his ability walk safely with a 4 wheeled walker.

- Has your child's disability had any impact on his/her education or work? If so, how?
- What would your child need to be able to function in his/her day-to-day life or with less help from you? Are there any kinds of services that you think your child could use (e.g., assistive devices, rehabilitation)? (Only ask question if interviewee has not addressed this previously)

If caregiver identifies that his/her child has accessed rehabilitation services previously then proceed to "YES" questions. If not, proceed to "NOT YET" questions.

# YES

# **Awareness**

- How did you become <u>aware</u> of the rehabilitation service for your child?
  - Prompt if no answer: doctor, family, friend or someone from disability organisation, internet)
  - PROBE: what did they say?

# Referral Process

- Did your child require a referral to access the rehabilitation service?
- If so, can you describe the <u>referral process</u> to me? If not, why didn't s/he need a referral?
- Did anyone help you with the referral process? Was it helpful or not? And did it make the referral process easier or more difficult?
- How long did the referral process take for you and your child? From the time you started the referral process to the time your child received her/his first appointment?
- Is there anything you can suggest that might make the referral process easier?

#### Access

- Tell me about your experience when you tried to make an appointment for your child's rehabilitation service.
- What kind of service was it for? For example, physical therapy? Sign language lessons? Assistive devices?
- Where was the service located?
- Did you experience any challenges? If so, what where they? Were you able to resolve them? Did anyone help you?
- How difficult or easy was it to <u>access</u> the service for your child?
  - PROMPT if no answer: For example, travelling to the service (e.g., how long was the trip? Cost?)? Entering into the building (e.g., was there an elevator?),
- Can you describe the experience to me? For example, what could have made it easier for you and your child?

# Cost

- How did you cover the <u>cost</u> of the rehabilitation service for your child? Did you
  pay for it yourself? Did you receive any assistance from friends or family?
  - PROBE: Did you use funds from the Disability Allowance or access other programmes (e.g., Aasandha, Medical Welfare) to cover the cost?
- What impact did the cost of the rehabilitation have on your personal finances?
  - PROMPT (if no answer): For example, did you find you had less money to spend on other things?
  - (PROBE: If yes, ask what they had to forgo)

# Quality of Service (Met Need)

\*Ask question below for those who received "**rehabilitation service**" (e.g., physical therapy, hearing service, cognitive therapy, etc.)

- Do you think the rehabilitation service was useful (or helpful) for your child? In what ways?
  - PROMPT (if no answer): Did you see any differences or changes in your child (e.g., ability to function without assistance; less pain; easier to communicate with others?)
- What was your child's experience like receiving the rehabilitation service? For example, what was her/his relationship like with his/her service provider? Did your child feel comfortable with her/him? What was the quality of the equipment like?

# OR

- \* Ask question below for those who use an "assistive technology" (e.g., walking aid, wheelchair, hearing aid, etc.)
  - Do you think the assistive device your child uses is helpful? What benefit does it provide for him/her?
    - PROMPT (if no answer): Do you see any differences or changes in your child (e.g., ability to hear others better; ability to walk further with walking aid?)
  - What happens if the device breaks? Who repairs it? Where do you go to get it repaired? Who covers the cost of repairs?
  - What has been you and your child's overall experience with assistive device?
     Please describe.
  - Do you have any suggestions on how to improve your experience?

#### **NOT YET:**

- What do you know about rehabilitation services for your child in your area/community/Maldives?
- Do you think rehabilitation services would be useful for your child's disability? Why or why not?
- Has your child ever been recommended rehabilitation services (or assistive technology) by anyone? (e.g., doctor, family member, friend)?

- Can you tell me why you have not looked for rehabilitation services for your child yet?
  - o PROMPT (if no answer): What are the reasons?
    - Prompt ONLY if no answer: location, travel, cost, referral process, service quality, family dynamics?
- What would make a difference to your decision about seeking these services?
- Are you aware of any other assistance programmes that maybe helpful in accessing rehabilitation services for your child? If so, which ones?

<sup>\*</sup> Includes Assistive Devices

# Qualitative Interview Guidelines for Adults with Disabilities Accessing Rehabilitation Services

Objective: To find out about the experiences of adults with disabilities in accessing rehabilitation services. In particular:

- Awareness of services
- Referral process
- Access of services
- Cost of Services
- Quality of Services

These questions should be used to guide discussion but do not have to be used in the sequence listed below. The interviewer should follow up on any additional issues that may arise and seem important in relation to the issues above.

# Introduction

Good morning and thank you for your time.	I am (Interviewer's name)
from	

Remind them of the issue of confidentiality and anonymity which is fully explained in the information and consent form that they completed. Check if they have any questions from the information and consent form about the research. Remind them that they are free to decline to answer any of the questions or stop the interview at any time.

Code	
Interview Date and time	
Interview venue and location	
Interviewer	
Interviewee	
Gender	
Age	
Nature of impairment(s)	
When was impairment	
acquired?	
General observations	
(anything which might impact	
how the interview is	
conducted)	

I am going to ask you some questions about a time when you had to access rehabilitation services\* for your disability. For example, a person with cerebral palsy may see a physiotherapist to improve her/his ability walk safely with a cane.

- Has your disability had any impact your ability to work or attend school?
   If so, how?
- What do you think you would need to help you function in your day-to-day life? Are there any kinds of services that you think you could use (e.g. assistive devices, rehabilitation)? (Only ask question if interviewee has not addressed this previously).

If interviewee identifies that s/he has accessed rehabilitation services proceed to "YES" questions. If not, proceed to "NOT YET" questions.

#### **YES**

## <u>Awareness</u>

- How did you become <u>aware</u> of the rehabilitation service for yourself?
  - Prompt if no answer: doctor, family, friend or someone from disability organisation, internet)
  - PROBE: what did they say?

# Referral Process

- Did you require a referral to access the rehabilitation service?
- If so, can you describe the <u>referral process</u> to me? If not, why didn't you need a referral?
- Did anyone help you with the referral process? Was it helpful or not? And did it make the referral process easier or more difficult?
- How long did the referral process take you? From the time you started the referral process to the time you received your first appointment?
- Is there anything you can suggest that might make the referral process easier?

#### Access

- Tell me about your experience when you tried to make an appointment for your rehabilitation service.
- What kind of service was it for? For example, physical therapy? Sign language lessons? Assistive devices?
- Where was the service located?
- Did you experience any challenges? If so, what where they? Were you able to resolve them? Did anyone help you?
- How difficult or easy was it to access the service for yourself?
  - PROMPT if no answer: For example, travelling to the service (e.g., how long was the trip? Cost)? Entering into the building (was there an elevator?)
- Can you describe the experience to me? For example, what could have made it easier?

# Cost

- How did you cover the <u>cost</u> of the rehabilitation service? Did you pay for it yourself? Did you receive any assistance from friends or family?
  - PROBE: Did you use funds from the Disability Allowance or access other programmes (e.g., Aasandha, Medical Welfare) to cover the cost?

- What impact did the cost of the rehabilitation have on your personal finances?
  - PROMPT (if no answer): For example, did you find you had less money to spend on other things?
  - (PROBE: If yes, ask what they had to forgo)

# **Quality of Service (Met Need)**

- \*Ask question below for those who received "**rehabilitation service**" (e.g., physical therapy, hearing service, cognitive therapy, etc.)
- Do you think the rehabilitation service was useful (or helpful) for you? In what ways?
  - PROMPT (if no answer): Did you see any differences or changes in yourself (e.g., ability to work without assistance; less pain; easier to communicate with others?)
- What was your experience like receiving the rehabilitation service? For example, what was your relationship like with your service provider? Did you feel comfortable with her/him? What was the quality of the equipment like?

#### OR

- \* Ask question below for those who use an "assistive technology" (e.g., walking aid, wheelchair, hearing aid, etc.)
  - Do you think the assistive device you use is helpful? What benefit does it provide?
    - PROMPT (if no answer): Do you see any differences or changes in yourself (e.g., ability to hear others better; ability to walk further with walking aid?)
  - What happens if the device breaks? Who repairs it? Where do you go to get it repaired? Who covers the cost of repairs?
  - What has been your overall experience with assistive device? Please describe.
  - Do you have any suggestions on how to improve your experience?

#### **NOT YET:**

- What do you know about rehabilitation services in your area/community/Maldives?
- Do you think rehabilitation services would be useful for your disability? Why or why not?
- Have you ever been recommended rehabilitation services (or assistive technology) by anyone? (e.g., doctor, family member, friend)?
- Can you tell me why you have not looked for rehabilitation services yet?
  - o PROMPT (if no answer): What are the reasons?
    - Prompt ONLY if no answer: location, travel, cost, referral process, service quality, family dynamics?
- What would make a difference to your decision about seeking these services?
- Are you aware of any other assistance programmes that maybe helpful in accessing rehabilitation services yourself? If so, which ones?

<sup>\*</sup> Includes Assistive Device

#### **Qualitative Interview Guide for Rehabilitation Service Providers**

Objective: to understand the perspectives of service providers in the delivery of rehabilitation services/therapies or assistive devices to persons with disabilities in the Maldives. This topic guide will look at:

- 1. Strengths and weaknesses of rehabilitation service delivery
- 2. Impact of rehabilitation service delivery on persons with disabilities
- 3. Use of social protection programmes for rehabilitation for persons with disabilities
- \* For the purpose of this topic guide, rehabilitation services include rehabilitation therapies and assistive devices.

#### Introduction:

Good morning and thank you for your time. My name is Tim O'Fallon and I am a doctoral research student at the London School of Hygiene and Tropical Medicine and I am collecting information for a research project I am doing on access to rehabilitation for persons with disabilities in the Maldives.

Remind the participants of the issue of confidentiality that is fully explained in the information and consent forms that they completed. Remind them that they have the option to have their response attributed to them or to remain anonymous. Check how they would like to be cited (e.g., by job title, by organisation, both). Check if they have any questions from the information and consent forms about the research. Remind them that they are free to decline to answer any of the questions or stop the interview at any time.

Interview Code	
Interview Date and Time	
Location	
Participant Name	
Occupation	
Organisation/Centre	
Type of rehabilitation service	
provided	
General observations	
(anything which might impact	
how the interview is	
conducted)	

# 1. Organisation Background

- Please tell me about your role here at this organisation
- What kind of activities are you involved in on a day-to-day basis (e.g., treat clients, sit on external advisory committees for persons with disabilities, etc.)
- How long have you worked here?
- How long has your organisation been involved in providing rehabilitation services in the Maldives?

#### 2. Rehabilitation Services

- Please describe the different types of rehabilitation services you offer at your organisation.
- On average, how many clients do you treat per week?\*
- Based on the definition of disability introduced at the start of this interview, how many persons with disabilities seek services here, on average, per week?\*
- Depending on the client's condition, how long do persons with disabilities who receive rehabilitation from your organisation typically remain in your care?
- Does your organisation have a discharge policy? If so, please describe. If not, why not?
- Do you provide information to your disabled clients regarding self-care at home? Home exercise programme?
- How involved are the families of persons with disabilities in the treatment/education process?
- How do you monitor progress? How do you know that the treatment you offer is making an impact for the person with disabilities? Do you use outcome measures (e.g., Numeric Pain Scale)? If so, which ones?

\* Interviewee will be informed prior to interview to provide this data

# 3. Access to Rehabilitation Service

- How does a person with a disability access to or gain the use of the rehabilitation service you offer?
- Who is eligible to use your service? What criteria do you use?
- Is there a catchment area system? Are individuals from other islands able to use your service?
- Can you talk me through the process a person with a disability has to go through in order to use your service? Do they require a referral? If so, please describe this process. If not, why isn't a referral required?
- Are there any forms a person with a disability must fill out to use your service?
   What is the registration process like? Could you provide me with a copy of it?
- What do you think are some barriers persons with disabilities may face when accessing your rehabilitation service?

# PROBE (Do not prompt)

- Physical (e.g., stairs into building, no elevator)
- Communication (e.g., braille signs, availability of sign language interpreter, lack of information on condition)
- Attitudinal (e.g., attitude of service provider)
- Knowledge (e.g., lack of understanding of disability by service provider)
- Transportation (e.g., no access)
- Financial (e.g., cost of treatment/service)
- What does your organisation do to overcome these barriers for persons with disabilities?
- Tell me what you think your organisation does well in terms of service delivery? For example, the registration system is easy to use; the large number of services offered for persons with disabilities across all age groups, etc.

- What you think are some of the challenges you face in delivering your services?
   PROBE (Do not prompt):
  - Staff turnover
  - Staff competency
  - Quality of service
  - Supervision
  - Equipment and resources (both staff and financial)
  - Working with other organisations/services/NGOs nearby
  - Internal guidelines and/or policies
- How have you overcome some of these challenges?

#### 4. Cost of Services

- How are the costs of your services covered by your disabled clients?
- Do your clients pay out of pocket? Private insurance?
- Does your organisation have a system in place that can cover the cost of services if a disabled client is unable to pay?
- Does your organisation receive external funding from the government or other agencies to provide rehabilitation services to persons with disabilities?

(Ask head of organisation or manager)

# 5. Social Protection Programmes

 Are you aware of any social protection programmes available to persons with disabilities in the Maldives? If so, please describe?

(Looking to see if interviewee will identify Disability Allowance, Medical Welfare, Aasandha – **DO NOT PROMPT**)

- Do you check to see if your disabled clients have access to social protection programmes? If so, how? If not, why not?
- What are your thoughts on the different social protection programmes for persons with disabilities in terms of the delivery of rehabilitation services?
- Do you think persons with disabilities benefit from these programmes?

(PROBE if not mentioned: What about the Disability Allowance programme?)

### 6. Government and Policy

- Which Ministry is responsible for **Rehabilitation**? Responsible for **Disability**?
  - Do you think this is appropriate in terms of meeting the rehabilitation needs of PWD?
  - Which Ministry should be responsible for Rehabilitation and Disability?
- What types of government **legislation and/or policies** are in place to ensure the persons with disabilities have access to rehabilitation services in the Maldives?
  - In your opinion, are they effective?
  - Do persons with disabilities benefit from them?
  - If not, how does this impact persons with disabilities?
  - If NO policy/legislation in place, what needs to be done to change this?

<sup>\*\*</sup>Question for Policy-Level Interviewees\*\*

- How is rehabilitation embedded into the Maldives Health System? (e.g., Health Centre, Atoll Hospital, Regional Hospital, Tertiary (Male')
  - Do you think this works well for PWD?
  - What needs to be in place to improve it so PWD have access to rehabilitation at all levels of the Health System?

# 7. Delivery of Rehabilitation Services

- From your perspective, what are the strengths and weaknesses of the overall delivery of rehabilitation services for persons with disabilities in your organisation?
- What are some things that need to be improved or what needs to change?
- Do you think other rehabilitation centres in the Maldives face similar challenges as you? Please describe.
- \*\* Ask Policy Level Individuals \*\*
- What needs to be in place (e.g., policies) for this change to occur?

# 8. Supportive Supervision

Supportive supervision is a performance management tool found within the health sector and founded on the principles of MENTORSHIP, 2-WAY COMMUNICATION, and INCLUSIVE PROBLEM SOLVING....

- Is supportive supervision used in your organisation? If so, how well does it work? And how do you know? (e.g., good staff morale, low absenteeism, quality work)
- If not, have you thought about using it?
- 9. My final question to you: are there any steps your organisation can take to ensure persons with disabilities have access to your programme or service?

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Observational / Interventions Research Ethics Committee

LONDON SCHOOL of

HYGIENE &TROPICAL MEDICINE

Dr Hannah Kuper LSHTM

15 March 2019

Dear Hanna

Study Title: Impact Evaluation for the Disability Allowance of the Maldives

LSHTM Ethics Ref: 12071 - 2

Thank you for your letter responding to the Observational Committee's request for further information on the above amendment to research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above amendment to research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

Approval is dependent on local ethical approval for the amendment having been received, where relevant.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Other	Qualitative Interview Guide Rehabilitation Service Providers V3	12/10/2018	3
Other	Protocol 4	15/10/2018	4
Other	CV-Timothy O'Fallon	15/10/2018	2
Other	Information sheet & consent form (service providers)- qualitative v3	15/10/2018	3
Other	participant information sheet_service providersV4	12/03/2019	4
Covering Letter	participant information sheet_service providersV4	12/03/2019	4
Covering Letter	Response to LSHTM Ethics	12/03/2019	1
Other	Response to LSHTM Ethics	13/03/2019	1

#### After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event Form.

An annual report should be submitted to the committee using an Annual Report form on the anniversary of the approval of the study during the lifetime of the study.

At the end of the study, the CI or delegate must notify the committee using an End of Study form.

All aforementioned forms are available on the ethics online applications website and can only be submitted to the committee via the website at: http://leo.ishtm.ac.uk

Additional information is available at: www.lshtm.ac.uk/ethics



Professor John DH Porter Chair

ethics@ishtmac.u

http://www.lshtm.ac.uk/ethics/

Improving health worldwide



National Health Research Council

Ministry of Health

Male'

Republic Of Maldives

30th May 2019

Dr. Shaffa Hameed Male, Republic of Maldives

# Approval of Amended Research Proposal

Title of Study Proposal: "Impact Evaluation for the Disability Allowance in Maldives"

Researcher: Dr. Shaffa Hameed, London School of Hygiene & Tropical

Medicine (LSHTM)

Dear Dr. Shaffa Hameed,

The members of the National Health Research Council have reviewed amendments made to your research proposal "Impact Evaluation for the Disability Allowance in Maldives". Following the review, the amended study has been approved by the council.

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For the Chair of National Health Research Council (NHRC) Aishath Samiya Ministry of Health

