



UMEÅ UNIVERSITY

# **BEING YOUNG AND PHYSICALLY IMPAIRED**

**Voicing the needs and challenges of  
children, adolescents, and their carers  
in northeastern Tanzania**

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Dissertation for PhD

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*“There can be no keener revelation of a society’s soul than the way in which it treats its children”*  
– Nelson Mandela

To my family, who have always been behind my success, and to all children and adolescents with physical disabilities, their carers, and families, whose needs and challenges are voiced in this thesis.



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## Abstract

**Background:** In Tanzania, 13% of families have a member with a disability, presenting unique challenges for entire household. Despite its complexity, disability is often overlooked in development and research agendas. However, disability has gained significant attention over the past decade, particularly with its integration in the 2030 sustainable development goals that were adopted by all United Nations member states in 2015. These goals are intended to promote inclusion and equal opportunities for all, including young people with disabilities. Nevertheless, young people with physical disabilities face considerable barriers to participation in society, driven by negative norms, discrimination, and stigma. This population remains underrepresented in research, and there is a significant gap in public health knowledge, particularly in resource-poor settings. This thesis aims to describe and explore the needs and challenges associated with being young and having a physical disability, drawing on the perspectives of children, adolescents, and young adults with disabilities – along with their families and carers – in northeastern Tanzania.

**Methods:** The research was conducted in the Kilimanjaro region of northeastern Tanzania, using both qualitative and quantitative methods. A quantitative survey was completed by the primary carers (aged 18 years or older) of 212 children and adolescents with physical disabilities, aged between 2 and 18 years. The data collected during the survey were analysed in Studies I and III. The SurveyCTO software was used to collect data electronically via a questionnaire. The questionnaire was developed based on the International Classification of Functioning, Disability, and Health (ICF) framework. Statistical analysis (Studies I and III) was performed using IBM SPSS version 28. For the qualitative aspect of the research, Study II employed constructivist grounded theory, while Study IV analysed the experiences of adolescents and young adults regarding inclusion using reflexive thematic analysis.

**Results:** Children and adolescents with physical disabilities have significant difficulties with walking, self-care, and participating in social activities, household chores, and schooling. Furthermore, they were reported needing assistive devices, therapeutic exercises, and nutritional support. Regarding essential services, most families lived near health facilities that did not provide rehabilitation services. Additionally, a quarter of the children and adolescents with physical disabilities had never received any rehabilitation service. More than two thirds did not have health insurance. The carers faced psychological challenges, with over half of the 212 carers surveyed reporting poor psychological wellbeing, and 42% and 38% describing symptoms of anxiety and depression, respectively. Support from extended family members was linked to better psychological wellbeing and a lower likelihood of experiencing anxiety and depression. Support systems, particularly via social networks, were crucial in helping families meet basic needs and ensure the safety of



their children. The adolescents and young adults, however, reported feeling marginalised, facing significant barriers to full societal integration, and experiencing an uncertain future with little hope.

**Conclusion:** This thesis found significant activity limitations among children and adolescents with physical disabilities in areas such as walking, self-care, communication, and participation in social activities, household chores, and schooling. Access to essential services, particularly healthcare, is inadequate, or in many cases impossible to access. Adolescents and young adults face both present and future barriers to full inclusion in society, and families are constantly adapting to meet the challenging needs of their children, with carers experiencing a considerable psychological burden. To address these challenges, it is crucial for the Ministry of Health to strengthen rehabilitation services within primary healthcare settings. Health-insurance reforms are also necessary to ensure the societal inclusion of young people with disabilities. Public-awareness campaigns that highlight the potential of people with disabilities and promote inclusion are crucial for supporting social networks and challenging negative societal norms.

**Keywords:** physical disability, adolescents, young adults, challenges, disability-related needs, rehabilitation, carers, Tanzania, Kilimanjaro region, young people

## Acronyms

BCC	Building Caring Community
CBR	Community-Based Rehabilitation
CCBRT	Comprehensive Community-Based Rehabilitation in Tanzania
UNCRPD	The United Nations Convention on the Rights of Persons with Disabilities
HSCL-25	Hopkins Symptoms Checklist – 25 items
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health – Children and Youth version
KCMUCo	Kilimanjaro Christian Medical University College
LMICs	Low-middle Income Middle Income Countries
MOH	Ministry of Health
UNICEF	United Nations International Children’s Emergency Fund
WHO	World Health Organization
UN	United Nations
PWDs	Persons With Disabilities
SSA	Sub-Saharan Africa
UHC	Universal Health Coverage
NGOs	Non-Governmental Organisations
TASAF	Tanzania Social Action Fund

## Glossary

Impairments:	Refers to the problems in body structures or functions such as a deviation/deformity or loss [1].
Activity limitations:	These are difficulties a child or adolescent or a young adult may have in performing activities [1].
Participation restrictions:	Refers to the problems a child or adolescent or young adult may experience in involvement in life situation like interacting within society [1].
Disability:	Refers to an umbrella term representing body functions, structural impediments, activity limitations related to problems in executing tasks and participation restrictions relating to, constraints in life interactions [1, 2].
Social modal of disability:	This is a modal that stresses about social oppression and regards disability as something imposed by the society barriers on top of impairments which isolate and exclude individuals from participating fully in life [3].
Medical modal of disability:	Is a way of viewing impairments or disability as a problem located in the biological entity or in an individual [4].
Children:	According to the Convention on the Rights of the child a 'child' denotes a person below the age of 18 [5]. Notably, this definition includes both children and adolescents.
Adolescents:	Are defined by the world health organisation (WHO) as a life phase from ages of 10 to 19 which is between childhood and adulthood [6].
Young adults:	According to WHO young adults are persons aged between 18 and 24.
Physical disabilities:	Refers to lifelong structural or functional impairments with or without associated cognitive or mental deficits which might be present at birth or acquired and in interaction with societal barriers the primarily affect the mobility, functioning and participation in life [1, 2].

Carer:	Also termed as ‘caregiver’ in this thesis refers to a close family member who is responsible for caring a child or adolescents with a physical disability in all aspects of life, and who does not get a financial reimbursement for doing so [7, 8].
Disability-related needs:	Refers to the needs of children, adolescents, or young adults, as well as their carers and/or families, which arise because of impairments, activity limitations, or challenges related to participation in life.
Challenges:	In this thesis, ‘challenges’ have been defined as any form of social, physical, psychological, or economic difficulties related to caring for a person with or living with a disability.

## Original papers

This thesis is based on the following four papers, referred to as studies I – IV:

- i. **Elia Asanterabi Swai**, Sia E. Msuya, Haleluya Moshi, Marie Lindkvist, Ann Sörlin, and Klas-Göran Sahlén. Children and adolescents with physical disabilities: describing characteristics and disability-related needs in the Kilimanjaro region, northeastern Tanzania – a cross-sectional survey. *BMJ Open* 13, no. 1 (2023).
- ii. **Elia Asanterabi Swai**, Haleluya Imanueli Moshi, Sia Emmanueli Msuya, Marie Lindkvist, Ann Sörlin, and Klas Göran Sahlen. Adaptive adjustment to the needs of families caring for children and adolescents with physical disabilities in northeastern Tanzania: a grounded-theory study. *Global Health Action* 17, no. 1 (2024/12/31 2024).
- iii. **Elia Asanterabi Swai**, Haleluya Imanueli Moshi, Sia Emmanueli Msuya, Ann Sörlin, Klas-Göran Sahlen, and Marie Lindkvist. Psychological wellbeing among carers of children and adolescents with physical disabilities in northeastern Tanzania—a cross-sectional survey study. *Frontiers in Public Health* 12 (2024-October-09 2024).
- iv. **Elia Asanterabi Swai**, Kelvin Frank Haukila, Haleluya Imanueli Moshi, Sia Emmanueli Msuya, Ann Sörlin, Klas-Göran Sahlen, and Marie Lindkvist. Listening to the voices of adolescents and young adults with physical impairments: exploring experiences on inclusiveness in the Kilimanjaro region, northeastern Tanzania. *Manuscript under review*.

The original publications are in Open-Access journals.

## Prologue

My interest for the disability studies has been shaped by my father's experience of severe impairment caused by a stroke. During his eighteen years of illness, I witnessed firsthand the hardship of inaccessible or absent support and resources. In the early 1990s, at just six years old, I moved from the village to live with my father after his initial, minor stroke. Even at that young age, I stayed with him in town where he was working as an army official, watching over him in case something happened overnight. I had to move away from my mother, the rest of my siblings, and my childhood friends in the village. This marked the beginning of my understanding of the crucial role of family support during times of illness.

Nine years later, after retiring from the army, my father suffered multiple major strokes, leaving him severely impaired. This resulted in several hospitalisations, and a need for extensive healthcare services that were difficult to access. With no health insurance, he quickly exhausted his pension because of out-of-pocket expenses for healthcare. During this time, I met my cousin a physiotherapist, who inspired me to pursue physiotherapy. Throughout my father's illness, he faced complications, mostly due to a lack of essential care, such as physiotherapy, and other rehabilitation services. This strengthened my resolve to enter the field.

After beginning my physiotherapy training in 2006, I had the opportunity to engage in community fieldwork, where I met children with physical disabilities in remote rural areas. I remember that my first experience was in Olkokola, a Maasai village. This experience not only deepened my interest in the area of disability but also led to frequent involvement in outreach activities with families caring for children with disabilities. These encounters widen my understanding that the health system, health policies, infrastructure, and socioeconomics are essential in addressing these challenges.

In 2011, the Linnaeus-Palme collaboration between the Faculty of Rehabilitation Medicine at KCMC University (formerly Kilimanjaro Christian Medical University College) and the Department of Community Medicine and Rehabilitation at Umeå University connected me to pursue a master's degree in physiotherapy at Umeå. My PhD journey has been linked to my previous experience at Umeå University; however, I had to apply for the scholarship independently, and I remember applying more than once. My persistence in applying for a PhD position was greatly encouraged by Professor Gunnevi Sundelin and Professor Sia Msuya.

In May 2019, I was warmly welcomed to the Department of Epidemiology and Global Health at Umeå University as a prospective doctoral candidate. Since my admission in December 2019, the journey has been incredibly fruitful, providing immeasurable life and learning experiences. My PhD journey was somewhat interrupted by the outbreak of COVID-19 just as I had enrolled and was about to begin. The year 2020 was largely affected by challenging lockdowns and disrupted travel opportunities for courses. Despite this global adversity, the journey gradually

resumed at the beginning of 2021 and has exceeded my expectations in my academic career.

During this time, I have also networked with organisations such as Comprehensive Community-Based Rehabilitation in Tanzania (CCBRT) and Building Caring Communities (BCC). These experiences not only deepened my interest but also significantly expanded my knowledge and skills in the field of disability.

Opportunities provided by the Erling-Persson Foundation through the *Forming New Leaders in Global Health Programme*’ scholarship have allowed me to thrive in a nurturing environment that has consistently shaped my understanding of global public health. The diverse network fostered through my unique multi-professional research group has been invaluable. The guidance from my supervisory team has broadened my potential and shown me that I can positively impact the wellbeing of young persons with disabilities (PWDs), their carers, and families, while also contributing to the improvement of Tanzanian society.

This PhD journey has been full of diverse experiences—some challenging, some sad, and some incredibly fulfilling. I believe that this research will give a voice to vulnerable young people with disabilities, their carers, and families, sparking actions and initiatives to create a more inclusive society.





# 1. Introduction

## **An overview of disability**

Disability is a complex phenomenon that intersects with multiple sectors, relating to social, cultural, economic, and political dimensions [9]. This complexity is further compounded by negative factors like poverty and stereotypes [9-11]. Despite the diverse perspectives on disability, the topic remains underexplored in research, particularly in resource-limited settings, where the challenges are even more pronounced [9, 12-14]. To ensure that no one is left behind, the United Nations (UN) has recognised disability as a cross-cutting issue within the 2030 sustainable development goals (SDGs) [15-17]. In line with this, UN has integrated disability across SDGs 4, 8, 10, 11 and 17. Persons with disabilities remains marginalised in society, and experiences poor access to modern technologies, higher rates of poverty, limited employment opportunities, low wages and inaccessible environment at public spaces [18]. However, progress in many SDGs remains off track, largely due to persistent social, and environmental barriers in society [17].

Defining disability is inherently complex due to varying perspectives; however, the World Health Organization (WHO) provides a comprehensive definition [1, 11]. The WHO's definition overlaps with that of the UN Convention on the Rights of Persons with Disabilities (UNCRPD)[1, 2]. Disability is therefore regarded as an umbrella term that encompasses impairments of body structures and functions, difficulties in performing tasks, and participation restriction [1, 2]. Disability can as well denote a long-term health condition involving physical, mental, intellectual, or sensory impairments, which, when coupled with social barriers, can hinder person's participation in society [2]. Both the WHO and UNCRPD definitions emphasise that disability arises from the dynamic interaction between impairments, and societal barriers as shown in Figure 1 [1, 19].

Physical disabilities refer to impairments in body structures or functions that affect the ability to move [1, 19]. These mobility impairments can result from injury, illness, or conditions that occur at birth or are acquired later in life. When impairments are not identified, and addressed through timely, appropriate interventions, they can exacerbate functional limitations, and worsen participation restriction [1, 10]. Globally, the rates of disability are rising due to the increasing chronic diseases, injuries, and the aging population [10, 15].

An estimated 16% of the global population, or about 1 in every 6 people, have some form of disability [9, 20]. The global burden of disease data [21] indicates that 11.3% of children younger than 20 years have disabilities. Many of these young individuals live in under-resourced areas particularly Sub-Saharan Africa (SSA), where essential services are scarce or absent [9-11].

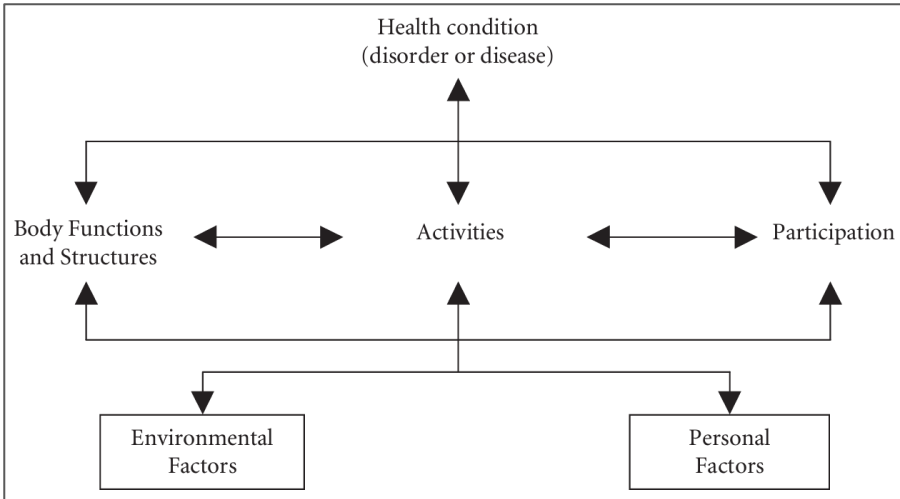


Figure 1: The dynamic interaction between the health conditions and societal barriers according to ICF framework

This thesis highlights the importance of including young PWDs in research by drawing on relevant examples from northeastern Tanzania. Not only that, adolescence is of significant public health interest, as young persons with physical disabilities are among the most vulnerable, and socially excluded groups in society [9, 11]. Despite the existing social inequality mainly resulting from poor beliefs, the right to a fulfilling life is fundamental for all children, and young people [5, 22]. Also, adolescents, and young adults with physical disabilities are often prone to violations of their human rights [23]. As a result, children and adolescents with physical disabilities, along with their families, face numerous challenges mostly imposed by social and environmental barriers in society.

Societal barriers prevent young people with physical disabilities from participating equally in life [3]. These inequalities place disability agenda for young people at the top of the global health concern [10, 11, 14, 16, 17]. Poor inclusion in society in this regard stems from physical barriers, negative attitudes, violence, abuse, inadequate policies, and lack of access to education and economic opportunities [23]. Inclusion for children, adolescents, and young people with disabilities is a concern tied to fundamental rights and social justice, serving as a crucial indicator for fostering a better future for society [5, 23]. The dynamic interaction between societal barriers and inclusion is emphasised in this thesis, as it is embodied in the social model of disability [3].

### Disability in children, and adolescents

Childhood is a vulnerable phase of life, crucial to both society and public health, as a child's wellbeing depends on family structure, parenting, and societal support [24-

28]. All children irrespective of their biological status, race or economic backgrounds have equal rights which includes love, shelter and opportunity to participate in playing and schooling [5]. This phenomenon is often termed as inclusion in society.

The UNICEF and the Global Burden of Disease [21] provide recent estimates on the prevalence rates of disabilities among children and adolescents. According to UNICEF, the prevalence rate of moderate-to-severe disability is observed in 4.3% of children globally aged 0 to 4 years, 10.1% of children aged 0 to 17 years, and 12.5% of children aged 5 to 17 years [21]. The Global Burden of Disease 2019 analysis shows that 7.5% of children aged 0 to 5 years and 12.6% of children aged 5 to 19 years live with mild-to-severe disabilities [21]. Despite differences in measuring, and reporting the metrics, both datasets suggest that SSA, and South Asia together account for more than half of the global burden of childhood disabilities [9, 21].

Children and adolescents make up a 53% of Tanzania population [29, 30]. Notably, substantial progress has been made in reducing early childhood mortality, particularly in low- and middle-income countries (LMICs) including Tanzania [31-33]. While more infants and children are surviving, many still experience disabilities, underscoring the need for additional resources to address the growing demands of care for children with disabilities [10, 11].

In this thesis, adolescents' and young adults' perspectives on societal inclusion have been incorporated because this area is poorly researched [13, 14, 17, 22, 34]. Furthermore, adolescence is a period during which important physical, social, and psychological transformations occur [22, 35]. Investing in health during this transitional age is of paramount importance in public health.

Adolescents accounts for the 16% of the world population, and 90% of them live in LMICs, particularly SSA [22]. In Tanzania, 23% of the population is comprising adolescents aged between 10 and 19 [36]. Subsequently, essential services for physically disabled adolescents (education, rehabilitation, civic, and protection) are highly needed, particularly in LMICs, yet they are often rare, absent, or of low quality [10, 11, 22, 34]. Needs such as knowledge about sexual and reproductive health (SRH), employment and educational opportunities, legal support, and skill acquisition—relating to physical impairments during childhood and adolescence—are unique. These needs require more targeted resources from both families and healthcare systems. [10].

In Tanzania, a situational analysis by UNICEF reported a disability prevalence rate of 2.3% among children and youth aged 5 to 24 years [34]. Additionally, a prevalence rate of 1.2% for walking difficulties in Tanzania was identified within the same age group. These findings highlight global disparities in childhood disabilities and

underscore the importance of targeted interventions [10]. However, interpreting disability statistics requires caution due to the lack of a universally agreed definition of disability and the diverse methodologies employed in assessing and reporting prevalence data [37].

The WHO report on disability and rehabilitation, which includes data from 29 countries, documented the main causes of disabilities in African settings [38]. Infectious diseases such as poliomyelitis, leprosy, meningitis, measles, onchocerciasis, and malaria were identified as the primary causes of disability in most countries [38]. The report also highlighted war, trauma, and accidents as the second leading category of causes, with wars ranking as the most significant within this group [9, 38]. Moreover, congenital and non-communicable diseases were the third leading causes, with congenital malformations being common in more than 50% of African countries. The final category of disability causes in African settings based on this report [38] were poverty, and health service-related factors. Health-related causes involved issues such as incorrect injections, and improper treatments. Although mentioned last, poverty and insufficient medical services remain significant risk factors that can exacerbate the severity of impairments [10, 38].

#### **Sub-classification of disabilities in children**

Disability encompasses diverse classifications and subtypes, making it crucial to understand the subcategories as they significantly influence the needs and challenges faced. For example, it is documented that individuals with intellectual, mental, and behavioural disabilities are at a more risk of marginalisation compared to other groups [39]. Werner [40] in his book about the 'disabled village child', also described how physically impaired children face discrimination in village settings. However, in rural areas, they are still able to participate in schooling. The approach to classifying disabilities varies widely depending on the purpose and framework employed, reflecting the complexity and multifaceted nature of this field.

Common types of disabilities include vision impairment, hearing difficulties, intellectual disabilities, acquired brain injury, autism spectrum disorder, physical disabilities, attention deficit hyperactivity disorder (ADHD), and other neurodevelopmental disorders [41, 42].

Most sub-classifications of disabilities in children and adolescents are based on the medical model, often referred to as the 'medicalisation of disability.' This approach focuses primarily on diagnosing and treating the condition, rather than considering the broader context of the individual's life. However, the WHO international classification of functioning disability and health (ICF) framework presents a biopsychosocial model [19]. This model views disability not merely as a medical condition, but as an interaction between an individual's health condition, their

environment, and the social barriers they encounter [2, 3]. This perspective underlines a more holistic approach to understanding and addressing disability.

According to the ICF, different forms of disability may involve one or more of three dimensions: impairment, activity limitation, and participation restriction [1]. The ICF provides a broader perspective, recognising that health conditions can impact the body or mind in areas such as vision, movement, thinking, memory, learning, communication, hearing, mental capacity, and social relationships. Some health conditions present at birth, such as muscular dystrophy and Down's syndrome, can affect mobility, learning, vision, behaviour, and other aspects, depending on the interaction with social and environmental factors in society [1, 19]. Other health conditions encountered during child development, such as autism spectrum disorder and ADHD, can also lead to disabilities. Additionally, conditions related to injury, such as spinal cord injuries or traumatic brain injuries, can result in impairments affecting mobility, overall functioning, and participation in society [43].

This thesis primarily focuses on physical disabilities. These are physical impairments that may be present at birth or acquired, and they impact mobility and the ability to function such as walking, selfcare, communication, and playing [2]. Physical disabilities in children are often associated with neurodevelopmental conditions, with cerebral palsy being a common underlying diagnosis for physical disabilities [44, 45]. In this thesis, cerebral palsy is of particular interest, as most of the physical impairments observed were a result of cerebral palsy as documented in other studies [44-46]. Cerebral palsy refers to a group of permanent disorders that affect the development of movement and posture, leading to activity limitations. These disorders are attributed to non-progressive disturbances that occur in the developing fetal or infant brain. The motor disorders associated with cerebral palsy are often accompanied by disturbances in sensation, perception, cognition, communication, and behaviour, as well as epilepsy and secondary musculoskeletal problems [47].

### **Needs and challenges related to physical disabilities**

According to the ICF, health conditions such as physical disabilities in young people interact with societal barriers, known as 'contextual factors' [1, 19]. This interaction creates unique needs, which, without adequate resources, lead to challenges for their carers, and families [48]. Moreover, children and adolescents with physical disabilities face challenges to inclusion, which are linked to various barriers in society. The ICF biopsychosocial model recognises these inclusion challenges as the interaction between individual's health conditions, impairments, and negative contextual factors leading to difficulties in participation. [1, 19]. This phenomenon is conceptualized as disability, resulting in additional needs for the young people with physical impairments, their carers, and the entire family. The central concepts in this thesis are the needs and challenges related to caring and life participation for young people with physical disabilities. This thesis conceptualises the complexity of

emerging needs, and the challenges associated with fulfilling them using Maslow's hierarchy of needs theory [49, 50].

Maslow's hierarchy of needs theory has been previously used in various settings as a tool for categorising human needs and understanding the motivations associated with fulfilling them [51]. Maslow's hierarchy theory is five-tier classification of human needs in the form of a hierarchy [49]. The three lowest levels are the 'deficiency needs', consisting of basic, safety, and love/belonging; the upper two are the 'growth needs' of self-esteem and self-actualisation. Maslow's hierarchy of needs theory states that, the lower needs must be completely satisfied before the upper needs can be addressed [51].

Fulfilling the needs in situations where resources are insufficient to meet the demand is challenging and often complicates the approach to addressing them. The needs of young people with physical disabilities and their families arise because of health conditions, functional problems, and participation restrictions. The difficulties in meeting these needs are described in this thesis as challenges, which includes physical, social, psychological, and economic dimensions.

Almasri et al. [52] define "family needs" as the aspirations of family members, especially carers or parents, for information about their child's condition, services, and support to help achieve family goals. These needs tend to be more complex and dynamic for families of children and adolescents with physical disabilities, compared to those without [52, 53]. Furthermore, the needs of children and adolescents with physical disabilities evolve over time due to growth and development, requiring families to continuously adjust and adapt [24]. 'Disability-related needs' is another term operationalised in this thesis. It refers to the unique needs that emerge as a result of impairments, such as healthcare, rehabilitation, and other broader necessities that enhance the functioning, participation, and overall well-being of young people with disabilities [46].

The WHO and the World Bank [37] highlight common unmet needs for families of children with disabilities, including support for child's personal care, access to assistive devices, education, and home modifications. In resource-limited settings, accessing assistive technology is particularly challenging [10]. For children, the need for the devices is worsened by the necessity for replacements as they grow [53, 54].

National surveys in Malawi, Zambia, and Zimbabwe have highlighted the needs of young people with disabilities, including assistance, financial support, and help with daily life tasks [55-58]. The most prominent needed services in these countries include healthcare, rehabilitation, counselling for the carers and/or family, education, and assistive devices [55, 56]. Children, and adolescents with physical

disabilities without associated cognitive impairments, especially in urban areas, tend to have better access to educational opportunities [40, 57].

In Tanzania, the 2008 disability report found that 97.5% of children with disabilities were not using assistive devices [29]. A recent UNICEF survey in Tanzania also highlighted gaps in education, access to assistive devices, and inequalities in service accessibility. While the full extent of the need for assistive technology remains unclear, these findings emphasise a significant inadequacy of access to such devices in the country.

Families and carers, regardless of their background, face a variety of challenges related to caring for young people with disabilities, including social, economic, psychological, and physical difficulties [59]. However, non-medical challenges, such as psychological stress, economic strain, socio-cultural barriers, and coping mechanisms, have received less attention [52, 59, 60]. The challenges of caring for children, and adolescents with physical disabilities are more pronounced in LMICs compared to high-income countries (HICs) [10]. This disparity arises from differences in policy frameworks, the allocation of funds, limitations within healthcare systems, and the inadequate integration of services with community support structures.

Caring for young people with physical disabilities often places additional strain on families, affecting both carers and the youths themselves [59, 61]. Carers of children and adolescents with physical disabilities face increased caring demands due to the lifelong nature of the caring task [59, 62]. High levels of stress, and low parenting satisfaction are common, alongside challenges such as isolation and insufficient time for other responsibilities [59, 61, 63].

The nature and intensity of challenges faced by families often vary based on the type and severity of the disability [64, 65]. In resource-poor settings, additional challenges such as concerns about the child's future, financial strain, stress, and poverty are prevalent [63]. These are often compounded by chronic physical pain experienced by carers, which hampers daily caregiving activities [59, 66].

While some challenges, such as exhaustion, frustration, anxiety, anger, and poor communication with healthcare providers, are shared across developed and developing contexts [28], existing literature are skewed towards developed settings [64]. Consequently, most evaluation tools for needs, and interventions are tailored to these contexts, leaving gaps in applicability to low-resource settings [25, 28, 52].

Families in these settings face challenges such as disrupted communication, poor problem-solving skills, financial hardships, stigma, and isolation [67, 68]. In the Kilimanjaro region, issues such as family abandonment, indecision about having

more children, and neglect of other siblings are reported [67]. Financial constraints, caregiving burdens, and employment difficulties are also widely reported [67, 68], emphasising the need for comprehensive support strategies tailored to these challenges. The wellbeing of carers is critical, as it directly influences the wellbeing of children and adolescents with disabilities [60, 69]. The intricate relationship between young people with physical disabilities, their carers, and their families is complex and calls for more focused research.

### **Health insurance for PWDs and CBR services**

In Tanzania, various sectors and ministries are involved in implementing policies and services for PWDs, including children. The Ministry of Health (MOH) plays a leading role in coordinating essential healthcare services, such as rehabilitation [70]. Additionally, the MOH oversees the health insurance system in Tanzania. In this section, we will briefly review health insurance coverage, and CBR.

Tanzania has committed to the UN goal of achieving universal health coverage (UHC) by 2030, ensuring that all individuals can access healthcare without financial barriers [71]. However, when considering PWDs, including children, the progress toward UHC is significantly behind [72]. Scaling up the national health insurance fund in 2001 was among the initiatives of ensuring UHC which has been outlined since 1967 during the Arusha declaration, and in several health policies even before UN millennium development goals, and 2030 SDGs [73-75]. The Arusha Declaration was a political statement rooted in the principles of socialism and equality, proclaimed a few years after Tanzania gained independence.

In Tanzania, two primary public health insurance funds are available: the community health fund and the national health insurance fund, with several private insurance schemes also operating within the country [76]. An improved version of the community health fund was introduced as part of significant reforms in health financing under the 2016–2026 health financing strategy [74]. However, the improved-community health fund supports services primarily at the primary healthcare level [74], and does not cover costs related to assistive devices, or specialised services. Tanzania has further introduced the 2023 Universal Health Insurance Act, which mandates health insurance for all citizens and residents [76]. The implementation of this law, which includes merging insurance funds and mobilising resources to cover the majority, is still in progress.

Despite these efforts towards UHC in Tanzania, population coverage with health insurance remains low at 15%. This includes 8% covered by the national health insurance, 6% through the improved-community health fund, and only 1.3% through other private insurances [76, 77]. The primary beneficiaries for the national health insurance are public employees, leaving out the majority of the population, particularly those living in rural areas, and working on low wages [78]. The national



health insurance fund packages do not include CBR services or coverage for assistive devices [70]. This exclusion creates significant barriers relating to access to essential services for families, and PWDs themselves, including children. Additionally, both service providers and consumers have expressed dissatisfaction with the national health insurance fund packages. Issues such as limited access to essential medicines, and delays in service provision are commonly reported by beneficiaries of the National Health Insurance scheme [78].

Family-centred care and CBR are promising approaches for addressing the special needs, and challenges faced in resource-constrained settings. Launched in the 1970s through initiatives by the UN, CBR empowers PWDs and their families to tackle challenges within their respective communities [79]. In Tanzania, the CBR concept is not new; however, its practice remains underreported, and inaccessible to the majority [70]. Moreover, there is limited understanding of the extent to which this approach empowers carers, and families to effectively manage their needs, and challenges in society.

### **Family and care perspective**

To ensure the well-being of children with disabilities, the support of their families and carers is essential. Family is an interconnected system where the needs of one member affect the others [80]. Caring for the children, and adolescents with physical disabilities can be mentally, and physically exhausting, particularly when resources are limited, health systems are inadequate, and there is little external support [81-83]. Over time, the burden of care often falls entirely on the nuclear family, or more commonly, on the mother alone [67].

Carers play a vital role in supporting the wellbeing of children, and adolescents with physical disabilities. Carer in this thesis denotes a close family member (majority being parents) who is responsible for caring a child or adolescents with a physical disability in all aspects of life, and who does not get a financial compensation for doing so [7, 8].

Family has long been recognised as a significant social institution worldwide [80]. In African cultures, life is traditionally organised around the extended family [84]. Extended family refers to a structure that includes spouses, children, and other relatives such as grandparents, uncles, nephews, aunties, nieces, and cousins [84, 85]. One unique aspect of the extended family arrangement is the sharing of family responsibilities, including childcare [84, 86]. In this regard, family members in resource-poor situations collaborate, and share common duties within their network. When extended family network is utilised to enhance, and benefit the wellbeing of children and adolescents with physical disabilities, as well as their carers, and that of their family, is in this thesis being conceptualised as ‘social capital’ [87, 88]. *Social capital refers to ‘social networks, the reciprocities that arise from them, and the value they hold for*

*achieving common goals'* [87]. However, traditional extended families have undergone transformations, including a shift towards a more modernised nuclear family setup [89]. Despite this shift, which threatens the extended family network in the African context, the tradition remains strong, and continues to play a vital social role in challenging situations, such as caring for children, and adolescents with disabilities [84].

In LMICs including Tanzania, the care responsibility usually falls on the family due to the lack of formal support systems for children, and adolescents with disabilities [90-92]. In Tanzania, as in other SSA countries, mothers often take on the primary caring role for children with disabilities, while fathers typically focus on providing financially [93]. This one-sided burden on mothers, coupled with research indicating that fathers or husbands often neglect or abandon the mother to care for the disabled child alone [59, 67, 93], makes caring a gendered issue. The wellbeing of the family members particularly carers have a direct impact on the child's wellbeing, and vice versa. However, how unmet needs and challenges affect families in Tanzania has not been fully explored. Research that includes the perspectives of families, carers, and children will provide valuable insights to inform policies and interventions [14].

Tanzania has committed to international conventions on the rights of people with disabilities, including the UNCRPD in 2007 and 2009 [94, 95]. National policies, such as the 2004 Disability Policy and the 2010 Disability Act, have been introduced to promote inclusion and protect the physical, social, and economic welfare of young people with disabilities and their families [75, 96]. An example can be found in the 2010 Persons with Disabilities Act, which mandates that the care of PWDs, including their settlement, be the responsibility of the family and relatives.

Despite these policies, the resources and services needed to address the growing demand for care remain insufficient [97]. Furthermore, early identification of disabilities and formal registers for children with disabilities are rare in Tanzania. Key interventions, like family-centred care and community-based rehabilitation (CBR), which are outlined in Tanzanian policies, are often poorly documented [70]. As a result, families and carers face significant care-related burden and challenges.

### **Policies relevant to disability in Tanzania**

Since Tanzania's independence in 1961, the government has provided services to PWDs through the Department of Social Welfare [75]. However, it was not until 1981 that a specific policy for PWDs was introduced, following the proclamation of that year as the international year of PWDs. This led to Cabinet Paper No. 19, which outlined the responsibilities for caring for PWDs, followed by the disabled persons care and maintenance act (1982), and the disabled persons employment act (1982) [75]. These laws aim at enabling PWDs including young people to secure

employment and assigned care responsibilities to families, local government, and non-governmental organisations.

The current Tanzania national health policy of 2007 mandates that the services, and affairs of PWDs be addressed from both medical, and social perspectives [98]. Furthermore, this policy commits the government to ensure public-private partnerships in the early identification and provision of treatment for PWDs at all levels of service provision. This commitment also extends to the provision of assistive devices, and the creation of a conducive environment for the provision of rehabilitation services at all levels, including primary healthcare.

In 2004, Tanzania launched the national policy on disability, followed by the persons with disability act in 2010 [75, 96]. The Persons with Disability Act of 2010 [96] provides a comprehensive framework for the rights and rehabilitation of PWDs, including access to health services. Section 26 of the Act mandates that PWDs must be able to access healthcare without discrimination, placing the responsibility on health facilities to ensure the provision of accessible services. However, a gap exists in defining and regulating standards for these facilities, leading to inconsistent implementation.

The persons with disability act of 2010 also stresses the importance of family and community support for young people with disabilities [96]. Settlements for PWDs are only considered when family or community assistance fails, but such settlements have yet to be established. Regulatory measures to monitor the quality of services are underdeveloped, leaving PWDs vulnerable to inadequate care.

Section 30 of the 2010 persons with disability act empowers the Minister to establish regulations for industrial rehabilitation courses, but these regulations have not been implemented [70]. Additionally, the Act envisions the creation of a National Fund for PWDs to support education, vocational training, and rehabilitation. However, the absence of this fund further hinders effective implementation. Key committees outlined in the Act are also not fully operational, limiting their effectiveness. For future proposals, it is essential to prioritise the establishment of regulations, funding mechanisms, and institutional frameworks to ensure effective service delivery and fulfil the objectives of the 2010 Persons with Disabilities Act.

### **Rationale**

Research on children and adolescents with physical disabilities is scarce in Tanzania. The little involvement of children and adolescents with disabilities in research undermines the progress towards creating an inclusive world by 2030. In line with the research gap, Tanzania has made substantial progress in reducing neonatal and infant mortality rates by investing in maternal, neonatal, infant, and under-five child health. Children are getting chance to live longer but not necessarily

disability-free. This situation highlights the need for resource mobilisation and the provision of essential services.

Moreover, children and adolescents make up 53% of Tanzania's population. This population pyramid, with larger proportion of young people contributes to the escalation of disability statistics. Correspondingly, access to essential services at the primary healthcare level remains limited within Tanzania's health system, as is also the case in many other LMICs.

Furthermore, children and adolescents with physical disabilities are a vulnerable group mostly relying on support from their families, parents and/or main carers to manage daily life and reach their potential. This complex and dynamic relation is important when attempting to address the needs and challenges. Triangulating the perspective of families, carers and their physically disabled children's needs and challenges is important to inform the gaps in policy or interventions.

The Tanzania health systems lack a comprehensive early identification program for children with disabilities. This gap may contribute to the lack of robust routine data to inform about the needs and challenges encountered in caring for the children, and adolescents with physical disabilities. Leveraging the transparency and usefulness of the ICF framework, which systematically documents the interaction between disability, social, and environmental barriers, is a vital step. In line with that, describing the impairments, activity limitations, and participations restrictions together with the disability-related needs is an important public health attempt.

Challenges faced by families and carers of children and adolescents with physical disabilities, including limited access to essential rehabilitation services, are poorly documented in the Kilimanjaro region. Existing literature also highlights societal barriers, such as negative beliefs and attitudes towards children and adolescents with physical disabilities. Collectively, these complexities contribute to substantial physical, economic, and psychological burdens on carers and families.

Documenting these challenges can highlight the needs for essential public-health interventions and bring to light the voices of families', carer's, children and adolescent's needs and challenges in Tanzania. This thesis is aligned with the global efforts to improve healthcare access, create inclusive environments, and ensure social participation for all.

## **Thesis aims**

This thesis aims to describe and explore the needs and challenges associated with being young and having a physical disability drawing on the perspectives of children, adolescents, and young adults with disabilities – along with their families and carers – in northeastern Tanzania.

To achieve this goal, four specific objectives were formulated:

**Study I:** To describe the characteristics and disability-related needs of children and adolescents with physical disabilities in the Kilimanjaro region, northeastern Tanzania.

**Study II:** To explore the needs and challenges faced by families that care for children and adolescents with physical disabilities in the Kilimanjaro region, northeastern Tanzania.

**Study III:** To evaluate the psychological wellbeing and symptoms of anxiety and depression, along with associated factors, among carers of children and adolescents with physical disabilities in the Kilimanjaro region, Tanzania.

**Study IV:** To explore the experienced challenges on inclusion among adolescents and young adults with physical disabilities in the Kilimanjaro region, northeastern Tanzania.

## **Conceptual framework**

In this study, three theoretical frameworks have been utilised at various stages: the ICF [19], social capital [88], and Maslow's hierarchy of needs theory [49, 51]. The ICF framework was endorsed by the WHO in 2001 [1], and the children and youth version, abbreviated as ICF-CY, was brought up in 2006 [19]. The ICF-CY is specifically designed to document the characteristics of the growing children and their interaction with the surrounding environment. This framework is suitable for researchers, clinicians, educators, and policymakers, as it provides a uniform and universal language for assessing and documenting health conditions i.e., disabilities in children and youth. As one of the WHO classification systems, the ICF offers a common nomenclature for documenting issues related to body functions and structures, activity limitations, and participation restrictions manifested during childhood and adolescence, particularly in relation to contextual (social and environmental) factors.

Under the social model of disability [3], it is argued that disability is primarily associated with social barriers. In contrast, the medical model ties disability to individual impairments that need to be fixed. Disability scholars have often emphasised the social model while neglecting the biological aspects of disability, as

seen through the medical model. Both are essential, as medical model highlight personal experiences related to impairments and health conditions. The social model [3] acknowledges that disability results from social barriers created by society.

In this study, we have incorporated the ICF framework, as it emphasises a biopsychosocial view of disability, positing that disability is a complex phenomenon arising from multiple factors, including social, physical, and biological elements. The ICF framework has been employed throughout this study, from the conceptualisation and design of data collection tools to the discussion of the interconnections between studies. The landscape of the studies within the ICF framework is illustrated in Figure 2.

The Social Capital Framework has informed the design and discussion of qualitative grounded theory Study II [88]. In this context, the role of sociocultural protection—manifested through informal family support—has been viewed as both individualistic and collective social capital. Maslow’s Hierarchy of needs theory has informed the analysis of Study II [49, 51] and has been utilised as a sensitising concept to organise the theoretical categories and explain the notion of adaptive adjustment.

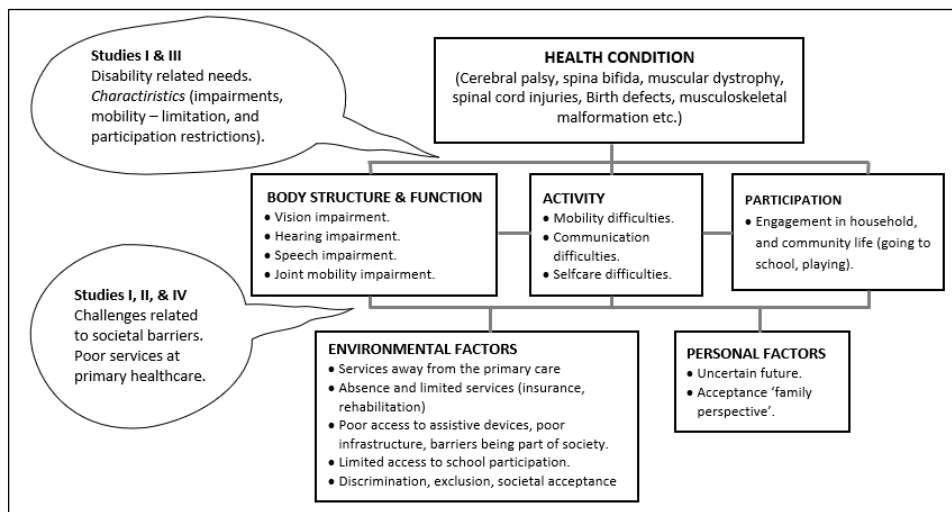


Figure 2: The ICF framework including the sub-studies of this thesis.

### The link between the frameworks

Family relationships are mutually inter-dependent; however, they become more complex when caring for a child or adolescent with a physical disability. The needs of these families, particularly the primary caregivers—who are predominantly

mothers—and the children themselves, are dynamic and influenced by contextual factors. Maslow’s hierarchy of needs theory provides a stepwise perspective on human needs and offers a universal categorisation of these needs. In this thesis, the fulfilment of family needs is described in relation to Maslow’s hierarchy of needs theory, while also demonstrating that these needs may follow a more complex and arbitrary pattern that extends beyond Maslow’s hierarchical model. This complexity necessitates contextual adjustments to cope with the challenges faced by these families.

The poor societal inclusion of children and adolescents with physical disabilities, along with the challenges faced by their families and carers, often arises from social and environmental barriers. This interaction is effectively illustrated by the ICF biopsychosocial framework. The difficulties in meeting various categories of human needs are closely linked to barriers created by society, which are intricately connected within both the ICF framework and Maslow’s hierarchy of needs theory.

Understanding how families, carers, and children with physical disabilities navigate these obstacles is essential for informing policy and identifying feasible solutions. The presence of informal and unstructured support from both nuclear and extended families’ networks offers valuable insights from a public health perspective. The social capital framework emphasises the importance of sociocultural support in promoting health and wellbeing [88]. Therefore, in this thesis, Maslow’s hierarchy of needs theory, the ICF framework, and social capital frameworks have been integrated to provide a comprehensive understanding of the needs and challenges related to the wellbeing of children and adolescents with physical disabilities in northeastern Tanzania.

## 2. Methods

*Table 1: An overview of four studies responding to four objectives.*

<b>Sub-studies</b>	<b>(Study I)</b>	<b>(Study II)</b>	<b>(Study III)</b>	<b>(Study IV)</b>
<b>Aim</b>	To describe the characteristics and disability-related needs of children and adolescents with physical disabilities in the Kilimanjaro region, north-eastern Tanzania.	To explore the needs and challenges for the families of children and adolescents with physical disabilities in the Kilimanjaro region, Tanzania.	To evaluate the psychological burden and associated factors among caregivers of children, and adolescents with physical disabilities in the Kilimanjaro region, Tanzania.	To explore the experienced challenges on inclusion among adolescents, and young adults with physical disabilities in the Kilimanjaro region, Tanzania
<b>Approach</b>	Quantitative	Qualitative	Quantitative	Qualitative
<b>Data source</b>	Primary Data through household community-survey	Primary data through In-depth Interviews (IDIs).	Primary Data through household community-survey	Primary data through In-depth Interviews (IDIs).
<b>Perspective</b>	Children and adolescents	Family	Carers	Adolescents
<b>Data collection period</b>	November 2020 to June 2021	February to June 2022	November 2020 to June 2021	June to July 2024
<b>Respondents</b>	Carers (n=212)	Family representative [carers] (n=12)	Carers (n=212)	Adolescents, and young adults (n=17)
<b>Analytical approach</b>	Descriptive statistics.	Constructivist Grounded Theory	Multivariable linear, and Binary logistic regression.	Reflective Thematic Analysis

### Study settings

All studies were conducted in Kilimanjaro, one of Tanzania’s 31 administrative regions. This region, located in northeastern Tanzania and bordering Kenya to the northeast, has an approximate population of 1.9 million people [36]. Most of the population live in rural areas across the foothills and slopes surrounding Mount Kilimanjaro, the highest peak in Africa. Administratively, Kilimanjaro is divided into seven district councils: Moshi Municipal, Moshi Rural, Hai, Rombo, Mwangi, Same, and Siha. Each district is further divided into wards, which are subdivided into streets in urban and villages in rural areas. The number of wards ranges from 17 in Hai and Siha to 32 in Same district. In rural areas, villages are further divided into hamlets, which break down into ten-cells (approximately ten households), the smallest administrative unit.

In Tanzania, healthcare operates through a public-private partnership, with both government and private hospitals offering services, including rehabilitation, to citizens. The healthcare system is integrated into the administrative framework and



follows a referral-based structure. The lowest health facilities include dispensaries (providing only day-based care and does not admit patients) in villages, health centres (bigger than dispensary and can admit patients) in wards, and district hospitals [99]. These facilities fall under the category of primary healthcare [99]. Secondary healthcare consists of regional referral hospitals, with tertiary care provided by zonal and specialised hospitals. Rehabilitation services in Tanzania's healthcare system remain underdeveloped, with few personnel available at primary care facilities [100].

The situation in Kilimanjaro mirrors that of many rural African settings, characterised by challenging economic conditions, informal transport networks, and inadequate road infrastructure. Figure 3 illustrates the environmental barriers, including 'hilly paths', 'uneven road used for commuting from place-to-place', and 'poor home surroundings'. The region's primary economic activities are small-scale agriculture and tourism, with family carers of children and adolescents with disabilities also involved in farming and livestock keeping. Notably, caring responsibilities are predominantly managed by women, particularly mothers.

According to the 2022 census of Tanzania's population and households [36], Kilimanjaro has a total of 461 healthcare facilities, with only 7% classified as hospitals providing referral or specialised services [9]. Referring to current operating staffing levels from the Tanzanian Ministry of Health of 2014 and 2019 [100], rehabilitation services for children and adolescents with disabilities are available at district, regional, and tertiary hospitals, making up less than 10% of all healthcare facilities in the area. Essential rehabilitation services for children with disabilities are sparse, mainly found in urban locations, and often provided by non-governmental organisations (NGOs). Although services for children with disabilities are available through both public and private facilities, access remains a significant challenge for rural families.



*Figure 3: A photographic illustration of the study context*

## **Design**

To achieve the objectives of this thesis both quantitative and qualitative approaches were employed. This thesis uses both quantitative and qualitative approaches to gain a comprehensive understanding of the needs and challenges experienced by the children, and adolescents with physical disabilities, their families, and carers [101, 102]. The use of both quantitative and qualitative approaches strengthens the study's conclusions by bringing together insights from both methods. The quantitative component assessed the characteristics of and disability-related needs of children and adolescents with physical disabilities in Study I. Also, I investigated the psychological burden, and associated factors among carers of children and adolescents with physical disabilities in Study III. The qualitative component explored the needs and challenges from the family perspective in Study II, and challenges relating to inclusion among adolescent, and young adults with physical disabilities in Study IV.

## **Household survey**

The survey, conducted from November 2020 to June 2021, gathered data on the characteristics, and disability-related needs of children and adolescents with physical disabilities, as well as on the psychological burden of their primary carers. Households of a child or adolescent with a physical disability aged 2 to 18 years were included in the survey. Primary carers, aged 18 and above, informed about the characteristics of children or adolescents they care for, contributing to the data for Study I, as well as general household information. Additionally, these same carers reported on their own psychological wellbeing, including symptoms of anxiety and depression, which formed dataset of Study III.

Households were selected in three stages using a simple random technique (lottery) and total sampling, refers to Studies I and III. First stage, all seven district councils in the Kilimanjaro region were listed for consideration. From each district, nine wards were randomly chosen using a lottery method. To mitigate bias, the researcher wrote down the names of all wards on pieces of paper, rolled them up, and placed them in a box. After shaking the box to mix the papers, a third-party volunteer, who was unaware of the study, randomly selected nine pieces. This process was repeated for the remaining districts. At the next stage, all villages (n=124) in the randomly selected wards were included. When researchers arrived at the village, all households caring for a child or adolescent with a physical disability were included in the survey.

To increase the representation of Moshi municipality, an additional sample of nine wards was drawn using the same procedure. This was necessary because the initial sample mainly consisted of public or business areas, such as industrial zones, a railway station, and educational institutions. Additionally, fieldwork and data

collection in the Siha, Mwanga, and Same districts were affected by Covid-19-related challenges.

### **Qualitative approach**

In this thesis objectives 2 and 4 were addressed qualitatively. In Study II we explored needs and challenges from the family perspective by using a constructivist grounded theory design. Identification of participants in Studies II and IV were informed by the survey and were sampled purposively.

The researcher observed the African culture, particularly in rural areas, where the husband heads the household, and the mother looks after the children. Respectful and culturally sensitive, the researcher considered inviting fathers to participate in the interviews (Study II). However, after being informed about study, fathers willingly trusted mothers alone to represent the family in all interviews. One grandmother (widowed), and single mothers (separated, divorced, or never married) were also invited. In Study II we included 12 female primary carers aged between 24 and 80 years.

In Study IV, an exploratory design was used to explore experiences of social inclusion among adolescents with physical disabilities. We included 17 adolescents aged between 15 and 22, with varying characteristics and physical disabilities, to gain a broader perspective on their experiences of inclusion within society.

In the grounded theory study, saturation was defined as the point at which inclusion of new participants no longer generated novel insights. In Study II, saturation was anticipated after the tenth interview. To confirm this, an additional two interviews were conducted, verifying that saturation had indeed been achieved [103, 104].

### **Data collection**

#### **Data collection team**

The survey data were collected by a team of three: two trained research assistants and the main investigator. Data collection was conducted via face-to-face interviews using a questionnaire and the digital platform SurveyCTO, which is suitable for collection, monitoring, and archiving surveys [105]. Data collection was undertaken using Samsung Galaxy Tab 2. Interviews for Study II were conducted by the main investigator from February to June 2022. In Study IV, interviews were conducted by the main investigator, supported by one research assistant, from June to July 2024.

## Questionnaire

### ***General information, children characteristics and disability related needs***

The questionnaire gathered key information on children's disability characteristics, their needs, and the carers' psychological burden. Questions on disability-related characteristics were based on the ICF [19]. Additional sections on social demographics, comorbidities, and healthcare access were adopted from a local survey by the Institute of Public Health at Kilimanjaro Christian Medical University College (KCMUCo) [106]. Most of demographic items used nominal (yes/no) responses, with a continuous scale for age. Impairments and activity limitations were assessed using an ordinal scale (0 = no impairment, 1 = some impairment, 2 = severe impairment, 3 = complete impairment), aligned with the Washington Group Short Set on Functioning (WG-SS) [107, 108]. For activity limitations, and participation restrictions only the term changed from 'impairment' to 'difficulty'.

Questions on disability-related needs were designed based on a literature review of assessment tools for children with disabilities and their family's needs [25, 52, 108]. After pre-testing for clarity, content validity was confirmed by two physiotherapists and two occupational therapists specialising in child rehabilitation. Responses were coded as either "need" (1) or "no need" (0), with an open-ended option for additional needs. The questionnaire was translated into Swahili by two language experts—a Swahili university teacher and a secondary school instructor—in collaboration with the research team. The questionnaire was pre-tested on 24 carers of children aged 2 to 18, followed by a pilot phase to ensure practical application.

### ***Psychological wellbeing***

The self-reported psychological wellbeing of the carers was assessed using the WHO-5 Wellbeing Index [109, 110]. This tool is widely used worldwide and has since been translated into more than 30 languages, including Swahili [109-112]. The Swahili version of the WHO-5 is valid and reliable [109, 112, 113]. The tool assesses the state of wellbeing over the preceding two weeks and comprises five items, detailed in Appendix IV. Response options range from 0 to 5, with 0 indicating 'at no time' and 5 indicating 'all the time'. The psychological wellbeing was calculated as the sum of the scores of the responses, ranging from 0 (indicating the lowest possible wellbeing) to 25 (the highest possible wellbeing). For the purposes of comparison and interpretation, the raw scores were converted to a 0–100 scale, with lower scores indicating worse wellbeing. A score of  $\leq 50$  can indicate poor wellbeing, suggesting further screening for depression [114]

### ***Symptoms of anxiety and depression***

Symptoms of anxiety and depression were captured using the Swahili- version of the Hopkins Symptoms Checklist-25 (HSCL-25). This is widely used instrument and has been translated into and validated in various languages, including Swahili [115-119].

The HSCL-25 involves 25 items (Appendix V) that relate to symptoms experienced over the preceding month: the first 10 items relate to anxiety, and the following 15 to depression. The response options are “Not at all”, “A little”, “Quite a bit”, and “Extremely”, and are scored 1 to 4, respectively. The final score is derived by summing the scores of all items in respective symptoms of anxiety and/or depression and dividing by the number of items (scores range from 1.00 to 4.00, 10 items for anxiety and 15 items for depression). A score of  $\geq 1.75$  on those two scales are indicative of symptoms of anxiety and/or depression [115].

### ***Semi-structured interview guide***

The semi-structured interview guide for the grounded theory study (Study II) was inspired, and informed by the social-capital framework of Pierre Bourdieu [88]. The interviews started with grand-tour questions to establish rapport, which was followed by more specific content themes [120]. Similarly, the tool for Study IV was refined based on the pilot interview which was revised by a team of qualitative researchers including the main investigator. The final interview-guide was finetuned to fit the adolescent’s context.

### **Data collection procedures**

During the survey, community entry was enhanced by the ward executive offices in the sampled areas. We acquired contact information for village/street and sub-village (hamlet) leaders. Prior to the fieldwork, these local leaders (ten-cells and hamlet leaders) who are administratively proximal to households, in collaboration with community health workers (CHWs), identified the locations of the children and adolescents with physical disabilities and connected the research team with the households. The identification of households was based on the definition of physical disability provided by the research team. The operational definition was expanded involving statements such as *"children aged 2 to 18 years with bodily/physical impairment affecting their mobility with or without a combination of intellectual or mental impairment"* to comprehensively capture the study population. The research assistants obtained informed consent, screened the children and adolescents for eligibility criteria, and interviewed the carers when the criteria were fulfilled.

During the survey the research assistants read out each question exactly (word-by-word) and made notes regarding the response on the Tablet. Regarding to open-ended questions, the answer was written exactly as expressed by the participants. On average, an interview took 30 minutes and took place at the households in their respective areas. Archiving of the data involved an end-to-end encryption on a server accessible only by the main investigator [105]. To address the risks of bias during data collection, the research team held regular debriefing sessions and checked protocol compliance every second day of data collection. Daily checks were also conducted on response patterns, interview, and GIS accuracy to the location.

Regarding Study II the interviews lasted between 59 and 135 minutes, and were digitally recorded, transcribed verbatim, and translated from Swahili to English by the main investigator. Interviews for Study IV lasted between 26 and 94 minutes. To ensure the accuracy of the translations, the co-author fluent in Swahili cross-checked the translations. The field observation notes were recorded in a logbook by the main investigator. Data collection and the initial open coding were conducted simultaneously for the grounded theory study.

### **Data analysis**

Quantitative data were analysed using IBM SPSS Statistics V.28. In Study I descriptive statistics, including t-test, Pearson's chi-square and/or Fisher's exact tests, were applied to identify proportional/mean differences across variables. Bar graphs were used to describe the disability-related needs, impairments, activity limitations, participation restriction among children, and adolescents with physical disabilities. In Study III, three dependent variables were analysed: psychological wellbeing, symptoms of anxiety, and symptoms of depression. Psychological wellbeing was measured on a continuous scale, ranging from 0 (the worst possible wellbeing) to 100 (the best possible wellbeing). For psychological wellbeing, a linear regression with a backward elimination approach was performed. Anxiety and depression symptoms were treated as binary outcomes, and multivariable logistic regression was applied.

The independent variables analysed for potential associations included sociodemographic factors, as well as caring- and disability-related characteristics. A backward elimination procedure was performed during the regression analysis until only factors with p-values less than 0.05 remained in the model for each outcome.

In Study II, the constructivist grounded theory analysis involved open, selective, axial, and theoretical coding [121], with Maslow's hierarchy of needs as the guiding framework [49, 51]. This analytical approach involved continuous comparison, supported by memos, field notes, and transcripts. The Open Code software Version 4.03 was used for the coding process and organisation of codes [122]. In Study IV, reflective thematic analysis, as outlined by Braun and Clarke [123, 124] was conducted. Reflective thematic analysis emphasises the role and position of the researcher throughout the entire study process. The findings were organised into themes and sub-themes.

### **Ethical considerations**

Ethical approval was granted by the Institutional Review Board of the KCMUCo Research Ethics and Review Committee (ID: 2477). A written permission to conduct the study was also obtained from the executive directors of each district council involved. All data collected has been securely stored and managed solely by the main investigator.

Given that participants were from a vulnerable population, more attention was given to issues of power dynamics. The investigator's role as a male physiotherapist within a culture that traditionally accords greater authority to men, combined with the potential for mixing-up care and research roles, was carefully considered and addressed. Local leaders helped introduce the research team to households, fostering rapport and a sense of security for participants. Before commencing data collection at the household, the research team read the study details word-for-word to participants, making it clear that participation was voluntary and that they could refuse or stop at any time. They were also assured that non-participation, or withdrawal would not affect their future access to healthcare services. Participants were informed that this study was solely research linked to PhD studies and unrelated to any care services access for their child.

To ensure voluntary participation, each participant signed a consent form; those unable to write could select a next of kin to sign on their behalf. Confidentiality and anonymity were assured, with no personal identifiers used in the data. The study posed minimal physical or emotional risks, and participants were informed there were no direct, immediate benefits but their contributions could help bring change in the future. Conducted during the Covid-19 pandemic, the survey adhered to Ministry of Health safety regulations to protect both participants and the research team.

Assent for minors was granted by their parents or legal guardians. To minimise potential bias from intimidation or disrespect, adolescents were addressed individually to ensure their responses remained genuine. For participants under 18, written consent was formally obtained from their guardians. Further ethical reflections, particularly concerning the qualitative sub-studies, are discussed in the section on methodological considerations and reflexivity.

### 3. Results

In this chapter, the findings of each specific study are narrated and summarised in Table 2.

*Table 2: Key findings of all four studies*

<b>Studies</b>	<b>Key findings</b>
Study I (children and adolescents)	<p>Over three-quarter of children and adolescents had no health insurance.</p> <p>Nearly a quarter had never received any rehabilitation service.</p> <p>More than half (above 5-years) had severe-and-complete difficulties in selfcare activities (washing oneself, grooming, toileting, dressing, eating, and drinking).</p> <p>The majority needs assistive devices, therapeutic exercises, nutrition supplements, special education, and regular hospital visits.</p>
Study II (family perspective)	<p>Families struggle to fulfil basic needs for their disabled children and adolescent.</p> <p>Families face safety and security problems in aspects of finances, healthcare, emotions, and child's physical safety.</p> <p>The sociocultural protection partly brings support and enhance the fulfilment of the needs through family networks or informal social networks.</p> <p>Barriers in form of poor societal norms and attitudes impeded the families to reach their dreams in life.</p> <p>These families adapt and adjust to these challenges by searching for alternatives, facing the reality "acceptance" and avoidance "hiding away".</p>
Study III (carers perspective)	<p>Most carers present with poor psychological wellbeing with 42% having symptoms of anxiety, and 38% depression.</p> <p>Findings of multivariable regression show that family support positively associate with better psychological wellbeing, and less likelihood of anxiety and depression symptoms.</p>
Study IV (adolescents and young adults' perspective)	<p>Adolescents feel marginalized in society due to social and physical barriers that hinder their inclusion.</p> <p>Adolescents experienced difficulties engaging with society because of infrastructure and transportation challenges that affect their interactions.</p> <p>Furthermore, adolescents and young adults with physical disabilities experience uncertainty about their future, with limited hope, particularly regarding educational opportunities.</p>

#### **Insights from the survey**

The survey included 212 households of children and adolescents with physical disabilities in Kilimanjaro. The households form the dataset for Studies I and III. Each household surveyed had one child or adolescent with a physical disability. The descriptive data for the children, and adolescent with physical disabilities are presented in Figure 4. Over half of the children (62%) were between 2 and 9 years old, with 60% of them living in rural areas. Cerebral palsy was the predominant condition, affecting 67%, with an additional 13% experiencing cerebral palsy



combined with other conditions. Of 212 children, and adolescent, 52% of their impairments were reported as acquired after birth.

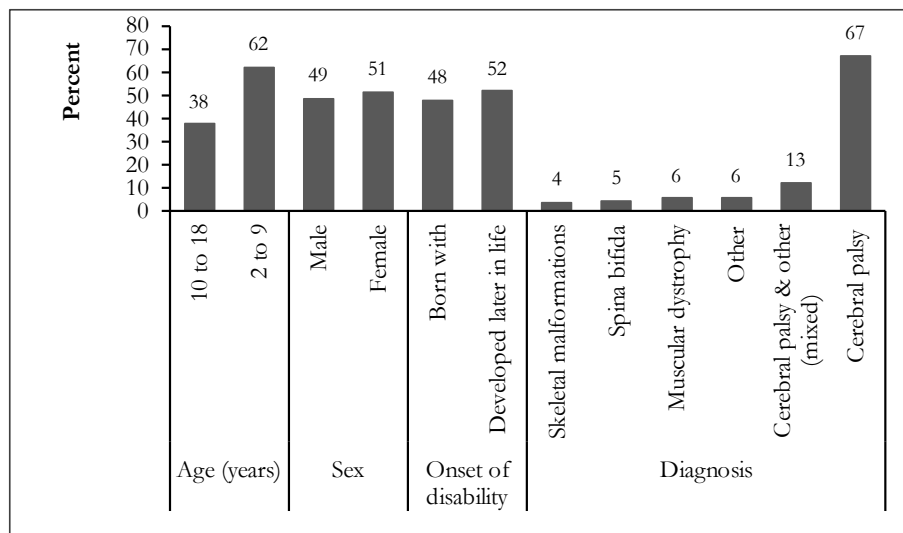


Figure 4: Descriptive characteristics of the children, and adolescents

#### Availability and access to healthcare and services

Table 3 presents findings on the availability and accessibility of essential care and services for children and adolescents with physical disabilities and their families.

Table 3: Healthcare-related characteristics for children and adolescents with physical disabilities in the Kilimanjaro, northeastern Tanzania

Variables	Frequency	%
<b>Nearest health facility to the household</b>		
Dispensary†	119	56.1
Health centre	32	15.1
Hospital††	61	28.8
<b>Utilization of the nearest health facility by the household</b>		
No	18	8.49
Yes	194	91.51
<b>Availability of rehabilitation services at the nearest healthcare facility (n=194)</b>		
No	135	69.6
Yes	59	30.4
<b>Access to rehabilitation past month</b>		
Yes	77	36.32
Lost continuity of care	84	39.62
Never had any before	51	24.06
<b>Rehabilitation service provision approach (n = 77)</b>		
CBR	11	14.3
Non CBR	66	85.7
<b>A child covered by health insurance</b>		
No	164	77.4
Yes	48	22.6

Most households (56%) were located closer to a dispensary, with 92% relying on these facilities for healthcare, including services for children with disabilities. However, only 30% of nearby healthcare facilities offered rehabilitation services. Notably, almost a quarter (24%) of children and adolescents with physical disabilities had never received any form of rehabilitation.

### Impairments, activity limitation and participation restriction

This thesis describes disability-related characteristics using the ICF framework, with detailed findings presented in Study I. The findings in Figure 5 show that more than half of the children, and adolescents with physical disabilities experienced severe-to-complete difficulties in participating in social events (52%), household chores (56%), and schooling (58%).

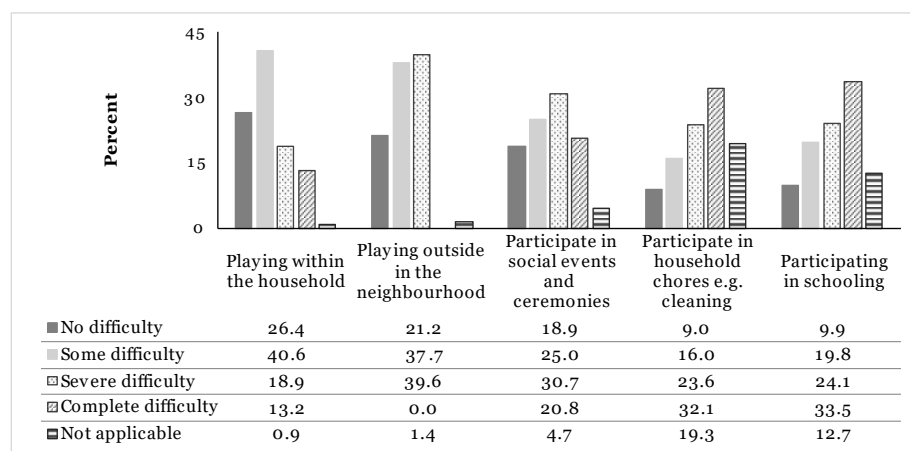


Figure 5: Participation restrictions among children and adolescents with physical disabilities

### Disability-related needs for the children and adolescents

This thesis considers disability-related needs as things essential for addressing impairments, activity limitations, and participation challenges. Children with disabilities, along with their families and carers, have specific needs that are vital for providing effective support. Disability-related needs for children, and adolescents are described in Study I.

Children with physical disabilities had 5 ( $\pm 1.6$ ) identified needs, as reported by their carers. The number of reported needs for children, and adolescents varied significantly with age. The most common disability-related needs were assistive devices, therapeutic exercises, nutritional supplements, special education, and regular hospital visits.

### Families self-reported needs

Family needs, as reported by the primary carers representing the family, are illustrated in Figure 6. These needs were self-reported during the survey. Most families expressed a need for financial support for medical care (94%), transportation (89%), and assistive devices (78%) for their children with physical disabilities. Additionally, families highlighted the need for consulting rehabilitation professionals for their children (88%), information on childcare (87%), training on handling skills (79%), and access to their children's exercise therapy (69%).

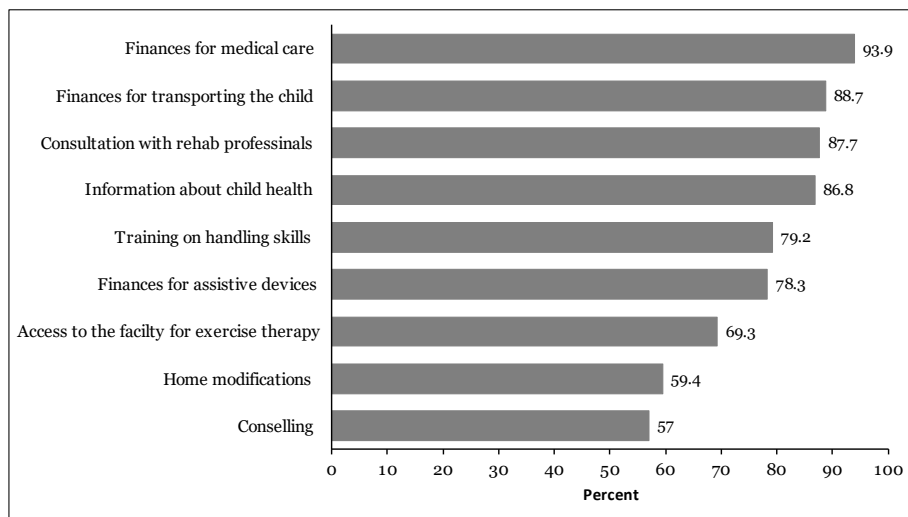


Figure 6: The distribution self-reported needs of family of children and adolescents with physical disabilities

### Maslow's hierarchy of needs perspective

This thesis demonstrates a complex approach to fulfilling the needs of families caring for children and adolescents with physical disabilities. Families often experience significant strain in addressing basic needs, with many barely surviving due to overwhelming challenges related to poor resources. Poor societal norms are evident in various forms, such as fathers/husbands abandoning mothers to care for the children alone. Discriminatory behaviours have been experienced with some healthcare providers, health insurance subscriptions, and in public spaces. Healthcare difficulties are further complicated by transportation costs to facilities, inadequate services in public primary care facilities, and poor health insurance coverage that does not include assistive devices or rehabilitation costs.

According to Maslow, individuals fulfil each level of need stepwise before progressing to the next. However, families caring for children with physical disabilities often struggle to achieve their life aspirations, leading to uncertainty about the future. Supportive networks from both nuclear and extended families, as well as informal societal networks, help bridge the challenges in fulfilling basic needs.

Adaptive adjustment is a dynamic process involving both short-term strategies, such as finding alternatives or avoidance. These approaches have both positive and negative dimensions: avoidance leans toward negative coping, while searching for alternatives represents positive adaptation. In Figure 7, the illustration shows that families often remain within the cycle of basic needs, supported by social capital from family networks. In their pursuit of survival, families resort to alternative means and, over time, may come to accept their situation as their reality. Ascending through the hierarchy of needs becomes complex due to unsupportive societal norms, symbolised by a dashed circle in the illustration. Family members tend to avoid discriminatory encounters and face the reality that certain aspirations may remain unattainable. These challenges weigh heavily on women, who often face confinement and limited freedom to earn an income. With growing needs and financial instability, family members become vulnerable to severe poverty, impacting their mental and physical wellbeing.

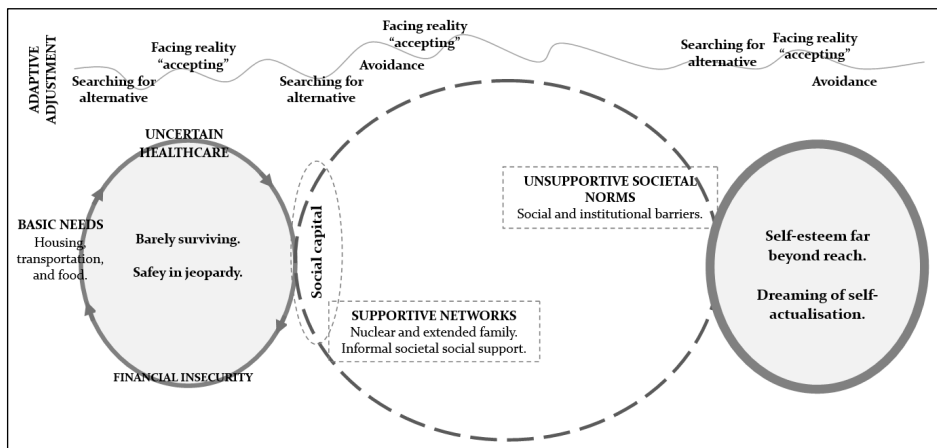


Figure 7: Illustration of adjustments and adaptation of the families caring for children and adolescents with physical disabilities

### Carers psychological burden

In this thesis, I describe psychological wellbeing of the carers', measured with the WHO-5 Well-Being Index, with scores ranging from 0 "worst wellbeing" to 100 "best possible wellbeing". Symptoms of anxiety and depression were categorised as a binary outcome and measured using the HSCL-25. Table 4 shows 51% of carers of children and adolescents with physical disabilities exhibited poor psychological wellbeing. Of the 212 carers, 42% had anxiety and 38% depression symptoms.

Table 4: The psychological wellbeing and symptoms of anxiety and depression among cares of children and adolescents with physical disabilities (n=212)

Variables	n (%)	Range of values	Subcategories
Psychological wellbeing	107 (50.5)	0-100	≤ 50 Poor Wellbeing
Anxiety	89 (42.0)	1-4	≥ 1.75 Symptoms of anxiety
Depression	81 (38.2)	1-4	≥ 1.75 Symptoms of depression

Figure 8 illustrates the multivariable logistic regression model, showing that extended family support and access to the child’s rehabilitation are significantly associated with lower odds of experiencing anxiety symptoms.

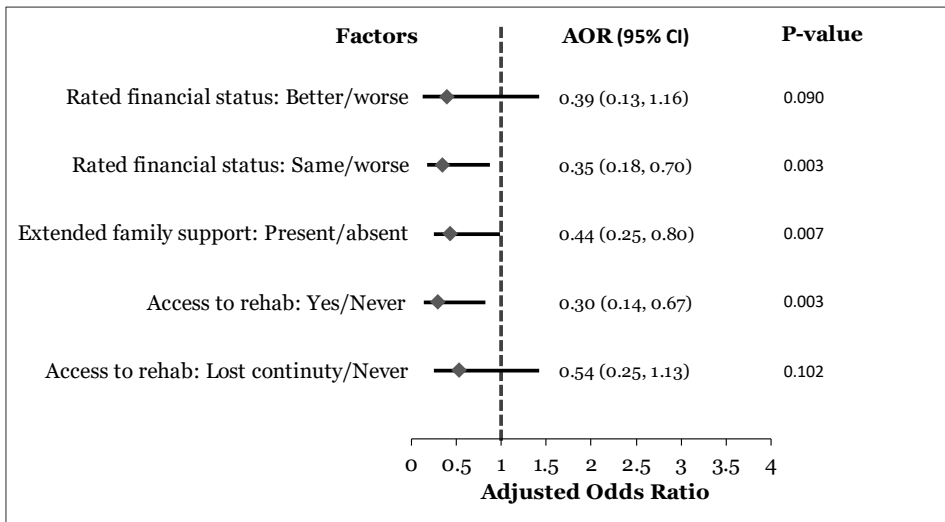


Figure 8: Multivariable regression analysis of factors associated with anxiety symptoms among carers

Figure 9 indicates a reduced likelihood of depression symptoms with extended family support, spousal support, and a monthly income of at least \$22.

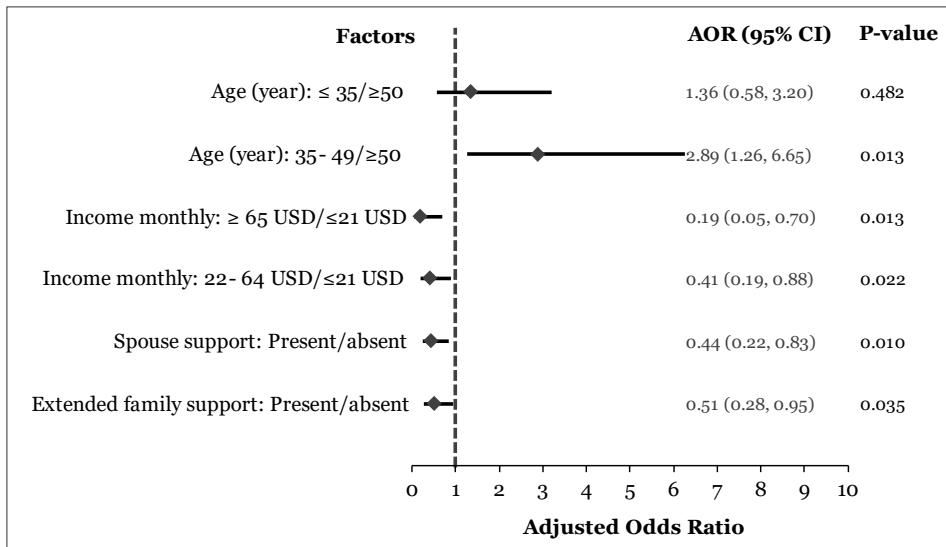


Figure 9: Multivariable regression analysis of factors associated with depression symptoms among carers

### Inclusion for adolescents, and young adults with physical disabilities

In Study IV, adolescents and young adults with physical disabilities expressed feeling partially integrated into society. This sense of marginalisation stemmed from both challenging family dynamics and societal barriers, which made them feel like outsiders. Participants faced significant obstacles in becoming fully integrated members of society. When considering their future, adolescents and young adults had a mixture of hopes, expectations, and fears.

Figure 11 illustrates a timeline perspective, showing how participants viewed their journey from present circumstances toward the future. The connection between "barriers to being part of society" and the "hope and uncertainty about the future" is highlighted, with schooling seen as a key factor in minimising these barriers.

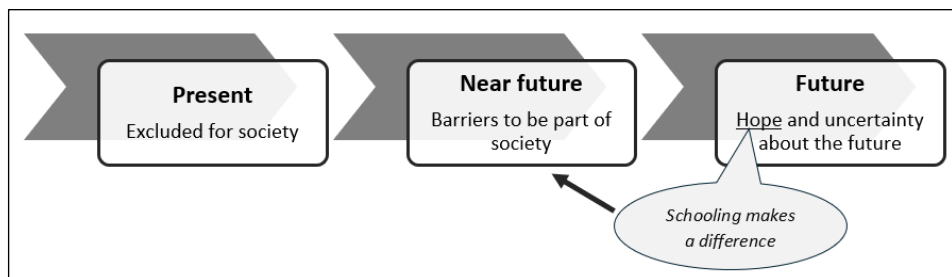


Figure 10: Timeline illustration of adolescents, and young adults experiences of societal inclusion

## 4. Discussion

### Contextual challenges

The ICF framework highlights contextual factors as either facilitators or barriers to functioning and life participation for young people with disabilities. These factors can be environmental, such as infrastructure or access to assistive devices, or personal, including aspects like self-image and perception [19]. The disabling social, and environmental challenges highlighted in this thesis can also be zoomed through the lens of both the social, and medical models of disability [2, 3, 19]. The thesis findings highlight difficult access to rehabilitation services, inadequate health insurance, poor societal norms and attitudes, and insufficient transportation systems. This interplay between impairments, day-to-day challenges relating to the contextual determinants underscores the biopsychosocial conceptualisation of disability [19].

The results from Study I highlight the limited availability, and accessibility of essential rehabilitation services in Tanzania. With facilities located far from primary healthcare settings, families encounter significant financial burdens due to costs of travelling to access rehabilitation services. The findings show that 24% of children, and adolescents with physical disabilities had never accessed rehabilitation in their lifetime. Consistently reports from other LMICs also highlight a similar shortage [67, 97, 125, 126]. Similar findings are further reported in a scoping review from SSA, which highlight that poor access is attributed to long distances to services, limited availability, and cost-related challenges [127-129]. Poor access to services in LMICs is due to inadequate transportation systems, and insufficient healthcare capacity. Additionally, rehabilitation often receives lower priority, with resources being allocated to more urgent health concerns like infectious diseases and maternal health. Fewer training capacities, leading to inadequate healthcare workforce, particularly in rehabilitation [127], can contribute to insufficient services. While alternative digital rehabilitation has the potential to reach remote populations, this approach is hindered by poor connectivity and limited technological literacy.

Also, the inadequacy of personnel for rehabilitation in primary healthcare in Tanzania further widens the accessibility gap [100]. Inadequate health personnel and resource for rehabilitation is highlighted in the world disability report [9], and other literature [10, 34, 127, 128, 130]. Poor access to essential care may discourage families of children and adolescents with physical disabilities from seeking the services. Enhancing the capacity for rehabilitation within primary care facilities is necessary [67, 70]. The WHO, UNICEF, and the UN 2030 SDGs all advocate for removing of barriers to essential services for young people with disabilities [19, 37, 71, 130-132]. However, healthcare systems in LMICs often lack the capacity to meet these demands [127], constrained by limited budgets and the dual challenge of managing both communicable and non-communicable diseases [10, 11, 37].

These care challenges are self-perpetuating, as shown by the limited access to health insurance in Study I. Similar to many SSA, health insurance coverage in general remains below 20%, a trend commonly seen in many LMICs. [133]. Low coverage is often linked to voluntary subscription schemes and low socioeconomic status [133, 134]. There is scarcity of data comparing coverage for young persons with disability globally. Azizatunnisa et al. [135], provide a snapshot showing that more than 80% of PWDs in HICs are covered by some form of health insurance. In middle-income countries, coverage ranges from 40% to 70%, while fewer than 40% of PWDs in low-income countries have health insurance [135]. This situation affects access to essential healthcare for the majority, including children, and exposes individuals to significant out-of-pocket healthcare expenses [68]. Compared to other LMICs, where health insurance coverage for general population ranges between 25% and 100%, Tanzania is still lagging towards achieving universal health coverage [136]. Children, and adolescents with physical disabilities typically use more health services than the general population due to their disability-related needs, hence poor insurance coverage imposes a significant financial burden. This situation excludes young people with disabilities from accessing essential health services, as it makes it difficult for families to rely on out-of-pocket expenditures.

Moreover, Tanzanian health insurance does not cover costs related to assistive devices, further burdening families financially. These barriers are further compounded when families live in rural areas, are unemployed, or work in the informal sector. These factors, combined with Tanzania's poverty threshold [134], lead to severe financial insecurity for families caring for children and adolescents with physical disabilities. The thesis findings align with previous research, which highlights the close relationship between poverty and disability [22]. Caring for young people with physical disabilities often prevents family members, especially carers, from having time to earn an income [137]. On the other hand, adolescents and young adults with disabilities may face limited opportunities for education and employment [138].

Findings from Study IV highlight numerous barriers experienced by adolescents, and young adult with physical disabilities in society. Similar, barriers have been highlighted by the UNICEF [22, 23, 34, 130]. Experiences show challenges related to infrastructure, such as limited classroom access and barriers to using toilets or stairs, which complicate wheelchair users' accessibility. Similar findings have been reported in other African settings, highlighting how these barriers contribute to late enrolment for children with disabilities [139]. Securing a specialised school environment suitable for children with severe physical impairments is complex and often incurs additional costs for families. While Tanzania advocates for inclusive education [34, 140], there is a need for the provision of specialised schooling environments to better accommodate these children. These findings are parallel to the UNICEF situation analysis in Tanzania which revealed a shortage of teachers



skilled in caring for children with special needs, as well as a lack of supportive learning equipment [34]. Outcome of these challenges, enrolment for children with disabilities remains significantly lower than that of children without disabilities [29, 130]. These barriers undermine the rights of children with disabilities to education free from discrimination and to equal access [5, 75, 96].

Another dimension highlighted by this thesis is the difficulty related to transportation. In Study II, participants reported challenges when travelling with a physically disabled child using public transport [141]. The unsuitability of public transport, along with the necessity of using private transport, which is often costly and unaffordable for many families, was emphasised. The Persons with Disabilities Act of 2010 in Tanzania clearly stipulates that the transportation system should be inclusive for PWDs [75, 96]. Transportation infrastructure remains a challenge in Tanzania. While public tricycles, known as "bajaji," may be useful in urban areas, access to this transport for children and adolescents with physical disabilities is not well documented. The severity of impairments, particularly in adolescents, can complicate access to public transport. Poor road infrastructure further exacerbates transportation challenges, especially for those in rural areas. A scoping review from low-income settings highlights similar difficulties [26]. Additionally, insufficient government funding for infrastructure may contribute to these transportation barriers.

### **Societal beliefs towards physical disabilities**

Findings from qualitative Studies II, and IV in this thesis reveal discriminatory attitudes within various layers of society, which are categorised as institutional and non-institutional. Shakespeare [3] describes these social barriers through the social model of disability, emphasizing how they exacerbate disabilities for individuals. Furthermore, the WHO and the UNCRPD emphasise that disability is brought about by the dynamic interaction between these social barriers and impairments [1, 2].

Institutional barriers, for example, are highlighted in Study II, where participants shared experiences of discrimination from healthcare providers. These experiences led some to avoid healthcare services, opting instead for managing treatment at home. One young mother, for instance, chose to care for her physically disabled daughter at home after a burn injury, fearing potential discrimination from healthcare providers [141]. Findings further highlights instances of verbal abuse from care providers. Similar negative experiences are reported by UNICEF [130], which impact care-seeking behaviours and increase the exclusion of young people with disabilities from society. In the Kilimanjaro region, similar findings are reported by McNally [68], where carers of children with disabilities experience isolation, stigma, and pity. Notably, discriminatory experiences are reported not only in LMICs [142, 143] but also in high-income countries, where carers of children with

disabilities face similar challenges [144]. Such behaviours often stem from a lack of understanding and empathy, highlighting the need for targeted awareness and sensitivity training among healthcare staff to ensure inclusive, respectful, and supportive care. Moreover, discrimination is likely to occur in schools, public places, healthcare facilities, and other settings, particularly in rural areas and for individuals with severe physical impairments.

Discriminatory attitudes were also encountered by participants during the national health insurance subscription process. Some reported being told that their children, referred to as “broken vehicles,” would not be insured. This discrimination violates the rights of children [2, 5] and contradicts Tanzania's 2010 persons with disabilities act [75, 96], which mandates that all individuals, including children with disabilities, have the right to accessible healthcare without discrimination. With health insurance coverage in Tanzania remaining below 25% (22.6% in this study), these social barriers further exacerbate socioeconomic inequalities for families of children with disabilities. Such institutionalised negative norms not only hinder access to healthcare but also increase out-of-pocket expenses for these families. To address these disparities, Tanzania’s health insurance policies must improve, expanding inclusion criteria to ensure coverage for children with disabilities, in line with the principles of equity and accessibility [145].

Another barrier identified was the exclusion of families from the Tanzania Social Action Fund (TASAF). Participants mentioned that subsidies were often given to people who needed them less, such as those who can work and face fewer challenges. TASAF is a government initiative aimed at supporting poor families. Including the families caring for children or adolescents with physical disabilities would greatly ease their financial strain. This exclusion highlights an important issue that needs to be addressed to ensure families of children with physical disabilities are not overlooked. Few studies have examined how effectively TASAF benefits are distributed [146], and there is a lack of transparency in its local implementation. More focus should be placed on including families caring for children and adolescents with physical disabilities in this support programme.

Non-institutional barriers, such as discrimination from the community and even close family members, lead to social exclusion of children with disabilities. This negatively affects the wellbeing of both the children and their carers. Similar findings have been reported in Moshi, Kilimanjaro, where mothers face stigma and negative beliefs towards their disabled children [68]. In Tanzania, these attitudes are often due to a lack of awareness about the rights and potential of young people with disabilities.

The thesis findings show that family members, particularly fathers, often abandon mothers due to misconceptions and misplaced blame, leading to significant

psychological and physical strain on mothers [67]. These mothers are left to care for children with disabilities without support, limiting their ability to contribute financially [27, 147-149]. Family-based discrimination, which is under-researched in Tanzania, is driven by misconceptions and lack of awareness. Addressing these social barriers would improve the wellbeing of both mothers and children. Similar attitudes are reported in a UNICEF report on care reform in Africa [132], highlighting a broader societal lack of awareness about disability.

Adolescents and young adults with physical disabilities reported experiencing discrimination, not only from their families but also from society at large. These harmful societal norms create significant barriers to inclusion, leaving these individuals feeling undervalued and sidelined. These findings highlight the need for public awareness intervention in Tanzania to address these social barriers. The challenges faced by adolescent with disabilities regarding transportation, accessibility, and social stigma, hinder a smooth transition from adolescence to adulthood, violating basic human rights. Similar exclusionary challenges are reported by UNICEF [22], underscoring societal barriers that prevent adolescents from reaching their full potential and enjoying their human rights.

#### **Adaptations to challenges and fulfilling family needs**

Study II shows that family needs are complex and go beyond the hierarchy suggested by Maslow's theory. Homogeneous findings have shown that human needs are interdependent and emerge concurrently [150]. Additional arguments suggest that meeting needs in a fixed order often misses the complex and connected nature of human needs. The hierarchical approach of fulfilling family needs doesn't fully reflect the changing priorities that families attempt in their daily basis.

The findings reveal that securing essentials like food and shelter is difficult for these families. Access to healthcare, financial stability, and a sense of safety are significantly affected. The lack of resources is linked to social and environmental barriers, with poverty adding to the difficulties [134]. For these families, achieving higher aspirations in life often remains a dream. Carers, especially, find it hard to socialise or earn an income. These burdens take a toll on the physical, social, and mental wellbeing of carers and their families, leading to worry, uncertainty about the future, hopelessness, and unhappiness.

Families' efforts to protect their wellbeing are reflected in both short-term adjustments, such as seeking alternative ways to meet needs, and avoidance strategies. Short-term adjustments like avoidance, as described by Abery [24], may offer temporary relief but can negatively affect overall wellbeing. For example, avoiding healthcare due to discrimination can worsen a child's condition and lead to higher healthcare costs. Long-term adaptation, in contrast, involves families accepting their situation and adjusting to the challenges over time.

The findings show that more than half of carers experience poor psychological wellbeing, with 42% showing symptoms of anxiety and 38% of depression. Similar trends of psychological burden is documented in LMICs settings where women are more affected [151, 152]. Parallel to the findings of this study, other studies have shown that poor psychological wellbeing is closely related to and often correlates with, anxiety and depression [109, 110, 114]. Support from family networks and a stable monthly income are associated with reduced symptoms and improved mental health. Family networks have been documented in other low-resource settings [153], offering crucial support to carers by providing temporary relief and short periods to earn income through informal work. Uninterrupted social connections also positively impact carers' psychological wellbeing, underlining the value of strong social support systems. Moreover, the wellbeing of children, including their access to essential care and school participation, positively influences carers' psychological wellbeing.

For children and adolescents with physical disabilities, various factors impact their inclusion in society. The findings of Study I reveal several comorbidities, including convulsions, joint spasticity, and contractures. Additionally, 24% of these children lack access to any rehabilitation services. School participation is low, with only 30% facing few or no difficulties in attending. These inclusion challenges underscore the impact of social and environmental barriers. The inadequacy or absence of essential services, as reported in other LMICs, can exacerbate these challenges [125]. Our findings acknowledge the nature of the impairments, yet emphasize the importance of accessible rehabilitation within Tanzania's primary healthcare system [100]. When impairments go unaddressed, especially in settings lacking early identification of disabilities, functional limitations may worsen, affecting life participation. According to Tanzania's Disability Policy (2004) [75] and the Persons with Disability Act of 2010 [96], these services should be readily accessible within primary healthcare facilities.

### **Methodological Considerations**

While this thesis provides valuable insights into the wellbeing of children and adolescents with physical impairments, as well as that of their carers and families, there are several methodological considerations to address. This thesis makes an inclusive attempt by describing the needs and challenges of an overlooked population in research. The use of both qualitative and quantitative findings enhances the strength of the thesis' conclusions and recommendations. This thesis has several limitations that should be considered when interpreting the findings.

The cross-sectional design is often associated with selection bias. Although the sampling technique incorporated elements of randomness when selecting potential wards for the survey, the selection of participants could have been affected by misinterpretation of the definition of physical disability. The researcher made efforts

to define physical disabilities according to the ICF and CRPD, which offer a broader approach to capturing specific 'physical' impairments. Additionally, the definition was contextualised and customised in the native language to ensure that no physical impairments were overlooked. Despite these efforts, the recruitment of survey participants may have missed some intended children and adolescents with physical disabilities in the sampled areas.

The survey involved ten-cell, hamlet, village, and ward leaders to compile a list of households known to have a child aged 2 to 18 years with a physical impairment. The initial identification of households was based on the definition provided by the researcher, and the leaders were not involved in screening for eligibility criteria. The research believes this approach is an exhaustive and comprehensive representation of the societal organisation. This procedure primarily captured young people with physical disabilities, while also including individuals with other impairments who were not part of the survey's intended focus. Table 5 summarises the trustworthiness for the qualitative studies in the lens of Lincoln and Guba's criteria for credibility, transferability, dependability and confirmability.

**Table 5: Trustworthiness of the qualitative Study II**

<b>Criteria</b>	<b>Strategy</b>	<b>Procedure to fulfil rigor</b>
<i>Credibility</i>	Prolonged engagement with study settings.	The researcher brings prior experience in community outreach and quantitative research in similar contexts, ensuring familiarity and trust-building
	Establishing researchers' autonomy.	A multidisciplinary research team, including experts in physiotherapy, epidemiology, health economics, reproductive health, and neurorehabilitation, enhances theoretical depth and exploratory capabilities.
	Regular debriefing.	Debriefings were conducted after each interview during data collection and analysis to ensure consistent reflection and refinement.
	Data collection credibility	A funnel approach in structuring the interview guide allowed flexibility, rapport-building, and cumulative data refinement. Interviews in the native language, followed by transcription, ensured authenticity and cultural relevance.
<i>Transferability</i>	Sampling techniques	The sampling technique considered a maximum variation.
	Data saturation	Saturation in the sense of concepts/information redundancy was reached during the interview. Analysis for grounded-theory sub-study and data collection went concurrently which enhanced us to see the emerging codes and theoretical saturation.
	Settings and participants' description	A detailed description of the study area and the socio-cultural and economic contexts has been provided in the methods section to facilitate transferability.
<i>Dependability</i>	Detailed description of study methods	Comprehensive documentation of data collection and interactive analysis processes enhances transparency.
	Data authenticity	Transcripts were reviewed against audio files for accuracy. Translations underwent review and random back-translation, with all quotations checked by bilingual members proficient in English and Swahili.
<i>Confirmability</i>	Triangulation	Using of quantitative studies during purposive sampling and utilising individual interviews with field observations. Triangulation of cultural and professional background of the research team.
	Reflexivity	Reflective memos were used throughout data collection and analysis. Remaining transparent and open regarding the researchers' background and influence that might have brought during data collection.








Reflexivity in qualitative methods is crucial, especially when considering power dynamics. In this study, the researcher, a male physiotherapist, interviewed only female participants in Study II, and adolescents and young adults in Study IV. This relationship may have been influenced by cultural and hierarchical power factors during the interviews. The researcher made efforts to be aware of these dynamics throughout the recruitment process, including informed consent, and during data collection. The informed consent process clearly communicated that the purpose of the research was purely academic and had no connection to routine care or services.

## Research dissemination


Several efforts, both locally and internationally, have been made to ensure that the research findings have implications for various sectors and stakeholders.

Locally the research findings have been shared with various stakeholders in child health, including rehabilitation in Tanzania. These dissemination efforts have fostered connections, dialogue, and networks that can serve as a foundation for current and future interventions. An example of this is highlighted by the ongoing discussions provoked by the research findings.

Reaching out from Tanzania

 To   Reply  Reply All  Forward  

Tue 3/11/2025 3:46 PM

 This sender mobilitycare2025@gmail.com is from outside your organization.


Dear Mr Swai  
Habari za leo.

I am writing to you from Tanzania. My husband and I have a small workshop where we are making wheel chairs for children especially this e with Cerebral Palsy, so we have an interest in better understanding the needs of disabled children. We are trying to establish an estimate of the need for for wheelchairs among children nationwide.

We have been reading your paper "Children and adolescents with physical disabilities: describing characteristics and disability- related needs in the Kilimanjaro region, north- eastern Tanzania – a cross- sectional survey". Thank you for this great work.

We have some questions if you don't mind ?:

1. The 212 children sampled are from a total population of how many ? You mention 126 villages. What can this tell his about the incidence of disability in the whole population ?
2. The type of disability quoted seems to be in different proportions to those reported elsewhere ? Unicef give



Disability Type	Percentage
1	1.5%
2	1.3%
3	1.2%

*Email dialogue with a potential stakeholder trying to find out more about how we could join hands in improving access to wheelchairs in Tanzania.*

Locally, the research findings have been presented at several academic forums involving physiotherapists and students, as well as at a local rehabilitation network conference organized in Arusha, Tanzania.

Internationally, the research findings will be presented at a World Congress for physiotherapists in Tokyo, Japan, which will be held in May 2025.



## 5. Conclusion and recommendations

### Conclusion

Children and adolescents with physical disabilities in northeastern Tanzania face significant challenges in school participation and experience considerable activity limitations in communication and self-care. Adolescents and young adults with physical disabilities experience marginalisation, which is intensified by societal barriers. The future for young people with physical disabilities in northeastern Tanzania is uncertain, and any hope could be strengthened by inclusive education. In addition to these difficulties in functioning, rehabilitation services are either poorly accessible or entirely absent at primary healthcare facilities, such as dispensaries and health centres. As a result, many children and adolescents with physical disabilities remain without any form of rehabilitation support or lose continuity of care. These issues significantly affect the wellbeing of families caring for these children. Parents and carers often struggle to meet basic needs while confronted with healthcare and financial burdens. These challenges not only strain family resources but also hinder family members from pursuing their personal aspirations and goals. Furthermore, poor societal norms and discrimination exacerbate the challenges and provision of care, leading to poor social and psychological wellbeing. In Kilimanjaro, many carers experience symptoms of anxiety and depression, further impacting their ability to provide care. However, sociocultural support, such as extended family networks, plays a vital role in helping families adapt to these challenges.

### Recommendations

#### *Recommendations for rehabilitation*

Strengthening rehabilitation services at dispensaries and health centres would significantly reduce costs on families, and improve accessibility, promoting service seek behaviour. To address this, I recommend:

1. An urgent revision of staffing levels for the Ministry of Health facilities. Revision of the staffing guideline should prioritise the allocation of physical, speech, and occupational therapists, along with others-related professional to the primary healthcare.
2. Due to the limited access to, and continuity of rehabilitation services for children and adolescents with physical disabilities, the Ministry of Health should incorporate the CBR model into primary healthcare. This integration would enhance the coordination of CBR services and, in collaboration with NGOs, would extend services to reach more families and children with disabilities across Tanzania.

3. Considering the poor psychological wellbeing observed among carers, CBR programs and routine services for children and adolescents with physical disabilities to include mental health care. This would foster holistic care by screening carers and/or parents, and connecting them to appropriate interventions, including counselling.
4. In Study I, a significant proportion of children and adolescents with physical disabilities were reported to have speech and communication challenges. Speech therapies should be integrated in the healthcare system. Additionally, the Tanzanian government through ministries of Health, and that of Education, Science and Technology should scale-up the training for speech and language therapists.

### ***Recommendation for promoting inclusion in society***

1. The Ministry of Education, Science, and Technology of Tanzania should consider allocating more resources, such as infrastructure, learning equipment, and human capital, to promote the inclusive education for children and adolescents with physical disabilities.
2. Significant social barriers highlighted in this thesis emphasize the need for public awareness campaigns. Multiple stakeholders, including the media, the Ministry of Education (via public and private schools), religious institutions, local government, and researchers in Tanzania, should collaborate to develop awareness content and establish reinforcement programs for future generations. Bridging gaps in public awareness and knowledge about the potential, rights, and inclusion of young people with disabilities will also help strengthen social support networks, including extended families. Additionally, involving organisations representing PWDs would strengthen the awareness campaigns. Incorporating awareness messages into primary to higher education training programmes would further contribute to fostering an inclusive society.

### ***Policy implications***

1. Policy alignment and revisions are essential to accommodate current practices and indicators for inclusion. The focus should be on addressing the underlying factors that contribute to the slow implementation of existing disability-specific policies and laws in Tanzania. Notable examples include the National Health Policy, the Disability Policy of 2004, the 2010 Persons with Disabilities Act, and the 2023 Tanzania National Health Insurance Act, all of which aim to promote the wellbeing of PWDs. These policies should be aligned to ensure coherence and effectiveness.
2. Furthermore, I recommend that the government put additional emphasis on monitoring and evaluating policy implementation to track progress, identify potential obstacles, and ensure that improvements are made and challenges addressed.

### ***Recommendations for health insurance***

- 1 National health insurance reforms should introduce customised tariffs for PWDs. These tailored tariffs should cover rehabilitation services, including Community-Based Rehabilitation (CBR) and assistive devices, with low subscription costs to ensure affordability for low-income families.

### ***Future research directions***

- 1 Research focusing on policy analysis, particularly regarding services for PWDs in Tanzania, is recommended to identify existing gaps and produce a concrete policy brief.
- 2 Expanding similar exploratory research to include adults and other types of disabilities is recommended to gain a comprehensive understanding of the disability challenges in Tanzania.
- 3 More qualitative studies are recommended to explore potential coping mechanisms, strategies, and resources for addressing the challenges faced by adolescents and young adults with physical disabilities in Tanzania.
- 4 An analytical study is recommended to evaluate the economic burden on carers of children and adolescents with physical disabilities in Tanzania.
- 5 In the absence of an early identification programme in Tanzania, we recommend the development of a disability register/database to improve the availability of reliable data for informing research.

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## Appendices

Appendix I: Applying ICF to the questionnaire	
<b>FUNCTIONAL IMPAIRMENTS</b>	<b>INCLUDED IN THE STUDY</b>
<b>Chapter 2: Sensory function and pain</b>	<b>Section 2: Part C: Functional impairments</b>
b210: Seeing functions (Sensing the presence of light and sensing the form, size, shape and colour of the visual stimuli).	Does the child have a vision impairment?
b230: Hearing functions (Sensing the presence of sounds and discriminating the location, pitch, loudness and quality of sounds).	Does the child have a hearing impairment?
<b>Chapter 3: Voices and speech</b>	
b310: Voice functions (Production quality of voice; functions of phonation, pitch, loudness, and other vocal qualities).	Does the child have speech difficulties?
<b>Chapter 4: Functions of cardiovascular, haematological and respiratory systems. Chapter 5: Functions of the digestive, metabolic and endocrine systems. Chapter 6: Genitourinary and reproductive function.</b>	<i>Not included</i>
<b>Chapter 7: Neuromusculoskeletal and movement-related functions</b>	
b710: Mobility of joint functions (Functions of the range and ease of movement of a joint)	Does the child have mobility impairment at any of her/his joints?
<b>Chapter 8: Functions of the skin and related structures</b>	Not included
<b>ACTIVITIES AND PARTICIPATION</b>	
<b>Chapter 1: Learning and applying knowledge</b>	Not included
<b>Chapter 2: General tasks and demands</b>	Not included
<b>Chapter 3: Communication</b>	
d310: Communicating with receiving-spoken-message	Can the child receive and understand verbal message?
d315: Communicating with receiving non-verbal message	Can the child receive and understand non-verbal message?
d330: Speaking	Can the child produce and communicate a verbal message?
d335: Producing non-verbal message	Can the child produce or communicate a non-verbal message?
<b>Chapter 4: Mobility</b>	
d410: Changing basic body positions (Changing body position from lying down, from squatting or kneeling, from sitting or standing, bending and shifting the body's centre of gravity).	Is the child able to change basic body positions?
d415: Maintaining a body position (Maintaining a lying, squatting, kneeling, sitting and standing position).	Is the child able to maintain a body position?
d420: Transferring oneself (Moving from one surface to another, such as sliding along a bench or moving from a bed to a chair, without changing body position).	Is the child able to transfer oneself?
d430: Lifting and carrying objects (Raising up an object or taking something from one place to another, such as when lifting a cup or toy, or carrying a box or a child from one room to another).	Is the child able to lift and carry objects?
d445: Hand and arm use	Is the child able to use hands and arm?

(Performing the coordinated actions required to move objects or to manipulate them by using hands and arms, such as when turning door handles or throwing or catching an object).

**d450: Walking**

Is the child able to walk?

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**Chapter 5: Selfcare**

**d510: Washing oneself**

(Washing and drying one's whole body, or body parts, using water and appropriate cleaning and drying materials or methods, such as bathing, showering, washing hands and feet, face and hair, and drying with a towel)

Is the child able to wash oneself (bathing, drying, washing hands)?

**d520: Caring for body parts**

(Looking after those parts of the body, such as skin, face, teeth, scalp, nails and genitals, that require more than washing and drying)

Is the child able to care for his/her body parts (brushing teeth, combing, grooming)?

**d530: Toileting**

(Planning and carrying out the elimination of human waste (urination and defecation), and cleaning oneself afterwards)

Is the child able to manage toileting on his/her own?

**d540: Dressing**

(Carrying out the coordinated actions and tasks of putting on and taking off clothes and footwear in sequence and in keeping with climatic and social conditions, such as by putting on, adjusting and removing shirts, skirts, blouses, pants, undergarments, saris, kimono, tights, hats, gloves, coats, shoes, boots, sandals and slippers)

Is the child able to put on his or her dress(ess)?

**d550: Eating**

(Carrying out the coordinated tasks and actions of eating food that has been served, bringing it to the mouth and consuming it in culturally acceptable ways, cutting or breaking food into pieces, opening bottles and cans, using eating implements, having meals, feasting or dining)

Is the child able to eat on his or her own?

**d560: Drinking**

(Taking hold of a drink, bringing it to the mouth, and consuming the drink in culturally acceptable ways, mixing, stirring and pouring liquids for drinking, opening bottles and cans, drinking through a straw or drinking running water such as from a tap or a spring; feeding from the breast)

Is the child able to drink on his or her own?

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**Chapter 6: Domestic life and household tasks**

**d 6402: Cleaning living area**

Can the child participate in cleaning the house? e.g. sweeping?

**d 6401: Cleaning cooking area and utensils**

Can the child participate in washing the dishes?

**d 6400: Washing and drying clothes and garments**

Can the child participate in washing clothes?

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**Chapter 7: interpersonal interactions and relationships**

**Chapter 8: Major life areas**

**d 820: School education**

Attending school (e.g. enrolment, informal education, vocational etc)

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**Chapter 9: Community, social and civic life**

**d 920: Recreation and leisure**

Playing with other children in the household  
Playing with other children in the neighbourhood e.g. few houses away or outside the house. (include simple games such as rede, ball throwing, hide and seek etc)

**d 910: Community life**

Is the child able to participate in community/social events e.g. ceremonies, gatherings

**d 930: Religion and spirituality**

Is the child able to participate in religious events or gatherings e.g. going to church/mosques

**d 950: Political life and citizenship**

Does the child have a birth certificate

(Having legal status as a citizen)

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## Appendix II: Semi-structured interview guide for Study II

### INTERVIEW GUIDE

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#### Questions

1. Can you talk about the social services at your area?

#### *Probing questions:*

- 1.1. *Social services (transportation, schooling, religious)*
- 1.2. *Healthcare services (hospital care)*
- 1.3. *Other services (religious)*
- 1.4. *Caring for old people or sick people or people living with disability.*
2. Can you talk about the family structure in your society?
3. Can you now talk about the family needs the way you understand it?
4. Can you talk about your experience with the family needs required specifically for your child with disability (insert name)?
  - 4.1. *Healthcare related needs related to caring for the child.*
  - 4.2. *Social needs (including access to education).*
  - 4.3. *Any other additional needs you have encountered in caring for the child as a family?*
5. What challenges have you experienced as a family relating to the needs of caring for your child with disability?

#### *Probing question:*

- 5.1. *Tell us about challenges relating to societal structure (transportation, access to social services)*
- 5.2. *Tell us about challenges relating to the health care system (access to services e.g. health insurance, medications, rehabilitation, assistive devices).*
- 5.3. *Was it a challenge to decide about having more children?*
- 5.4. *Has it been a challenge on family relationships?*
- 5.5. *Has it been a challenge with marital relationship (including sexual contact?)*
- 5.6. *Has it been a challenge with caring for the other children?*
6. How is it to live with a disabled child in your neighbourhood?
7. How is it to live with a disabled child in your family?
8. How does the family manage with these challenges?

#### *Probing questions:*

- 8.1. *Can you talk about the family resources you have for supporting the care of your child?*
- 8.2. *Can you talk about family structure and how it supports the care?*
- 8.3. *Have you experienced any support from the neighbourhood?*
- 8.4. *Have you experienced any support from NGOs including religious organisations?*
- 8.5. *Have you experienced any support from the Government (local/central).*
9. Are there any aspect of family needs or challenges we have not touched upon?

Thank you for your time and participation in this interview.

---

**INTRODUCTION**

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1. How would you describe the current situation regarding living conditions here in Tanzania?

2. In general, how do you perceive the parenting of children here in Tanzania?

*Probes:*

*How is parenting a child with a disability different?*

*How does parenting in rural areas compare to in urban areas?*

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**DISABILITY AND ADOLESCENCE**

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3. How do you view the situation of adolescents with disabilities?

*Probes:*

*How would you describe the situation in rural areas compared to urban areas?*

*How would you describe your own situation?*

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**EXPERIENCES OF AVAILABLE OPPORTUNITIES**

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4. Can you discuss the opportunities that are available to or designated for adolescents with physical disabilities in Tanzania?

*Probes:*

*What can you say about educational opportunities?*

*Can you elaborate on employment opportunities?*

*How have you experienced government-provided opportunities, either in general or in specific situations?*

*Can you expand on and share more about these matters?*

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**DIFFERENT ASPECTS OF INCLUSION**

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5. Can you talk about whether you have felt a part of society, as far as you can remember, from your childhood until now? (Feel free to ask if you don't understand the question.)

*Probes:*

*Can you elaborate on your personal situation and experiences?*

*Have you felt included in government programmes, national opportunities, and public affairs such as vaccination programmes, politics, sports, and employment opportunities?*

*How have you been treated when accessing services, for example shops, hospitals, churches, and local government offices, in terms of inclusion?*

*How have you experienced reproductive health services as an adolescent/young adult with a physical disability?*

*What has your experience been using transportation services, such as motor vehicles or public transportation?*

*Could you talk more about your interpersonal relationships, for example with your peers, teachers, and others in your social circle?*

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**FAMILY SITUATION**

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6. Can you talk about how you've felt about being a part of your family?

*Probes:*

*Could you share some positive and negative experiences you've had with your family?*

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*How would you describe the situation in your family, including your home environment, the support you receive, and your relationships with both your immediate and extended family members?*

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**PERSONAL EXPERIENCES**

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7. Can you describe what your day-to-day life is like?

*Probes:*

*What are the things you find most interesting in your daily routine?*

*How do you think people perceive you, and what are your expectations in this regard?*

*Could you tell me more about your dreams for the future, such as your career plans?*

*How do you see yourself achieving them?*

*What are your thoughts on intimacy and sexual relationships? Do you have any future plans regarding having your own family?*

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**CLOSING**

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8. You are welcome to ask or share anything that we have not covered or that you were expecting to discuss with us. Thank you for your time.

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## Appendix IV: The WHO-5 Wellbeing Index.

s/n	<p>For each of the five statements, please choose the answer that is closest to how you have been feeling over the <b>LAST TWO WEEKS</b>  <i>(Kwa maswali yafuatayo, tutazungumza kuhusu hisia zako kwa muda wa wiki mbili zilizopita.</i>  <b>KWA WIKI MBILI ZILIZOPITA, ni mara ngapi:</b></p>	<p>All of the time  <i>(Kila Wakati)</i></p>	<p>Most of the time  <i>(Maru nyingi)</i></p>	<p>More than half of the time  <i>(Zaidi ya nusu ya wakati)</i></p>	<p>Less than half of the time  <i>(Chini ya nusu ya wakati)</i></p>	<p>Some of the time  <i>(Wakati mwingine)</i></p>	<p>At no time  <i>(Hakuna wakati)</i></p>
		(5)	(4)	(3)	(2)	(1)	(0)
1	<p>I have felt cheerful and in good spirits.  <i>(Umejibisi kuwa mchangamfu na mwenye furaha?)</i></p>						
2	<p>I have felt calm and relaxed.  <i>(Umejibisi kuwa mtulivu na aliye pumzika)</i></p>						
3	<p>I have felt active and vigorous.  <i>(Umejibisi kuchangamka na mwenye nguvu?)</i></p>						
4	<p>I have woken up feeling fresh and rested.  <i>(Umeamka ukijihisi mvepesi na aliye pumzika?)</i></p>						
5	<p>My daily life has been filled with things that interest me. <i>(Maisha yako ya kila siku yamejaa vitu vinavyokufurahisha?)</i></p>						



## Appendix V: The Hopkins Symptoms Checklist – 25 (HSCL-25)

s/n	How much have the following symptoms bothered you during the <b>PAST MONTH?</b>	Je katika <b>MWEZI ULIOPITA</b> ikiwemo LEO ni kwa kiasi gani dalili zifuatazo zimekusumbua?	Not at all	A little	Quite a bit	Extremely
			(Hakuna)	(Kidogo)	(Kiasi)	(Sana)
			(1)	(2)	(3)	(4)
1	Sudden fear for no reason	Wasiwasi wa ghafla bila sababu				
2	Feeling fearful	Kuhisi woga				
3	Faintness, dizziness, or weakness	Kupoteza fahamu, kizunguzungu au kukosa nguvu mwilini				
4	Nervousness or shakiness inside	Hofu au kutetemeka ndani				
5	Heart pounding or racing	Mapigo ya moyo kupiga kwa nguvu au kwenda mbio				
6	Trembling	Kutetemeka				
7	Feeling tense or keyed up	Kujisikia umekakamaa au una wasiwasi mwingi				
8	Headaches	Kichwa kuuma				
9	Spells of terror or panic	Vipindi vya hofukuu au kiwewe/ wasiwasi mkubwa				
10	Feeling restless, unable to sit still	Hisia za kutokutulia, kukaa sehemu moja				
11	Feeling low in energy or slowed down	Kujisikia kukosa nguvu au uvivu				
12	Blaming yourself for things	Kujilaumu mwenyewe kuhusiana na mambo Fulani				
13	Crying easily	Mwepesi kulia				
14	Loss of sexual interest or pleasure	Kukosa hamu ya mapenzi au starehe				
15	Poor appetite	Kukosa hamu ya kula				
16	Difficulty falling asleep, staying asleep	Kushindwa kupata usingizi, au kuendelea kuwa usingizini				
17	Feeling hopeless about the future	Kukosa matumaini kuhusian ana siku zijazo				
18	Feeling blue	Kuhisi huzuni				
19	Feeling lonely	Kujihisi mpweke				
20	Feeling trapped or caught	Mawazo ya kuwa umefungiwa au umekamatwa				
21	Worrying too much about things	Kuwa na wasiwasi sana kuhusiana na mambo				
22	Feeling no interest in things	Kujisikia kutokuwa na hamu na kitu chochote (vitu ambavyo ni muhimu kwako).				

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23	Thoughts of ending your life	Mawazo ya kukatisha uhai wako
24	Feeling everything is an effort	Kujisikia hali ya kujilazimisha ili kuweza kufanya kitu chochote.
25	Feelings of worthlessness	Hisia za kutokuwa na thamani

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