

# A Report of a National Disability Situation Analysis Ministry of Social Development Government of Lesotho December 15, 2019





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# **List of Acronyms**

ABC All Basotho Convention

BEDCO Basotho Enterprise and Development Corporation

CBR Community-Based Rehabilitation
CDC Centers for Disease Control

CEDAW Convention on the Elimination of All Forms of Discrimination Against Women

CGPU Child and Gender Protection Unit

CSO Civil Society Organization

CRPD Convention on the Rights of Persons with Disabilities

DAC Development Assistance Committee
ECCD Early Childhood Care and Development
EMIS Education Management Information System

FDG Focus Group Discussion

DPO Disabled Persons Organization

IDAL Intellectual Disability Association of Lesotho

IDP Inclusive Development Partners
ILO International Labour Organization

JAD Jot-a-Dot Portable Brailler

JICA Japanese International Cooperation Agency

KII Key Informant Interview

LDHS Lesotho Demographic and Health Surveys

LNAPD Lesotho National Association of Physical Disabilities

LNFOD Lesotho National Federation of the Disabled

LNLVIP Lesotho National League of Visually Impaired Persons

LSL Lesotho Sign Language
M&E Monitoring and Evaluation
MB Pro Mountbatten Pro Brailler

MOES Ministry of Education and Science
MOET Ministry of Education and Training
MOHSW Ministry of Health and Social Welfare

MOJ Ministry of Justice, Human Rights, and Correctional Services

MOSD Ministry of Social Development MOWT Ministry of Works and Transport

NADL National Association of the Deaf in Lesotho NDRP National Disability and Rehabilitation Policy

NGO Non-governmental Organization

NISSA National Information System for Social Assistance

OECD Organisation for Economic Cooperation and Development

PWD Persons with Disabilities

SADC South African Development Community

SDG Sustainable Development Goals

SINTEF Stiftelsen for industriell og teknisk forskning

SRH Sexual Reproductive Health
STI Sexually Transmitted Infection

TVET Technical/Vocational Education and Training

TWG Technical Working Group

UNCRPD United Nations Committee on the Rights of Persons with Disabilities UNESCO United Nations Educational, Scientific, and Cultural Organization

UNFPA United Nations Population Fund UNICEF United Nations Children's Fund WCG Washington Consulting Group WASH Water, Sanitation, and Hygiene WHO World Health Organization

## 1. Executive Summary

The situation of persons with disabilities has recently drawn attention worldwide. The enacting of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006) and subsequent ratifying by over 180 countries solidified international commitments to the rights of this population. As a result, many countries are assessing their current policies and services to determine how they can better align with the CRPD and provide fully inclusive services to men, women, adolescents, children and young people with disabilities. Lesotho, a ratifying country, has strong advocacy and governmental support to enhance the access to services and rights of persons with disabilities and looks for opportunities to strengthen existing services as well as fill any gaps in support.

The research team at Inclusive Development Partners (IDP) worked closely with the Ministry of Social Development (MOSD) with the support from United Nations Populations Fund (UNFPA) United Nations Children's Fund (UNICEF), Sentebale, and LNFOD (members of the Technical Working Group or TWG) along with relevant stakeholders to conduct a national disability situation analysis that provides up-to-date information on the current social, economic, and human rights status of persons with disabilities. The purpose of the Situation Analysis is to understand the situation of persons with disabilities and to identify the key-duty bearers responsible for upholding the rights of persons with disabilities. This includes recognizing that services needed to address how disability may impact persons with disabilities differently based upon their age and other characteristics (such as gender, rural status, etc.). The findings and recommendations will inform the future work of the TWG and the design of programs and policies targeting persons with disabilities.

The report is comprised of three main sources of information:

- 1. International perspectives (drawing upon guidance from the CRPD and other international proclamations and treaties as well as published research).
- 2. Lesotho-specific considerations (such as existing laws, publications from programs, etc.).
- 3. Data from field interviews (further informing each section of this report).

In total, the team reviewed 88 documents and conducted 32 interviews with 131 stakeholders and conducted one validation workshop attended by 50 stakeholders. The report itself is organized into four major sections: 1) Introduction, 2) Background, 3) Barriers to Inclusion, and 4) Situation of Persons with Disabilities. The Situation of Persons with Disabilities section presents the main findings of the report, which are followed by Recommendations and Conclusions. Through the extensive review of literature and intensive interviews in the field, the below findings and recommendations emerged and are highlighted in Figure 1 as well as in detail in sections 5 and 6.

**Figure 1: Report Findings and Recommendations** 

# Findings

#### Recommendations

#### 1. Legal Framework and Policy

Lesotho's Disability Bill has gained political support but is not yet signed into Law. The law's likely passage in 2020 will allow for better alignment with CRPD as well as legal enforcement of the rights of persons with disabilities.

Assuming the Bill will soon be passed into law, begin immediate work on implementing and reporting on CRPD and establishment of a National Disability Advisory Council to provide oversight and advice on implementation of the law.

#### 2. Community Living

Adults and children with disabilities face isolation and discrimination in home communities. New institutions run by nongovernmental organizations are emerging in Lesotho, but there is currently no standard of care provisions or oversight by government ensure quality service delivery. Government financial support of such institutions misaligns with the aims of the CRPD.

- e Establish systems of community sensitization, early support for families, and early intervention for young children with disabilities in order to align with community living standards outlined in the CRPD and implemented by MOSD and MOHSD.
- Establish MOSD standards for community living for children with disabilities and end subventions for organizations that threaten standards.
- Establish care norms, staffing expectations, and transition expectations for all non-governmental institutions, homes, and centers for children with disabilities that operate in Lesotho.
- Maintain current community living expectations for adults but improve conditions for livelihoods and political participation.

#### 3. Education

Lesotho's recently adopted inclusive education policy provides a framework for upholding the educational rights of children with disabilities, but these children are  MOET, MOSD, and MOH to incorporate inclusive-education pedagogies into preservice education programs in Lesotho and focus in-service education efforts on under-enrolled in Early Childhood Care and Development (ECCD) programs and little data exists on school-aged children beyond enrollment.

early childhood centers, daycares, and creches to support early identification, community outreach, and development of socialization and learning opportunities for children with disabilities (as per national ECCD Strategy).

 MOET and the Exams Council to develop data collection measures to ensure children with disabilities are receiving quality education and are benefiting from inclusive education. In order to ensure outcomes data is valid, learning and testing accommodations must be in place.

#### 4. Employment

The majority of persons with disabilities in Lesotho are unemployed, and most individuals with disabilities have not yet benefited from government services that support short-term employment. Overall, there are no quotas or tax incentives to promote hiring of persons with disabilities. Entrepreneurship opportunities are present, and when coupled with social protection and access to work, may provide a range of options for persons with disabilities.

- Ensure all government-supported employment programs are inclusive and promote the active participation of persons with disabilities through mandatory hiring quotas of persons with disabilities in government offices and programs (MOSD, MOWT, Local Government).
- Create inclusive Technical Vocational and Educational Training (TVET) by merging MOSD habilitation into inclusive TVET centers (MOES and MOSD).
- Develop disability-targeted interventions to address the high unemployment rates, such as tax incentives for hiring of persons with disabilities in private firms (Parliament, MOSD).
- Expand entrepreneur training opportunities for persons with disabilities (LNFOD, MOSD).

#### 5. Gender-based Violence and Abuse

Instances of sexual violence against girls and physical violence against boys and girls is high in Lesotho. Stakeholders report that instances may be even higher for children and women with disabilities, who face communication barriers in legal and health systems.

- Mainstream disability issues and awareness into existing gender-based violence prevention programming (Ministry of Gender, Youth, Sports, and Recreation MGYSR).
- Ensure that sign language and tactile sign language interpretation options are always available for testimony related to gender-based violence in courts (MOJ, MOSD).

#### 6. Health

Stakeholders cited a series of lifelong gaps that, according to interview data, lead to a cumulative impact of disability across the lifespan. These impacts are exacerbated by lack of available resources, personnel, and equipment.

- Commit resources to early outreach, identification, parent training, and intervention related to disability (MOH and MOSD).
- Commit funds to training or hiring sign language and tactile sign language interpreters who can professionally interpret at all government hospitals (MOH).
- Evaluate and create inclusive sexual reproductive health materials in order to provide adequate information to persons with disabilities (MOES, MOH, MOSD).

#### 7. Political Participation

Lesotho has made recent changes to include persons with disabilities in national elections as well as supported participation in political parties. However, participation and leadership in local government remains a challenge.

- Remove barriers for persons with intellectual disability to vote and continue to support other inclusive programs at the national level (Lesotho Independent Election Commission, Parliament, LNFOD, MOSD).
- Fund (MOSD) and develop (LNFOD) electoral and leadership training for persons with disabilities to ensure participation and contribution to local and

national government.

#### 8. Social Protection

Lesotho currently has three mechanisms for social protection (Public Assistance in Cash, Child Grants, and bursaries). Persons with disabilities generally view Lesotho's social protections support as insufficient. Additional expenses related to disability necessitate additional supplements. Accurate identification data is needed—through National Information System for Social Assistance (NISSA) or other sources—to facilitate social protection.

- Analyze current NISSA data on disability to determine if incidence of disability identified in NISSA aligns with global norms. If it does not, include Washington Group questions in household surveys to more accurately identify disability incidence (MOSD).
- Establish a targeted disability-specific social protection fund that is proportionately aligned with other social protection funds. This fund will offset additional costs of access to services and equipment above and beyond existing social protection.

The situation of persons with disabilities in Lesotho is complex, but when analyzed through an inclusive development framework, it allows concrete policy and programming measures to be identified. Lesotho's development relies on the contributions of all Basotho and non-Basotho<sup>1</sup> residing in the country. Inclusive development for persons with disabilities will require policy and resource inputs, along with a recognition of the specific rights required by the CRPD (such as accessible environments, communication accessibility, etc.). Such inputs, coupled with continued commitment to social models of disability that focus on barrier removal and service development, should produce positive social and economic impacts for Lesotho.

# 2. Introduction and Conceptual Framework

The rights of persons with disabilities have become a central priority of nations worldwide. Since its inception in 2006, 180 countries have ratified the Convention on the Rights of Persons with Disabilities (CRPD), including Lesotho. An additional 96 countries have ratified the Optional Protocol, which establishes an individual complaint mechanism for the CRPD (United Nations Department of Economic and Social Affairs, n.d.). Lesotho's Government signed and ratified the treaty but has not yet signed the Optional Protocol (United Nations Department of Social and Economic Affairs, n.d.). The human rights framework outlined by the CRPD requires persons with disabilities not only participate but contribute to economic and social development in their countries. In order to do this, nations must commit policy, resources, and social structures to ensure all people experience equal opportunities.

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<sup>&</sup>lt;sup>1</sup> In Lesotho, 99.7% of people identify as "Mosotho" (or the plural, "Basotho"). The term is used broadly to define all people who are ethnically, linguistically, and nationally of Lesotho. "Non-Basotho" refers primarily to international partners and others within the country who contribute to its development.

This report's main objective is to identify the opportunities and gaps for societal inclusion, the upholding of human rights, and the social and economic development by and for persons with disabilities in Lesotho. The report will address these issues from both international perspectives (drawing upon guidance from the CRPD and other international proclamations and treaties) and Lesotho-specific considerations (such as existing laws, programs, and guidance provided in stakeholder interviews).

#### 2.1 International/National Conceptual Framework

To understand how human rights are defined, it is important to reference the CRPD, which outlines the various societal rights expected by signatories. Specifically, the CRPD is relevant because it is disability-focused and recognizes that "human rights are about promoting human rights for all...[and]...may also be about delving deeply into issues of identity, survival, and dignity of particular groups" (Mégret, 2008, p. 496). This comparative analysis determines how actors (policy makers, civil society organization, community members, etc.) in Lesotho are upholding the spirit and requirements of the CRPD and how actors have not.

A second conceptual framework for this report is "inclusive development." Inclusive development considers all aspects of economic, social, and political life in a particular country and requires that *all* persons have the opportunity to engage in such activities. Hickey, Sen, and Bukenya (2015), however, warn that mere participation is not adequate for such engagement. Rather, inclusive development requires equitable *representation* to ensure:

Social and material benefits are equitably distributed across divides within societies, across income groups, genders, ethnicities, religious groups, and others. These benefits necessarily comprise not only economic and material gains but enhanced well-being and capabilities as well as social and political empowerment being widely experienced. (Hickey, Sen, & Bukenya, 2015, p. 5).

For persons with disabilities in Lesotho, human rights commitments and inclusive development will require a combination of legal protections, political representation, social protection policies, accessibility standards, quality education, and economic opportunities. This Situation Analysis provides an overview of opportunities in the Government of Lesotho by investigating current service infrastructure, policies, services, and attitudes. The information in the report aims to provide concrete information to the Government of Lesotho and non-governmental organizations as they plan legislation and activities for 2020 and beyond.

#### 2.2 Methodology

The methods for accomplishing the aims of this report fall into three main areas: 1) comprehensive review of literature, 2) field-based interviews, and 3) conceptual validation. These methods are described below in more detail.

#### **Comprehensive Literature Review (Desk Review)**

The research team conducted a comprehensive literature review of health and demographic data, literature (academic and grey literature), and other contextual information surrounding

the social, economic, political, and health context of disability in Lesotho. The systematic literature review used NVivo Research Software for coding and analysis. Systematic desk reviews of research shed light on which interventions were adopted, resisted, or ignored in Lesotho as well as their effectiveness on the lives of persons with disabilities. For this study, researchers used electronic databases such as ProQuest, PsychInfo, JSTOR, Google Scholar, and EBSCOHOST. In addition, the research team focused on grey literature such as newsletters, NGO reports, and unpublished Ministry documents. A total of 88 international and national documents were reviewed as part of this study.

#### **Stakeholder Interviews**

A "systems change" is an intentional process designed to alter the status quo by shifting the function or structure of an identified system with purposeful interventions. However, to change the system, its stakeholders first needs to understand the system. Mapping the actors in the system and their relationships with one another is a useful exercise to create a common understanding of what's "in", and "out", of the system. This mapping informs the evaluation team of key stakeholders, processes, and institutions including government officials, Ministries, local NGOs and key disabled persons organizations (DPOs) that should be part of the analysis.

In late July and early August of 2019, IDP's local consultant and technical expert mapped a system to identify and develop a list of key-duty bearers responsible for upholding the rights of persons with disabilities, including their traditional roles and responsibilities. Follow-up visits by the national consultant occurred in late August and mid-September of 2019. These interviews helped to identify challenges and opportunities related to inclusive development for persons with disabilities in Lesotho. Annex D provides an overview of all the interviews that took place over the course of the project period. This annex provides information on the types of interviews as well as the specific stakeholders involved. Approximately half of the interviews involved individuals with professional associations with disability-related opportunities and challenges, lived experience with disabilities, or both.

In late July and August, IDP conducted field-based interviews with stakeholders in Leribe and Maseru districts. The team conducted follow-up interviews in late August in the Qacha's Nek and Thaba Tseka districts by the national consultant. In total, 32 interviews were conducted with 131 stakeholders. Figure 2 provides additional details on the interviews that took place as part of this situational analysis.

**Figure 2: Interviewee Overview** 

Affiliation or Demographic Overview	Male	Female
Adults with Disabilities in Communities or Rehabilitation Centers		24
Parents of Children with Disabilities		9
Vocational or Rehabilitation Centre Training Staff/Administrators		7
Organizations of Persons with Disabilities Representatives		13
Lesotho Government Ministries (Education, Health, Social	3	11
Development)		
Education Representatives (Schools for Children)		5
Hospital Personnel (Therapists)		2
United Nations Population Fund		1

International Non-governmental Organizations (Development)	1	2
Total	57	74

IDP used the Process Model for Assessment Design (Chatterji, 2003) to develop both the key informant interview (KII) and focus group discussion (FGD) scripts (i.e. a series of interview questions). This model is comprised of four phases which include 1) Background and Purpose, 2) Assessment Specification, 3) Choice of Assessment or New Assessment Design,<sup>2</sup> and 4) Content Validation. The literature review directly designed the data collection instruments (KII and FGD scripts) through the development of domains and indicators. These KII and FGD took place within four districts selected as part of this analysis. An illustration of this process is outlined below.

#### 1. Identify "whom" to assess (Target Population):

Key stakeholders relevant to promoting, protecting, and ensuring the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promoting respect for their inherent dignity (as defined under the Convention on the Rights of Persons with Disabilities) in Lesotho.

Sample population: The national study was conducted in the Maseru, ThabaTseka, Qacha's Nek, and Leribe districts. The systematic literature review informed the stakeholder selection and included government officials, civil society organizations (transnational and Lesotho-based), persons with disabilities and their families, and employees of government service organizations such as schools, clinics, and economic development units.

#### 2. Identify "what" to assess (Construct):

The current situation of persons with disabilities in Lesotho with respect to their human rights and fundamental freedoms as outlined by the CRPD.

#### 3. Identify "why" to assess (Purpose):

The purpose of this review is to establish and present a clear, detailed, and realistic picture of the opportunities, resources, challenges, and barriers related to disability in Lesotho. In addition, this report seeks to outline priorities for strategic planning that are aligned with the CRPD, CRC, and CDAW; to identify key-duty bearers; and to develop and present a framework for measuring Lesotho's progress as compared to international standards such as UNCRPD. The over-arching societal aim of these activities is to improve the inclusion of persons with disabilities in all aspects of Lesotho society.

#### **Data Validation and Finalization of Report**

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<sup>&</sup>lt;sup>2</sup> The research team will review and build upon existing classroom/school-based assessment tools currently being used in Ghana (Learning Curriculum, ASER scores, etc.) as well as available teacher training guidance, manuals, and children workbooks using an inclusive-education lens.

In November of 2019, IDP held a final series of meetings and workshops to share the draft report with relevant stakeholders. The validation process included individual meetings with UNFPA and LNFOD to discuss overall feedback on the report and recommendations for finalization. On Friday, 29 November, a one-day workshop was hosted at the Avani Maseru Hotel. The workshop drew 50 participants from a variety of governmental, civil society. religious, and advocacy organizations. The workshop was structured in an interactive way and facilitated by the international consultant. Participants were given the opportunity to review main findings and recommendations, then evaluate them on: 1) the relevance of recommendations to Lesotho; 2) the potential of the recommendation for creating change; 3) the cost-effectiveness of the recommendation; 4) the impact that might be felt from specific recommendations: and 5) the sustainability of recommendations.<sup>3</sup> In total, 11 pages of notes were compiled from the meeting. Some notes affirmed the findings and recommendations while others suggested new directions. All recommendations from stakeholders incorporated into final version of the report where available data supported the recommendation. In places where available data and recommendations contradicted, notes on future data collection directions are noted in this report.

# 3. Background

Lesotho is geographically located entirely within the Republic of South Africa's borders. According to the 2016 Census, Lesotho has a population of approximately 2 million people (Lesotho Bureau of Statistics, 2016). Lesotho faces great economic challenges with more than half of the country's population estimated to be below the national poverty line (Oxford Poverty and Human Development Initiative, 2017). The prevalence of individuals who are considered to be very poor has increased from 29.1% in 2002-03 to approximately 35% in 2014-2015 with the poorest individuals living in rural areas (World Bank, 2015). Lesotho's position as a landlocked country within South Africa may explain many of the economic challenges the country faces. At the same time, its unique geography has created economic opportunities such as the sale of water to South Africa and recent mineral discoveries. Similarly, while many of the country's remote villages face challenges to access electricity and reliable pumped water, the same geographies have created opportunities for close extended family networks and support systems.

#### 3.1 Historical Background

Lesotho's history in regard to disability policy and services is unique. Lesotho's status as a primarily agricultural nation from the early 1800s under the rule of King Moshoeshoe I meant that persons with disabilities were scattered throughout small communities across the land and were either included in regular community activities or cared for by families. Education, at the time, was traditional and focused on practical activities for adulthood for males and females such as agriculture, housebuilding, hunting, and cooking (Lye & Murray, 1980). There is no historical mention of who may or may not have been included in such traditional education activities, but the community expected all able males and females to participate in gender-specific education. No published research exists on how or if children with disabilities

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<sup>&</sup>lt;sup>3</sup> These discussion points were drawn from the Organisation for Economic Cooperation and Development (OECD) Assistance Committee (DAC) Evaluation Guidelines. See <a href="https://www.oecd.org/dac/evaluation/daccriteriaforevaluatingdevelopmentassistance.htm">https://www.oecd.org/dac/evaluation/daccriteriaforevaluatingdevelopmentassistance.htm</a>

participated in traditional activities, but it is likely that participation relied on the ability of children to independently complete activities taught (homebuilding, cooking, farming, etc.).

In the 1880s, Dutch expansion in South Africa created a scenario where the then elderly King Moshoeshoe I cooperated with French missionaries as a way to both slow Dutch influence in his domain and engage Basotho with the broader world. French missionaries brought formal schooling with curriculum and buildings. Later, British missionaries followed suit and established a variety of schools. By the late 1880s, Lesotho was a colonial protectorate of Great Britain and followed British policies in relation to social services (Lye & Murray, 1980). Until Lesotho's independence in 1966 and onward into the 1990s, missionary organizations and churches ran education, including education and programming for children with disabilities. Historically, disability was primarily addressed through religious organizations that viewed persons with disabilities as beneficiaries of religious-based charitable acts or through extended family support networks without any formal services.

The practice of mission-run schools and social services continued throughout much of Lesotho's history even after independence. However, as Lesotho's government began to take over the management of schools, the country established a rights-based focus on education for children with disabilities (Mariga & Phachaka, 1993). From the time of its independence in 1966 to the early 2000s, Lesotho's government gradually disentangled itself from charitable social services to create its own social protection policies and government services. A key point in this change was in 1987, when King Moshoeshoe II's social organization *Hlokomela bana* (care for children) charged Lesotho's parliamentary government with creating a plan for the education of children with disabilities in its country (Mariga & Phachaka, 1993). Lesotho's government, in collaboration with external advisors, concluded that inclusive services were the most cost effective given the dispersed population of its country and the most aligned with the nation's extended family and caretaking traditions (Csapo, 1987).

#### 3.2 Definition of Disability in Lesotho

Disability is a natural part of the human condition. However, as disability is complex, dynamic, and multidimensional, defining disability can be a challenge in many circumstances (World Health Organization, 2011). This challenge can be exacerbated because definitions of disability can vary significantly by country, which impacts global prevalence rates and how countries understand possible barriers to inclusion. Due to this variance, many governments and bilateral and multilateral donors use the definitions of disabilities supplied within the CRPD. Article 1 of the CRPD states:

Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (United Nations, 2006, Article 1).

The CRPD also supports a social model of disability as within its preamble it states:

...that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that

hinders their full and effective participation in society on an equal basis with others (United Nations, 2006, Preamble).

The Government of Lesotho appears to define disability using three different methods. The first is through enumerator evaluation in the national Census (personal communication, Ministry of Social Development, July 29, 2019). For example, when a census enumerator enters a household, he or she asks if a person has a disability and marks forms accordingly. In this process, disability is defined by individual and enumerator agreement. The second method is through medical diagnosis. In this case, medical professionals evaluate the conditions related to various disabilities for the purpose of prevention, cure, or rehabilitation (personal communication, Ministry of Health, July 31, 2019). Such diagnoses are under the purview of medical professionals and their clients but may not have any policy relevance except in the case of workers' compensation for injuries obtained on the job. Finally, disability is defined as a mitigating factor related to larger livelihoods vulnerabilities, meaning that current MOSD practice considers multiple intersecting vulnerabilities when considering social assistance (personal communication, Ministry of Social Development, July 29, 2019). At present, disability is not considered as an automatic trigger for social assistance.

The three definitions of disability above vary greatly and exemplify that there are not common, official definitions for disability in Lesotho. Lesotho's most comprehensive disability policy to date, the National Disability and Rehabilitation Policy of 2011 (NDRP), does not specifically define disability. Rather, disability is framed in two different ways. The first is through the lens of the "social model" of disability. Social models examine societal barriers that inhibit the full participation of persons with disabilities (see Figure 3). NDRP first frames persons with disabilities as a group that has been discriminated against and has not experienced equal opportunities in Lesotho. The Policy then goes on to describe demographics of persons with disabilities, including "illness", blindness, deafness, paralysis, "lameness", mental illness, and "mental retardation." As of December 2019, Lesotho's Disability Act was in final stages of approval and may provide updates to definitions in 2020.

Figure 3: Social Model vs. Medical Model of Disability

#### **Social Model**

# "The social model of disability says that disability is caused by the way society is organised, rather than by a person's impairment or difference. It looks at ways of removing barriers that restrict life choices for persons with disabilities. When barriers are removed, persons with disabilities can be independent and equal in society, with choice and control over their own lives."

#### **Medical Model**

"The medical model looks at what's 'wrong' with the person and not what the person needs. It creates expectations and leads to persons losing independence, choice, and control over their lives...Under the medical model, these impairments should be 'fixed' or changed by medical and other treatments, even when the impairment or difference does not cause pain or illness."

Source: Disability Nottinghamshire, 2019

Interviews with stakeholders indicated that specific definitions are lacking in Lesotho's policy. According to some stakeholders, this absence is purposeful. Ministry of Social Development (MOSD) representatives, for example, stated that the Ministry explicitly embraces a social model of disability (CBR Manager, Ministry of Social Development, personal communication, July 31, 2019). For purposes of providing social services, the model of disability was highly

functional. In this case, if a person was unable to perform activities that generate income or contribute otherwise to their household, he or she was deemed to have a "disability" and eligible for social support disbursements. Exact specifications of the extent of a disability and its impact on livelihoods were documented but only in medical records (and not part of a larger identification registry for "disability"). At the national level, the Ministry of Health determined disability for workers injured on the job. In this case, the extent of disability was calculated using assessments for functioning. Such assessments were not, however, used for identification of disability in the larger population.

In terms of social protection, MOSD uses a "Community-Based Targeting" (Ulrichs, Scott, & Mphale, n.d.) approach to identify persons most in need of social or economic supports. Within this targeting, persons with disabilities are one of a small number of specific populations targeted for participation but not necessarily as direct beneficiaries unless livelihoods circumstances dictated a need. According to a Community-Based Targeting implementation manual (Ulrichs et al., n.d.) used in Lesotho:

In some areas, people who are not able-bodied and unable to engage in crop farming are automatically ranked as ultra-poor. In the case of the elderly people who receive a pension, the pension should be considered as a source of income when categorizing the household. In the case of MOSD, transfers households should be categorized on the basis of their overall situation - regardless of the transfer. Otherwise, households who manage to be categorized as non-poor due to the transfer might no longer be eligible despite their overall situation remaining unchanged since they were considered to be eligible initially. Consider whether the household would be considered poor without the transfer or whether it depends on the transfer to meet its basic needs. Emphasize that households differ - even those which have a member receiving a transfer. If the household would not be able to meet its basic needs, such as purchase food, without the transfer, it should still be considered "poor". In the case of households with OVCs or disabled people, explain that the situation of the family as a whole needs to be considered, to assess whether it is capable of ensuring the wellbeing of these particularly vulnerable household members. (p. 8)

In summary, there is no specific, nationally agreed-upon definition of disability in Lesotho. Rather, disability is identified in three different ways in Lesotho. The first method is through self-disclosure on census forms. The second is through medical diagnosis in clinics or hospitals, generally by using medical definitions of impairments and understanding the impact on an individual's daily functioning. The final definition relates to social vulnerability and considers disability in relation to capability (see Ulrichs et al., n.d) and livelihoods activities. In this final case, a medical diagnosis is not as important as an assessment of barriers to livelihoods activities.

#### 3.3 Prevalence Rate of Disability in Lesotho

Obtaining accurate prevalence rates of persons with disabilities is a challenge for many countries. Differences in understanding disability, reluctance to self-identify or to identify a family member due to cultural stigmas, and challenges associated with data collection methods can all influence disability prevalence rates (Hayes et al, 2018). Surveys and censuses often

use very different data collection methods that can impact the reliability of disability data results worldwide (Mont, 2007). This lack of reliable data can impede countries' development of high-quality policies and practices to serve this diverse population.

Worldwide, disability prevalence rates for persons with disabilities can vary significantly ranging from 0.4% to 12.7%, depending on the study and assessment tool used to collect the data (Maulik & Darmstadt, 2007). The World Health Organization' (WHO) *World Report on Disability* estimated that approximately 15% of any population has a disability with potentially higher rates in countries that have experienced conflict or have extreme poverty rates. The same report estimates that 150 million children worldwide have a disability, while 93 million children have a moderate or severe disability (WHO, 2011).

To address the associated challenges related to data collection, in 2001, the United Nations convened a group of experts, referred to as the Washington Group, to develop a set of questions to determine disability prevalence rates. These questions asked respondents about functionality or activities (e.g., "Do you need help feeding yourself?"), rather than asking them directly whether they have a disability. This tool typically results in prevalence rates of between 10-20% (Mont, 2007). The Washington Group on Disability Statistics and UNICEF, together, have also developed questions, referred to as the Child Functioning Module, for children between ages 5 and 17. These questions are designed to address and identify the unique needs of children with disabilities; expand the functional domains for children; incorporate a fuller age range; recognize the range of disability; identify age-appropriate difficulties; rely on proxy respondents; preserve international comparability; and follow rigorous standards of development (Washington Group on Disability Statistics, 2017). As with other general questions developed by the Washington Group for survey and census use, these questions were based on functionality. However, they were expanded to approximately 24 questions and thus allowed for a more nuanced approach. The full questions can be found on the Washington Group's web pages (Washington Group on Disability Statistics, 2016).8

Identification of persons with disabilities is complex in Lesotho as well, and largely dependent on the functions and aims of the Ministerial unit from which an individual engages. One example of this is the national Census. The Lesotho census included disability for the first time in 2006 and indicated that 3.7% of the population has a disability. of which 2.1% are males and 1.6% are females (Lesotho Demographic Survey, 2006). The Census inquired if persons had a disability by asking them to select from one of the following categories: "amputation of foot/leg/fingers/arms/toe, lame/paralyzed limb, blind (total partial), deaf (total/partial), mental retardation/illness, and speech problems" (Lesotho Demographic Survey, 2006). The Ministry of Education conducted additional prevalence studies in 2002 and the Ministry of Health and Social Welfare conducted studies in 2008, estimating the disability prevalence rates to be 4.2% and 5.2% respectively (World Population Review, 2014). The Lesotho Demographic Survey of 2011 estimates 2.61% of the population has a disability, with the most common category of disability being blindness (Government of Lesotho, 2011). A 2014 study by the MOSD, however, reports approximately 8% of all children have some form of disability (Government of Lesotho, 2014). In all of these cases, the determination of prevalence of disability depended on three factors: 1) how disability was

defined; 2) how individuals understood their own impairments to be a "disability"; and 3) how enumerators asked for the data, interpreted the data, and uploaded disability-related data. Because disability was defined differently on different instruments, people have varying interpretations of their own abilities, and enumerators have varying levels of understanding disability. Overall, rates will likely fluctuate in reports.

In order to introduce a degree of expertise in the lived experience of disability along with internationally-accepted indicators, in 2011, LNFOD and SINTEF conducted a household survey to compare the living conditions of persons with disabilities compared to those without disabilities. This study surveyed 1,220 households and used the Washington Group Question to determine possible disability rates. This LNFOD and SINTEF found:

Based on our operational definition of disability with at least two disability domains in WCG questions were answered with "some difficulty", the prevalence of households having at least one member with disability was 10.1% with a confidence interval of 9.5%-10.7%. Severe disability with at least one of the six WCG questions was answered with "a lot of difficulty" or "unable" had a prevalence rate of 5.7% with confidence interval of 5.3%-6.2%. The prevalence rate of the general question on general disability was higher than severe disability rate, 7.4% and 5.7% respectively.

Because the LNFOD household survey utilized instrumentation to identify degrees of functioning and impaired functioning, it could be presumed that the LNFOD survey most accurately reflects disability incidence as understood by international organizations such as the World Health Organization and others. The most recent data available regarding disability incidence is the National Information System for Social Assistance database. The database is currently under analysis in order to produce disaggregated data on disability and. As of December 2019, such data was not available. The degree to which NISSA incidence estimates align with estimates found by LNFOD in 2011 will be an important consideration for future policy planning. Because the LNFOD survey used the most robust instrumentation for identification, it may be considered the most realistic estimate of incidence. If NISSA data aligns with these estimates, the NISSA process may be a valid way of estimating disability incidence in the future. If NISSA over- or underestimates disability incidence in comparison to LNFOD data, new instrumentation may need to be included. Figure 4 provides a summary of the different prevalence rates used within Lesotho.

**Figure 4: Different Lesotho Disability Prevalence Rates** 

Organization/Data Collection Method	Year	Estimated Disability Rate
Ministry of Education	2002	4.2% of children
Bureau of Statistics, National Census	2006	3.7%
Ministry of Health and Social Welfare	2008	5.2%
Bureau of Statistics, Lesotho	2011	2.61%
Demographic Survey		
LNFOD and SINTEF, Household Survey	2011	10.1% of households with at
		least one member
Ministry of Social Development	2014	8% of children
Ministry of Social Development NISSA	2019	Currently under analysis
Database		

#### 3.4 Practices and Methods to Identify Disability

In many countries, children are first identified as having a disability through health or education systems. In the health system, a developmental screening may be given to a child during an immunization visit or growth check at a community health center (UNICEF, 2013). Within the education system, several countries conduct routine hearing and vision screenings within classrooms to identify children with potential hearing and vision disabilities (Hayes et al, 2018). Although these are both common avenues for screening in high-income countries, they are still emerging practices in low- and middle-income countries.

Adults, on the other hand, may acquire disabilities through a slow onset (for example, hearing or vision acuity that becomes worse over time) or through accidents. In many ways, age is an equalizer between ability and disability, as physical and sensory disabilities become more present as one ages. At the same time, adults who acquire disabilities at more sudden rates may face challenges in adapting to inaccessible environments. Around the world, rehabilitation centers often fill the gap for adults who need to re-learn activities of daily living as a result of an acquired disability.

Identification of a disability may depend on the age of the individual and, as noted above, the relevant ministerial unit that interacts with the individual. Lesotho's 2019 Inclusive Education Policy, for example, calls for childhood screening and identification approaches similar to those described in the paragraphs above (See section 5.1 for more information about the Policy). The policy calls for new assessment centers that will be staffed with experts who can identify the type and degree of disability of a child. At present, teachers are encouraged to perform basic vision and hearing screenings and ask parents to take children to clinics for further diagnoses as needed. However, early childhood screening only takes place upon request from parents.

In terms of medical diagnoses at any point in life, Lesotho has a network of district-level clinics and hospitals. Disability screening and identification already occur at these hospitals and clinics but are limited in two ways. First, hospitals and clinics depend on individuals to use their services. According to a physiotherapist at Leribe Hospital who was interviewed for this study, resources are limited for outreach into communities, childhood care centers, or schools to encourage screening (Leribe Hospital, personal communication, July 30, 2019). The second limitation relates to the core functioning of Ministry of Health clinics and hospitals. Central Ministry of Health officials identified that the core functions of medical professionals are to "prevent, cure, and rehabilitate" any functioning limitations or health disabilities. This model's limitations, as described by both professionals and stakeholders who use clinic and hospital services, were related to the availability and geographic accessibility of services to individuals, many of whom need to travel long distances at great expense in order to secure services.

As noted above, MOSD, the ministerial unit that provides financial and social support to persons with disabilities across the lifespan, relies on social data for disability identification. In this case, disability is considered part of a broader vulnerability-alleviation agenda undertaken by the Ministry. Through the NISSA data collection tool, MOSD has collected vulnerability data on 331,000 households at the time of this report and plans to expand

nationwide (Mohalenyane, 2019), but disability identification systems have yet to be evaluated for alignment with global norms or effectiveness in delivering social protection programs. For example, in MOSD disability identification is tied to social protection schemes. Under the purview of MOSD, diagnostic categories of disability are used (speech disability, visual disability, etc.), but determination is made through self-identification, the conversation with the Social Worker enumerator, and the relationship between experienced functional limitation, economic vulnerability, and food security. This line of questioning identifies disability within a broader social milieu but does not follow specific medical protocol for diagnosis.

In a 2014 report, Makakole concluded, "In Lesotho, the common causes of childhood disabilities are poor maternal health, poor nutrition, poor medical access, home-based deliveries, the childhood accidents, and the complex medical conditions among infants and young children (Makakole, 2014). Following these statements, the Government of Lesotho further concluded that in a country where more than half of the population is living in poverty, the children with disabilities are said to be among the most vulnerable in all societies" (Government of Lesotho, 2014). These factors indicate an urgent need to locate children and adults with disabilities in order to provide access to education, health, and social protection.

#### 3.5 Stakeholder Mapping

A variety of organizations and individuals comprise what are known as "stakeholders" in Lesotho. In the paragraphs below, these will be organized at three levels: international, national, and local. The relative proximity of many of Lesotho's districts to the capital city of Maseru means there is often interaction between local and national stakeholders. At the same time, the relatively small number of national organizations focused on disability allows for familiarity between national and international stakeholders.

#### 3.5.1 International Stakeholders

For this report, there are two types of international stakeholders: the United Nations (UN) system and international non-governmental organizations. The two main UN stakeholders involved in disability-related activities are the United Nations Population Fund (UNFPA) and UNICEF. UNFPA sponsors this study and focuses on inclusive programming in sexual reproductive health (SRH) and considers the unique vulnerabilities to exploitation and to social stigmas regarding consensual relationships that persons with disabilities face. The United Nations Children's Fund (UNICEF) is also active in supporting inclusive education (Ministry of Education Special Education Unit, personal communication, July 31, 2019). According to a recent outreach by the UN to develop the priorities for the next UNDAF, most persons with disabilities in Lesotho were unaware of UN activities; unaware that the UN lacks programs that facilitate the CRPD in Lesotho; and unaware of existing programs carried out through DPOs. The three priorities raised by persons with disabilities in this process were inclusive education, poverty, and unemployment (United Nations Development Programme, 2017).

In addition to UN organizations, Lesotho hosts a wide range of international non-governmental organization stakeholders. However, among these, few are directly involved with disability service delivery or advocacy. One exception is Catholic Relief Services, which

has supported inclusive education for children who are blind or who have low vision (Catholic Relief Services, personal communication, August 2, 2019). A subcontracting model is more predominantly used whereby international organizations subcontract to LNFOD to initiate projects. LNFOD works directly with the following international organizations: Open Society Foundation, Austria Foundation, Bank Information Center, the European Union (which is a governmental agency), and the Maseru-US Foundation.

#### 3.5.2 National Stakeholders

Lesotho has two major types of disability stakeholders at the national level. The first is government agencies and the second is non-governmental organizations. The Ministry of Social Development is one of the most long-standing governmental bodies that focuses on disability. The ministry has a long history but has faced multiple challenges over the years. "In Lesotho, the Department of Social Welfare was first established in 1976, as a way of responding to increasing levels of poverty and other social problems" (Nyanguru, 2003). It was first housed within the Ministries of Internal Affairs, then Justice and then Employment, before being transferred, in 1993, to the Ministry of Health and Social Welfare (MOHSW). According to Nyanguru (2003), "its six moves in 17 years are indicative of the low status afforded the Department, which together with a long-standing lack of departmental policy has left its service provision fragmented, dispersed, and lacking in focus. This consequently impacted negatively on the extent to which the Department was able to deliver services to its intended clients" (Leshota, 2013). Currently the MOSD has a Director of Disability Services, which demonstrates a central level of commitment to the population. As noted above, disability is a phenomenon considered as part of a broader agenda of reducing vulnerability, enhancing livelihoods, and ensuring social protection.

The second major governmental ministry that focuses on education is the Ministry of Education and Training. Lesotho's Ministry of Education and Training outlined a strategy for inclusive education and allocated a Special Education Unit to the Ministry of Education and Science in the early 1990s (Mariga & Phachaka, 1993). The unit started with three full-time staff members and has grown to include a special education officer in every district. Despite the growth in staffing over the past 20 years, unit representatives stated that having a single district officer is not enough to address the high needs of schools attempting to implement the inclusive-education strategy. According to participants in this study, the level of activity of district officers ranges widely, but all officers are responsible for negotiating solutions to inclusive-education challenges in schools through professional development, liaising with parents, "encouraging" (as stated by one Special Education Unit) schools to be more inclusive, and additional activities. For example, one district education representative in Leribe printed a booklet entitled Success Stories of People with Disabilities in Leribe (Nkhasi, 2019) that she shared with stakeholders in order to provide an accounting of positive educational outcomes for children with disabilities in Lesotho. Lesotho's Ministry of Education launched a new inclusive education policy in August of 2019. The policy elevates Lesotho's current "strategy" and explicitly focuses on the inclusion of persons with disabilities from early childhood through postsecondary education.

Lesotho's non-governmental organizations are highly active in the country. Under the auspices of the LNFOD, Lesotho currently has five DPOs that drive a wide range of activities in the country. LNFOD was formed in 1989, along with the Lesotho National League for

Visually Impaired Persons (LNLVIP) and the Lesotho National Association of Persons with Physical Disabilities (LNAPD). Later, the Intellectual Disability Association of Lesotho (IDAL) and the National Association of the Deaf in Lesotho (NADL) also emerged. All are registered non-governmental organizations in Lesotho. LNFOD, as the cross-disability umbrella organization, is responsible for a cross-disability agenda that includes policy advocacy. promotion and protection of human rights, and training designed to create a more-inclusive Lesotho. Specific programs currently undertaken by LNFOD include a disability awarenessraising program for community councils in order to expand local development efforts (such as government labor schemes) to be more inclusive. LNFOD is also responsible for technical assistance to all other DPOs in the country as they engage with disability-specific communities. At a policy level, LNFOD provides guidance on the CRPD to the Government of Lesotho. Finally, LNFOD has partnered with other agencies to provide short-term business development courses to individuals with disabilities in the Leribe, Maseru, Berea, Maefeteng, Mohale's Hoek, Quthing, Qacha's Nek, Mokhotlong, and Thaba Tseka districts. These short courses help persons with disabilities identify revenue-generating activities in their communities, provide basic business training, and secure seed loans, of which 50% must be repaid in three years.

LNFOD is supported internally by a small subvention from MOSD and externally by the organizations mentioned above, but much of the advocacy and advisory work it does is on a pro-bono basis. Despite being the most influential organization related to disability rights in Lesotho, LNFOD's leaders acknowledged that securing consistent and adequate funding from government and international donors has been a challenge (personal communication with LNFOD leadership, November 28, 2019).

As of December 2019, the organization has been successful in advocating for new policies in Lesotho, but LNFOD's leaders identified policy gaps that remain a challenge for the organization and for persons with disabilities in general in Lesotho. Leaders cited four main examples: the CRPD, the Disability Bill, the Disability Mainstreaming Policy, and the Ministry of Education Inclusive Education Policy. Full implementation of the CRPD is challenged by Lesotho's *dualistic* law system, which requires that a national law is passed before requirements of the treaty are enforceable, but new opportunities for CRPD alignment with the forthcoming passage of the Disability Bill.

In addition to LNFOD's cross-disability advocacy, each of LNFOD's constituent organizations has its own responsibilities. LNLVIP, for example, runs its own trainings on the rights of persons with disabilities and guides the operations of the Mohloli a Bophelo Training Centre (to be described in the paragraphs below), a center that caters to youth and adults with visual disabilities. LNAPD is one of the main advocates for accessible and inclusive education in the country. A LNAPD leader noted that "being free does not mean access is there" (LNAPD representative, personal communication, August 2, 2019) in reference to Lesotho's Free Primary Education scheme but relative lack of physical accessibility in classrooms. LNAPD is also active in consulting on the operations of the Ithuseng Rehabilitation Centre.

IDAL advocates for persons with intellectual disability, specifically in the areas of inclusive education, access to justice, sexual reproductive health, and access to government services. In addition to its advocacy roles, IDAL members meet with parents of children with

intellectual disability and provide community education.

NADL is the group responsible for promoting Lesotho Sign Language (LSL) in the country. It has been developing a dictionary and DVD of LSL, advocating for a greater number of sign language interpreters in the country, and advising Lesotho's two schools for students who are deaf (St. Paul and Kananelo) and the main high school destination for students who are deaf (Mt. Royal High School). The LNFOD organizations are highly active in promoting disability-friendly policies, ensuring access to justice and services, and advising on technical issues related to the education and training of persons with disabilities.

#### 3.5.3 Local Stakeholders

Two major stakeholders engage with disability in local areas. The first are government entities based in local areas. Such entities include schools, clinics, social workers, and local government. Each of these entities are responsible for implementing the various national policies. A full-scale analysis of implementation of inclusive education, social protection, and inclusive government was not possible in this report, but individual stories of implementation are reported in the sections below. The other group of stakeholders are persons with disabilities themselves as well as their families. This group of stakeholders are consumers of services, participants in local programming, and members of broader communities. The voices of these stakeholders were included in this report to reduce the chance of bias in perspectives by stakeholders who operate solely in Maseru or international contexts.

#### 4. Barriers to Inclusion

The following section outlines the attitudinal, organizational, and physical barriers that may limit the full participation of persons with disabilities in Lesotho. In this section, international and Lesotho contexts are provided. Conclusions are drawn from both literature, discussions that took place in August and September of 2019, and feedback provided during the validation meetings in November 2019.

#### 4.1 Attitudes and Cultural Barriers Related to Disability

Stigma and negative stereotypes or imagery around disability are pervasive around the world, with disability oftentimes being associated with incapacity (WHO, 2011). A review of the literature around disability stigma in East Africa found that traditional beliefs of disability continue, which include beliefs that disability is punishment for bad deeds or a result of witchcraft (Stone-MacDonald, 2012). This stigma can lead to infanticide, not registering the birth of children with disabilities, or violence and abuse. It can also result in ostracizing or reducing participation in society, as those with disabilities are hidden from view or forbidden to take part in community activities (Rohwerder, 2018). A survey conducted found that 38% of parents in Cameroon, Ethiopia, Senegal, Uganda, and Zambia reported that they hid their children away, either because of shame due to stigma or to protect them from harassment (Mosert, 2016). These derogatory views can serve as a barrier to persons with disabilities to realize their human rights on an equal basis as others.

Persons with disabilities in Lesotho also face stigma and discrimination based upon misunderstandings about disability, practices based on stereotypes about disability, and misperceptions related to disability. Having a disability is often perceived as negative by both persons without disabilities and often by persons with disabilities themselves. The traditional

beliefs and practices related to disability are a complex mixture originating from spiritual beliefs, the need for survival, and traditional attitudes to health (Khateli et al., 1995). In Lesotho as in other parts of the world, there is a misperception that disability is caused by a past sin or due to witchcraft. In fact, in a 2011 household survey conducted by LNFOD and SINTEF, approximately 13% of respondents stated that their disability was a result of witchcraft (LNFOD and SINTEF, 2011). These discriminatory views serve as a barrier to social inclusion for many persons with disabilities and often leads to isolation (Ministry of Health and Social Welfare, 2008). LNFOD and SINTEF (2011) found that 16% of persons with disabilities experienced being discriminated against in public services.

Attitudinal, institutional, and environmental barriers prevent persons with disabilities from equally participating in Lesotho society. The LNFOD and SINTEF (2011) stated that one of the most pronounced concerns facing persons with disabilities is:

...not taking part in one's own traditional ceremonies, and not making important decisions about one's life. These, and other indicators of social exclusion, imply that awareness creation, information, and education directed at the society, including public services, and families of individuals with disabilities is urgently needed. Combining this information with the relatively large proportion of individuals with disabilities who report mental health problems, we argue that this study indicates that individuals with disabilities are struggling in their daily life and that assistance is needed at this level (p. 6)

The concern of not being able to equitably participate in society or in decision making is reflected in other studies. For example, a 2015 study in Lesotho on women with disabilities and sexual and reproductive health reflects that 58% of persons with disabilities are excluded from these activities and decision making (Shale, 2015).

In an interview for this report, a female with a physical disability in a community setting revealed that the information found in literature aligned with her lived experience. She noted that the attitudes of community members themselves often cause the barriers to community participation, stating:

...discrimination by community people doesn't allow them (people with disabilities) to participate at community level, for example, during public gatherings. Most people with disability can be considered 'not living' in the community though they are living due to the lack of participation. This leads to a point that even the chief is not aware of other disabled people at his village hence a lack knowing the needs of the disabled people (Female with disability in Leribe District, personal communication, July 28, 2019).

In general, one of the greatest barriers that persons with disabilities face in Lesotho is assumptions about their *capabilities*. In both literature and examples provided by persons with disabilities themselves, communities appear to believe that persons with disabilities cannot make meaningful contributions to community-based decision making (often addressed in community meetings – *pitsos*, or in village-level work projects – *fato fato*). Attitudinal challenges also appeared present in the home. More than half of the persons with acquired disabilities interviewed in this study reported that their spouses left them *after* the

onset of their disability. Further surveying is needed to fully identify how common postdisability onset divorce is in Lesotho, but the number of cases of spousal fleeing in conjunction with disability was noteworthy.

#### 4.2 Physical and Environmental Barriers

Physical and environmental barriers often affect many other aspects of life for persons with disabilities, such as employment, healthcare and education. Without accessible buildings and services, many persons with disabilities are barred from accessing needs like transportation; water, sanitation, and hygiene (WASH) facilities; and health centers. Several studies found that access to WASH facilities was a major barrier to accessing healthcare for persons with disabilities (Pryor et al., 2018). In addition to physical barriers, environmental barriers, such as barriers to information and communication, can also exist and profoundly impact the ability of persons with disabilities to participate in their communities. For example, information is often not provided in braille for persons who are blind, sign language for persons who are deaf, tactile sign language for persons who are deaf-blind, or alternative formats for persons with intellectual disability, exclusion will occur.

The CRPD includes the principles of Universal Design, which defines "the design of products, environments, programs, and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design" (CRPD, 2006). Universal Design is also known as "accessibility from the start," wherein buildings are designed to be accessible from their inception, rather than modified after they have already been built. Lack of physical infrastructure or accessible communications serve as an additional barrier to the inclusion of persons with disabilities in Lesotho. Interviewed participants in this study identified two major areas of environmental barriers: physical barriers and communication barriers. Physical barriers were experienced differently by rural and urban participants, but barriers were present in both locations. In rural areas, one of the main barriers for persons with physical disabilities is the terrain itself. Lesotho is mountainous, with uneven ground and many dirt roads and pathways. The natural environment of Lesotho impacts social services in relation to shortages and frequent disrepair of wheelchairs. Learners and therapists at Ithuseng Rehabilitation Cetnre and Leribe hospitals both commented on the challenges of wheelchair shortages in Lesotho. There is a dearth of equipment overall and equipment that exists frequently breaks due to rough terrain. One learner at Ithuseng expressed worry about what would happen after she left the relatively accessible confines of the rehabilitation center:

In class we are enjoying ourselves, learning new things, but what will happen after? Wheelchairs are giving us a problem. Once they break, it is a long time to get another one. (Ithuseng trainee, personal communication, August 2, 2019)

Leribe hospital therapists also noted the lack of rehabilitative and mobility equipment overall, but particularly wheelchairs. To the extent possible, the hospital recycles wheelchairs and seeks out donations for new equipment as a way to supplement availability. In general, however, the lack of readily available mobility devices able to withstand environmental conditions in rural areas challenges physical accessibility for persons with disabilities is limited (Leribe Hospital Staff, Ithuseng Staff, and Ithuseng Students, personal communication, July 29-August 2, 2019).

In Maseru, buildings are often inaccessible. LNFOD explained the Building Control Act of 1995 is intended to ensure all buildings are physically accessible, but the Act is not strictly enforced (LNFOD Leadership and MOSD CBR Manager, personal communication, July 29-August 2, 2019). LNFOD leaders also stated that even if new construction meets the minimum requirements, overall, architects in Lesotho lack the technical knowledge about accessibility, and people who do have expertise (LNFOD and others) are not consulted on these matters.

In interviews conducted for this report, individuals who are deaf, deaf-blind, or hard of hearing most frequently reported communication barriers. In these interviews, individuals described challenges in accessible communication. Interview data with a woman who is deaf in Leribe district, for example, confirmed that sign language interpreters are not available in government offices or hospitals, which makes it very difficult for individuals who are deaf or hard of hearing to access services (Community Members of Maputsoe, personal communication, July 30, 2019). Because Lesotho Sign Language is not an official language and because its development falls largely upon one NGO in the country, there is a lack of infrastructure for a full-scale communicative inclusion.

#### 4.3 Institutional Barriers

Institutional barriers can be defined as policies, procedures, or situations that limit the equitable participation of person with disabilities. This can include discriminatory practices such as not allowing persons with intellectual disability to vote, persons who are deaf to obtain driver's licenses, or persons who are blind or deaf-blind to open bank accounts. In many cases, policies can also reinforce institutional barriers. The removal of discriminatory practices or policies is an important step to ensure the equal rights of persons with disabilities.

Lesotho has several discriminatory Acts slated for removal as the new Disability Bill passes into law. Section 57 of the Constitution (that requires that Senators be able to speak in order to serve); Section 219 of the Criminal Procedure and Evidence Act (that outlaws abortion *except* in the case that the mother carries an unborn child suspected of having a disability); and the Sexual Offences Act (that makes sex among persons with disabilities illegal) are examples of discriminatory laws and policies (Matsoha-Makhoali, 2015; Shale, 2015). Among stakeholders interviewed, the Sexual Offences Act was troubling because it made consensual sex among adults who have disabilities a crime (LNFOD and IDAL Leadership, personal communication, August 2, 2019). There was no mention in interviews that the Sexual Offences Act was ever enforced, but disability advocates opposed the stigmatizing language and the concept of limiting a normal human activity because of disability status.

Lesotho also has social policies intended to promote societal inclusion but there is little infrastructure or legal recourse to support such policies. As a result, the situation of persons with disabilities in Lesotho might be characterized as "casual integration." Miles (1990) described casual integration in contradiction to inclusive practice. Miles characterized "casual integration" in cases where there are no laws preventing access to societal activities, but also no active promotion of inclusion. Members of LNFOD described a similar scenario when asked about the barriers that persons with disabilities face in Lesotho. Participants

mainly spoke of the lack of resources and enforcement of existing policies in Lesotho, rather than specific barriers resulting from policy. For example, a leader from LNAPD described how rights discourses in Lesotho's policies were not upheld or resources distributed (LNFOD Leadership, personal communication, July 29, 2019). This leader provided two examples of how casual integration occurred in Lesotho: "Schools are free, yes, but being free does not mean access. Access is still a problem" (LNAPD Leader, personal communication, August 1, 2019). This quote related to the barriers that children with physical disabilities faced, even if policies encouraged their participation in mainstream schools. The second issue that the leader addressed was livelihoods. Similarly, no policies prevented persons with disabilities from entering the workforce or initiating entrepreneurial activities, but according to this interviewee, the general economic status of persons with disabilities in Lesotho is so desperate that "one cannot expect people to be empowered if the base human needs are not there" (LNAPD Leader, personal communication, August 1, 2019).

Finally, there are both institutional barriers that prohibit equal participation under law in Lesotho. First, there are a variety of disability-empowering policies, but a lack of implementation is present. Building on Miles's concept of "casual integration," the largest institutional barrier identified by stakeholders in Lesotho is a lack of judicial accountability that either supports the implementation of policies or allows individuals to claim their rights in courts. For the latter, Lesotho's dualistic system is one barrier (CRPD rights cannot be claimed until Lesotho's Disability Law is enacted, see section 5.1 for more information). A second barrier is the social stigmatization and stereotypes faced by persons with disabilities in the courts themselves. Anecdotal reports of the lack of access to sign language or legitimization of advocate testimony (for persons with intellectual disability) indicates that barriers exist both in the implementation and enforcement of policies that are otherwise inclusive in language.

#### 4.4 Additional Considerations for Specific Social Groups

When assessing barriers to participation, it is vital to look at certain social groups that may experience intersectional challenges due to both their disability and other characteristics. The below section reviews, in future detail, barriers to the inclusion of children with disabilities, caregivers of persons with disabilities, and women with disabilities.

#### 4.4.1 Children with Disabilities

Children with disabilities are often marginalized within the societies in which they live and are particularly vulnerable to abuse, neglect, and isolation (UNICEF, 2013). In Lesotho, adulthood legally begins at age 18 (Lesotho Government Gazette, 2012), although girls can still legally marry as young as age 16 (Centers for Disease Control, 2019). UNICEF (2013, p.4) states that "discrimination arises not as a result of the intrinsic nature of children's disability, but rather as a consequence of its causes and implications, fear of difference, fear of contagion or contamination, or negative religious or cultural views on disability." Children with disabilities are nearly four times as likely to be victims of violence compared to children without disabilities as well as almost three times as likely to be victims of sexual violence (WHO, 2019). Children with specific types of disabilities, such as deafness, blindness, or deaf-blindness were more likely to experience abuse, with children with intellectual disability five times more likely to experience abuse (UNFPA, 2018). To highlight these challenges, Article 7 of the CRPD recognizes the rights of children with disabilities by stating that State

Parties should take all "necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children" (United Nations, 2006, Article 7).

Children whose educational rights are upheld in Lesotho generally benefit from two types of advocacy: parental and professional. The Intellectual Disability Association of Lesotho (IDAL), for example, is an organization made up of both persons with intellectual disability and parents advocating for the rights of children with intellectual disability. IDAL has been very active in advocating for the rights of children in communities, for access to education, and for community sensitization. All LNFOD groups also advocate for improved educational opportunities for children with disabilities, whether through improved infrastructure, inclusive access, or working to improve sign language delivery at schools for the deaf.

The Ministry of Education and Training (MOET) also employs inclusive education officers in each district. In an interview with MOET officials, it became clear that these officers carry a heavy load, as they are responsible for all children with disabilities across the district. However, some officers have made remarkable progress in terms of professional development of teachers, advocating for schools to become more inclusive, and record keeping. Despite strong advocacy efforts, children with disabilities are still vulnerable to discrimination in Lesotho. In a 2013 article on the vulnerability of children with disabilities, Levy, Magar, and Sialondwe reported that:

...children are vulnerable to discrimination because they may be unable to voice instances of abuse. According to a CSO that serves disabled children, both the health and legal systems discourage special-needs children from reporting. It also indicates that families of children with special needs who have come forward have generally experienced unsatisfactory services. Communities don't see it as important to report when it involves a child with a disability, because they don't see the disabled child as valuable. —CSO representative

People think that [a] person with mental disability is attracting abuse. —CSO representative. (Levy, Magar & Sialondwe, 2013)

Key informant interview data from this study aligned with the findings of Levy et al. An interview with the Lesotho Mounted Police Service Gender and Child Protection Unit indicated that children with intellectual, physical, sensory, and communication disabilities may be at risk for neglect in households. The Gender and Child Protection Unit told stories of neglect cases they have investigated. At times, these cases were a result of abuse, but most often, officers claimed children with disabilities were left unattended in households and at times "locked in" because parents left the house to seek work. According to unit representatives, these neglect cases were most often reported by neighbors and either were tried in court or referred to the Ministry of Social Development social workers (Child and Gender Protection Unit, personal communication, August 2, 2019).

According to multiple interviewees, however, the most significant challenge children with disabilities face is *over*-protection. A retired government official who acquired a disability from a car accident reflected on what he has seen in his community over the past 30 years. These reflections were validated in numerous interviews during the field visit.

The challenge is that after parents discover that their child has a disability, they take a long time to counsel themselves. The child is then delayed further because the parents need counseling and they over-protect the child. Parents don't let children practice things on their own, then tend to get very tired, then they eventually wear out and leave the child alone. Some may even experience a stroke because they did not ask for help. (Community Member Outside of Hlotsoe, personal communication, July 28, 2019)

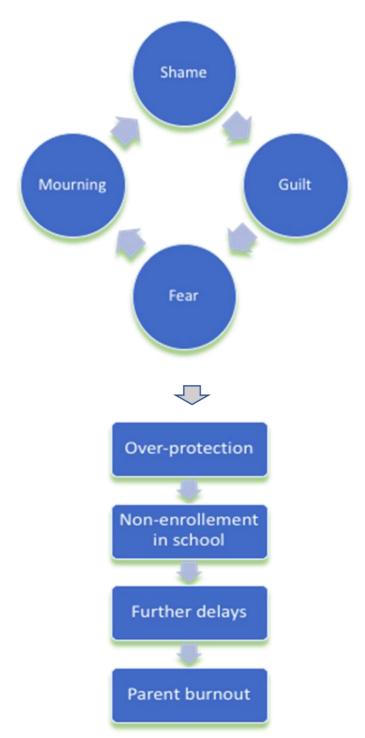
Figure 5 in the page below demonstrates a visual representation of a cycle and consequences of parental and community fears about engaging children with disabilities in everyday activities at a young age that may result from feelings of shame for having a child with a disability or a simple lack of information about disability in general. According to stakeholders, what is often meant as way of supporting children ends up limiting their functioning and later ability to meaningfully participate in household and community life.

#### 4.4.2 Families and Caregivers

Families and caregivers are an integral part of inclusive communities. Even though the CRPD states families have a right to an equitable standard of living that includes adequate housing and food (CRPD, 2006), many families that include persons with disabilities struggle financially. These households are more likely to live below the poverty line, both due to higher costs and the impact care for persons with disabilities may have on household employment (UNICEF, 2013).

Families and caregivers can play a big role in alleviating stigma for members of their household with disabilities through purposefully including persons with disabilities in community activities, challenging myths and attitudes that may exist in the community, and advocating for persons with disabilities on the community, district, or country level (Rohwerder, 2018). This advocacy often takes place within parent associations, which serve as a platform for parents to support each other but also to advocate for changes in laws or policy to better support persons with disabilities (McConkey, KLahonde & McKenzie, 2016).

Figure 5: Guilt, Overprotection, and Developmental Delays



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The situation for families and caregivers is exemplified in the text and figure of Section 4.4.1 above. Lesotho's Ministry of Social Development explicitly aligns with a social model of disability, which also helps explain the situation above. If a child is born with a disability, parents immediately face social stigma and isolation. Few programs exist (apart from LNFOD sensitization activities) to help parents understand both the limitations and potentialities of children with disabilities. Although a social model would indicate that early intervention can be supplemented with early education for parents about their rights, educational options, and responsibilities, such programs do not exist. Where available, rehabilitative programs exist only in hospitals and have a medical focus.

According to stakeholders who participated in interviews for this report, parents and caretakers of children with disabilities often become isolated in their communities and face additional difficulties in securing economic opportunities. Exact numbers were difficult to estimate, but there are only a few residential facilities for children with disabilities in Lesotho, meaning that most parents care for their children at home. Community-based rehabilitation efforts, as of December 2019, were stalled and according to LNFOD "not in alignment with current models of inclusive development in Africa" (LNFOD Leader, personal communication, August 2, 2019). Exact national data on incidence of divorce and homecare were not available at the time of this study, but interview respondents noted that the care of all children (including children with disabilities) disproportionately falls on mothers, who may face additional burdens if their spouses divorce them under the strain of family conditions, engage in labor outside of the community, or blame mothers for the birth of a child with a disability.

In summary, disability and related stigma and discrimination are present at all stages of life but are presented in different ways. The first six years of life for a child with a disability are often met with confusion from parents, gossip, a lack of understanding from community members, and a lack of available services for families and children. Although schools are increasingly inclusive in Lesotho, early childhood issues related to disability are unique and represent a challenge for families. During early childhood, early stimulation and participation is critical to the development of children with disabilities, but stakeholders expressed concern that under-stimulation and isolation may be occurring in many communities.

#### 4.4.3 Women and Girls with Disabilities

Women with disabilities in general are likely to face discrimination based on both their gender and their disability. They are less likely to complete primary school and more likely to be denied access to education, leading to a higher risk of social exclusion and poverty as adults (United Nations, 2017). Women with disabilities have a 19.6% employment rate, compared with 52.8% for men with disabilities and 29.9% for women without disabilities (United Nations, 2017). Globally, studies show that women are more likely than their male peers to think of disability as a negative attribute and thus hold a negative self-image. This, in turn, can make them more susceptible to harmful social interaction (UNFPA, 2018).

Consistent with international trends, women and girls with disabilities face discrimination in Lesotho based on both their gender and disability. Shale (2015) stated:

Women in Lesotho generally face discrimination on the basis of sex. Such

discrimination is often justified on the grounds of custom and culture as stipulation in section 18(4)(e) of the Constitution of Lesotho. Since PWDs also suffer discrimination because of the attitudinal and institutional barriers that prevent them from accessing human rights, women with disabilities suffer double the scourge because of their status as women and because of their disabilities. The discrimination leads to denial of sexual and reproductive rights, unemployment, lack of access to education, and limited participation in politics.

Shale's identification of "double discrimination" was validated in interviews with persons with disabilities in Maputsoe. In a focus group of community members with disabilities that was split by gender (one male, one female), participants indicated that they faced challenges related to access to reproductive healthcare. Women mainly reported that a lack of sign language capacity in clinics made access to healthcare difficult. Lesotho Mounted Police's Gender and Child Protection Unit also reported that communication barriers may result in cases of sexual abuse against girls with disabilities going unprosecuted. In cases where girls have complex communication disabilities or limited expressive language (or do not use formal Lesotho Sign Language or tactile sign language), the Child Protection Unit stated they depend on evidence from those accused of abuse, neighbors, and doctors. Unit representatives feared cases were not always as strong as they could be and noted that raising awareness among officers of the court about diverse communication strategies may help them to better prosecute offenders (Child and Gender Protection Unit, personal communication, August 1, 2019).

In terms of economic and social inclusion, women in general have higher levels of educational attainment than men in Lesotho, except for those at the lowest income bracket. NISSA and census data indicate that persons with disabilities are frequently at the lowest income levels, meaning that low-income women with disabilities themselves may face access barriers to education. Despite girls outperforming boys in schools, rates of leadership in society still favor men. For example, men hold approximately 75% of all parliamentary seats and 80% of all ministerial posts in Lesotho (World Bank, 2019). The Lesotho Council of Non-governmental Organizations (2016) lists 96 NGOs that work on women's and children's issues. Among these, the only organizations that have an explicit link to disability are LNFOD organizations. More data is needed regarding the specific employment and social barriers that women with disabilities experience. Interviews primarily revealed service-access barriers.

# 5. Situation of Persons with Disabilities in Lesotho: Key Findings

This section presents the main findings of the report and are organized within eight thematic areas identified in collaboration with the TWG that oversaw the research and development of the report. These thematic areas include 1) legal framework and policies, 2) community living, 3) education, 4) employment, 5) gender-based violence and abuse, 6) health, 7) political participation, and 8) social protection.

#### 5.1 Legal Framework

**Finding 1:** Lesotho's Disability Bill has gained political support but is not yet signed into law. The law's likely passage in 2020 will allow for better alignment with the CRPD as well as legal enforcement of the rights of persons with disabilities.

One of the most important policy actions Lesotho has taken in relation to disability is signing and ratifying the CRPD in 2008. By doing so, Lesotho joined the 180 countries around the world that have ratified the treaty (United Nations Department of Economic and Social Affairs, n.d.). Despite taking such an important step for disability rights, particular gaps remain in relation to Lesotho's alignment with international norms in relation to disability rights (Shale, 2015).

Lesotho, for example, has repeatedly deferred signing the CRPD's Optional Protocol (Shale, 2015). By doing so, Lesotho has avoided the adoption of a structure for persons with disabilities to report human rights abuses (as outlined by the convention). Lesotho is a *dualist* country, meaning that its international treaties obligations (such as the CRPD) are unenforceable until they are entered into domestic law. This dualism of human rights obligations was called into question in the *Fuma v Commander LDF & Others* High Court of Lesotho case, when the High Court found that the firing of Mr. Thabo Fuma because of a newly acquired visual disability violated both Lesotho's Constitution and its international human rights obligations (Shale, 2015). Despite the *Fuma* ruling, Lesotho still lacked a comprehensive law that protects the human rights of persons with disabilities until the very recent Disability Bill (which was pending to be signed into law in December 2019).

The *Disability Equity Bill* that outlines a wide range of legal rights for persons with disabilities. Provisions in the Bill include guidance on physical access, assurances for access to public services such as health and education, and the creation of a Disability Advisory Council at the national level. Additional considerations in the Bill include workplace accommodations, inclusive education provisions, and a reversal of all contemporary acts in Lesotho that are discriminatory towards persons with disabilities. The lack of a full-fledged disability law is has been a noticeable omission in the legal protection of human rights in Lesotho (Shale, 2015), but this omission will likely be addressed soon after the publication of this report, according to reports from advocates and Ministry of Social Development officials.

At present, Lesotho has multiple laws and policies related to persons with disabilities. In this section, disability-related policies will be organized in four themes: education, healthcare/rehabilitation, social development, and human rights. Policies are rules and procedures that guide how governments administer in a country. They guide how resources are distributed and may carry penalties if not adhered to but do not have the power of law, which can be challenged in court if not upheld. Supplemental information on laws and policies can be found in Annex A.

Lesotho has national legislation that addresses the rights of persons with disabilities. These laws and how they include persons with disabilities as well as an overview of the policy areas, objectives, strategies, and standards found in the NDRP are detailed in Annexes B and C.

There is a general consensus among disability advocates and scholars that the NDRP represented an opportunity for comprehensive inclusion of persons with disabilities, but lacked legally-binding enforcement. Matlho (2018), for example, points out a major gap that existed in Lesotho and will continue to until the Disability Bill is passed into Law:

In as much as the policy remains good, it remains the guiding tool and cannot be enforced before the courts of law, the major problem is that the current health legal system does not cater for people with disabilities; therefore, the best strategy would be to advocate for adoption of disability related health laws because as of 2011 when this policy was adopted, not much has been done to cater for the rights of people with disabilities (p. 36).

Matlho's critique aligns with critiques from Lesotho's disability communities that were present during the early data collection for this report. This Bill was debated and revised multiple times for over seven years in Parliament. The Bill was first conceptualized in 2012, then laid dormant until 2015, when a full draft was completed in order to align with the CRPD. As of December 2019, however, the Bill has not been officially passed into law by Parliament, but has enough support to likely ensure its passage.

Lesotho's Disability Bill will provide the domestic legal support to enforce and defend many of the human rights spelled out in the CRPD. The passage of the Bill will likely have similar impact and may stimulate ratification of the Optional Protocol of the CRPD. The Bill itself is still under discussion, but has strong political support (as per discussion in validation meetings). Overviews of the Bill found in popular press indicate that, if passed, the Bill would address issues such as accessibility in education; discrimination in the workforce; accessibility of sport and leisure activities; accessibility to information; voting rights; barrier-free environments (such as building and transportation services); assistive technologies; rehabilitative service provisions; legal protections; social protection funds; and self-advocacy provisions. According to advocates, the Bill is decidedly rights-based (Sebusi, 2019) and makes many of the provisions of the NPRD enforceable.

The passage of the law should also create opportunities for signing and reporting on the Optional Protocol of the CRPD in Lesotho. As of December 2019, there is no international mechanism for reporting, challenging, or upholding the rights of persons with disabilities through international channels.

In conclusion, Lesotho has strong policy in relation to education and social development and disability. Its Disability and Rehabilitation Policy and pending Disability Equity Bill are comprehensive in nature and cover a variety of rights and opportunities that should be available to persons with disabilities. Careful evaluation, however, is needed to monitor the extent of implementation. Experts from civil society organizations to legal authorities, for example, have commented that implementation will likely be uneven because resources have not yet been committed to human rights enforcement or programming.

Lesotho's 2019-2020 budget report from Honourable Moeketsi Majoro, Minister of Finance, indicates that the Bill has been "tabled" (meaning it has been introduced for discussion in Parliament), "to pave the way for disability grants and a disability trust fund" (Parliament of the Kingdom of Lesotho, 2019). Feedback in the validation meeting for this report indicated that passage of the Bill was forthcoming. The Bill's long ascension into law (from 2012 to

present) has been a source of frustration for disability advocates but upon passage opens up new opportunities for implementing the CRPD, enforcing the rights of persons with disabilities, and the creation of a national Disability Advisory Council. The Council, according to LNFOD leadership, should be an "implementing agency or structure, and appoint focal persons from private agencies to coordinate work around persons with disabilities. The Ministry of Social Development should develop a mechanism to bring people together" (personal communication with LNFOD leadership, November 28, 2019). LNFOD warned that the organizing structure developed by the government should have *external* oversight to ensure that policy goals are being carried out and government ministries are held accountable for such actions (personal communication with LNFOD leadership, November 28, 2019).

#### 5.2 Community Living

**Finding 2:** Adults and children with disabilities face isolation and discrimination in home communities. New institutions run by non-governmental organizations are emerging in Lesotho, but there is currently no standard of care provisions or oversight by government to ensure quality service delivery. Government financial support of such institutions misaligns with the aims of CRPD.

Article 19 of the CRPD mandates the right of persons with disabilities to live in the community. In addition, CRPD Article 23(5) states that "where the immediate family is unable to care for a child with disabilities" the State must provide care "within the wider family, and failing that, within the community in a family setting" (United Nations, 2006). However, worldwide, persons with disabilities are often denied this right and forced to live in institutions where they have substandard living conditions and often face abuse, neglect, and forced treatments (Human Rights Watch, 2014). Many countries often institutionalize persons with intellectual disability and psychosocial disabilities and deny the human right to live in the community. For example, in Europe, 1.2 million children and adults with disabilities live in long-term residential institutions and are denied their right to live in the community (United Nations, 2012). The exact number of children in residential institutions in Lesotho is unknown, because these are all operated by non-governmental and charitable organizations. However, it is estimated that the numbers do not exceed five hundred, based on the number of institutions (the five that receive government subventions and are not counting boarding schools have bed space for anywhere from 20-70 youth each). Additional students reside at boarding schools, but return home during holidays, so their permanent home is their community (focus group interview with institutions August 2, 2019).

#### 5.2.1 Children with Disabilities

Children with disabilities are living in communities throughout Lesotho. The timeframe for this project did not allow for a national survey of how many, or what conditions, children with disabilities are living in across Lesotho. However, the day-to-day conditions of children with disabilities can be triangulated in three ways: direct observation, reports from other community members, and reports from community agencies such as social workers and police. Box 1 (below) provides a case overview of "Palesa," a 14-year old girl with intellectual disability (as identified by her parents). Palesa's story exemplifies common themes found throughout this report – the story of children who may have accessed school at some point

in their lives but faced barriers, and for whom long-term transition into adulthood may prove to be a challenge because of a lack of childhood experiences that support successful adult life, and who will likely always live in their home community.

#### Textbox 1: Case Study of a Girls with a Disability Named Palesa<sup>4</sup>

The case study of Palesa provides context for the situation of children and youth with disabilities. Palesa is 14 years old has what was described as an "intellectual disability." She lives at home with her mother, father, and three siblings. Palesa is predominately non-verbal.

Palesa's parents sent her to school when she was five years old, but then pulled her out of school when she was seven. Her parents stated that she "wasn't learning anything" and worried that she was just sitting in school for no reason. When probed further, Palesa's father said it was the parents' decision to remove her from the school, but they largely felt that Palesa was not receiving any help in school.

Palesa's father's comments align with other findings from this study that indicate that the educational focus for inclusive education has largely been on access to schooling, but little more is known about children's experience in school. In this case, Palesa's father filled in details. Palesa attended school for two years, but did not receive any extra support from teachers so he believed it was not worth it to continue sending her. Further, Palesa was said to have difficulty getting along with the other pupils in school. It is not unusual for children with communication difficulties to experience social challenges with other children, but inclusive schooling, in theory, should support children's social and academic progress.

Palesa's father reported that she is a "hands on" girl – "she prefers to do projects." He noted that she works around the house to help the family, but that sometimes the parents will not ask too much of her because they worry about her getting upset. While working on projects, she might stop abruptly and the parents have not been able to always figure out why, which was frustrating for them.

As noted above, Palesa gets along well with her family most of the time. She sews small items with her younger cousin and will go along with the other girls of the family to fetch water. Her family has an income that qualifies them for the Children's Grant Programme (GCP) and the family receives 600 Maloti per month, which helps, but is not enough to meet all needs. Her family worries for her and her long-term future, about what job she will get, and about her future. A MOSD social worker visits Palesa and her family, but long-term plans for education and other services have not yet been developed.

The situation may be more dire for children who have less supportive family networks or access to social services. A group interview with parents of children with acute cerebral

<sup>&</sup>lt;sup>4</sup> Palesa is a pseudonym.

palsy, for example, revealed that none of the children were in school. A variety of reasons were cited, including difficulties with transportation, challenges with equipment to help children remain upright throughout the day, and the fact that the additional care that children need was not available at school. Similar to Palesa's story, education seemed out of reach for parents because of a lack of resources to support the learning and care of children. The children who were attending therapy at Leribe hospital appeared well cared-for and supported by their mothers and grandmothers, but parents and grandparents noted that the expense and time of attending therapy was challenging for them.

Other children may be less fortunate than those interviewed for this study. Community members reported stories of children who spend much of their day ignored or neglected because parents need to work outside of the home or are unsure of ways to appropriately stimulate children. The most extreme examples of such neglect were reported by the Lesotho Mounted Police, who told of cases of neglect that they investigated, then turned over to the Ministry of Social Development for intervention (personal communication with Lesotho Mounted Police Child and Gender Protection Unit, July 31, 2019). Further, Ministry of Education and Training officials noted that Early Childhood Care and Development centers have been largely untouched in relation to inclusive education training, and do not conduct outreach in communities to encourage parents to send children with disabilities to school (personal communication with MOET Special Education Unit, July 31, 2019).

A limitation of this study was that schools were closed during data collection periods, so it was difficult to visit schools and see a "counterweight" to the exclusionary and isolating practices described above. These no doubt exist in Lesotho, but case evidence suggests that even in caring families and communities, access to education is difficult for children with disabilities. In families under greater pressures or who may have fewer resources than others, the situation for children with disabilities appears to be worse.

#### 5.2.1.1 Institutional Care

Institutional care for children with disabilities is a worldwide trend, but institutions often fall short of providing acceptable levels of support for children with disabilities. The United Nations Study on Violence against Children expressed deep concern over the terrible conditions found in many institutions including documentation of violence and neglect; children left for hours on urine-soaked mattresses or physically or medically restrained; residential care facilities being understaffed; and a lack of monitoring or independent oversight (UNICEF, 2012).

There are no state-run orphanages or institutions in Lesotho, but interviews with MOSD personnel indicate that the Ministry currently supports five "centers" or "homes" for children and adults with disabilities through small subventions. These centers are run by non-governmental organizations and supported by ministerial subventions for operating costs.

The culture of institutional care for children likely started during the AIDS pandemic in the 1990s. During that time, approximately six orphanages were opened in Maseru during the 1990s and 2000s that were supported and managed by NGOs and religious organizations (Makepe, 2009). In these settings, staff care for orphans and social workers supported connections to foster and adoptive families. Children who are orphans receive housing, education, and food (Makape, 2009) and are often enrolled in local primary school when

they reach school age (age six or above). The majority of these institutions developed in response to the AIDS epidemic when 97,000 children were orphaned (Kimane, 2005). Although the majority of AIDS-impacted children found homes with extended families, the relatively few children who arrived in orphanages during the pandemic were generally either abandoned at birth at the hospital or orphanage, "found" in communities by community members, or delivered by family members (often elderly) who may not have had the capacity to care for children.

The practice of placing children with disabilities in institutions or orphanages has been historically limited by lack of infrastructure and by the cultural traditions of extended-family caretaking (Mariga & Phachaka, 1993), but new residential centers in Lesotho are opening up a "supply" of out-of-home options for parents of children with disabilities (field notes, August 2, 2019). The availability of institutional care and the relatively remote nature of most of Lesotho, it is reasonable to assume that most children with disabilities live in their communities, however, Ministry and civil society participants at the validation meeting noted that interest in specialized homes and centers is on the rise in Lesotho (personal communication with LNFOD, November 28, 2019; validation meeting feedback, November 29, 2019).

Institutions, "homes for the disabled", and centers supported by the Ministry of Social Development through subvention are St. Angela Home for the Disabled, Morapeli Disabled Centre, Thuso Etla Tsoa Kae Centre, and St. Paul/Kananelo Schools for the Deaf that provide boarding to children with disabilities and a variety of educational experiences (from fully inclusive to center-based segregated education). In each of these centers, boarding is considered an aid to accessing education that may not be possible within home communities, but center directors report that there is increasing interest from families to extend services through school holidays. During a focus group interview conducted August 2, 2019, institutional directors reported many challenges to their operations despite the growing demand. The main challenge, according to directors, was resources. Specifically, there are few, if any, trained staff in institutional centers and the number of children that can be served is limited due to space constraints. Center directors noted that there is a constant need for upgrading facilities, but often no funds to do so.

One center that operates year-round as an orphanage and "home" for children with disabilities is Phelisanong Home for Children with Disabilities. Phelisanong Home explicitly serves as a full-time residential home for children with disabilities, HIV/AIDS, and orphans. Not all children who reside at Phelisanong are orphans, and, according to staff at the home, many are referred to the home by the Ministry of Social Development social workers.

The home is staffed primarily by women who live nearby and have no training in disability, rehabilitation, psychology, or formal education beyond secondary school. According to an interview with a representative of the organization, most staff at Phelisanong have a primary-level education and possibly some secondary school education. According to the staff member interviewed, what these staff offer children is a degree of caring that they do not experience in their home communities (interview with staff member at Phelisanong, July 31, 2019). Children with disabilities were not interviewed for this study, but observed in different situations in Phelisanong. One child happily skipped and greeted guests as they arrived while others sat quietly in rooms. Phelisanong has a room with physical therapy equipment,

but, as noted above, no physiotherapists or special educators who work at the home. Rather, international visiting therapists periodically provide workshops when they travel to Lesotho.

Centers like Phelisanong raise important philosophical and human rights issues for Lesotho. Lesotho's status as State Party of the CRPD means that its government should not be supporting institutionalized care for children with disabilities and should focus on community-based settings and supports for children. At present MOSD provides small subventions to institutions, but does not carry out any sort of inspection or have any polices or standards on their operations (feedback from validation meeting, November 29, 2019). To stay viable, institutions fundraise and are often supported by international aid agencies and high-profile donors within Lesotho such as Sentebale to complement the small subvention from the Ministry of Social Development (field notes from observation of Phelisanong Centre; Phelisanong Information Officer, personal communication, July 30, 2019). By the admission of their own directors in focus groups, institutional centers are under-resourced, staffed by largely or entirely by untrained staff, and have no form of transition planning to move children or young adults back into communities.

It is unclear, then, what additional national value is added by continuing to support institutional centers with government funds. Further study is needed in this area, because there is not adequate data that characterizes the full situation of children with disabilities living in residential settings. Data from this study indicate that there are limited resources, staff lacking qualifications, and a lack of transition plans for moving children and young adults back into their communities. Because of this, closer scrutiny must be placed on the rationale for such centers and the use of public resources to support them. Demand from communities may for such centers may continue to grow. In such a case, an appropriate role for a government that has ratified the CRPD is to monitor the health and well-being of its citizens within such institutions, require that every child have a transition plan that focuses on re-entry into communities, and set standards for care such as professional qualifications of caretakers and staff on premises. Simply funding such centers through subventions may place the Government of Lesotho out of compliance with its own laws and treaties in relation to community living rights for persons with disabilities.

#### 5.2.2 Adults with Disabilities in Communities

Adults with disabilities have always lived in community in Lesotho. In all of the interviews conducted for this study, no interviewee mentioned institutionalization for adults with disabilities, as is common in other parts of the world. Rather, persons with disabilities in individual interviews outside of Hlotse, Maputsoe, Qacha's Nek, and Thaba Tseka all mentioned that living in the community was common but barriers to employment and political participation were present. These will be addressed below.

Sefotho (2019) conducted a single case study of an adult with dysarthria that describes, in depth, some of the opportunities and barriers identified in interviews conducted with community members for this report. Sefotho notes that his main research subject, Seithati, had always been a part of his community and, at times, faced discrimination because of his disability. Seithati was able to carve out a livelihood through first tending sheep, then later finding work at a local mill. Sefotho's 2019 study, published after all field work was

completed for this project, aligned with key interviews with persons with disabilities in community, but also presented a somewhat rosier outcome than many of the interviewees in this study experienced. Interviews with community members with disabilities revealed that community living was an assumed outcome for adults with disabilities but was fraught with challenges. Some of these challenges are described in section 5.4 below.

#### 5.3 Education

**Finding 3:** Lesotho's recently adopted inclusive education policy provides a framework for upholding the educational rights of children with disabilities, but these children are under-enrolled in ECCD programs and little data exists on school-aged children beyond enrollment.

Despite the global push towards universal access to education, children with disabilities still attend school at lower rates than their peers without disabilities. The World Report on Disability found that persons with disabilities reported significantly lower rates of primary school completion and fewer years of education overall than those without disabilities. This gap in education completion was found in both high-income and low- and middle-income countries (WHO, 2011). Additionally, in 2004, the United Nations Educational, Scientific, and Cultural Organization (UNESCO) estimated that only 2% of children with disabilities attended school (UNESCO, 2004), while a 2008 survey in 13 low- and middle-income countries found that children with disabilities ages 6-17 were significantly less likely to be enrolled in school than children without disabilities (Filmer, 2008). When children do attend school, the CRPD Committee Guidance on Inclusive Education states that inclusive education is the preferred setting, regardless of the type or degree of disability. As part of this guidance, country governments should move towards an inclusive education system, including transferring any budgets for segregated school systems towards inclusive systems (UN Office of the High Commissioner for Human Rights, 2016).

#### 5.3.1 Inclusive Education Policies

Lesotho's early adoption of an inclusive education strategy in the 1990s provided a pathway for increased inclusivity in primary schools. Despite the multitude of challenges related to the education of children with disabilities, several opportunities exist for improving inclusive education in the country. First, primary education has been free since the year 2000. Supplementary programs that support meals and books at schools allow children to attend school without cost barriers. Second, Lesotho's 2009 Curriculum and Assessment Policy reorganized schooling into learning areas that are assessed frequently and formatively, rather than relying on single end-of-year high stakes tests (Raselimo & Mahao, 2015). Coupled with universal design and accommodations for children for students with disabilities (Hayes, Turnbull, & Moran, 2018; Thompson, Johnstone, & Thurlow, 2002), assessment practices could become more precise in understanding children's day-to-day learning. Finally, research about inclusive education has been steadily increasing over the past decade. Several master's and PhD theses as well as faculty research from both the National University of Lesotho and South Africa's University of Free State have produced recent and relevant knowledge about inclusive education in Lesotho that can inform policy and practice.

The greatest promise for inclusion, however, is provided by two recently adopted policies on inclusive education. In 2019, the Ministry of Education and Training (MOET) adopted an inclusive education policy that guides the Ministry's actions and resources. The Government of Lesotho's *National Strategic Plan for Integrated Early Childhood Care and Development* is a multi-sector plan for enhancing early childhood care and development, with a focus on inclusivity.

The Ministry's Special Education Unit (the unit that oversees policy on inclusive education) stated that the inclusive education policy was developed "based on gaps" that have occurred since Lesotho began focusing on inclusive education in the 1990s. Four specific focal areas of the policy are 1) curriculum and assessment, 2) teacher training, 3) partnerships, and 4) resources.

Lesotho's *National Strategic Plan* for ECCD calls upon a multi-sectoral approach to ensure quality early childhood experiences for all children, including those with disabilities. The *Plan* calls for the Ministry of Health (MOH), MOSD, and MOET to work together to ensure

Early Childhood Intervention (ECI) services will be conducted through a partnership between the MOH, MOSD and the MOET, with help from the Department for National IECCD Policy Implementation. The involvement of the public health establishment is critically important because physicians and nurses identify and serve many high-risk infants and children as well as children with developmental delays, malnutrition, chronic diseases such as HIV and AIDS, disabilities and atypical behaviours. The participation of the education establishment is equally important with respect to: the provision of special education services; the training of early intervention specialists; the provision of services for children with atypical behaviours, such as the autism spectrum; and the inclusion of children with delays and disabilities and their families in all available education services, such as inclusive day-care centres, special education services, and inclusive pre-schools (Ministry of Education and Training, 2013, p. 31).

MOET acknowledged that progress on the ECCD plan has been slow. Although a comprehensive plan to identify, intervene, and teach children with disabilities at a young age was launched in the 2013 ECCD policy, implementation has been slow to follow. For this reason, ECCD and pre-primary education were named as explicit areas of focus in the new inclusive education policy.

Building on existing policies and strategies, MOET seeks to improve Lesotho's pre-primary to higher-education curriculum. Curricula at all levels will be revised and examined for its local relevance, capacity to support learners with different needs, and a decreased focus on high-stakes exams. Further, the Ministry officials plan to review primary-level curriculum and assessment practices and infrastructure at school (which interviewees admitted was a major challenge) to produce guidance on how to create environments that accommodate all learners (personal communication, July 31, 2019).

Teacher training will also be revised in order to support inclusion in education. Details of the exact structure of this were not available, but Ministry representatives indicated that such training would move beyond singular units on disability to facilitate opportunities for inclusion

across teacher training (Ministry of Education Special Education Unit, personal communication, July 31, 2019). After the passage of the policy, Lesotho's Ministry of Education and Training will undertake a review of teacher training programs and their methods through an inclusive-education lens. The Ministry will also undertake efforts to put more teachers in the field.

The policy also calls for renewed partnerships with Ministries of Social Development, Finance, and Planning to leverage resources for inclusive education. The Ministry of Education also will continue its relationship with partners such as UNICEF, World Bank, World Vision, the Japanese International Cooperation Agency (JICA), and LNFOD. The Policy will cover all areas of education. Annex D provides more details of the specific changes introduced from early childhood to postsecondary education.

#### 5.3.2 Teacher Training and Attitudes

Training teachers on inclusive education and how to support the learning needs of students with disabilities is critical. International evidence highlights teacher attitudes on inclusive education and how their perceptions of children with disabilities can impact the acceptance and learning outcomes of students with disabilities (Avramidis & Norwich, 2002). Immediately following Mariga and Phachaka's (1993) feasibility report, which first outlined Lesotho's inclusive-education strategy in the 1990s, the Ministry of Education began training all primary school teachers on classroom strategies for inclusive education, basic screening strategies for disabilities (using easily available materials to teachers), and a philosophical overview of why inclusive education was important for the nation. The efforts of the Ministry were laudable, but the relatively small budget and infrastructure of the Special Education Unit made it impossible to reach all schools in the country with training activities. In a study of teacher development activities, Johnstone and Chapman (2009) found the Ministry could intensively train teachers on inclusive education strategy at 10 schools per year but would never catch up to the needs in Lesotho's over 1,000 primary schools.

The new inclusive-education policy provides for ongoing professional development through enlarging the Special Education Unit. Specifically, the policy calls for a change from the current Special Education Unit to a department for inclusive education. Further, the number of district resource teachers (those who are responsible for overseeing inclusive education at the district level) will be enhanced. Finally, the Ministry of Education and Training will seek to place four itinerant special education teachers in each district to support inclusive education in schools. Itinerant teachers will conduct screening activities and consult with teachers and school leaders about the education of children with disabilities. The new policy also calls for alignment between the content found in pre-service and in-service education.

In the late 1990s, shortly after Lesotho College of Education became an autonomous institution, it began offering classes in special education to all primary teacher education candidates. A comprehensive study on teacher knowledge of inclusive education in Lesotho does not exist, but Ministry of Education officials confirmed certified teachers have had some exposure to inclusive education during their college training. At the same time, uncertified teachers who have not participated in the relatively limited MOET programs are likely to have no exposure to inclusive education. A study by Urwick and Elliott (2010) indicated that 53% of the research sample had no exposure to strategies for children with disabilities.

At present, inclusive education modules exist in all education programs (Diploma in Primary Education, Diploma in Secondary Education, and Degree in Secondary Education). The new policy pushes for "intensive training" in pre-service education, according to representatives of the Special Education Unit (Special Education Unit, personal communication, July 31, 2019). No specific directives were discussed in interviews, but the Special Education Unit mentioned the World Bank will sponsor a teacher training manual and the Unit will push for a "common first year" that will bring together cross-cutting units on disabilities combined with units on inclusive education within the primary or secondary education curriculum.

Evidence from the last decade also indicates that initial enthusiasm for inclusive education is waning in Lesotho. The Ministry of Education launched its inclusive education initiative on a philosophy that the Ministry would not provide special incentives to teachers in pilot schools teaching newly included students with disabilities, nor provide incentives to any mainstream school expecting to enroll local students with disabilities (Khatleli, Mariga, Phachaka, & Stubbs, 1995). Teachers and administrators, however, have started to question their capacity to meaningfully include children with disabilities because of a lack of relevant equipment, inaccessible structures, and lack of adequate toilet facilities (Sefuthi, 2016). Resource challenges, coupled with little opportunity for ongoing professional development (Urwick & Elliott, 2010) have placed Lesotho's longstanding and groundbreaking inclusive education strategy at risk in the second decade of the 2000s. Participants at the validation for this this report argued that, in the face of training challenges, pre-service teacher training at all levels would be the best investment for MOET because of its capacity to reach so many prospective teachers.

## 5.3.3 Participation in Early Childhood Care and Development, Student Enrollment and Learning Outcomes

Challenges also remain for children with disabilities who have yet to access school. For example, Eriamatloe (2013) estimated that 40% of children with disabilities between the ages of 5 and 10 (primary school ages) were not in school. For these children, widespread efforts to enroll children with disabilities have been constrained. At present, attendance in schools is compulsory in Lesotho, but the 2010 Education Act allows for non-attendance "in the case where suffering from disability or disease... prevents him or her from attending school." Such language, whether intended or not, could provide heads of schools, teachers, or parents, with a rationale for *not* sending or enrolling children with disabilities in schools. Given the resource challenges that some schools face (Sefuthi, 2016), such a decision may seem justifiable, but non-attendance of children with disabilities in school is contrary to Lesotho's inclusive education policy as well as the CRPD.

Recent EMIS data from the draft report of Lesotho's *Educational Statistical Report* reveals that, in primary schools, 5.2% of all students enrolled are identified as having disabilities. This rate of identification and enrollment is higher than the reported disability incidence in Lesotho overall, which may mean that the instrumentation that MOET is using to identify disability are more sensitive than community-based measures. The WHO estimates that 5% of the world's children have a disability, but the WHO figure does not include those with learning disabilities. A recent Ministry of Social Development report (Government of Lesotho, 2014) estimates children's disability incidence at 8%. The discrepancy between WHO and

MOSD may be the result of WHO data not including children with learning disabilities. In Lesotho, learning disabilities are often referred to as having "learning difficulties" and are the highest population group of children with disabilities in schools (MOET, 2019).

The most striking statistical gap appears to be in ECCD and the early grades of primary school. EMIS data indicate that children with disabilities are dramatically under-enrolled in ECCD programming. MOET statistics from the forthcoming *Education Statistics Bulletin 2018* indicate that only 1% of children in ECCD programs were identified as having disabilities. Such a rate indicates that either children who are already attending ECCD centers are under-identified, or that children with disabilities are not accessing ECCD programming and are instead staying at home. Those who were identified were disproportionately boys (55% of the identified population is boys).

The relative under-enrollment of children with disabilities in ECCD also appears to have a pipeline effect on early grades. According to EMIS data, among students with disabilities in Lesotho's schools, the highest concentrations are found in grades 5, 6, and 7. There are many possible reasons for such concentration. One might instructional – because of high-stakes exit requirements for primary grades, students who face learning challenges may be retained in higher grades at higher rates than children without disabilities. Another reason may be that disability identification takes time if screening is not occurring on a regular basis in schools. The most commonly identified disability in Lesotho's schools is "intellectual disability," which includes a category of children referred to as having "learning difficulty" (MOET, 2019). This may not be directly evident in the early grades but become clearer as academic expectations rise unless teachers are regularly monitoring student progress.

Triangulated community-based and systemic EMIS data indicate that there are community and systemic barriers to enrolling children with disabilities in early childhood and early primary grades. Children with disabilities are under-enrolled in ECCD programming and children with disabilities are more concentrated in the upper primary grades. Because early childhood and early grade programming are essential for intellectual development, socialization, and interventions that can maximize educational opportunities for *all* children (including children with disabilities), early childhood care and education are key strategic area of focus for Lesotho in relation to inclusive education and development.

Gaps in early identification and intervention were a recurring theme in this study. Community members in Hlotse (July 28, 2019); representatives from Mohloli oa Bophelo (July 29, 2019); the Ministry of Education and Training's Special Education Unit (July 31, 2019), and leaders of IDAL (August 1, 2019) all described a version of the information provided in Figure 5 above. Statistics from government EMIS systems confirm that children with disabilities are still enrolled at low levels. Stakeholders indicated this low enrollment may be explained by parental apprehension and community expectations of children's abilities to learn or early childhood care and development centers' unwillingness to enroll children with disabilities. However, early intervention and education for children with disabilities has long been understood as a catalyst for long-term academic and social development (Guralnick, 2005) and parental apprehension can be overcome through strategic outreach and child-friendly learning environments. The withholding of children with disabilities from early educational opportunities is a gap in Lesotho and places the country out of alignment with global norms and the CRPD.

For those who do attend school, little data exists on outcomes for students with disabilities. One NGO, Catholic Relief Services, has promising data from their Lesotho Literacy for Young Visually Impaired Persons project, which ran from 2015 to 2017. The project aimed to increase the reading skills of students who were blind or had low vision in 30 classrooms using two technologies: the Mountbatten Pro Brailler (MB Pro) and the Jot-a-Dot portable brailler (JAD). Early Grade Reading Assessment scores improved for all children in the project, and all students reported that the JAD brailler helped to improve their reading (School-to-School International, 2016). However, in-depth data on student learning beyond this project was difficult to secure for this study.

The Ministry of Education and Training's new Inclusive Education Policy calls for the Ministry and its schools to "collect data from different sources such as Education Management Information System (EMIS), affiliated stakeholders in inclusive education, learning institutions, learners, teachers, school boards, parents, and communities through routine, periodic, and annual data collection" (MOET, 2019, p. 30). Such data collection is important and will help provide data for decision making on inclusive education. However, children with disabilities who attend school need their student outcomes to have further specifications to ensure both access and outcomes are recorded. Such data would align with the call for "effective education" found in Article 24 of the CRPD. Without such data, there is no way of knowing the educational experiences and outcomes of children with disabilities in inclusive schools.

## 5.4 Employment

**Finding 4:** The majority of persons with disabilities in Lesotho are unemployed, and most individuals with disabilities have not yet benefited from government services that support short-term employment. Overall, there are no quotas or tax incentives to promote hiring of persons with disabilities Entrepreneurship opportunities are present, and when coupled with social protection and access to work, may provide a range of options for persons with disabilities.

State Parties, through <u>Article 27</u> of the CRPD, must guarantee the right to work and employment on an equal basis as others (CRPD, 2006). The International Labor Organization (ILO) estimates there are large disparities between unemployment rates of persons with disabilities and persons without disabilities when statistics on this topic are available (ILO, 2018). For example, the World Report on Disability found employment rates for persons with disabilities were below the overall population rate, with the disparity varying from lows of 30% of the overall rate in South Africa to 92% in Malawi. The rates for persons with disabilities were especially low for those with mental health or intellectual disabilities (WHO, 2011). Disability-disaggregated data are not available for Lesotho at present, but a recent NISSA (Oxford Policy Management, 2014) report indicates that 40% of rural households have vulnerable livelihoods. If the additional livelihoods factors of dependents are added, 89% of Lesotho's rural households are vulnerable or have a person who is over 69 or under 18 in the household.

Several countries have developed incentives to increase the number of persons with disabilities in the workforce through mandates and employer incentives. Many countries offer financial incentives to employers that hire persons with disabilities as well as employment services to increase the number of persons with disabilities in the workforce. In Saudi Arabia, at least 4% of employment in the private sector must be persons with disabilities while Ecuador mandates that 4% of public and private employees must be persons with disabilities (World Bank, 2012). However, the process of implementing this mandate in both countries has been slow. In Saudi Arabia, only 10% of persons with disabilities are currently employed and only 7% of companies have increased the number of employees with disabilities (United Nations, 2018). In Ecuador, companies are complying but often fail to give persons with disabilities meaningful work. One of the World-Bank-funded Regional Citizen Observatories complained that "it is not enough for a company to hire a blind person and then have him sit at desk without doing much simply to abide by the law" (World Bank, 2012). Though employment for persons with disabilities is mandated by the CRPD, it continues to be a challenge for many countries worldwide.

Consistent with international challenges, Lesotho also struggles with low unemployment rates for persons with disabilities. Though the unemployment rate in Lesotho is 23.5% (ILO, 2019), the LNFOD Living Conduction Study estimated that 70% of persons with disabilities are unemployed compared to 30% of individuals without disabilities. Of these individuals with disabilities, 59.8% stated that they have never been employed and 16% stated they are no longer working mainly due to issues related to their disability or an illness (LNFOD and SINTEF, 2011).

The absence of paid labor, self-employment, or subsistence activities places individuals and households in the vulnerable categories of "poor" or "very poor" (Oxford Policy Management, 2014) that trigger social protection benefits. At present, NISSA data is being disaggregated to gain a better sense of how statistically vulnerable persons with disabilities are in Lesotho. Interview data indicate barriers to employment result from an inability of employers to recognize capabilities of persons with disabilities and make accommodations as needed. In urban areas, LNFOD representatives noted there is a great deal of workplace inaccessibility for persons with disabilities who hold high levels of education (LNFOD Representative Groups, summary of focus group interview, August 1, 2019). In rural areas, opportunities for employment are few, but local governments often employ the general population in "fato fato" - a short-term employment scheme that allows payment for community development projects such as road building, environmental protection schemes (e.g., tree planting), or other activities. Six out of six persons with disabilities interviewed outside of Hlotse noted they had sought fato fato employment but were sent home by supervisors unwilling or unable to create workplace accommodations or modified work opportunities so persons with disabilities could participate in activities.

In order to prepare Basotho for employment or self-employment, two systems of technical and vocational education and training (TVET) exist in Lesotho. The first system is the mainstream TVET system overseen by the Ministry of Education. In this system, secondary school completers who wish to pursue training in technical fields enroll in one of several institutions around the country. MOET officials indicated that two of these centers, Thaba Tseka and Leribe, have recently begun to include individuals with disabilities. At the same time, two MOSD-funded centers, Mohloli oa Bophelo and Ithuseng, provide both habilitation

services and a degree of technical vocational training for person with disabilities. The merging of vocational training and habilitation at MOSD centers presents an overlap in services and indicates that persons with and without disabilities receive separate services to prepare them for jobs. This situation analysis did not evaluate the quality of technical education in either MOSD or MOET centers, but a duplication of services is present that is out of alignment with both the CRPD and the MOET inclusive education policy. It was unclear from this study whether misalignment created disadvantages for persons with disabilities, but interview data with staff from both institutions indicate that habilitation is a greater focus at MOSD centers than preparing persons with disabilities for competitive employment or entrepreneurial activities (focus group interview with LNFOD organizations, August 1, 2019; feedback from validation meeting, November 29, 2019).

A final area of consideration related to employment is self-employment. Entrepreneurial programs sponsored by LNFOD and the Basotho Enterprise and Development Corporation (BEDCO) have shown mixed results but, in some cases, have created improved livelihoods for persons with disabilities. In this study, two individuals who participated in LNFOD/BEDCO programs were interviewed. One woman outside of Hlotse ran a successful haircare business out of her home. She had a high likelihood of success in the program because prior to participating she "knew how to do hair, but not how to run a business" (Community Member with a Disability Outside Hlotse, personal communication, July 29, 2019). A second male with a disability had ran a successful perfume business but encountered challenges when his customers (who relied on social assistance payments) stopped paying for products when they ran out of cash (Community Member with a Disability Outside Hlotse, personal communication, July 29, 2019). Globally, more than half of businesses started by entrepreneurs fail (Kelley, Singer, & Harrington, 2015), so interview data in this study should be read with extreme caution. However, given the lack of formal employment opportunities in Lesotho, entrepreneurship, coupled with social protection and access to work, will provide a range of options for persons with disabilities.

#### 5.5 Gender-based Violence or Abuse

**Finding 5:** Instances of sexual violence against girls and physical violence against boys and girls is high in Lesotho. Stakeholders report that instances may be even higher for children and women with disabilities, who face communication barriers in legal and health systems.

Recent statistics indicate that as many as 59% of boys and 43% of girls experience physical violence as children. Further, 14.5% of girls experience sexual violence in childhood. Among girls whose first sexual experience was before 18 years of age, 18.3% reported that they were pressured or forced into the act (Centers for Disease Control - CDC, forthcoming). Disability disaggregated statistics on violence against women and children in Lesotho are not yet available from the CDC report. However, worldwide women with disabilities often risk abuse, violence, neglect, maltreatment, and exploitation in greater numbers compared to women without disabilities (United Nations, 2012; UNFPA, 2018). The Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) provides for specific protection from discrimination for women and girls. Its general recommendation No. 19 on violence against women states that by ratifying the CEDAW, States had undertaken legal

obligations to prevent and eliminate violence against women, including girls and women with disabilities (United Nations, 2012). <u>Article 16</u> of the Convention requires States to put in place legislation and policies and to prosecute instances of exploitation, violence, and abuse against persons with disabilities, including women and girls.

Even with these policies, gender-based violence and abuse against girls with disabilities takes place at significantly higher rates than persons without disabilities (United Nations, 2012). For example, in one study in Northern Uganda, over one-third of women and girls interviewed by Human Rights Watch reported they had experienced some form of sexual and gender-based violence including rape (Human Rights Watch, 2010). Girls and women with disabilities are wrongly perceived as non-sexual beings, which contributes to an increase in the sexual violence committed against them, and they are unable to distinguish inappropriate or abusive behaviors (Nixon, 2009). Individuals with sensory or intellectual disability are often targets of violence and rape as their disability can make it challenging to identify their abuser. Girls and women with intellectual disability are two-to-eight times more likely to experience sexual violence compared to peers without disabilities and are less likely to report the incidence (Hughes et al., 2012).

In Lesotho, it remains unclear the extent to which girls and women with disabilities have experience gender-based violence or abuse, but forthcoming CDC disability-disaggregated data may inform policy makers. At present, existing evidence suggests that services for gender-based violence are often not inclusive. According to Shale (2015):

...the Child and Gender Protection Unit['s] (CGPU)...main aim is to deal with cases involving children and victims of gender-based violence. This is a general unit that does not exclusively deal with persons with disabilities. However, some people with disabilities face barrier[s] including accessibility of CGPU offices as well as communication with the police officers stationed therein, all of whom are not trained in sign language. As a result, a woman with a hearing disability will have to rely on third parties, friends, or relatives to report the offence at the police station. The danger of reliance on a third party is that the story may end up being distorted or not adequately captured (pg. 59).

Shale's quote above about the CGPU was validated by the Unit themselves. One of the major challenges that the Unit said it faced was prosecuting sexual and abuse offenders when it came to persons with communication disabilities (Child and Gender Protection Unit, personal communication, July 31, 2019). Officers mentioned that both persons who are deaf or hard of hearing, deaf-blind, or with intellectual disability were at risk because certain magistrates only considered spoken or written testimony and questioned interpreted testimony. Further, the unit suggested cases of abuse and neglect may happen within families, and children with physical or intellectual disabilities who do not have the opportunity to leave home may be at risk. As noted in sections above, the CGPU stated they often depend on neighbors to inform them about cases of abuse and neglect. The Unit does not have a disability platform for communication or outreach but stated they occasionally work with LNFOD on collaborative programming (Child and Gender Protection Unit, personal communication, July 31, 2019).

#### 5.6 Access to Health Services

**Finding 6:** Stakeholders cited a series of lifelong gaps that, according to interview data, lead to a cumulative impact of disability across the lifespan. These impacts are exacerbated by lack of available resources, personnel, and equipment.

In 1948, the World Health Organization defined health as "a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity" (United Nations, 2018, p. 48). This identified health as not just treating disease but also affirming well-being. The right to health services access for those with disabilities is included in several international treaties and frameworks. Goal 3 of the Sustainable Development Goals called for health and well-being for all, including those with disabilities, while Article 25 of the CRPD calls for free or affordable access to healthcare for persons with disabilities (United Nations, 2018).

Despite the right to health services for persons with disabilities, significant disparities remain between the health of persons with and without disabilities. A study conducted in 43 countries in 2013 found that health was characterized as good or very good by only 21% of persons with disabilities compared to 80% of individuals without disabilities. Similarly, three times as many persons with disabilities reported not being able to access healthcare when they needed it compared to persons without disabilities. Research found the more severe the disability, the more difficulty the person had accessing healthcare. This was true in Sri Lanka and Cameroon, where the percentage of those underserved in health centers increased based on the severity of disability (United Nations, 2018).

This lack of access to healthcare also affects women and children. Global research found that women with disabilities were less likely to have an accredited health professional at their birth than women without disabilities (United Nations, 2018). Additionally, while the mortality for children under 5 has decreased to below 20%, it remains close to 80% for children with disabilities (UNICEF, 2013).

Many of the same global health challenges exist in Lesotho. For example, due to limited access to health services, Lesotho has high maternal mortality rates of 1,024 deaths per 100,000 births (Lesotho Demographic and Health Survey, 2014). According to a 2017 UNDP report which cites the Lesotho Demographic and Health Surveys (LDHS) in Lesotho:

The neonatal mortality rate is 34 per 1,000 live births; infant and under-5 mortality rate is 59 and 85 per 1,000 live births, respectively. This means that one in every 29 children die in the first month of life; one in every 17 children dies before celebrating a first birthday, and one of every 12 children die before their fifth birthday. (UNDP, 2017; LDHS, 2014).

Stakeholders revealed that a series of lifelong health gaps exist for persons with disabilities. According to parents and volunteers associated with IDAL, early childhood screening for disabilities is lacking, which then creates a scenario where young children with disabilities are under-stimulated and interventions are missing. Potentially impactful health and

rehabilitative supports that not provided at an early age often means the physical and psychological impact of disability accrues over time (focus group interview, August 2, 2019).

For children and youth with disabilities, health barriers continue to persist. According to a focus group with LNFOD umbrella organizations on August 2, village clinics often do not have trained staff to understand the complexity of disability. Parents may then seek alternative medical practices in an attempt to "cure" a disability of a child. Validation meeting participants identified parent training during the early years of children's life as an essential health and social development initiative (Validation meeting notes, November 29, 2019). By the time a child reaches adolescence, rehabilitative opportunities that may have offset the impact of a disability were lost. Further, parents who continue to seek a cure for disabilities may feel hopeless. From birth to early childhood, according to stakeholders, there is a lack of family counseling or open conversation about understanding the role of disability in family life, a focus on strengthening children's capabilities, or accepting that most disabilities do not have a cure, but can be mediated with rehabilitation, education, and support (focus group interview, August 2, 2019).

Adults with disabilities in Leribe district described health gaps that occur during adult years. During these years, people with disabilities often experience communication barriers (especially those who have complex communication needs, use sign language, or use tactile sign language) or healthcare professionals who are inexperienced with disability. In terms of communication, adults with disabilities reported that confidentiality between doctor and patient was often breached (focus group interview, July 29, 2019 and confirmed in validation meeting). In sum, reports from people with disabilities identified gaps in early identification and intervention, and challenges with accessing healthcare as adults. Confidentiality, the health rights enjoyed by all individuals in Lesotho are at risk for people with disabilities across the lifespan.

Interviews with healthcare providers offered systems-level perspectives on the gaps in healthcare for people with disabilities. An interview at Leribe Hospital revealed there are two major challenges related to health services (Therapists at Leribe Hospital, personal communication, July 30, 2019). The first challenge is remoteness. People who live in rural villages often have difficulty finding or affording transportation to bring them to local clinics or specialty hospitals for identification or rehabilitation. According to therapists at Leribe Hospital, long waiting periods, difficulty boarding inaccessible transportation (for persons with physical disabilities), and the cost of transportation keep some families from accessing medical care. Once at facilities, equipment and therapists are limited. Leribe Hospital, for example, serves five districts. They run regular neurological, cerebral palsy, and spinal injury clinics, but each of these requires individuals to come to hospitals on prescribed days for clinics. The barriers to formal healthcare are significant in relation to disability-specific care.

People with disabilities who were interviewed for this report had mixed reactions to the care they received at local clinics for their general health. Individuals who are blind or have low-vision were generally satisfied with the interactions and access they had to healthcare, but persons with hearing disabilities identified a lack of communicative supports in clinics, which made it difficult to share health concerns and resolve health issues. Communicative barriers were identified at both governmental clinics and special HIV/AIDS clinics run by non-governmental organizations.

#### 5.6.1. Rehabilitation and Community-Based Rehabilitation

The World Health Organization defines rehabilitation as "a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments" (WHO, 2011, p. 96). Article 26 of the CRPD (Habilitation and Rehabilitation) calls for countries to create and extend comprehensive and multidisciplinary rehabilitation programs to ensure persons with disabilities experience full inclusion (CRPD, 2006). Because many national rehabilitation programs reside in urban areas and are prohibitively far for many to access, numerous countries use community-based rehabilitation (CBR) to allow more persons to access rehabilitative services (WHO, 2011).

CBR programming has shown to be effective in many countries, with outcomes including increased independence, mobility, and communication skills. One example of a successful CBR program is Mobility India, which has programs in three settings: urban, peri-urban, and rural in the areas surrounding Bengaluru. Although all three settings focus on access to health and livelihoods services, community mobilizing, and self-help groups, they also have individual programming focused on the specific community (WHO, 2010).

Although implemented only two districts of the country, Lesotho at one time had a national CBR program (LNFOD, 2008). Programs were supported by the Leonard Cheshire Foundation with some of the activities being run through Kananelo Centre of the Disabled. The Programs had a focus in five areas: health, education, livelihoods, empowerment of DPOs, and social inclusion (LNFOD, 2008). At the time of this study, the Ministry of Social Development employed a coordinator for CBR, but at present the program is on hold as the Ministry is rethinking how to relaunch the program in all districts of Lesotho (CBR Director of MOSD, personal communication, July 29, 2019).

LNFOD also identified that CBR was not a preferred method of community engagement for persons with disabilities. Drawing upon a social model of disability, LNFOD representatives noted they preferred an "inclusive-development" model to CBR. Inclusive development examines all aspects of livelihoods for persons with disabilities within communities. The broader approach has some basic therapeutic functions, but also primarily focuses on barriers to participation and employment, social protection, and social stigma within communities. The broader inclusive development model is still in its nascence in Africa, but was framed by LNFOD as the model preferred over CBR to socially frame disability (LNFOD Leadership, personal communication, August 1, 2019).

#### **5.6.2 HIV/AIDS**

Persons with disabilities are at an increased risk of becoming infected with HIV and yet are less likely to receive information about HIV/AIDS prevention, or have access to treatment and care services (World Bank & Yale, 2004). Girls and women with disabilities are at a disadvantage to access services and are often left behind in policy planning, program development, service delivery, and data collection. One study in Sub-Saharan Africa suggests an increased risk of HIV infection of 1.48 times in men with disabilities and 2.21 times in women with disabilities compared with men and women without disabilities (Nixon et al., 2014). Another study in Ethiopia showed that adolescents with disabilities report a low

level of condom and contraceptive use but a high level of engagement in casual and transactional sex. Likewise, even though persons with disabilities have the same or higher risk of contracting sexually transmitted infections as their peers without disabilities, they are less likely to be tested for HIV/AIDS (Kassa et al., 2014).

HIV/AIDS has also had a large impact on Lesotho's population, with a national HIV prevalence rate of 24% among adult men and women between the ages 15-49, which ranks Lesotho as the second highest in the world based on prevalence (PEPFAR, 2016; UNAIDS, 2019). The extent to which persons with disabilities in Lesotho have HIV/AIDS compared to their peers without disabilities is unclear. For example, UNICEF Lesotho provides statistics on HIV/AIDS on their website including prevalence rates for women and children but does not provide information on the incidence rates of children or adults with disabilities (UNICEF, 2019).

The 2006 National HIV and AIDS Policy in Lesotho identifies persons with disabilities as a key target group and promotes equal services and information for persons with disabilities. However, stakeholder interviews with persons with disabilities in Leribe and LNFOD representatives in Maseru revealed that persons with disabilities are often excluded from services because of communication barriers or stigma regarding sexual activity. In 2008, the National AIDS Commission Fund and LNFOD conducted research to assess the capacity needs of DPOs in the management of disability and HIV/AIDS national response in four districts in Lesotho. As of 2008, LNFOD and other DPOs had only just begun to address the issue of disability and HIV/AIDS. The report stated that DPOs required increased capacity in identifying HIV/AIDS responsive issues. Most large organizations and donors working in the area of HIV/AIDS did not address the inclusion of persons with disabilities in their programming (LNFOD, 2008). In 2019, little appears to have changed. Interviews with NGOs that target HIV/AIDS-related activities (CHAI and JHPEIGO) as well as persons with disabilities interviewed for this study indicate persons with disabilities are not targeted in relation to HIV/AIDS education, care, or cure. Although HIV/AIDS impacts all Basotho, inaccessibility of communication may prevent persons with disabilities from receiving accurate information and care related to the disease (NADL Leaders, Maputsoe Community Members with Disabilities, and International NGOs, personal communication, July 29-August 2, 2019).

#### 5.6.3 Sexual Reproductive Rights

Despite the right to sexual and reproductive health care under Article 25 of the CRPD, many still view persons with disabilities as asexual or that they should not have autonomy when it comes to their sexuality (WHO, 2011). As a result, girls and women with disabilities worldwide have little knowledge to their sexual reproductive health rights and have limited access to service (Jahoda & Pownall, 2014). A UNFPA study (2018) also found that girls and women with disabilities "are almost without exception denied the right to make decisions for themselves about their reproductive and sexual health, increasing their risk of sexual violence, unplanned pregnancy, and sexually transmitted infection" (UNFPA, 2018. pg.6). Many countries also have cases of sterilization of women with disabilities, particularly those with intellectual disability (WHO, 2011). In other cases, medical professionals advise women with disabilities to terminate their pregnancies to avoid having children who will also have disabilities (United Nations, 2018).

In Lesotho, as in many countries, the common misperception that persons with disabilities are asexual persists, and therefore, persons with disabilities are often excluded from healthcare and information related to sexual health, family planning, and treatment of sexually transmitted infections (STIs), HIV/AIDS, etc. Because of these beliefs, evidence suggests when women with disabilities, in particular, try to access prenatal or sexual reproductive services, healthcare providers do not give these women the same level of services compared to women without disabilities (Shale, 2015). This may result in higher instances of maternal mortality and infant mortality, yet there are few research studies available that specifically address women with disabilities and sexual reproductive health (Shale, 2015).

LNFOD members discussed three main issues in relation to sexual reproductive rights. The first was the risk of abuse. A human rights advocate for the deaf community stated, "One of the main problems we have is sexual abuse, especially for females who are deaf. When we take the problem to the police, there is a problem because of communication barriers since the police don't know sign language" (NADL Leaders, personal communication, August 1, 2019). The second barrier identified is a lack of sexual health education for persons with disabilities. LNFOD members noted that sexual health education is lacking for persons with disabilities because of assumptions that they will not engage in sexual activities. Members agreed that this assumption that persons with disabilities are asexual is inaccurate. For youth with intellectual disability and for all persons with disabilities, research participants called for accessible sexual education focused on healthy sexual lives, including communication with partners, condoms in braille (for accessible information on expiry dates), and training for persons with intellectual disability on appropriate times and places for masturbation, if such activity is desired. The third issue is choice-making for consensual sex for persons with disabilities and the Sexual Offenses Act. A LNFOD member knowledgeable of this issue stated:

The Sexual Offenses Act regards people with disabilities to a certain extent as without competency, so if you do it in front of them, with them, it doesn't matter if they consented or not, they are believed to be incapable of consenting, so that's the law. So, it actually makes it difficult to get sexual reproductive health services because the competency is doubted. Of course, there are those that need to be protected, but without taking out those that consent. (personal communication, August 1, 2019)

Because of challenges related to accessible services and communication, many individuals interviewed cited accessible sexual reproductive rights as a continuous barrier for persons with disabilities.

#### 5.7 Political Participation

**Finding 7:** Lesotho has made recent changes to include persons with disabilities in national elections as well as supported participation in political parties. However, participation and leadership in local government remains a challenge.

Article 29 of the CRPD guarantees access to political participation for persons with disabilities, which includes the right to accessible voting, the right to run for office, and the right to form and participate in political groups (CRPD, 2006). Despite this, significant gaps exist, more than 30 percentage points in some countries (United Nations, 2018), between those with and without disabilities when it comes to voting and political engagement. This is due, in part, to restrictive voting laws in some countries, where those with psychosocial or intellectual disabilities are denied the right to vote. Of the 128 United Nations member states, 62 had voting laws including restrictions for persons with disabilities (United Nations, 2018).

For persons with disabilities who are given the right to vote by their country, other barriers may still stand in their way. Out of 13 capital cities in Asia and the Pacific, 7 had inaccessible conditions in 50% or more of their polling places (United Nations, 2014). Social and cultural barriers can also impede voting for persons with disabilities, often due to lack of education and literacy. This especially impacts women with disabilities, as research shows that the literacy rate for women with disabilities is estimated to be as low as 1% (IFES, 2014).

In addition to disparities when it comes to voting rights, persons with disabilities are also significantly underrepresented in political office. Only 15 United Nations Member States give persons with disabilities the right to run for office without exception (United Nations, 2018). However, some countries have taken steps to ensure increased participation of persons with disabilities within elected office. Uganda's constitution requires that five members of Parliament have disabilities (United Nations, 2018). Persons with disabilities are also elected through an electoral system at all levels, which has resulted in more disability-inclusive policy, and Uganda now has among the highest number of elected representatives with disabilities in the world (WHO, 2011).

In Lesotho, Section 30 of the National Assembly Electoral Amendment Act of 2011 ensures political participation by persons with disabilities by requiring that all political parties registered under the electoral commission must include persons with disabilities in all aspects of political participation. Likewise, political parties must ensure political venues are accessible to persons with disabilities and that their communication rights are also respected (Lesotho Government Gazette, 2011). However, in the 2015 national parliamentary elections, only the political party of All Basotho Convention (ABC) had a sign language interpreter at its rallies (Shale, 2015).

Political participation and civic engagement occur in many ways in Lesotho. Three important aspects of political and civic engagement are political parties, voting rights, and community deliberations. As noted above, participation in political parties may be limited if parties themselves do not have accessible communication. The high court recently overturned a provision in the National Assemblies Electoral Act, and in 2019 persons with intellectual disability are no longer barred from voting or having a voice in Lesotho's government (Validation meeting notes, November 29, 2019). However, no provisions support accessible transportation to or accessible communication at polling stations. The logistics of proxy voting were not discussed in this report, but in general any form of support identified by a person with a disability in order to politically participate is in alignment with the CRPD and the most recent interpretation of the National Assemblies Electoral Act.

The final form of political participation in which barriers were clearly identified were community-based deliberations and local government. Local governments make resource decisions on a variety of decentralization schemes. *Pitsos*, or village meetings, are the traditional place where chiefs or village leaders share information and gather input from community members on these measures. There is currently no provision for electoral education or leadership development for persons with disabilities so they can fulfill the role of counselors or other local government positions. Further, in almost all interviews with persons with disabilities in community settings, interviewees expressed that they felt ignored or excluded at *pitsos*. The most glaring examples included discrimination by other community members who discredited what persons with disabilities said. In other cases, persons with disabilities were ignored at meetings.

#### 5.8 Social Protection

**Finding 8:** Lesotho currently has three mechanisms for social protection (Public Assistance in Cash, Child Grants, and bursaries). Persons with disabilities generally view Lesotho's social protections support as insufficient. Additional expenses related to disability necessitate additional supplements. Accurate identification data is needed—through NISSA or other sources—to facilitate social protection.

The CRPD recognizes the right of persons with disabilities to equal access to social protection (CRPD, 2006), which WHO defines as "programmes to reduce deprivation arising from conditions such as poverty, unemployment, old age, and disability" (WHO, 2011, p. 309). Additionally, the United Nations Special Rapporteur on the rights of persons with disabilities has stressed social protection is integral for achieving social inclusion and full participation of persons with disabilities (United Nations, 2018). Most countries (91%) offer disability-specific social protection, including nationally mandated cash benefits. Sustainable Development Goals (SDG) indicator 1.3.1 also measures what percentage of the population with severe disabilities, or those with high support needs, collect social protection benefits for disability and found that only 28% of those with severe disabilities receive disability benefits, with significantly higher coverage in high-income countries.

Lesotho's social protection funds align with social protection schemes found across the Southern African Development Community (SADC) in that they are driven by demographics (i.e., poverty, age, etc.) but do not attach conditionalities in order for individuals or households to receive grants (such as the conditional cash transfers currently being utilized by governments across Latin America) (Adato & Hoddinot, 2010; NISSA Manager, personal communication, July 31, 2019). Research on Lesotho's social protection schemes identified the complexity of supporting persons with disabilities. For example, in a 2010 study, persons with disabilities were given public assistance of only one hundred Maloti a month by the Department of Social Welfare (Chitereka, 2010). Leshota (2013) identified the challenges of social protection for persons with disabilities. A reasonable option is to wait for disability grants, but this is not as simple as identifying oneself as such and then receiving it. Rather, it involves a normal welfare process of diagnosis, normally referred to as "assessment," which seeks to answer the question whether an individual qualifies to be categorized as disabled, and therefore deserving of a welfare benefit or disability grant (Swartz & Schneider 2006).

The studies above provide a helpful history but do not characterize the contemporary situation in Lesotho. Currently, persons with disabilities only receive social protection grants if they are otherwise vulnerable, and parents receive bursaries for children with disabilities to attend school. In addition, two social protection schemes currently support households in Lesotho. The first is "Public Assistance in Cash" that provides quarterly disbursements of 750 Maloti (LSL)<sup>5</sup> for households who fall within the "poor" or "very poor" categories described above. The second is the "Child Grant" for households who are in the "poor" and "very poor" categories and have children. For this grant, there are monthly disbursements dependent on the number of children living in a household (the more children, the greater the grant). Lesotho, like other countries in Southern Africa, organizes its social protection at the household level, which then allows all members of the household to benefit, whether or not they are biologically related, part of a nuclear family, or married (MOSD Social Worker, personal communication, July 28, 2019).

Households may either receive Public Assistance in Cash or the Child Grant but cannot receive both. If a household has a child or adolescent with a disability, however, that child will automatically receive a bursary to support their schooling (MOSD Bursaries Manager, personal communication, July 31, 2019). Bursaries can cover school fees, books, or housing if the child attends a residential school and school-related expenses (tuition, supplies, uniforms) if the child attends a community school. The exact amount of the grant varies by school. Lesotho has a Free Primary Education (FPE) policy, so bursaries may offset expenses beyond tuition. In Lesotho, secondary schools still charge tuition, and tuition varies by school. To that end, bursaries to students vary and are established through determinations by MOSD auxiliary social workers and central Ministry staff (MOSD Bursaries Manager, personal communication, July 31, 2019).

At present, there is no specific disability grant in Lesotho, but both the Ministry of Social Development and LNFOD indicated such a grant would be useful for the variety of costs related to having a disability (including additional clinic trips, equipment, adaptation to housing, etc.). Representatives from the Ministry of Social Development noted disability funds would be a targeted fund that would require some form of registration, but no details were available for how such a process would be conducted. At present, itinerant social workers identify vulnerable families based on livelihoods opportunities, and vulnerability criteria are validated by communities (Ulrichs et al., n.d.). The household-visit process could be effective for disability determination, but community validation would intrude on privacy and confidentiality, so would not be advisable (MOSD NISSA Manager, personal communication, August 1, 2019).

Overall, disability data that could be used to identify possible recipients of a disability grant is present in the NISSA system. However, disaggregation has just begun and there is not clarity on whether information aligns with global standards (NISSA Manager, personal communication, August 1, 2019). Disability advocates have sought to fast-track the disaggregation of data but have not yet received any data from the NISSA system (Validation meeting notes, November 29, 2019). Because disability is identified through a

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<sup>&</sup>lt;sup>5</sup> "Maloti" is the common and plural version of "loti" or Lesotho Loti (LSL) currency. The social payment of M750 is worth approximately \$49 US.

nomination process, there may further be errors in community identification processes (NISSA Manager, personal communication, August 1, 2019). At present, international questions identification tools such as the Washington Group questions are not being used in Lesotho.

Social protection grants were generally appreciated by community members who received them, but political battles caused delays in disbursement at the time of this study. Delays had serious implications for recipients. The field notes below from a community visit exemplifies how late payments impact livelihoods. The individual interviewed was blind and raising his two children alone. His wife left him after he acquired his disability, and he used various social protection and entrepreneurial initiatives to make ends meet.

When asked about a typical day, this stakeholder said he was worried for tomorrow, as school starts and his kids do not have shoes. He raises two children alone, ages 10 and 8. He currently sells consumer products in his surrounding areas. People buy his products, but several people owe him money, and he needs to collect. An NGO gave him a small loan for a small business to get started. In 2018, he started selling products after he took a small-business training. Prior to that, he only plowed his own garden and attempted to sell vegetables. He was unsuccessful at this because everyone already had their own vegetables.

According to the interviewee, the perfume business started out well, but recently became challenging due to the economic circumstances in Lesotho. Lesotho has a social protection scheme that provides funding to senior citizens (his description). Often these seniors will share part of the payment with their families who care for them. From there, he got his customers. However, Lesotho is now seven months behind on its payments, and he is now owed money by several people who expected to pay upon the arrival of the grant. The social protection grant is 750 Maloti every three months (so, about 250 Maloti per month).

The late payments left him concerned for his children. They will start school, don't have new clothes or shoes and only get a small amount of food at school. He is following up with customers, who can pay him with MPesa when they have funds, but many currently do not. He often calls them but does not like to collect in person because dogs are around their houses, and he cannot see them very well. The biggest problem he has right now is the late payments. (Individual with Disability Outside Hlotse, personal communication, July 31, 2019).

The interview above represents a micro-example of the complexity of social-protection funding. The funds have stimulated a degree of economic development in the village because people are now able to both meet their daily needs and spend a small amount on household items. However, when payments fail, the cash circulation comes to a halt. In such situations, those whose livelihoods depended on payments (directly or indirectly) face renewed stress regarding day-to-day expenses (Five Persons with Disabilities who Receive Social Protection Payments Outside Hlotse, personal communications, July 31, 2019).

### 6. Recommendations

This study identified a variety of issues related to disability and inclusive development in Lesotho. Stakeholders, through sharing stories, elaborated on areas where disability inclusion could be improved through the targeting of specific programming. The table below provides a restatement of the key findings identified above and specific recommendations related to them. Findings are then linked directly to the relevant stakeholders, including direct references to ministerial units.

Findings	Recommendations
1. Legal Framework and Policy	
Lesotho's Disability Bill has gained political support but is not yet signed into Law. The law's likely passage in 2020 will allow for better alignment with CRPD as well as legal enforcement of the rights of persons with disabilities.	Assuming the Bill will soon be passed into law, begin immediate work on implementing and reporting on CRPD and establishment of a National Disability Advisory Council to provide oversight and advice on implementation of the law.
2. Community Living	
Adults and children with disabilities face isolation and discrimination in home communities. New institutions run by non-governmental organizations are emerging in Lesotho, but there is currently no standard of care provisions or oversight by government to ensure quality service delivery. Government financial support of such institutions misaligns with the aims of the CRPD.	<ul> <li>Establish systems of community sensitization, early support for families, and early intervention for young children with disabilities in order to align with community living standards outlined in the CRPD and implemented by MOSD and MOHSD.</li> <li>Establish MOSD standards for community living for children with disabilities and end subventions for</li> </ul>
	<ul> <li>disabilities and end subventions for organizations that threaten standards.</li> <li>Establish care norms, staffing expectations, and transition expectations for all non-governmental institutions, homes, and centers for children with disabilities that operate in Lesotho.</li> <li>Maintain current community living expectations for adults but improve conditions for livelihoods and political participation.</li> </ul>

#### 3. Education

Lesotho's recently adopted inclusive education policy provides a framework for upholding the educational rights of children with disabilities, but these children are under-enrolled in Early Childhood Care and Development (ECCD) programs and little data exists on school-aged children beyond enrollment.

- MOET, MOSD, and MOH to incorporate inclusive-education pedagogies into preservice education programs in Lesotho and focus in-service education efforts on early childhood centers, daycares, and creches to support early identification, community outreach, and development of socialization and learning opportunities for children with disabilities (as per national ECCD Strategy).
- MOET and the Exams Council to develop data collection measures to ensure children with disabilities are receiving quality education and are benefiting from inclusive education. In order to ensure outcomes data is valid, learning and testing accommodations must be in place.

#### 4. Employment

The majority of persons with disabilities in Lesotho are unemployed, and most individuals with disabilities have not yet benefited from government services that support short-term employment. Overall, there are no quotas or tax incentives to promote hiring of persons with disabilities. Entrepreneurship opportunities are present, and when coupled with social protection and access to work, may provide a range of options for persons with disabilities.

- Ensure all government-supported employment programs are inclusive and promote the active participation of disabilities persons with through mandatory hiring quotas of persons with disabilities in government offices and (MOSD. MOWT. programs Local Government).
- Create inclusive Technical Vocational and Educational Training (TVET) by merging MOSD habilitation into inclusive TVET centers (MOES and MOSD).
- Develop disability-targeted interventions to address the high unemployment rates, such as tax incentives for hiring of persons with disabilities in private firms (Parliament, MOSD).

 Expand entrepreneur training opportunities for persons with disabilities (LNFOD, MOSD).

#### 5. Gender-based Violence and Abuse

Instances of sexual violence against girls and physical violence against boys and girls is high in Lesotho. Stakeholders report that instances may be even higher for children and women with disabilities, who face communication barriers in legal and health systems.

- Mainstream disability issues and awareness into existing gender-based violence prevention programming (Ministry of Gender, Youth, Sports, and Recreation - MGYSR).
- Ensure that sign language and tactile sign language interpretation options are always available for testimony related to gender-based violence in courts (MOJ, MOSD).

#### 6. Health

Stakeholders cited a series of lifelong gaps that, according to interview data, lead to a cumulative impact of disability across the lifespan. These impacts are exacerbated by lack of available resources, personnel, and equipment.

- Commit resources to early outreach, identification, parent training, and intervention related to disability (MOH and MOSD).
- Commit funds to training or hiring sign language and tactile sign language interpreters who can professionally interpret at all government hospitals (MOH).
- Evaluate and create inclusive sexual reproductive health materials in order to provide adequate information to persons with disabilities (MOES, MOH, MOSD).

#### 7. Political Participation

Lesotho has made recent changes to include persons with disabilities in national elections as well as supported participation in political parties. However, participation and leadership in local government remains a challenge.

Remove barriers for persons with intellectual disability to vote and continue to support other inclusive programs at the national level (Lesotho Independent Election Commission, Parliament, LNFOD, MOSD).

 Fund (MOSD) and develop (LNFOD) electoral and leadership training for persons with disabilities to ensure participation and contribution to local and national government.

#### 8. Social Protection

Lesotho currently has three mechanisms for social protection (Public Assistance in Cash, Child Grants, and bursaries). Persons with disabilities generally view Lesotho's social protections support as insufficient. Additional expenses related to disability necessitate additional supplements. Accurate identification data is needed—through National Information System for Social Assistance (NISSA) or other sources—to facilitate social protection.

- Analyze current NISSA data on disability to determine if incidence of disability identified in NISSA aligns with global norms. If it does not, include Washington Group questions in household surveys to more accurately identify disability incidence (MOSD).
- Establish a targeted disability-specific social protection fund that is proportionately aligned with other social protection funds. This fund will offset additional costs of access to services and equipment above and beyond existing social protection.

## 7. Summary

The situation of persons with disabilities in Lesotho is complex, but when analyzed through a livelihoods and inclusive development framework, it allows concrete policy measures to be identified. In Lesotho, persons with disabilities are disadvantaged and face discrimination from their very early days. Children with disabilities are often misunderstood, face stigma in their communities, and are overly protected by parents who are unsure how to best support their child. At an early age they also face exclusion from early childhood and early primary education opportunities.

Stigmatization and discrimination continue through schooling but are being partially addressed through new inclusive education policy form the Ministry of Education and Training. Despite inclusive innovations in primary and (to an extent) secondary schooling, a dual system of technical and vocational education still exists in Lesotho. Currently, the Ministry of Social Development and Ministry of Education and Training oversees institutes that have overlapping goals in relation to helping Basotho develop job-ready skills. The difference between the MOSD and MOES institutes is that MOSD also provides habilitation training for participants but appears to not focus as heavily on vocational and entrepreneurial skills as MOET institutes. Finally, barriers to the health system start at a very young age,

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which reduces opportunities for early childhood stimulation and development. Early intervention could pay dividends over the course of a lifetime for persons with disabilities.

Adults with disabilities face a variety of structural barriers, from exclusion in community gatherings to barriers to work and opportunities to improve livelihoods. Finally, persons with disabilities face barriers in terms of access and communication related to government services such as health, justice, and education. For all of these reasons, and because Lesotho's government and non-governmental sectors embrace a social model of disability, a livelihoods model is a culturally and philosophically appropriate model for addressing exclusion of persons with disabilities in Lesotho.

An inclusive development approach that considers services, access, rights, and economics as part of a broader empowerment agenda spanning the lives of persons with disabilities is needed. In this case, disability empowerment starts at birth, with community acceptance, access to early identification and stimulation, and access to early childhood education. The lives of children and youth with disabilities are enhanced by opportunities to attend school. Supports in the school system help children to have a quality experience and appropriate outcomes. As youth reach adolescence, accessible health services and sexual/reproductive health information, and opportunities to study in mainstream secondary schools, postsecondary institutions, and technical vocational centers without losing access to support services are paramount.

In adulthood, sustaining livelihoods will require several interventions. This includes 1) a dedicated social protection scheme that offsets expenses related to disability; 2) inclusive workplaces and entrepreneurial activities for persons with disabilities; and 3) inclusive government services such as healthcare, justice, and employment policies. Finally, a rights framework that is protected by law will ensure that policies and programs will be mandated and not just depend on the goodwill of stakeholders.

The presence of disability should not preclude development in Lesotho. Rather, Lesotho's development relies on the contributions of all Basotho. Inclusive development for persons with disabilities will require policy and resource inputs along with a recognition of the specific rights required by the CRPD (such as accessible environments, communication accessibility, etc.). Such inputs, coupled with continued commitment to social models of disability that focus on barrier removal and livelihoods development, should produce positive social and economic results for Lesotho.

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#### Annex A: National Laws and Inclusion of Persons with Disabilities

Below provides a detailed list of the different laws in Lesotho and how persons with disabilities are included.

- Constitution of Lesotho of 1993: Section 33 of Lesotho's 1993 Constitution calls for the country to "provide for training facilities, including specialized institutions, public or private, and place disabled persons in employment and encourage employers to admit disabled persons to employment" (Government of Lesotho, 1993). The rights of persons with disabilities are indirectly addressed in Lesotho's Constitution in Sections 4 and 18, which provide freedom from discrimination for all Basotho. Disability is not listed as a particular category against which discrimination may occur, but may be included in what were open-endedly described as an "other status" against which someone may experience discrimination (Shale, 2015).
- Inclusive Education Policy Direction of 1989: In 1989, Goal 7 of Lesotho's Operations Plan: Clarification of Lesotho's Education Policies and Priorities, Part 11, stated that initial training and continuing education of teachers should incorporate inclusiveness and that education for children with special needs (broadly defined) would be conducted inclusively. Following a feasibility study in 1993 by Lilian Mariga and Lineo Phachaka, the Ministry moved to train all teachers on inclusive education strategies, beginning with 10 pilot schools and following with pre-service and inservice training at Lesotho College of Education (Mariga & Phachaka, 1993).
- Education Act of 1995: This Act stipulates that a child who is "physically or mentally handicapped [sic]" should receive appropriate "treatment, education, and care" in relation to their disability (Ministry of Education and Training, 1995).
- Buildings Control Act of 1995: Section 19 of this Act provides accessibility to persons with disabilities in all public buildings. Any advertisement in Government Gazettes soliciting quotes require plans for accessibility of persons with physical disabilities (Parliament of the Kingdom of Lesotho, 1995).
- Ministry of Education Strategic Sector Plan (1995-2005): The Sector Plan built
  upon the Education Act and specifically identified the importance of education for
  children with disabilities. In 2001, Lesotho first implemented "Free Primary
  Education" for all children, removing cost barriers for attendance of all children in
  primary schools. The sectoral reform included financial provisions for school meals
  and materials for all learners (Ministry of Education and Training, 2005).

- Sexual Offences Act of 2003: This Act prevents persons from performing sexual acts on a person with a disability who does not have the capacity to consent and prohibits people from having sexual intercourse in the presence of a person with a disability. The rationale behind this Act was to protect persons with disabilities from unwanted or unrestricted sexual advances, but the "in the presence" clause has been criticized by disability advocates as a mechanism for prohibiting persons with disabilities from having consensual sexual relations based on an assumption that all persons with disabilities are asexual (Lesotho Government Gazette, 2003).
- Youth Council Act of 2008: In 2008, youth representation in policy-making was mandated by the Youth Council Act. This Act provides legal grounding for a representative body to advise the Minister of Gender and Youth, Sports, and Recreation (2019 Ministerial title). Within the Act is a provision for representation of youth with disabilities. One representative shall be nominated by Lesotho National Federation of the Disabled to serve on this council (Shale, 2015; Youthpolicy.org, 2014).
- National Assembly Electoral Amendment of 2011: Requires all of Lesotho's political parties to ensure membership has access to political communication and political venues (Lesotho Government Gazette, 2011).
- Children's Protection and Welfare Act of 2011: This Act provides protection of all children and has specific provisions for children with disabilities. For example, Section 13 ensures the right to dignity, special care, medical care, rehabilitation, family and personal integrity, sports, and recreation. Principle II Clause 6 prohibits discrimination against children with disabilities on the basis of their disability (Government of Lesotho, 2011).
- The National Disability and Rehabilitation Policy (NDRP) of 2011: This Act is a comprehensive policy that provides guidance on the inclusion of persons with disabilities in all aspects of life in Lesotho. The Policy is arguably Lesotho's most comprehensive and robust policies in its history. The Policy is divided into 11 "policy areas" (including prevention, early identification, and intervention; rehabilitation; accessibility; capacity building; quality and essential healthcare; social welfare and participation; protection: self-representation and sports, recreation, entertainment; research and appropriate technology; policy and legal protection; and monitoring and evaluation. In addition to the 11 policy areas outlined by the national policy, the policy outlines a national monitoring and evaluation process highlighted by National Standards on Disability Services that guide work for all providers of services for persons with disabilities.

# Annex B: National Disability and Rehabilitation Policy: Policy Areas, Objectives, and Strategies

Below is a summary of the policies areas, objectives, and strategies listed within the National Disability and Rehabilitation Policy.

Policy Area	Objective	Example Strategy
Prevention, Early Identification, and Intervention	Develop a coordinated system for prevention/identification/intervention of disabilities.	Make current information available to stakeholders for appropriate intervention, prevention, and
		programs. Develop and implement appropriate screening tools for the identification of disabilities.
Rehabilitation	Promote availability of equipment skills and services	Improve referral systems between rehabilitation and other sectors.
	to support maximum	Facilitate availability of regional/district
	functioning.	accessible medical and other rehabilitation services and facilities.
Accessibility	Promote access to physical	Develop the Lesotho Standards in
,	environment, transport, and	Design for Access as regulations and
	communication.	guidelines for surveyors, planners,
		and engineers to follow. Develop an
		effective monitoring and evaluation (M&E) mechanism to ensure proper
		implementation and compliance with
		all the relevant policy and legislative
		instruments, particularly the Building
		Control Act.
Capacity Building	Promote equal access in	Promote for the availability, and
	education and training	legislate for the production of,
	programs; improve access to	education materials in accessible
	entrepreneurial and TVET programming; maximize	formats to persons with disabilities throughout the education system from
	employment.	pre-, primary, secondary, and tertiary
		levels. Introduce a code of good
		practice in order to provide general
		guidance to employers and
		employees.
Quality and	Promote access to public	Upgrade a fully-fledged department of
Essential	health system and access to HIV/AIDS information.	rehabilitative services to administer
Healthcare	HIVAIDS IIIIOIMAIION.	services to persons with disabilities in all districts. Ensure affordable and
		accessible public health for persons
		with disabilities; ensure availability of
		human and financial resources to fight

		the HIV/AIDS pandemic among
		persons with disabilities.
Social Welfare and	Develop a coordinated and	Develop guidelines that will make
Protection	effective legislative and	provision for a disability grant/social
	administrative welfare system	security system for all persons with
	framework to enable self-	disabilities based on the nature of
	sufficiency, social integration,	their disability. This is particularly in
	and adequate housing.	regard to employment and/or self-
		employment in order for persons with
		disabilities to meet their basic needs.
Self-representation	Promote effective self-	Support and promote the work of
and Participation	representation of persons with	organizations of persons with
	disabilities at all levels of	disabilities (also known as DPOs).
	planning, decision-making, and	Promote the involvement of persons
	implementation of development	with disabilities and their families in
	activities.	service decisions. Establish provision
		to improve access to elections by
		persons with disabilities. Strengthen
		DPOs for participation and protection
		of women and children.
Sports, Recreation,	Promote the development,	Advocate for the participation of
and Entertainment	participation and inclusion of	persons with disabilities in sports,
	persons with disabilities in	arts, culture, and recreation. Advocate
	sports, leisure (recreation), and	for the sports commission to set up a
	entertainment, including arts	proper mechanism for following its
	and crafts.	financial and other policy-related
		commitments to persons with
		disabilities.
Research and	Promote and support research	Promote research studies in special
Appropriate	on disability-related issues.	needs education to influence policy in
Technology	Acquire and use appropriate	different ministries. Advocate
	technology.	innovations in appropriate
		technologies. Facilitate coordination
		and integration of gender
		disaggregated disability data in the
		national census, household surveys,
		etc. Adapt the regional sign language
		for development of Lesotho Sign
		Language Dictionary.
Policy and Legal	Raise public awareness and	Advocate for the review of all relevant
Protection	promote education on legal	legislation to ensure laws are
	protection of persons with	responsive to the needs of persons
	disabilities.	with disabilities. Advocate for the
		review and update of the Buildings
		Control Act - 1995, and enforce the
		Lesotho Standards in Design for
		access as regulations and guidelines
	I	

			for land surveyors, physical planners,	
			architects, and civil engineers.	
Monitoring	and	Regularly and systematically	Incorporate persons with disabilities	
Evaluation		collect and analyze information	into monitoring committees. Develop	
		related to the implementation of	monitoring tools for the	
		the NDRP and its Strategic	implementation of the rehabilitation	
		Plan.	program.	

Compiled from information found in Government of Kingdom of Lesotho (2011).

## Annex C: National Disability and Rehabilitation Policy: National Standards on Disability Services

Below are the standard and explanation of the different elements of the National Disability and Rehabilitation Policy.

Standard	Explanation		
Individual Needs	Each person with a disability receives a service which is designed to meet, in the least restrictive way, his or her individual needs and personal goals.		
2. Valued Status	Each person with a disability has the opportunity to develop and maintain skills and to participate in activities that enable him or her to achieve valued roles in the community.		
3. Service Access	Each consumer seeking a service has access to a service on the basis of relative need and available resources.		
4. Decision Making and Choice	Each person with a disability has the opportunity to participate as fully as possible in making decisions about the events and activities of his or her daily life in relation to the services he or she receives.		
5. Employment and Skills Development	The employment prospects of each person are maximized by effective and relevant training.		
6. Employment Support	The employment prospects of each person are maximized by effective and relevant support.		
7. Privacy, Dignity, and Confidentiality	Each consumer's right to privacy, dignity and confidentiality in all aspects of his or her life, including his/her AIDS status, is recognized and respected.		
Social Protection and Welfare	Each person with a disability enjoys comparable living conditions to those expected and enjoyed by the general society.		
Accommodation and Independent Living Conditions	Each residential and/or independent living agency adopts sound management practices in providing and maintaining boarding and lodging facilities in order to maximize outcomes for consumers.		
10. Participation and Integration	Each person with a disability is supported and encouraged to participate and be involved in the life of the community.		
11. Sports, Recreation, and Entertainment	Each person with a disability is supported and encouraged to participate and be involved in sports, recreation, and entertainment activities enjoyed by the community within which he or she lives.		
12. Research and Appropriate Technology	Each agency is up to date with the latest research findings on disability issues and adopts appropriate technological aids in order to maximize outcomes for consumers.		
13. Complaints and	Each consumer is free to raise and have resolved any complaints or disputes he or she may have regarding the agency		

Disputes	or the service.

## Annex D: Specific Issues Addressed in the Lesotho Inclusive Education Policy

#### Early Childhood Care and Development (ECCD) Centers

- All ECCD centers will be encouraged to accept children with disabilities.
- Special ECCD centers will be developed for children with severe and profound disabilities.<sup>6</sup>
- Government schools will have attached "reception centers" (this is a model of schoolbased education for 4-year olds that is intended to broadly initiate children into school culture in an age-appropriate way).

#### Primary and Secondary Education

- Activities and materials to be reviewed for how "accommodative" they are.
- MOES will "look at the big picture" of the learning objectives across all primary school ages.
- An evaluation of assessment practices and standardized assessments will be undertaken to find gaps in the "one-size-fits-all" approach to high-stakes testing.
- A revised curriculum is intended to inform assessment reform.
- Testing accommodations will be introduced.

#### Post-secondary Education

- Increase focus on inclusion in technical vocational education and training (TVET)
- Support and monitoring for government TVET centers related to enrollment of youth and young adults with disabilities.
- Three training centers (Leribe, St. Mary's, and Thaba Tseka) currently enroll youth with disabilities.
- Partner with National University of Lesotho (NUL) to re-examine school curriculum.
- Partner with NUL and NADL to further develop sign language dictionaries and tools.

#### Assessment

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- Pilot assessment centers in which multi-disciplinary teams can identify and develop plans for children with disabilities.
- Assessment center staff serve as resources to regular schools.
- Consider special schools only for children with "severe and profound" disabilities (according to interview data).

<sup>&</sup>lt;sup>6</sup> Specific policy information is needed on this initiative, but on the surface, it appears to contradict an overall inclusive education orientation.

<sup>&</sup>lt;sup>7</sup> Further information on this policy consideration is warranted as it may be contrary to inclusive education as it is understood in international documents such as the Convention on the Rights of Persons with Disabilities.

### **Data Collection**

- Enhance data collection on school-age population in Lesotho.
- Enhance monitoring and intervention of out-of-school children (OOSC).
- Review bursary support guidelines for children with disabilities.<sup>8</sup>

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<sup>&</sup>lt;sup>8</sup> Primary school is free for all children, but children with disabilities who continue through secondary education or beyond receive bursaries from the Ministry of Social Development to pay fees.

## **Annex E: Schedule of Field Based Interviews**

Date	Stakeholders	Location	Interview Notes
28 July	Persons with disabilities in	Leribe	Individual key informant
	community settings, various		interviews at homes
	villages near Hlotse		
29 July	Mohloli oa Bophelo	Maseru	Group interviews with Board
	Rehabilitation Center		Members and Director, then
			Program Alumni
	UNFPA Representative		Key informant interview with
			Representative
	LNFOD Leadership		Key informant interview with
			Executive and Legal
			Directors
	MOSD Departmental		Focused group discussion
	Representatives		with representatives,
			including Director of
			Disability Unit
30 July	Men/women with disabilities in	Leribe	Focused group discussion
,	gender-disaggregated interviews,		with 5 males and 4 females
	various villages near Maputsoe		with disabilities
	St. Paul School for the Deaf		Key informant interview with
			Director
	Phelisanong Home for Children		Key informant interview with
			Information Officer
	Leribe Hospital		Key informant interview with
			Physiotherapists and
			Prosthetics Experts.
			Focused group discussion
			with 12 parents of children
			with disabilities (all
			mothers).
31 July	MOSD Key Heads of Department	Maseru	Key informant interviews
	in Social Assistance and		with Department in Social
	Bursaries and NISSA Manager		Assistance Manager,
			Bursaries Manager, and
			NISSA Manager
	Ministry of Education and		Key informant interviews
	Training Special Education Unit		with three members of
			Special Education Unit
	Ministry of Health (doctors		Key informant interviews
	affiliated with disability		with two medical doctors
	determination for workforce		and legal expert affiliated
	compensation cases)		with workplace
	, ,		compensation claims
	Ministry of Justice		Key informant issue with
			head of Human Resources
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1 August	Lesotho Mounted Police (Child and Gender Protection Unit)  LNFOD umbrella groups,		Key informant interview with two members of Child and Gender Protection Unit  Focused group interview
	including LNLVIP, LNAPD, IDAL, NADL, and Sentebale (convening organization)		with 3-5 representatives from each organization (plus one Sentabale representative)
2 August	Ithuseng	Maseru	
	Centers and Special Schools (including St. Paul School for the Deaf, St. Angela Home for Disabled Children, Morapeli Disabled Centre, Seleso Inclusive Primary School, Thuso e tla Tsoa Kae Handicapped Centre, and Kananelo School for the Deaf.) Convened by Sentebale		Focused group interview with 1-2 leadership representatives from each organization
	JHPEIGO, Clinton Health and AIDS Initiative, Catholic Relief Services		Key informant interview with one representative from each organization
30 August – 1 September	Adults with disabilities and parents of children with disabilities in villages surrounding Qacha's Nek town	Qacha's Nek	Key informant individual interviews with persons with disabilities and family members of persons with disabilities
17-19 September	Adults with disabilities and parents of children with disabilities in villages surrounding Thaba Tseka town	Thaba Tseka	Key informant individual interviews with persons with disabilities and family members of persons with disabilities
28 November	Validation meetings with relevant organizations	Maseru	Key informant interviews with leadership from UNFPA, UNICEF, and LNFOD
29 November	Validation workshop at Avani Maseru Hotel	Maseru	50 participants contributed feedback to overall report, its findings and its recommendations